LIVING WELL WITH CHRONIC ILLNESS:
ALIGNING TENSIONS, ATTITUDES, STRATEGIES, AND MEANINGS

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

The Faculty of Graduate Studies
(Interdisciplinary Studies)

UNIVERSITY OF BRITISH COLUMBIA

September 2006

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ABSTRACT

Chronic illnesses have an enormous impact on individuals and society and consume considerable resources. Increasingly, studies have shown that some people have a good life with these long-term conditions despite the economic hardship, pain, suffering, and disability they create. This raises questions about what characterizes these experiences and how they develop in the context of these challenges. In this interpretive study, these issues were explored using the interview data of 27 women and 4 men who self-identified as living well and were diagnosed with multiple sclerosis, scleroderma, or lupus.

The findings revealed that the participants had diverse and challenging lives and experienced disease-related tensions and losses in daily life. In this context, living well represented meaningful experiences that evolved over time in relation to the tensions and losses they experienced and their understandings of what was valuable. Meaningful experiences were obtained through attitudinal and behavioural strategies as well as cognitive shifts in understanding that aligned their tension-centred realities with what was important in life. Within this process, the women and men made decisions and choices about how to live in relation to their goals and values rather than in relation to just managing, coping, or adapting to the illness. The meaningful experiences associated with living well varied over the course of living with illness and positive emotions about life and illness were associated with having these experiences.

By interpreting the data in relation to the interrelated conceptualizations of tensions, meanings, and alignment, some patterns and themes were illuminated that help to extend current knowledge of the nature and dynamic processes involved in living a good life with illness. Also, the angle of vision taken in interpreting their experiences created a framework within which we
can better understand some of the complexities inherent in this kind of illness experience and make sense of some of the competing ideas and contradictions that are found within existing bodies of knowledge. The overall value of the research comes from looking at the phenomenon of chronic illness from a perspective of truly living well rather than one of coping or managing disease.
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ACKNOWLEDGMENTS

I would like to extend my sincere appreciation to the women and men who engaged in this research process as voluntary participants and shared their life experiences of living well with illness. I was humbled by your courage, not only in relation to dealing with the challenges you faced with illness but also the many other life events and traumas that many of you experienced throughout the course of your lives. You inspired me with your drive to create a rewarding and meaningful life. I also want to express my sadness over the death of Annie, one of the participants, who passed away before my dissertation was completed. I vividly remember her talking passionately about the books, ideas, and people that had shaped her way of life and the way she lived with scleroderma. She was a remarkable woman. In addition, I would like to thank the BC Lupus Society, Scleroderma Association of BC, and the BC Division of the MS Society of Canada for their support in the recruitment process.

This dissertation would not have been possible without the guidance and support of my research committee. Dr. Jim Frankish, my co-supervisor, provided immeasurable practical guidance and emotional support throughout the research process and gave me a space to be authentic. He helped me negotiate each stage of the PhD program, provided enormous in-kind support through the Institute of Health Promotion Research, and gave me valued teaching opportunities. I profoundly thank you for all that you have done to make this PhD happen and for believing in me despite all the challenges that occurred in my life during the process. Dr. Sally Thorne, my co-supervisor, provided extensive research expertise and in-depth knowledge of the field of chronic illness research. Thank you for your remarkable patience and perseverance in teaching me how to be a doctoral student and how to practice good scientific research. Dr. Bonnie Long was also an active member of my research committee and used her knowledge to provide guidance and feedback throughout my PhD program. Thank you for contributing your experience and knowledge to the process. I would also like to extend my appreciation to Dr. Larry Green who gave me the opportunity to do my PhD at the Institute of Health Promotion Research and was my supervisor for the first few years of my doctoral program before returning to work in the US. In addition, I am greatly appreciative of the support I received from the staff and directors of the Individual Interdisciplinary Studies Graduate Program at UBC. Further, I would like to extend a warm thank you to my PhD colleagues and friends including Dr. Colleen Reid, Pam Brett-Maclean, and Czesia Fuks Geddes for travelling this journey with me and sharing the excitement and struggles of being a graduate student.

I am grateful to the Canadian Institutes of Health Research, the BC Health Research Foundation (now the Michael Smith Foundation for Health Research), the Syd Vernon Foundation, the Lions Gate Healthcare Research Foundation, and the Association of Universities and Colleges for their financial support during my PhD program. I am also incredibly grateful for the continuous support I received from the Disability Resource Centre at UBC. In addition, I would like to thank Jeanette Hansen at the Institute of Health Promotion Research for her continuous help in solving practical issues. As well, I extend my appreciation to Bonnie Sherr Klein for providing a peaceful retreat on the Sunshine coast to write part of my dissertation.
Most importantly, I would like to thank my family and close friends for standing by me while I pursued this challenging road and providing support in countless ways. My husband and son, Jan and Max Mascini, travelled every inch of the research process with me and frequently sacrificed our family time so that I could finish my dissertation. My sister, Tracy Mills, was a great listener and a continual source of strength, inspiration, and laughter over the years. Dan van Klei, my brother-in-law, always brightened my world with his creative and passionate way of seeing and living daily life and made the world of illness experience very vivid in the context of family life. My parents (Carole and Frank Mills) have always supported me in everything I attempted to do and never gave up hope that their daughter would one day finish school. In the last month of writing they went out of their way to provide enormous practical support while I invaded the tranquility of the family cottage with my suitcase of articles and laptop. Thank you for all that you have done to help me in this educational process.
For Jan and Max

who gave me endless love and support, and who sacrificed so much,

I love you and profoundly thank you.

You are my sunshine.
What man actually needs is not a tensionless state
but rather the striving and struggling for some goal worthy of him.

What he needs is not the discharge of tension at any cost,
but the call of a potential meaning waiting to be fulfilled by him.

Viktor E. Frankl
CHAPTER 1: LIVING A GOOD LIFE WITH CHRONIC ILLNESS

Overview

The purpose of this study was to explore the experiences of living well or having a good life in women and men with MS, lupus, or scleroderma who self-identified as having this experience. I posed three research questions:

1. What is the nature and important characteristics of living well experience?
2. What are the biopsychosocial factors and processes by which the experience of living well develops in daily life?
3. How do the various dimensions of living well experience interrelate?

I used an interpretive qualitative research approach embedded in a social constructionist framework to seek answers to these questions and I analyzed the participants’ experiences from an interdisciplinary perspective that considered physical, psychological, and social processes in relation to the life context of the individuals.

The study is described in nine chapters. Chapter 1 provides an introduction and a rationale for studying chronic illness and, in particular, reasons for researching a good life with illness. In Chapter 2, I critically review and analyze the theoretical and empirical literature on what is currently known about living a good life with chronic disease. Through gaps in current knowledge, I show the need to develop a more in-depth and integrated understanding of this experience from the subjective vantage point of those who self-identify as living well. Chapter 3 outlines the research process and design that guided the research process and describes the methods, process of analysis, and strategies for addressing trustworthiness. In Chapters 4 through 7, I present my findings, illuminating the tension-centred context in which the participants situated their living well experiences and then describing and interpreting the nature of these experiences and how they developed within this setting. I show that living well was
about experiencing meaningful aspects of their lives and reveal how two major approaches (and the processes they implied) helped them to align and attain these experiences in relation to their tension-filled lives. In Chapter 8, I discuss my findings and interpretation of the participants' living well experiences in relation to current knowledge and in chapter 9, I concluded with a summary of the research process and findings, and identify some potential implications of the key findings in relation to current research, practice, and policy. I also suggest avenues for future research that have the potential to advance evolving knowledge in the field of chronic illness studies.

**Chronic Disease and Society**

Chronic disease is the number one health problem in developed countries and is “accelerating globally, undaunted by region or social class” (World Health Organization [WHO], 2002, p. 13) due to the aging population, lifestyle changes, urbanization, global marketing, and advances in medical science (Thompson & Kyle, 2000; Watt, Roberts, Browne, & Gafni, 1997; WHO, 2002). Although it is difficult to determine the precise number of Canadians with a chronic disease, it has been estimated that approximately 16 million or more than half of the population lives with some type of chronic condition (Public Health Agency of Canada, 2006; Statistics Canada, 1996). Approximately 10% of adults report long-term disability (40.5% in the over 65 age group; Statistics Canada, 2001) mostly caused by chronic disease (Public Health Agency of Canada, 2006). Autoimmune diseases such as multiple sclerosis (MS), lupus, and scleroderma are an important part of this chronically diseased population and comprise approximately 5 to 8% of Canadians (Canadian Institutes of Health Research, 2003). These diseases are a priority health issue for women given that many of them disproportionately affect the female population (e.g., as much as an 8 to 1 ratio of woman to men with lupus, Canadian Institutes of Health Research, 2003).
Persons with chronic diseases frequently require ongoing monitoring, testing, and treatment by health care professionals over a period of years (Corbin & Strauss, 1988; Dimond, 1983; Rolland, 1988; WHO, 2002), and consume considerable health and social resources (Maes, Leventhal, & de Ridder, 1996; Watt et al., 1997). It is estimated that the total cost of illness, disability, and death from chronic diseases in Canada is more than $80 billion annually and this figure is expected to increase significantly in the next decade with a predicted 58% increase in health care costs (Alliance for the Prevention of Chronic Disease, 2002). Consequently, chronic diseases “challenge the efficiency and effectiveness of current health care systems” (WHO, 2002, p. 11). Canadian research suggests that the overall costs and societal impacts of chronic disease are more related to how an individual lives with the condition than the severity of the underlying illness (Browne, Arpin, Corey, Fitch, & Gafni, 1990) and researchers argue that developing more knowledge on how to support individuals to live well with chronic disease will have beneficial cost savings as well as quality of life (QOL) benefits (Browne et al., 1990; Watt et al., 1997).

**Favourable Outcomes and Experiences**

Over the past few decades, researchers have made considerable effort to understand how individuals live with chronic disease and have frequently documented the adverse impacts and consequences it creates in their lives such as economic hardship, pain, suffering, disability, and social isolation (Charmaz, 1983, 1987, 1991). Diverse fields of research, however, have also provided evidence that some people have a good life despite the challenges those long-term conditions present. Favourable experiences or aspects of chronic illness are increasingly documented in the fields of nursing, medicine, psychology, and sociology, and are expressed in terms of favourable health outcomes, psychological benefits, positive illness experiences, or certain kinds of narratives. For instance, Albrecht and Devlieger (1999) found 54.3% of persons...
with severe disabilities (e.g., arthritis, MS, diabetes, paralysis, head injury, mental illnesses) felt they had a good or excellent QOL. Also, coping studies show that positive emotions and well-being are experienced by some individuals experiencing chronic stress (Folkman, 1997; Folkman & Greer, 2000). Further, research exploring the subjective experience of illness revealed that individuals with chronic illness can experience a wide range of positive phenomena (Thorne & Paterson, 1998). These include experiencing connections with others, growth, transformation, expanding consciousness, transcendence, meaning and purpose in life, and feeling healthy (Baker & Stern, 1993; Charmaz, 1983; Coward, 1990; Fife, 1994; Lindsey, 1996). Persons with chronic illness also describe positive experiences in relation to performing valued roles and functions and participating in desired activities (Loomis & Conco, 1991; McWilliam, Stewart, Brown, Desai & Coderre, 1996). Favourable illness experiences are also identified in narrative research. For instance, Robinson’s (1990) study on the lives of people with MS revealed that some men and women had positive and optimistic ways of living with chronic illness. Moreover, some autobiographical accounts describe experiences of finding new meaning and perspectives of life (Duff, 1993; Wendell, 2002; Yocum, 1995) and suggest that spiritual, intellectual, and emotional capacities are enhanced through living with long-term conditions (Ruffing-Rahal, 1985).

Accordingly, researchers in diverse disciplines have identified the need to learn more about the nature of these experiences and the dynamics of how they develop in daily life (Albrecht & Devlieger, 1999; Asvall, 1992; Cott, Gignac, & Badley, 1999; Thorne & Paterson, 2000). Yet, despite increased awareness that some individuals have favourable illness experiences and that more research had explored these kinds of experiences in recent years (Thorne & Paterson, 1998), we still have a more in-depth and comprehensive understanding of the adverse aspects of living with illness than we do more favourable ones. Until fairly recently, the dominant social and research climate made it more acceptable to develop knowledge on the
challenging and negative aspects of illness (e.g., discrimination, stigma, pain, and suffering) than on the positive ones (Thorne & Paterson, 1998). As a result, many understandings about positive experiences and how they develop have arisen from research looking at variations in chronic illness experience rather than from studies specifically exploring the experiences of those who have a good life with illness. It is possible that those who have positive illness experiences may adapt, cope, or live differently than other individuals and different or additional factors and processes might be involved that have yet to be described and explored.

The knowledge that has been specifically developed on positive experiences is fragmented and fails to provide a cohesive conceptual understanding of the nature of these experiences and how they develop in individual lives (Thorne & Paterson, 1998, 2000). This is partly explained by the fact that chronic illness research has developed along disciplinary lines with specific theoretical perspectives that have led researchers to focus on particular aspects or phenomena in the overall experience (Thorne et al., 2002). Few studies have explicitly explored living a good life with illness from broader and more encompassing perspectives (Mills, 2004). Moreover, research on positive illness experiences rarely considers dynamic aspects or interrelationships that might exist between various elements that comprise the experience or how it develops, or studied these experiences in relation to the broader overall context of an individual's illness experience and life (Thorne & Paterson, 1998). Knowledge that some individuals have a good life or live well with chronic disease pushes us to examine illness as a more multifaceted experience and to create more comprehensive and nuanced understanding of the inherent complexities and variations in chronic illness experience (Thorne & Paterson, 1998).

Consequently, there is a need to develop more knowledge on living a good life with chronic illness by specifically studying this type of experience from the vantage point of those living it. There is also the need to use broader interdisciplinary perspectives that not only consider the nature of the experience and explanatory processes by which it develops but the
dynamic aspects and interrelationships between various elements of the experience and how they work in relation to the totality of living with chronic illness.
CHAPTER 2: UNDERSTANDING A GOOD LIFE: RESEARCH APPROACHES AND FINDINGS

In this chapter, I review what is currently known about living a good life with chronic illness as described in the fields of nursing, medicine, epidemiology, psychology, sociology, and rehabilitation, and show the gaps in current knowledge that formed the basis for the research questions I posed. The first section, “Conceptualizations of a Good Life,” describes theoretical, conceptual, and empirically derived ideas found in writing on health and related ideas, health outcome measures, and interpretive research. In the second section, “Explanatory Understandings of Living a Good Life,” I review understandings of why and how some people have more favourable outcomes or experiences with chronic illness as described in positivistic and interpretive research findings. I conclude with the research questions that emerge from my review of the literature and articulate why I chose the term living well as the working concept to represent a good life in the study.

Conceptualizations of a Good Life

The idea of a good life is complex and theorists and researchers have tried to articulate the essence of this experience, or parts of it in different ways for a variety of purposes. I begin by reviewing the major ideas on health and related concepts that have been influential in the way we think about living a good life. Then, I identify the conceptual ideas inherent in health outcomes that represent well-accepted, population-based understandings of what is important or optimal in living with chronic disease. From here, I describe findings in interpretive research that illuminate aspects of favourable illness experiences and provide further insights into the nature of a good life from the perspective of individuals living with chronic disease.
**Theoretical Perspectives**

Theoretical perspectives are not always explicitly acknowledged or considered in the interpretation of data and development of chronic illness knowledge and yet, influence our understandings and the way knowledge has evolved (Thorne et al., 2002). Hence, it is useful to briefly review the major perspectives of health and related ideas that have influenced chronic illness research in order to illuminate the different perspectives they provide on what a good life can present. A review of the biomedical, humanist, developmental, WHO, wellness, adaptation, and functional perspectives describes the most dominant and influential ideas and enables me to show the different ways in which a good life with chronic disease can be constructed from different vantage points. The theoretical ideas presented have emerged in dominantly Caucasian and Western culture where they have been largely constructed from the vantage point of an individual’s feelings and interpretation of his/her life and thus, do not reflect understandings that might be found in other cultures (e.g., constructions of a good life in relation to a person’s moral responsibility to the community; Taylor, 1994).

In the biomedical model, health is freedom from disease, disability, and physiological abnormalities (Bowling, 2001; Larson, 1991) and is represented by a body with physiological integrity (Kagawa-Singer, 1993). This perspective is centred at the physiological level and provides a means of thinking about a good life with illness in relation to survival, cure, disease remission, and a lack of symptoms. A number of other interpretations, however, construct health in terms outside of, or in addition to the physical state of the body. For example, the humanist and developmental perspectives view health in relation to particular psychological states and processes and provide a view of good life in terms of self-actualization, transformation, or expanding consciousness that occur through human-environment interaction. The humanist model was developed in the field of psychology by Abraham Maslow (1971) who defined it as
an experience of self-actualization and conceptualized it as both an end state and a “process of actualizing one’s potentialities at any time” (p. 47). From his perspective, self-actualization is a holistic experience that focuses on an individual’s inner world and is a latent ability within all persons (Maslow, 1971). Disease can impede or prevent the process of self-actualization because optimal physiological functioning is considered to be one of the important prerequisites (Smith, 1983); however, a number of people have constructed a self-actualized version of health in the context of disease (Seedhouse, 1986). Along similar lines, the developmental view of health originating in nursing science by theorists such as Newman (1986, 1991), Parse (1990), Pender (1987, 1990), and Rogers (1970) conceptualizes health in developmental and transformative terms such as expanding consciousness or transformation (Newman, 1991). Although there are a number of different interpretations, many of them assume that health is represented by the dynamic whole of life experience, not just the physiological integrity of the human body, and that developmental and transformative experiences can coexist in the context of illness (Lindsey, 1994).

Other perspectives of health consider the physical and mental dimensions as well as the social aspects and promote understandings that equate positive experiences of chronic illness with notions of a complete or integrated sense of well-being. For example, the WHO (1947) defines health as a “state of complete physical, mental and social well-being, not merely the absence of disease or infirmity” (p. 29) and as such, conceptualizes health as a positive and enhancing experience beyond the absence of disease (Larson, 1991, 1996) and situates it in a social context (Chisholm 1948; Larson, 1996). As another example, Halbert Dunn (1961), a physician and statistician, introduced the concept of high-level wellness as an interpretation of the WHO’s notion of complete well-being. This perspective constructs a good life as a way of living that involves the complete integration and functioning of an individual’s mind, body, and soul in relation to his/her environment. Dunn (1961) defined wellness as an “integrated method
of functioning which is oriented towards maximizing the potential for which the individual is capable within the environment where he is functioning” (p. 4). In this understanding of wellness, mind, body, and spirit of human beings are an interrelated and interdependent whole, and individuals continually move towards higher and higher levels of integrated functioning. A variety of other interpretations have been articulated in the literature but most of them define it as the complete integration of an individual’s physical, mental, emotional, spiritual, and social dimensions that is achieved via a reciprocal communication process between the individual and their environment (Ardell, 1985; Greenberg, 1985; Jones & Kilpatrick, 1996). In recent years, the concept of wellness has become synonymous with a specific type of lifestyle aimed towards disease prevention, health promotion, and a future state of holistic health (Ardell, 1985; Larson, 1991) that requires individuals to actively enhance their health rather than just trying to maintain it (Bruhn, 1997). Dunn (1961) viewed high level wellness as an approach to disease prevention but more recent interpretations do not preclude wellness in the context of disease (Davidhizar & Shearer, 1997; Mullen, 1986).

Adaptation and functional models of health focus more on the relationship between an individual and their environment or the society in which they live. From these perspectives, a good life with chronic disease is one where the individual achieves flexible adaptation or maximum functioning in society through the performance of appropriate social roles and behaviours. Rene Dubos (1968), a microbiologist and experimental pathologist, developed an adaptational view of health in opposition to the WHO perspective. He moved beyond the absence of disease and an ideal state of well-being to an understanding of a whole person interacting with their physical and social environment (Smith, 1983). Dubos (1968) argued that “health is not an ideal state of well-being achieved through the complete elimination of disease but a modus vivendi enabling imperfect men to achieve a rewarding and not too painful existence while they cope with an imperfect world” (p. 32). From his perspective, health is the
ability of an individual to maintain a flexible two-way interaction with the environment by continually adjusting his or her biological and social responses to cope with the environment and also, changing the environment to meet his or her needs (Dubos, 1961, 1965). A more functional interpretation by Talcott Parsons (1951, 1958), a medical sociologist, conceptualizes health in relation to the social world an individual inhabits and was developed using systems theory in physiology and biology and structural functionalism in anthropology (Parsons, 1951, 1958). Parsons (1958) defined health 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.176) and created a view of health that was constructed in relation to social role structure and control.

Overall, these understandings of health construct a good life in terms of a physical state of the body; a psychological state or way of being; a way of living that integrates mind, body, and soul; adaptation with the environment; or as a way of functioning in daily life or society. Although most of these theories have been developed outside the domain of illness research and hold various assumptions about the nature of the health-disease relationship, they contain ideas that have been influential in the evolution of chronic illness knowledge, particularly, in shaping the conceptual development of health outcomes and the forms of inquiry and findings in interpretive research.

Applied Concepts

Positivistic research has developed some important concepts used in health measures that portray ideas related to a good life. These are expressed in functional ability, well-being, and QOL terms and often represent well-accepted, population-based standards of optimal outcomes for people living with chronic disease. These concepts reflect the influence of the adaptation, functional, and WHO perspectives of health (Bowling, 2001; Hanslувка, 1985; McDowell & Newell, 1996) and suggest that being able to function in society and partake in desired activities,
experiencing pleasant emotions and moods, and achieving a global sense of satisfaction or happiness are important dimensions of living a favourable life with illness.

Functional ability is conceptualized as an individual’s ability to perform certain behaviours in their environment such as physical and daily self-care activities and sometimes more complex self-maintenance activities required to live in the community (McDowell & Newell, 1996). Conceptualizations of function can also include psychological and social functioning (Bowling, 1997; Goodinson & Singleton, 1989; Hawthorne, 1993; Karlson, Katz, & Liang, 1996). In contrast, well-being is described as subjective perceptions of a good life and is defined in relation to affective and cognitive states (Diener, 2000). People have a high level of well-being when “they feel many pleasant and few unpleasant emotions, when they are engaged in interesting activities, when they experience many pleasures and few pains, and when they are satisfied with their lives” (Diener, 2000, p. 34). In recent years, well-being has been increasingly conceptualized in positive terms such as personal growth and interpersonal relationships (Ryff & Keyes, 1995).

In chronic illness research, QOL has largely been conceptualized as a composite of functional status (mental, physical, and social functioning), well-being, life satisfaction, and overall perceptions of health although there are many interpretations in the broader literature (Anderson & Burckhardt, 1999; Bowling, 1997, 2001; Haas, 1999; McDowell & Newell, 1996; Ware, 1996). Within this general framework, however, many conceptualizations of QOL are modified to reflect understandings of disease-specific populations (Bowling, 2001; Hobart, Lamping, Fitzpatrick, Riazi, & Thompson, 2001). Some conceptualizations of QOL reflect cross-cultural understandings (WHOQOL Group, 1998, 1999) but many are grounded in Western culture (Schipper, 1990; Schipper, Clinch, & Olweny, 1996) and reflect Caucasian values of what is important in life (DeJong, 1997). In recent years, some frameworks have been developed that can be modified to reflect a person’s values and account for the fact that different
people value different aspects of their lives and vary in their overall understandings of what is important (e.g., Felce & Perry, 1995; Hickey et al., 1996; Ruta, Garratt, Leng, Russell, & MacDonald, 1994). Some conceptualizations also account for changes in understandings of QOL over time in response to studies showing that individuals with chronic disease undergo a shift in their understanding of the meaning of QOL as a result of living with illness (response shift; Allison, Locker, & Feine, 1997).

Despite the multidimensional nature of QOL conceptualizations and the fact that some of these understandings reflect disease-specific and individual differences, it is widely acknowledged that they do not reflect the complex depth and breadth of what a good life represents from individual perspectives (Carr & Higginson, 2001; Hendry & McVittie, 2004; Zittoun, 1992). QOL conceptualizations in this field of research fragment understandings of a good life into a variety of parts in order to be operationalized in discrete, quantifiable terms (Thorne, 1999b). In addition, they are comprised of domains that are most likely affected by disease or treatments (Cella & Tulsky, 1990; Siegrist & Junge, 1989) and often neglect other aspects of life that might be more important in an individual’s more global understanding of their QOL (Carr & Higginson, 2001; Lawton, 1999; Lubkin & Larsen, 2002). Also, they largely fail to consider the social context (Koch, 2000b) that has been shown to be an important aspect of individuals’ understandings of their QOL (Hendry & McVittie, 2004).

**Interpretive Research**

Interpretive research extends these theoretical and conceptual understandings of a good life by describing this experience from the subjective perspective of those living with illness. Given that this type of research has shifted its focus in the last decade to “uncovering those aspects of chronic illness that are healthy, transformative, and positive” (Thorne & Paterson, 1998, p. 175), there is a growing body of literature on phenomena associated with having a more
favourable or good life with illness. Findings have emerged in studies exploring individual understandings of QOL for persons with chronic illness, in research investigating positive experiences and in more general studies on chronic illness experience.

Studies exploring subjective interpretations of QOL often produce a list of elements found to be important in individuals’ understandings with the understanding that women and men with illness and disabilities feel they have a high QOL when they can attain or accomplish meaningful goals in the important aspects of life (Goode, 1994; Stuifbergen & Rogers, 1997). This research shows that the areas of physical/functioning, psychological/spiritual, family and interpersonal interactions, social environment/work, economics, and sense of self are important in individuals’ understandings (Archenholtz, Burckhardt, & Segesten, 1999; Bertero & Ek, 1993; Dale, 1995; Ferrans, 1994). For example, in studying the subjective perspective of 204 individuals living with different chronic diseases (e.g., diabetes, colon cancer, colitis, rheumatoid arthritis, osteoarthritis), Burckhardt, Woods, Schultz and Ziebarth (1989) found that “independence, being physically active, ability to care for self, being healthy, having a sense of security, positive interaction and relationships with others, and meaning in life” (p. 351) were important dimensions of the participants’ QOL understandings. Similarly, Archenholtz et al. (1999) found that relationships with family and friends, having a comfortable living environment, feeling healthy, receiving social support and functional services, being able to participate in important activities, having a sense of psychological, physical and economic independence, and having self-integrity were essential elements of QOL for 100 women living with lupus or arthritis. Likewise, in a study looking at the QOL experiences of persons with MS, Stuifbergen and Rogers (1997) found that participants described their QOL in relation to “family, functioning to maintain independence, spirituality, work, socioeconomic security, and self actualization” (p. 9).
Although these studies commonly described the importance of relationships, being active and engaged in activities, feeling healthy, and having independence, they differed in some areas such as meaning in life, sense of security, and having a comfortable living environment. This reflects the fact that interpretive studies on QOL reflect commonalities as well as some variations. For example, research that has explored understandings of QOL in individuals with different chronic diseases has expressed a number of common themes but also noted some important variations. For example, in the aforementioned study by Archenholtz et al. (1999) income was an important part of QOL for individuals with lupus whereas being able to work was essential for those with arthritis. On the other hand, in a study by Burckhardt et al. (1989) individuals with osteoarthritis emphasized freedom from pain in their understandings of QOL whereas those with diabetes focused on being in control. Yet, in another study, the living conditions and amount of personal space were significant aspects of the QOL of individuals living with ulcerative colitis (Brydolf & Segesten, 1996).

In general, findings on understandings of QOL in persons with chronic illness support the important areas articulated in population-derived conceptualizations of QOL but also identify some variations and additional dimensions that have not been well captured in dominant conceptualizations. Some research, for example, has shown that the aspects of QOL that are important to individuals with chronic illness are intertwined and take on meaning in relation to the relationships and context of their lives (Albrecht & Devlieger, 1999; Hendry & McVittie, 2004). For example, in their study of 153 people with disabilities (arthritis, MS, heart conditions, HIV, spinal cord, and head injuries), Albrecht and Devlieger (1999) concluded that a good QOL represents a balance between body, mind, and spirit, and a harmonious set of relationships within the social context and external environment. In another study on QOL understandings in older persons, Hendry and McVittie (2004) found that participants did not “segment their lives into component parts” and “commonly linked one aspect of QOL to other aspects of the experience.”
Moreover, they found that the participants’ interpretations of QOL were not entirely constructed around their own lives and often included understandings of, and comparisons to other people and the way they lived. These authors also found that participants viewed their experiences of QOL as ones that they actively shaped and controlled. In addition, some researchers have commented on how the participants’ understandings of QOL were constructed in relation to both positive and negative illness experiences (Hendry & McVittie, 2004; Reynolds & Prior, 2003).

Studies exploring positive illness experiences described as thriving (e.g., Loffer, 2000), experiencing health (e.g., Leonard, 2002; Nosek et al., 2004; Schmidt, Brauer, & Peden-McAlpine, 2003) and transformation, transcendence or expanding consciousness (Neill, 2002, 2005; Paterson, Thorne, Crawford, & Tarko, 1999) have identified aspects of positive experiences that support interpretive findings on QOL (e.g., the importance of function and relationships). For example, Nosek et al. (2004) found that women with physical disabilities constructed the experience of being healthy in terms of their functional ability. However, this body of research has largely focused on exploring and illuminating the importance of spiritual dimensions including meaning and purpose as well as positive and transformative experiences of self. For example, Loffer (2000) found that being connected to self, having meaning, being in control, feeling connected to and supported by others, and new perspectives were important aspects of thriving with illness for women living with rheumatoid arthritis. Similarly, Lindsey (1994) found that honouring the self, seeking and connecting with others, creating opportunities, celebrating life, transcending self, and acquiring a state of grace were essential aspects of experiencing health for persons with a range of chronic illnesses and disabilities. Other studies such as those by Moch (1989, 1990, 1998) have also supported these kinds of findings. She found that self-awareness, connectedness with others, and a supportive environment were essential components of experiencing health in the context breast cancer. Thus, a favourable
sense of self was an integral part of positive illness experiences but as these examples suggest, the findings were described and interpreted in different ways (connected self, transcended self, or awareness of self). In addition, other studies have described a positive sense of self in terms of social roles. For example, in Kagawa-Singer’s (1993) study of cancer she found that the experience of health was related to an individual’s self-integrity that was conceptualized as a sense of self in which one’s roles in life are integrated and meaningful.

Research that has not explicitly sought to explore positive illness experiences has also documented a wide number of phenomena that seem part of having a better life with illness. These include feelings of control (e.g., Kendall et al., 1989; Michael, 1996), positive attitudes and thinking (e.g., Gloerson et al., 1993; Kendall et al., 1989; Loomis & Conco, 1991; Neill, 2005), connectedness (Koopman & Schweitzer, 1999; Predeger, 1996; Predeger & Mumma, 2004); meaning and purpose (e.g., Baker & Stern, 1993; Fife, 1994; Scammell, 2001; Taylor, 2000), and transformation and transcendence (e.g., Carpenter, Brockopp & Andrykowski, 1999; Coward, 1990; Coward & Lewis, 1993; Curtin, Mapes, Petillo, & Oberley, 2002). Some studies have also described doing things you want to do (Loomis & Conco, 1991; McWilliam et al., 1996), being active (Gloerson et al., 1993) and fulfilling social roles (Kagawa-Singer, 1993) as essential aspects of the experience.

Overall, findings on positive illness phenomena support many of the ideas found in the previously described bodies of literature. However, the sheer diversity of terminology and concepts emerging in this research has created a confusing and fragmented body of knowledge about living a good life with chronic illness (Lindsey, 1994; Thorne & Paterson, 1998, 2000). These limitations reflect the fact that much of this research has been shaped by theoretical and conceptual views of health, particularly developmental and humanistic perspectives (e.g., Leonard, 2002; Neill, 2005; Schmidt et al., 2003). Specific conceptualizations of QOL (e.g., Hendry & McVittie, 2004) advance knowledge on particular aspects of the experience but do not
necessarily promote the development of a more comprehensive and integrated understanding of what a good life might entail for persons living with chronic illness (Mills, 2004). Although some authors acknowledge interrelations between the themes in their studies (e.g., Lindsey, 1994; Paterson et al., 1999) or between their study and other work in the field (e.g., Barroso, 1996; Fife, 1994; Paterson et al., 1999), a lack of discussion of interrelatedness of findings both within and across studies has made it difficult to get a clear understanding of major patterns and themes involved and to advance a more cohesive conceptual understanding from subjective and individualized perspectives (Lindsey, 1994; Thorne & Paterson, 1998). Also, few studies have explored how the nature of having a good life with illness or having favourable experiences might change or evolve. Consequently, there is a need to study experiences of having a good life in a way that promotes the development of a more comprehensive understanding and considers interrelationship between various elements of the experience and their nature over time.

**Explanatory Understandings of Living a Good Life**

Positivistic and interpretive bodies of research have also developed knowledge on the factors and processes that seem to be important for enabling individuals to do better with chronic illness and a review of this research reveals some important gaps. These studies are often embedded in specific explanatory frameworks and theoretical perspectives on what influences health and QOL or what influences adjustment, adaptation or coping with chronic illness. These models have been developed within particular disciplinary orientations and as such, reflect perspectives developed within biomedicine, epidemiology, psychology, and nursing. As well, some approaches represent an amalgamation of a number of different perspectives (e.g., biopsychosocial, ecological, or health promotion frameworks). The more common approaches used to develop explanatory understandings in chronic illness research include the biopsychosocial model (Engel, 1977), stress and coping theories (e.g., Lazarus & Folkman,
adoption models (e.g., Livneh & Antonak, 1997; Pollock, 1986; Roy, 1984), and QOL frameworks (e.g., Stewart, Ross, & Hartley, 2004; Stuifbergen & Rogers, 1997; Walker, Jackson, & Littlejohn, 2004).

**Positivistic Research**

Health and social science researchers have tested a large number of biological, demographic, and psychosocial variables in the search for explanations of why some individuals with chronic illness do better than others as measured in terms of functional ability, health status, well-being, and QOL. Although the knowledge developed within these studies is limited by looking at relationships between factors and discrete, measurable outcomes that do not reflect a comprehensive understanding of what living a good life with illness entails, this research has provided insights into factors that are likely important for living a better life with chronic illness.

Although findings are complex and sometimes contradictory, there is a general understanding in the literature that socioeconomic status, ethnicity, sex, disease severity (and other disease measures), social support, perceptions of control, and self-efficacy are associated with better health outcomes for persons living with long-term conditions (Mitchell, Benito-Leon, Gonzalez, & Rivera-Navarro, 2005; Seawell & Danoff-Burg, 2004). Research generally shows that higher levels of income and education (Alarcon et al., 2004; Karlson et al., 1995), social support (Bae, Hashimoto, Karlson, Liang, & Daltroy, 2001; Moser, Clements, Brecht, & Weiner, 1993; Schwartz & Frohner, 2005), perceived control (Livneh, Lott, & Antonak, 2004; Persson, Berglund, & Sahlberg, 1999; Scharloo & Kaptein, 1997); and self-efficacy (Barnwell & Kavanagh, 1997; Riazi, Thompson, & Hobart, 2004) are associated with more favourable outcomes. As well, lower levels of disease severity or other disease indices (Georges et al., 2004; Henriksson, Fredrikson, Masterman, & Jonsson, 2001); and being White (Odutola & Ward,
2005; Sutcliffe, Clarke, Gordon, Farewell, & Isenberg, 1999) seem to be related to doing better with chronic illness.

Even though this research provides evidence of a number of explanatory factors, it is acknowledged that no single factor or simple combination of factors can fully explain why some people have higher levels of functioning, well-being, or QOL. For example, studies looking at the complex interplay of a number of variables (e.g., disease severity, social support, self-efficacy, health promoting behaviours) influencing QOL in persons with chronic illness showed that these determinants do not account for all the variance in perceived QOL (Stuifbergen, Seraphine, Harrison & Adachi, 2005; Stuifbergen, Seraphine, & Roberts, 2000). In addition, the mechanisms of interaction involved in these relationships are not well-understood (Anderson & Armstead, 1995; Bird & Rieker, 1999; Callaghan & Morrissey, 1993; Kington & Smith, 1997). Studies suggest that biological, psychological, behavioural, and sociocultural processes are operating in complex ways to create these relationships (Adler & Ostrove, 1999; Kristenson, Eriksen, Sluiter, Starke, & Ursin, 2004). For example, in research on the sex-health relationship, biological differences do not provide complete explanations for sex differences in outcomes and researchers recognize that there are psychological (e.g., differences in personality, social support, coping skills) and sociocultural (e.g., shared beliefs about behaviours, socioeconomic status, physical environment) explanatory mechanisms operating (Widom, 1984).

Researchers also suggest that individualized and contextual elements are important for understanding the exact pathways (Berger, 1998; Dimsdale, 2000; Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991). For example, there is increasing awareness that ethnicity influences a wide range of perceptions, beliefs, and behaviours of an individual that may influence health outcomes and treating ethnicity as a quantifiable variable fails to expand our understanding of the complex and individualized elements that may help to explain the ethnicity-health relationship (Anderson & Armstead, 1995; Bates, Rankin-Hill, & Sanchez-Ayenez, 1997;
Berger, 1998; Dimsdale, 2000). As another example, research on social support and health emphasizes the importance of individual and situational elements in understanding the mechanisms of interaction (Bredenberg, 1991; Williams, Barclay, & Schmied, 2004). Studies show, for example that not all social support interactions have a positive influence on health outcomes and that the nature of the relationship depends on the needs of a particular individual (Coyne & DeLongis, 1986; Nosek et al, 2004; Revenson et al., 1991).

There is evidence to suggest that coping and related processes also play an important role in positive health outcomes for persons living with illness (Aldwin, 1994; Cohen & Lazarus, 1983; Maes et al., 1996). Studies in the stress and coping paradigm have contributed extensive knowledge on cognitive and behavioural processes and factors that are important in understanding variations in how people cope with the stress of living with chronic disease (de Ridder & Schreurs, 1996; Maes et al., 1996). In relation to understanding how coping influences health outcomes, a large number of studies have looked at the relationship between coping strategies and QOL in chronically ill populations (e.g., Burckhardt, Clark, O’Reilly, & Bennett, 1997; Curtis, Groarke, Coughlan, & Gsel, 2004; Herbert & Gregor, 1997; Vosvick et al, 2002). Despite the fact that social support or problem solving forms of coping are associated with positive outcomes in some studies (Folkman & Moskowitz, 2004), coping strategies have not been shown to have a strong relationship with measures of QOL or other indicators of adaptation (de Ridder & Schreurs, 1996).

However, recent studies have begun to explicitly explore coping processes related to psychological health at both theoretical and empirical levels as part of a shift in psychology towards focusing on health and thriving (Ickovics & Park, 1998; Seligman & Csikszentmihalyi, 2000) and creating a more balanced view of individuals’ coping experiences, particularly their adaptive strengths (Holahan, Moos, & Schaefer, 1996; Lazarus, 2000). Awareness that positive outcomes can result from stressful situations (Holahan et al., 1996; Stewart, Sokol, Healy, &
Chester, 1986) and that the factors and processes creating positive outcomes may differ from those that produce more distress-reducing effects (Aldwin, 1994) have led to research that has illuminated other kinds of coping processes that seem to be important for influencing positive outcomes in situations of chronic stress such as living with chronic disease (Aldwin, 1994; Folkman & Moskowitz, 2004).

Studies in the last decade have suggested that particular types of coping such as meaning-based coping (Folkman, 1997; Folkman & Greer, 2000; Folkman & Moskowitz, 2000), benefit-reminding, and benefit-finding (Affleck & Tennen, 1996; Tennen & Affleck, 1999) that are individually-centred processes, and relationship-based coping (O’Brien & DeLongis, 1996, 1997) that involves interpersonal mechanisms are associated with positive outcomes (positive affect or emotion) in persons living with chronic stress. Folkman and colleagues, for example, have been exploring positive emotion in the context of stress and have concluded that the “common theme in the coping processes related to positive emotion is their link to the individual’s important values, beliefs, and goals that comprise the individual’s sense of meaning” (Folkman & Moskowitz, 2004, p. 766). In one study on caregivers of persons with AIDS, Folkman (1997) found four major types of coping processes associated with a positive psychological state: the use of cognitive strategies to reframe a situation in positive terms; pursuing personally meaningful goals; spiritual beliefs and practices; and finding positive meaning in everyday events. In addition, she found that positive psychological states not only result from meaning-based coping processes but also served to sustain coping and appraisal processes in the context of continual stress. These findings indicated that a recursive relationship between positive affect and appraisal and coping processes might be operating (Lazarus, 2000). Folkman and Moskowitz (2000) concluded that these kinds of processes all involve “creating, reinstating, or reinforcing meaning in the midst of stress” (p. 651).
Another rapidly growing body of literature explores relationships between benefit-reminding, benefit-finding, and emotional health and well-being (Tennen & Affleck, 2002) and suggests that these processes may influence the ability of individuals to experience psychological well-being in the context of unfavourable conditions (Affleck & Tennen, 1996; Tennen & Affleck, 1999, 2002). For example, Affleck and Tennen’s (1996) review of the literature found that the process of benefit-reminding was linked to positive adaptation and well-being in groups coping with a number of major medical problems such as heart attacks, breast cancer, chronic rheumatic diseases, and stroke. In one of their own studies on women with fibromyalgia who were experiencing chronic pain, Tennen and Affleck (1999) found that individuals who reminded themselves of the benefits of their illness were more likely to experience a positive mood regardless of how much pain they had on that particular day. Benefit-finding has also been increasingly explored in the coping and trauma literature (Tennen & Affleck, 2002). For example, a study exploring benefit-finding in MS found associations with life satisfaction, positive affect, and dyadic adjustment (Pakenham, 2005). A growing body of research suggests that finding benefits in difficult circumstances is associated with positive emotions and health outcomes (Affleck & Tennen, 1996; Tennen & Affleck, 2002), although the relationship is complex and findings do not always show a strong relationship (Sears, Danoff-Burg, & Stanton, 2003; Tomich & Helgeson, 2004).

In addition, there is an evolving awareness that appraisal and coping processes take place in an interpersonal context and increasing evidence that interpersonal relationships and social transactions profoundly influence coping and well-being in situations of chronic stress (O’Brien & DeLongis, 1997). Studies show that specific types of relationship-focused processes are also important for enabling individuals to have more favourable outcomes with chronic illness by helping them to build strong relationships with family and friends (O’Brien & DeLongis, 1996, 1997). These coping processes help individuals to manage, regulate, build, and preserve
relationships in times of stress by using active engagement, protective buffering, negotiation, conflict resolution, collaboration, or accommodation (Coyne & Smith, 1991; O'Brien & DeLongis, 1996, 1997).

Research in this field also shows that doing well in adverse conditions depends upon a dynamic interaction between appraisal and coping processes, and personal and environmental resources (Eckenrode; 1991; Kessler & McLeod, 1985). Individual characteristics (e.g., personality), environmental factors (e.g., social support) and disease-related factors (e.g., characteristics of a chronic illness) influence positive outcomes through their interaction with appraisal and coping processes (Folkman & Greer, 2000; Schaefer & Moos, 1992). For example, Folkman and Greer's (2000) work suggests that personality variables that influence the primary appraisal of a stressor as a challenge are important in creating positive affect in situations of chronic stress. The literature suggests that variables related to a sense of personal control may be important for having positive outcomes in the context of chronic stress (Folkman & Greer, 2000; Holahan et al., 1996; Moos & Schaefer, 1993) and reviews by the aforementioned authors suggest that self-efficacy, hardiness, dispositional optimism, mastery, and a sense of coherence may also play a role, although findings are inconsistent in the literature (Tennen & Affleck, 1998, 1999). Other types of personal and demographic factors such as age, gender, social class, race, philosophical or religious commitments, and prior crisis experience seem to also influence the ability of an individual to respond to a crisis in a favourable way but many studies do not address these variables (Maes et al., 1996; Schaefer & Moos, 1992).

In addition, environmental factors (e.g., social support, family cohesion, supportive services, community resources, and post crisis environment; Schaefer & Moos, 1992) have also shown to play a role in the relationships between coping and psychological health. For example, research has explored the role of social support in individuals coping with chronic illness (Schreurs & de Ridder, 1997; Thoits, 1986) and Holahan and Moos (1990) found that individuals
whose functioning improved in the context of high stressors had an increase in family support and in later research, found that strengthening of interpersonal relationships may be involved in the creation of psychological growth in the context of stress and crisis (Holahan et al., 1996).

Characteristics of a chronic illness or associated tasks may also influence the nature of the relationship between stress, coping, and favourable emotions and some theoretical models suggest that disease-related characteristics likely influence how coping processes relate to positive outcomes (e.g., Maes et al., 1996). Although knowledge on how these characteristics influence coping processes and positive outcomes is limited (de Ridder, Schreurs, & Bensing, 1997), a review of studies on life crisis and personal growth provides evidence to suggest that severity, duration, predictability, controllability, and pervasiveness of the stress producing event may be important for influencing outcomes such as personal growth (Schaefer & Moos, 1992).

Overall, coping research has provided further insights into some coping processes that seem to play an important role in positive outcomes for persons living with chronic stress or illness and as such, extends knowledge on the determinants of health outcomes previously described. New developments such as meaning-based coping, benefit-reminding, benefit-finding, and relationship-based coping seem to be important for understanding positive emotions and outcomes in the context of chronic stress. Studies also suggest that personality characteristics, environmental factors such as social support, and disease-related factors play a complex and interactive role in the relationship between coping and health outcomes. However, most of this research has explored coping processes in relation to measures of positive affect and consequently, provides limited knowledge on how these coping-related processes and factors might influence other types of positive outcomes or play a role in a more multifaceted understanding of living a good life with chronic disease. Folkman and Moskowitz (2004) argue that “we seem only to have scratched the surface of understanding the ways in which coping actually affects psychological, physiological, and behavioural outcomes both in the short- and
the longer-term” (p. 748). Also, coping studies have largely been concerned with particular cognitive and behavioural efforts at the individual level (Folkman & Moskowitz, 2004) and although there is increasing recognition that coping is situated in an interpersonal context (O’Brien & DeLongis, 1997), there is a more limited emphasis on understanding how context interacts in the coping-health process in situations of chronic stress and illness (Aldwin, 1994; Lazarus, 1991, 1992). Further, even though the literature discusses the role of person, environment, and disease factors, there is not a complete understanding of how all the various elements of the coping process interrelate (Holahan et al., 1996). Consequently, researchers increasingly argue for using more interpretive approaches and methods to gain deeper insights into the processes and context that shape more favourable outcomes in situations of chronic stress and illness (Folkman & Moskowitz, 2000).

**Interpretive Research**

Interpretive research has also begun to develop a body of knowledge on the explanatory factors and processes involved in having a good life or more favourable experiences with chronic illness and this knowledge is augmented by extensive findings in the broader qualitative literature on what shapes chronic illness and causes variation in experience. It has long been recognized that a whole range of factors influence an individual’s chronic illness experience (Corbin & Strauss, 1985, 1988) and researchers acknowledge that they are shaped by a gendered and socially constructed environment in which they are located (Lorber, 1997; Radley, 1994; Thorne, McCormick, & Carty, 1997) and sociocultural and political processes (Jensen & Allen, 1994; Thorne, 1999b; Thorne & Paterson, 2000). Based on her extensive research on chronic illness experience, Charmaz (1994, 1995, 2000a) found that complex social processes related to social class, economic status, and gender are important for understanding the way individuals live with chronic illness. The literature shows that processes related to socioeconomic factors
and ethnicity (Anderson, 1985, 1987, 1991; Anderson, Blue, & Lau, 1991; Anderson et al., 1995; Zeddies, 2001) play an important role in variations in chronic illness experience. It is likely that these processes play some role in how individuals come to experience a better life with chronic illness, although they have not been well explored in positive illness experiences.

There is a developing body of knowledge on individual and interpersonal processes that shape how individuals have positive experiences. Although many of these studies have been descriptive and exploratory in nature, in recent years some have explicitly sought to develop explanatory understandings of how these experiences evolve in the context of individual lives. Even though the exact composition of the explanatory factors and strategies vary in scope and nature between studies, this body of research has commonly illuminated processes involved in connecting with others and establishing positive relationships; developing spirituality; functioning and engaging in day-to-day life; finding purpose and meaning; developing favourable understandings of self and identity; and having positive attitudes. These processes largely parallel the important domains of life identified in people's understandings of a good QOL or having a positive illness experience. These themes are commonly described as the factors and strategies that participants feel have helped them to have a good QOL, do well, thrive, feel healthy, or experience wellness. Albrecht and Devlieger (1999), for example, found that developing a sense of control over body and mind; a 'can do' approach to life; a sense of purpose, meaning, and harmony; a spiritual foundation and outlook; and giving and receiving emotional support from others were the most common approaches for having a good QOL for persons with serious or moderate chronic disabilities (arthritis, MS, spinal cord injury, HIV/AIDS, heart conditions). Also, in a study on being healthy, Nosek et al. (2004) found that having a positive, active mental state, and social support were important aspects for women with physical disabilities and in other research on women thriving with rheumatoid arthritis, Loffer
(2000) found that it involved a journey of self-discovery, taking control of what they could do in life, making connections and building support, gaining perspective of life, and sharing what they learned with others who had chronic illness. Other research also supports these common explanatory ideas. For example, based on findings of a meta-study of 292 qualitative studies on chronic illness, Paterson (2001) described how individuals experienced wellness by learning about their disease, understanding their body’s unique response to illness, sharing knowledge of the disease with other people, and creating supportive environments. Many other studies have also illuminated the importance of managing physical illness (often through health promoting behaviours; e.g., Stuifbergen & Rogers, 1997).

Some research has illuminated specific cognitive approaches that seem to be important for having a good life (King et al., 2003). Also, some studies have described processes of self and suggested that a good life with illness involves being able to transform, integrate, or reformulate one’s sense of self (e.g., Loffer, 2000; Paterson, 2001; Paterson et al., 1999). For example, in a study of individuals with Type 1 diabetes, Paterson et al. (1999) suggested that a process of restructuring oneself could bring feelings of health, a renewed sense of life, and deeper connections with others. However, the descriptions of these processes and interpretations of what they seem to achieve in an individual’s life differs between studies. In Kagawa-Singer’s (1993) study, for instance, she found that experiencing health with cancer was created by the processes of negotiating and reestablishing a sense of self as a productive and valued individual in society. Albrecht and Devlieger (1999), on the other hand, found that the experience of a good QOL was dependent upon the “ability of the self to build and manage a balance between the body, mind, and spirit ... and to establish and maintain an harmonious relationship with the environment” (p. 986).

Also, a number of studies have identified the importance of particular behavioural and lifestyle strategies. For example, Loffer’s (2000) research on women who are thriving with
rheumatoid arthritis found that counselling, exercise, martial arts, volunteer work, alternative therapies, participating in religious activities, medication, music, humour, relaxation and stress management techniques, education, and building a support system enabled individuals to achieve a sense of health and well-being in their lives. Similarly, in Stuifbergen and Rogers’ (1997) study of individuals with MS, participants used exercise, nutritional strategies, lifestyle adjustments, and seeking and receiving interpersonal support to live a good QOL. In addition, in a study of why some people do well with AIDS, Gloerson et al. (1993) found that participants used strategies such as participation in leisure and social activities, developing social interactions, and using social support to live a more favourable life.

Findings also show that cognitive, emotional and behavioural approaches for having a good life are influenced by an individual’s personality, resources such as social support and assistive devices, spiritual beliefs, past experiences, and advice of friends, family, and health care professionals (Albrecht & Devlieger, 1999; King et al., 2003; Paterson et al., 1999; Stuifbergen & Rogers, 1997). For example, Paterson et al. (1999) found that personality styles (e.g., being able to see opportunities, being action oriented, and having a sense of responsibility) played a role in a participant’s ability to interpret a new event as a challenge to be embraced. Also, King et al. (2003) found that the personality traits of perseverance and determination and having social support and spiritual beliefs were important protective factors in enabling some individuals to do well with chronic disabilities. Further, the use of social support and assistive devices helped in the process of enabling some individuals to have a good QOL by “reducing the gap between individual capacity and environmental constraints” (p. 985) in Albrecht and Devlieger’s (1999) study of 153 persons with chronic illnesses and disabilities. Paterson (2001) also suggests that there is some evidence in the literature that health care professionals, partners and family, or individuals with same illness can influence the development of a more favourable perspective and response to illness although this has not been well researched.
Overall, the studies using interpretive frameworks reveal some deeper insights into the complexities and individualized elements of having a good life with chronic illness and provide some knowledge of the complex processes operating at cognitive, behavioural, and interpersonal levels. However, this body of knowledge is limited in a number of respects. At a conceptual level, it is sometimes difficult to distinguish what reflects the nature of living a good life from the factors, strategies, and processes by which it develops over time. It is not always clear whether the phenomena described comprises a favourable life with illness or is an explanatory process shaping the experience. For example, several authors describe elements of living a good life in relation to having a sense of control or mastery over disease and life (e.g., Loffer, 2000) whereas other studies suggest that a sense of control is a factor influencing the development of more favourable illness experiences (e.g., Albrecht & Devlieger, 1999; Gloerson et al., 1993; Paterson et al., 1999). Also, within the same study, some researchers have found that transformation can be both an outcome of living with illness and a process for managing and reducing impacts (Paterson et al., 1999). Lindsey (1994) eluded to this conceptual challenge when she argued that the linear, sequential categorization of her findings into the “healing journey” and “experiences of feeling healthy” was only for purposes of data presentation because the “healing journey and the experience of feeling healthy are expansive, synergistic, interconnected, and inter-related” (p. 152) in individuals’ experiences of feeling healthy.

In addition, findings range from detailed cognitive strategies to general attitudes to broader behavioural or lifestyle approaches and although these findings collectively provide an important body of knowledge, they do not provide many insights into how these different kinds of approaches might work together or inter-relate in developing more favourable illness experiences. Reynolds and Prior (2003) argued that the interdependence of values, attitudes, and strategies was important for understanding how their participants had a good QOL with MS but most of the literature has not discussed relationships between processes involved in the creation
of a good life with illness. Thorne and Paterson (2000) suggest that there may be a “kind of embedded complexity that may be uncovered when research methods permit analysis of various co-existing factors in interaction rather than in isolation” (p. 17) and researchers argue that there is a need for more research on how various types of processes interact to create specific types of illness experiences (Kelly & Field, 1996; Thorne & Paterson, 1998). Also, researchers often list factors or important strategies without exploring when or how they are used over time. Reynolds and Prior (2003) found that having a good QOL for women with MS required a number of flexible and evolving approaches over time and noted that in most circumstances “several years elapsed before participants had successfully constructed positive ways of interpreting the illness experience, clarified goals, experimented with different lifestyles, and accepted support” (p. 1243). However, most other research has not explored the nature of these explanatory processes over time in any depth and there is need for more studies on how some individuals with chronic illness live a good life that explores interrelations between explanatory processes and the dynamics of how these processes might work over time.

**Research Questions and Living Well Concept**

Based on these identified gaps in current knowledge, I studied the experiences of living a good life with chronic illness using the subjective understandings of those who had experienced the phenomenon. I posed three research questions to further knowledge development:

1. What is the nature and important characteristics of living well experience?
2. What are the biopsychosocial factors and processes by which the experience of living well develops in daily life?
3. How do the various dimensions of living well experience interrelate?
In the research, I choose to use the working term *living well* to represent a good life with chronic illness because this concept is not situated in a theoretical view of health or predefined conceptualization of QOL, wellness, or other related concepts and thus, enabled me to explore these experiences outside of a specific conceptual framework. The term *living* reflected the view that chronic illness is a dynamic experience firmly rooted in the broader life context (Gerhardt, 1990) and the qualifier *well* acknowledged that persons living with long-term conditions evaluated these types of experiences positively in relation to other types of illness experiences. Chronic illness was defined as the experience of living with a medically diagnosed disease that is incurable, dynamic, and continuous across an individual's lifespan (Curtin & Lubkin, 1990), and was interpreted as a complex and multifaceted experience that extends through all aspects of life (Corbin & Strauss, 1988; Paterson, 2001; Royer, 1998; Thorne & Paterson, 1998).

A social constructionist epistemology, interpretive theoretical stance, and grounded theory methods formed the basis of the research approach used to explore my research questions and living well with chronic illness was analyzed as an intersubjective experience shaped by physical, psychological, and sociocultural processes.
CHAPTER 3: RESEARCH CONTEXT AND PROCESS

The purpose of this chapter is to provide an overview of the theoretical perspectives within which the research process and findings of the study are situated and to describe the design and methods used to develop my constructed interpretation of the participants' living well experiences. This includes an overview of the major analytic strategies and methods I used for data collection, analysis, and interpretation as well as my approach to addressing the goodness or trustworthiness of the research.

Theoretical Perspectives

In the previous chapter, I revealed the importance of using people's subjective and interpretive experiences as an important avenue to further knowledge on shared experiences of living well and emphasized the need to look at the nature and development of these experiences using the individuals' thoughts, feelings, and actions to reveal insights in the biopsychosocial processes involved. Current gaps in knowledge suggest that the role of cognitive and behavioural processes need to be considered in relation to social and contextual processes to advance understanding of the interrelations between understandings, interactions, and context in living well with chronic illness. The resulting research questions situate this research on living well with chronic illness in a social constructionist epistemology and an interpretive theoretical stance.

Social constructionism is an epistemological understanding that knowledge is constructed by the mind rather than something discovered by human beings (Schwandt, 1994) and it assumes the existence of a real material world (realism) and multiple social realities (relativism) that are created through the words and interactions of individuals (Charmaz, 2000b). Material things in the world exist independently of our consciousness but meanings are created by consciousness
and cannot exist without it (Crotty, 1998). Knowledge exists in the relationship between a person and the world and is created or constructed in the intersubjective interaction between individuals (Guba & Lincoln, 1994; Kvale, 1996; Schwandt, 1994). Because knowledge of what people are doing and saying “always depends upon some background or context of other meanings, beliefs, values, practices, and so forth,” (Schwandt, 2000, p. 201) knowledge and understanding of human behaviour in a social constructionist paradigm is interpretation. Within this construction of human experience, “data do not provide a window on reality. Rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts. Researcher and subjects frame that interaction and confer meaning upon it” (Charmaz, 2000b, p. 524). This epistemological stance predetermined that the outcome of the research process was a socially constructed interpretation of living well experience that reflected the interaction between me and the participants and the contexts within which we are situated.

The philosophical and theoretical foundations of the interpretive perspective guiding this research are best reflected in symbolic interactionism of The Chicago School (1920-1950, Blumer-Mead model) (Blumer, 1969), and American Pragmatism (Annells, 1996; Strauss & Corbin, 1990). This theoretical perspective derived from the philosophy of Pragmatism in the early 19th century (Schwandt, 1994) and was influenced by George Herbert Mead, a social psychologist, who taught philosophy at the University of Chicago in 1962. Mead’s interactionist perspective looked at self through social roles, expectations, and perspectives cast on self by society and by those within society and these ideas were developed into a distinct sociological paradigm and methodology known as symbolic interactionism by Herbert Blumer, a sociologist of The Chicago School (Blumer, 1969). Symbolic interactionism is both a theory of human behaviour and an approach to the study of human conduct and group life (Annells, 1996; Chenitz & Swanson, 1986). Although there are many variations of this theoretical perspective (Schwandt, 1994), there are three basic tenets: “a) human beings act towards things on the basis
of meanings that these things have for them; b) the meaning of objects derives from social interaction, and c) meaning is arrived at through an interpretive process” (Blumer, 1969, p.2).

This tradition has historically been interested in the micro, individual experience of illness and in giving primacy to the patient’s perspective of illness (Conrad, 1990) and from this theoretical perspective, researchers have explored chronic illness as an experience that was shaped and influenced through the thoughts, feelings, and actions of the ill person (Corbin, 1998). In this research, symbolic interactionism provided a means of looking at the nature and development of living well experience in relation to the meanings that people gave to their situations (Lindesmith, Strauss, & Denzin, 1988) and the meaning-making processes involved in their lives (Denzin, 1992).

Research Design and Methods

Overview

The design of the study involved interviewing 31 women and men who felt they were living well with MS, lupus, or scleroderma and analyzing the resulting data using methods developed in grounded theory and interpretive research. In this section, I describe the research process and provide an outline of the specific “how-to” or methods I used to answer the research questions and create an interpretation of their living well experiences within the boundaries established by the social constructionist and interpretive theoretical and philosophical assumptions of the study. The outcome or product of the research process was a “constructed truth” or shared understanding (Thorne, Kirkham, & O’Flynn-Magee, 2004) of the nature of living well with chronic illness experience.

The study received ethical approval through the Behavioural Research Ethics Board at the University of British Columbia prior to the commencement of data collection. Throughout
the research process I maintained a reflexive attitude and carefully considered ethical issues (Davies & Dodd, 2003).

Data Collection

Sampling Strategy and Recruitment Process

In order to answer my research questions and develop knowledge on living well with chronic illness experience, it was imperative that I find individuals who could share their subjective interpretations of the nature of this experience and how it developed in their lives. Consequently, I recruited 27 women and 4 men who felt they were living well and were diagnosed with the chronic diseases described as MS, lupus, or scleroderma. It is widely accepted that chronic disease processes interact within an individual’s body, mind, and broader life to create a particular type of human experience commonly described as chronic illness.

I looked at the experience of living well in persons with a number of different diseases because I was interested in finding commonalities and patterns of living well related to generic experiences of living with chronic illness (Conrad, 1987; Lindsey, 1996; Thorne & Paterson, 2000). MS, lupus, and scleroderma are autoimmune diseases that typically have a gradual and early adult onset, an episodic and/or progressive course, and create functional limitations. Moreover, they were of sufficient severity to influence everyday life and necessitate ongoing management and coping, and thus, represented three examples of diseases that had some common features of what we typically consider chronic illness. I chose individuals who had been diagnosed for at least five years so that they had lived long enough with their disease and the impacts it creates in life to be able to reflect on their illness experience and aspects of their lives that enabled them to live well. Further, I recruited women and men who were 20 years of age or older and spoke English fluently as I was interested in studying the experiences of adults and wanted to be able to communicate effectively during the interview process.
I used a multifaceted recruitment approach in hopes of finding participants with diverse
disease and life experiences so that my data would be rich and reveal a range of common and
divergent aspects of living well experiences. Because individuals identified through different
sources and organizations might have had different types of experiences and emphasize different
processes in how they lived well, I recruited women and men in a number of different locations.
I placed advertisements in community magazines (Shared Vision and Common Ground) and
community centres on the west and east side of Vancouver and in two medical clinics (Lupus
Clinic at the Mary Pack Arthritis Centre and the MS Clinic at UBC Hospital) (Appendix A). I
also recruited participants via illness organizations (BC Lupus Society, Scleroderma Association
of BC, and the BC Division of the MS Society of Canada) using newsletters, email distribution,
and support groups. To ensure that participation was voluntary and confidential and did not
impact on the participant's relationship with any organizations or the use of an organization’s
services and programs all potential participants called me directly for further information and
screening. The assistance of illness organizations and medical clinics in the recruitment process
was in accordance with the ethical guidelines of UBC and the policies within these
organizations.

Although the advertisement process was relatively straightforward, it was difficult to
recruit individuals for this study. Participants with scleroderma were the most difficult to recruit
followed by persons with lupus and this may reflect the smaller numbers of persons living with
these diseases. To get sufficient numbers, I had to collect data from participants who were living
on the Sunshine coast and Vancouver Island in addition to the Lower Mainland. In the end, I was
able to obtain 31 participants who self-identified as living well and met the criteria for the study.
This number was in line with the minimum sample size recommended for developing good
interpretive and explanatory insights into a phenomenon (Morse, 1994; Swanson, 1986). I
accepted individuals who met the research criteria in the chronological order that they contacted
-me unless we were unable to co-ordinate schedules, they lived outside of the Lower mainland, Sunshine Coast, or the east side of Vancouver Island, or I already had a sufficient number of individuals with their disease diagnoses. I intentionally aimed to have an almost equal number of individuals with each of the three disease diagnoses, MS \( n=11 \), lupus \( n=11 \), and scleroderma \( n=9 \), to help me tap into a more general understanding of the phenomenon of chronic illness, rather than the specificities of any one disease. Although I originally hoped to get a large number of women and men through community recruitment strategies to increase the likelihood of diversity in my sample, all but 2 of the 31 participants responded to advertisements sent by illness organizations or posted in medical clinics.

**Research Participants**

In my sample of 31 research participants, there was a range in the severity of diseases and in the number of years they had lived with their disease since diagnosis (from 5 to more than 30 years). Slightly more than 50\% of the women and men \( n=16 \) had lived with their diagnoses for more than 11 years. Because many of them lived with symptoms from a few years to more than 20 years before having a diagnosis, the number of years since diagnosis underestimated the length of time that the participants had been living with illness prior to partaking in the research. (For schematic representation of the following demographic and illness information, see Appendix B).

The participants were diverse in age and ranged from 27 to 73 years with the majority of them (81\%) being between 41 and 70 years of age. However, there were four participants between 20 and 30 years of age and two women over 70 years. The majority of the participants were women (87\%) even though I did not specify sex on the recruitment notices. This may reflect the higher prevalence of these autoimmune diseases in women as well as the fact that members of the female population seem to participate in qualitative studies more often than men.
(Thorne & Paterson, 2000). The group was almost split equally between those who are married or living common-law (48%) and those who lived on their own (52%) and considered themselves to be single, separated, divorced or widowed. Almost all of the individuals considered themselves to be White except for two participants who described themselves as Filipino and Vietnamese.

Education ranged from elementary school to graduate degrees but overall, the participants had a relatively high level of education with 77% having college diplomas or university degrees. They revealed a broad range in total household income that extended from the poverty level of less than $10,000 per year to an upper income bracket of $91,000 to $100,000, suggesting that individuals in this study had access to different levels of financial resources. However, the majority of the participants (71%) lived with lower to moderate incomes, having total household incomes of less than $50,000. The remaining participants (29%) had incomes between $50,000 and $100,000. Women and men with lower household incomes tended to be single and/or living on government disability pensions. Participants who had middle to higher total household incomes tended to have private disability or retirement pensions from their past jobs, were still working, and/or were married to someone working full-time.

The majority of individuals gave up their jobs and careers due to their illnesses. Twenty-five of the men and women (81%) were not working and were either on private or governmental disability and/or retired at the time they participated in the study. Out of the remaining six (19%), three worked part-time and three worked full-time jobs although many participants were actively engaged in volunteer work. About two-thirds (68%) of the women and men had raised children.
Interview Process

Interviews provide a means for people to describe their experiences and self-understanding in relation to their own lived world and generate in-depth, intersubjective data (Kvale, 1996). As such, they are often used in research on chronic illness that requires detailed, personal accounts (Charmaz, 1990). Theoretical perspectives of the social world, phenomenon of interest, and research methodology influence the interview process (Kvale, 1996). In this study, a social constructionist and interpretive understandings shaped the process and from this vantage point, one-on-one interviews are a mechanism for constructing and interpreting understandings of social reality and “knowledge is constructed through interaction of interviewer and interviewee” (Kvale, 1996, p. 36). Symon, Cassell, and Dickson (2000) note that “we can only gather different accounts of reality” and “these accounts can only be represented through our own interpretation” (p. 460). As such, the “product … is the outcome of an interviewer’s own construction of their world and the given interview situation” (Cassell, 2005, p. 170).

To collect the subjective and individualized data that I required, I conducted 31 one-on-one interviews during a seven-month period that ranged in length between 1.5 and 3 hours. Most interviews took place in the participants’ homes but for issues of confidentiality and other undisclosed reasons a few of the individuals requested that they be interviewed in the researcher’s residence. I supported their choice of interview location because environments where participants are more comfortable facilitates rapport and trust and permits the participants to control the degree of confidentiality they are able to maintain during the actual interview process (Kvale, 1996).

Before conducting the interview, I engaged in the process of informed consent with the women and men. I informed them about the purpose of the study, the interview process, confidentiality, and the potential risks that they might have incurred and I received their written agreement to participate in the study (Kvale, 1996). During this process, I sought their
permission to audiotape the interview and outlined the steps I was taking to ensure their confidentiality by using pseudonyms in the audiotapes and written materials and by separating the raw data from names and consent forms. I also informed them that given the relatively small sample, it was possible that some people might recognize them through written descriptions of their perceptions and experiences even with the use of pseudonyms and other efforts to ensure confidentiality. In addition, I addressed the risk of potential harm during the research process (Borbasi, Chapman, Gassner, Dunn, & Read, 2002). They read the UBC Ethics Committee consent form (Appendix C) and we each signed two copies, one of which they kept for their own personal records. The consent form clearly indicated that participation was voluntary and that individuals could refuse to participate or withdraw from the study at any time. Prior to the interview, I also had participants complete a demographic and illness interview questionnaire to gather data on age, sex, ethnic origin, socioeconomic status, medical diagnosis, duration of illness, and major symptoms (Appendix D). This information was important for sensitizing me to the participant’s background prior to the interview and for situating the final results of the study in relation to the general demographic and illness characteristics of the participants.

Before and after each interview, I recorded my thoughts and feelings about the process on audiotape and then had it transcribed into field notes to record details of the research process and create supplementary data to the transcripts (Wellard & McKenna, 2001). This process was an essential aspect of being reflexive in the interview process and maintaining an awareness of my own subjectivity (Cassell, 2005). It helped me maintain integrity with the interview process and consciousness of the complexities of interviewing within a social constructionist framework where my subjective lens was an integral part of the interview context and the construction of the data.

Because it is well known that the questions asked and how they are framed and managed in the interview all influence the type and quality of data (Charmaz, 1990), I developed a
semistructured interview guide as a starting point in the interview process (Appendix E). The initial questions were guided by the research questions forming the foundation of the study and reflected the social constructionist and interpretive perspectives within which the research was situated. The initial questions were tested on several volunteers with chronic illness prior to the commencement of the formal data collection process to determine whether they were straightforward, easy to understand, and explored issues pertinent to my research. This helped me identify the key questions used in the data collection process (Gillham, 2000). The predetermined questions began by exploring the history of their disease (i.e., onset, symptoms, process of diagnosis, life context before and after diagnosis and significant challenges they faced at the time) to provide a sense of their illness experience and the context of their lives. Then, I spent most of the interview exploring their understandings of living well and the biological, psychological, and social factors that enabled them to have this kind of experience in the context of illness. Although I used the questions in the guide as a starting point, the exact questions, content, and direction of each interview depended on the nature of the participant’s experiences and their responses (Sandelowski, Davis, & Harris, 1989). As I moved through the data collection process, I added additional questions to explore ideas and themes that emerged from data analysis and the interview guide continually evolved. For example, when it became obvious that some of the participants’ understanding of what was meaningful and important in their lives shifted during the course of living with their illnesses, I specifically explored this in more depth in future interviews.

Given that the researcher is the instrument of data collection in qualitative inquiry (Gillham, 2000; Rubin & Rubin, 1995), and the “interviewer and the subject act in relation to each other and reciprocally influence each other” (Kvale, 1996, p. 35), I had considerable influence over the dynamic exchange between me and the interviewees (Marshall & Rossman, 1995). This influence carried a responsibility for moral research behaviour that involved an
awareness of ethical issues, sensitivity, and a commitment to moral action in the interview process (Kvale, 1996). Inherent in this responsibility was the importance of presenting myself honestly to research participants as a doctoral student and conducting the research in a professional and sensitive manner (Keats, 2000). As part of this process, I carefully considered and reflected on issues of trust, rapport, power, and safety (Borbasi et al., 2002; Fontana & Frey, 2000; Lincoln & Guba, 1985). I worked to gain the trust of the participants by displaying professional behaviour throughout all phases of the research project and by being open, honest, and straightforward about the purpose of the study and the interview process. I made a concerted effort to create an environment where participants could talk openly and freely without feeling judged (McDougall, 2000) and tried to establish good rapport with the women and men by being an active, thoughtful, and nonjudgmental listener (Keats, 2000). Because it is well documented that differences in age, socioeconomic status, and ethnicity between interviewer and interviewee may impact on rapport (McDougall, 2000), I used the demographic and illness information gathered prior to the interview to sensitize me to any demographic differences between me and the interviewees and to gain an awareness of how their life experiences and viewpoint differed from my own (Fontana & Frey, 2000). As power and social identity (e.g., class, race, age, and gender) were undoubtedly part of my interactions with participants (Nunkoosing, 2005; Price, 2002; Seidman, 1991), I strove to maintain a conscious awareness of how my own social identity might have been impacting on the interviewees during the interview process (Seidman, 1991). I also looked for signs that might have indicated that they were having difficulty reliving their illness experiences, disclosing personal information or answering research questions (Borbasi et al., 2002).
Data Analysis

Data analysis is defined as a “process of bringing order, structure, and meaning to the mass of collected data” (Marshall & Rossman, 1995, p. 11) and this process temporally and conceptually overlaps the data collection, preparation, and interpretation processes as well as the writing phase (Sandelowski, 1995). To make meaning out of the data and build an interpretation, “data are broken down, conceptualized, and put back together in new ways” (Strauss & Corbin, 1990, p. 57). This requires a researcher to comprehend and find meaning in the data, and then, recontextualize it into findings (Morse, 1994). Within a social constructionist and interpretive study, the researcher “drives the interpretation” and “ultimately determines what constitutes data, which data arise to relevance, how the final conceptualizations portraying those data will be structured, and which vehicles will be used to disseminate the findings” (Thorne et al., 2004, p. 11-12).

My data included 31 transcripts and demographic and illness questionnaires as well as numerous field notes. To gain a feel for the nature of the women and men’s experiences of living well with chronic illness, I transcribed the first few audiotapes and then had the transcripts and field notes produced by an experienced transcriptionist. I reviewed every transcript against the audiotape to ensure accuracy. I used coding processes such as “sampling, identifying themes, building codebooks, marking texts, constructing models (relationships among codes) and testing these models against empirical data” (Ryan & Bernard, 2000, p. 780). The unit of analysis I used for the coding changed over time from sentences to paragraphs to large sections of text. Although I began by doing line-by-line coding as a way of initially immersing myself in the data and developing initial codes, I quickly moved into more focused coding that enabled me to code large chunks of text at a time (Charmaz, 2000b). By comparing data within and between participants, and within and between the categories of data (Charmaz, 1983, 2000b; Glaser 1978, 1992) using a constant comparative process (Glaser & Strauss, 1967), I was able to develop and
refine the codes and themes I saw in the data. To work out and record relationships between codes, I used other techniques such as conceptual mapping and memoing that were essential processes for enabling me to link my analytic interpretations with the empirical data (Charmaz, 2000b). The process was highly iterative in that I moved back and forth between coding pieces of data, developing a conceptual framework and solidifying my interpretation.

Although the analysis involved technical processes (i.e., sifting, sorting, and organizing), cognitive activities were most important for constructing an interpretation of the participants’ accounts. This required me to use my mind’s “inherent capacity to see patterns, follow intuitions, and retrace a line of logical reasoning among and between the pieces of data” (Thorne et al., 2004, p. 14). As part of this process, I needed a "heightened awareness of the data, a focused attention to the data, and an openness to the subtle, tacit undercurrents of social life" (Marshall & Rossman, 1995, p. 114) that repeat immersion in the data helped to facilitate (Lincoln & Guba, 1985). I read the transcripts and listened to the audio recordings of the interviews a number of times. Reading them helped me develop codes, themes, and patterns in the data, and listening to them helped me move beyond the obvious and hear the most interesting or essential aspects of their living well experiences. Hearing the audiotapes also helped me grasp the nature of the complexity of their daily lives within which their understandings were embedded. I repeatedly asked questions such as: What is happening here? What does this mean? How does this relate to other ideas? During this process, I tried to open my understandings to multiple meanings and perspectives and modified analysis and interpretive techniques to work with my own cognitive processes (Hunter, Lusardi, Zucker, Jacelon, & Chandler, 2002). Overall, it felt like the data analysis process was a more creative and experiential process than a technical one (Thorne et al., 2004, p. 14).

In the end, I created an interpretation of the participants’ living well experiences using their thoughts, emotions, actions, and interactions in day-to-day life to illuminate the unique
aspects of their lives within common and shared understandings and processes. The complexity of their living well experiences was portrayed through “a multifaceted web of interactions” (Kearney, 2001, p. 146) or linkages between findings, as well as through the degree of transformation of the data (Sandelowski & Barroso, 2003).

**Trustworthiness**

There is considerable discussion in the literature about the scientific quality, trustworthiness, or goodness of qualitative inquiry, and understandings of how to define and establish it in a research study are continually evolving (Davies & Dodd, 2002; Emden & Sandelowski, 1998; 1999; Lincoln & Guba, 2000; Rolfe, 2006; Smith & Deemer, 2000; Thorne, 1997; Thorne et al., 2004; Tobin & Begley, 2004). In the context of this ongoing debate, Lincoln and Guba (1985) argue that the basic concept of trustworthiness is simple: “How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?” (p. 290). Sandelowski (1993), Thorne (1997), and others suggest that the answer is less about claiming to be right about a phenomenon and more about practicing good science.

Lincoln and Guba (2000) argue that there is methodological rigor as well as rigor in the interpretation of human phenomena where the question is whether our co-created constructions can be trusted in their representation of human experience. However, the issue of what rigor represents in a qualitative paradigm is highly debatable (Davies & Dodd, 2002; Tobin & Begley, 2004). Some feel that criteria for assessing rigor and overall trustworthiness must fit with the philosophical assumptions, purposes, and goals of the specific type of qualitative inquiry, whereas others feel there should be quality criteria that apply to all research in a qualitative domain (Emden & Sandelowski, 1998). Some argue that criteria for assessing the research process and interpretation that are frequently described in the literature (e.g., reporting audit
trails, having research participants validate findings, and providing thick description, Lincoln & Guba, 1985) are not meaningful for assessing whether a study and the interpretive product represents good science (Long & Johnson, 2000; Rolfe, 2006; Sandelowski, 1993; Thorne et al., 2004). There is a developing awareness of the importance of considering forms of accountability other than evaluative criteria and standards (Thorne, 1997).

Davies and Dodd (2003) suggest that it is useful to use ethical principles to “rethink rigor in terms of attentiveness to research practice” and to conceptualize the integrity of the research process and its outcomes in relation to “attentiveness, empathy, carefulness, sensitivity, respect, honesty, reflection, conscientiousness, engagement, awareness, openness, [and] context” (p. 288). The relationship between ethical principles and research integrity is increasingly described by other researchers as well (Guillemin & Gillam, 2004). Davies and Dodd (2003) suggest that “practicing accountability begins by acknowledging the researcher and laying open for examination, or making visible, the research process” (p. 281). In a similar vein, Thorne and colleagues (2004) suggest that the rigor and credibility of the research process is more dependent on “integrity to the interpretive process” than “rigid adherence” (p. 17) to detailed technical activities. They argue that the final product is dependent upon the overall transparency of the research process whereby a researcher’s lens must be “accessible and visible” (p. 17) in analytic decision-making process and the reconstruction of the data into findings. Within this understanding, acknowledging the researcher as interpreter is essential for creating findings that have credibility or “interpretive authority” (Thorne, 1997).

In line with this understanding of trustworthiness or goodness, I endeavoured to create a coherent logic to my design and analytic framework and to be honest and open in all phases of the research process. I frequently checked my emerging findings with my supervisors during the inductive analysis process (as suggested by Creswell, 1998; Maxwell, 1996; Thorne et al., 2004) to clarify my findings and increase the credibility of my interpretation. As recommended (Finlay,
2002), I was reflexive about my subjectivity and the intersubjective elements that shaped the
data collection and analysis processes and used field notes as the vehicle for engaging in this
process. In the written description of the research and findings, I took ownership of the analytic
decisions I made and provided explanations for why I decided to engage in the process in the
way I did. I strove to make my inductive reasoning processes obvious to the reader and used my
voice to explicate the transformation of the data into findings and construct the interpretation of
the participants living well experiences. I also tried to be “mindful of the partiality and limits” of
the research process and the findings I created (Davies & Dodd, 2003).
CHAPTER 4: LIVING TENSION: THE DISEASE-LIFE INTERFACE

Overview of Findings Chapters

Using the research questions as the guiding framework, I set out to make sense of the participants’ experiences in relation to the nature of their living well experiences and how they developed over the course of living with chronic illness. Through the analytic process of describing and interpreting their accounts, I came to the understanding that their living well experiences were about having meaningful experiences. These experiences of value were created by negotiating the tensions and loss that developed in the interactions between their disease experiences and their broader lives, and by shifting their understandings of what was meaningful to fit the kinds of experiences that were possible in their day-to-day worlds.

When they talked about living well, the women and men described valued aspects of their lives, particular attitudes towards life and illness, strategies for negotiating daily life and having meaningful experiences, changes in their understandings of what was important, and positive emotions. Although all these elements were integral to their living well experiences and reflected both aspects of what living well was and how it was created, some of these dimensions of human experience more strongly illuminated the nature of living well, whereas others provided more insight into the processes by which it was developed and enacted over time. For example, they frequently spoke of the aspects of life they considered important and meaningful when they talked about living well, yet talked about their attitudes towards living with illness and the strategies they used when they described how they lived in daily life. Also, when they used these dimensions of human experience (i.e., values, emotions, attitudes, strategies, and understandings) to describe their living well experiences, they did so in relation to a wide range of disease factors, internal struggles, and problematic interactions with family and friends,
institutions, and environments. Because they made sense of, and interpreted their living well experiences in relation to disease-related challenges and losses, it became imperative to describe and interpret the nature of these struggles in order to reconstruct the experiences of living well portrayed in their accounts. I conceptualized the difficult interactions that I saw operating between the biological, psychological, and social domains of their lives as tensions to best reflect the dynamic, elastic, and challenging nature by which they were portrayed. Within this tension-centred framework, I used their understandings of what was meaningful in their lives to illuminate the nature of their living well experiences and their attitudes and strategies, and shifts in understandings of what was meaningful to interpret and build an understanding of the major processes that facilitated the development and sustainability of their living well experiences over time. This enabled me to show how the women and men used these two kinds of processes to align the meaningful aspects of their lives with the tensions and realities of day-to-day life and created congruency between the life they led and a life that held meaning.

To construct this understanding of the women and men’s living well experiences, I divided the analysis and interpretation of the data into four chapters. Chapter 4 describes the nature of the tension-centred worlds they all inhabited and reveals the common types of problematic interactions they experienced. I emphasize the diverse nature of their struggles and the enormity of the challenges they continually faced in order to live well. In Chapter 5, I construct their living well experiences in relation to the aspects of their lives that were important and meaningful and the common domains of human experience that they reflected. Within these common patterns, I show that participants’ understandings of living well were based on their unique values and interests. In Chapter 6, I describe some of the key attitudinal perspectives and strategies they used to address the tensions they experienced and to help them attain meaningful

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¹ In the following findings chapters, meaning is used in two distinct ways – meaning as making meaning and the meaning one makes.
experiences in daily life. Then, I describe some of the ways their understandings of what was important and meaningful shifted when they were unable to alter some of the tensions in their lives and experienced loss. I show how this process helped them to keep their understandings of living well aligned with what was possible with their bodies and daily lives. In the last findings chapter (Chapter 7), I further advance understandings of the process and nature of their living well experiences by describing how their experiences and the approaches they used to create them worked over time in relation to the commonalities and diversity reflected in their accounts.

Quotes that I cited from the participants were edited to remove repetition and "..." indicates that words were eliminated to enhance the readability and comprehension of the ideas expressed.

**Living Tension**

In talking about their lives with illness, the women and men illuminated the pervasiveness of their disease experiences beyond the physical realm into the broader psychosocial domains of life. In Mary's words:

[Chronic illness] altered everything. It altered the concept I had of myself. It altered my relationship with my husband. It altered my relationship with family, friends, [and] children. It just changed my whole dynamics, my whole person ... my self-concept. Who I was. Where I was going. It changed my life plans.

Their chronic diseases and the symptoms they created interacted in their lives to create struggles in daily life. In this chapter, I describe these oppositional processes or tensions in intrapersonal, interpersonal, and extrapersonal categories to show the nature, intensity, and diversity of their life circumstances in relation to the domains of life within which they situated these challenges. This provides a means for showing how their approaches for living well were often oriented towards altering tensions that arose within the individual, between the individual and family and friends, or between the individual and social institutions/systems of daily life.
Intrapersonal Tensions

The participants revealed numerous internal struggles that were related to the changing nature of their disease, changing functional capacity, changing notions of self and identity, and competing demands between their illness and the rest of their lives. Within these broad areas, the tensions manifested themselves in different ways for different individuals over time. All of the individuals described inner turmoil related to the continually changing nature of their diseases and the uncertainty of what was evolving in their bodies. Betty said the biggest challenge of living with illness was “not knowing what’s going to happen” and she was not alone in this understanding. Mary said that the problem was that “you don’t know what you’re going to get and when” and explained that the “uncertainty of the disease is the hardest thing to deal with … the fear of what’s going to happen in life.” Many of them described how they constantly had to interpret new signs and symptoms and they worried that something else was going wrong.

Dianne portrayed the essence of this kind of struggle when she said:

I think the worst part of this is [that] every ache and pain you get, you’re thinking, okay, this is it. Swallowing [difficulties], okay, I am going to have this and this is going to get worse. I’m not going to be able to eat. Soon, there are going to have to tube me … I think psychologically that has a great effect on a person living with chronic disease.

Although many of them spoke of similar struggles, they were often related to different concerns and changes in their bodies. For example, Sabina said:

Sometimes I feel why am I having this pain here? I know it’s not my heart. My heart’s good … [but] your mind travels to what’s happening next … I’m going piddle all the time through the night. Is it affecting my kidneys or what’s happening?

Their accounts suggested that these kind of struggles prevailed at some level over the course of their illnesses. For example, Tyler said, “I’ve survived for 20 some odd years, almost 25 years
with scleroderma and I'm still around . . . [Yet], every time something new comes up, you're thinking, ah jeez, is this the final thing? Is this the last thing?"

They also all talked about the challenges they experienced within themselves when they tried to do activities that were now difficult or impossible to do. These tensions were articulated through feelings of frustration and turmoil and expressed in statements like “I get ... frustrated and mad when I can’t do things.” In fact, “not being able to do what you used to do” was considered one of the biggest internal hurdles they faced. The nature of these struggles reflected the severity of their diseases and whether the symptoms created minor or major functional changes or limitations. Some individuals had mild involvement of muscles, nerves, and joints that had limited impact on function, whereas others had significant loss of mobility or serious organ involvement that greatly altered daily life. Participants with similar diagnoses often had similar kinds of symptoms but these did not necessarily translate into identical functional challenges or similar kinds of frustrations in daily life. For instance, those with MS often struggled with a loss of mobility (five of them used wheelchairs and several others used canes), visual problems, and cognitive limitations. Individuals with scleroderma emphasized vascular problems in their hands and feet, changes in skin, swallowing difficulties, and respiratory and gastrointestinal problems, whereas the participants with lupus talked mostly about joint inflammation, kidney problems, rashes, and cognitive challenges.

Both across and within these similar groupings of physiological changes and symptoms, they experienced a range of challenges with their physical and/or mental functioning. A number of them struggled with their inability to use their hands to do basic activities of daily living or hobbies they enjoyed but the nature of their challenges differed. Tyler, who has scleroderma, had difficulty being able to move his hands and fingers in ways that facilitated daily activities. He said, “The biggest thing was banging my fingers. They were always in the way ... I couldn’t think how to get my fingers out of the way because I’d been using my fingers all my life.” He
also explained that his hands were a problem because they were so sensitive to temperature that it made it difficult to carry out activities of daily living. He said, “It scares the living daylights out of me every time I have to cook because sometimes I can’t grab the pot … I’m afraid I’m dropping the pot or a pan … because my hands are sensitive to hot or cold [temperatures].”

Rose, on the other hand, talked about the difficulties she had in using her hands because of the inflammatory effects of lupus. She said, “I can’t type or write for very long or my hands cramp up.” A number of them struggled to use their legs to walk or engage in other physical or athletic activities but the nature of these challenges and the levels of frustration they described varied in relation to the severity of their disease and how it expressed itself. Mary, for example, struggled with her mobility because of the effects of MS on her motor function but also because of changes in her vision. In contrast, Hazel experienced frustrations in not having “enough breath to walk” and also because her “hip would just give out”.

In addition to the frequent challenges with physical function that they all expressed in some way, almost half of the participants described changes in their cognitive abilities including memory loss or difficulties in reasoning, reading comprehension or focusing that made it hard to engage in some activities. For example, in describing her experience of lupus, Eryn said, “I think the biggest challenge … is the central nervous system part, the cognitive dysfunction, and the memory problems.” Then, she went on to say, “At one time, I was very sharp, and just intelligent, and … [had a] great memory, was on top of everything, and completely organized, and over the past six or seven years, that’s all fallen apart.” Tyler, on the other hand, gave a more specific example. He said, “I made a list of stuff that I had to do today because I still have trouble organizing things in my mind.” Some like Eryn and Tyler suggested that these changes in cognitive functioning were ongoing, whereas others presented them as transitory changes in their lives. Sarah said for example, “There was a period where I couldn’t remember anything. I could not, could not, could not remember. Like if you had just said something to me an hour ago, I
wouldn’t be able to remember it.” The changes in cognitive functioning varied on a daily basis for others. For example, Tammy said, “Sometimes my cognitive skills just aren’t what they should be. Other days, it’s really great.”

The cognitive challenges and the frustrations they created were more predominantly featured in the accounts of those with MS or lupus but even within these groupings, there was a wide range of different ways in which they played out in daily life. For instance, Tammy talked about the challenges of getting a new digital stove. She said, “My husband came home from work to find me sitting in the middle of the kitchen floor crying. I could not figure out how to work this stove.” Then, she explained, “I have a hard time reading and following instructions. If they’re short that’s fine but if the instructions go on for two or three pages I get completely bogged down in it,” and “I get so frustrated that I just can’t do it.” BB, on the other hand, said that once he developed MS, he struggled to do the calculations in his accounting job.

Almost half of the women and men explicitly described struggles with their sense of self and identity and it was evident that most of the others also experienced this kind of internal turmoil over the course of living with illness. When Mary said, “[I] feel that I’m less of a person because I have this disease,” she expressed an understanding that many of the others seemed to share at some point in their illness experience, most often in the early years. In most cases, they related challenges to their sense of self and identity to changes in functional capacity, the impact of their disease on the roles they played in daily life, changes in appearance that it created, or to developing a disease in childhood when their sense of self was forming. Some participants talked about challenges in their understandings of who they were when they made a transition from being a mobile and able-bodied person to being someone with functional limitations or disabilities. BB, for example, talked about how he saw himself as a “cripple” when he started to use a scooter, whereas Patricia described feeling “kind of diminished [and] demeaned” as a human being when she used mobility aids.
Also, some of them expressed confusion over their identity when they had to give up activities, work, or other important roles in their lives due to changes in functional capacity. For example, Laurentia described how she became physically and mentally impaired during CNS lupus flares that made her unable to fulfill her roles as a mother, wife, and working woman. In talking about these challenges with her sense of self and identity, she said:

It was the trauma of what I was missing out with my daughter, and what I couldn’t do, and how it was affecting her, and how it was affecting the marriage, and all that sort of stuff, and I just couldn’t play any of my roles ... At one point I felt I was letting everybody down including myself because I wasn’t able to perform at work, and then not work at all. And I’d never been without my own income. I had never been dependent on a man. I married late. I’d always had my own salary, and I just had never had to be dependent ... I wasn’t a dependent person at all.

For many, the loss of important roles in life such as having a particular job or career, or being a mother or wife challenged previously held understandings of themselves. Job loss seemed to be a particularly strong catalyst for challenging the sense of identity of many of participants who were forced to give up meaningful employment due to changes in their functional ability. For example, BB said:

You spend eight to ten hours a day [at work]. It’s a major, major part of your existence. So all of a sudden, this major part of your existence is taken away and you start wondering, well, who am I? I’ve defined myself by my job and now I no longer have a job.

Many of the individuals also expressed struggles with their sense of self and identity in relation to changes in their appearance resulting from the effects of their diseases or from using assistive aids like wheelchairs. Those with scleroderma or lupus tended to articulate these tensions in relation to changes to their skin or changes in weight, whereas many of those with MS struggled over changes in their appearance from using wheelchairs or other assistive aids. Within these patterns, there was considerable variation in the kinds of bodily changes that were problematic for the participants. For example, Tyler talked about changes in his face from living with scleroderma. He said, “I [don’t] have any eyebrows anymore ... my skin [has] gotten tight
around my forehead.” Then, he went on to say, “I realize that I do look different. I’m not who I used to look like when [I] look in a mirror ... I’m thinner, [have a] smaller mouth, don’t have my eyebrows.” He talked about how these changes made him feel less attractive and comfortable with himself and less confident in social situations. In contrast, Betty, a woman with scleroderma, described how her disease had caused severe weight loss that made her look like a “skeleton” and feel terrible about her body and sense of self. Eryn, a woman with lupus, also described challenges with her self-esteem due to extreme weight loss that made her feel she wasn’t a woman because she “had no curves.” Yet, another woman with lupus, Rose, described struggles with her sense of self when her body changed “from being on prednisone [medication] and gaining weight so quickly.” She said, “I have stretch marks on the back of my arms, on my breasts, on my legs. I have them on my belly of course. I’ve had children. But I have them everywhere ... really where you shouldn’t have them.” Then, she illuminated how these changes affected her sense of self:

I’m not that person that I was before I got sick. I look in the mirror, and I don’t recognize the person that I see. I mean I was always very fit and very thin, and now I have extra weight and my face is completely changed from what it used to look like from being on the prednisone, and my chins and all these things that I never had before. And I look in the mirror and I don’t even see that person any more.

Other participants described struggles with their sense of self from using assistive aids. Patricia talked about the challenges she experienced in her body image and self-perceptions when she went from being five foot nine to only four feet high when seated in her wheelchair. A few also articulated the difficulties they had with their sense of self to developing chronic disease in their childhood. For example, Dawn who developed scleroderma in the early years of life, said, “That’s sort of something that I am struggling with now is I have to find out who I am without the illness ... I sort of wish I could have a sense of myself without the illness.”

Many of the men and women revealed internal struggles over the competing demands of illness and life. Within their diverse and complex life demands, they struggled to accommodate
or balance the demands of looking after their diseases in terms of the practical things they had to do, as well as the ongoing mental efforts required for monitoring their bodies. Collectively, they spoke of a vast range of activities they engaged in including taking medications, ongoing monitoring and testing, appointments with medical or alternative practitioners, and using complementary and alternative therapies. Given the enormous demands of taking care of their diseases, it was not surprising that Samantha and others talked about how looking after their illnesses was a “full-time job” that was difficult to manage in the context of other life events and activities.

Besides the demands of taking care of their chronic diseases, most of the participants had experienced other challenging and difficult life events such as being adopted; childhood and adult trauma (physical, emotional, and/or sexual abuse); extramarital affairs, separation, divorce, and/or remarriage; and/or serious illness or death of children, partners, or parents. Some of their lives were also filled with the emotional and physical demands of working, raising children, dealing with alcoholism in parents or partners, and/or caring for elderly parents. Elizabeth, for example, illuminated a number of these types of demands when she talked about what was happening in her life when she got ill. She said:

[It’s] hard to know ... where to start. That was probably the busiest time of my life ... I had three children and a husband ... I was teaching ... but I had moved into doing consulting, and I was on a national project where I travelled across the country ... and of course, children and all their lives, and then ... social demands ... because of my husband’s job. So it was a very busy time, and then it was just the beginning of parents getting ill and eventually dying, and taking care of all that ... it was incredibly stressful ... also, my marriage broke down in the middle of all of that so it was divorce at the same time ... a lot to deal with.

Many of them struggled to balance these kinds of life pressures with the daily requirements of taking care of their disease. Laurentia provided a good example of this tension when she talked about her struggles to balance her responsibilities of being a mother with the demands of her medical appointments. She said:
I had a daughter ... at the time she was four-and-a-half and I had to be dealing with her and my illnesses and all my doctors' appointments. I was being seen weekly and adjusting to the whole thing and it was just a really horrendous, horrendous time.

It was not only the practical effort but also the mental demands involved in continually thinking about or listening to their bodies that created ongoing tensions. Kate provided a powerful example of this when she said, “I have to become aware of stuff that I’d rather not become aware of. Who wants to be tracking whether you had a shit today ... I mean it’s stupid.”

Overall, all the participants experienced internal tensions over their changing bodies and ability to do things and over changing understandings of self and identity during the course of living with their chronic diseases. They also described at least one and often many instances when they struggled to balance the often competing demands of taking care of their illnesses and meeting life’s other demands and responsibilities. Although these types of struggles were common in the group, the nature and intensity of the turmoil they experienced reflected a variety of personal elements such as the type of symptoms they had, the kinds of changes the disease created in functional ability and appearance, the medical and self-care activities required to take care of their diseases, other significant life challenges they faced, and the overall complexities inherent in unique lives.

**Interpersonal Tensions**

The women and men’s accounts also portrayed tensions in their relationships with family, friends, and other individuals they encountered in daily life. At a general level, they often attributed these problematic interactions to people’s lack of understanding of their illnesses and the ways in which they impacted on their daily lives. Dawn, for instance, reported that her sister said, “I can’t understand you because you live in a totally different reality than I do.” They spoke of discrepancies between their perspectives of illness and that of others, and between how they
could function and other people’s expectations of how they should function. They also described the tensions they experienced in relation to people’s reactions to their physical appearance.

The majority of them held the understanding that the problems in their relationships were about differences between their view of the course and outcome of their disease and their family or friends perspectives. In many cases, they described the opposing perspectives articulated by loved ones as pessimistic or negative in comparison to their self described positive or optimistic outlooks. Maria illuminated one example of this when she talked about conflict with her husband. She said:

[My husband] just said, “[Maria] you’re getting worse, and you’re going to end up in [a long term care facility], and let me give you a tour” … everything was negative about my disease, and I just always was like, “What are you talking about? I’m never going there. I’m not going to live in that place.”

Although Maria’s comments illuminate a rather dramatic example of a tension derived from opposing understandings, it provides a good illustration of how conflicting perspectives over the impacts, course, and outcomes of illnesses created tension in the participants’ lives.

The conflicts they described also reflected discrepancies between the functional expectations of their loved ones and their own functional capacities and desires. For instance, many of them spoke of being pressured to maintain the roles and responsibilities of their predisease lives inside or outside their homes. In talking about her problematic relationship with her daughter, Sabina spoke of feeling continually pressured to cook dinners as she had been doing for years even though it was increasingly difficult for her to do so. She said that her daughter also thought she “should be out doing more,” “out everyday swimming or … [joining] a senior’s group.” Laurentia, on the other hand, spoke about her struggles with her husband in trying to meet his expectations to engage in athletic activities in their free time as she had done prior to developing chronic disease. She said, “My husband was really struggling with me being different than what I had been, and he couldn’t adapt to any changes.” Then, she explained, “I
had to be the woman I always was. I had to bike as far as I ever did. I had to golf as much as I ever did.” Differences in expectations of behaviour were also illuminated in troublesome relationships with close friends. Joan, for example, recounted a story about an interaction with a close friend who wanted help dropping off her kids at school. She said:

So she’d drop [the kids] off, and then we’d walk to the school or whatever, and the whole time I would be resenting [it] because I was barely functioning at eight in the morning. But could I tell her? No. Because she thinks well you’re just sitting around. I have to get to work. One comment was “Well, if you’re lying around there, could you come lie around at my house?”

In contrast to stories of struggling to meet the high expectations of loved ones, a few participants described interpersonal conflicts over expectations that were below their capacity or desired level of functioning. For instance, Donna, who used oxygen because of a reduction in her lung capacity from scleroderma, said that family and friends were “very sympathetic” about her illness but that she felt limited by their understanding of what she could do. She described an incident with her husband when she was “transplanting some winter vegetables” in her garden. Her husband got really angry with her and said, “If you’re sick, why are doing that?” Donna explained that even though she was more than capable of working in the garden, her husband really wanted to restrict her activities because of her illness. She said, “He doesn’t want me to travel anymore, and he doesn’t want me to go here, and there. And that’s not right for me.” Maria, on the other hand, talked about how her mother wanted to move around furniture and remodel her home with safety and assistive devices to accommodate the functional limitations she had from MS. She felt this caused considerable strain in their relationship because she was able to get around and felt that she “didn’t need any of it.”

A number of them also associated interpersonal conflicts with the ways in which people responded to the presence or absence of visible changes in their appearance, although there was a wide range of variation over when and how they experienced these problematic interactions, and whether their experiences were related to visible or invisible symptoms. As described earlier,
many of the participants described some changes in their physical appearance due to MS, scleroderma, or lupus. In some cases, the changes were visible in intimate relationships but not necessarily visible to others (due to clothing or make-up) or easily interpretable as illness (e.g., weight gain or loss is not specific to having disease). Some of those with invisible symptoms talked about the challenges they experienced with family, friends, or acquaintances that could not understand how they could be sick but not look sick. Katrina, who had lupus, described a fairly common experience amongst the participants when she said, “Sometimes, they have a very hard time [knowing] what is wrong with me. I can sometimes see this look in their eyes where they’re not sure whether I’m making this thing up or whether it’s really there.” A few of the individuals reported that families and friends had denied they were chronically ill and called them hypochondriacs because it did not look like there was anything wrong. Some of these men and women also talked about experiencing similar conflicts with people outside of their immediate family. For example, several of them recounted stories of being accosted by strangers when they used handicap parking spaces because it did not look like they had a disability. Eyrn said, “If I’m having a bad day and I’m parked in a handicap spot, even though I have a handicap sticker, I get people yelling at me all the time.”

Some of the participants who had changes in their bodies that were visible to the outside world or used assistive devices or treatments that showed that something was wrong (e.g., wheelchairs, scooters, or use of oxygen) also described problematic relationships with people’s reaction to their appearance. These tensions differed according to the nature of the alterations in their appearance and the kinds of relationships affected by the changes. For instance, Sanora described how changes in her body from lupus influenced her relationships with the men she dated. She said, “I’ve had boyfriends [at] different times … but most of them don’t want to be around,” and then went on to explain that the physical changes to her body were not attractive to men:
I get very, very violently sick. I mean my stomach blows up. My intestines swell. I look pregnant, and I’m vomiting, and [having] diarrhea. And it’s not a pleasant sight. And then of course they give you cortisone, and then you puff up and look like a banana.

Lee also spoke of struggles in an intimate relationship but she related the difficulties to her husband’s response to the “weeping sores” she had on her body. In contrast, Dawn, who had apparent changes in her physical appearance in the form of a scleroderma rash on her face, provided examples of conflicts she experienced with friends, acquaintances and people she encountered in daily life. In talking about the early years of living with her disease, she described how children rejected her because she looked different. “They’d call me ‘pizza face.’ They’d call me ‘chicken-pox face.’ They wouldn’t play with me. They wouldn’t talk to me. They picked on me,” she explained, and then added, “I use to get beat up.” She also provided stories about the kinds of conflicts that arose in her adult life due to the reaction of people she met doing day-to-day activities. In one story about working out, she said:

I was at the gym one day ... in the middle of pumping weights. So I’m on my back. I’ve got 20 pound dumbbells above my head. Don’t interrupt me. Some lady leans over, and she’s literally a foot away from my face. She’s like, “What’s that all over your face? Are you having like some weird reaction to something?”

Dawn summed up her thoughts by saying, “Whether it’s at the gym, at the grocery store, [or] walking down the street, someone will ask me [about my face] at least every other day.”

Overall, all the men and women experienced tensions in their interpersonal relationships due to living with illness. These struggles were often described in relation to differences in understandings of the course and outcome of their illness and how it impacted on their functional capacities and the roles they could play. They also articulated these tensions as being about people’s reactions to their appearance and the visible or invisible signs of disease. Within these common tensions, the struggles they expressed reflected differences in their lives such as the kinds of people they interacted with and the nature of these relationships, as well as the specific ways in which their disease expressed itself in their bodies.
Extrapersonal Tensions

The participants also illuminated challenging interactions with a number of organizations or systems that they had to interact with in day-to-day life. Here the struggles were most often related to processes or the environment rather than particular interactions with other people. Across their accounts, they most frequently articulated these tensions in relation to health care facilities, government agencies, and insurance companies that they were required to deal with because of their diseases. Many also described conflicts in the workplace at some point in the course of living with illness. Moreover, they often described struggles between their ill bodies and the physical environment within which they lived.

Given the number of years many of them had lived with symptoms and the different ways they had to interact in the health care system over that time period, it was not surprising that they described a vast range of difficulties in their interactions with health care professionals, hospitals, or the health care system at large. A large number of them were concerned about having their symptoms, disease, and illness experiences acknowledged and validated, obtaining information on their diseases, and getting the care and services they required to manage their illnesses over time. Many of them spoke of how difficult it was to have their symptoms taken seriously by health care professionals, particularly physicians who provided a number of alternative explanations for their specific symptoms or feelings of sickness. Laurentia said that when she got ill the doctors told her, “Oh, you just have a virus. Go home and rest and you’ll be okay,” and she described these “judgments” as “very frustrating.” Dianne, on the other hand, struggled with having her symptoms of scleroderma attributed to idleness and weight gain. She said, “My hands would be severely cold. The fingertips would be very, very cold, and they turned white, and I knew that something was not right.” She explained that she “went to the doctor … and he said, ‘Oh Dianne, your children are growing up. You’re not doing anything
anymore so you’re getting heavy, putting on weight.” Although some of them experienced these kinds of struggles for a short period of time, others experienced them for many years. Katrina said:

I have been going to doctors, I think for 25 years, with problems related to the lupus, and they never found anything. They always told me I was a very healthy person. So by the time I really had noticeable symptoms, I was in my menopausal years, and then, of course, the doctors had a heyday with that, and they blamed all my symptoms on being menopausal, and they suggested that I see a shrink.

As Laurentia, Dianne, and Katrina’s experiences suggest, these conflicts were often related to the process of getting a diagnosis. Yet, some participants also provided examples of how the validation of their disease was continually challenged as they encountered new professionals or new symptoms over the course of living with their illness. For example, Eryn said, “When I went to see my GP [general practitioner] last week because of neck pain and [a] migraine, they had a resident look at me, and the resident sat there questioning whether or not I had lupus.” Then she continued, “I had to sit there for 15 minutes justifying the 20 odd doctors that had diagnosed me, and she’s like, ‘Well, you’re fine, you’re fine, you’re fine,’ and I’m like, ‘I’m not.”

Tensions were also commonly related to difficulties in obtaining information from doctors and other health care professionals in order to understand and manage their diseases. When reflecting on their early experiences of living with illness, almost all of them talked about how hard it was to obtain medical information on their diseases and the symptoms they experienced. Larry described a rather common experience in the group when she spoke of her struggles to make sense of new symptoms. She said, “I had no knowledge. The doctors weren’t telling me anything … the frustration [was] so huge.” Then, she went on to explain that in her situation the specialists only provided limited information when she developed a new symptom. She said, “When you go to a specialist, and I’ve got about 12 or 13 specialists, they may just say, ‘Well, this is getting worse. We’re going to change your medication, mumble, mumble, mumble.’ That’s all they say.”
The majority of those who identified struggles in their interactions with the health care system also described difficulties they encountered in trying to get the services and care they needed in hospitals and the health care community as their diseases evolved over time. The nature of these difficult interactions and how they played out in their lives generally seemed related to the severity of their diseases, the type of care they required or desired, and the nature of their health care providers. For example, in describing her search for obtaining care for the ulcers on her finger caused by scleroderma, Larry said, “It took me an eternity to find out how to look after this wound because it’s a nasty wound. My general practitioner didn’t know. My dermatologist didn’t know. He said: ‘I’m no good at dressing wounds.” Then, she went on to express her sense of frustration with the system by saying, “There’s so much that is not known [about] where the care is,” and “there’s so much ignorance ... within the whole health world.”

Some individuals struggled to gain access to different types of services such as seeing specialists or being admitted to hospital. For example, in talking about her experiences in trying to get care in an emergency department of a hospital, Laurentia said:

I finally had to swear at them at the hospital ... and say, “I’ve got CNS [central nervous system] lupus, brain lupus. What the hell are you people doing? Why are you treating me like this?” And finally this mental health care nurse came and told me that I was refusing to leave and I went, “I can’t walk, what do you mean? I can’t function at home. What do you mean, leave?” I said, “I’m not refusing. It’s just I can’t function.”

Although Laurentia’s account of struggling to get the care she needed in a hospital emergency department was more vivid than some of the other participants’ stories, her experience illuminated the difficult challenges that many of them experienced in trying to access care at some point throughout the course of living with their illnesses. Some of the individuals also expressed frustration in getting services that did not necessarily meet their needs. For example, in recounting one experience with a gastroenterologist who wanted to do a throat scan, Kate said, “I feel that sometimes their stuff is to just plot things on a little graph and say, ‘Oh, you’re worse than before!’ But, that’s of no particular value to me.” Some of them, in particular those with
scleroderma or MS, struggled over not being able to get all the help they needed because they felt the doctors and health care system had nothing substantive to offer for the treatment of their disease.

Tensions involving the participants' interactions with a wide range of other institutions, most notably government agencies and private insurance companies were also evident in their accounts. In most cases, they focused on describing struggles they experienced in getting and maintaining disability pensions either from the government or private insurance companies and the difficulties these pension plans or disability benefits created in their lives. A number of individuals mentioned conflicts between themselves and these organizations as they tried to figure out the process and meet the right criteria to receive benefits or services. Given that some of the women and men had private disability through their employers and others had to solely rely on the government disability benefits, the specifics of these struggles differed. Those who relied on government money described more intense conflicts in trying to receive benefits than did those who received money through their previous employer. For instance, in talking about government assistance, a number of participants described the frustrations they experienced during the application process. Patricia said, “It seems ridiculous but almost everybody who applies first time [is] rejected.” Many of them described how stressful it was to try and figure out the idiosyncrasies of the process. In talking about why people get rejected, Hazel said, “It may be something as simple as the doctor’s letter wasn’t worded properly or it wasn’t strong enough, or maybe you weren’t taking enough drugs, or maybe you’re one of those people who don’t want to take the drugs.” Some of them also described the challenges they had in trying to live with the rules and regulations of these benefits and to survive financially on the amounts of money they received. For example, in describing the struggles one faces in trying to have their basic needs met through the government disability plan, Samantha said:
A crisis grant, $826.42 a month is what I get. That includes a $40 protein allowance because I need a high protein diet ... Okay, so every so many months there are 5 weeks between cheques not 4. Now trying to stretch that amount of money for an extra week is damn near impossible. Used to be you could phone and get a crisis grant of $40 a month. It has now been reduced to $20 a month for a single person ... It’s not a quick process. Anyway, so in my worker’s office, I said, “I’m going to request a crisis grant while I’m here” ... [She says], “What caused your financial crisis this month? I said, “The economy.” She says, “What are you going to run out of?” I said, “Tampons.” These are the things you have to say in order to get $20 out of them.

The process of receiving government benefits forced Samantha (and others who relied on this income) into ongoing negotiations to make ends meet. This made her feel “degraded” and “insulted.” Many of those who received disability pensions through private plans also struggled with the rules and regulations of insurance companies but more so with the strict rules about doing paid work than receiving benefits. BB, for example, spoke of how he was slowly getting back into playing and writing music but said: “If I make two cents doing anything, I lose my disability benefits ... If I make a mildly successful song, I lose my benefits forever.” Several of them talked about working under the table doing odd jobs to help make ends meet but then worrying about the implications if they got caught. Also, those who felt they might be able to work again chose not to because of the fear that they would not be able to get disability in the future if required.

Workplace conflicts were also a common theme in their accounts, in particular when they talked about the earlier years of living with illness. In many situations, changes in their functional ability and the things they needed to do to manage their illness did not fit well with employers expectations of performance or the overall work environment or culture. As such, they described a myriad of struggles that erupted in the workplace when they could not meet expectations and these varied in relation to the nature of their jobs and the types of symptoms they experienced. Toby, for example, talked about how he struggled to keep working as a welder as his fatigue increased and his mobility and vision declined from MS. He said it became
"dangerous in the work situation." Maria, on the other hand, struggled to maintain her duties as a flight attendant when her legs started to have periods of numbness due to MS:

There was a period where the company doctor said, "Why don’t we just get Maria a scooter or one of those golf carts to get down to the gate" ... Once I got to the aircraft I was totally fine. But the company totally pooh-poohed that [idea].

Some of the individuals also talked about the challenges in being able to do the things they needed to manage their illness while on their job. For example, Sanora’s doctor encouraged her to continue working but made it clear that she needed afternoon naps to manage her illness. She worked for an oil company, and said, "not many bosses give you afternoon naps." In frustration over trying to meet the needs of her body and the demands of her workplace, she told her doctor, "Listen, you want me to have an afternoon nap, well, you get me a job [and] I’ll work for you.”

A few also described the struggles they experienced when they left their jobs for medical reasons and then tried to reenter the workforce. For instance, Joan talked about the difficulties she experienced on a back-to-work program because her new employers were not willing to accommodate her needs. She said:

I went back to work for a little while and then it was so unsupportive. It was agonizing. I took this data entry job because I couldn’t think of really working in the office. It was this terrible atmosphere ... I’m like, “Well, I’m supposed to be on a back-to-work program here, isn’t anyone going to talk to the boss or help me?” I wanted a new workstation, and they said, “Well, we just can’t have everybody asking for different things.”

The minority of participants who had maintained their careers or jobs or found work that better suited the needs of their illness, also struggled to maintain their ability to function in the workplace. For example, Dawn who had developed a career in the film industry in the presence of scleroderma described the expectations of her workplace in this way:

I’m in a team of four people ... they’re your colleagues and they hire you, and they’re the [people] you support and they support you. But they also want to know that you’re capable of doing that. They want to know that you’re strong and you can support them, and you can do a good job and make them look good. They don’t want to know that you’re sick. They don’t want to know that you’re having a shitty day because you have to come to work and put a smile on your face no matter what.
She said, “Once you step out in front of the cast and in front of the directors and the producer you have to be happy, smiley girl all day” and indicated that it was difficult to meet these expectations when she experienced pain, fatigue, and other symptoms.

Most of them also described extrapersonal tensions of a completely different nature when they talked about struggles between their bodies and the physical surroundings in which they lived. In many cases, their diseases had altered their capacities to physically adapt and respond to the environment. They struggled to accommodate the needs of their bodies to the weather or climate in which they lived or to fit their mode of functioning with the urban and physical landscape. There were some commonalities in the struggles amongst participants with the same diagnosis or similar functional limitations but there was also variation that seemed to reflect the way the diseases expressed themselves in each individual. Those with scleroderma often talked about how they struggled to function in the cold or extreme temperature changes. Tyler, for example, talked about how he continually struggled with cold weather and said, “I feel better in the sunshine … It’s hard getting dressed for what’s going on outside …. Anything below 10 degrees is very difficult for me.” In contrast, those living with lupus often had problems being in the sun or dealing with humidity. For example, Tammy said, “I get rashes and I get physically ill. I feel like I have the flu. I can get really bad headaches … I’ve even thrown up simply because I’ve spent an hour and a half in the sun without sunscreen.” In contrast, another woman with lupus, Belle, emphasized how her body could not cope well with humidity. She said, “I get a little bit of a flare up when the weather changes. The barometer seems to affect me and the humidity and then I’ll get these aches. It’s like a toothache that just won’t go away.” For many of the participants with MS, the challenges were not about the sun per se but about functioning in hot weather. Colleen said, “The heat just flattens me,” and Toby talked of how difficult it was to travel in warm climates because of his insensitivity to high temperatures. Consequently, the
different types of interactions they experienced with the weather or climate created tensions over when, where, and how they could function in daily life. For instance, Sabina said, “I can’t be outside too long because of the daylight. I have to wear dark glasses outside because [of] my eyes.”

In addition to the constant struggles that arose between their bodies and the climate where they lived, some also experienced difficulties in using a wheelchair (or scooter) in their physical environment. The nature of these tensions differed according to the types of assistive aids they used and where they wanted to go. For example, Colleen, who used a wheelchair because of MS, said that “not being able to access buildings and things” was the biggest source of tension in her life. “I have a lot of friends that I would love to go see and I can’t get into most of their houses if they have stairs and things like that,” she said. Then she described the challenges in negotiating the physical space in her workplace: “They don’t have an accessible bathroom in the office where I work right now so everyday I have to go out ... to another building, and there’s stairs.” Others, such as Patricia and BB, talked about different kinds of challenges such as negotiating the streets in their neighbourhood, using public transportation, partaking in community events, or using public washrooms.

Overall, at some point in their illness experiences, the men and women all experienced struggles or conflicts in their interactions with the health care system, government agencies, private insurance companies, or the workplace. They also frequently talked about the ongoing difficulties they had trying to accommodate the needs of their bodies with the climate and physical environments in which they lived. Within these common tensions, the level of frustration and nature of the struggles varied in relation to things like differences in their health care providers, insurance plans, employers, workplace, and physical environments as well as in relation to the nature of the things they needed or required from these organizations.
Summary

In summary, all the participants described tensions related to the challenges of living with chronic diseases in the context of their lives. These tensions represented different kinds of oppositional or conflict-based interactions that arose within themselves, between themselves and family or friends, or between themselves and the social institutions, structures, or environments within which they carried out daily life. The examples cited emphasize the diversity of these struggles and illuminate the powerful roles these tensions played in their overall illness experiences. In each of their lives, these tensions formed a complex and dynamic web that reflected both common types of struggles found amongst the group, as well as unique elements reflecting their disease, relationships, and the psychosocial and cultural domains of their day-to-day world. As such, this tension-centred context provides a clear sense of the enormity of the challenges they continually faced in order to live well and provides the context for reconstructing their understandings and experiences of living well as described in their accounts.
CHAPTER 5: LIVING MEANING: ENGAGING IN MEANINGFUL EXPERIENCES

In this chapter, I explore the participants' understandings of living well and show that they constructed the experience in relation to the domains of life that were important and the particular experiences within these areas that were most meaningful.

**Multiple Meanings of Living Well**

When the participants talked about their lives they often spoke of having a good life or a satisfying life but it was challenging for many of them to directly articulate their understanding of living well. Elizabeth said, for example, “When I think about living well and I’m fairly certain I do ... [It’s] hard to break it into components.” They often talked around the issue and seemed to find it more concrete and straightforward to describe what they did to have a favourable life with illness. In their accounts, however, it was evident that they constructed the experience in relation to the areas of life that were meaningful as defined by their unique interests and values. They described a wide number of experiences that were important but the common ones related to functioning in daily life or doing things they enjoyed, having a sense of purpose, having fulfilling relationships, feeling good about their sense of self and identity, and having a sense of spirituality. Quite often, the participants described meaningful experiences related to many or all of these domains. Joan, for instance, found fulfillment in having “really good relationships,” finding purpose in educating people about illness, and being able to do her creative hobbies. The men and women found different kinds of experiences meaningful within these common areas and valued some areas of their lives more than others. Some placed greater value on doing things and functioning in daily life, whereas others emphasized connecting and relating to others. Moreover, these domains of meaning were not mutually exclusive in that the experiences the individuals described as being important often related to more than one area. For example,
Katrina said the act of painting was something really important in her life but also described how being an artist was fundamental to her identity and at the core of her life purpose. Katrina’s experience along with others revealed that the meaning and fulfillment associated with functioning, relationships, purpose, sense of self and identity, and spirituality were quite interrelated in the participants’ understandings of living well.

The experiences they identified as being meaningful in their lives seemed to partially reflect values they had prior to developing an illness. For instance, in talking about what was meaningful, Larry said she tried as “many different things as possible” in the early part of her life so she could determine what was most essential:

In terms of knowing what is important to me as a person … I’ve always known that my cultural activities were very important to me. I’ve always known that being able to read and continue on with history of any form or other was something that I needed too. I’ve always known that I needed human interaction in order for my brain to be with it, so to speak … And I’ve always found travelling rather useful.

Understandings of what was meaningful also emerged, evolved, and shifted during the course of living with chronic disease. Larry and some of the other participants suggested that the process of living with illness brought the experiences that were meaningful into sharper focus and over time altered particular aspects of their understandings of what was important in their lives. In Chapter 6, I explore the ways in which their understandings of what was important and meaningful changed and shifted over time in relation to losses they experienced, but now I turn to describing some of the common experiences that were meaningful as well as some of the diversity inherent in their understandings.

**Being Able to Function**

Maria reflected a common understanding when she said that living well was about “functioning in day-to-day society and doing things you want to do.” Functioning was about being able to do physical, mental, or social activities that were meaningful. In keeping with their
diverse lives, activities ranged from partaking in social and cultural events, engaging in artistic pursuits, doing athletic endeavours, engaging in the tasks of one’s job or career, doing volunteer work to fulfilling the tasks related to being a wife, husband, mother, or father. For example, Larry said that being able to do her cultural activities, travelling, and sports was important whereas Mary valued “being able to have a social life [with] family and friends [and] being able to … do things with them.” Dawn, on the other hand, emphasized the importance of being able to do her job while Tammy deeply valued being able to organize and run the lupus support group in her community. Thus, although they focused on different kinds of activities, they all found meaning and fulfillment in being able to engage in activities in daily life that were important and constructed living well in relation to what these entailed.

Having a Sense of Purpose

Many of the participants also found meaning and fulfillment in having a sense of purpose. A number of the women and men said they reflected more deeply about their lives and sought to make a bigger contribution to community and society after they had developed an illness. Larry’s comments portrayed this common understanding when she said, “Living well for me means being able to … do something that might have value to society.” Hence, living well was not just about doing things in daily life that were of interest, but about doing things that made a contribution to something outside of their own personal lives and helped people and the community in which they lived.

Their notions of purpose were articulated in relation to their interests and varied considerably. A large number of participants described their purpose as making a contribution in the illness community of which they were a part, whereas others found a sense of purpose in other domains. Patricia, for example, described her purpose as being an advocate for people with disabilities in the community. In contrast, Larry talked about making a difference by passing on
Experiencing Fulfilling Relationships

Meaningful relationships with family and friends were also an important aspect of living well. For many, relating to other people and having really good relationships were the most essential aspect of their lives. For example, Sarah said that her relationships with her husband, family, and friends were the most valuable aspect of her life. The participants described a number of different kinds of relationships as meaningful (e.g., relationships with partners, family members, and friends) and a large number of them made meaningful connections with individuals who had in-depth knowledge of illness or personal experience with these conditions.

Even though the nature of these meaningful relationships was quite diverse, there were a number of common elements. One was being able to share interests and activities and enjoy the person’s company. Mary, for example, said that she really valued relationships where she could do activities together such as movies, dinners, and holiday cruises. Another common aspect was that the family or friend provided practical support for the participant’s illness experience. Eryn, for instance, talked about how the meaningful relationships in her life were with individuals who helped out in daily life and provided support for her and her husband as they struggled to balance the complex demands of her illness. The other essential aspect was that their experience of
illness was understood and validated in the relationship. For example, in talking about the most rewarding relationships in her life, Joan said, “I don’t feel like I need to justify that I had a rest in the afternoon or that I like sitting in the evening by the fire or that my life is slower. I don’t need to explain.” Hence, the meaning of living well for many of the women and men was about having fulfilling relationships that involved shared interests and being able to do things together and provided practical and emotional support for their illness.

**Having a Positive Sense of Self and Identity**

A number of the individuals also associated favourable understandings of themselves and their identities with living well. Although different sorts of interpretations of self and identity were associated with these understandings, a number of them described their positive sense of self and identity in relation to the ways in which their experience of chronic disease had interacted with their self-perceptions. Some of them suggested that seeing themselves as individuals outside or in addition to being an “ill person” was important and meaningful. For example, in talking about living well, Kate said, “I really do believe that not having illness as my identity is certainly key for me.” Some of the other participants also emphasized the importance of having non-illness-related identities in their lives. For instance, Katrina said that her identity as an artist (rather than as an ill person) was integral to her understanding of living well. In contrast, others valued seeing themselves as persons with a chronic disease and as having illness identities. Overall, feeling comfortable or good about how they saw themselves in relation to their disease and the roles they played in life were meaningful aspects of their lives.

**Being Spiritually Engaged**

A number of the women and men also described how their spiritual feelings, awareness, or perspectives of life were meaningful. The nature of their spirituality took different forms such
as being connected to abstract forces or other living things or having an appreciation for the preciousness and beauty of life. Some, like Elizabeth, explicitly talked about their beliefs and relationship with God. She said, “I really value my spiritual life. It’s really important to me. I get a lot of strength from God [and] from giving spiritual things time.” Others such as Patricia expressed their spirituality in aesthetic terms. She said, “Living well is living somewhere where there’s beauty around me.” Further, some individuals described their spirituality in relation to appreciating the sanctity or preciousness of life. Toby, for example, suggested that living well was about being appreciative of the life he had even though it was filled with the challenges of chronic disease. Ultimately, for these individuals connecting to or expressing their spirituality was an important aspect of what living well encompassed regardless of what form it took in their lives.

**Summary**

In summary, the essence of living well became evident in the participants’ comments about the importance and meaningfulness of being able to function, having a sense purpose, experiencing fulfilling relationships, feeling good about their sense of self and identity, and being spiritually connected. Their interpretations of these domains of human experience and the specific things they valued in each of these areas differed considerably from one individual to another and reflected the meaningful interactions they experienced with their bodies, other people, and the broader world around them. These meaningful experiences created anchors around which the participants made decisions and negotiated daily life so that the day-to-day realities of what they experienced aligned with the experiences they valued and enabled them to live fulfilling lives.
CHAPTER 6: LIVING ALIGNMENT: ALIGNING TENSIONS, ATTITUDES, STRATEGIES, AND MEANINGS

In describing their living well experiences, the participants talked about the attitudinal perspectives and strategies they used for negotiating the tensions in their lives and engaging in meaningful experiences. They described how they shifted their understandings of what was meaningful so that they could continue to have fulfilling experiences when their functional ability and other aspects of their lives changed over time. This chapter addresses how the women and men used these two different kinds of approaches to align and attain meaningful experiences with the tensions and losses they incurred in day-to-day life.

Negotiating Tensions

The participants described a number of attitudinal perspectives and strategies that they felt helped them negotiate daily life and live well with their chronic illness. By exploring the reasons why they used the specific approaches they did as well as their perceptions of the effects or benefits they had in their lives, I provide insights into some of the ways they attained meaningful experiences and lived well. This involves illuminating some of the actions they used to alter or remove the tensions that seemed to be inhibiting them in some way from living the way they wanted to, as well as actions that seemed more directly aimed at enabling them to experience the things they valued.

Attitudinal Perspectives

The women and men described ways of looking at disease and life and ways of thinking about the tensions of chronic illness that influenced the decisions they made and the strategies they used, as well as their understandings of what was meaningful in life. Their reflections about
their experiences, the stories they told, and their observations and judgments about others experiencing illness reflected various attitudinal perspectives that helped to create living well experiences. Although these attitudes varied, there were some striking similarities in the kinds of perspectives they presented in their accounts. For instance, the majority of the participants emphasized the importance of focusing on the meaningful things in life rather than on the experience of disease. A large number of them also talked about how essential it was to have a positive and optimistic outlook about living with disease and the challenges it created. Moreover, most of them looked at the difficulties they faced from very pragmatic, proactive, and problem-solving perspectives. In addition, quite a few had the view that they could shape the quality and nature of their lives by making choices and taking control over how they integrated their disease experience into the broader realm of their lives. Lastly, many of them showed considerable determination and drive that they felt helped to create the life experience they wanted and valued.

**Living Life Orientation**

When talking about living well, the participants emphasized the importance of being oriented towards life, that is, being oriented towards things outside of illness-related issues, treatments, and self-management activities. Maria said, for example, “I don’t want to just live with MS, I want to live.” Many of them emphasized the importance of being able to move beyond living disease to living life regardless of the severity of their condition. At a general level, this perspective was about focusing on other aspects of their lives and on the things that interested them. Instead of directing all their attention to their disease experiences, the symptoms they had, and their day-to-day management activities, they focused on making a life where they could engage with people and accomplish things in spite of the challenges and tensions they
encountered. At an individual level, their living life perspectives reflected their unique values and life interests and the particular things that held meanings in their lives.

The living life focus was expressed in different ways. For example, when Colleen was talking about how she lived well, she said, “I just don’t live with my focus in life being the MS.” Joan, on the other hand, expressed this orientation more indirectly when she stated, “I have stacks and files of all these things that I’m interested in,” and “I can’t think that my life is sleeping, taking medications, and worrying about my health all the time. I just can’t stand it.” In contrast, Lynx said he was so engaged in living that he seldom thought about his condition:

I frequently forget I have MS. Every time I go to do something I can’t do because of the MS, I’m reminded [of it]. But ... even some days when I’m not doing some things I’d like to be doing, MS is not in my mind .... I honestly don’t really remember I have MS ... and not because I have no memory. I mean, my memory’s fine ... It’s just that it’s not that important to me.

Other participants expressed this view by saying how much they disagreed with individuals who made illness the focus of their lives. For example, Kate said, “You do come across people whose life focus is their illness and that’s the sum total of their horizons. To me, that’s pointless. To me, that’s not living and certainly wouldn’t be living well.” Dawn articulated a similar understanding but elaborated further:

It’s like their life becomes the illness. Maybe they were struggling to have a purpose in general and all of a sudden there’s this focus and it becomes all encompassing and their life revolves around it - when they were taking their medication and how much they were taking and when their next doctor’s appointment was going to be. Its just mind numbing how much time and effort they put into being sick. And I’m not taking away from the fact that some people are so sick that they have to do that. I can appreciate that. But I think a lot of these people forgot what it was like not to be sick.

Although all of them emphasized the importance of living life in one form or another, it was apparent that it was not always easy to maintain this way of thinking in the context of disease and related tensions. Some of them described how they had to use will power to override symptoms in order to stay mentally oriented towards living life, in particular pain and fatigue. Given the forces and tensions working to centre their lives on illness, many of them had to
continually work at preventing their illness from becoming the sole or major focus of their thoughts. Despite these challenges, however, they all felt that their lives were more than their experiences of disease and that being able to focus on life was essential for the living well process. As Laurentia stated, living well requires that you “live your life” and “keep life going.”

**Optimistic Outlook**

When I asked Mary what was the most important thing enabling her to live well, she stated, “My attitude.” Patricia expressed a similar view. She said that her “attitude toward life” and “about other people” was essential to the way she lived. Many participants has the same understanding and portrayed the sense that having a positive or optimistic attitude helped them engage in activities and feel better about their situation. For example, Maria said, “The fact that I am positive ... allows me to do everything that I do,” and Sarah explained that a “positive attitude” enabled her to “live so well” because it influenced how she dealt with her illness and how she felt about her life. She said, “It’s all about ... the attitude that you use ... I truly believe that played a huge factor. ... It’s all about how you deal with it. If you can have that positive attitude and work with what you have, it really helps.”

From the participants’ perspectives, being positive and optimistic was largely about being able to focus on what they had and what they could change. For example, in describing her approach to life with illness, Katrina said, “I try to focus on the things I have, not the things I don’t have.” Similarly, Lynx stated, “I focus on what I can do rather than what I can’t do.” For many, it also had to do with being able to focus on the current state of their illness rather than worrying about a potentially undesirable outcome that might arise in the future. Dianne, for instance, said:
Just take every day, and enjoy it. That’s all you can do. You can’t dwell on what could happen. You can’t say, oh, that’s going to happen because it may not. ... I haven’t got that thus far. I’m doing okay with this. I’m coping with this ... you have to think as positively as you can.

Being positive was also about comparing themselves to others who were worse off or to other periods of their life when their disease was more active. For example, Lynx said, “When you see what some other people are going through, I feel blessed that I have it pretty good ... even though I have MS, there’s lots of positive ... it could be so much worse.” Laurentia, on the other hand, talked about taking a positive view of things because she never knew when she might have another lupus flare. She said:

Because I flare so badly and so critically and because I have various complications that could get me in real trouble like no cortisol ... I live each day knowing how bad it could be and [I’m] just glad that I’m alive and surviving and just enjoying the really good side of things.

A number of them felt that they had this outlook before developing a chronic disease. For example, Tyler said he had “always been a student of positive mental attitude,” and Sarah remarked, “Even before I was sick, I had a positive attitude ... I joked around and I had fun and I lived my life and I didn’t let a lot of things get in my way.” However, their accounts also suggested that many of them made concerted efforts to develop and maintain this perspective during the course of living with their conditions. They described how they read books, attended workshops, or got professional help to support and reinforce their ability to look at life with illness in a favourable ways. Maria, for instance, became “a big reader of Norman Vincent Peale” who is a “huge promoter of the power of positive thinking”. Laurentia commented on how getting “kernels of thoughts” from a social worker helped her to see things in a more favourable light: “She’d come along again and give me another little kernel that I could fly on and that’s all I was looking for was the positive things.” “Not a lot of bellyaching and commiserating about how terrible everything was and ... how awful my disease was,” she said. Tyler, on the other hand, described how he put Post-It notes all over his house to help him
maintain a positive view of things. One stated: “Thank you God for the first day of the rest of my life.” Another one proclaimed: “I’m living with scleroderma, not dying from scleroderma,” and the third one said: “The only disability in life is a bad attitude.”

Overall, many of them felt that a positive and optimistic outlook in the context of ongoing challenges was extremely important for shaping how they approached and experienced daily life and consequently, their ability to have meaningful experiences.

**Pragmatic, proactive, and problem-solving perspectives**

Many of the individuals also had pragmatic, proactive, and problem-solving ways of thinking about life with illness and the specific challenges it presented. For example, in talking about her experience of lupus, Sarah said, “This is what I have and this is what I have to deal with and okay, let’s deal with it and move on.” This pragmatic way of thinking about illness was echoed by many others who portrayed the understanding that there’s a way to do almost anything and provided numerous examples of how this way of thinking (along with the necessary actions) helped them negotiate the tensions of daily life and attain valuable experiences. Patricia talked about how she could not get around the streets in her neighbourhood using her scooter so she lobbied the city to change the curbs. In more recent times, she described how she was “phoning the city continually” to resolve accessibility issues that emerged as she went about her day-to-day activities. Donna, on the other hand, described travelling to visit her sister in the U.S. while she required daily oxygen to deal with the effects of scleroderma. After doing research, she found an airline and medical care facility that could supply the oxygen she required.

Their pragmatic, proactive, and problem-solving stance was also reflected in the way they anticipated future issues and problems. For example, Lynx said, “You have MS. Why worry about it. You can’t do anything about it,” but then added, “What I can do is take steps to combat
the things I know might happen. I can have a plan in my mind on how to deal with it. I can come up with solutions [for daily] stuff.” Toby provided a more specific example of this approach when he talked about how he managed to travel and take vacations with the limitations MS created:

With mobility issues to deal with, I have to sort of stop and think about well, if I take my scooter with me, how do I get it there, and what the accessibility is going to be like. And if I don’t take it, what’s public transportation [like]? How readily available are taxis, or bus systems, or whatever arrangements we [can] make for somebody else driving us? And it all lends itself to do as much or the best planning and just hope it’s going to work well and sort of always anticipating that something is not going to work quite right.

The participants often contrasted their pragmatic and proactive approaches to life to more emotional responses. Toby said, for instance, “[I don’t] sit and whine and complain about having MS and take a negative perspective on having a disability.” Instead of saying, “I can’t do this or I can’t do that … [I think] how can I do it?” They suggested that this kind of stance was more effective in helping them to negotiate life and do the things they valued than using emotional responses such as self-pity. However, they also indicated that they had to work hard at dealing with their emotions so that they could take this approach in daily life. Eryn said, “I make a conscious effort. I really do. I don’t feel sorry for myself …. I just say what are you fretting about? What are you stressing about? Is it really going to help to freak out about this?”

Some of them talked about the role that their upbringing and the expectations of those around them in their ability to approach life from this stance. For example, Tammy said, “I was brought up in a very British way, stiff upper lip. You don’t whine and snivel. You just get on with it and you just do whatever you have to do.” Patricia, in contrast, attributed these ways of thinking to her nursing career where she learned how to stifle her emotions and focus on the problems at hand. Regardless of the origin of these perspectives, it was evident in their accounts that having a pragmatic, proactive and problem-solving approach to illness and life oriented
them towards dealing with their emotions and finding practical solutions for obtaining the experiences or things they valued in the context of the tensions they faced.

**Taking Control and Shaping Life Experiences**

A number of the participants held the understanding that they could influence the nature and quality of their lives. Lynx, for example, said, “I think we control an awful lot of our own destiny,” and similar ideas were common. Often, their sense of being able to shape and control their lives was expressed as an awareness of being able to make choices in how they responded to, and lived with their disease. For example, in speaking about how she lived her life, Samantha said:

> It’s my life. I’m going to do the best I can daily with it. MS affects me differently every day. But every day is my day. I can choose to spend my day in bed whining and complaining and not dealing with life. But I choose to get up, get dressed, take a walk, look outside, take a picture, listen to music, dance, exercise, [and] and take care of myself.

It was also expressed as having control over how they lived with their disease. Sarah provided an illustration of this when she described her experience of recovering from her first lupus flare. She said:

> All of a sudden, it was like I can’t let this thing get me. Like it was really weird ... I was crying, crying, crying ... and wallowing and all of a sudden I thought, I can’t let this thing control my life anymore ... I can’t let this happen to me. I can’t let it ruin my whole life.

Then she went on to say, “And it just hit me that I can change it ... I’m not going to let this ambiguous thing control my life.”

For a number of them, taking control and making choices seemed grounded in an underlying belief in themselves and their ability to do things. For example, Samantha said, “I have always believed I could do anything I put my mind to,” and Maria expressed a similar understanding. She said, “Nothing is impossible if you believe it’s possible. There’s nothing you
can’t do. If you believe it can be done, it can be done.” Some participants suggested that this belief evolved out of their experiences of having to overcome previous life challenges. For instance, Laurentia said that she had had “lots of hard knocks in life” and explained:

Before I got this [lupus]... I’ve had life go bad and then come out and be very, very good. And so I know to hang onto the bad times for better times, so that sense of nothing’s going to beat me is always there.

Laurentia felt that these experiences had given her “this really strong sense” that she could “make it through anything”. As such, many individuals felt they could alter and shape the nature of their day-to-day lives with chronic disease by taking control of their lives and making choices that often seemed related to underlying beliefs in themselves and their capacity to change and overcome life challenges.

**Determination and Drive**

The participants also expressed very determined and driven outlooks. For example, Joan said, “What keeps me going? Determination. Absolute, sheer, determination,” and then she explained, “I’m not going to let chronic illness get in the way of the things [I want], I am still driven.” A number of them felt that being determined and driven helped them to address the struggles of living with chronic disease and enabled them to go forward and find ways to live well. For example, Larry felt that it was her determination that enabled her to continue engaging in life amidst the challenges of living with scleroderma. She said, “I have this determination to get through this come what may and that has been my whole approach to life, my whole life, incredible determination.” Then, she continued:

I just make up my mind to carry on. I make up my mind to get out, to meet people, to go to continuing education classes at UBC, to go [to the] the opera, to go to the symphony, [and] to go away for a weekend. It’s just sheer willpower, absolute willpower that I operate on.
As such, they radiated the understanding “if there’s a will, there’s a way” and Betty illuminated this attitude well when she described digging up her front yard “by hand” using a shovel:

I had men out on the corners saying they were taking bets ... and then when I was all done, one of them said to me ...“I could not have done that job myself.” He said, “I have no idea how you did it.” And then another one said, “Oh, I never thought ... that you would finish that.” I said, “Well, you don’t know me very well.”

Then she explained, “I get so damn mad to think that I can’t do something [so] I’m going to do it whether it kills me or it doesn’t.” Dawn, on the other hand, revealed a determined attitude when she talked about training to run a marathon. She said, “I think the marathon is going to kill me but ... don’t tell me that I can’t do it. I want to do it.” In contrast, Colleen expressed her determined and driven stance when she talked about being a single mom living in a wheelchair and raising two teenage boys:

It was really tough for me to get into a wheelchair. It was really, really tough ... And so [I] finally got in the chair and I thought, ... I’m just going to start zipping around and I’m just going to be a real smart ass about it. And I was ... To be quite honest there’s just no way I’m going to let anybody see me give up. There’s absolutely no way. I have that complete drive in me [so] I just won’t do it.

From the vantage points of these participants, being determined and driven played an important role in helping them to continue to function amidst the challenges they faced and to engage in meaningful activities.

**Summary**

In summary, a number of attitudinal perspectives such as living life orientations; positive and optimistic outlooks; pragmatic, proactive, and problem solving perspectives; taking control and shaping life experiences; and being determined and driven were commonly described in the women and men’s accounts as helping them to live well within the tensions they experienced. These ways of thinking about life with illness helped to shape how they looked at the challenges and tensions they faced, the decisions they made, the strategies they used, and their
understandings of what was meaningful. The important role they played in the living well process will become even more evident in the remaining sections of this chapter when I describe the strategies they used and the shifts in understanding that occurred in their lives.

**Strategies**

In explaining how they lived well, the women and men focused on the actions they took to negotiate the tensions in daily life and attain meaningful experiences. Although they used a wide range of strategies, the most common ones included developing knowledge; managing their disease; using assistive aids, devices, and services; developing new activities; changing relationships; and hiding and disclosing their illness. Insights into how these strategies helped them live well emerged in the reasons they gave for using these approaches and in their understandings of what influence or benefits they had in their lives.

**Developing Knowledge**

According to most of their accounts, accessing information and developing knowledge were important activities. In explaining how she lived well, Annie said, “I’m always learning about my illness ... I’m always learning” and “I’m always reaching out to people who [can] tell me things.” Annie and other participants obtained the knowledge they needed by reading books, using the Internet, talking with other people who had illness, interacting with illness-related organizations (e.g., newsletters, support groups), and speaking with health care professionals. In general, they developed knowledge of their disease and symptoms, medical treatments, alternative and complementary therapies, and the psychosocial dimensions of living with illness.

Given that the participants’ lives were full of multiple tensions and constant change, it was not surprising that they needed different knowledge over the course of living with their illnesses. On the whole, many of them described actively seeking medically-related information
when they first got ill and when they experienced new symptoms and changes in their bodies in order to deal with uncertainty and to manage the disease. However, it seemed that many of them put less emphasis on expanding this type of knowledge when their illness was stable, in remission, or they had lived with it for a number of years. In these situations, they seemed to switch the focus to developing more knowledge of the psychosocial aspects. Those who had a keen interest in the nature of their disease, ran support groups, or wrote for newsletters continued to develop medically-related knowledge during the course of their illness because it enabled them to engage in activities that brought meaning to their lives.

Within this general pattern of developing knowledge over time, participants displayed strong preferences for certain types of knowledge. For instance, Mary said she did a lot of research on MS using medical books but found that they were too technical so she turned towards literature on alternative and complementary approaches. Patricia said she found that books on people’s experiences of living with illness was the kind of knowledge she needed because it reinforced coping with MS in daily life and gave her hope for the future. Kate, in contrast, said she rejected medically-related knowledge and people’s illness stories because they did not meet her needs. She said, “I actually feel a real need to stay away from [medically-related knowledge] because that leads me to focus on do I have this, do I have that problem, and then [I] start getting discouraged or bogged down.” She also felt that she “had more to lose than to gain” by reading personal illness stories as she might see their problems and limitations as her own. Instead, Kate pursued knowledge about alternative and complementary therapies that she felt enabled her to manage her disease and to live life with scleroderma in relation to her own experience. Thus, the kind of knowledge that the participants developed reflected their unique needs and as Kate’s comments suggested, involved weighing the potential benefits of having a particular type of knowledge with any detrimental effects it might have on the tensions they experienced or their attitudinal outlooks on living with disease.
Despite the fact that medically-related knowledge did not meet the needs of Mary, Patricia, or Kate, a number of other individuals felt that a good understanding of their disease helped them to manage their disease, cope with the psychosocial tensions it created, and engage in meaningful activities. Lee reflected this understanding when she said, “If you have a good understanding of what the disease is and how it can affect you, then you’re better equipped. You have better tools to deal with it on a day-to-day basis on your own.” Some participants felt that they needed disease information or medically-related knowledge to be able to control or stabilize their condition. For example, Tammy said that knowing the “danger signals” helped her to prevent her lupus from flaring. Also, a number of them used the medically-related knowledge to make informed decisions about which strategies to use to manage their disease and negotiate the challenges it created. Larry, for instance, described how having knowledge of scleroderma gave her a basis for making informed choices. She said, “All of my actions are predicated on a body of knowledge ... I’m not really a person that does things without knowing what I am doing.” As such, this kind of knowledge helped many of the participants decide which strategies to adopt and which ones to avoid. For instance, BB said, “There are a lot of quacks out there on the Internet who will say, ‘You’ve got to take this stuff and this will cure you.’ That’s bullshit,” he declared. Then, he stated, “This is the other reason why you have to educate yourself about multiple sclerosis, otherwise, you’ll fall for the quackery.”

Medically-related knowledge of disease also helped them deal with the challenging emotions and psychological tensions inherent in living with illness such as the unpredictability of disease and the uncertainty it created. Tammy said, “The more I know about [lupus], the more comfortable I am with it. I don’t like the unknown. That’s my big thing. I want to know.” Katrina and others echoed this understanding. “If I understand it, I can cope with it ... And if I know what can happen to me ... [the] panic is gone,” she explained.
Most of them also sought out other kinds of knowledge through illness-related groups (e.g., self-help groups), Internet or books that were not specifically related to their disease. This was often on alternative and complementary approaches and psychosocial aspects of living with illness but many of them also developed specialized knowledge on topics like self-healing, grief and loss, self-hypnosis, meditation, visualization, cell talk, nutrition, the philosophy of being, Buddhist teachings, positive thinking, and mind control. These served to help them develop strategies outside the medical realm for managing their disease and illness in daily life. As well, these kinds of information and knowledge helped to develop and reinforce favourable attitudes and perspectives towards living with chronic conditions.

Overall, it was clear that the type of information they sought and the knowledge they developed helped them address the tensions they encountered. This strategy also enabled them to achieve the kinds of experiences that were important and meaningful either by directly helping them to have meaningful experiences that required a particular type of knowledge (e.g., running support groups, writing in newsletters) or indirectly by aiding them make informed decision about other kinds of strategies they should use to manage their illness and have important experiences. Developing knowledge also fostered the development of attitudinal perspectives that supported the living well process.

**Managing Disease**

The women and men used a number of approaches to manage their disease in ways that minimized the tensions it created and maximized living a meaningful life. In talking about living well, Joan said, “It’s important for me to do things that I feel are keeping the health I have ... doing my stretching and taking my medications ... to take care of myself.” Collectively, they engage in a wide range of activities including, taking medications or taking other types of treatments, having ongoing monitoring and testing, using complementary and alternative
therapies (e.g., massage, chiropractic services, acupuncture, homeopathy, naturopathy), doing exercise (e.g., swimming, hiking, weight training, biking, yoga, Tai Chi), using nutritional programs (e.g., specialized diets, nutritional supplements, vitamins), engaging in relaxation techniques (e.g., rest, meditation, yoga), and avoiding harmful substances (e.g., alcohol).

The exact composite of approaches they used varied considerably between individuals and their accounts revealed highly personalized strategies for managing lupus, MS, or scleroderma. For example, in talking about the things he did to manage his MS, Toby said, “I’ve tried quite a few different avenues,” and then explained, “Aside from the kind of [medications] that doctors prescribe I’ve also ... done acupuncture. I’ve worked with a naturopath and had my amalgams replaced.” Mary, on the other hand, said:

[I] do yoga for my eyes to improve my vision... I take supplements, evening primrose oil ... I take a very good multiple vitamin ... and I’m going to a Reiki class ... I go for massage weekly ... [and] I’ve had lymph drainage to improve my right leg.

Developing their overall management strategy was viewed as an individual process often involving an intensive period of collecting information and developing knowledge on the various options that were available and then experimenting with them over time until they found things that they felt worked. Mary illustrated this process when she said, “I’ve gathered a lot of information because of my diagnosis, explored different things, [and] tried different things.” This extensive and ongoing search was most evident in the accounts of those who used complementary and alternative approaches, perhaps because such a large number of options are available. Maria, for instance, described the stages she went through as she explored different alternative and complementary approaches over time. She said:

I guess you go through phases. In the beginning ... I remember somebody told me to take my blood pressure or take my pulse after I ate food. Well, that took just forever ... And then I went through the naturopath phase and they’re expensive and to me not that effective.
In relation to her “current phase,” she said, “I’m into ... colloidal silver. I’m into Kombucha tea.
I do my Rebif [drug], and [I’m thinking], okay now it’s time to step it up a notch and move [to] another phase.” Most of the participants described a similar kind of exploratory process even if they did not use alternative and complementary approaches. There was also an overall awareness that what worked now might not work for them in the future. For example, when Hannah was talking about the nutritional approach she used to manage her MS, she said, “I’ve worked out that that’s what works for me but it’s been a long process that may not work for me forever.”

A few participants said they used these approaches to try and cure their disease. For example, BB talked a lot about “metabolizing a cure” for MS and felt that he was strengthening his body in ways that would enable his body to eventually get rid of the disease. He said, “I’ve gotten better because I think I’m doing the right stuff” and described how he regularly lifted weights, was conscious of his diet, did visual imaging, and took supplements. As another example, Kate said, “I think a lot of times people with chronic illness ... just sort of keep things from getting worse. [But] I very much ... want my health back.” She explained that she wanted to “heal physically” and get rid of scleroderma in her body.

In contrast to these individuals, most of the men and women used these approaches to try and stabilize their disease or prevent it from progressing. For example, Dawn said, “I do a lot of cardio because it’s good for my lungs because I do have 50% diffusion ... so the oxygen transfer isn’t very good.” Then, she explained, “The more I can keep my lungs active, the less chance there is of it getting worse.” It was also evident in her account that maximizing her lung capacity enabled her to engage in the physical activities she really enjoyed and train for an upcoming marathon. Indeed, most of the participants associated favourable changes in their physical, mental, or social functioning to the approaches they used, and as would be expected given the range of disease effects and symptoms they experienced, expressed improvements in different areas. For example, Samantha did pool exercises to strengthen her muscles and described the
favourable results in relation to her mobility. She said, “We’ve been exercising in the pool for
the last two years. My mobility has improved. My strength has improved. My endurance has
improved.” Colleen, who is in a wheelchair, also swam regularly to stay “strong” but did so in
order to be able to look after her teenage boys and function well as a mother in their own home.
Betty said that by exercising as much as she could, taking vitamins and eating properly, she
could keep walking and doing the physical activities she really liked. In contrast, Annie, a “great
believer in nutrition,” attributed improvements in her strength and flexibility to “nutritional
supplements.” “I had braces made so I could garden, and now I don’t need those braces …
because I am on a nutritional system,” she explained.

Some of the men and women also spoke about the benefits these approaches had on how
they felt about themselves. For instance, Dawn talked about doing fitness and cardiovascular
activity not only to maintain her lung capacity but also to help her feel better about herself. She
said, “Because I am limited in a lot of things, being strong makes me feel good.” Sarah
expressed this kind of benefit in different terms. She said, “I think diet and exercise are very
important … [for my] self-image and confidence,” and Betty talked about how walking and daily
exercise helped her self-esteem.

The approaches they chose were influenced not only by the specific tensions their disease
created and what they were trying to achieve but also by a variety of other individual factors. In
Maria’s case, the amount of effort involved, the effectiveness of the approach, the associated
cost, and the amount of control she felt she had over the process were important considerations.
As such, her overall strategy for managing MS was centred on things that she could do on her
own such as self-healing techniques that did not cost a lot of money or take a lot of effort. Other
individuals’ comments suggested that their choice in approaches were shaped by the particular
beliefs and attitudes they held about different types of treatment and care, in particular Western
medicine and the health care system. For example, when Mary was explaining why she was
embracing alternative, complimentary, holistic methods,” she said, “I’ve learned a lot about Western medicine … I’ve learned a lot about drugs [and] drug therapies … how people [are] treated by medical practitioners. I don’t like it. I resent it. It’s insulting. I’ve chosen not to go that route.” In contrast, Colleen spoke of her choice to use medical treatments because alternative and complementary strategies did not fit with her scientific orientation. She said, “I’ve never really bought into any of it. I’m [a] science kind of person. I have a really hard time with some of the things, all the energy flowing and all these things.” Others implied that the perspectives of their family influenced their understandings of the approaches they should use. For example, when Hannah was explaining why she used alternative and complementary therapies to manage her MS, she said, “My great-grandfather and my mother were both traditional healers in [their] … communities.”

Overall, the women and men described personalized approaches for managing their disease and illness experience that continually evolved over time and comprised a unique combination of activities that were oriented towards addressing the challenges they faced (e.g., reduced mobility, failing vision, decreasing lung capacity). Regardless of the approaches they used, most of them felt strongly that the specific actions they took to manage their disease made a difference in their bodies and helped them to have meaningful experiences by maximizing or improving functional capacity or strengthening their sense of self.

**Assistive Aids, Devices, and Services**

Assistive aids, devices, and services played an essential role in how many of them negotiated the tensions they experienced and engaged in activities they enjoyed. When talking about what helped her to live well, Taffy said, “[I] have the scooter.” Although many of the participants were not as explicit as Taffy in linking the supportive aids and services they used to the experience of living well, most of the women and men described temporary or ongoing
situations where they used aids or services in order to be able to do things they needed and valued in daily life. In general, they seemed to be very resourceful in finding "something else to do the job." Their drive, determination, and problem-solving approaches helped them find aids or services that worked over time to meet their needs as the parameters of their illness and functional capacities changed.

Given that they often had different functional challenges to contend with, they described a vast range of approaches that were effective in helping them to bridge the gap between their functional capacity and the functional requirements of the activities they enjoyed. Sometimes these aids were simple things they put in place in their homes to maximize their ability to function during the day and sometimes they were more elaborate devices or services to help them participate in a number of meaningful activities. These included things like mobility aids (e.g., canes, walkers, scooters, wheelchairs), cognitive aids (e.g., making notes, using computers), social aids (e.g., volunteers, Internet), and activity aids (e.g., devices for gardening, baking, or traveling; practical support of friends and family; caregivers or housekeepers.) They largely viewed these aids as tools to help them achieve things they wanted to do in life. For example, BB said, "You just use your wheelchair often enough and it becomes part of you and becomes just a daily tool, just like taking the subway to work and bicycling are daily tools. It becomes part of your daily reality."

Their accounts show that the devices and services they used not only improved their functional ability and let them do some basic activities of daily living but also helped them to partake in other activities of importance such as hiking, gardening, and swimming. For some, they also facilitated communication and the development of meaningful relationships. For example, Tammy used a variety of devices so she could bake and garden:
For the longest time I didn’t bake anything because I couldn’t do the baking because of my hands, and then ... I went out and I bought myself a Cuisinart and I bought myself one of those great big Kitchen Aid mixers. And now I’m back to baking again ... the same with gardening ... I gave up the gardening for quite a while and then I thought no there has to be a way. So I went and I found specialized garden tools and I’ve got this garden cart thing ... I think it’s called a Scoot and Go or something ... and you can just sit on that and garden.

Maria used a cane to help her to continue hiking and participating in demanding activities such as 10k walks whereas Hannah used a volunteer to help her swim several times a week at the local pool. She said, “I have a wonderful volunteer who comes to the swimming pool with me and helps me.” A volunteer not only helped her maintain her strength and enhanced her functional capacity but resulted in a meaningful relationship. “[She has] become a great friend and that relationship means a lot to me ... She comes to the pool three times a week and helps me in and out and helps me get dressed [and] that’s real dedication and love,” Hannah explained.

Some of them also used caregivers or housekeepers as a strategy to maximize their ability to do the things they valued. These helpers often did meal preparation, cleaning, and other daily errands such as shopping and driving children to school. Laurentia said, “If I didn’t have a caregiver, I would go ... downhill pretty fast,” and she described how having help around the house enabled her to have quality time with her daughter.

A number of them also described things they did to address cognitive limitations and continue participating in important activities. For Tammy, something simple like Post-It notes as well as a computer enabled her to continue running a support group that was one of the most meaningful things in her life. Several of the participants also talked about how they worked with challenges in sensory function. For example, Mary described how she managed her visual limitations by putting “things in place to make it easier” such as using a magnifying glass, computer programs, and calling people for help. She often used friends to drive her places so that she could continue to do her volunteer work and other social activities she enjoyed.
In summary, most of the women and men used some form of assistive devices or service to help maximize their functional capacities and bridge the gap between what they could do and what they wanted to be able to do in life. The kinds of aids they used varied to meet their particular functional challenges and the specific needs of their lives and also seemed to vary over the course of their illness as needs shifted. As such, these tools became an important and effective means for addressing the tensions related to function and for being able to experience the things that were meaningful in their lives.

Reconnecting with Old Activities and Developing New Ones

The participants also emphasized the importance of reconnecting with lost areas of interest and getting involved in new activities such as taking up new hobbies, engaging in creative pursuits, partaking in religious or spiritual activities, or doing various kinds of volunteer work. Laurentia, for example, went back to playing the piano again after 30 years because she was “trying to surround” herself with hobbies that she could still do once she became ill with lupus. When she talked about playing the piano, she said, “I don’t think I can play that piece and then I can, and it sounds beautiful and so I get the enjoyment of the music as well as the challenge.” Then, she said, “[It is] my little way of having an accomplishment, of having done something.” By connecting to past interests Laurentia felt that she could still do things she enjoyed and have a sense of accomplishment despite the difficulties she experienced. Katrina also reconnected to a previous interest when her “health was getting so poor” that she had to give up her job. In her case, it was painting that helped her to deal with her functional challenges and gave her fulfillment. She said:

I had periods where I was so weak that I could maybe just [do] 20 minutes or half an hour [of] work on something. And I worked on this painting upstairs [for] about seven weeks and as I got better, I could spend a little bit more time. But it was such a triumph for me at the end of this really, really down period to come out and have a beautiful painting.
Art became Katrina’s new career and she saw it as fulfilling a deeper life purpose. By selling her paintings in her art studio she discovered that she benefited from sharing life experiences with other people and helped them to experience some “joy and happiness” through her art. The sense of fulfillment she derived from painting came as much from the interactive process of sharing it with others as from the act of creating. She said, “It gave me back my self-esteem which I had totally lost for a while because my identity was lost.” Taffy, on the other hand, took up stitching as a strategy to improve the difficulties she was having with her hands and to address the sense of frustration she felt over not being able to use them properly. She said:

I [had] bad tremors, but I thought well there must be something I can do ... I don’t know what made me think about needlepoint but I must have seen someone doing it ... and I thought well I can do that. I can put a needle with wool through a hole. That should help my hands.

Then she went on to say, “My hands are really good and I don’t know whether the [stitching] works as well as I think it did but I don’t have tremors hardly at all anymore.” Like Katrina, her account revealed that what started out as a strategy to address a functional challenge (i.e., to improve the motor function in her hands) went on to become something much more – a “life passion.” “It’s not just a social outlet, it’s my life,” she explained. Not only did it seem to help Taffy’s hands and enable her to do something she really enjoyed but it also opened up a whole new social world. She explained that her friends were “all stitchers” that she met at stitching guilds in Canada and the United States.

Some of the men and women got involved in religious or spiritual activities as a means of responding to the tensions of chronic illness and as a way of helping them develop and fulfill their sense of spirituality. Although a few implied that they got involved with these activities for the first time after they became ill, most of them talked about reconnecting to previous spiritual interests or engaging in different religious or spiritual activities than they did before. For example, in talking about her religion and spirituality, Elizabeth said, “It wasn’t something I
invented or found after [I became ill] but it just became ... more personal.” “I did things like go 
[to] silent retreats with a couple of friends ... It was a time for yourself and your relationship 
with God and ... I never gave time [to that kind of thing] before,” she explained. Elizabeth spoke 
about how these activities greatly enhanced her spirituality and the way she was able to live with 
her illness in daily life. In contrast, Laurentia reconnected to spiritual activities after she became 
il with lupus. “[Illness] actually even brought me back to a bit of religion,” she explained but 
noted that it was a “very different type of church,” a “metaphysical” one about “empowering the 
individual.” Attending church and engaging in spiritual activities provided her with ideas and 
strategies of how to manage her illness. She also suggested that perspectives she acquired 
through church and other spiritual practices such as meditation and reading spiritual books 
played an important role in the quality of her personal relationships and the fulfillment they 
provided. Eryn also talked about the importance of spirituality and her involvement in church 
and prayer groups. In contrast to the experiences just described, however, she focused on how 
these activities helped her deal with changes in her appearance from her disease and the 
struggles it created with her body image and sense of self. Like others, it also helped her to 
nurture and strengthen relationships, in particular with her husband.

Many of the individuals spoke of how important their volunteer activities were for living 
well. A number of them got involved in illness-related volunteer work after they became sick but 
a number of them also partook in other types of volunteer activities before and after the onset of 
their illness. For example, Annie described how she was involved in the hospital auxiliary, the 
cat rescue group, and the garden club in addition to being very active in the Arthritis Society, 
and being the contact person for scleroderma in her community. Some of the participants chose 
not to become involved with illness-related organizations at all and focused on doing volunteer 
activities in areas of interest.
Like the other activities previously described, the kinds of volunteer work they did varied in accordance with their individual needs and enabled them to fulfill different areas of importance in their lives. Patricia, for example, got involved with a group of individuals who wanted to improve transportation for persons with disabilities because she experienced so much frustration in trying to move around in the city in her wheelchair. In the process, she became an advocate for persons with disabilities in the community. She explained that getting more accessible transportation such as wheelchair accessible buses gave her a sense of purpose in life. On the other hand, Mary got involved in doing volunteer work with the MS Society to help address the sense of frustration she experienced in no longer being able to work and contribute to society through her job. She felt that doing this kind of work improved her sense of self and identity because it provided a means for her to use some of her skills and abilities. Similarly, Joan described how doing volunteer activities for various illness groups as well as for community organizations made her feel better about herself: “I’m a volunteer counselor at a community organization. I was really excited to do that. That was really helpful to me to get out and actually feel good about some of my skills again.” Engaging in volunteer activities was also about keeping busy and helping them to focus on life rather than their illness or the tensions they experienced. For example, Tammy said, “I’ve always been busy and if I haven’t been working, I’ve been volunteering. I think I need to be busy. Because if I’m not busy … [then] I do dwell on the disease.” Partaking in new activities helped Tammy and others focus on “living life,” an important attitudinal perspective that contributed to their living well experiences.

In summary, the women and men described how they engaged in new activities or previous interests as a strategy to help them negotiate the struggles they faced in daily life and have meaningful experiences, however defined. As such, the types of activities they chose depended on the tensions in their lives and their interests and values. For some, reconnecting to old interests or doing new activities was primarily about the meaning they obtained from doing
activities they enjoyed. For others, it was about maintaining or reconstructing a positive sense of self and identity, developing and fulfilling a deeper life purpose, creating more fulfilling relationships, or enhancing spirituality. These activities also helped to facilitate meaningful experiences in more indirect ways by fostering attitudes that they said supported and facilitated their living well experiences.

**Changing Relationships**

In talking about their life experiences, the women and men described how they altered the nature of their personal relationships in ways that facilitated living well with illness. They made conscious choices about the types of relationships they formed and maintained, ending those that they felt created barriers to a meaningful life and building new relationships that supported it. A number of participants described how they distanced themselves from, or eliminated relationships with friends, family, or health care professionals that were not meeting their needs in living with illness. For example, Annie explained that she did not need “negative” friends in her life because their pessimistic attitudes adversely affected her mood and outlook on life with scleroderma. She said, “I still see [these friends] and we can talk now but I keep them at a distance.” As another example, Maria found her family’s attitudes towards her illness oppressive so she avoided interacting with them so she would not be influenced by their negative understandings. She said, “My family hasn’t really ever acknowledged my disease and if [they have], it’s always that sort of condescending ‘Oh well, you should be careful’ and ‘Are you getting enough rest’ and so … my family’s not too huge [in my life].” Dawn also distanced herself from her family but for different reasons. She said, “They don’t get my lifestyle and being around them is not a positive environment for me to be in because I have to pretend [that] I’m not sick.”
Of the 12 marriages that ended after the participants developed symptoms or were diagnosed with disease, 6 participants said they chose to end their relationships partly because their partner’s attitude and understanding of their condition created tension and prevented them from living with their illness in a positive way. The breakdown of their marriages was also related to a number of other complex factors including abuse, mental illness, and a lack of common interests. BB expressed the illness-related reasons for ending his marriage when he said:

> Here I am going to see every doctor in town. There’s something seriously wrong and … she’s trying to blame me for it and saying, “All you have to do is get outside … [and] just get over it.” … [A] complete lack of support, I couldn’t deal with [it].

In contrast, Maria said that she got a divorce because of her ex-husband’s abusive behaviour and pessimistic view of her illness and she described how ending the relationship eliminated the frustration and tension these things created in her life. From her perspective, the stress of her marriage and his attitudes adversely impacted on the state of her MS and functional capacity and she felt that both of these things improved when the marriage ended:

> At the end … everything was so negative and I could just watch my health going straight down hill. I mean … before I left I was really ill. I couldn’t do the Grouse Grind [hike] … just going up a set of stairs was a challenge so once I got out of that relationship then all of a sudden, I could do the Grouse Grind. I never thought I could do it again.

For Maria and the five others, ending relationships helped remove sources of tension in their lives. They saw the decision to leave their partners as a turning point in their journey to live well because of the positive effects it had on the way they were able to live afterwards. The benefits they associated with terminating their relationships included improved functional capacity, gaining a stronger sense of control over their lives with illness, believing in themselves, having a more positive attitude and perspective on living with their condition, having more time and energy for managing their disease and being able to develop more meaningful relationships. For example, Mary felt that her attitude and sense of self improved after she left her husband. She
said that when she decided to leave her husband, people thought, “Oh my god, you better hang onto him. You have MS. You’re ill. What the hell are you thinking of, leaving him? Are you nuts?” and then she explained, “Allowing myself to do that made me realize … I have this disease, it doesn’t have me … I can be strong and independent even with this disease. I’m going [to] manage it. I’m going to learn how to live with it.” Ending her marriage helped Mary regain a sense of control over her life and tap into her inner strength. It also created the kind of attitude or mindset she needed to live well with MS in daily life. BB also felt that his life with MS improved considerably when he divorced because he was able to find the energy to focus on doing what he needed to do to manage his disease instead of using it to deal with conflicts in his marriage. Colleen, on the other hand, described how the end of her marriage enabled her to move to a new community where her family and friends lived and to build more meaningful and fulfilling relationships that supported her life with MS.

At the same time as they were purposefully ending or distancing themselves from relationships that were inhibiting them from living well, many of them were actively seeking out opportunities to meet new people and develop relationships that better met their needs. Although they developed new relationships in a number of different ways with a number of different kinds of people, many participants emphasized the importance of building connections with other chronically ill people because they lead to more meaningful and fulfilling relationships. Most of them used face-to-face encounters within illness-related groups and organizations to build these connections but a few described using the Internet. For example, BB said:

The Internet was just really coming into being around [the] time [when I was diagnosed] and I was able to find some multiple sclerosis discussion groups which was just wonderful because all of a sudden I could find … a group of people who had the same problems that I did and who understood it because they knew, because they had it themselves … I made a lot of friends on the Internet chatting with other people with multiple sclerosis.
As BB suggested, developing relationships with people who had similar problems or a shared understanding of the illness experience was important in establishing meaningful connections in the context of the participants’ lives. Dawn concurred when she said, “I’m with my partner right now because he has an illness and I really feel that unless you have one or you’ve been really close to someone who has, you don’t get it.” In describing what this shared understanding entailed, she said:

I don’t have to tell him I’m having a bad day. He can sense it. He knows if I’m having trouble getting out of bed and he’ll come over and help me ... He walks that fine line between being understanding [and] not treating me like I’m sick and no one else has ever been able to do that. They either coddle me and make me feel like, “Oh, get away. I’m not a child. You don’t have to baby me,” or they’re so disconnected that they don’t see what I need. With him, it’s unspoken.

By having a shared understanding with her partner, Dawn was able to get the emotional and practical support she needed. Overall, the participants’ accounts indicated that shared understandings of illness lead to emotional and practical support, humour and fun, and support for their attitudinal and strategic approaches to living well.

Many participants found these supportive relationships through their involvement in illness-related groups. For example, Sanora said that the people in her support group helped and supported each other outside of organized activities. She said, “If somebody hasn’t been to a support group for a while or we haven’t run into them or they haven’t called, we call each other and say, ‘How are you doing? What’s happening? Where have you been?’” In addition to providing a network of mutual support, Sanora felt that her group provided opportunities to partake in social events and develop meaningful relationships with some members of the group. Developing relationships with people who had a shared experience of illness also provided the basis for humour and fun. In talking about friends she made through MS-related organizations, Mary said, “It’s just given me ... a lot of laughs. I mean we’re always goofing off.” Then she
added, “This meeting I’m going to … we [all] have MS, and we’ll just [go] ‘ah, had an MS moment’ or something. I mean it gives you a bond and it can be very funny.”

Shared understandings of illness also enabled some participants to engage in activities they valued. For instance, Dawn described how being able to snowboard with a person who had an illness was much more enjoyable because they respected each other’s limits. She said:

There’s one guy that I snowboard with and he’s sick as well … we both have to take our time. And instead of like, “How are feeling? Can you do one more run?” … We’re always checking in, and if somebody’s had enough for the day, then we go home.

Dawn contrasted this experience to “snowboarding with a healthy person” and said, “They’re always like ‘one more, one more.’ They don’t understanding that when I’m done, I’m done. And I don’t like bringing it up because it makes them uncomfortable … so I surround myself with people who get it.” Thus, building relationships with persons who have an illness not only provided many of the participants with more meaningful relationships but also afforded some of them the opportunity to engage in the activities they loved to do in less stressful and more fulfilling ways.

Friendships with people who are ill also fostered and supported their attitudinal and strategic approaches to living well. For example, Mary chose her volunteer activities within an illness organization so that she would be with optimistic and “upbeat people.” Similarly, Maria said she developed relationships with people who were determined to help themselves. She said, “I don’t need to sit with a bunch of people that are really depressing and they’re going to give up and there’s no hope. That doesn’t help.” Then, she gave the example of how she had become involved in a self-help group at an illness society with people who were motivated to make things better for themselves. She said, “I really enjoy the self-help groups … because then you get to meet other people that are like-minded, that want to help themselves, as opposed to people that are quite content to accept their lot in life.” Forming relationships with other ill people also helped to develop their knowledge about various different strategies they could use to manage
their illness and live well. For example, through the establishment of a self-help group, Hannah was able to create relationships with people who were “interested in holistic ... [and] natural approaches” to living that fit with her beliefs and needs and supported the development of knowledge and strategies for managing her MS.

Although a large number of the participants seemed to develop new relationships with persons who had illness via illness-related organizations not all the women and men found these kinds of relationships beneficial. Some stated that they did not enjoy or intentionally avoided developing relationships with others who had chronic illness as they found relationships outside the illness community more meaningful. Kate, for example, had the understanding that being around other ill people made her feel like her life and identity were at risk of becoming centred on illness and this was in opposition to her living life perspective. She explained:

It’s been suggested to me a couple of times, [that I should] get involved with organizations. ... I really felt that if I were to get involved, let’s say in a little group thing with a bunch of other scleroderma people, my fear was actually that I would fall into the “I am scleroderma.” ... I would get into that place of thinking that was who I am ... I didn’t see that it would be a place for me to get healthier ... And so I didn’t want to participate in any of the sort of support groups or those things.

For those whose preference was developing new relationships with people outside of the illness community, the emphasis was on finding people who had similar interests, life situations, or values. For instance, Colleen said that “unless they’re people you really click with outside of the MS stuff” she would rather develop relationships with people that shared her interests and experiences as a parent. She explained, “I deal more with the people who have kids. Like all the people that I hang out with are ones [that] have kids the same age as my kids.” Eryn, on the other hand, talked about the importance of creating relationships with people who valued spirituality and had a similar kind of outlook on life. She said:

I surround myself with people that have goals and have a fun and positive outlook on life, [and] have some element of spirituality. And I don’t care what religion you are. I don’t even care if you’re religious as long as you have a sense of spirituality ... even if it’s just faith in being a better person.
Eryn suggested that by surrounding herself with people who met these criteria she was reinforcing a positive outlook on living with illness and supporting the development of her spirituality that was important and meaningful in her life.

In summary, the women and men created and shaped their social interactions in ways that helped influence the nature or course of illness-related tensions and fostered not only the development of fulfilling and meaningful relationships but also positive views of self and identity, opportunities to engage in valued activities, finding a sense of purpose, and spiritual development. Although they developed a range of new relationships during the course of living with their illness, the development of relationships with people who had shared experiences of illness and similar ways of thinking about their conditions and life seemed to be a particularly important means for many of them to be able to reduce the tensions arising in their interpersonal life, build more meaningful relationships and create a supportive social environment that fostered living well.

**Hiding and Disclosing Illness**

Some of the women and men’s accounts suggested that the choices they made over whether or not to present themselves as healthy or ill influenced their capacity to live well. These individuals portrayed the understanding that presenting themselves differently in social situations had different consequences in their lives. By consciously choosing when to adopt or avoid being seen as “ill,” they were able to influence the nature of their lives in ways that best met their individual needs. The choices they made helped them avoid or eliminate tensions in their lives and have meaningful experiences.

Although many of them described changes in their physical appearance from their diseases, many of these changes were either not readily evident to most people or could be
effectively covered up through the use of make-up or clothing. In some cases, they were able to pass off the changes in their appearance or function as something of a more minor nature or as an isolated condition (e.g., back or hand problem). The individuals who used mobility aids such as canes and wheelchairs did not have the option of using this strategy. However, some of their accounts suggested that they may have used it during the earlier part of their illness experiences when their disease and related changes in function had not altered their appearance in ways that were impossible to hide. Accordingly, many of the participants were in the position to selectively choose, all or part of the time whether or not to reveal that they had lupus, scleroderma, or MS.

A number of them gave examples of situations where they decided it was in their best interest to keep their chronic disease confidential and hide any visible signs. They seemed to feel that they had more to lose than to gain by making their illness “public.” They implied that people’s reactions to their illness impacted on the way they wanted to live and by choosing not to disclose their disease they were able to create social situations or an overall environment where people’s behaviour favoured rather than inhibited them from doing what they wanted to do. The reasons they gave for making this choice included avoiding emotional reactions, rejection, or discrimination; preventing themselves from being subjected to altered expectations of their behaviour and roles; gaining access to activities they want to do; or maintaining valued identities. For instance, Dawn said she lied about the rash on her face or wore make-up to hide it because she was rejected and often subjected to intense emotional reactions when she told people she had scleroderma. “If you tell somebody, they freak out,” she explained. She said she hid the signs and symptoms to develop relationships and carry out activities she enjoyed without coming into conflict or uncomfortable situations. Other individuals also said they did not disclose their illness in all situations because they felt it would lead to rejection and a loss of relationships. For example, Elizabeth said, “It is not important to tell everybody because you’re going to lose everybody if you do.” A few of them also chose to keep their illnesses confidential in the
workplace to avoid potential discrimination or loss of employment. Dawn, for instance, said she
confided in a potential boss about her illness and he never hired her again so she decided not to
reveal her illness to other employers. She explained:

   I had one person who is in a position to hire me … He used to hire me a lot. One day he
asked me about [my health] and I thought, you know what, I’m not going to lie to him …
I’m going to be honest. He stopped hiring me. And I found [out that] … he’s afraid that
I’m going to get sick on set which is then going to let him down and make the show look
bad.

Some of participants said they also chose not to disclose their illness because they did not
want to be subjected to altered expectations. These individuals felt that being perceived as an “ill
person” created expectations for certain kinds of behaviours that were limiting and incompatible
with how they wanted to act and live with lives. For example, Dianne said, “Only my closest
friends realize there [is] a problem. I don’t go around telling everybody, oh well, I have
[scleroderma] because … I don’t want to be treated differently than anybody else.” Other
individuals provided similar rationales. For instance, when Kate described why she didn’t tell
people she had scleroderma, she said:

   Partly I feared the way I’d be treated … People sort of not expecting the same things out
of you as they would someone else, or “Oh well she can’t do it,” or just that kind of
thing. So for the longest time very few people ever knew anything except maybe [that] I
had problems with my hands … because that’s the only visible, really visible thing that
they [saw].

Some of the participants who used oxygen or canes that were clearly visible also spoke of hiding
them in certain circumstances. For example, Donna said, “I haven’t been really exposing myself
to friends with the oxygen. I haven’t done that. I mean … not even all my relatives.” She
explained her reasons in this way, “I know when I put on [the oxygen tank] and people see me,
they’ll think the worst of me. And I don’t want that.” Then, she went on to say, “People will start
asking ‘Why are you volunteering when you have this thing and that thing? … It’s just an aid for
me.” A few of them also said they made this choice so they could have access to activities that
would have otherwise been off limits because of their disease status. Dawn, for example, talked
about how she did not tell “the people at the scuba diving place” that she had an illness so that she could take a course. She said, “My doctor wouldn’t sign the forms … so I went to a doctor who didn’t know my medical history and I got him to sign it for me.” She also said that she “didn’t divulge” her illness on her application to acting school because she did not feel that it was relevant. She said, “People don’t need to know that I’m sick … It’s not like I have asthma or I have a heart defect where … if you make [me] run, [I’m] going to pass out on the floor, [I] might die.” Some participants also suggested that they chose this course of action in order to maintain valued roles. For example, Maria made efforts to maintain the expected behaviour of a mother and to hide MS-related behaviours because it was meaningful for her to be a “normal” mom. She said:

Most people that would meet me would never know I had MS. I mean I do everything other kids’ moms do. I mean … I don’t ice skate or ride a bike, not all moms do that…. But I participate in everything. It’s not like I take tremendously long naps every day…. And, because I work out and I have no problems weight lifting, most people don’t know I have MS…. I mean I do have to catheterize at night but nobody would know.

Conversely, the women and men also cited instances when they chose to disclose their disease either verbally or by revealing changes in their physical appearance and this approach seemed to be more common after they had lived with their illness for some time. Many of them described situations when they were open about living with a chronic disease in order to access services and treatments, receive emotional, and practical support, develop intimacy, establish meaningful relationships with other persons with illness or feel positive about their sense of self. Some of them also felt that being open about their illness status was an effective means of avoiding things they did not want to do. For instance, Mary said, “MS can give you a whole lot of excuses to get out of situations,” and she went on to explain that it enabled her to get out of doing things and being with people that she did not enjoy so she had the time and energy to engage in more rewarding activities and relationships.
Many of the women and men used these two opposing approaches over the course of living with their illness. The choice about whether to disclose or hide their disease often varied from situation to situation and within particular contexts or relationships based on what they were trying to achieve. The approaches sometimes differed over time in the same relationships or in relation to the developmental stages of a participant’s life or illness. For example, Tyler talked about how the approach he took with his male buddies shifted over time from keeping his illness confidential to disclosing his condition. He said:

I’ve been playing pool with these guys for 25 years and a lot of them didn’t realize that I had an affliction, a chronic disease. They just knew that I had cold hands ... I had bandages or something ... They ask you, “Oh, what have you got?” I said, “I’ve got an ulcer on my finger.” You don’t say, “Well, I’ve got scleroderma.” ... You don’t go through that. So a lot of the people that I’ve been associated with ... just know I’ve got an ulcer on my finger. It’s bad circulation.

Then, he went on to explain that in the last few years he had become more open about his illness with this group of men as the signs of scleroderma became more apparent and his relationships became more established. He said, “Over the last three or four years ... I had bandages on and fingertips taken off and they all ask me what was going on, and ... [finally] I gave everybody a brochure on scleroderma.” Alternatively, Dawn’s account suggested that she changed her approach between being a child and teenager and an adult in current life. She described wearing lots of make-up to cover up her facial rash to prevent teasing and rejection in the early part of her life with scleroderma, but when talking about more recent times, described how she had become more comfortable with disclosure and seemed to be able to cope with people’s reactions in a different way. She said:

I don’t wear [make-up] now. I wear it to work because ... I like to look professional at work. If we’re going to go out for a nice dinner, I wear it. But 90% percent of the time I don’t because I just hate it. And I don’t care anymore I guess. This is me. Take it or leave it. But I wasn’t ready for that [before].

Thus, making decisions over how and when to disclose or hide their illness was complex and seemed to be a continuous decision-making process in many of their lives in order to have
meaningful experiences. Joan expressed the ongoing dilemma of whether to disclose or hide their illness when she said, “I’m sorting out stuff in my head all the time about … what I should tell people. ... Should I say my hand’s hurting or just use the other one?”

Overall, the men and women who altered their illness identities (either through verbal or physical means) felt that the approach they chose was effective in helping to prevent or eliminate some of the tensions in their lives and attain what it was they wanted to achieve in particular relationships or social situations. These individuals’ accounts reflected the understanding that the reactions of other people helped to shape aspects of their daily lives and thus, by adopting strategies to change these responses, they changed the nature of their illness experiences and their capacity to have the meaningful experiences they desired.

**Summary**

In summary, strategies helped them overcome tensions or struggles that acted as barriers or impediments to meaningful experiences, fostered attitudes that supported the living well process, and helped them fulfill the important parts of their lives through more direct means. This enabled them to maximize their ability to function and engage in the activities they enjoyed most, create a favourable sense of self and identity, find and enact a sense of purpose, experience deep connections with others, and develop their spiritually. Within the common strategies, the participant’s used ones that best addressed the specific tensions they experienced and the meaningful experiences they were trying to achieve while meeting their unique needs, beliefs, and personal circumstances. Given that they valued multiple aspects of their lives and often experienced a number of tensions simultaneously, they had to make choices about the potential impact of using one strategy in relation to its effects on other tensions in their lives and other meaningful experiences they were trying to achieve.
Negotiating Loss

In this section, I describe another important process for living well that was inherent in their accounts. This involved shifts in the participants' understandings of what was meaningful in response to experiences of loss. These shifts facilitated alignment between the life the men and women wanted to live and the one that was possible in the context of their disease and the tensions and losses it created.

When the individuals described how they lived well, they not only talked about the struggles and tensions of living with illness and the strategies they used to address them, but also about the losses they experienced and how they responded to them. They gave numerous examples of how changes in the nature of their disease and functional abilities interacted in their lives such that they were not always able to hold on to everything that was important and meaningful despite considerable effort. They often experienced so many losses that a number of them constructed their illness experiences as a process of continuous loss. For example, Samantha said, "Sometimes you gain, but most of the time you're losing. And not just losing today, you've been [continually] losing ... that's what a disability is."

These losses were frequently expressed in similar areas of life (e.g., physical activities, career, relationships, sense of self) but they often focused on different ones. For example, Tammy talked about her sense of loss over no longer being able to dance, whereas Elizabeth described "one of the big losses" in her life as her work and the sense of fulfillment she got from her professional career. BB also described a sense of loss over giving up his job but focused on the loss of his work-related identity. He said, "I mean all of us invest a lot of who we are in [our] job. ... It's a major part of your existence [and then], all of a sudden, this major part of your existence is taken away." Rose, on the other hand, spoke of losing her sense of self due to changes in her body image from her disease and medications. She said, "I'm not that person that I was before I got sick. I look in the mirror and I don't recognize the person that I see." In
contrast, Katrina talked about losing important relationships in her life. She said, “I lost … 75% of my friends [who] could not accept what was happening.” A number of them also experienced loss over missed opportunities to pursue their dreams. For example, Joan spoke of the significant loss she experienced in not being able to have a child because of impaired kidney function, whereas Rose spoke of giving up her dream to be a child psychologist because she could not function well enough to continue her education. Despite the variation in losses, all of them described some degree of loss in physical function (either transient or permanent) that seemed to be the cause of many of the other forms of loss they experienced (e.g., loss of job, loss of sense of self or identity).

Shifting Meaning

As might be expected, they talked about their responses to these losses in terms of sadness and grief. However, many of them also situated their experiences of losses in relation to changes in their understandings of what was meaningful in their lives. Elizabeth said, “One way you could almost describe how lupus affected my life was … [as] a series of losses and I just had to learn to grieve the losses and then, carry on and substitute what was meaningful after that.” Amongst their accounts, losses seemed to be the catalyst for two different kinds of shifts: (a) changes in understandings of what gave them meaning or constituted fulfillment in an important area of their life (within domain shift); and (b) changes in understandings of the relative importance or amount of fulfillment they obtained from various aspects of their lives that held value (between domain shift). Some of the women and men talked directly about these transformations in understanding but in many other cases they were discernable in their comments about what they valued prior to developing an illness, the activities and experiences they had lost, and the aspects of their lives that were important and meaningful to them at the time of the interview.
Many of them expressed these changes in understanding in relation to losses of functional capacity even though they articulated a range of different losses in their accounts. As such, the loss of physical function seemed to be the most important trigger for altering perceptions of what was valuable and important in life. This likely reflected the fact that all of them experienced some significant functional loss throughout the course of living with illness. Some accounts also suggested that the perceived effectiveness of strategies in helping them to have meaningful experiences played an important role in determining whether a change in understanding occurred. Hannah, for example, partially related changes in her understanding of what was meaningful to the ineffectiveness of the strategies she used. She said that she made shifts in what was meaningful once she realized that the strategies she used were not enabling her to walk again and to regain some of the meaningful areas of her life that were dependent upon mobility. In explaining how she changed her understanding, Hannah said, “I guess how I moved there was through time and experience … working hard doing everything that these [other] people who are all better have done to get where they are and seeing it [wasn’t] going that way for me.”

When they made shifts in understanding of what was meaningful, the nature of the tensions they experienced altered. For example, when Laurentia was talking about what happened in her life when she shifted her understanding of what was meaningful, she said, “As soon as you surrender … everything shifts, the whole tension, the whole struggle.”

**Within Domain Shifts**

In regards to within domain shifts in understanding, many of the participants continued to value the same activities and experiences in their lives after developing a chronic disease (e.g., being able to function, relationships, spirituality). However, almost all of their accounts revealed changes in some aspect of their understanding of what was important and meaningful in these
areas of life. These shifts were expressed in a number of ways but most often as changes in the
amount or kind of experience that brought them fulfillment in an area they valued or as a more
fundamental change in what a particular area of value constituted. Tammy, for instance, found a
lot of fulfillment through her volunteer work, but said that “over the years, piece by piece” she
had to give up involvement in all groups except the lupus support group because she no longer
had the physical stamina to do it all. However, her work with the support group had become the
most important and meaningful activity in her current life. Larry, on the other hand, spoke of
having to give up the sports she valued because of the impacts of scleroderma but described how
she came to find fulfillment in the other two activities that she was still able to do – travelling
and cultural events. She said, “The sports have had to go. There was no way that could be done.
They’ve gone. But I still find I live very well if I can still go to opera … and as long as I can do
some travelling.” Hence, Tammy, Larry, and some of the others who expressed within domains
shifts, changed the focus of meaning in their lives to the aspects of life they could still
experience and away from those they had to abandon because they were no longer able to do
them.

A handful of participants also talked about having a more restricted or more limited life
and of finding meaning in the simple things that comprised daily life. This reflected a shift away
from the bigger activities or experiences they valued to the more simple, routine, and spiritual
aspects of day-to-day life. For example, Samantha said, “MS is in my life. But it’s still my life
… I’m going to enjoy what I can of it … I get enjoyment out of the simple things. And I think
that’s probably one of the biggest lessons I’ve learned.” Then, she went on to describe how much
meaning she found in the day-to-day action of life. She said, “I see wonderful things everyday. I
enjoy the music. I hear the birds. I watch the rain. I enjoy the wind on my face.” Laurentia
articulated this shift in meaning somewhat differently. She talked about how she never knew
when her flares were coming and she would become severely ill again so she learned to find meaning in doing the day-to-day activities and simple things with her daughter:

   I feel very grateful I’m able to go on some field trips with my daughter at school. I’m able to pick her up at school if I want to or I’m able to take her to her activities and enjoy her activities. I can take her shopping. I can play with her.

Lynx, on the other hand, said, “[Enjoying] each day is the biggest meaning to me,” and he talked about the value he attached to visiting his mother and family and helping out people on the Internet who have problems with their MS.

Within domain shifts in understanding were also expressed as changes in the types of experiences that brought fulfillment in a particular area of their lives. For example, in talking about the effects of MS on her life and the losses it created, Mary said, “I just have to adjust what I do. I can’t run five miles anymore. I can’t do certain things anymore but I can do other things … it just takes me longer.” Then, she described the sense of fulfillment she got from the new activities such as writing and reading that did not require the same level of physical capacity as her prior athletic endeavours. Donna, on the other hand, described how her career was a very important part of her life but said she came to find meaning in “making a career out of staying home” and being a good wife and mother. In fact, a large number of them talked about how they found new kinds of activities, interests, and experiences to provide the sense of fulfillment that they once derived from their jobs or careers. Joan, for instance, talked about how she shifted the focus of her life from having a nursing career to her creative passions such as painting and singing because she was no longer able to function as a nurse. She said, “My mission, I think, is just to … explore my gifts that aren’t to do with medicine [or] nursing anymore,” and then added, “I’ve given up on the nursing thing now … and I’m going to be doing my artwork and getting it out to galleries.” At the time of the interview, she emphasized the fulfillment she found in being able to engage in her creative activities, however, it was clear that nursing was very meaningful in her pre-illness life. Similarly, Patricia said she had to give up her career as a nurse
educator when her MS progressed but then she unexpectedly found a sense of fulfillment in
being an advocate for persons with disabilities on accessibility issues. She said, “It kind of gave
me a whole new career…. It’s not something that you plan but it just kind of fell into my lap.”
She went on to say, “I think it made me feel better about my life because it gave real meaning …
to be able to be doing something that ended up having such wonderful outcomes.” A number of
other participants also found new meaning through their volunteer work with illness or
disability-related groups or organizations. For example, Hazel said that when she was no longer
able to work she found her life focus in her volunteer work with the Scleroderma society. She
said, “I enjoy talking to people and I enjoy the feelings of helping when [I] can” and before
developed an illness, “never even gave [volunteer work] a thought.”

In contrast, a few of the individuals described how they held on to their life passions that
used to be fulfilled in their jobs or careers by altering the kind of activity that gave them a sense
of fulfillment. BB was a professional musician who played double bass for part of his working
career but had to stop when his MS prevented him from having the “physical strength to do it.”
However, he eventually found the strength to play guitar and began to write music that enabled
him to continue finding a deep sense of fulfillment in music. He said, “I can just do my music
and say, okay that’s cool. … No one else has to hear it. … It’s enough … to work out the stuff
that’s inside [me] and write it down.” Dawn, on the other hand, enrolled in acting school because
her dream was to become an actress but when she lost that opportunity because of the effects of
scleroderma she became an assistant director working in the film industry with other actors. She
said, “I thought acting would be great and I still feel pangs of it now when I see an actress my
age” but she noted that she “just fell in love” with her current career as an assistant director. “I
always knew I wanted to get paid to do what I love and not to get paid to just do a job for the
sake of making money, and I have that, so that’s amazing,” she explained. Alternatively,
Laurentia said she always thought she would find fulfillment in her relationship with her
daughter by being a “model ... of a strong, athletic woman” and “teaching her sports.” Once she developed CNS lupus and was unable to be that role model she said that she learned to find fulfillment in her relationship with her daughter by doing things “in a different way” and giving her “different things” such as teaching her to never give up when learning new things.

Some individuals also expressed changes in their thinking about what an area of value represented or constituted in their lives in response to the losses they experienced. For example, Mary talked about how the kinds of relationships she valued changed after her MS became more prominent in her life and she lost some of her vision. She said, “At first I didn’t need support friends because I didn’t need the support ... I hadn’t had any major flare-ups or anything like that.” But when her illness became more active, she valued relationships that could provide both friendship and the practical support she need to get around. Laurentia, on the other hand, talked about how her sense of identity, which had evolved around the activities she did and the career she had, became more about her sense of “being” and “spirit” once she lost a great deal of functional capacity. Alternatively, Elizabeth described how her understanding of spirituality shifted after she became ill and lost some of the things she valued such as her career. She had been involved in church-related activities her whole life because her parents were missionaries, but after she developed lupus her sense of spirituality changed:

When you grow up in a really religious sort of surroundings ... some of it is just borrowed ... comes from outside and you have to decide how much of it is for you. And, I don’t know that I spent enough time figuring that out before because I kept myself busy.

She explained that after developing lupus her spirituality became “real, much more personal, and ... more [about] ... the reflective, meditative part of spirituality” that she’d “never made time for before.” In comparison, when Toby discussed how the progressive loss of function he experienced with MS affected his life, he described changes in his understanding of what a sense of fulfillment in this area entailed. He said that he increasingly found meaning in trying to do
things. As such, finding meaning through his activities became more about “feeling like you tried to do something, whether you [could] do it or not”.

*Between Domain Shifts*

Almost half of the participants’ accounts not only revealed within domain shifts in understandings but also changes in the relative value or sense of meaning they attributed to different areas of their lives (between domain shifts). Most of these individuals found deeper fulfillment in something that was already part of their lives but then became more important relative to other activities or experiences when they faced loss. Some also found fulfillment in an entirely new area or domain of life. Tyler, for example, found a lot of fulfillment in playing snooker and golf but after scleroderma greatly reduced his ability to use his hands he was able to do these activities in a much more limited way. In describing his current life, he said he found a sense of fulfillment in his relationships with his grandchildren and his girlfriend and placed far less emphasis on the importance of physical activities. In comparison, Sarah spoke of how the main source of fulfillment in her life changed when she developed lupus in her 20s and was forced to change her priorities. She said:

> I had this whole vision ... I was going to become a nurse and I was going to work with kids ... I wanted to work with kids in a children’s hospital. And then, I was going to get married ... and then I was going to buy a really nice house and I was going to have kids of my own. That was my grand plan.

In explaining why she had to give up her plan for a career in nursing, she said, “There’s just no way physically that I could do it, and [I was] going to be in hospitals [and] ... environments where there [were] germs flying everywhere.” In her present life, Sarah found meaning and fulfillment in her family and friends and explained that her current job at a bank was only something she did to earn money. She had recently gotten married and at the time of the interview was contemplating starting a family. Similarly, Elizabeth talked about finding more
meaning in her relationships. She said that when she lost her job, the focus of her life and source of fulfillment became her relationships with God and her sons. Alternatively, when Laurentia’s body “failed” in terms of being able to physically function well and she lost her capacity to do all her athletic activities, the main sources of meaning in her life became her spirituality. Although it had been part of her life in the past, it had not played a prominent role. She said, “I’ve learned a lot more that life isn’t about doing, that was a real addiction of mine – doing, doing, doing.”

Process of Shifting Understandings

The question of how their experiences of loss led to changes in what was important and meaningful in their lives was partially revealed in their comments on accepting illness and seeing the opportunities for fulfillment in the new life that illness created. Almost half of the women and men talked explicitly about accepting their illness and most of the other participants’ accounts suggested that they had gone through some sort of process that had altered their understanding of daily life. For example, in talking about having lupus, Katrina said, “I’ve accepted it ... I’m not happy because I’m sick. I would rather be well but that’s what it is and I can’t change it so I must accept it.” Then in explaining how she came to accept her illness, she said, “It was a process. It was a timely process ... you go through the anger stage, you go through the lost stage, you go through the grieving state and then slowly, slowly, slowly you accept it.” A few of them said that when they encountered significant loss they felt they were making a choice between accepting illness (i.e., changing their understanding about the nature of their lives) or experiencing depression. Laurentia said, “When you get to a certain degree of incapacity, you have to change your thinking or you’re just lost in a sea of depression.” Then she noted, “You can fight all you want but you may still ... lose the battle.”

A number of their accounts suggested that a loss in physical function drove the process of accepting a new life. For example, BB spoke of how the concreteness of living in a wheelchair
and not being able to walk forced him to acknowledge and come to terms with the fact that his day-to-day life had changed. He said, “You can accept something intellectually. ... I have multiple sclerosis but the reality of not being able to walk is something else again ... So how do you accept it? You just keep not being able to walk.” BB was not alone in this understanding. Hannah also described how the experience of losing her mobility caused her to change her understanding of life but she articulated it in different terms. She said, “I would say my understanding of acceptance is much, much different now than it was at the beginning. What can I do? I’m in a wheelchair.” She explained how her mental approach changed from being one of not giving in or letting the disease beat her to accepting her current limitations. Hannah described acceptance as grasping “what’s going on in your body ... being there with it and knowing it ... in every single moment” and “not being in the past, not being in the future, just being right here.”

Others also talked about the importance of letting go of past understandings and being centred in the present. For example, Laurentia explained that acceptance involved realizing that “the past is gone. It’s not coming back. You’re in a different reality.” She spoke of “accepting what is ... accepting that the pain exists and is not going away, accepting that the illness is not going away.” She said, “I don’t waste energy fighting or looking to beat the disease or whatever. I accept it’s there. It’s a chronic disease. It’s not curable at the moment. It may be down the line. I leave that possibility there.” From Lynx’s vantage point, acceptance was about not dwelling on “things beyond your control ... being realistic and choosing to do things because you have choices, though they may be limited.” Along similar lines, he said, “The reality is it’s going to interfere with your life so you might as well accept it and move on.” Although BB, Hannah, Laurentia, Lynx, and others had different ways of articulating the process of acceptance, being able to accommodate the notion that the past way of life was gone and that life with illness was different was a similar thread running through their understandings. For the majority of the men
and women, it seemed that accepting the realities of their bodies and changes in functional ability (e.g., physical loss) was an important prerequisite for being able to shift their understandings and find meaning and pleasure in new or different kinds of activities and experiences.

The data also suggested that it was not only essential to come to an altered view of daily life but to be able to see that new life as an opportunity for meaning rather than an experience of loss. About one quarter of them spoke of how the experience of loss gave them opportunities in their lives but it was clear that many of the others found new activities and interests in their lives as a direct result of losses they had experienced. As Tammy explained it, “There are lots of things that you give up but then you fill the gap with something else.” The capacity to see loss as opportunity was also reflected in the fact that some spoke about how the experience of illness had provided benefits and gifts in their lives. For example, Mary said, “[MS] closed a lot of doors but it opened a lot of others. I know that sounds a little paradoxical but it’s true.” Then, she went on to say, “I’ve found a lot of doors have closed in that I can’t do certain physical things that I used to do. However, doors have opened in that I can do [other] things.” Elizabeth articulated it in different terms. She said, “There’s a flip side to all these losses. If things are taken away like work … suddenly you’re given an enormous amount of time.” A number of others also saw the opportunities in relation to having time to fulfill meaningful aspects of their lives. For example, Katrina talked about how losing her capacity to work enabled her to engage in something more meaningful such as painting. In talking about the impact of losing her job, she said, “It was actually a godsend because I had time to paint. I could do what I wanted to do.” Laurentia also felt that losing her job provided her with a “great opportunity” but in her situation it was about reconnecting to her spirituality and developing a more meaningful relationship with her daughter:
I'm getting all these precious moments with my daughter that I wouldn't have had even if I was healthy and not working ... because I would have been out biking and golfing and running around doing all these wonderful activities ... I wouldn't have that one-on-one time with my daughter, that slow down into the moment child time mode that you can get into when you're physically slowed down like I am.

A number of additional factors seemed to contribute to the new opportunities they found. Hannah, for example, said that experiencing the loss of her mobility and academic career as well as having no financial obligations, gave her the chance to find fulfillment in her creative writing: “Being sick, being in a wheelchair, being a kept woman has given me the opportunity to do this which I never would have been able to do before.”

The participants’ ability to reframe the losses they experienced as opportunities reflected their attitudinal perspectives, in particular their optimistic outlooks. As noted earlier, many of them revealed a capacity to focus on the things they had and the things they could do in their lives and this perspective seemed to help them perceive their new life as one of opportunity rather than loss. For example, when Elizabeth explained how she lived with loss, she said, “I think a lot of it is the attitude in your head. It’s like how you choose to live with your loss ... instead of fighting it so that there’s part of turning a liability into an asset.” By reframing her experience, she was able to see her experience of loss as an asset in her life. For Elizabeth and most of the other participants, using their attitudinal perspectives to reframe their new lives as opportunities to find new meaning seemed to be an important aspect of shifting their understandings in relation to the losses they experienced.

Summary

In this section, I have shown that the experience of living well was not only about using attitudes and strategies to help them address tensions and have meaningful experiences, but about being able to shift their understandings of what they valued in relation to experiences of loss, in particular losses in physical function. The process of shifting meanings (both within and
between domain shifts) enabled the participants to feel that they were living the experiences that were important and meaningful by valuing aspects of their lives that could be fulfilled in the current day-to-day realities and context of living with chronic disease and the losses it created. The women and men used shifts in understanding in different ways over time to facilitate the living well process. For many, this involved being able to develop an understanding of day-to-day life that matched the realities of their bodies and ability to function, and being able to see and interpret their altered life with chronic disease as opportunities for meaning.
CHAPTER 7: THE DYNAMICS OF LIVING WELL

In this chapter, I show some of the nuances of how major processes worked to align the day-to-day realities of their tension-centred lives and the ways they were able to live with their evolving understanding of what was meaningful in life. Also, I reveal some of the dynamic features of their overall experiences. This provides a more in-depth portrayal of living well over time as constructed within the dynamic and tension-filled worlds they inhabited. I describe the findings in two sections, alignment over time and fulfillment.

Alignment over Time

Many of the participants said that figuring out how to experience the meaningful aspects of their lives took a lot of time and effort and was an ongoing process. The women and men described a learning process and a gradual journey that involved continual effort to find and try different approaches for negotiating the tensions and losses they experienced as they evolved over time and for more directly attaining experiences of value. Elizabeth exemplified this common experience when she said:

I don’t think [you get to] any of those [meaningful] places ... easily in this life, they’re hard won ... I guess you have to have courage to fight for that ... or to work at it .... If somebody isn’t willing to work at it, then well I guess it limits the results. It certainly was true for me. I [had] to be willing to work towards something that I wouldn’t have immediately.... It takes time to get those ... wanted kind of results.

Living well experiences took time to develop and were not associated with the early years of developing symptoms or getting a diagnosis. Joan said, “I found things I can do now. I found people I can be with. It’s taken me a long time and I’m still learning.” The learning process involved finding specific ways to use attitudinal perspectives, strategies, and shifts in understanding to create ongoing alignment between what they valued and how they lived over time.
Strengthening Attitudes and Focusing on Meaning

At a general level, the women and men's attitudinal perspectives created an overall focus on life and meaningful experiences. They said their living life orientation and optimistic outlooks helped them stay focused on the life they wanted to live as their disease, the tensions it created, and their broader life context evolved. Their attitudes also worked in more specific ways to support the development and implementation of strategies and facilitate changes in their understanding of what was meaningful. For example, having a pragmatic, proactive, and problem-solving perspective, as well as the drive and determination to shape the nature of their lives seemed to help them make choices and use effective strategies. Certain attitudes, such as being optimistic, also facilitated changes in their understandings of what was important by supporting their ability to find opportunities in losses they experienced. The attitudinal perspectives they used to live well seemed fairly consistent as they described their experiences over the years although a number of them recounted transitory moments when they found it hard to maintain a positive or optimistic outlook or to focus on living life because of changes in their disease. Many of them described anger, frustration, sadness, and grief, as well as periods where they focused on loss, struggled against the things they could not change, and worried about their future. A number of them talked about giving themselves permission to struggle, have darker days, and be negative about life with illness. For example, Mary described her approach to life with illness as being very positive but said:

That's not to say I don't have my dark days. I certainly do and I believe those days need to be acknowledged but you don't let them overwhelm you. Okay, I'm having a pity party today. Okay, I'm giving myself an hour here and then I'm moving on.

Others felt the same way. For instance, Sarah said she had down days like anyone else. "I bitch. I vent. I complain," she explained, "and then, I get over it." However, they said they did not dwell in these negative places and that more optimistic perspectives dominated and prevailed over time.
in the context of less favourable attitudes and feelings. Although these transitory periods of having negative attitudes might have had a detrimental effect on the living well process and their overall ability to have meaningful experiences, some participants suggested that these “moments” were actually beneficial because they created a space where it was okay to struggle and deal with their emotions. It seemed that the process of acknowledging and experiencing negative or pessimistic perspectives and feelings about unfavourable changes in their disease or life was helpful in enabling many of them to regain and sustain more optimistic outlooks over the changing course of their lives. Many of their accounts suggested that they tried to find a balance between maintaining attitudes that supported their ability to have meaningful experiences and letting these more favourable perspectives go in order to process the intense emotions that arose with loss and change.

Also, a number of them made comments to suggest that the attitudes facilitating the living well process became more prominent and stronger over time. For example, Sarah felt that having a positive attitude was one of the most important aspects of how she was able to live well and noted that she had this approach to life before developing lupus. However, she indicated that the “whole positive attitude and positive thinking” had “grown and evolved.” Some of the other individuals also talked about how their experiences further strengthened their confidence in being able to deal with hardship and take control of their lives. Laurentia, for example, said that the process reinforced her sense of being able to “make it through anything” in life and Sarah said that it had made her a “stronger person” who could “deal with whatever” happened and feel that “it’s not the end of the world.” These findings suggested that the process of learning how to live well with illness continually strengthened and enhanced the attitudes that the women and men identified as essential for the experience.
**Using, Trading-Off, and Abandoning Strategies**

In contrast to the apparent consistency of the participants' attitudes, the strategies that they used changed over time in order to address tensions and losses that continually evolved and understandings of what was important in life that shifted over the course of living with disease. For instance, strategies like developing knowledge were more heavily emphasized when they described the earlier years of living with their illnesses and were dealing with a lot of fear and uncertainty, whereas strategies for developing new activities were often described after living with illness for some years and experiencing loss. Strategies for managing disease, on the other hand, were often described throughout the course of their experience but changed as their disease symptoms and life changed. As expected, different strategies often helped them attain different goals and they often used opposing ones at different points in time. For example, Dawn said that in order to reduce tension in her social life and conflicts in her day-to-day life with acquaintances and maintain her meaningful job, she needed to hide her illness. However, to create a strong and positive sense of self she felt she had to disclose her illness because when she made the choice to hide it, she was sending herself a “negative message” that she needed to be ashamed of being ill. She chose which of the opposing strategies to use in relation to what she needed and valued most deeply at certain points in time. Other participants also talked about trading-off different strategies to help them address different tensions and find fulfillment in different areas of their lives as their diseases and lives evolved.

The strategies created alignment between what they valued and how they lived and helped them to have meaningful experiences by indirectly addressing tensions they faced or more directly by going after valuable experiences. In some instances, however, strategies that helped them address particular tensions in their lives worked against attaining meaningful experiences. In these circumstances, being able to abandon strategies for a period of time was an equally important part of living well. Often they spoke of having to give up disease management
strategies even though most of them felt strongly that strategies for managing their diseases were important for living well (i.e., dealing with tensions they experienced, stabilizing and improving their functional capacity, strengthening sense of self). Many of them said they abandoned these approaches for certain lengths of time because the meaningful experiences they wanted to have required them to engage in behaviours that contradicted these approaches. Because these choices often involved some negative consequences for their physical well-being (usually expressed as periods of incapacity or substantially lower functional ability), they often spoke of “making trade-offs” between having experiences of value and meeting the needs of their disease and bodies.

As would be expected in the context of their unique lives, the intent or drive for trading off their physical well-being varied considerably. For example, rest was an important strategy for managing Elizabeth’s lupus in day-to-day life but she made the decision to forfeit it in order to do strenuous overseas trips in developing countries that gave her fulfillment and quality time with her sons. She said the trips were exhausting and forced her to rest for two or three weeks after she returned. In contrast, Tammy described sacrificing the management of her disease in order to be able to organize important and meaningful events for her lupus group. She explained:

Living with a chronic illness [requires that] you do a lot of trade-offs. Say for instance there’s something you really want to do ... I’m putting on this forum.... I really want to do this. So I work and I push and there’s a week’s worth of preparation ... hard preparation ... and I know for a fact that I’m going to be down for the next week.... It might be two or three days in bed and two or three more days in the easy chair or the couch.... But I mean that’s what you do.

Alternatively, Sarah illuminated how she had to “make sacrifices’ in taking care of her illness in order to engage in important social activities:

Last weekend, I wanted to have a BBQ and have my friends over because it was just gorgeous. So I spent the day getting stuff ready to BBQ and having people come over and we played badminton ... [and] chatted. I knew the next day that I [couldn’t] do anything or else I wouldn’t be able to face the week. So, last Sunday I did nothing.

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There were also numerous examples where they talked about engaging in behaviour that contradicted their disease management approaches in more general ways in order to have fulfilling relationships, careers, or experience other important aspects of their lives. For example, Joan described how she made the choice to drink alcohol on special occasions with her husband in order to celebrate their relationship even though she knew that it was not good for her lupus nephritis and against her standard strategies for managing her body and maximizing her health. Dawn said she chose a job in the film industry because it gave her so much fulfillment even though she knew she “shouldn’t be doing it” because it forced her to abandon her regular disease management strategies during work hours such as getting adequate sleep, staying warm, and avoiding stressful situations. She said:

It’s high stress. I’m outside. I’m in the elements. I’m getting four hours of sleep a night. I shouldn’t be doing it on paper but I love it. And I would rather live for five years doing what I love that live for ten years just existing.

As Dawn’s comments so eloquently expressed, most of the participants were oriented towards having meaningful experiences even if it required sacrificing the well-being of their bodies and illnesses for certain periods of time. This choice reflected their orientation towards living life and their desire to focus on meaningful experiences rather than on illness. In order to maximize meaningful experiences over the longer term, however, the data suggested that they needed to be able to use and sacrifice strategies to achieve a balance between meeting the needs of their disease and their desire to engage in life and have meaningful experiences. As Eryn expressed it, living well was about working with the “human side and the disease side” of life and finding a “balance between the two that works.”

In summary, the participants used, traded-off, and abandoned strategies over time to promote alignment between the tensions in their lives and the nature of daily life and their understandings of what was important so that they could experience the areas of life they valued.
Finding More Meaning in Relational and Spiritual Domains

Shifts in understanding enabled many of them to feel that they were living the experiences that were most meaningful as the nature of their context changed over time. This process created situations where their understanding of what they valued was in line with what was feasible for them to attain or experience. Many of their experiences suggested that these shifts became an increasingly important approach for living well over time. This likely reflected the fact that functional loss was an important catalyst for these changes in understanding but their functional capacities often took a number of years to significantly decline (e.g., living in a wheelchair). A few participants described changes in what was meaningful to them while talking about the earlier years of their illness experience but these individuals typically experienced a more sudden onset of disease that created immediate and severe functional loss (often in the form of a severe lupus flare). However, shifts in meaning were likely influenced by a wide number of other personal and contextual elements as suggested in their accounts. For example, Hannah said that although losing her mobility provided the impetus for shifts in her understanding of what was meaningful, the timing of these changes was related to her age, life experience, and spiritual development.

Some individuals' understandings of what was meaningful to them seemed to be evolving at the time of the interview, whereas others implied that it was unlikely to change further even though they had experienced shifts in their understandings in the past. Those who felt that their understandings were pretty stable suggested that it was because they reconstructed what constituted important functional aspects of their lives in ways that enabled them to find meaning in a different way or because they came to deeply value areas of their lives (e.g., relationships, spirituality) that could be fulfilled over the longer term regardless of their functional capacity. Toby, for instance, felt that his understanding of what was important was unlikely to change even with further changes in his MS and functional capacity. He had learned
how to get deep fulfillment and meaning in trying to accomplish things rather than in having to achieve them so the decline in function no longer impacted on his ability to have meaningful experiences. Also, a number of the participants suggested that in shifting their focus and source of meaning away from being able to function towards more spiritual and relational realms, they were able to find fulfillment in areas that could always be strong regardless of how their disease affected their physical body or capacity to function. For example, Laurentia said, “What I found was my belief in spirituality, when everything else is stripped away from you, you’re still spirit and that spirit can always be strong. It’s only the body that has failed ... the physical sides that failed.” In a similar way, Elizabeth felt that by placing more importance on relational and spiritual areas like “relating to other people ... and to a God,” she was able to experience a sense of meaning and fulfillment “in whatever circumstances” she faced with her disease. Examples like these suggest that shifts in understanding may have enabled the participants to have meaningful experiences over the longer course by reducing the impact of disease and loss on their ability to have experiences of value.

Balancing Approaches

Although the two approaches (i.e., strategies and shifts in meaning) were important for helping the participants live well, some of their accounts placed a lot of emphasis on using strategies in daily life, whereas others stressed the importance of changing their understandings of what was important in life. Within this general emphasis, however, most of their accounts revealed tensions between using these processes as the course of their disease and lives unfolded over time. These were expressed in the dichotomous notions of doing/not doing, fighting/accepting, pushing/giving in, or holding on/letting go found in their explanations for living well in daily life. At a fundamental level, this seemed to represent a struggle between two opposing ways of attaining alignment: changing their disease, nature of their tensions, or daily
life in ways that enabled them to fulfill their understanding of what was meaningful; or changing their perceptions of what was important to reflect the nature of their bodies and what was achievable in daily life.

The push and pull between these different ways of changing their illness experiences to live well was most evident in their descriptions of how they responded to loss and the resulting transitions they experienced moving from past ways of life to new ways of living. In recounting the course of their experiences, many of them mentioned the struggles they faced in these situations over whether they should fight to hold onto what they had using various strategies or let go and accept the loss and change in their lives and learn to find meaning in different ways. Hannah, for example, talked at length about spending years using all kinds of alternative treatments to try and regain her mobility and prevent further functional loss and described how she resisted changing her understanding of life and what she valued to reflect the nature of her day-to-day reality. This tension was also apparent in their descriptions of what they did to prevent further loss and changes in their lives. Larry, for instance, said that she had reconceptualized her understanding of what was meaningful to reflect the two aspects of her life that she could still fulfill (i.e., travel and cultural activities), but at the time of the interview was resisting against any further changes in her understanding and life by doing everything she could to reduce and slow down functional loss created by scleroderma. She was “trying desperately to continue on with the other two-thirds” of her life. Patricia, on the other hand, said that when she started to use a scooter she struggled with getting around in her neighbourhood and community. At the time, she struggled over whether to try to find a way to change her environment so she could get around (e.g., have the curbs redesigned, make the buses wheelchair accessible) or accept the changes and develop a lifestyle that reflected the current realities of the situation. Examples like these show that the tensions played out in different ways for different individuals.
and were most often expressed as a tension between altering their body or mind, and changing their social or physical environment or understanding of life.

Their accounts suggest that the process of living well was not about resolving this tension but rather about achieving a continually evolving balance between fitting the context and day-to-day experiences of their lives and bodies with their understandings of what was meaningful, and changing their perceptions to fit the realities of the body and world in which they lived. Where this balance lay for each individual at any moment in time seemed to depend on the nature of their dynamic, tension-filled lives and the amount of loss they experienced.

**Fulfillment**

Fulfillment in their lives was grounded in the understanding that having a meaningful life was possible in the context of long-term disease and the tensions and losses it generated.

Laurentia portrayed this common understanding well:

I don’t live going [I’ll] only win if I no longer have symptoms, if I no longer have this disease that would be success. No, I can be as sick as a dog and still have success. I can live a successful life. I can live a happy life while having these symptoms, while having this illness.

Amongst the participants, however, the degree of fulfillment that a successful life or living well represented varied greatly.

**Varying Kinds and Degrees of Fulfillment**

As noted in Chapter 5, the participants found meaning in aspects of their lives that commonly concerned function, purpose, self and identity, relationships, and spirituality, and they constructed living well in relation to meaningful experiences in these areas. However, the degree to which these areas of value were fulfilled in daily life varied greatly from individual to individual and it was evident that living well did not equate with complete fulfillment in all areas.
of importance for most of the women and men in the study. Although several of them suggested that they had attained meaningful experiences in all areas that mattered, most individuals succeeded in experiencing fulfillment in several important aspects of life. Rose, for example, described her life as "good" and "happy" and felt satisfied being a wife and mother:

I have the family life that I wanted.... So my personal life ... with my family and my children [is] where I wanted to be. I have an awesome husband. We have a life, not a grand life but we have a happy life. We have a great marriage. We have two healthy, beautiful children. I can't ask for anything else.

However, elsewhere in her account she confided that she was "very disappointed" in her career and said, "[It] is not what I wanted for my life." In elaborating further, she explained, "I don't think I'm contributing very much.... I kind of just feel like I'm just kind of lobbing along." As another example, Laurentia indicated that she found deep meaning and fulfillment in motherhood but missed "having something meaningful to do." "I still have to find meaning in my life apart from parenting ... because [my daughter] won't always be here," she explained.

Rose, Laurentia, and a number of the other individuals were in the process of searching for ways to find fulfillment in areas of their lives that they had identified as being meaningful but had yet to experience or fulfill. Laurentia said:

I don't think I'll ever get back to a five-day a week job. I won't get back to the type of work I was doing but I also don't want to get back to that rat race. I want to do something more meaningful, something gentler.... I'm trying to get my life slowed here a bit so I can fit a volunteer day in at a seniors' home or something doing therapeutic touch and just see how that feels on me. Helping other people would make me feel better than going out and rushing through some paper work and stuff for the company.

As these examples suggest, some participants were still trying to find a way of having a meaningful purpose in life after they had lost their jobs or intended careers. Even some of those who indicated that they had found areas of meaning that replaced their previous career were still looking for more fulfillment in the career-related area of their lives. Joan, for instance, said she found fulfillment in her creative activities after she was not able to continue with her nursing career but also noted that she was "still searching" for additional ways to be fulfilled. On the
other hand, those who had managed to maintain or find fulfillment in meaningful careers often expressed the desire to have more fulfillment in their relationships or have a stronger sense of self. Dawn had a meaningful career but still struggled to find deep fulfillment in her personal relationships and with her sense of self.

Thus, the nature of living well for the women and men in the study was not only reflected in the meaningful experiences they had attained but also in the ongoing process of searching for how to attain and experience more fulfillment in their lives. Living well did not represent a particular destination as much as it represented a dynamic and often challenging process of finding and experiencing different kinds and degrees of meaning and fulfillment throughout the course of living with illness amidst the context of tensions and losses it involved. Elizabeth expressed this well when she said:

I don’t feel like I’ve arrived. I think living well doesn’t mean ... that I’ve arrived. I think it just means it’s a process that is working pretty well and I am able to get or find or receive the things that are important to me.

She went on to say that the process was “always a struggle” and for her as well as many others, living well was an ongoing challenge because they had to find ways to experience meaningful aspects of their lives amidst ongoing tension, loss, grief, and pain that varied in nature but often continued through the course of their illness experience. For example, Dawn said, “My illness is an ongoing process ... and everyday you continue to work on what you feel your challenges are.” In describing her life today, she said, “It’s not am I in pain, it’s what’s my level of pain today and can I deal with it.”

Living Well as Present and Future Fulfillment

At the time of the interview, their understandings of living well evolved around what was meaningful to them at that point in their lives. As such, the nature of their experiences reflected the current context of their lives and the realities of their disease and the tensions and losses it
had created as well as any shifts in understanding that had occurred. Given what living well
represented, it was not surprising that they constructed their future experiences in relation to
areas of meaning and fulfillment rather than future changes in disease and additional loss. For
example, when I asked a number of them what the future would be like or probed in that
direction, those who interpreted the question as being about what the state of their disease would
be some years down the road, refused to talk about it or were reluctant to discuss it at any length.
For example, when I asked Mary about what her life might be like in five years, she said:

To be honest with you ... I don’t go there ... You can scare yourself half to death making
yourself afraid. Like “Oh my God, what’s it going to be like in five years?” and I did do a
little bit of that at the beginning and I think that is a really negative path to take so I don’t
go there.

Some other individuals talked about it but made it clear that they would not accept more loss.
Maria, for instance, repeatedly said that she could not conceive of being in a wheelchair in the
future. She said, “I will not accept that I will sit in a wheelchair ... I’m just not going there.” In
explaining why she felt this way, she said, “I don’t want my kids to get to the part in their life
where they’re out doing all this stuff and mom’s sitting home in a wheelchair. Like that will just
not cut it.” The wheelchair represented the change that would force Maria to give up the things
she valued most in her current life (e.g., partaking in hiking activities, engaging in physical
activities with her daughters) and that was unacceptable from her current vantage point because
it would not enable her to do the things that were most meaningful now.

A few individuals did talk about the possibilities of more loss and of having to find
meaning in different ways in the years to come and two of them suggested that adjusting to
future loss would be like adapting to the aging process. For example, in explaining what living
well might be like in the future, Larry said, “Your world does get smaller as you get older. You
do become resigned to not having the same movement and I think that you do take pleasures in
the small things.” However, these understandings were the exception rather than the common
pattern and most of them not only refused to entertain any notion of additional loss in the future but refused to construct a future life that would not enable them to fulfill essential areas of value.

Instead of focusing on loss, the majority of the men and women talked about finding more fulfillment and meaning in the years to come. For example, when Maria imagined her life in five years, she said she saw a “girl rollerblading, a girl in great shape, a girl running, a girl biking,” as well as a strong family. This understanding included important areas of her life that she wanted to have more fulfillment in (e.g., family life) and also reflected some areas that she had lost but hoped to regain (e.g., running). Some other participants also held out the hope of regaining meaningful aspects of their previous lives at some point in the future even if other areas of their lives had taken on greater meaning and importance. Women and men whose functional capacity varied over time through a relapse and remitting disease course expressed this understanding as did some individuals who seemed to be permanently disabled (e.g., used a wheelchair). For example, Elizabeth whose functional capacity fluctuated in relation to the degree of lupus activity in her body said, “I think [I was] the best … around the year 2000, 2001, just before I moved. I was the very best I’ve been and … my goal is to get back to that level.”

Hannah expressed her sense of hope differently. She said, “I’m in a wheelchair. I don’t want to be. I know that. I don’t believe that I will be forever.” Although she had come to accept that she was currently living in a wheelchair and had learned how to find fulfillment in her current life, she held onto the hope that she would one day regain her mobility and the meaningful experiences associated with it.

The Feelings of Living Well

Living well was also described in relation to positive feelings about life, sense of self and illness. In a number of accounts, they talked about feelings of satisfaction, happiness, and contentment. Larry said that living well was about doing the things that gave her a sense of
“pleasure and satisfaction.” Donna said she felt satisfied and fulfilled because she accomplished things she valued, “It just gives me satisfaction ... [that] I can still do things.” Laurentia described feeling content and peaceful:

Just this week when it was beautiful and sunny I had a day where I went, I’m so content. I was able to drive my daughter to gymnastics, pick her up, take her out to supper, bring her to brownies, [and] pick her up. The day was beautiful. I was well. All is good in the world. And I found [that] I have achieved a point of peace and contentment that I didn’t have before when I was healthy.

When I asked her why she felt more content now than before she developed lupus, she said:

I feel I live a deeper, richer life now than I did then. Then, I ran around doing lots of stuff, not necessarily soul-filling stuff. I was very active but there was a lot of shallowness in all of it.

Laurentia associated the feelings of contentment and peacefulness with experiencing a “deeper, richer,” and more meaningful life and other participants also emphasized the richness of their lives. For example, Elizabeth said, “Even though I’ve talked so much about loss and dealing with it, ... my primary emotion isn’t loss. It’s richness. That’s what it feels like. And maybe that’s kind of the way that wellness translates for me.” She said that her life felt “rich in a lot of ways” and then explained, “I think it’s because of the children. It’s because of friends, it’s family, and it’s because of activities and things I can give to other people.” As suggested in her comments, Elizabeth’s feelings of richness were attributed to being able to experience meaningful relationships with her family and friends and being able to engage in activities that were significant in her life.

Feelings of appreciation about the life they had were also associated with attaining meaningful experiences and living well. For example, Sarah said, “My outlook on life has completely changed” and then she explained that her experience of lupus had enabled her to “see things in a totally different light.” “I’ve got a better appreciation for what I have and a better appreciation of life,” she stated and then added:
If I didn’t go through what I went through, I would’ve probably continued on with my life, ho-hum, doing what I was doing, and not really understanding what I have and how lucky I am to have the relationships and my health and where I’m living…. So it just makes me better appreciate what I have.

Some other participants expressed it in terms of gratitude and thankfulness. Dianne, for instance, described her outlook as “just being thankful for the day.” She said, “I take every day and I enjoy it. I really do. I’m thankful for every day that I have.”

In addition, some of the participants associated feelings of accomplishment in being able to live well and overcome some of the challenges they faced in daily life. Toby, for example, described how he felt “a sense of accomplishment” in his life from being able to “do a lot of things” such as travelling and writing articles for a society’s newsletter. These feelings of accomplishment seemed related to the feelings of confidence many of them developed in being able to overcome obstacles they faced. Laurentia talked about how her experience of illness reinforced the feeling of being able to “make it through anything” in life and Sarah said that her experience of illness enabled her to feel that she could “deal with whatever” came her way knowing it was not “the end of the world.”

A number of them also associated their experiences of living well with favourable feelings about themselves. Although they expressed these in different ways they largely described feelings about becoming a better person. For instance, Sarah said, “You know what? I would never ever trade [my illness] experience. I would never trade that experience for anything. [It’s not] just the experience itself but the whole learning [process].” She explained: “I think it’s made me a better person. It’s made me a stronger person. It’s made me a more humble person.” Joan also associated positive feelings about herself with living well but articulated it differently. She said, “I’ve had time to become a bit of a better person because I’ve had these opportunities to be with people and do things for people … [and to] be more sensitive to people.” Lynx, on the other hand, said that his experience of MS and living in a private hospital made him “much more
compassionate.” He said, “I mean, I always [thought] I was compassionate but not to the level I am now.”

As well, a number of them came to see their illness as a gift or benefit in their life. Laurentia said, for example, “[Illness] can be a great source of growth, just a fabulous chance to grow ... and you can have tremendous gifts.” Then, she went on to say, “I always shock people by telling them so many good things came out of being sick.” Then she explained:

I wouldn’t wish it on anybody but I wouldn’t have missed the experience in [terms of] the people I’ve met, the things I’ve learned, the things I’ve felt, the things I’ve been able to contemplate that I wouldn’t have done otherwise, all sorts of growth that happens that wouldn’t have happened without the illness. I would have carried on in this busy, busy world constantly doing and accomplishing without ever getting to the depths of life.

Sarah described her illness as a “blessing in disguise” because she came to have a clearer understanding of the meaningful things in her life. As these examples suggest, many of the participants described their illness in this way because they were able to have meaningful experiences that they felt they would not have otherwise attained.

Summary

In summary, the women and men’s accounts suggested that their living well experiences involved a dynamic process of using attitudinal perspectives, strategies, and shifts in meaning in specific ways to experience different kinds and degrees of meaning and fulfillment over time in the context of ongoing disease, tension, loss, grief, and pain. This involved continually aligning the nature of their bodies and daily lives with the understanding of what was important and meaningful. On some occasions they were able to alter their environment or body to fit their expectations and help them attain meaningful experiences and at other times, they had to change their understanding of what was valuable to fit the realities of their body and day-to-day life. Hence, there was an ongoing process of negotiation and alignment between context, body, and understanding in the pursuit of living well. Their attitudinal perspectives provided an overall
framework within which they worked to keep the focus on life and attaining meaningful experiences as they negotiated their lives over time.

In the process of having meaningful experiences there were constant trade-offs between attaining different areas of value in life and taking care of their physical well-being as reflected in the ways they used, traded-off, and abandoned strategies over time. It was clear that although the strategies they used accomplished specific activities in their lives such as managing their disease or developing knowledge for example, they were the means and not the end of the living well process. In addition, their understandings of what was important seemed to shift away from functional domains of life towards relational and spiritual domains and may have reduced the need for alignment between their inner and outer worlds over time. The attainment of meaningful experiences also created positive feelings towards life such as satisfaction, happiness, contentment and a tendency towards favourable feelings about their sense of self and illness.
CHAPTER 8: DISCUSSION: LIVING WELL FINDINGS IN THE CONTEXT OF CURRENT KNOWLEDGE

The findings presented in Chapters 4 to 7 described my interpretation of the nature and development of the living well experiences of the participants. The answers to the research questions: (1) What is the nature and important characteristics of living well experience?; (2) What are the biopsychosocial factors and processes by which it develops in daily life?; and (3) How do the various dimensions of this experience interrelate? were conceptualized in relation to finding and enacting meaning in daily life through processes that aligned the participants’ inner and outer experiences in a tension-centred context. In the preceding chapters, I built this interpretation in multiple layers starting with an understanding of the tensions created at the disease-life interface in interactions within the participants and between the participants and family, friends and other people and organizations in daily life. Within this tension-centred view, I described how their living well experiences were oriented around meaningful events and experiences. I showed how two interrelated processes helped the women and men align the tensions in their daily lives with their understandings of what was important and valuable and this enabled them to find and experience some meaningful aspects of life and a sense of fulfillment in some domains of value. The first process involved negotiating tensions to maximize valuable experiences using attitudinal perspectives and strategies (or more directly using these approaches to engage in meaningful activities) and the second involved negotiating losses by making changes in their understandings of what was important.

This interpretation revealed that the phenomenon of living well with illness is a highly complex, multifaceted, dynamic, subjective, and individualistic experience within which there were some patterns and themes worth reporting and reflecting on in relation to the larger body of chronic illness knowledge. In this chapter, I locate my findings and this interpretation of living
well in relation to existing literature using the three different lenses that emerged in the analysis and writing process: living well as tension, living well as meaning, and living well as alignment. From each of these vantage points, I describe how my findings support, extend, or challenge understandings in the literature and describe a few key issues that emerged in each of these areas.

**Overview of Research Findings**

The women and men in this research faced diverse and enormous challenges in living with chronic disease over time. As such, the individuals whose accounts I built my findings on were not those who had the mildest forms of disease or easy lives but rather those whose diseases had progressed in ways that created significant and ongoing tensions and losses. Many of them experienced other difficult or even traumatic life events before or during the course of living with illness (e.g., divorce, parenting, loss of a child, parent, or partner, physical, emotional, or sexual abuse). As a result, the individuals in my study represented people living challenging lives.

In general, the findings about their living well experiences were largely in keeping with the patterns and insights that have been found by others or are considered to be understood in the present context of knowledge, especially that which is derived from qualitative studies of subjective experience with chronic disease. Yet, by interpreting the data in relation to the interrelated conceptualizations of tensions, meanings, and alignment I was able to illuminate some patterns and themes that help to extend current knowledge of the nature and dynamic processes involved in living a good life. The angle of vision I took in understanding and interpreting their experiences created an interesting framework within which we can better understand some of the complexities inherent in this kind of illness experience and some of the competing ideas and contradictions found within existing bodies of knowledge. Overall, the
value of my study derives from looking at the phenomenon of chronic illness experience from a perspective of truly living well rather than one of coping or managing.

**Living Well as Tension**

Given that tensions formed the context within which the participants constructed their living well experience, it is important to briefly situate my findings on the types of tensions found in the participants’ accounts, the conceptual underpinnings of their tension-centred perspectives of life, and the tension-centred features of their living well experiences in relation to current literature and existing knowledge. Identifying the particular window this perspective provides into the women and men’s experiences sets the stage for discussing the existence of negative phenomena in living a good life in relation to the broader issue about the co-occurrence of positive and negative elements of chronic illness experience.

**Conceptualizing Tension**

The kinds of challenges the participants faced (e.g., uncertainty, physical and mental functional changes, struggles with sense of self and identity, competing demands between the needs of disease and life, interpersonal problems, difficulties with health care professionals and obtaining services, challenges with government agencies and the workplace, financial hardships, accommodating to climate conditions and physical space) support extensive findings on the kinds of problems persons generally encounter when they develop and live with a chronic illness over time (e.g., Flavo, 2005; Lubkin & Larsen, 2002; Reynolds & Prior, 2003; Royer, 1998; Thorne, 1993). The conceptual understanding that these struggles arise at the disease-life interface through a variety of interactions supports the interpretation of other researchers in the field of chronic illness and disability research. Lutz and Bowers (2005), for instance, argue that seeing disability and its impacts as “created by both the disabling condition and the social
context” is essential for being able to understand “how persons with disabilities integrate the experience of disability into their lives” (p. 1051). Constructing these struggles or tensions as interactions between disease processes and other psychosocial domains of human experience also supports the views of researchers and theorists who argue for the need to integrate functional and social perspectives on the impacts of illness and disability (Bury, 2000; Hurst, 2000; Taylor, 2005; Verbrugge & Jette, 1994).

The participants’ understandings that their struggles were dynamic and changing over time (because their disease and broader lives were continually evolving) fits with a general understanding in the literature about the changing nature of the challenges chronic illness presents over the course of an individual’s life (e.g., Charmaz, 1991; Lubkin & Larsen, 2002; Royer, 1998). The fact that the women and men saw their struggles as relational challenges (i.e., problematic interactions within themselves, and between themselves and others) and as ones that were always in their lives, permeating and shaping their lived experiences supports theoretical perspectives articulated in the field of social psychology. In particular, this understanding of tension supports the work of researchers and theorists such as Radley (1996) who look at “contexts” as “forms of relationships” that are “not around or outside of individuals” but rather “run through” them (p. 631).

The overall benefit of constructing disease-related challenges as dynamic tensions is that it shifts the focus away from an emphasis on fixing or managing problems or illness-based stressors to negotiating and managing the challenging interactions that erupt at the disease-life interface. This provides a broader framework for making sense of the approaches people use and the complexities they must address in daily life as part of the living well process.
Tension-related Features of Living Well: The Coexistence of Positive and Negative Experiences

The tension-centred understanding of life within which the women and men constructed living well revealed particular features of their experiences. One of the more important findings was that their struggles and all that they entailed (e.g., pain, suffering, uncertainty, loss of self-esteem, conflict ridden relationships, social discrimination, financial hardships) were intrinsically part of their experiences of living a good life. One of the common assumptions in the literature is that people who do better living with illness have found ways to manage, adapt, or cope with the pain, suffering, and overall struggles they face in daily life. In my research it was evident that the participants felt they were living well even though they did not always cope or adapt to every tension or loss they encountered over the course of living with illness. Although some tensions were resolved, many were not, and new ones emerged as their diseases and lives and the interactions between them changed over time. Thus, the tension-centred understanding revealed that a good life was not a perfect life or a life where they had worked out all the illness-related problems and challenges, or even one where they felt they had a high state of well-being all the time. Rather it was a life where they had some deeply meaningful and fulfilling experiences that seemed to dominate the nature of their lives but not eliminate all the tensions they faced in daily life.

This finding supports other recent studies documenting the coexistence of positive and negative experiences in those living a good life with illness. For instance, Reynolds and Prior’s (2003) study on the good QOL of 27 women with MS found that “the women’s narratives revealed a complex mixture of negative and positive life experiences” (p. 1231) that they described as a “mesh or tapestry” (p. 1225) of coexisting phenomena. They concluded that even though almost all of their participants “described their quality of life as good … none depicted
their lifestyles in wholly favourable terms” (p. 1231). This study reflects the kinds of findings emerging in diverse fields of research such as QOL (Hendry & McVittie, 2004; Reynolds & Prior, 2003), coping (Folkman, 1997; Folkman & Moskowitz, 2000), and more general interpretive work on illness (Asbring, 2000; Plach, Stevens, & Moss, 2004a, 2004b; Sanders, Donovan, & Dieppe, 2002) in recent years.

One of the dominant understandings to explain these diverse phenomena is that an individual learns to live with and negotiate the initial impacts of developing disease before being able to adapt and have more positive illness experiences (Reynolds & Prior, 2003). Other researchers explain positive phenomena through processes that reframe or reinterpret negative experiences into more positive ones (Paterson, 2001; Thorne & Paterson, 1998) through strategies such as positive reappraisal, benefit-finding, and benefit-reminding (Folkman & Moskowitz, 2004). My research suggests that negative experiences were not totally left in the past after the initial adjustment period was over nor were they all reframed or reconstituted into positive and meaningful experiences after they had lived with their illness for a long time. Instead, the women and men describe the simultaneous experience of having meaning and fulfillment as well as loss, suffering, pain and ongoing struggles. As Laurentia, one participant said, these kinds of experiences “are not mutually exclusive. They’re not incompatible. They happen together.” Reynolds and Prior (2003) expressed a similar understanding when they explained that in their study on living a good QOL with illness “the narratives were not ... simply ‘heroic tales’ or redemption or restitution narratives (where positive is represented as coming out of the negative)” (p. 1243). Instead, they found that the women had a wide range of difficulties that were sometimes put into the background of their lives through the use of various strategies but at other times were quite present in daily life. Similarly, Nosek et al.’s (2004) study on the meaning of health for women living with disabilities found that perceptions of
disability and the challenges it created alternated between being in the foreground or background of their experiences of being healthy.

The ideas presented in my findings and the other studies just described support the Shifting Perspectives Model (Paterson, 2001) that was recently developed to help explain the coexistence of seemingly contradictory phenomena. It was developed from a meta-synthesis of 292 qualitative research reports on the subjective experience of chronic illness and is based on the understanding that illness and wellness perspectives of disease (perspective being defined as a "representation of beliefs, perceptions, expectations, and attitudes, and experience about what it means to be a person with chronic illness within a specific context", p. 23) undulate between the foreground and background of a person’s life. The illness perspective is sickness, suffering, and loss while the wellness perspective is seeing illness as opportunities for change and meaningful experiences. In this understanding the degree to which either perspective is in the foreground or background depends upon the nature of one’s illness and one’s personal and social context and hence, is a “continually shifting process” (Paterson, 2001, p. 23).

Other understandings have also been proposed to account for some of the contradictions found in illness and disability experiences. For example, King’s (2004) Meaning of Life Experiences Model “helps us to understand the nature of a number of paradoxes concerning success versus failure ... loss versus gain, good versus bad” (p.81) inherent in the experiences of those living with illness and disability. This Model and The Shifting Perspectives Model both present more complex and multidimensional interpretations of positive and negative phenomena than more linear or phase understandings and the findings in my research along with these Models support the need for more three-dimensional understandings of chronic illness experience where opposing kinds of phenomena not only change and evolve over time in a linear sense but also interrelate with each other in the moment in different planes of experience.
In summary, there seems to be an increased awareness of the importance of looking at illness as a multifaceted experience comprised of both negative and positive experiences (Thorne & Paterson, 1998; Plach et al., 2004a), but there is not yet a well developed body of knowledge that explains how these kinds of phenomena interrelate simultaneously over time in an individual’s experiences of living a good life. One of the biggest challenges to the advancement of this kind of knowledge is that we tend to think of experiences and emotions in black and white terms: They are good or bad; positive or negative. Accordingly, there is a prevailing belief in our understandings of life that positive and negative emotions can not be experienced simultaneously (Russell & Carroll, 1999) and that one can not have a high QOL and be experiencing pain and suffering at the same time (Albrecht & Devlieger, 1999). Researchers in various fields of research have started to challenge these kinds of assumptions and illuminate how they limit our potential for understanding some of the complexities inherent in chronic illness and disability experience (e.g., Koch, 2000a; Russell & Carroll, 1999; Thorne & Paterson, 1998; Thorne, Ternulf Nyhlin, & Paterson, 2000; Zautra, Potter, & Reich, 1997). My work supports the recent effort of these scholars in challenging and trying to break down these kinds of assumptions about chronic illness.

Although meta-synthesis has been shown to be one helpful approach to reconciling the “numerous conflicting conceptualizations, patterns, and themes” (Thorne et al., 2002, p. 447) that emerge in chronic illness research, we need to continue to develop theoretical frameworks and methodological approaches that do not see these diverse kinds of illness experiences as inherently opposing, contradictory, or paradoxical in nature. We need research that can illuminate a range of phenomena (including positive and negative ones) inherent in a good life in order to further develop explanatory understandings of how these experiences might work in relation to each other in living a good life with illness.
Living Well as Meaning

Meaning is recognized as a fundamental part of human experience (Bruner, 1990; Frankl, 1984) and was the overriding framework for understanding the essence of what living well entailed for the women and men in this study. The importance of meaning in understanding the nature and processes of living well supports the trend towards a greater focus on the role of meaning within and outside chronic illness research. Emmons (2003) notes that "the many ways in which humans conceptualize, create, and search for meaning has become a recent focus of behavioural science research on quality of life and subjective well-being" (p. 105). Researchers in the field of chronic illness increasingly emphasize the importance of meaning in coping and adapting to illness (Fife, 1994; Thorne, 1999b; Thorne et al., 2002). In this context, the focus has largely been on understanding the processes by which individuals find meaning because this is theorized to be an essential piece of the adjustment or adaptation process (Taylor, 1983).

There were four interrelated dimensions of meaning that arose in the findings. The first was the women and men's overall orientation towards meaning (i.e., focus on meaning) and the construction of meaning in the broader context of their lives (i.e., meaning in life). The second was the meaningful experiences and things that the participants wanted to accomplish or have in daily life (i.e., multiple meanings of living well). The third involved the process by which the women and men changed their understanding of these multiple meanings (i.e., shifts in meaning) and the fourth was about the attitudes and strategies they used to help them attain the experiences that were important and meaningful to them (i.e., meaning fulfilling processes). Within these four areas, my research findings generally reinforce what has been written about the importance of meaning in the lives of those living with long-term conditions, but also illuminate a number of interesting meaning-related features of their living well experiences and the processes by which it developed in their lives. These findings question some of the assumptions we make about
living a good life with illness and push us to see some of the complexities inherent in these kinds of experiences.

In this section, I compare the findings in each of the four dimensions with current knowledge. I describe the meaning-related characteristics of living well and then, explore the meaning-related processes of how they developed this kind of experience in their lives. This involves briefly showing how the ideas on meaning in life, multiple meanings of living well, and shifts in meaning in this study support, extend, or contrast with understandings in the literature. I also explore the findings on the role of attitudes and strategies in fulfilling areas of meaning in the participants' lives in comparison to how they are viewed within managing, adapting, or coping frameworks. I have chosen to emphasize the finding that they maximized meaningful experiences by trading-off some of the approaches they used to manage their disease because of the current emphasis on chronic disease management in policy, community, and health care settings.

Meaning Orientation and Meaning in Life

One of the most important findings was that the participants' perspectives and ways of living were centred on the relationships, events, activities, and other aspects of life that were meaningful and important rather than their disease or experience of illness. Although their experiences of living with a chronic disease were undoubtedly a core aspect of their lives (i.e., they shaped the context within which they had to negotiate life and influenced the aspects of their lives that were most meaningful), their diseases were not the central focal point around which their lives evolved. The participants' attitudinal orientation towards finding meaning in life supports Frankl's (1984) understanding that finding meaning in one's life is a particular perspective towards living. The life orientation of the women and men in the present study was grounded in the belief that they could have meaningful experiences in the context of their
illnesses and this echoes the work of other researchers such as Robinson (1990) who found that the progressive narratives of individuals with MS conveyed the belief that they could still attain meaningful goals.

The women and men stressed the difference between living disease and living life and described how the later orientation provided the source of meaning in day-to-day life. Because meaning was associated with experiences situated in the broader life context, it was about *meaning in life* (rather than meaning of illness - the meaning they attributed to their disease or experience of illness, Conrad, 1990; Thorne, 1999b; Thorne et al., 2002). This understanding of meaning aligns with existential views of life and health (Frankl, 1984; Tamm, 1993) and researchers have explored and written about meaning in life in the context of long-term illness (Lukas, 1998) usually within the framework of spirituality (McCormick, Holder, Wetsel, & Cawthon, 2001). In contrast to my research, where meaning in life was an overarching conceptualization within which to construct and make sense of a good life with illness, many of the studies interpret meaning in life as a resource or determinant of adaptation (McCormick et al., 2001), a type of coping process (Folkman, 1997), associated with or an aspect of spirituality (Albaugh, 2003; Bauer-Wu & Farran, 2005; Daaleman, Cobb, & Frey, 2001) or as part of QOL (Albrecht & Devlieger, 1999; Burckhardt et al., 1989; Loffer, 2000). However, there are some exceptions in the literature. For example, King’s (2004) Meaning of Life Experiences Model provides a means of understanding how persons with illness and disabilities live well through an overall framework of meaning and the processes of attaining it in daily life.

**Multiple Meanings of Living Well**

The idea that living well can be represented by meaningful experiences in certain life domains reflects well-established understandings and approaches used to understand a good life in the fields of nursing, health, behavioural, and social sciences research. For example, much of
the work on QOL in both quantitative and qualitative research conceptualizes the idea of having a good life in relation to multiple life domains (Archenholtz et al., 1999; Bowling, 2001) with the overall understanding that these domains represent important aspects of an individual’s life (Bowling, 2001) or their goals and expectations (WHOQOL Group, 1995). Similar conceptualizations are evident in other fields including interpretive research and studies on personal goals where, for instance, a goal orientation to human experience conceptualizes a vision of a good life where “rewarding domains of goal activity ... render lives meaningful and purposeful” (Emmons, 2003, p. 113).

The participants described meaningful experiences in five life domains: function, purpose, relationships, self and identity, and spirituality. These multiple meaning domains support common understandings in research on subjective experiences of illness, QOL, meaning, and spirituality for persons with chronic illness and disability (Albrecht & Devlieger, 1999; King, 2004; McCormick et al., 2001). For instance, qualitative studies describing the experiences of living a good QOL, feeling healthy, or doing well have described the importance of physical, psychological and spiritual functioning; interpersonal relationships; purpose; and sense of self (Albrecht & Devlieger, 1999; Archenholtz et al., 1999; Leonard, 2002; Lindsey, 1994). As well, my results endorse understandings in spirituality research. Based on a review of spirituality in illness literature, McCormick et al. (2001) concluded that meaning in life represents “a person’s knowledge of self, interaction with others, and sense of purpose” (p. 59) and this understanding reflects some of the key domains of meaning that comprised the participants’ interpretations of living well.

Researchers who have looked at meaning-related aspects of human experience from a more process-oriented (rather than domain centred) view also described similar findings. For example, based on findings from a study on persons with chronic disabilities (King et al., 2003) and a review of theories in the literature on the meaning of life events, King (2004) concluded
that people find meaning in “interconnections with others (belongings), taking part in activities (doing), and seeking to understand their own nature and the world around them (understanding)” (p. 73). The meaning domains in my study also support research findings on personal goals and meaning such as the “taxonomy of meaning” (p. 108) articulated by Emmons (2003) outside of chronic illness and disability research. In a review of the literature, Emmons (2003) concluded that “achievements/work, relationships/intimacy, religion/spirituality, and self transcendence/generativity” represent “most of the domains in which people strive for a sense of meaning” (p. 108).

The fact that the participants associated life meaning with similar domains of life and that these domains largely reflected those identified in general populations suggests that they likely reflect societal understandings of what is important in life. Thorne et al. (1997) argue that “social practices, values, and cultural beliefs create a collective sense of what is right and valuable in society and influence the formation of subjectivity” (p. 2). Yet, within the common life domains in my study, the specific experiences each participant valued reflected the nature and context of his or her unique life. This suggests that the nature of living well (as reflected in meaningful experiences) should be best understood as portraying patterns of social discourse that shift across contextual changes in individuals lives rather than truths that prevail over time.

The activities, relationships, and aspects of life that the participants found important varied within these common life domains making the composite of meaningful experiences comprising their living well experiences unique for each individual. This fits with the general understanding that there is great diversity in what people value in their lives (Sprangers & Schwartz, 1999) and suggests the need to consider one’s beliefs, values, and interests to adequately grasp the nuances and nature of an individual’s living well experience. Accordingly, findings in my research support concerns articulated by other researchers (e.g., Albrecht &
Devlieger, 1999; Hendry & McVittie, 2004) over the meaningfulness of using standardized QOL measures to capture the essence of what QOL represents for individuals living with illness.

Experiences of value in the domains of function, purpose, self and identity, relationships, and spirituality reflected interactions with their bodies, other people, and the broader world around them and portrayed an understanding of meaning as connection (Baumeister & Vohs, 2002) or as “relationship between the individual and his/her world” (Fife, 1994, p. 309). Because the women and men oriented their lives around these experiences and strove to attain them in daily life, they represented positive outcomes or goals (Park & Folkman, 1997; Skaggs & Barron, 2006). In addition, the meaningful experiences and their associated domains of life reflected both ways of being and ways of interacting in one’s environment and support a number of different theoretical interpretations of a good life including elements of humanist, developmental, wellness, adaptation, and functional perspectives as well as more existential theories. This suggests that research exploring a good life with chronic illness should consider broader theoretical frameworks that encompass multiple facets of human experience (i.e., multiple or integrated theoretical perspectives) to help advance more comprehensive understandings of this experience (Thorne & Paterson, 1998).

**Shifts in Meaning**

Another important meaning-related finding that arose in the study was that the participants’ understandings of what was important and meaningful shifted over time. This meant that the nature of their living well experiences was dynamic and temporally situated. The idea that persons living with chronic illness undergo changes in their understandings of what is important over the course of living with disease has been described in a range of different research fields. Studies show that goals, hopes, and dreams change over the life course with chronic illness and can lead to different priorities or goals in life (Becker, 1997; Weitzenkamp et
al., 2000). Of interest, similar kinds of shifts in what is important have also been documented as a response to aging (Rapkin & Fischer, 1992) and the day-to-day realities of life (Krause, 1994).

The finding that both the specific experiences they deemed meaningful and the relative importance of life domains shifted over time for most participants supports understandings described in the response shift, personal goal, and life schemes literature. Considerable research has shown that people change their understanding of QOL over time in the process of accommodating or adapting to illness (Allison et al., 1997; Sprangers & Schwartz, 1999). The phenomenon called response shift is defined as “a change in the meaning of one’s self-evaluation of a target construct as a result of: (a) a change in the respondent’s internal standards of measurement; (b) a change in the respondent’s values, or (c) a redefinition of the target construct (i.e., reconceptualization)” (Sprangers & Schwartz, 1999, p. 1508). Research on personal goals has also described changes in people’s understandings. For example, individuals with changes in their health status have been found to shift their personal goals through “reconceptualization (e.g., different goals matter to me now) or reprioritization (e.g., the same goals matter, but they have changed in their relative importance)” (Rapkin, 2000, p. 55). The changes in personal goals, as well as understandings of response shift capture the conceptualization of within and between meaning shifts that I identified in the women and men’s accounts. In addition, work on life schemes shows that people find meaning in negative or traumatic experiences by changing goals, reordering priorities, or reframing their perceptions about what is important (Thompson & Janigian, 1988). Further, authors studying subjective experience of illness also describe changes in understanding of what is important but these are often observations made in the context of their research rather than the main findings (e.g., Lutz & Bowers, 2005). Overall, this review shows that shifts in understanding similar to that which has been described in my research have been explored in diverse bodies of literature.
Researchers have frequently explored how people find new or different value or meaning in situations of suffering and loss (Baumeister, 1991; Frankl, 1984). My findings suggest that loss of physical function was the most obvious cause of the participants’ shifts in understanding of what was meaningful and valuable and this concurs with other research showing that changes in functional status (Daaleman et al., 2001) or overall health status (Schwartz, Spranger, Carey, & Reed, 2004; Spranger & Schwartz, 1999) are catalysts for changes in values. The findings in the present study also suggest that changes in functional status may not continuously act as a trigger for shifts in understanding as individuals’ illness journeys evolve. A number of the women and men seemed to move away from finding meaning in functional areas to finding it in relational and spiritual domains and this trend seemed to have the net effect of reducing the impact of changes in functional status on their ability to have experiences they deemed important and meaningful. Other researchers have described a similar phenomenon. For example, Wright (1983) found that people subordinated values related to body and function relative to other values and decreased the relative importance of physical appearance compared to other individual abilities and values in the process of acceptance of loss and psychosocial adjustment to disability. Moreover, some literature suggests that people’s understandings of what is meaningful in life becomes resistant to further threats and changes in function once their “world and personal views can accommodate negative experiences” and they develop “the belief that goals can be reached despite misfortune” (Thompson & Janigian, 1988, p. 277).

According to their accounts, the participants made these shifts by developing an understanding of day-to-day life that matched the realities of their bodies and ability to function, and reframing or reinterpreting their altered life with chronic disease (and the losses it created) as opportunities for meaning. Similar mechanisms have been described in coping (Richards & Folkman, 2000), QOL (Sprangers & Schwartz, 1999), adjustment (Walker et al., 2004) and personal goal research (Weitzenkamp et al., 2000). As well, interpretive research on turning
points for persons living with illness and disability (defined as a “fundamental shift in meaning, purpose, or direction of a person’s life,” King et al., 2003, p. 186) has described the importance of processes like contextual reframing and replacing a loss with a gain (Coward, 1997; King et al., 2003). In the literature, mechanisms for changes in understanding have been articulated as acceptance and positive reinterpretation (Kennedy, Lowe, Grey, & Short, 1995) coping, social comparison, social support, goal reordering, reframing expectations, spiritual processes (Sprangers & Schwartz, 1999), and positive reappraisal, benefit-finding, and benefit-reminding (Folkman & Moskowitz, 2004).

The questions of when, how, and to what degree changes in understanding of meaning took place in the living well process were not easily answerable using my study design of one-time retrospective interviews. Yet, my findings along with other research in the field, suggest that exploration of the contextual elements of shifts in meaning would be fruitful for further understanding how people live a good life with illness. The use of interpretive methods and longitudinal designs to study this process of change could help us gain insight into the triggers involved in creating shifts in meaning. It would be helpful to understand to what degree shifts in understanding were influenced by loss of function or other kinds of losses and factors so that these kinds of changes could be predicted and better understood in the context of individual lives.

Changes in understanding of what was meaningful were essential processes for being able to live well over time as the participants’ diseases and lives evolved. Researchers have suggested that shifts in meaning occur to make individuals’ understandings reflect what is possible in their lives and give them the greatest chance of fulfilling the experiences in life that are important to them (Keany & Glueckhauf, 1993; Myers & Diener, 1996). This understanding concurs with my results in that the process of shifting meanings enabled the participants to value aspects of their lives that could be fulfilled in the current day-to-day realities and context of
living with chronic disease and the losses it entailed. Knowing more about these changes in understanding could help health care professionals and others to know how they might support individuals in different ways at different times.

**Meaning Fulfilling Processes: Disease Management as a Means not End of Living Well**

The last meaning-related dimension of the participants’ living well experiences concerns the approaches they used (i.e., attitudinal perspectives and strategies) to help them have meaningful experiences. Findings on why they used specific approaches and their understandings of the effects or outcomes of these actions provided insight into how living well experiences developed in their lives. Many of the findings support current knowledge but some also challenge assumptions in the literature about what is always necessary for living a good life with illness.

The attitudes that the men and women commonly associated with being able to live well (i.e., living life orientation; optimistic outlook; pragmatic, proactive, and problem solving perspectives; taking control and shaping life experiences; and determination and drive) largely concur with findings on attitudes and personality characteristics that facilitate coping and adaptation (Folkman & Greer, 2000; Holahan et al., 1996, Moos & Schaefer, 1993), and more favourable experiences (Albrecht & Devlieger, 1999; King et al., 2003; Loffer, 2000; Nosek et al., 2004). Although the findings indicated that these attitudinal perspectives were important for living well, the results showed that the participants did not maintain these approaches 100% of the time. In contrast to what the associations between these characteristics and coping or other outcomes might suggest, my data indicates that the process of having negative or pessimistic perspectives and feelings about unfavourable changes in their disease or life was helpful in enabling many of the participants to regain and sustain more favourable perspectives over the changing course of their lives. Favourable attitudes coexisted with feelings of anger, frustration,
grief, and sadness and although the women and men felt that favourable attitudes greatly facilitated the living well process, they let go of these perspectives from time to time to help them experience and move past the challenging emotions they faced. These findings reveal a more nuanced understanding than can be captured in looking at the relationship between attitudes (i.e., determinants) and favourable health outcomes. At a practical level, understanding that more negative attitudes play a vital role in the maintenance of more favourable ones suggests that it might not be helpful for a health care professional to try and cheer up an individual during a down period when that period may serve a useful purpose in helping them to live well over the longer term.

The strategies that were identified as part of the living well process have also been described in a number of bodies of literature (e.g., subjective experience research, health promotion, QOL, self-management studies) as important means for enabling people to live with illness. For example, seeking information and developing knowledge (Lee & Poole, 2005; Loeb, Penrod, Falkenstern, Gueldner, & Poon, 2003); managing disease (Reynolds & Prior, 2003), using assistive aids, devices, and services (Albrecht & Devlieger, 1999); developing new activities (Lutz & Bowers, 2005); changing relationships (Paterson, 2001); and hiding and disclosing illness (Joachim & Acorn, 2003) have all been articulated in the literature as approaches that facilitate living with illness and as behaviours that promote more favourable illness experiences.

The research revealed that the participants’ overall intention in using these strategies was to attain meaningful experiences in day-to-day life. This view supports research that has looked at behavioural strategies in the context of QOL, doing well, or thriving. For example, Loffer (2000) noted that although participants with rheumatoid arthritis used a wide range of behavioural strategies, all of the approaches seemed directed towards increasing self-awareness and meaning, having a sense of control over disease and life, and developing a deeper sense of
belonging or connection with family and friends. Within these common strategies the women and men selected approaches that best addressed the meaningful experiences they wanted to achieve while meeting their unique needs, beliefs, and personal circumstances as they changed over time. This suggests that over reliance on general approaches that have been shown to be helpful for living with illness could lead us to ignore the important variations in approaches that people require to meet their individual needs (i.e., the tensions they face and the particular areas of life they value).

As might be expected, coping and disease management literature has emphasized the importance of using strategies to cope with or manage disease and the functional limitations they create. This knowledge has increased the understanding of the wide range of behavioural approaches individuals use to respond to the effects and impacts of developing and living with chronic disease. Royer’s (1998) research on the experiences of chronic illness found, for example, that most behavioural strategies were used to “compensate for the nature and extent of their limitations and to cover up the type and extent of the changes in physical appearance and bodily functions so they can continue to function at premorbid levels” (p. 95). However, in contrast to the implicit assumption in some understandings that coping and managing processes are the goal or endpoint of living with illness, my findings suggest that the strategies identified as part of the living well process were largely oriented towards attaining meaningful aspects of life.

In line with my results, there is growing awareness in the literature that individuals have motivations and intentions in their lives other than managing or coping with the demands and tensions of illness. As such, these processes become one part of accomplishing something of greater importance. For example, Reynolds and Prior (2003) discussed the strategies women with MS used to help them cope with the “flux of difficulties” (p. 1231) and problems that illness created in their lives but noted that “achieving quality of life in the context of illness
required a much broader approach” (p. 1244) such as engaging in valued activities and relationships and valuing positive experiences. In my research, coping with and managing the disease and related tensions and challenges was an important aspect of the context that shaped the overall nature of the participants’ lives, influenced their evolving understandings of what was meaningful, and determined the kinds of strategies that worked to have meaningful experiences within the disease-related contexts of their lives.

Of interest, the women and men also abandoned or traded-off strategies in specific ways over time to maximize meaningful experiences. In many cases they traded-off the management of their disease and sacrificed the well-being of their bodies and illnesses for certain periods of time to enable them to have the experiences they really wanted. Although participants in the current study described strategies that helped them manage their disease and facilitated living well by increasing their functional capacity and strengthening their sense of self, they also indicated that these activities sometimes inhibited them from maintaining a living life focus and doing the things they valued. Charmaz (1991) found similar results in her research where some people were willingly to endure pain or fatigue to engage in a meaningful activity or play with children. Extensive studies do show that disease management strategies and behaviours make a difference in how an individual responds to illness (Lorig & Holman, 2003) and studies also suggest that managing one’s disease is necessary for maintaining a wellness perspective (Paterson, 2001) or having a good or successful life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 1999; Lorig & Holman, 2003). However, my findings along with those of Charmaz and others in the field challenge the dominant understanding that managing one’s disease is always essential for being able to live well with illness in daily life.

Given that there are no consistent interventions that are known to always work for persons living with scleroderma, lupus, or MS focusing on life instead of disease management makes most sense. This approach might hold true for some other disease groups as well. For
example, Cicutto, Brooks, and Henderson (2004) found that "self care activities directed at
disease management were reported to be time-consuming and to impede on day-to-day activities
and enjoying life" (p. 175) for persons living with chronic obstructive pulmonary disease. These
authors reported that their participants wanted to "live life and not spend all of their time on
disease management activities" (p. 172). However, it is also evident in the literature that disease
management strategies are essential for persons living with some chronic diseases such as Type
II diabetes where self-care behaviours are required to regulate the disease and maintain health.

In the current policy and practice arena in many Western countries, chronic disease
management programs are a highly acceptable means of improving the lives of those living with
the challenges of illness (Barlow et al., 2002; Lorig & Holman, 2003; Walker, Swerissen &
Belfrage, 2003). The most prominent ones are based on the important disease-related tasks of
medical management, role management, and emotional management as described in Corbin and
Strauss's (1988, 1990) seminal research on the work involved in living with chronic conditions
(Lorig & Holman, 2003). The findings in the current study suggest that strategies need to be
considered in relation to the broader context and meaning of a person's life. The fact that
participants traded-off disease management approaches from time to time to achieve meaningful
experiences suggests that many of the chronic disease management programs may be at cross
purposes with the larger objectives of living a meaningful life at certain points in time at least for
those living with diseases with no definable or consistent interventions that work. Overall, the
results of this study suggest that exploring ways of restructuring or reframing chronic disease
management programs in a broader framework of values, goals, and areas of meaning in an
individual's life would likely further the development of living well experiences for those living
with long-term conditions.

These strategy-related findings also support work in the field of self-care decision-
making in chronic illness, in particular, emerging views that we need to consider self-care
decision-making and medical compliance in relation to the broader needs, desires, and goals of an individual’s life (Paterson, Russell & Thorne, 2001). A lot of research on self-management has focused on compliance with medications and decision-making in relation to treatment and symptom control but not on how people make decisions about which options to select on a daily basis to manage and live with illness (Thorne, Paterson, & Russell, 2003). It is increasingly recognized that the decisions persons with illness make in regards to medical compliance “reflect a wide range of thoughtful and legitimate coping strategies or self-care management initiatives” (Thorne & Paterson, 2000, p. 12). Thorne (1999a) argues that “health care professionals cannot simply assume an understanding of what a valued life entails and therefore predetermine what compromises must be made in the process of achieving it” (p. 235). Thus, understanding the experiences people value in their lives and the meaningful experiences they are hoping to attain would enable health care professionals to make sense of and appreciate the decisions persons with illness make regarding their medical and self-care.

Overall, my findings and similar understandings in the literature suggest that we need to consider the choices and decisions persons with illness make in daily life in relation to a broader meaning in life framework rather than in relation to just taking care of their disease or in relation to meeting the expectations of health care professionals, family, and society for managing their health.

**Living Well as Alignment**

In this research, meaningful experiences were the product of the alignment or fit between context and meaning. The nature of the approaches participants used and the intent or purpose they served brought into focus the relationship between their inner and outer experiences and individual and social domains. Conceptualizing the development of living well experiences as a process of alignment provides a means of seeing and understanding the dynamic nature of their
lives and provides insights into the interplay between their attitudes, strategies, and shifts in meaning in relation to context and meaning, and in relation to each other. Further, this understanding shows how seemingly opposing approaches can be part of the same overall process of living well and provides a means of making sense of some of the diversity in their living well experiences in terms of the approaches they used, and the kind and degree of fulfillment they experienced over time. In this section, I examine these dimensions of their experiences in relation to current conceptualizations and frameworks in the literature for understanding a good life and show how my findings coupled with understandings in the literature point towards directions for future research and particular kinds of program development.

**Explanatory Perspective of Alignment**

Explanatory understandings differ in how we construct the challenges of living with illness that need to be addressed and by what we envision as the outcome, goal, or target of life, as well as the nature and temporal aspects of the processes that link these two dimensions. In the current study, the alignment perspective portrayed a view of the nature and overall process of living well as constantly shifting to accommodate changes in disease, life, and individual perceptions, understandings, and values.

The explanatory perspective that a good life is created by aligning context or daily activities and reality with an understanding of what is meaningful in life supports some understandings articulated in QOL and personal goal research. For example, QOL has been conceptualized as the relationship between one's expectations in life and one's actual experience (Carr, Gibson, & Robinson, 2001) and as the appraisal of one's current life in comparison to what is perceived as desired or possible (Cella & Tulsky, 1990). Personal goal research also examines an individual's life in relation to the fit between what an individual values and what they can have or how they live in daily life (Brunstein, 1993; Brunstein, Schultheiss, &
Grässmann, 1998). Although much of this research has involved quantitative studies on healthy populations (Kuijer & de Ridder, 2003), a few recent studies have explored this relationship in persons with illness (e.g., Affleck et al., 1998; Kuijer & de Ridder, 2003). For instance, Kuijer and de Ridder (2003) looked at the importance and attainability of goals for the QOL of persons living with asthma, diabetes, and heart failure but focused on illness-related goals (or adaptive tasks) rather than life goals or meaningful experiences as described in my research.

Some researchers conducting studies in interpretive frameworks have also described the explanatory understandings of a good life in relation to a fit between the individual and their environment, although not necessarily in relation to attaining meaningful experiences or valuable goals. For example, a recent study by Lutz and Bowers (2005) showed that the ability to integrate disability into life depended on the fit or match between the participants' perceptions of self and what was important in their lives and their life context. As another example, Albrecht and Devlieger (1999) explained experiences of living a high QOL with chronic disabilities through processes that integrated body, mind, and spirit, and created harmonious relationships between the individual and their family, community, and environmental context.

In much of the chronic illness research, models of adaptation (e.g., Livneh & Antonak, 1997) and coping (e.g., Lazarus & Folkman, 1984) have served as the dominant explanatory frameworks for understanding how individuals live with illness in daily life, and sometimes how they live well. Although coping and adaptation processes comprised part of the mechanisms of alignment portrayed in my research, these frameworks conceptually differ at a number of levels. They often construct the disease-related challenges in different terms (problems, tasks, or stressors versus relational tensions derived from one's disease processes in interaction with their body, mind, and life). Also, they are usually oriented towards adaptation, coping, or some psychological state as the measure of how someone lives with illness rather than meaningful experiences. Further, some of these understandings present the nature of illness experience in
linear, phased, or causal terms (Paterson, 2001) rather than as a dynamic two-way fit or congruency between the inner and outer aspects of an individual’s life as the current results suggest.

An alignment perspective of how an individual works with the various aspects of illness experience (i.e., tensions, attitudes, strategies, and meanings) to create a good life provides a means of making sense of disease-related struggles and how individuals cope with and manage them in relation to a broader framework of aligning day-to-day realities with experiences of value. This pushes coping and adaptation frameworks to extend further into more complex understandings that can account for some of the additional insights that an alignment perspective can provide. For example, the understanding of alignment suggests that a person can live well if they find a way to align and attain meaningful experiences in daily life, even if they are unable to address or cope with all the disease-related challenges or tasks that their illness presents.

Understandings of alignment also provide a framework for exploring the diversity in approaches used by different people. For instance, this perspective provides a way of understanding or making sense of how very different approaches might work for different people in the living well process because they represent a relationship between the specific tensions and specific living values that each individual experiences in his or her life. This vantage point enables one to explore the roles that attitudes and strategies might play in the living well process in more depth. In my research, I focused on documenting attitudes and strategies that the participants identified as helping them have experiences of value often by addressing particular kinds of disease-related tensions they faced. However, they also used some strategies that did not serve their overall goals for meaningful experiences but instead helped them to manage and cope with day-to-day disease-related issues and hassles. Some approaches outlined in my study facilitated both. As such, developing knowledge on the kinds of strategies that help people address and cope with disease-related tensions and also enable them to have experiences of value
would be useful for the development of programs to promote living a good life with illness. A good starting point for advancing understandings in this area would be to ask questions such as whether the approaches they use are directed towards changing tensions, shifting understandings of meaning, or both, and in what ways do these approaches facilitate or hinder the alignment process and attainment of meaningful experiences.

The alignment framework also suggests that it would be useful to know whether or not there may be patterns of alignment between and within individuals over time. My findings suggest that participants may have found patterns of response or ways of approaching constant change that reduced the effects of a highly dynamic environment such as valuing aspects of life that were less dependent on their external world. It is possible that individuals have other ways to reduce the impact of change and the effects it has on alignment that would be interesting to explore. My findings also hint that the need for alignment might dissipate over time as people come to value spirituality and other areas of their lives that are more internally-centred and this might have important implications for the nature and process of living well over the course of one’s illness experience.

Alignment and Fulfillment

It was evident that the participants obtained different degrees of congruency between their inner and outer worlds and the degree of alignment in each of their lives also varied over time in the course of living with illness. Hence, the degree to which the areas of value in their lives were fulfilled in daily life greatly differed from individual to individual and it was evident that living well was not equated with complete fulfillment in all areas of importance for most of the women and men in the study. This raises the issue of whether there was a hierarchy of values in the life meaning domains and in the experiences that were important to the men and women in these areas?
Although quantitative methods can rank the degree or level of an individual’s QOL score, for example, studies in interpretive research tend to explore doing well or thriving or having a good QOL by listing the various dimensions or themes inherent in the experiences without delving into whether or not there are some key aspects that set the parameters around having those kinds of experiences or are absolutely necessary in an individual’s life. My findings suggest that most of the participants had a clear understanding of which areas of their lives they had to have to be fulfilled, which ones were nice to have, and which ones they could live well without, although this clearly evolved over time in keeping with the conditions of their lives. For instance, a number of participants seemed to have fulfillment in their relationships with partners, children, or family and seemed to value this aspect of their lives more highly than having fulfillment in their vocations or careers that many of them were still trying to fulfill in some other way. Those who continued to live well over time learned to rally around new meaningful experiences or reconceptualized previous ones so that they could be fulfilled as their lives changed.

The findings suggest that positive feelings towards life (e.g., satisfaction, happiness, contentment) were the outcome of the alignment process and the meaningful experiences that it created. This understanding supports the documented relationship between meaningful experiences and positive emotion in the literature (e.g., Folkman, 1997). Folkman and Moskowitz (2004) argue that positive meaningful events are associated with positive emotions because they “affirm what one values and help one focus on those values while coping with the ongoing stressful event” (p. 766). Research suggests that favourable emotions help to sustain coping processes over time (Folkman, 1997) and it is possible that they facilitate the alignment process in a similar way although this was not explored in the current study.

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Mechanisms of Alignment: Integrating Adaptation, Coping, QOL, and Meaning Perspectives

My findings suggest that alignment was achieved through two major mechanisms, namely, using attitudes and strategies to alter tensions or to directly attain meaningful experiences, and by making changes in understanding of what was meaningful in response to situations of loss. Some research (e.g., studies on personal goals) has described similar types of processes in an alignment framework similar to that outlined in the present work. For example, Kuijer and de Ridder (2003) talk about “reducing discrepancy between importance and attainability of goals either by making important goals more attainable or by setting more realistic goals” (p. 329) to enhance a good life with illness. More commonly, however, these two processes (or aspects of them) have been described in different bodies of literature. Shifts in meaning have been primarily explored in response shift and personal goal research, whereas attitudes and strategies as a means of addressing disease-related problems and challenges lie at the heart of most coping and adaptation studies on chronic illness.

Some research has explored and described relationships between strategies and attitudes and QOL (or other related outcomes) for persons with illness and some work has looked at how strategies and changes in understanding relate to meaningful experiences. However, studies exploring these kinds of relationships have not always found strong relationships (e.g., how one adapts or copes with illness-related struggles is not strongly related to QOL; de Ridder & Schreurs, 1996). Also, it is not always clear whether the findings obtained in these different bodies of research reflect entirely discrepant orientations of living well in chronic illness or contribute differently to a coherent portrait of the phenomenon. The findings in the study described herein suggest that we need more research that attempts to bridge the understandings and findings on adaptation, coping, QOL, and meaning as articulated in qualitative and quantitative studies if we want to further advance knowledge on living well experience.
By exploring the process of altering one’s daily life context (via attitudes and strategies) to attain meaningful experiences and the process of shifting their understanding of what was meaningful, I noted some important aspects of the interplay between these mechanisms in the creation of living well experiences for the participants in my study. Some findings suggest when and how each approach was used in relation to the other and also illuminated the tension the participants’ accounts emanated between changing one’s understanding or trying to change one’s day-to-day life. For example, the women and men’s attitudes seemed to play a pivotal role in their ability to make shifts in understanding and, conversely, changes in what was most meaningful seemed to determine attitudinal perspectives and strategies that were most useful for helping them have these experiences in daily life.

Exploring these two processes in the same study provided a means for understanding the dichotomous approaches and explanations for living well that the participants provided (e.g., doing/not doing, holding on/letting go, and fighting/accepting). When these two processes are considered in relation to each other from the perspective of alignment, the seemingly opposing and dichotomous approaches become different ways of accomplishing the same goal and are no longer constructed in contradictory terms. Although all of these seemingly opposing approaches have been described by various authors as part of the chronic illness experience, the present study suggests that diverse approaches need to be used by individuals to meet the continually changing nature of their inner and outer lives. On some occasions, participants had to be able to alter their environment or body to fit their expectations and help them attain meaningful experiences and at other times, they had to change their understanding of what was valuable to fit the realities of their body and day-to-day life. Hence there was an ongoing negotiation between context, body, and understanding in the alignment process.

Overall, the current findings confirm the results of other research that persons with illness need to be able to use a range of diverse approaches in flexible ways in order to attain
meaningful experiences in the tension-centred and dynamic context that illness creates. However, the alignment perspective helps to extend this understanding by reconstructing the seemingly opposing and dichotomous approaches as different ways of accomplishing the same goal.

Summary

In summary, the answers to the research questions were conceptualized in relation to finding and enacting meaning in daily life through processes that aligned the participants' inner and outer experiences in a tension-centred context. This understanding portrayed perspectives of living well as tension, meaning, and alignment. The findings described through these three lenses were largely in keeping with current understandings in qualitative studies of subjective experiences with chronic disease and some quantitative research. The tension perspective extends current knowledge by showing the relational, interactive, and dynamic nature of disease-related challenges and reinforcing the coexistence of, and interrelationship between, negative and positive phenomena. The vantage point of meaning shows how meaning in life was the goal or focal point around which the women and men in the study oriented and negotiated daily life. This shifts the primary focus of using attitudes and strategies to attaining meaningful experiences rather than managing or coping with disease and provides an explanation for how and why people sometimes trade-off disease management strategies or are noncompliant with medical treatments. The alignment model brings into focus the relationship between meaning and context, inner and outer experiences, and individual and social domains. It provides a means for better understanding the dynamic nature and diversity inherent in the lives of those living with illness as expressed through tensions and meaning, and the ongoing interplay between understanding, body, and daily life in the living well process.
CHAPTER 9: REFLECTIONS, CONCLUSION, AND IMPLICATIONS

Summary of Study

A valuable and massive body of knowledge has developed on chronic illness experience in recent years that includes studies exploring the experiences of those who live a good life or have more favourable experiences. This research reflects particular theoretical perspectives and disciplinary orientations and has focused on a range of different concepts and aspects of the experience. However, much of this literature has placed greater emphasis on articulating themes and patterns than on the interrelations between different aspects of it or how it develops over time. To address these gaps in understanding, I explored how persons lived well with MS, lupus, or scleroderma. I sought to understand the nature of their experiences of living well and some of the biopsychosocial processes by which it developed in their lives, as well as how these processes interrelated over time. To achieve this, I designed an interpretive research study grounded in a social constructionist framework that involved interviewing 31 participants who self-identified as living well.

Most of the women and men in the study had lived with chronic disease for many years and had diverse and challenging lives. Their diseases had progressed in ways that created significant challenges in daily life that reflected ongoing tensions and loss. By viewing the data through the lenses of tension, meaning, and alignment, I came to understand their experiences of living well as living meaningful experiences that were obtained through an ongoing process of aligning the tension-centred reality of living with illness and their understandings of what was important in life. These processes involved attitudinal and behavioural approaches as well as cognitive shifts in understanding of what was meaningful. These approaches either worked to change their body, relationships, or environment to fit their expectations of life and help them
attain meaningful experiences, or they altered their understanding of what was valuable to match the realities of their bodies and lives. Positive feelings about life, disease, and themselves seemed to emanate from this alignment process and from living experiences of value.

Within this conceptual understanding, the findings about living well experiences largely support current ideas and knowledge in the field. However, some findings illuminate elements of these more general understandings that have not yet been well articulated in the literature. In my study, positive and negative experiences were inherent in living a good life. As well, pessimistic feelings and views of life were an integral part of the experience, although more positive and optimistic perspectives dominated over time. Even though living well involved strategies and approaches that helped participants manage and cope with the tensions they faced, most of them were ultimately oriented towards helping them achieve meaningful experiences. The participants' priorities were not managing their disease per se but rather living a fulfilling and meaningful life in the context of illness. Accordingly, the women and men sometimes sacrificed the disease management strategies that helped them maintain their physical well-being because they hindered their ability to experience something of value. Also, approaches that seemed contradictory actually worked towards the same goal of maximizing meaningful experiences in daily life. Overall, living well represented different kinds and degrees of alignment and fulfillment within and between the participants over time and hence, the nature and processes that enabled them to live meaningful experiences were continually evolving.

Reflections on the Research

Conceptual Understandings and Theoretical Approaches

I used the concept of living well to study a good life for persons with illness because this concept was not situated in a specific theoretical or conceptual view. This enabled me to explore understandings of a good life outside of a predefined framework, thereby avoiding any a priori
assumptions about what it entailed. However, all language is interpreted in specific ways according to shared sociocultural understandings and individual meanings. Therefore, using living well as the phenomenon of interest may have preselected persons with a particular kind of experience that is different from others described using different terms (e.g., QOL and wellness). It is impossible to know whether or not the same participants would have volunteered to partake in the research and described a similar kind of experience if I had advertised for people to participate in a study looking at a good quality of life. However, it is likely given that the apparent difference between living well and QOL may be more of an academic and theoretical issue than one that reflects differences in how individuals make sense of and understand the nature of their lives. Results from other studies using QOL terminology to recruit participants have described similar kinds of findings about the nature of living a good life and the kinds of processes that are involved in its development throughout the course of living with chronic illness as those I have described in my research (e.g., Albrecht & Devlieger, 1999; Reynolds & Prior, 2003).

During the process of constructing my research findings, I reflected on a number of theoretical issues in relation to current developments and debates in the field of chronic illness research. One of them was how the understanding of living well experience that was evolving in my analysis fit within the broader debates in the literature on how to look at relationships between individual and society and the role of agency, structure, and context in creating illness experience (e.g., Williams, 2003). In this study, I came to know living well experience through the subjectivity of the participants and by using the various lenses of tensions, meaning, and alignment, I constructed their subjective experiences of living well as arising from different forms of relationships between the participants and the society in which they lived. For example, tensions arose from the relationship between physiological disease processes and an individual's internal and social context (e.g., people, organizations, environment). The processes of
alignment represent a relationship between an individual’s understanding of what is important and valuable in their life and the nature of their lived experience in social context. Yet, these interactions are primarily ones between the participants and microsocial contexts such as family, friends, and immediate daily life. Even though I conceptually situated their experiences as the product of various individual-social relationships, I analyzed and interpreted the processes by which the participants lived well solely from the vantage point of the individual’s thoughts and negotiated actions. Thus, I used the women and men’s subjective interpretations to understand their living well experiences from inside out, that is, their internal perspectives of socially constructed experiences.

Emphasis on microsocial contexts and personal agency reflect the health and social psychological perspectives that informed my research, in particular the theoretical view of symbolic interactionism (Blumer, 1969). Within this framework, it is assumed that the "individual and the context in which the individual exists are inseparable" and "that each individual and his/her environment are inextricably linked through reciprocal relationships" (Benzies & Allen, 2000, p. 542-544). From this theoretical lens, knowledge is developed through a person’s interpretation of reality in a social context (Benzies & Allen, 2000). Thus, the individual is a "perceiver of an (external) social world" (Eiser, 1996, p. 613). According to Benzies and Allen (2000), "symbolic interactionists take a nondeterministic view of the individual and assume that there is freedom of choice of human behaviour" (p. 544) although that choice is implicitly understood to be shaped by societal and cultural norms. People act according to the meanings they attribute to things and are understood to be actively shaping their realities through the process of interpreting the meaning they assign to various dimensions of their lives (Benzies & Allen, 2000; Blumer, 1969).

Consequently, the understanding of living well that arose in my research reflects how the participants perceived and negotiated the bodily aspects of disease and the immediate social
relationships, communities, and environments within which they lived. It does not explicitly conceptualize or reflect on the role of broader more macro sociocultural processes, constraints, and structures that inevitably played a role in the overall nature of their experience and how it developed. One of the unintended consequences of solely exploring living well experience from the vantage point of human agency is that a reader might view this kind of experience as only being created and shaped by the individual and their skills and abilities. This could be viewed as supporting the notion that individuals have complete responsibility for the way they are able to live with long term illness even though this understanding is not supported in the broader literature showing the importance of sociocultural structures and forces.

Sociocultural processes have not been given as much attention in the subjective paradigm of illness research (Charmaz, 2000a; Thorne & Paterson, 2000) and are not well explicated within a symbolic interactionism framework (Benzies & Allen, 2000), although some researchers argue that this theoretical perspective can be used to understand the role of broader social and cultural structures due to its emphasis on meaning-making in shaping human behaviour (Denzin, 1992). It is argued that attention to the point of view of an individual requires consideration of both microsocial and macrosocial contexts within which action is situated (Benzies & Allen, 2000) and that understandings of chronic illness need to consider forms of constraint and negotiated action (Radley, 1989).

**Research Design and Process**

As part of the sampling strategy, I originally hoped to recruit a large number of women and men who had self-selected through advertisements in the general community in hopes of attaining a diverse sample. However, the majority of my sample had strong connections to illness-related organizations and being involved with these organizations may have affected their illness experiences. It may have influenced the way they think about living well, as well as the
attitudes and strategies they use to develop and enact this kind of experience in daily life. For example, a number of the participants were very involved in association affiliated self-help groups that shared knowledge of various strategies used to manage illness. Not surprisingly, these individuals strongly favoured alternative and complementary approaches in their accounts of living well. Also, individuals who self-selected through recruitment strategies within these organizations might have had more capacity or support for living well (or a different kind of support) than those who did not respond or those living in the community who do not interact with illness-related groups. This means that my findings on living well were based on the experiences of those involved in illness-related activities and only captured a few experiences of those who live well with no affiliation with these organizations or medically-related clinics. Also, women and men who volunteer to partake in research studies represent a particular subset of the general population of ill individuals whose experiences likely differs from those who choose not to volunteer for research. Thus, my findings describe the experiences of some of the group of people who are motivated to partake in research-related activities.

My sample reflected the dominant demographic characteristics of most research participants in studies on the subjective experience of living with chronic illness. In line with Thorne et al.’s (2002) finding that “the sample population of many studies are heavily weighted in the direction of White, educated, middle-class women, regardless of the extent to which that subgroup represents the total demographic picture of any particular chronic condition” (p. 444), the self-selected sample in my study was predominantly White, educated, and middle-class. The majority had total household incomes of less than $50,000/year (although they ranged from the poverty level to more than $90,000/year). Obtaining a sample with these demographic features could be the result of many different factors including the process used to recruit individuals (e.g., language and location of advertisements), as well as the type of individuals most interested in partaking in this kind of research. The limitation of using this kind of sample is that my
findings contribute to an existing body of work that is already "strongly influenced by dominant values, beliefs, and assumptions common to that particular subgroup" (Thorne et al., 2002, p. 444). As a result, it does not further efforts to illuminate the diversity inherent in illness experience or capture some of the features that may specifically pertain to demographic profiles of more marginalized groups living with long term conditions. Also, even though the women and men in my study described themselves as having a range of disease severity and symptoms, only a few of them were acutely ill or just recovering from being very ill at the time of their interview. Thus, the study sample largely reflects those who were not in an acute crisis at the time of the study and reinforces typical samples used in chronic illness research (Thorne & Paterson, 2000) and the particular kinds of knowledge they create about illness experience.

Also, my sample was comprised of individuals who had a diagnosis of one of three autoimmune diseases – multiple sclerosis, lupus, or scleroderma. These diseases undoubtedly create some tensions and processes that differ from other disease groups such as central organ diseases, for example. Chronic diseases have different underlying physiological processes that create different impacts on the human body and the way it is able to function. Moreover, different diseases present different kinds of sociocultural impacts for individuals (e.g., degree of stigma). Consequently, the variations in tensions and dimensions of living well experience portrayed in these findings may not reflect the nature of the experience for other disease groups. In addition, there are different biomedical options for different diseases. In the case of MS, scleroderma, and lupus there are more limited options than there are for diseases like Type II diabetes or hypertension. Hence, some of the findings relate primarily to the context in which there are limited treatment or intervention options.

Concerning data collection methods, interviews are recognized as one of the best approaches for capturing the lived experience of an individual and for exploring their “cognition, emotion, and behaviour as a unifying whole rather than as independent parts to be researched
separately” (Nunkoosing, 2005, p. 699). However, this method has limitations in relation to the use of subjective, co-constructed, and retrospective data. I used subjective and self-reported (conversational) data collected through one-on-one interviews because it is well recognized as providing an insider view of chronic illness and can advance understandings of the dynamic, multidimensional, and complex nature of this experience (Thorne & Paterson, 1998, 2000). However, Radley and Billig (1999) note that “[subjective] accounts of health and illness differ according to circumstances, intentions, and audiences” (p. 18) and other researchers concur (e.g., Charmaz, 1987, 1995). What people talk about and the stories they tell reflect the “aspects of his or her life that he or she is most interested in telling” (Nunkoosing, 2005, p. 701) and also can be used to “account for, and even justify themselves and their actions” (Sandelowski, 2002, p. 106). Charmaz (2000a) argues that “as reconstructions of the past, interviews never replicate experience, they render it. Stories in interviews serve new and different purposes than when originally experienced and first told” (p. 288). For example, the process of the interview can bring out certain aspects of illness experience, more favourable or more negative ones, as participants try to fulfill the interviewer’s expectations of having a particular kind of experience (Paterson, 2003).

Individuals in my study were giving retrospective accounts of their experiences of living with an illness over a period of 15 years or more. This provides participants with the opportunity to have the necessary distance and perspective to describe their experience in context (Sandelowski, 1999) and yield rich data (Thorne & Paterson, 2000), yet it is hard for people to remember all the details of how life unfolded over such an extended period of time. Hence, it is likely that their accounts of living well were weighted towards their current perspective of living well and what works well in their lives at the present time. Their accounts may have also reflected the phenomena that had the strongest impact on their lives. Retrospective accounts are also limited in that they cannot fully capture evolving and dynamic experiences over time in the
same way that a concurrent or prospective study would. This was exemplified in the comments of one participant who made a point of stressing that I was only seeing her at one “point in the journey.” In addition, because it is known that reflective processes often reframe people’s experiences in ways that make the form of knowledge different from that which would capture more direct experience (Sandelowski, 1999), the insights I obtained into living well experience and how it developed over time in the participants’ lives using retrospective data likely differs in some respects from what would have been obtained through prospective research that explored their experiences as they unfolded in daily life in real time.

Using single interviews to collect data also has some limitations in regards to capturing processes and changes over time. It has been argued that “stories from single interviews are partial and may isolate moments that relate to life course” (Charmaz, 2000a, p. 288) and that these snapshots of a complex experience make it harder to gain deep insights into an individual’s chronic illness experience (Paterson, 2003). For these reasons, it is generally accepted that two or three interviews with participants over a 1- to 2-year period is more likely to capture change and develop insights into some of the major processes occurring in their lives than one time retrospective accounts (Conrad, 1990).

The generic approach to knowledge development that I used in the data analysis process has been recognized as being important for describing common patterns and phenomena in individuals with different chronic diseases (Paterson, 2000). However, authors like Paterson (2000) note that studies like mine are limited by the fact that they fail to account for differences as well as commonalities among different diseases in the reported findings. Also, the process of data analysis that I used broke down the data into discrete parts and then I reorganized them in a meaningful way to create my findings and interpretation of living well experience. This process necessarily fragmented the participants’ experiences into various components (e.g., attitudes, behaviours, feelings) supporting the notion that many qualitative methods do not reflect a
holistic approach to inquiry (Morse, 2003). Morse and Chung (2003) argued that “qualitative methods are never completely holistic, containing assumptions and perspectives that partition reality and provide subtle biases, often silently excluding as they focus and as inquiry becomes directed as it proceeds” (p. 3).

Conclusions

Notwithstanding the limitations apparent in the study, I am able to make the following general conclusions by situating my findings in the context of an emerging body of knowledge in the field:

- Living well with chronic illness requires the balancing of a number of tensions associated with disease and its impact. These tensions arise from the interaction between the chronic disease, individual, and their social milieu.
- Tensions are dynamic and continually evolving in their lives and although some can be altered or removed, some are always present in the lives of those living well with illness.
- Living well is comprised of both negative and positive experiences that coexist; the relationship between these aspects of the experience is not well understood.
- Living well involves engaging in experiences that are important and meaningful. These experiences reflect commonly valued domains, such as those characteristic of life in Western society, as well as the unique beliefs, values, and interests of the individual. Consequently, living well experiences can only be fully understood in relation to the nature and values of each person.
- Understandings of what is meaningful shift and evolve over time in relation to losses and, consequently, the nature of living well is continually changing.
• Over the long-term, living well seems more closely aligned with purpose, spirituality, and relationships than it is with physical functioning in daily life.

• Persons with chronic illness perceive living well to be consistent with an orientation towards life and seeing challenges from an optimistic perspective.

• Living well involves making decisions and choices about how to live (i.e., what strategies to use) in relation to one’s goals and values and the tensions they experience rather than in relation to just managing disease or meeting the expectations of others (e.g., family, friends, health care professionals).

• Managing and coping with diseases is one part of the overall efforts that people make to live well with chronic illness.

• In living well with illness, positive emotions are related to meaningful experiences.

**Implications for Policy, Programs, and Practice**

Because most chronic illness-related policies, programs, and practices fall within the domain of health care systems and services, the emphasis is largely on how people manage their symptoms and get the necessary care they need to live with disease. This involves finding ways to better support them over long periods of time, often with increasing disease severity and functional limitations while at the same time reducing the demands they place on valuable health care resources. Although the scope of my research does not have direct implications for health care structures or service delivery, the findings as situated in the context of developing knowledge do have implications for the health care providers working within these macrostructures and systems, and illness organizations that often play an extensive role in the lives of persons living with illness. They are also relevant to the development and
implementation of chronic disease programs that are being widely promoted at community and system wide levels.

The understanding that living well represents meaningful experiences for persons living with illness and that these experiences are achieved through strategies that align daily life with understandings of what is valuable suggests that it would be beneficial for health care professionals to learn more about the importance of looking at the self-care decisions and approaches people use in relation to an individual’s goals and values and the specific disease-related tensions they face in daily life (rather than only in relation to whether they help them achieve medical or health objectives). Current knowledge suggests that being able to provide effective support and care for individuals with chronic illness requires an understanding of approaches that can enable individuals to meet the needs of their disease and bodies within the larger framework of what is important and meaningful in life. Because many chronically ill individuals interact with health care professionals on an ongoing basis over many years, this understanding would likely promote better compliance of medically-related interventions and greater understanding and acceptance of those times when individuals choose not to follow recommended treatments in order to best meet their needs outside of the direct care of their disease.

Historically, helping people manage and cope with illness in daily life has been a highly valued goal within many illness organizations and, in fact, largely represents the mission of these associations. Many of the activities have been centred on helping persons with illness understand their diseases and effectively negotiate services with health care providers, as well as providing information and services to help people address the impacts of their diseases on daily life. My findings along with the larger body of literature suggest that it would be useful to start to integrate meaning-based information, support, and programs with the idea that managing and coping would be viewed as one part of the overall aim of living meaningful lives. Although this
seems rather simplistic, it represents a paradigm shift from a disease-centred model of supporting individuals with illness to a life-centred approach where disease is one part of a broader understanding of what life with illness represents. It is highly unlikely and perhaps even inappropriate that these kinds of organizations might ever suggest that a meaningful life with illness requires one to make managing their disease a lower priority than other activities or that it would be helpful for individuals with certain illnesses (i.e., those without effective treatments) to forfeit disease management strategies in the short-term to obtain experiences of value. However, encouraging individuals to make decisions in relation to their values and the way of life that is most meaningful would likely help them to achieve their mandate of supporting people to live well with chronic disease. Movement in this direction could be supported by having workshops or support groups that focus on understanding and identifying what is important and meaningful in one’s life and provide ideas for how to obtain these kinds of experiences in the context of ongoing disease-related tensions and struggles. Further, such initiatives could emphasize the skills and understanding needed to shift one’s understanding of what is meaningful if altering their daily life is not sufficient or they experience losses that cannot be easily changed.

As described earlier, chronic disease management programs and interventions are increasingly being endorsed and promoted as a means of helping people with chronic illness to live better lives and as a means of reducing health care utilization and related health care costs. The most commonly used programs are grounded in extensive research and aimed at teaching individuals how to effectively manage their symptoms, health care service and treatments, daily impacts of living with illness and emotional responses. However, one of the main conclusions in this study suggests that it is important to consider these strategies in relation to the broader context and meaning of a person’s life because living well seems to derive more from using approaches that facilitate the attainment of meaningful experiences than managing disease per se. As such, exploring ways of restructuring chronic disease management programs in a broader
framework of values, goals, and areas of meaning in life would likely support the process of living well for those with long-term conditions.

**Ideas for Future Research**

The conclusions and the limitations of the study point to research questions that have the potential to advance the current state of knowledge in four different but inter-related directions: a better understanding of the evolution, dynamic, and interconnected dimensions of living well experience; an integrated understanding of living well across subjective, cultural, and social domains of experience, the roles of sociocultural structures and processes, and the development of intervention, practice, and policy relevant data on living well experience. Questions include: How do living well experiences evolve and change over time? How do social structures and organizations that are an important aspect of chronically ill people’s lives shape living well experiences? How do gender, culture, and socioeconomic processes influence how people live a good life in the context of illness? How do illness-related organizations influence the living well process of persons living with illness? For persons who have a good life, what is the nature of their interactions with health care providers and health care services? How do traditional chronic disease management and meaning-based programs differ in being able to promote living well experiences for persons with illness?

The study described herein and others that use one-time retrospective interviews are unable to fully capture processes of change and to gain insight into the nuances of when and how living well processes begin and evolve in the lives of people living with chronic illness. Longitudinal and prospective research designs are necessary to capture more of the dynamic changes in areas such as shifts in understanding of what are meaningful over time and how alignment patterns might evolve during the course of one’s illness. Knowing, for example, if there are any patterns in how long it takes before people start to become successful at negotiating
daily life, aligning the disease-related tensions with what they value, and having meaningful experiences in the context of illness would be useful information for developing programs and interventions to support individuals as they move through their illness journeys. Undertaking longitudinal research that records situations, decisions, strategies, and intentions or purpose for these actions along with current understandings of what one values would capture some of the kinds of data necessary for advancing knowledge on the dynamic and interrelated aspects of living a good life over time. Daily recording methods frequently used in psychological research have been shown to be useful in looking at the dynamic and evolving processes.

Knowledge on living well could be further advanced through studies that aim to identify the interrelations between cultural and social structures/processes and subjective experience. One approach would be to conduct research that uses a multilayered analysis and multiple methods to study living well in community-based clusters of people and organizations. For example, you could study people with chronic illness who are living well, a few of their significant family and friends, members of their community or cultural group, and some of the major organizations (e.g., workplace, health care services, government facilities) within which they play out their daily lives. Although this kind of research would be complex and time consuming, it would create an understanding and interpretation of living well as expressed through multiple voices, perspectives, and truths and illuminate a more comprehensive and multi-dimensional view of living well.

To broaden understandings of the nature and processes involved in living well experiences beyond the scope of this research, we need to consider how sociocultural structures and processes are actively engaged in the process and development of these experiences. We need to explore the role of macro sociocultural aspects of life in supporting and facilitating these experiences, as well as their role in creating barriers, constraints, and limitations. Also, my research and most other studies on subjective experience of chronic illness as well as some
population based related research usually use White, female, and middle-class participants and thus, little is known about differences or similarities in experiences of having a good life between men and women who have illness, between those who have chronic illness in different cultures, and those who have vastly different financial resources. Given that living well is about having meaningful experiences that are shaped by sociocultural understandings and that different genders and cultures likely view disease-related tensions differently, comparative studies would extend our knowledge of how these dimensions shape the nature of living well experience. This research approach could also be used to further explore the role of resources in how people live well. These results would be beneficial for health care, community, and illness-related organizations in their efforts to support people living with illness and enable researchers to develop programs and interventions that take cultural and gender-related differences into account. It would also provide useful information on the role of financial resources that could be used as the basis for policy and program development decisions. A greater understanding of how these structures and processes shape living well experiences would enhance awareness of the areas of day-to-day life that could be targeted through advocacy initiatives to promote living well for individuals over the longer term.

Because illness-related organizations figure so prominently in the lives of many people with chronic illness either directly through their involvement or indirectly through their advocacy and fund raising efforts, it would extend our knowledge to have a better grasp of the role of these organizations in shaping the lives of those who are living well with illness. A community-based research study involving persons who are living well and interact with these organizations and individuals who choose not to get involved, as well as the organizations themselves would promote insight into the nature of the interactions that individuals have with these organizations and the role they may or may not play in facilitating the living well process.
In order to assist health care practitioners in being able to provide care that helps individuals to live well with illness, it would be useful to conduct research to explore the experiences of those who have a good life with illness to see if there are patterns in the ways they select, interact, negotiate, or avoid relationships with health care professional in day-to-day life and how these processes facilitate or hinder the individual’s ability to have meaningful experiences and negotiate the disease-related tensions in their lives. This could be done using a combination of participant observation, focus group, and interview methods and incorporate the subjective experiences of the chronically ill individuals as well as health care providers.

Mixed method research that incorporates both quantitative and qualitative methods could be used to compare traditional chronic disease management programs, meaning-based programs and interventions that encompass both components using health outcomes, health care utilization, and life satisfaction measures, and perceptions of living a good life. This would provide more information for determining the relative advantages or disadvantages in implementing these different kinds of interventions in health care and community settings and provide more data upon which to determine the importance and relevance of meaning based approaches for supporting persons with chronic illness in health care settings and interactions.

Summary

In conclusion, the women and men who participated in this study revealed important insights into the nature and development of living well with chronic illness from the perspective of their subjective experiences. Through their thoughts, actions, feelings, and values we were able to see some of the complex, dynamic, and inter-related dimensions inherent in their daily lives, and to appreciate the nature of their meaningful life experiences amidst the tension-centred worlds they inhabited. Their experiences have helped create knowledge on the phenomenon of chronic illness from the perspective of truly living well rather than one of coping or managing
disease and the interpretation of these experiences provides a conceptual understanding within which we can better understand some of the complexities inherent in living well experience and some of the competing ideas and contradictions found in existing bodies of knowledge. Overall, their accounts of living well serve to remind us of the importance of finding ways to help as many chronically ill people as possible to feel that they are “living well” by continuing to search for deeper understandings of how people live a good life in such a challenging context.
REFERENCES


Are You Living Well With Chronic Illness

and have a diagnosis of lupus, multiple sclerosis or scleroderma?

I am a doctoral student at the University of British Columbia undertaking a study of how people live well with chronic illness. I am interested in learning about the factors and processes in your life that have made an important difference in the way you live with illness.

If you are interested in participating in this important research study,

Please Call

Sue @ 604-822-0634
Appendix B: Summary of Demographic and Illness Questionnaire Data

In the group of thirty-one (N=31) research participants, there were almost an equal number of individuals with each of the three disease diagnoses – MS (n=11), lupus (n=11) and scleroderma (n=9) and within each of these three sub-groupings there was a range in the severity of diseases.

Table 1
The Participants' Medical Diagnosis

<table>
<thead>
<tr>
<th>Medical Diagnosis</th>
<th>Number of Participants (N=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple Sclerosis</td>
<td>11</td>
</tr>
<tr>
<td>Systematic lupus erythematosus</td>
<td>11</td>
</tr>
<tr>
<td>Scleroderma</td>
<td>9</td>
</tr>
</tbody>
</table>

Participants were diagnosed with their chronic disease anywhere from 5 to more than 30 years ago. Slightly more than 50% of the participants (n=16) had lived with their diagnoses for more than 10 years. Because many participants lived with symptoms from a few years to more than 20 years before having a diagnosis, the number of years since diagnosis underestimated the length of time that the participants had been living with illness prior to participating in the research.
Table 2

*Number of Years the Participants Lived with Chronic Disease since Diagnosis*

<table>
<thead>
<tr>
<th>Number of Years Since Diagnosis</th>
<th>Number of Participants (N=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>6-10</td>
<td>10</td>
</tr>
<tr>
<td>11-15</td>
<td>2</td>
</tr>
<tr>
<td>16-20</td>
<td>6</td>
</tr>
<tr>
<td>21-25</td>
<td>6</td>
</tr>
<tr>
<td>26-30</td>
<td>1</td>
</tr>
<tr>
<td>&gt;30</td>
<td>1</td>
</tr>
</tbody>
</table>

The participants were diverse in age. Individuals range in age between 27 and 73 with 81% of them (n=25) being between 41 and 70 years of age. However, there were 4 participants between 20 and 30 years of age and 2 women who were over 70.

Table 3

*Age of Participants*

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Number of Participants (N=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-30</td>
<td>4</td>
</tr>
<tr>
<td>31-40</td>
<td>2</td>
</tr>
<tr>
<td>41-50</td>
<td>7</td>
</tr>
<tr>
<td>51-60</td>
<td>10</td>
</tr>
<tr>
<td>61-70</td>
<td>6</td>
</tr>
<tr>
<td>&gt;70</td>
<td>2</td>
</tr>
</tbody>
</table>
The majority of the individuals were women (87%; $n=27$) even though I did not specify sex on the recruitment notices.

Table 4

*Sex of Participants*

<table>
<thead>
<tr>
<th>Sex</th>
<th>Number of Participants ($N=31$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>27</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
</tr>
</tbody>
</table>

The group was almost split between the 48% who are married or living common-law ($n=15$) and the 52% who lived on their own and considered themselves to be single, separated, divorced or widowed ($n=16$).

Table 5

*Participants’ Domestic Status*

<table>
<thead>
<tr>
<th>Domestic Status</th>
<th>Number of Participants ($N=31$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>9</td>
</tr>
<tr>
<td>Married</td>
<td>14</td>
</tr>
<tr>
<td>Common-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
</tr>
</tbody>
</table>
Over half of the participants had children (68%; \(n=21\)).

Table 6

*Participants' Parental Status*

<table>
<thead>
<tr>
<th>Children</th>
<th>Number of Participants ((N=31))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>21</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
</tr>
</tbody>
</table>

Almost all the individuals (94%; \(n=29\)) considered themselves to be White (Canadian, French, Irish, German or British decent) except for two participants who described themselves as Filipino and Vietnamese.

Table 7

*Participants' Race and Ethnicity*

<table>
<thead>
<tr>
<th>Race and Ethnicity</th>
<th>Number of Participants ((N=31))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>29</td>
</tr>
<tr>
<td>Filipino</td>
<td>1</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>1</td>
</tr>
</tbody>
</table>

Education ranged from elementary school to graduate degrees but overall, the participants of this study had a relatively high level of education with 77% having college diplomas or university degrees (\(n=24\)).
They revealed a broad range in total household income that extended from the poverty level of less than $10,000 per year to an upper income bracket of $91,000 to $100,000 suggesting that individuals in this study had access to different levels of financial resources. However, 71% of the participants ($n=22$) lived with lower to moderate incomes of less than $50,000 per year. The remaining 29% of the individuals ($n=9$) had incomes between $50,000 and $100,000. Women and men with lower household incomes tended to be single and/or living on government disability pensions. Participants who had middle to higher total household incomes tended to have private disability or retirement pensions from their past jobs, were still working, and/or were married to someone working full-time.
The majority of individuals gave up their jobs and careers due to their illnesses. 81% of the men and women (n=25) were not working and were either on private or governmental disability and/or retired at the time they participated in the study although many were actively engaged in volunteer work. Out of the remaining 19% (n=6), three worked part-time and three worked full-time jobs.
Table 10

*Participants’ Employment Status*

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Number of Participants (N=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time</td>
<td>3</td>
</tr>
<tr>
<td>Full-time (on nondisability leave)</td>
<td>1</td>
</tr>
<tr>
<td>Part-time</td>
<td>3</td>
</tr>
<tr>
<td>Retired</td>
<td>6</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
</tr>
<tr>
<td>Volunteer</td>
<td>11</td>
</tr>
</tbody>
</table>

*Note: Participants often selected more than one of these options and some did not select any.*
Appendix C: Consent Form

The Institute of Health Promotion Research (IHPR)
The University of British Columbia (UBC)
2206 East Mall
4th Floor, LPC Building
Vancouver, BC
V6T 1Z3

Consent Form

Study on Living Well with Chronic Illness

Principal Investigator/Faculty Advisor: Dr. Jim Frankish
Institute of Health Promotion Research
University of British Columbia
604-822-9205

Co-Investigator/Contact Person: Sue Mills, PhD Candidate
Individual Interdisciplinary Studies Graduate Program, UBC
604-822-0634

Purpose:

The purpose of this study is to advance knowledge of how some people live well with chronic illness, and to increase understanding of the factors, and processes that make a significant difference. You have been asked to participate in this study because you are living well with illness and/or have intimate knowledge of this experience, and may be able to provide some important insights. This research is for a doctoral thesis.

Study Procedures:

If you participate in this study you will be interviewed at your home or office, or at the University of British Columbia 2-3 times over a 4-month period for a maximum total of 4.5 hours. Each interview will last a maximum of 1 and ½ hours. At the first interview you will be asked to complete a brief questionnaire to collect demographic, and illness information. The interviews will be audio taped, and transcribed by a professional transcriber. You will receive a copy of the results of the study, if requested.

Risks:

The study is interested in your experience, or knowledge of living well with illness, and will be focusing on the factors that lead to a favourable or positive illness experience. If you are a participant with an illness, the interviews will explore this experience, and you may feel some discomfort or distress. In this situation, you have the option of withdrawing from the study, or rescheduling the interview for another time. A list of resources for support and counselling are available.
Confidentiality:

Every effort will be made to keep your identity confidential by giving you a pseudonym on the audiotape, and in all written material. Also, your name and consent form will be separated from the raw data, and will be stored in separate filing cabinet. However, this study has a small number of participants (15-25), and it is possible that even with the use of pseudonyms, some people might recognize you through written descriptions of your illness, and life.

The raw data (paper copies of transcripts, data on computer, floppy discs and/or CD-Roms) will be stored in secure facilities (e.g., locked filing cabinets). Access to computer files will be controlled through the use of a password. Audiotapes will be stored in secure facilities (e.g., locked filing cabinets).

The principal and co-investigators, and a professional transcriber will have access to the data. The transcriber will be informed in writing of his/her responsibility to ensure privacy, and confidentiality, and will not have access to any personal or identifying information on the audiotapes.

The data may be used again for additional analysis, and/or publications related to the same topic of living well with chronic illness. Any secondary use of data will adhere to the policies of the Behavioural Research Ethics Board at the University of British Columbia. Your identity will remain confidential, and all procedures to ensure confidentiality in this study will be followed in future analysis, and reporting of results.

Contact for Information about this study:

If you have any questions or desire further information with respect to this study, you may contact Dr. Jim Frankish (604-822-9205) or the doctoral student at (604-822-0634).

Contact for Information about the rights of research subjects:

If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Remuneration:

You will be eligible to receive an honorarium up to a maximum of $15 for interview related expenses such as parking, bus fares and/or childcare. You will be reimbursed upon submission of appropriate receipts.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.
Your signature indicates that you consent to participate in this study.

Your signature indicates that you consent to secondary use of the data on the same topic in the future in accordance with UBC research policies.

Your signature does not waive any of your legal rights.

Participant Signature  Date

Printed Name of Participant

Witness Signature  Date

Printed Name of Witness
Appendix D: Demographic and Illness Interview Questionnaire

The Institute of Health Promotion Research (IHPR)
The University of British Columbia (UBC)
2206 East Mall
4th Floor, LPC Building
Vancouver, BC
V6T 1Z3

Demographic and Illness Interview Questionnaire

Study on Living Well with Chronic Illness

Name: ________________________________________________________________

Phone Number: ________________________________________________________

Address: ______________________________________________________________

_____________________________________________________________________

Age: __________________________________________________________________

Sex: □ male   □ female

Domestic Status: □ single  □ married  □ common-law  □ Other _________

Do you have children? □ yes     □ no

How would you describe your ethnicity/race? _____________________________

Highest level of
Completed Education:
□ Elementary School
□ High School
□ College
□ University Degree
□ Graduate Degree
□ Other ______________________
Total Annual Household Income:

- Below $10,000
- Between $10,000 and $20,000
- Between $20,000 and $30,000
- Between $30,000 and $40,000
- Between $40,000 and $50,000
- Between $50,000 and $60,000
- Between $60,000 and $70,000
- Between $70,000 and $80,000
- Between $80,000 and $90,000
- Between $90,000 and $100,000
- More than $100,000

Employment: ________________________________

- Full-time  
- Part-time  
- Student  
- Volunteer

Medical Diagnosis: ________________________________

Date of Diagnosis: ________________________________

Number of years with illness: ________________________________

Major Symptoms: __________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

Other comments: __________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

Would like to receive a copy of the findings:  

- Yes  
- No
Appendix E: Interview Guide

- Can you tell me about the history of your illness?
- What was your life like at the time you developed symptoms? Got diagnosed?
- What were some of the changes that occurred in your life?
- What were the biggest challenges you faced?
- How would you describe your current life?
- What do you consider to be the most essential aspects of your life now?
- How does your way of living with illness compare with others in similar situations?
- What does it mean to live well?
- How have you been able to live well?
- What has played the most important role?
- How has this changed over time?
- What has influenced the way you live?
- What kinds of things have you done to create this experience?
- How does the way you lived with your illness in the early years compare to how you live now?
- How do you see your life five years?