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An Interpretive Inquiry Into
The Paradox Of
Living Well With A Life-Threatening Cancer Diagnosis

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ABSTRACT

This interpretive investigation, into the meaning of living well after a life-threatening cancer diagnosis, was undertaken in order to open up a dialogue between the voices of those who struggle to live well during illness and the theories and practices which have evolved around the topic of health in Western society. A hermeneutic-phenomenological approach has been brought to bear on the topic in an effort to understand what it means to experience well-being during illness. The ways in which people are positioned by the beliefs and attitudes, the language and metaphors, of the prevailing perspectives on health are given consideration. These approaches are then contrasted with the stories ill persons tell about their experiences of living well after a life-threatening cancer diagnosis. The stories of twelve women who feel they are living well after such a diagnosis, along with the stories of numerous first person accounts of illness, are presented through a series of paradoxes. Helps and hindrances to the process of living well, as suggested by these people, are also considered. The written account of the investigation ends with a look at the claims these stories make on our lives, especially those of us who work with people experiencing illness.
DEDICATION

This effort is dedicated to
Carol,
who never had the opportunity to
see the results of her participation.

The same stream of life that runs through my veins
night and day runs through the world and dances in
rhythmic measures.
   It is the same life that shoots in joy through the
dust of the earth in numberless blades of grass and
breaks into tumultuous waves of leaves and flowers.
   It is the same life that is rocked in the ocean-
cradle of birth and of death, in ebb and flow.
   I feel my limbs are made glorious by the touch
of this world of life. And my pride is from the life-throb
of ages dancing in my blood this moment.

Rabindranath Tagore,
    Gitanjali
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Maureen

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CHAPTER ONE

THE GROWTH OF A TOPIC

_The well need to be well for the world to continue, just as the sick need to be sick so the world can be regenerated. Both have a role to perform._

(Kat Duff, 1993, p. 83)

At the end of his life, the father of the germ theory of illness, Louis Pasteur, considered his efforts at delineating a single causal factor for disease to be misspent (Capra, 1982). His labors would have been more beneficial, he believed, if they had been directed toward understanding the remarkable human capacity for maintaining well-being, despite our being constantly surrounded by disease causing germs. Pasteur suggested that the mind plays an influential role in our physiological resistance to disease and our ability to heal, though the relationship between psyche and soma remained a mystery to him.

In this century, the powerful effects of human belief on physiology remain an enigma; but one which is gaining much popular attention. Modern "allopathic medicine" or "biomedicine", has employed scientific technique and technology in the drive to alleviate the suffering of illness and to extend life. This drive has often caused practitioners trained in biomedicine to overlook or even disparage the human ability to maintain well-being and our capacity for self-healing, relying on physiological procedures to dispel disease. Currently, growing numbers of people, especially those suffering from serious acute and chronic diseases, are searching for alternative and complementary therapies, some of which are physiologically based and others placing more emphasis on the mind. People are becoming increasingly motivated to take an active role in their own healing processes and health maintenance.
Although mainstream medicine has made significant progress since the time of Pasteur, a plethora of questions remain to be addressed. Why do some of us experience illness, when others subjected to similar circumstances remain well? Can we, during periods of serious illness, cultivate well-being or wellness? Does cultivating well-being during illness increase our ability to heal? Does healing necessarily mean curing or can we heal into dying? Are we perhaps wrong to see illness and wellness as opposite ends of a linear continuum - one end of the spectrum the desired good and the other avoided as evil? Is it possible to break out of the dualistic understanding of wellness versus illness, to find ourselves cultivating well-being during periods of illness and seeing the dis-ease we participate in during periods of relative health? Having become ill, what steps can be taken to help us access wellness during illness? Also... What is the relationship between physical and mental illnesses (as we tend to separate them)? Must physical illness be treated physiologically and mental diseases psychologically, or are these distinctions arbitrary, the result of reductionistic science and the disciplinary divisions used to simplify the complex whole of being human? Is it possible that all illness is a result of a systemic imbalance, and that intervening anywhere within the system can restore balance? - or within the larger systems which encompass the individual? These are some questions which positivist medical science has abandoned as unanswerable, but which continue to fertilize my growing interest in human health and well-being, an interest which planted the seeds of this inquiry.

As a teen I learned the discipline of Yoga to extend the strength and flexibility of my physical body and found it had a beneficial calming effect on my mind as well. Continuing to practice and teach the discipline of Yoga, and
developing a regular meditation practice, over the past twenty years has increased my belief that mind and body are less distinct than our Western approaches to the practice of medicine and psychotherapy seem to assume. I believe that our capacity to tap into our healing abilities may be limited by our attitudes and beliefs about health and well-being and by our reliance on scientific expertise. Choosing to birth my three children at home and opting for naturopathic remedies for the minor illnesses I have experienced, I have relied on my body's natural healing abilities as much as possible (though this is not to say that I do not consult biomedical doctors as well). Integrating my experiences in Yoga with my recent training and practice as a counsellor in the area of psychosocial oncology has increased my desire to understand more fully the relationship between mind, body and well-being.

Reading about recent advances in behavioral medicine and in mind-body approaches to illness, hearing about the abrupt physiological shifts which people who experience multiple personalities can undergo, and learning of the recent developments in the fields of psychoneuroimmunology and psychosocial oncology: are experiences which have also fueled my passion to understand our health, and to question strict biomedical approaches to sickness. The larger question which concerns me is: What is the relationship between our selves as conscious, embodied, social beings and our experiences of health (ease and dis-ease, well-being and being unwell, wellness and illness)? This study has narrowed the focus of that larger issue down to the smaller, more practical questions: Can we cultivate a sense of well-being during a period of serious illness? or; What does it mean to live well after a life-threatening diagnosis of cancer? and; How are people helped or hindered in this process?
I want to understand the meaning of the phenomenon of living well after a life-threatening cancer diagnosis - not from some theoretical or scholarly distance - but from the perspective of the everyday lived reality of people who find themselves in the middle of this experience. I want to understand how our society positions people who are ill: What words, images, and metaphors are available to us for taking up illness? What roles do our present theories and practices in healthcare envision? Perhaps what is most important about this study is the creation of a dialogue that will open a space of possibilities for those of us faced with our mortality through a life-threatening illness: the opening up of a conversation which will inform the work of those of us who labor to alleviate the suffering of persons experiencing illness. I sincerely believe we all have something to learn about living well through an increased awareness of the inevitability of suffering and death, an acceptance of the finite span of our physical existence. The question is not whether we will experience illness in our life time, it is: How can we live well during an experience of illness? - which in turn may shed light on how well we are living now.

Interpretive Stories

In these postmodern times, stories proliferate (Frank, 1995). As many begin to call into question the modernist metanarratives of rationality, linear progress, and absolute truths, the danger of being deafened by the multitude of voices arises. The sheer numbers of stories, which bombard us daily, can overwhelm. The postmodern context is one of myriad and often contradictory worldviews competing for our understanding and allegiance. As cultures cross and the world becomes a global village, we find ourselves in “a multistoried world” (Anderson, 1995, p. 5). Given this proliferation of perspectives, we are
necessarily faced with making choices, with choosing which stories will provide the truths by which we live. As our understanding of the part we play in the construction of our reality grows, so our ability to question the powerful metanarratives of our times increases. This dissertation is about the ongoing dilemmas and choices, which face a number of people who are trying to live well after receiving a life-threatening cancer diagnosis. The stories they tell interrupt the dominant social discourses of illness as a dualistic opposite to well-being; of illness as something to be denied, avoided, or ignored; of illness as an event to be covered over as quickly as possible. Their stories make a space for the experience of heightened well-being through an encounter with illness. Their stories also disrupt the medical science division of human health issues into neat categories of mental illness and physical disease. My goal has been to develop a context for those stories to highlight the ways in which living well with illness differs from the dominant perspectives on health in Western society in the late twentieth century.

As we interpret ourselves and the world around us, we tell stories to others and ourselves about how we live our lives. Stories such as Pasteur’s in the opening paragraph, those of the people who participated in this study, and the first person accounts of illness which inform this work are but a few of the many stories possible. My hope is to emphasize the stories not usually heard, the quiet voices speaking a new way of understanding illness into the world, a way which differs from our usual models for encountering illness, a way that has more in common with the most recent theories of illness as a valuable and transformative experience. As I was deep in the investigation of this topic, Jean Vanier’s Massey Lectures were aired on the CBC series Ideas, and later published in a slim collection called Becoming Human (1999). Through his
stories he expressed eloquently how our very human vulnerability, our experiences of illness, disability, aging, suffering and even our dying, rather than diminishing us, can be taken up in ways which promote growth towards wholeness - a wholeness of the individual which necessarily includes a sense of our undeniable communal interdependence.

*Our lives are a mystery of growth from weakness to weakness, from the weakness of the little baby to the weakness of the aged.*

*Throughout our lives, we are prone to fatigue, sickness, and accidents. Weakness is at the heart of each one of us. Weakness becomes a place of chaos and confusion if in our weakness we are not wanted; it becomes a place of peace and joy if we are accepted, listened to, appreciated, and loved.* (Jean Vanier, pp. 39-40, 1999)

By interrupting our common-sense, our taken-for-granted ways of viewing illness, with the stories of people who are living well with a cancer diagnosis, perhaps we can gain a new perspective on human vulnerability to disease and death. By viewing health from a place that lies beyond the restrictive notions of positivism, steeped as it is in scientific methods and quantifiable objectivity, perhaps we can find a perspective which integrates illness into the text of our lives as a valued storyline. A new perspective might allow those of us experiencing illness to feel affirmed rather than infirm, validated rather than an invalid, actively involved rather than passively patient. One man who has journeyed many years on the paths of illness framed his growing understanding this way:

*Life is a passage we get to book without any advance payment; we do, however, have to earn our way as we go.* It is not always
cheap. Clearly, not everyone finds the journey worth the ordeal. Some have a rougher trip than others; some learn better than others how to draw value and meaning from whatever occurs along the way. ...so long as the spark of life remains, the opportunity remains that one may discover the blessing that seems latent in the miracle. Even illness, dying and death, so often seen as our great curse, can be the instrument of this discovery. (Andrew Bard Schmookler, 1997, p. 232)

This inquiry brings forward the possibility that a life-threatening illness provides us with an opportunity to draw increased value and meaning from the blessing of life.

The remainder of this chapter briefly considers a variety of ways to conceptualize the notions of health, illness, disease, sickness, wellness, and well-being. A more detailed discussion of the theories and practices found in our current approaches to health are taken up in the third chapter of this dissertation, after the story of the investigative process is considered in chapter two. The fourth chapter introduces the voices and stories of people who have had a life-threatening diagnosis, through a series of paradoxes, and the final chapter reconsiders current perspectives on health in the light of the puzzles and contradictions being negotiated by people who want to live well with illness.

Western Interpretations of Health

As I read of the numerous interpretations of health that have been tendered over the years, I found the focus rarely strayed from a juxtapositioning of "good" or "positive" health against experiences of illness, sickness, disease,
or death. "Health", usually denoting the positive end of this spectrum, has been variously viewed in the West as: the simple absence of disease, pain, or disability; survival; the normal and expected condition of life; physiological efficiency; the ability to adapt; options for responding to life; complete physical, mental, and social well-being; the fulfillment of needs; growth; creative expression; and communion with the universal (Reed & Lang, 1987). It has been suggested that the difficulty we have in pinning down a definition of health stems from the fact that its meaning changes dependent "on one's view of the living organism and its relation to its environment" (Capra, 1982, p. 124). As our worldviews, our stories of what it means to live a human life, have changed over time and between cultures, so have our understandings of what it means to experience well-being and/or illness in our lives.

Reaching back to our earliest Western notions I found that health was defined as "the state or condition of being sound or whole" (Payne, 1983, p. 393). The words "healing" and "health" come to us from the Anglo-Saxon root hale meaning "making whole or holy" by "restoring integrity and balance" (Weil, 1988, p. 42). These notions of health would seem able to admit encounters with sickness within well-being, if those encounters did not upset one's sense of being whole. Historically, then, illness was not necessarily diametrically opposed to wellness. One could live well with a disease. This seemed to be very different from the prevailing views of illness in our society.

For the past century in Western society, modern allopathic medicine or biomedicine has dictated the authoritative notion of health. Despite its holistic origins, Western biomedicine seems to have narrowed the perspective on health to a purely mechanistic understanding of the human body. Health, in biomedicine, is defined as the simple absence of physical disease; the
subjective and social experiences of illness are ignored or relegated to other disciplines (Capra, 1982; Stachenko & Jenicek, 1990). Throughout this work I have continued to use the words "disease" and "illness" deliberately to distinguish between the medical and human experiences of sickness respectively. "Disease" denotes the biomedically-appropriated conception of the physiological signs and symptoms of a body that is showing signs of disrupted functioning. "Illness" signifies the human experience of that disrupted functioning. Psychiatrist and medical anthropologist Arthur Kleinman (1992) has suggested that disease is the concern of biomedical experts, whereas illness is our encounter with disease - the lessons, joys and hopes, the suffering, fears and despair.

Over 50 years ago the World Health Organization (WHO) realized the restrictive nature of the biomedical conception of health as simply "the absence of disease". They offered the following radical departure from the biomedical understanding: "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (cited in Dunn, 1961). This definition continues to be problematic for me as it retains the dichotomy between good and bad health, between wellness and illness. Various other attempts have been made over the years to expand beyond the biomedical notion of health. For example, Dunn (1961) defined health as an on-going process which he called high-level wellness: "an integrated method of functioning which is oriented towards maximizing the potential of which the individual is capable" (p. 4-5). In 1968, Rene Dubos offered the following definition of health: "a modus vivendi enabling imperfect men [sic] to achieve a rewarding and not too painful existence while they cope with an imperfect world"
(cited in Antonovsky, 1980, p. 53). Again, these definitions do little to relax the dichotomy between illness and wellness.

Ivan Illich (1976) was one of the first to question the dichotomous model of health. He suggested that health is the ability to adapt to, and make meaning of, all of human life - including birth, illness, aging, suffering, and death. He criticized biomedicine for medicalizing such natural aspects of living and disrupting our ability to live well throughout our lives, even during periods of physical duress. Also in reaction to the biomedical model, George Engle (1977) prescribed a shift to what he called the biopsychosocial model of health for use in clinical practice. This model views the individual as a whole system made up of various interacting subsystems embedded in larger family, community, social, and environmental systems. Aaron Antonovsky (1980; 1987), in direct protest of the pathogenic focus of biomedicine, developed what he called a salutogenic model of health encompassing both ease and disease. These models have shored up my belief that living well with illness is a probable and useful human ability.

As recently as 1986 the WHO perceived the need to expand their notion of health even further redefining it as:

...the extent to which an individual or group is able, on the one hand, to realize aspirations and satisfy needs; and on the other hand, to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the object of living; it is a positive concept emphasizing social and personal resources, as well as physical capacities (in Robertson & Minkler, 1994, p. 298).
While this redefinition incorporates a systemic perspective, encompassing the person in their environment (Capra, 1989), it continues to retain a sense of health as a "positive" resource which might be mined, or squandered, or lost resulting in a "negative" experience of illness.

Only in the "holistic" and "wellness" models have I found an integration of well-being and illness. These notions of health take an openly systemic perspective, focusing on the whole person and person-environment interaction (Allen & Hall, 1988; Capra, 1982; Reed & Lang, 1987; Street; 1994) and have, I believe, given rise to increasingly creative attempts to re-story health experiences. The dichotomous model of wellness versus illness is being reconsidered in many of these models. For example, Margaret Newman (1986) developed a notion of health as expanding consciousness, in which health and illness are viewed as aspects of "a single process...moving through varying degrees of organization and disorganization, but all as one unitary process" (p. 4). These more complex approaches to health seem to me to provide an antidote to the simplistic patho-physiological focus of the prevailing biomedical model, opening up new directions for investigating how one might live well with illness, even though they continue to have some problems of their own.

Biomedicine has yet to take these new models into account. In a 1986 publication of the International Dictionary of Medicine and Biology the biomedical conceptualization of health continued to be limited to: "a state of well-being of an organism, or part of one, characterized by normal function and unattended by disease" (cited in Freund & McGuire, 1991, p. 6). This limited dichotomous view indicates the continued resistance of biomedicine to change. Despite the fact that many people are clamoring for an approach to
health which focuses more on dignity and caring than on curing and that allows them to participate more actively in their own healing, the predominant model for health remains focused on treating the physical aspects of disease (Garrett, 1994; Weil, 1995). I believe that much of what it means to be human is difficult to objectify and quantify and thereby is ignored in our present scientifically based model of medical "care".

Towards an Integrative Interpretation of Health

The terms "wellness", "living well", and "well-being" are used interchangeably in my writing to signify a movement towards an ideal or optimal way of being human. I consider illness and wellness (or well-being) to be interpenetrating, dynamic experiences which are related to the social, emotional, mental, physical and spiritual beingness of people. I assume that these experiences overlap in such a way that wellness/well-being can be experienced during encounters with illness and also that, while we might be physically "well", we can at the same time be mentally, emotionally or relationally unwell. I have avoided using the phrase "health during illness" as I understand the word "health" to be an over-arching concept which integrates illness and wellness, as found in the question: "How is your health?"

As noted earlier the Anglo-Saxon root of the English words "health" and "healing" also gives us the words "whole", "hale" and "holy". It seems obvious to include wholeness and being hale, with their relative connotations of completion and vigor or heartiness, in our understanding of health, but I have puzzled over how to integrate holiness. I have concluded that spirituality is an important and often neglected part of what makes up a whole human being - the physical, mental, emotional, social and spiritual aspects mentioned above.
(Spirituality is proffered here in its broadest application as anything, which moves us towards a deeper connection with what it means to become more fully human. It should also be noted that the concept of spirituality, within the discipline of counselling psychology, is by no means a clear one.) As Andrew Weil (1988) notes, spiritual and healing practices have never been far apart. The word religion means, "to bind again", as if our spiritual growth and practices could bind the broken places of our lives, be they bodily, relational or situational.

Health, from a perspective informed by the idea of wholeness and holiness, can conceivably be viewed as a balanced completeness, which can encompass interpenetrating periods of greater and lesser well-being (Dossey, 1984; Kabat-Zinn, 1990; Weil, 1988). Broadening our perspective on health to include illness, we can see illness experiences, our own or those of others, as a natural consequence of living (Schmookler, 1997), an indication of human finitude (Weil, 1988), an experience to be learned from (Moch, 1994), or even a spiritual opportunity, a transformational experience, which helps us to reconnect with what it means to be truly human (Duff, 1993; Frank, 1991; Vanier, 1999). Interestingly, native shamans in many cultures, those who were called upon to heal the "bodies, souls and situations" (Weil, 1988, p. 47) of their communities, were often seriously wounded individuals who had experienced dramatic healing in their own lives (Achterberg, 1985).

Coming to the Question

My own questioning of our societal penchant for distancing illness from well-being comes as a consequence of a long-standing interest in how the mind and body connect. I came to the doctoral program in Educational
Psychology knowing I wanted to both deepen my understanding of this interaction and to consider the body-mind connection in the realm of health and well being. I have wondered often and long how healing within one aspect of the system, be it physical, psychological, or spiritual, might be influenced by healing occurrences taking place in another aspect. For example: Does what we think, feel, and believe about our illness experience have an effect on our ability to heal?; Can the healing of emotional wounds have an effect on our physical being? At first glance, most of us would agree that our physical health effects our mental stability - that proper rest, exercise and good dietary habits improve our mental as well as our physical functioning. Many of us would also agree that our expectations of an illness, our beliefs about both the nature of illness and our ability to resist it, would influence our experience of it. But, because of our continued reliance on the biomedical model, the fact that our understandings of these processes are subjective and intuitive (rather than rational, logical or, most importantly - measurable) renders them of little importance in the high tech world of modern bio-scientific medicine.

Working as a psychosocial oncologist at a provincial Cancer Centre, the question evolved into the need to understand what it might mean for a person to live well after receiving a life-threatening cancer diagnosis. As a counsellor, I became aware that many were searching for a way to live well during an encounter with illness. I found myself wanting to provide people who were living with cancer, and who were dealing with the often painful biomedical treatment regimes, with some possible suggestions for enhancing their well being. A life-threatening diagnosis disrupts the normal course of life events initiating a journey on pathways most of us would not otherwise tread, at least not with the same intensity. People I was working with struggled to understand
how their mind and body might influence their disease and their illness experience, and many suffered under the weight of large amounts of guilt for having brought the illness on and/or being unable to effect a cure. As I developed and facilitated groups for people living with cancer who were interested in learning more about the mind-body connection through Yoga and meditation, I met and read about some who seemed to flourish as a consequence of their illness experience, regardless of whether they continued to live with it, or died from it. Some people seemed to have found an alternative to our usual aggressive or avoidant pathways for negotiating illness and death. In the extremity of illness and under the threat of death they had found a way to live life more openly, more wonderingly and more thankfully than most of us, even those of us without a diagnosis. I wanted to understand what it might mean to travel the pathways of an illness experience in ways that promoted such well-being.

Working as I was with people who were experiencing considerable distress after receiving a cancer diagnosis, I wanted to know what more could be done beyond the goals of "adjustment" and "accommodation". I wanted to hear first hand what people who were seriously ill and dealing with it well had to say about their own beliefs and understandings. This dissertation is the result of that effort. I wondered how people could live well with a life-threatening diagnosis in a society so obsessed by health and youth - what kinds of resistance did they perform, outwardly or inwardly, to carry on with their lives? Are there things which help or hinder them from feeling a sense of well-being? I wondered if people who had learned how to live exceptionally well with a life-threatening illness, had found out something important about life, something all of us could learn from.
Was it possible, as Ivan Illich (1976) proposed, that the medical separation of body, mind, and spirit - and the consequent desire to avoid and deny pain, sickness and death - anaesthetizes our experience of life? The cost of denying our vulnerability, Illich suggests, is "giving up intense aliveness" (1976, p. 152). Have we accepted the pretense that we can live forever young and healthy in exchange for a fully engaged form of living? Could we find in our experiences of illness a renewed understanding of ourselves, and our place in the world? Could we revere the opportunity illness provides - "the opportunity to discover the strengths and resources required to meet the crisis it presents" (Frank, 1997, p. 132)? Could we raise the question of what it might mean to be "successfully ill" (Brookes, 1994, p 227) in a way which did not instill guilt or blame? Could the presence and absence of disease be "complementary cycles of the world" as some are beginning to suggest (Duff, 1993 - see the opening quote)?

My questioning also arose from my desire to understand what it was that some people were doing and thinking to enhance their own well-being after a life-threatening diagnosis, and to see if that understanding could open up new possibilities in how to proceed as counsellors working with people in similar circumstances. I believe that by understanding what it means to live well after a serious cancer diagnosis, by opening up a conversation about what promotes or enables the experience and what detracts from or disables it, we may be in a position to enhance the work counsellors and other health professionals engage in.

Our ability to counsel depends on our sense of what it means to live well, and in counselling those encountering illness we need to understand how illness might provide a route to living more aware, intense and alive. By
investigating how some people living with illness retain, regain, or attain for the first time a sense of well-being, of being fully engaged in life, I believed we could learn new ways of negotiating the pathways of illness. Our ability to counsel people experiencing illness with care and tact should be enhanced by a deeper understanding of what living well with illness means. I wondered what effect it might have on us if we viewed illness and even death as integral human experiences? How differently might we approach people who are going through these experiences, if we, as individuals and collectively, all connected closely with human frailty and vulnerability? Could our tendency to avoid and denigrate death and illness, and consequently those who are ill or dying, be exchanged by embracing these experiences (even vicariously) as an opportunity to learn and grow, as reminders of what is truly important in our living?

Health, obviously, is not a simple given - it is a large, unwieldy, and ongoing conversation in which we all participate. The remainder of this dissertation considers in more depth how modern medical science arrived at its particular vision of health, how it became the authoritative discourse in our society, and the current difficulties associated with a biomedical model. Competing alternatives to the biomedical model are also discussed in more detail, along with their respective attendant possibilities and problems. The practice of psychosocial oncology is also re-viewed for the story it presents of "the psychosocial needs of cancer patients", as are anthropological and sociological accounts of medicine. These stories are detailed in order to highlight the ways in which people who are experiencing illness are positioned by them. Our societal understandings of what it means to be ill are later re-considered in light of the paradoxical understandings of people who are
currently experiencing, or have recently written about, their experiences of living with a life-threatening cancer diagnosis. But first, the following chapter will present how I have engaged in the topic of what it means to live well during illness.

My goal is to consider the possibilities that might serve to broaden the on-going conversation about health. I have not set out expecting to find a "recipe" (Shin, 1986) or some "exemplary way to be ill" that others can follow (Frank, 1991, p. 5), but only to trace the markings of some alternative pathways to the broad and well-trodden paths of illness set out in our society. Like Arthur Frank: "I hope ill persons will talk back to what I have written. Talking back is how we find our own experiences in a story someone else has written" (Frank, 1991, p. 4). This dissertation is my interpretation of what it might mean to live well during an illness experience, an interpretation informed by my own journey through the stories and writings of others. In some ways our whole experience of life is storied.

We follow the paths laid out for us by our stories, each present moment being influenced by and influencing the stories we tell of our past and the stories with which we construct our futures. These stories evolve and change as we do, and occasionally our stories break down. When we find the pathways of our usual stories obstructed, we may simply follow the most well-worn pathway in the near vicinity. What this dissertation does is to follow the most common approaches to illness, those worn deeply into the societal psyche, as well as those that as yet have left only faint traces. By following the ways in which we might experience well-being during illness, by understanding the ways in which illness might contribute to our experience of living well, I will mark the trails of some alternative routes more clearly. The complex nature of
this topic and the intricacies of interpretive work wreak havoc with all attempts to present this material in linear, sequential format. The paths these stories take cross and re-cross, linking various aspects in numerous assorted ways. I hope that readers will feel free to consider what I have written in the light of their own experiences, making room for their own stories - for the directions well-being and healing might take in their own lives. This is just the beginning of a new conversation about well-being during illness.

Through thinking, talking, and writing we can begin, as individuals and as a society, to accept illness fully. Only then can we learn that it is nothing special. Being ill is just another way of living, but by the time we have lived through illness we are living differently. (Frank, 1991, p. 3)
CHAPTER TWO
ENGAGING WITH THE TOPIC

*Do not hide your emotions when you write, say what you feel; a scientist is not, never was, neutral.*

(Paulo Friere as quoted by A. Araujo Friere, 1997)

This chapter describes the investigative process undertaken to deepen my understanding of what it means to live well after a life-threatening diagnosis. It traces the decisions I made as the study progressed, and the reasons for making them. The procedures used to engage people in conversations about their experience with the phenomenon, the first person stories of illness which also influenced this interpretation, and the circular process of reflective writing, conversing, reading and interpreting are delineated here.

Settling on an Approach

As I began to consider the topic I was interested in pursuing, I proposed to use a hermeneutic-phenomenological approach to the work. I chose an interpretivist investigative process because my goal has been to engage deeply with the intricacies of living well with illness and I felt that the only way to do this was to immerse myself as thoroughly as possible in the topic. My desire was to enter into the complexity and the idiosyncrasies involved in the human experience of wellness during illness, to reveal the topic in all its richness and original difficulty by bringing to bear all that served to illuminate it (Gadamer, 1994). At a philosophical level, I agree with Heidegger (1962), and those who came after him, especially Maurice Merleau Ponty (1962, 1964) and Hans-Georg Gadamer (1994), that we always, already, find ourselves in the
world as embodied, interpreting beings, and that our interpretations are necessarily informed by our cultural and experiential history. We live in reciprocity with our surroundings, never free from influencing them and always under their influence. I acknowledge that "language and history are both the condition and the limit of understanding" (Schwandt, 1994, p. 120). As Gadamer points out, our understandings are a fusion of the various horizons of meaning of which we become aware, horizons that include the traditional and historical understandings, the taken-for-granted meanings, established within our culture, as well as lived experiences of the phenomenon. Both Heidegger and Gadamer contend that language and understanding are inseparable. As Gadamer says: "Language is the universal medium in which understanding occurs" (Gadamer, 1994, p. 389). We are not only embodied but also enlanguaged.

Thus, if my goal was to gain a deeper understanding of the topic that would be grounded in my philosophical beliefs, then my method ought to serve that goal: by remaining open to the meanings people ascribe to their embodied experience of the topic, as well as to the ways in which the topic works itself out in the world through the words we use. After exploring numerous qualitative approaches to research, I found that particularly phenomenology, with its emphasis on the lived experience of the phenomenon, coupled with hermeneutics, which goes beyond pure description by bringing historical, linguistic, and lived meaning to bear on the understanding of the phenomenon, seemed to fit with my research goals.

My desire to proceed in this manner also stemmed from my understanding that positivist, quantitative, or "natural" science approaches to research, which rely on reducing the world to quantifiable objects, would not
help me to understand the complex meanings involved in the subjective human experience of living well after a life-threatening diagnosis. The multidimensionality of human health experiences raised concerns for me that quantitative methods, in an attempt to predict, control, and find causal explanations, may have missed important aspects and facets of what it means to live well during illness. The use of computer coded checklists to quantify people's "quality of life" and "response to intervention", in recent research in this area, has not fostered an in-depth understanding of how a person diagnosed with cancer can carry on and live well through the often arduous treatments, the fears and concerns, that must arise with the threat of their own mortality. As Plager argues: "Human beings can be reduced to objects and studied as in the natural science mode, but something essential will elude the investigator" (1994, p. 76). A scientific interpretation "...is quite different from the immediate experiencing of that 'reality' in the everyday world" (Toombs, 1987, p. 223). My goal in this inquiry has been to produce an interpretive text, which helps us to more fully understand the nature and the meaning of the experience of well being after a life-threatening diagnosis of cancer.

I have used the hyphenated label "hermeneutic-phenomenology" to describe my approach because: while I wanted to look phenomenologically at people's lived experiences in an attempt to understand the phenomenon of living well after a diagnosis of cancer; I also wanted to pay attention hermeneutically to past and present sources of understanding about the topic (Gadamer, 1994). I wanted license to consider how medical and psychological language might distort or silence aspects of the experience as individuals describe it, how our usual approaches to illness might position us in ways which would render living well with illness problematic. It is a concern of
hermeneutics "... to bring to consciousness those possibilities of being that the scientific-technological project, by reason of its methodological abstraction from lived experience, necessarily conceals and closes off" (Madison, 1988, p. 45). This is what I proposed to do.

I have also made an effort to understand how our current and traditional conceptions of wellness and illness are legitimated and perpetuated within the language, the words and images, we commonly use. In my writing, I have interrupted the various theoretical and practical approaches to illness with my own voice, highlighting what we take-for-granted about the topic, questioning and wondering about alternatives - and thereby opening up new possibilities of meaning (Gadamer, 1994). I have listened carefully to the words those living well with illness use to story their experiences, in order to consider new possibilities for encountering illness. The double label then, is used to signify how I have combined hermeneutic interpretive license with a phenomenological approach to understanding the meaning of the human experience of living well after a life-threatening diagnosis.

Approaching the Phenomenon

Because the appropriate methodology for interpreting a phenomenon must be allowed to unfold as the question engages the phenomenon itself (Gadamer, 1994), the steps taken, and the processes of decision making, have been detailed in an on-going field journal and are condensed in this chapter. Throughout the investigation I have remained mindful of retaining an ethic of well-being, both toward all those who contributed time and effort to the project and toward myself. Because of this ethic, some questions remain unanswered. For example, the participants are less diverse than one might
choose for the optimal enhancement of the stories (as suggested by van Manen, 1997). But, in keeping with my wellness ethic, I was unwilling to put pressure on any individual to become involved, beyond a simple invitation and the offering of my introductory letter. It is my hope that the respectful dialogue created by this study will stimulate further engagement and more answers over time.

Hermeneutic-phenomenology strives to ground the topic under consideration within the lived experience of it. This type of investigation begins in the everyday practical activities of those experiencing the phenomenon under investigation (Plager, 1994). In this study, discovering the daily practicalities of living well after a diagnosis entailed finding people who felt they were engaged in this process and who were willing to share their experiences with me. My conversations with these people have become the guiding text which has influenced my interpretation. I have struggled "to bring to light an underlying coherence or sense" (Taylor, 1985, p.33) to the reams of transcripts from these multiple conversations. And I have combined this material with a number of first-person written accounts of illness, as well as my own understandings gleaned from working closely, in group and retreat settings, with people who are experiencing cancer in their lives. Over the past four years, I have also read in the areas of health, the mind-body connection, psychosocial oncology, nursing, medical sociology and anthropology, phenomenology, hermeneutics, and embodiment; these readings also influence the interpretation offered here.

Self-reflexivity

Hermeneutic-phenomenological research demands a high degree of reflection to "grasp the essential meaning" of the phenomenon (van Manen,
1990, p. 77). By beginning with my own experiences of well-being and illness, I have tried to examine what I initially assumed or took-for-granted about the topic and I have watched to see how the investigative process has brought to light and/or changed those assumptions and prejudices (Wilkinson, 1988). Because my own biases, expectations, and deliberations necessarily inform my understandings and interpretations, this was not intended to be a Husserlian "bracketing" (Osborne, 1994). I have not attempted to escape my own position, but to make it a part of the interpretation offered here. In agreement with Heidegger and Gadamer, I feel our biases, our pre-judgments, represent the necessary fore-understanding upon which our understanding depends. The difficulty inherent in Husserl's phenomenological reduction is that we can never fully disengage from our own historical, cultural, and linguistic involvement in the world. Thus, I have engaged in a process of uncovering my own presuppositions throughout the inquiry process, presenting my orientation to the topic, how it has changed over time, and how meaning has been co-created between myself and the participants (Osborne, 1990).

My method questions from the outset the monologic, third person voice of authority that is so prevalent in the on-going science project of our society (Bordo, 1993a, 1993b; Haraway, 1988). I have constantly located myself within the discourse; aware that I am not a valueless, disembodied voice from nowhere. I have used a first-person stance to present my own process and also my own questioning and wondering. I have used "we" and "our" to denote my inclusion in various intersubjective kinships (Jardine, 1994). Examples of this include my membership and participation in the following various families: the families of caregivers in the field of health, psychosocial oncologists, counsellors, society in general, or the human family. I have been actively
involved in the exploration of the topic through a dialectical relation between myself, and the topic (Paget, 1993).

I have emphasized the reflexive voices of those I spoke with, and my own voice, in order to interrupt the cool and distant voices of the medical and psychosocial "experts". Perhaps the jarring feeling of encountering what an "I" does or thinks, within a scholarly paper, can disrupt our complacent acceptance of the dominant, scientific discourse in health and healing. By bringing in my own self-reflexive voice, the difficulties I have encountered, the questions raised and answers attempted by both those I engaged in conversation and those whose work I have pondered, I want to problematize the authoritative science-based view of illness and well-being in modern Western biomedical culture. This study is grounded in the lifeworld struggles of people who resist the authority of biomedical expertise in their own small ways as they attempt to live well with a serious illness. My hope is to inform and transform biomedically based practices with a wisdom gleaned from the attitudes, beliefs, and practices of people who have found a pathway to wellness during illness.

Self-reflexive interpretive writing, as I have attempted it, is not a seamless or simple process. Occasionally, I may seem to be "all over the map" as I take up the many paths of investigation this topic offers. It is important to remember that I too stand within a certain context which limits my capacity to see and write about all the possibilities, thus readers should be aware that there are more possibilities to living well after a life-threatening diagnosis than presented in this interpretation.
Gathering the Text

The primary sources of information, the texts that have been most influential in this interpretation, have come from multiple in-depth conversations with twelve women who feel they are living well after a life-threatening diagnosis, and from numerous autobiographical accounts of the experience of illness. Journals, both fieldnotes and learning reflections, have been kept and periods of writing have interspersed the two years of my involvement with this study.

Conversations

I have purposely used the word "conversation" to describe my interaction with those who participated in this study, to imply a process less regimented than that which is commonly expected in an "interview". I was not interested in doing a survey, wherein the same questions would be asked of each participant in a one-time-only approach. My awareness of the co-constructed, give and take, nature of all dialogue precluded such an approach, as did my desire to keep the dialogues as open as possible. I wanted to allow the participants' understandings to come to light without being overly influenced by the direction of my questioning (Kvale, 1996; Mischler, 1986). My goal was to develop a conversation between myself, and the participants, a dialogue in which my research interest in the topic and the participants' experience of it could be explored. In the spring of 1998 I set out to find an indefinite number of people with whom I might enter into this conversational relationship. I had spent the year prior to that immersing myself in the literature of wellness, embodiment, and interpretive research documenting my own understandings, as mentioned, in a journal I kept throughout the research endeavor. I felt as ready as I ever would be to address the relational aspect of the project, though I
noted in my journal a continued sense of trepidation. I wondered whether I was worthy of taking up peoples' time, especially people living under the extreme circumstances of a life-threatening cancer diagnosis (Fieldnotes, March, 1998).

I began looking for participants among the people experiencing cancer with whom I had been involved as a group facilitator of meditation classes. As each of three seven week groups, offered in the spring and summer of 1998, ended I made available to the group members a letter introducing my research project (see Appendix A). I described my goals for the study and asked them to contact me if they had something to say on the topic of living well after a life-threatening diagnosis. Five participants came to me in this way. Five others came through word of mouth, having heard of my investigation from a mutual friend or from another participant. And the last two I initiated contact with after hearing their stories in other contexts, as I felt their stories would add significantly to an understanding of the topic. Because all those who agreed to participate were women, I also directly invited five men to converse with me. But, in keeping with my ethic of care, I was reluctant to put much pressure on people I knew were already stretched by the gravity of their situation. Consequently, I never managed to convince any of these men to engage in the project, although I did have some informal conversations with several of them. Women, it seems, are more willing to engage in a taped conversation about their illness experiences. Perhaps the acceptance on the part of women was influenced by the fact that they were being asked by another woman. It is also possible that the men did not see the value in the effort, felt they had little to contribute, or were reluctant to share the intimate details of their illness experiences - a repetition of their reluctance, as compared to women, to enter into the intimacy of a counselling relationship. Or, perhaps the men I
approached were simply too busy coping with the practicalities of a life interrupted by illness.

As it turned out, the twelve people who chose to participate in this project are quite uniformly female, middle class, and white. (The women’s stories have been summarized in individual compositions found in Appendix B, with a brief summary of their particulars presented here.) They are all over 30 years old, ranging in age from 30 to 66 years. All are currently married, except the eldest participant, who divorced in her thirties and has since remained single, and the youngest. And all but one of the women have between one and three offspring, many of whom have grown to adulthood and left the family home. These women have each been given a diagnosis of "malignant" cancer: half had a breast tumor, three had gynecological cancers, one had growths in her bowel, and another had tumors throughout her lymph system. Cancer has metastasized, spread to secondary sites, in more than half of these women; although in three of the women diagnosed with metastases more recent tests have shown no sign of cancer in their bodies at this time. Three others have returned to active treatment for a further spread of cancer. One woman died in November 1998.

The women either contacted me by phone, or they mailed the form I had given them back to me and I subsequently arranged a meeting over the phone. As each participant made herself available, I engaged with her in an initial 1-2 hour taped conversation. Prior to starting the tape, each woman completed a consent form (see Appendix C) and chose a pseudonym. I began each conversation by asking them to simply tell me about their illness experience and what living well has meant to them since their diagnosis. Especially in the first round of conversations, I openly discussed my own interest in the topic
with the hope of developing a dialogue in which the other person could relax and feel comfortable conversing about their own experiences (following Bergum, 1989; Colaizzi, 1978; Osborne, 1990). I tried to remain mindful throughout the various conversations to encourage people to discuss their personal views; for example, if they spoke in generalities I would ask if they agreed with that perspective, wondering aloud what their own take was on the issue. I was aware that I could easily influence what they said through expressions of disagreement, so I used my counselling skills to listen in as unbiased a manner as possible, prompting them with minimal encouragers, such as head nodding and verbal agreement to show that I was following them.

In all conversations the focus was on the illness experience, the meaning of living well after a life-threatening diagnosis, how well-being is experienced, and what increases or inhibits a sense of wellness for the participant. I carried a prompt sheet to the initial interactions, outlining a number of open-ended questions, such as: How have others contributed to or inhibited your well-being? and; What is your bodily experience of well-being? These questions were available to keep the conversation "oriented to the substance of the thing being questioned" (van Manen, 1990, p. 98), but I found the discussions rarely needed such formal prompting. As each initial conversation seemed to be winding down, I took a moment to look over this sheet and asked about any items that I felt had not been spontaneously addressed. I also asked if they would be willing to have another conversation with me later; all agreed they would. In the end, I taped two conversations with all but two participants who I only managed to meet with formally once. I also had many more informal conversations in person, by phone, or through e-mail
with several of the women. All taped conversations with these twelve women took place between May 1998 and June 1999; informal conversations are ongoing.

Stories of Living with Illness

Throughout the two years of my involvement with this study, I have also sought out and read numerous stories written by people living with serious illnesses. Long before the investigation was formulated, I had been fascinated by Norman Cousin's (1981) account of resisting the medical prognosis of his illness and treating himself with massive doses of vitamin C and humour. As I struggled to become a good counsellor in my practicum placement at the Tom Baker Cancer Centre, I became interested in reading accounts of people's encounters with cancer. My supervisor loaned me Audre Lorde's (1980) Cancer Journals and Cancer in Two Voices, by Sandra Butler and Barbara Rosenblum (1991). The cancer Centre library provided me with Arthur Frank's At the Will of the Body (1991) and The Wounded Storyteller (1995). And I came across a critical essay by Judith Hooper (1995) titled Beauty Tips for the Dead. Reading stories such as these helped me to understand the difficulties and joys, the questions asked and answers found by those who were compelled to write about what it means to live with cancer. These stories helped me to recognize and empathize with similar struggles among those I listened to and, occasionally, stories such as these allowed me to help the people I counselled at the Cancer Centre to find new possibilities for themselves in the midst of illness.

As I began to immerse myself in the topic, I found the literature critic Anatole Broyard's (1992) amazing essays on his encounter with prostate cancer in a slim little volume he had entitled Intoxicated By My Illness. I too
became intoxicated by the metaphors and language Broyard used as he considered the problems and possibilities which illness opened up in his life. I read and shed many tears over, and continue to read and cry over, Christina Middlebrook’s (1996) Seeing the Crab. Her subtitle, A Memoir of Dying Before I Do, gives an inkling of the task she set for herself, attempting to write very matter-of-factly about the despairs, fears, angers, grief, intimacies, and hopes of what it has meant to live with her approaching death.

Middlebrook’s book pointed the way to Nan Shin’s (1986) Diary of a Zen Nun and Grace and Grit by Kenneth Wilber and Treya Killam Wilber (1991). The former is another matter-of-fact account of living with dying written by an American Zen nun while she was undergoing chemotherapy for ovarian cancer. She had wanted to title her book Everyday Living (but was thwarted by a worried publisher), to indicate her sense that illness, however difficult, was simply more grist for the mill of everyday living. And dying, as well, was just another aspect of life. The latter book is a chronicle of Treya Killam Wilber’s journey after a diagnosis of aggressive stage four breast cancer. The book is written by her partner, Kenneth Wilber, using material from Treya’s journals and it traces their joint struggles with her illness. Because Kenneth Wilber has a reputation as something of a New Age guru (a title he rejects), the possibility that Treya was “creating” her illness came up frequently for them. They dealt with this attitude on the part of others by pointing out the violence it does to the person who is ill and suggesting that the only thing people have control over is what to do with the experiences life presents them with. Treya’s journey was a remarkable engagement with conventional and complementary therapies as she developed an attitude she came to call “passionate equanimity”, which she
describes as a process of living her life intentionally and hopefully while being open to her death.

Other first person accounts I read include: Evan Handler's (1996) story of living with leukemia and undergoing two bone marrow transplants, in *Time on Fire*; Elizabeth Simpson's (1997) experience of lung cancer which she calls *The Perfection of Hope*; and *My God, I Thought You'd Died* by Claude Dosdall (1998), the founder of the Hope Support Program for people living with cancer in Vancouver. Marc Ian Barasch (1993) writes of his own encounter with thyroid cancer, as well as tracing numerous other survivors' experiences, in *The Healing Path*. And Paul Pearsall (1991) is a medical doctor who wrote a book called *Making Miracles* after he survived massive abdominal tumors. These last two were both books I had read years earlier, which I returned to for this study.

Terry Tempest Williams (1991) wrote a moving story of losing her mother to breast cancer and her grandmother to ovarian cancer, which is entwined with the story of the loss of bird habitat due to the flooding of Great Salt Lake. Terry is an ornithologist who herself has had breast cancer and her book, *Refuge: An Unnatural History of Time and Place*, is a compelling look at changing our attitudes from resisting to accepting illness and dying as a natural and inevitable aspects of life. Another story of the possibilities arising from illness, one of the few first person accounts I used which was not based on a cancer experience, is Kat Duff's (1993) *The Alchemy of Illness*. Finding this book very late in the investigation gave me pause. So many of the ideas Kat brings forth are very similar to those I had been writing about. She had even used some of the same quotes out of other people's illness stories as I had. At first I felt troubled by this overlap, but in the end I have interpreted it as
confirmation that I have, in fact, brought forth something important about living well with illness through this investigation. Also, the fact that this author was writing from her experience of chronic fatigue syndrome suggests that the pathways toward well-being during cancer that I have traced may be similar for other serious and chronic illnesses.

Journal Notes

Throughout the investigation I have kept Fieldnotes in several notebooks which I carried with me, as well as a on-going computer file journal of my growing understandings, questions, and insights - something I called a "Learningsjournal". I kept field notes as I engaged in conversations with the women who agreed to participate. I tried to capture the flavor of my initial reactions to each person, any surprises or concerns I had, and any sense of what their overriding issues were. For instance: after I made the arrangements for my first taped conversation I wrote of my trepidation and of my excitement, of how amazing it was to have someone willing to take up their time in conversation with me; but also I wrote about how worried I was about whether I could produce something worthy of their time (Fieldnotes, March 23/98). After the event I wrote:

It was great - very inspiring to dialogue with Dianne! But I'm worried that I allowed the conversation to go all over - not very focused on well-being or living well. My inclination was to just listen and allow what she needed to say be heard. I think (I hope) what has been life giving/healing will be apparent ...in the transcripts (Fieldnotes, March 31/98)

Later I added a note that I had run into Dianne on campus and she claimed to have really felt heard by me. She said, and later reiterated, that our
conversations were helping her to understand her own experiences at a
deepen level. She had been struggling to do some of her own writing about her
illness experience and said she had been inspired to write more after our
conversation. This allayed my fears of the need to be more directive and it also
seemed in keeping with my ethic of promoting, or at least not interfering with,
the well-being of those who chose to participate. It has been suggested
elsewhere that interview research is the "quintessential ethical project"
because it is an "aid to self-reflection" (Miller, 1996, p. 131).

In another journal entry, after interacting with the fifth participant, I wrote:
This conversation went much better than I anticipated.... The most
surprising thing was that half way through the conversation she
suddenly remembered that she had been given a previous
cancer diagnosis (thyroid cancer) 14 years ago. This is the second
time I have heard this from a participant. (Fieldnotes, May 4/98)

My surprise consisted of trying to imagine how anyone could "forget" about an
encounter with cancer, a noticing which later informed my understanding of
how the awareness and understanding illness brings can be easily "forgotten"
as life returns to its "normal" pace. Another day, after meeting consecutively
with two people interested in participating, I wrote:

I think the biggest lesson I learned today was not to do two of
these in a row. These conversations are just too emotionally
draining. I was completely done-in by the time I arrived home.

(Fieldnotes May 7/98)

These fieldnotes have been very useful in reminding me of my impressions
and concerns as I moved on to further conversations and as I worked at
gleaning understanding from the transcripts.
Paradoxical Pathways

After each audio taped conversation I arranged to have the tapes transcribed. I then listened to each tape while reading the resulting transcript. In these initial readings I indicated emotions on the transcripts, highlighted portions I thought were of importance, and made margin notes about what was unclear, what questions I might need to ask in a subsequent dialogue. In my proposal I had suggested that further conversations would allow me to clarify participants unstated assumptions and unclear meanings, bringing forth the depth and complexity of their lived experience (after Colaizzi, 1978; Mishler, 1986; Fiumara, 1990); and that "analysis" of transcripts would be on-going, informing subsequent dialogue with participants. Multiple conversations were used to create what Osborne (1990) calls a "respiralling effect" to "enable a more complete illumination of the phenomenon" (p. 84). My intention was to enter into the hermeneutic circle of deepening understanding by having the meanings gleaned from the initial round of conversations, and the growing awareness from further reading, inform subsequent conversations. These efforts, in turn, would increase my understanding of what it means to live well with a life-threatening diagnosis. But, at the end of the first round of conversations, having spoken to eleven people and listened to each taped conversation, I felt no closer to forming a picture that could be written up coherently, so I began another round of listening carefully to each tape.

I had expected, as noted in my proposal, to find significant statements (Colaizzi, 1978) and thematic insights (van Manen, 1990) in the transcripts. But, having completed this lengthy process of pouring over the transcripts endlessly and listening to the tapes through twice, as well as reading numerous other first-person accounts, I still felt bewildered as to how to write
the material up in any sensible and sensitive way. It all seemed too disjointed and convoluted, there was so much ambiguity. I felt extremely fearful that I would never do justice to the poignancy of these stories. I had the sense of dealing with quicksilver; in my open palm I could contain it, there were important meanings in these stories, but as soon as I tried to grasp them by putting them down on paper, they slipped through my fingers, eluding every attempt to hold on. In my journal I wrote:

"There is so much paradox and contradiction, so many multiple meanings being negotiated within each person’s story and across the stories. I find myself reluctant to write and carry on with the work because I am finding so little consensus. But, in a recent conversation with [one of my advisors] I was reminded that if we as human beings are meaning making creatures, then it is not so earth shattering that we will all find different things significant for our healing." (Fieldnotes, June 18/98)

As I struggled with the material I had collected I became increasingly aware that part of my struggle lay in the non-linearity of the stories I was hearing. I wanted a list of themes and categories that would line up neatly. I wanted to pin down the results and feel secure in the knowledge that I had identified the truth of the phenomenon. I wanted a straightforward pathway through the jungle of details. Having spent a good deal of time "dwelling with the data", it came to me that perhaps I was working against myself and the topic by trying so hard to find linear, logical patterns. Was my need for firm, linear, conclusive statements a remnant of my desire for the scientist's assumed objectivity? Was I still so immersed in the positivist traditions of research that I could not find the value in the narratives my research had
uncovered? Walking the pathways at a favorite wilderness retreat that summer, I noticed how easily I missed my desired path if it happened to be the one less trodden. Even after I had clearly marked the spot where the smaller trail branched off from the larger, more used one, unless I was very aware, I simply missed the juncture and continued on the broadest trail. It dawned on me that I was having a similar experience in my attempts to undertake an interpretive approach. In my journal I wrote:

*I had this sudden revelation, given the material I was reading (I was reading about interpretive approaches to human science research), that we always do this - that we always follow along the most deeply trodden pathways in our thinking as well - that it takes serious, mindful effort to get beyond our entrenched patterns to find new ways of thinking about things.* (Learningsjournal, August/98)

Reminding myself that interpretation resists settling on a singular solution - but is, as Gadamer describes, dedicated to opening up possibilities - I began to see how the paradoxes and contradictions I was struggling with were an important feature of the process of living well during illness. Wasn't the whole idea of wellness during illness a paradox in itself? As I read and reread the texts I heard again and again how fear was both harmful and useful, how being ill had given new meaning to being well and how meaning making was essential but also dangerous in its penchant for engendering blame and guilt. How could I frame contradictions such as: the sense that facing dying could bring new meaning to life; that one both needs to trust the experts and to accept themselves as their own best expert; that illness both burdens us but
also frees us up? The to and fro imagery of paradox began to create a pathway into the writing.

Writing

Ruminating on paradoxes gave me a certain courage to proceed, as did the desire to keep the project moving on to the next stage. I had contracted with myself and the participants to engage in some writing between the first and second conversations; and I was also aware of the injunction that writing and rewriting comprises much of the work of interpretation. According to van Manen, hermeneutic phenomenology "is fundamentally a writing activity" (1990, p.5). Gadamer, as well, suggests "that the fusion of horizons that takes place in understanding is actually the achievement of language" (1994, p. 378). As a consequence, I felt there would be little point in returning for a second interaction, without having attempted some initial understanding of the topic from the first set of transcripts and the reading I had done. I felt I owed the people who had taken the time to talk with me some attempt at writing up that understanding, even if it was preliminary, so we could create further, more informed dialogue around the topic.

Shortly after the journal entry noted above, I sat at my large dining room table with a clean notebook in front of me, surrounded by the piles of transcripts from each conversation. I reminded myself that I was not looking for consistency or universal themes; that my goal was to understand something about the phenomenon of living well after a life-threatening diagnosis. I gave myself the freedom to write whatever came to me, whatever seemed important to the people whose words were laid out across the table in front of me, by reminding myself of van Manen's (1990) contention that interpretation is: "a process of insightful intervention, discovery or disclosure...grasping and
formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning" (p. 79). What I arrived at was a whole series of paradoxes.

Taking the idea of paradox into my interpretation of the "data" allowed the participants and me more room to maneuver. Suddenly I had no need to fit the stories into neat categories or static themes, but instead I could open up a range or arena of concern in which each person's story could settle at its own level. The paradoxes encompassed issues that seemed disparate but in fact were integral to various participant's struggles to live well after the diagnosis. As I puzzled through the process, I came across a paper suggesting that there is a sense in which searching for themes and categories within qualitative data is itself a process fraught with paradox. Renata Tesch (1987) proposed that bringing out metathemes and themes from a gathering of qualitative data, engages the investigator in a paradoxical process. A process of attempting to look with fresh eyes at a phenomenon which they have been immersed in for months, if not years; a process requiring a deep engagement or "dwelling with" the data in which they should be both focused intently and yet open to new ideas; a process that demands both diligent effort and playful creativity.

Further Conversations

In September 1998, as I moved to engage in the second round of conversations, I still had a great deal of trepidation. In my journal (Fieldnotes, September 19/98) I wrote about feeling overwhelmed by the pressure that returning to the participants put me under. I felt I had to have done "a good job" of the interpretation so far, to justify taking up more of the participants time, and I worried that I hadn't made sense of it in a way that they would appreciate. To allay my continuing anxiety I wrote up the paradoxes I had arrived at and as far
as possible for each participant I illustrated them with their own quotes from our first conversation. I also included a page of ideas for further consideration, ideas that had come up in only a few conversations, or that I had gleaned from my readings. I then delivered a copy to each of the women in advance of our second meeting.

When one woman said to me on the telephone, after receiving her copy of the paradoxes, that I seemed to have really captured what the experience has meant for her. She felt that my ideas for further consideration were pushing her to consider other, less obvious, ways in which the process has affected her life, and I felt this confirmed that I had uncovered something of importance to the topic (Fieldnotes, Feb. 2/99). I continue to wonder if I have written up the understandings I have come to in a way that will inform and inspire the practices of those who work with people who are living with a life-threatening diagnosis. If this work is generative in this way, then I will be satisfied that my efforts have been worthwhile.

Further Writing and More Conversations

As I attempted to formalize the writing into the dissertation, I felt myself facing another paradox: how could I present material that was so ambiguous and puzzling, so full of paradox and overlap, in something as linear as a dissertation with its formulaic chapters, its expectations of a logical beginning, middle, and end? As I undertook the development of several years' worth of writing into a cohesive piece for the dissertation, I wrote the following in my journal:

This writing terrifies me in my desperation to do justice to the words I have been entrusted with. ... My soul cries out to bring in the poetry, the passion, the tears of suffering, and living laughter of
these precious women's too short lives. Can I do that in a way acceptable to academia? - or must I save that for some later writing that I may never get to? (Learningsjournal, March 5/99)

This dissertation is the result of the tension I felt then, and continue to struggle with, between what is expected of me academically, my need to complete the doctoral program, and my desire to write these stories into the world in a way which might make a difference.

It has been very important to me that what I write makes sense to the women who have so generously contributed to this project, as well as to those whose practice it might influence. I believe that:

*Hermeneutic understanding is in the end, a matter of communication in which the task of understanding is to find a common language so that the one who speaks can be heard by the other.* (Risser, 1997, p. 14)

Consequently, I have continued throughout this spring and early summer to bring pieces of the writing to several of the women who participated, and to others who have shown an interest. Their reactions have helped to continue stimulating my thinking.

**Summarizing**

The conversations I have had and the reading I have done provide horizons of understanding which have fused with the perspectives I have gained through my continued interaction with people who are living with a cancer diagnosis. As noted earlier, my lived experience over the past four years has been bound up with the struggles of people who are learning to live with the knowledge of a cancer diagnosis: striving to endure the standard
procedures and treatments, making decisions about complementary therapies, and attempting to acknowledge and prepare for a continuance of their life or its foreshortened end. I have spoken to many individuals, read widely in the literature on illness and well-being, and brought to the endeavor my own understandings and observations. The interpretation of the topic presented here has resulted from a "respiralling" through these various sources and resources of information and understanding available to me.

This interpretation is my attempt to find a middle way between my experiencing self and the world in which I find myself. In the words of Maurice Merleau-Ponty: "The world is inseparable from the subject, but from a subject which is nothing but a project of the world, and the subject is inseparable from the world, but from a world which the subject itself projects" (1962, p. 430). I recognize myself as an embodied participant of the lifeworld, constructing and reacting to it - living out a middle path between the two extremist positions of "one sure truth" and solipsism. Truth is not some universal, unquestionable law, nor is it captured in the words of one individual; rather it is something constantly being worked out as we participate in the lifeworld. I have sought this form of truth as I have moved back and forth "between collective and subjective understandings... seeking to develop an appreciation of the meanings of illness" (Kleinman, 1992, p. 130) and of well-being, as I have brought societal, local, and personal meanings to bear on this topic. Truth, from this acknowledged lifeworld perspective, brings with it an understanding that what I derive from this research are interpretations ever in need of reinterpretation (Smith, 1994). We are always working out our understanding of the world from within "the conversation that we ourselves are"
and "being transformed into a communion in which we do not remain what we were" (Gadamer, 1994, pp. 378 & 379 respectively).

In the next chapter I trace the pathways that are tread by those who work with, and theorize about, people experiencing illness. I consider various discourses on health and how those discourses position people who are living with illness. In the following chapter I trace the routes taken by people who are attempting to live well within the experience of illness and end by comparing the roles laid out by our many approaches to illness. In the final chapter I consider the claims these narratives make on those of us whose theories and practices influence and support people living with illness. My hope is that by delving deeply into what it means to live well with illness, more people who desire to live well after a life-threatening diagnosis will find pathways toward well-being.
CHAPTER THREE
QUESTIONING THE LITERATURE

Opening the Dialogue

The idea that human beings live within a socially constructed environment - a culture - created and transmitted predominantly through language, is not a new one (Anderson, 1995). What is new is an acknowledgment of the numerous and diverse sub-cultures at play within any given society, as is the idea that these sub-cultures not only act on and influence us, but we in turn influence the various cultures in which we find ourselves. Culture, in this postmodern era, is no longer viewed as a singular, totalizing system with some special hold on the ultimate "truth". Rather culture, from a postmodern perspective, is perceived as something constantly constructed by our participation in myriad on-going discourses or narratives (Kvale, 1995). While "participation" suggests a level of willingness, our individual agency is both made possible and constrained by the various societal stories we are caught up in or subjected to (wittingly or otherwise). "In the very act of telling a story, the position of the storyteller and the listener, and their place in the social order, is constituted; the story creates and maintains social bonds." (Kvale, 1995, p. 21). The regulation of behavior through the various role definitions and expectations that devolve from different discourses speaks to the production of power in our society (Foucault, 1988). Narratives or discourses give shape to bodies of knowledge, which in turn give rise to institutions, which in their turn exercise considerable, though often subtle, influence over the embodied lives of those who come into contact with them (Bordo, 1989, 1993b; Butler, 1990, 1993; Grosz, 1994). Some of these
narratives or discourses hold greater sway over others in our society; some provide more opportunity for dialogue and choice than others; and some are ignored or denied a hearing.

Within the culture of health in our society there are numerous competing discourses, narratives, "habits of mind" (Toombs, 1987), or "worlds of meaning" (Kleinman, 1992) which encompass our experiences of illness, disease, wellness, or well-being. Some of these "stories" wield considerable power over us while others struggle to gain a foothold in our society. Modern biomedicine, for example, having aligned itself with the dominant Western narrative of scientific positivism, has developed vast networks of culturally sanctioned institutions and professional roles. Even so, there is a complex discursive arena in health where many voices are trying to be heard; some are heard clearly and heeded with alacrity, others contradict and compete for our attention, and still others are only vaguely heard voices crying in the wilderness. Beginning with the dominant voice of biomedicine, various discourses on health are brought into play in this chapter. How the beliefs, values, and assumptions of each discourse position people, and the limitations inherent to each approach, will be foregrounded in the search for alternative models by which to understand the meaning of the human experiences of illness and well-being.

In keeping with the dialogic nature of competing discourses in these post-modern times, this interpretation of the literature on health and well-being will be taken up as a dialogue between the numerous factions competing to be heard and my own wondering and questioning and suggestions of missing elements. My hope is that the spell of the dominant discourses can be broken by these interruptions, which occur in an alternative
font. By giving voice to questions long ignored or brushed aside as irrelevant and raising issues not commonly attended to I also hope to evoke your questions and concerns as you read. The biomedical model is given particular attention as it has become so well entrenched through our modernist alliance with science and rational individualism. This critical attention is not to deny the many benefits of modern medical science. Rather, the goal is to take the conversation about our health in some fruitful new directions; opening it up by disrupting the usual and taken-for-granted answers while searching for new, more generative understandings (Gadamer, 1994).

(Re) Viewing the Biomedical Discourse

Modern biomedicine has, in this century, become a practice strongly oriented to a scientific worldview. The observable and measurable aspects of the human body are the objects of study for the science of medicine. People's illness experiences are diagnosed as particular disease entities and are presumed to have specific etiologies which, once understood, can then be treated through biopharmaceutical interventions directed at the physical body. Aspects of the human experience of illness which are not physically observable and quantifiable, such as mental, spiritual, or social events, are generally left for others to deal with. The focus of medical science is on the preservation of physical life through the eradication of disease and the mitigation of physical trauma. With this focus and the vast growth in technology, biomedicine has made some important and awe-inspiring breakthroughs.

Some basic contentions of the biomedical model are: a distinct separation of mind and body, without regard for social and environmental contexts (Capra, 1988; Berliner & Salmon, 1979); a mechanistic and reductionistic view of the body (Allen & Hall, 1988) as if the body were a machine which could be reduced to parts and functionally repaired (Capra,
1988; Laffrey, Loveland-Cherry & Winkler, 1986; Payne, 1983); a focus on pathology, with disease given ontological status and treated as if separate from the person who has it (Budd, 1992; Neuhaus, 1993); a belief that each disease has a single pathogenic cause and is therefore amenable to cure as technology advances (Freund & McGuire, 1991). While biomedicine continues to advance, many practitioners have begun to question the strict adherence to scientific principles (see for example Baron, 1994; Bolen, 1994; Campo, 1997; Groopman, 1997; Pearsall, 1991; Remen, 1996; and Weil, 1988, 1995).

What does medical science reveal and make possible and what does it conceal? By taking a perspective that limits its knowledge to physiology, what happens to the existential issues people grapple with when their well-being is threatened? Is it possible that a focus on curing disease eclipses a more fundamental need to continue living well even within illness? It seems useful to remain aware that Pasteur, though he focused his research on the causative role microbes play in disease, continued to be very interested in what he called the “terrain” - the inner and outer environments of the diseased organism (Capra, 1988). What aspects of the terrain does modern medicine conceal?

Why does disease occur in one person and not in another, even when they share a similar environment? So how did it come about that modern medicine ascribes itself to such a truncated version of what human beings are, to such a limited understanding of human well-being?

**Historical Basis of Biomedicine**

Historically, medicine was not so aligned with science. The origins of Western medicine lie in the healing "arts" of the ancient Greeks, as evidenced by the staff of the Greek god of healing, Asclepius, remaining as the symbol of
Western biomedicine today. Asclepius was said to have two daughters who focused on prevention rather than pathology, Panakeia who used herbs and diet to prevent illness, and Hygeia, who promoted prevention through exercise and proper lifestyle (Dossey, 1982). The triangle formed by the two aspects of prevention and the healers art provided the foundation for Greek and Roman medical practices and for many centuries thereafter.

From the time of Hippocrates in 460 B.C. healers attended to the life circumstances and emotions, of those suffering from illness, as these were thought to have considerable impact on the natural healing capacity of the human body (Cousins, 1994). The sense that human wholeness consisted of both bodily and mental events is prevalent in the works of Aristotle in 348 B.C, who argued that the body was a material expression of the mind. Both, Maimonides, a Jewish philosopher of the eleventh century, and Paracelcius, a German physician of the sixteenth century (often considered the father of chemistry), believed the body-mind was an indivisible whole and that emotions were key in mental and physical illness. As late as 1895, a physician named George Brown presented the argument that "high mental tension on any subject, continuing long enough, will cause disordered function, which will in time surely be followed by organic change" (as cited in Myers & Benson, 1992, p. 4). Medical practices prior to this century reflected an understanding that how a person experienced and perceived of their life, as well as the social and environmental factors they were exposed to, were connected to their physical health.

Even though most serious pursuits of knowledge were converted to positivism much earlier, the Newtonian-Cartesian legacy did not subsume the healing art of medicine until very late in the 19th century. As experimental
methods became the most highly sanctioned route to knowledge in our society, and as laboratory technology improved, disease was no longer viewed as an imbalance involving, not just the individual, but social and environmental factors as well. The experience of illness came to be seen as a measurable deviance in the physical functioning of a singular person, to be rectified by direct bodily interventions. Thus modern biomedicine was born from the technological advances of the twentieth century.

It is important to recognize that the discourse of science on which biomedicine is based is the discourse infused with considerable power in our culture. In the words of Francesco Varela (1991): "...science provides the voice of authority in our culture to an extent that is matched by no other human practice and institution" (p. xvii). Perhaps medicine simply followed appropriate preservationist instincts, as did many other practices (law, nursing, psychology), by "buying in" to the cultural legitimacy afforded by adopting a scientific stance. Perhaps medicine became a "hard" science in order to distance itself from its "soft" origins as a healing "art". I also wonder if there is something about the female aspects being preventative and their father - the patriarch? - dispensing curatives? The ascendancy of science in medicine took place over the same time period as the witch burnings - did this speed the loss of the "female arts" in medicine?

Whatever the reason, there were considerable consequences to the scientizing of medicine.

**The Effects of a "Science" of Medicine**

The scientific worldview adopted by modern biomedicine rooted itself deeply in the soil of Cartesian-Newtonian thought. Newtonian imagery of nature as a giant clockwork, which can be reduced to analyzable parts, has
served to divide medicine into dozens of disciplinary specialties and sub-specialties. This mechanistic metaphor has had significant ramifications for ill people:

_The patient is the owner of the body-machine which is brought to the physician for repairs. A rational patient adheres to the rules of the sick-role: seeking out medical expertise, giving the body over to be examined and complying with the treatment regimen. When patients deviate at any step in this process they may be judged irrational or responsible for their illness. Even when the norms of illness behavior are strictly followed, if medicine cannot explain or alleviate the illness, the patient may be blamed for its failure. These maneuvers act to maintain the rationality and coherence of the biomedical worldview even while they disqualify the patient's suffering or moral agency._ (p. 57-8, Kirmayer, 1988)

The experiential and existential reality of people as conscious, self-reflective beings situated in a social web is rarely explored, and the bodily manifestation of illness is translated through laboratory findings into a set of mathmatizable facts (Berliner & Salmon, 1979; Pelletier, 1992). These "facts" are then statistically compared to the numbers derived from other similarly ill persons in order to construct a diagnosis, a prognosis, and a treatment plan. This scientifically based approach sets the physician up as the authoritative expert leaving the person who is ill in a very passive role (Hunter, 1991).

**Limitations of the Biomedical Model**

This foregrounding of the limitations of biomedicine does not negate the many important successes of the scientific model of medicine. There have
been vast improvements in the alleviation of human suffering from illness and biomedical techniques continue to be particularly effective in trauma intervention. Scientific medicine has served us well in the near irradiation of the devastating effects of infectious diseases such as polio and smallpox (although the specter of increasingly resistant strains of microorganisms has recently arisen, see Garrett, 1994). Currently, though, the major causes of suffering in our society have shifted away from simple, germ based, infectious diseases towards chronic social problems and illnesses with complex etiologies (Adams & Mylander, 1998; Alcorn, 1991). As well, healthcare has been influenced by another dominant societal discourse, that of capitalism. Medicine, in recent years, has become a commodity influenced by economic cost-benefit analyses and by its consumers, who are currently making demands for more humane and morally cognizant medical treatment. Other critical issues in modern medicine include iatrogenesis (ill effects due to diagnosis and treatment), growing numbers of drug resistant stains of bacteria and viruses, general abuse of pharmaceuticals, and the ever increasing cost of treatment.

Is it possible to transform biomedicine, expanding beyond its limited scope of physical causes and linear effects, to have it encompass the fullness of human experience. I wish to open the door for a broader acceptance of what it means to be a human being within the complex web of the lifeworld. Undeniably modern pharmacological medicine does save lives. (Although many would argue that the most significant improvements in human health, often credited to modern medicine, may have resulted from increased levels of public sanitation and the provision of clean drinking water (Dossey, 1982; Nandy, 1995). Still, the issue is not to condemn, but only to temper the hegemony of
modern biomedicine. What went missing when the art of healing became a science? Would an aesthetics of well-being provide us with more humane possibilities for taking up illness?

One Disease, One Cause. Many have argued that the prevailing biomedical model has serious consequences for those whose experience of illness falls outside of the common tenets of the medical model (Adams & Mylander, 1998; Ornish, 1990; Lerner, 1994). Especially problematic are those who experience illnesses with no specific etiology, but with numerous debilitating symptoms, such as chronic fatigue syndrome and fibromyalgia (Allen & Hall, 1988). Diseases without a singular cause - the foremost being cancer, cardiovascular disease, and substance abuse - currently form the largest portion of our morbidity and mortality (Altmeier & Johnson, 1992; Capra, 1982; Jasnoski & Warner, 1991). Doctors tend to be trained to work with acute cases in a "diagnose and prescribe" format; they do not have time and are not trained to consider how the individual's whole life might figure into their illness experience (Freund & McGuire, 1991). The prevailing health concerns of our time have behavioral and stress related origins, as well as environmental antecedents (Allensworth & Kolbe. 1987; Altmaier & Johnson, 1992; Gordon, 1990).

Clinical Iatrogenesis. In the late 1950's, vocal critics of modern medicine asserted that not only is biomedicine limited in its impact on disease processes, in many cases it creates new problems (Illich, 1977). Since Illich coined the term "iatrogenesis" to describe medical interventions which cause harm, many investigators have criticized medicine for its inhibiting effect on the human capacity for self-healing (Allen & Hall, 1988; Black, 1989; Robbins, 1996; Weil, 1995). Modern medicine tends to, again using Illich's term,
"medicalize" natural human processes such as pregnancy, grief, menopause, aging, and dying. This transformation turns intersubjective human experiences into individual biological events promoting an increasing alienation from natural human events and a reification of the medical establishment (Allan & Hall, 1988; Pelletier, 1994; Robbins, 1996). The resulting dehumanization of biomedicine is the most common criticism of those who seek alternative therapies, especially in the area of cancer care (Cunningham, 1995; Lerner, 1994; Sobel, 1995).

**Curing Over Caring.** The dehumanization described above is evident when battles are waged against disease with little regard for the cost in human suffering, as in the "biomedical war being waged" on cancer (Robbins, 1996). The treatment process, which is aimed at eradicating every last cancer cell, in some cases seems to cause greater suffering than the course of the disease might (Allen & Hall, 1988). Despite the lack of success, the eradication approach to curing cancer remains the prevalent method (Schipper, Goh and Wang, 1993). As long ago as 1977 Leon Eisenberg stated that:

> The momentum of the technological imperative to do what we have the virtuosity to do (without pausing to consider whether it is worth doing) drives the physician's hand and increasingly brings him [sic] into conflict with what the patient seeks from him. (p. 10)

Modern biomedical imperatives to eradicate disease and overcome death, result in ignoring suffering or quality of life issues in favor of pursuing treatment - even, at times, when hopes of cure have been exhausted. While doctors used to have little more to offer the dying person than a compassionate hand to hold, they now have many ways to
radically intervene. Yet, the questions remains: Is what can be done always commensurate with what should be done? And who gets to decide?

**Escalating Costs.** Over the past 30 years healthcare expenditures in Canada have doubled; in 1994 an estimated 70 million dollars were spent (Rachlis & Kushner, 1994). Increasingly expensive medical technology, especially diagnostic imaging, bone marrow transplants, coronary by-pass surgery, and neonatal care units consume vast sums of healthcare dollars (Adams & Mylander, 1998; Allen & Hall, 1988; Altmeier & Johnson, 1992). Most healthcare expenditures have a triage effect, whereas money spent at earlier stages on prevention and health promotion could be less costly (both in suffering and in dollars spent) in the long run (Berliner & Salmon, 1979; Sefferin, 1994). By locating "disease" in the individual, medicine loses the opportunity to impact on sociopolitical problems, such as poverty and chronic underemployment, which have a major impact on our collective well-being.

**Moral Issues.** While medicine's scientific status has conferred an image of moral neutrality, its increasing capacity to intervene in people's lives "raises questions of meaning and quality in life which strip away the illusion that technology is value-free" (Eisenberg, 1977, p. 10). Once the technology is in place, it seems morally reprehensible not to apply it to every case: "The technological imperative is deeply embedded in many institutional responses to health crises", (Freund & McGuire, 1991, p. 255).

But who gets to authorize such decisions? Take, for example, the case of the Saskatchewan boy, Tyrell Dueck. He was subjected to court proceedings and ordered to submit to high dose chemotherapy and the amputation of his leg in
a bid to save his life, when the choice he had made, together with his family, was to use a less invasive alternative therapy. (This story is complicated by age of consent issues as well, but it points to the authoritative power of the medical establishment to dominate the individual.) The powerful medical establishment is answering important moral questions with little regard for individual and social well-being. It is hard not to wonder: When might a person be better off to refuse further treatment, or choose less invasive treatment on the basis of maintaining quality of life over quantity? and; Who would/could be responsible to advise them?

*Medicine has done little to help us understand what it means to live well in the midst of a serious illness, and less to help us consider how to die with dignity having lived well right to the end. In fact, biomedical institutions have segregated us from the ill and dying, resulting in an alienation from human experiences of suffering. We may be one of the first generations of human beings that get through life without ever experiencing the impact of having a relative die at home. What does this do to our ability to accept illness, pain, suffering, and death as normal aspects of our lives? While much has been gained by the scientific approach to health and disease, much has also been concealed. As Ashis Nandy claims: "Modern medicine is a politically powerful knowledge system which shows immediate practical results in some areas but is intellectually, socially, and morally disorienting" (p. 194, 1995). Perhaps it is time to turn our attention to what has been eclipsed by the modern medical approach.*

**Pressure to Move Beyond Biomedicine**

It has been the contention of a number of writers that change comes slowly to established scientific paradigms as the weight of contradictory
evidence builds (see for example Kuhn, 1970). As the number of anomalous findings increase, the existing knowledge structures in a given field begin to shift in response. In recent years the science of biomedicine has been subjected to increasing evidence that there is more to human health and healing than physical science allows.

**Spontaneous Remissions and Placebo Effects.** Throughout the history of medical science there have always been documented cases of spontaneous remission (Hirschberg & Barasch, 1995; Weil, 1995). These are cases in which people pronounced terminally ill by the medical experts have spontaneously, and from the medical scientist's point of view, inexplicably become cured of their illness. Another arena of anomalous findings in medicine is what is commonly referred to as the placebo response, wherein the arousal of a person's belief about the positive outcome of a specific drug or treatment results in the expected physiological response (Pelletier, 1992). In effect, belief or expectation about the effects of an inert treatment becomes a biophysical reality. The usual response to these anomalous findings has been to explain away cases of spontaneous remission as mistaken diagnoses and to view the placebo effect as error to be controlled for in biomedical research.

**Stress Research.** Over the past century, psychological research on stress has also been instrumental in affirming just how integrated physiological events and consciousness experiences are. From Cannon's concept of the "flight or fight" response in the 1900's, through Benson's relaxation response in the 60's to Lazarus and Folkman's cognitive coping model in the 80's, awareness of mental influences on physiological processes has been growing (Selye, 1991). In the 70's a biopsychosocial model was developed by Engle (1977) in which the individual is viewed as a system made
up of various interacting subsystems and embedded in larger family, community, social, and environmental systems. The multidisciplinary field of behavioral medicine has developed in response to our growing understanding of the fundamental unity of mind and body (Newman, 1986). Behavioral medicine combines research from behavioral psychology with medical science in an attempt to encompass the whole person (Kabat-Zinn, 1990).

**Psychoneuroimmunology (PNI).** PNI is a biomedically based discipline which considers the relationship between people's psychological functioning and their neurological, endocrine, and immune systems. This discipline has begun to provide evidence of a complex, interactive communication system between the mind and body, which uses biochemical messenger molecules to connect the brain, thymus, lymph nodes, spleen, and bone marrow (Pelletier, 1992; Pert, 1991, 1997). This "research is starting to show that human behavior, attitudes, emotions, beliefs and thinking can alter both humoral and cellular immune responses" resulting in significant effects on disease processes (Jerry, 1996, p. 1731). PNI research is reinforcing modern medicine of the inextricability of mind, body, and environment in the processes of health. At the same time the sea-change in scientific thought due to evidence from quantum physics (Bohm, 1980), systems theory (Bowler, 1981), and chaos theory (Prigogene & Stengers, 1984) is beginning to seep across disciplinary lines signaling the need for a paradigm shift (Borgen, 1992).

*It seems that as we gain the technology to study the minutest processes within the physical body we are faced with a growing awareness that human beings are not separate body and mind systems. PNI research is providing scientific evidence that the mind, brain, and body function as an interwoven network (Pert, 1991, 1997). With*
meaning and emotions as the catalysts for setting off cascades of messages throughout the brain and body, one can only begin to imagine what takes place when a person interprets a medical pronouncement about their condition as hopeful versus hopeless. But, there are dangers lurking in these waters as well. Must a person always remain hopeful during illness? Is there room in this hopefulness for an acceptance of death?

What if we view human beings as part of an interconnected web of energetic systems and sub systems, in which perturbation at any level reverberates throughout the system, and chaos or disintegration are seen as natural precursors to reintegration at a more comprehensive level (c.f. Barton, 1994; Bowler, 1981; Capra, 1989; Prigogene & Stengers, 1984). Applying this to human health/illness, I find the linear cause and effect model of medical science far too simplistic to capture the complexity of the energetic interactions occurring within me and between my environment and myself. Illness, from this perspective, can be viewed as a reorganizing event; and treatments as something less like an "intervention" and more akin to the supportive provision of optimal conditions in which the system can right itself. Attempts have been made to incorporate the new scientific paradigms into theoretical models of health. Perhaps the most influential have been the wellness and holistic models.

Wellness and Holistic Models of Health

The wellness and holistic approaches to health and healing have been called the "ecologization of medicine" (Callicot, 1996, p. 153). The ecological worldview underlying these movements view nature as a vast organism rather than the clockwork machinery of Newtonian physics and Cartesian philosophy (Capra, 1982). An understanding of the interrelatedness and interdependence of parts and wholes, and a sense of the dynamic equilibrium between and within systems, are at the basis of the ecological worldview; a perspective
which grew out of von Bertalanffy's groundbreaking General Systems Theory (Callicot, 1996). Holism in health, a concept which developed along with wellness theories, contends that our well-being is multidimensional, including biological, mental, spiritual, sociopolitical and environmental systems in a process of increasing integration and harmony. Health is described as a dynamic balance of mind, body, and environment, and there is an acknowledgment of the healing forces inherent within all living organisms. Treatment strategies in holistic approaches to health are often aimed at more than one system (Moyers, 1991).

*It is important to be aware that understandings of dynamic balance and systemic functioning were integral to the worldviews and healing traditions of many ancient cultures, particularly Chinese Traditional Medicine and Ayurvedic Medicine in India (Capra, 1982; Nandy, 1995). I have often wondered how much our changing views of health can be attributed to the "Global Village" effect of cross-cultural exchange.*

Rene Dubos in the 1950's was one of the earliest public proponents of holism in health. He defined health as "the condition of the whole person engaged in effective and fruitful interaction with the physical and social environment" although he retained a sense of health as a static state, a "freedom from physical and mental discomfort" (Allen & Hall, 1988, p. 31, paraphrasing Dubos). Dunn (1961) expanded this view by taking a more active, process-oriented view of health. He believed that education was the key to attaining increased wellness, making him an early voice of the health promotion movement as well. These early ecological models of wellness and holism have in common the beliefs: that illness and well-being are "phases of
a more comprehensive phenomenon" comprising life itself (Allen & Hall, 1988, p. 31); and that the health of the individual is inextricable from the well-being of the community, the society, and the physical environment (Callicot, 1996; Swinford & Webster, 1989). Despite this professed orientation, wellness and holistic models have tended to focus most directly on the individual. In the 70's the wellness model was taken up within the zeitgeist of humanism and the human potential movement with an increasing emphasis on the individual's responsibility for health maintenance and growth towards "peak" experiences (Kingswell, 1999). This prompted the adoption of a "lifestyle" approach to well-being. Wellness has been described as "a way of life - a lifestyle you design in order to achieve your highest potential for well-being" (Travis & Ryan, 1988, p. 1). This model contends that illness and wellness are on a linear continuum; the signs and symptoms of illness, disability, and death at one end are contrasted with awareness, education, and growth towards high-level wellness at the other. Individual self-responsibility for integrating nutrition, fitness, environmental sensitivity, and stress management into a balanced whole, is the major focus of the lifestyle approach to wellness (Ardell, 1986). In 1977 the University of Wisconsin formed the National Wellness Institute (NWI), under the direction of Dr. William Hettler. This organization continues to hold an annual wellness workshop which draws international participation for five days each summer (Callicot, 1996). Wellness is defined by the NWI as a seven dimensional process including emotional, intellectual, spiritual, physical, social, occupational and environmental well-being, and defining health as "an active process through which the individual becomes aware of, and makes choices toward, a more successful existence" (Hettler as cited in Swinford & Webster, 1989, p. 4).
These last definitions begin to allow room for the social, political, and environmental forces, which may limit or promote an individual's ability to make healthy lifestyle choices. Yet, most wellness programs continue to focus on change at the individual level. Such approaches leave me wondering what "healthy lifestyle choices" are available to a child who is raised in abject poverty. The lack of attention to existing political and social issues continues to be a major criticism of these wellness-lifestyle models.

Questioning Wellness

Although the wellness and holistic approaches have broadened our understanding of health in some ways, they continue to promulgate some of the limitations which plague medicine and have developed a few new ones as well.

Disregard for Social and Environmental Ills. Berliner and Salmon (1979) voiced concerns nearly 20 years ago that the wellness movement's emphasis on the individual's capacity to cope with stress continues biomedicine's ignorance of the political and social dynamics, which produce the stress in the first place. They wanted to re label "stress" as "social assault" and suggested that the impact of the sociopolitical economy on the individual should be our primary health concern. The lifestyle focus of the wellness and holistic movements also ignore the pressing ecological problems on the planet (Boston, 1997). Callicot (1996) maintains, along with many in the environmental movement, that our collective and individual wellness is thoroughly dependent on our ability to restore the balance of our ecological home (also see Hillman, 1995; Nollman, 1990).
**Health as a Commodity.** There is also a problem with continuing to define health as some ideal state that can never be truly attained (Capra, 1982; Stachenko & Jenicek, 1990). This ideal state then becomes an end in itself, to be pursued for its own sake, rather than being viewed as simply a balanced way of living (Antonovsky, 1980). The lifestyle model has turned health into a commodity: another item to be purchased and consumed; something earned through self-sacrifice and effort, or lost through "poor lifestyle management". Newman (1986) contends: "We have become idolatrous of health. We have created places of worship of health at which we carry out the recommended rituals to obtain and maintain health" (p. 7).

**Blaming the Victim.** The focus on individual responsibility has also lead to viewing those experiencing illness as morally deficient (Newman, 1986; Pelletier, 1994; Sontag, 1978). Pelletier criticizes the "neurotic self-absorption" that results from the health fascination produced by lifestyle models of wellness. He believes that health is currently pursued as a moral virtue, with the beautiful, youthful, healthy looking body being the manifest sign of this virtue and suggests that: "We have come to the facile conclusion that if health-promoting behavior is moral and virtuous, then illness must be the result of a moral failure or lapse" (p. 28). This moral stance stems from maintaining a dichotomous view of health, in which illness and disease are judged as negative. Because holistic and wellness approaches continue to contrast disease and disability with high level wellness, and to assume individual responsibility, those who experience illness and/or disability are viewed as culpable (Bergner & Rothman, 1987; Callicot, 1996; Capra, 1989; Newman, 1986; Pelletier, 1994).
The idealization of the healthy youthful look has fueled an incredible industry in fitness equipment and centers, as well as cosmetics and cosmetic surgery. Are our bodies the new temples at which we worship with religious fervor? Are youthful and able bodies the only "good" bodies? Wellness-lifestyle models create another form of "ableism". Those experiencing disability, especially disability through illness, are positioned at the negative end of the spectrum and viewed as responsible for not caring for themselves sufficiently. Biomedicine carries on as if in a scientifically sanctioned moral vacuum, but wellness models create a new dogmatism. If we develop healthcare models based on wellness (especially within a government sponsored healthcare system) are we in danger of dictating the requirements of "good health" for all citizens? On the upside, this might allow for legislation against harmful food additives and industrial wastes; on the downside, would we have exercise police? - thought and character police? How can we avoid such quandaries?

Health Beyond Wellness

In all of science there is currently a search going on for more comprehensive models which fit our (relatively new) understanding of the interconnectedness of space and time, mass and energy, mind and body, person and environment (and even consciousness and the universe). In medical science, the application of advanced laboratory science to disease processes is providing increasing evidence of complex, and simultaneous, biochemical interactions occurring throughout the brain and body (Pert, 1991, 1997). Changes in the natural science perspective - from dualisms to continuities, from mechanistic to systemic understandings - are pushing us to understand health in new ways (Kabat-Zinn, 1990). Capra (1989) has argued that the wellness and holistic models were remiss in incorporating a true ecological paradigm; the required paradigm, he asserts must be more
dynamic and systems oriented than the polar opposition of health-illness at the individual level.

Deep Ecology

Many recent theorists have advocated for a truly ecological perspective, in which human beings are viewed as only one part of a whole living planetary system (Boston, 1997; Callicot, 1996, Rozak et al., 1995). As Callicot expresses it:

...if we are interested in being well, then we must do more than pay attention to eating right and working out, to the quality of our character and our relationships, to maintaining occupational satisfaction and intellectual stimulation in our personal lives, and so on. We have to work to prevent further environmental degradation and restore the environmental quality that we have already allowed to seriously erode. (1996, p. 148)

Boston (1997) argues that human beings cannot be truly well without being aware of, and working to further, mutual interdependence between ourselves and our planetary home. This requires a "coming to our senses" which reconnects us to the way in which we are supported and sustained by the very ground upon which we tread (Abrams, 1996). Wellness and holism, thus, become vibrant, variable and intersubjective practices that go well beyond the individual lifestyle model.

An ecological model of health, according to Boston, encompasses various "truly holistic, emancipatory and situated 'wellnesses' allowing for differentiations of wellness praxis that exist, for example, along the lines of race, class and gender" (1997, p. 23). Under the rubric of "situated wellnesses" Boston includes several overlapping branches: a natural wellness which
encompasses an awareness and acceptance of our interconnections and interdependence with the world and all beings in a web of life; a spiritual ecological wellness with a "reverence of nature's rhythms and processes" (p. 25); an empowerment sense of well-being which requires a commitment to socio-ecological justice issues; an emotional wellness which entails acceptance and expression of emotion and emotional connections with others; and a physical well-being wherein the connections between body and mind are understood and given adequate consideration through appropriate diet and exercise.

Dialectical Fusion of Illness/Wellness and Illness as Transformation

Other health theorists have focused less on a systems perspective and more on relaxing the strict dualistic opposition of wellness and illness. Dossey (1982, 1984) has suggested a view of human health as a dynamic process inclusive of the varying degrees of wellness and illness experienced over the life span. He believes we are essentially dynamic patterns of energy connected, not only to our physical bodies, but also to the images and words we use to apprehend our universe and to the beliefs of those around us. Health in this model becomes synonymous with life. Periods of illness and wellness/well-being are considered in a dialectical fusion as 'health experiences' (Moch, 1994; Newman, 1986). Newman (1986) also asserts that disease, as one manifestation of health, can be viewed as an unsettling process, which may be required for transformation to another level of awareness. The transformational nature of illness has been the focus in numerous recent studies in nursing (see Moch, 1994).
Two researchers, Jensen and Allen (1993), synthesized the results from 112 qualitative studies on health, disease, wellness, and illness deriving a dialectical model of wellness/illness. They describe the model as follows:

*Health, disease, wellness, and illness become one and the same, acknowledging the changing person in the changing world. They are discrete yet part of a whole. For example, physically healthy individuals may not be experiencing wellness as they lead an unintegrated life. Equally, individuals could conceivably experience disease as wellness by accepting disease as an integral part of themselves. The dialectic process of health-disease involves creating a pattern of meaning in everyday life* (p. 361).

This conception of health, voiced within the holistic nursing discipline and echoing the tenants of systems theory, predicates that "the experience of illness can accelerate personal growth through increased awareness and transformational change" (Moch, 1989, p. 24). The task is to change our belief system, from seeing illness as a problem or a limitation, to a perspective of illness as an opportunity to make changes in one's life, as an impetus for growth and learning.

**Illness as Metaphor or Narrative**

Still other theorists have given more consideration to the issues of language, believing that the biomedical tendency to reify disease weakens the agency of the individual and disguises the contextual nature of illness experiences. Budd (1992), Kleinman (1992) and Neuhaus (1993) argue that our experiences of ill health could be more promisingly viewed as interpretations: as attempts to ascribe meaning to a set of symptoms. This approach requires that health practitioners listen carefully for ways of
approaching illness that fit within the individual's worldview. Practitioners could
tune their ears to hear the possibilities for transformation and growth in the
stories ill people tell (Budd, 1992; Nadler, 1997; Neuhaus, 1993). The ill
person's experience, how they describe or narrate their own engagement with
the illness and treatment procedures, becomes equally as important as the
biomedical knowledge of the practitioner (Hunter, 1991). This approach has a
large popular following judging by the success of such author-practitioners as
Bolen (1994), Seigel (1986; 1989; 1993), Northrup (1994), Pearsall (1991), and
Weil (1988; 1995), who all advocate getting in touch with the metaphors and
meanings presented by the symptoms of an illness.

Active Patients

Others have argued that we need a model of health that better reflects
the relational quality of person and environment wherein... "individuals are not
passive recipients.... They are self-determining in their continuous interaction
with the environment, affecting and being affected by it" (Allen & Hall, 1988, p.
32). Particularly at issue, is the relationship between the ill person and their
practitioner. "[R]egard for people as human beings and concern for quality of
life of patients, friends, and family" comes to the foreground in this model (p.
33). Health promotion, as well, becomes an important factor in this equation,
as sociopolitical influence is viewed as the appropriate vehicle to enhance
individual and societal well-being.

Synthesizing

Pelletier (1994) developed a model of health through a consultative
process, by intensively interviewing people who have lived lives that represent
high levels of human functioning. Through this process he came to a model
that seems to weave together the various strands of health beyond the
wellness model. He argues for an understanding of health as an open-ended process, rather than an objective end-in-itself. Agreeing with the proponents of the dialectical fusion model, he describes health as an ever-evolving process, which includes the possibility of experiencing well-being during illness and even the possibility of dying well. He also concurs with the interpretive perspective, viewing health as an orientation comprising our most basic values and beliefs about the world, which, as noted, requires practitioners to develop trusting and mutually interactive relationships with those who seek them out. Health-beyond-wellness is an integration of numerous subsystems within larger systems; individual physical, mental, and spiritual well-being and social and environmental well-being to produce a balanced whole.

Individual efforts are necessary but insufficient, because health-beyond-wellness requires that we: "create approaches and systems in economics, environment, politics, and the delivery of medical care, that elicit and sustain individual strategies" (Pelletier, 1994, p. 17).

These models encourage my questioning of the biomedical approach to health. They provide an opportunity to consider well-being within illness. Illness experiences can be the motivation to actively engage in transformative change. Caring for the earth and its various communities becomes analogous to caring for oneself. What would happen if we could take-up illness as a natural part of life; an indication of human vulnerability and finitude (Weil, 1983) or another life experience to be learned from (Moch, 1989)? Could we thereby reorganize our treatment "regimens", our "intervention strategies", and the "marshaling of our immune forces" into something less violent, something more amenable to growth and well-being? Health-care could become a more caring
valuable, don't fit well in alternative paradigm research agendas (Dossey, 1996). Allen and Hall (1988) argue that: "...the biomedical stranglehold over clinical and research funding results in alternative approaches remaining unsanctioned" (p. 30, see also Weil, 1995 for the same argument). Consequently, the new health paradigm remains "unproved" and the biomedical approach continues to hold sway.

I wonder if anxiety over illness and mortality has been the driving force which permitted our own knowing to be usurped by the medical authorities. I know the relief I experienced as I handed my child, who had been writhing with the pain of an inflamed appendix, over to the surgeon. Has the success of biomedicine in some aspects of health led us to become pawns within its numerous functional subsystems? [See Frank (1992) for an application of Habermas' concept of institutional power to medical settings.] If we returned to a conception of ourselves as just one of the myriad parts of this planetary whole, then we might develop a new awareness of how illness and death are also simply inevitable aspects of the whole (the enfolding and outfolding of energy (Bohm, 1980). With this awareness we may be able to proceed with less rigor and more compassion, putting human dignity and the need for community before the "functionality" of the health provider's sub-systems. I also wonder how the economics of the companies which provide medical machinery and pharmaceuticals - the economic subsystems which underwrite our healthcare system by providing the funds for research - affect our ability to change our perspective on health? But this is a question that lies beyond the horizon of this study. More appropriate to this investigation of living well after a life-threatening cancer diagnosis is a consideration of how psychosocial care has been established within the purview of biomedical oncology.
The Psychosocial Discourse in Oncology

As psychological and social issues have gained credence as important "factors" in the care of people living with illness, psychosocial departments have begun to appear in many major medical centers. Particularly in oncology, the biomedical establishment has accepted that the diagnosis and treatment of cancer has significant psychological and social effects, and has designated these concerns to a separate subspecialty called psycho-oncology or psychosocial oncology (Holland, 1998). Psychosocial oncologists are generally considered "support staff" and "psychosocial departments" are variously comprised of one or more psychiatrists, psychologists, social workers, and/or spiritual counsellors.

Psychosocial approaches to cancer have followed closely in the footsteps of biomedicine. Consequently, the language used by psychosocial professionals generally conforms to scientific traditions of rationality, reductionism, and objectivity. (Examples include: "treatment interventions for patients", "psychosocial correlates", emotional "states" or "factors", "diagnosis of psychosocial sequelae", and "subspecialty of psychosocial oncology." ) It seems impossible to edit out all such language as I bring this material into play, but please bear in mind the implications of these words as you read.

Changing Attitudes Towards Cancer

Historically, cancer was ascribed to various personality traits and/or personal life events, much like other diseases that medicine has had difficulty understanding, such as tuberculosis (Sontag, 1990). In the early part of this century a diagnosis of a "malignant" tumor conveyed a serious stigma, similar to leprosy or syphilis, and as late as the 1960's a diagnosis of cancer was
generally considered a death sentence (Holland, 1998). Surgery was the only treatment option in those days, otherwise... "In cases not curable by surgery, the doctor's role was one of offering comfort" (Holland, 1998, p. 7). With growing treatment options and some successes in curing cancer, especially childhood leukemia and Hodgkin's disease, cancer became somewhat less stigmatized in medicine and, consequently, in the public eye. An American survey published in 1961 determined that 88% of physicians did not reveal a cancer diagnosis to their patients, but by 1979 another survey showed that 98% did, indicating a significant shift in the way medical doctors viewed the illness (Cassileth, 1995). Service groups such as the American and Canadian Cancer Societies (ACS & CCS) were established over this period, with the goals of mitigating public fears through the dissemination of information, raising awareness about the need for early detection, and developing funds for research and treatment. As increasing numbers of people experienced longer periods of remission, there was a greater need to consider the psychological and social strains, which a cancer diagnosis and subsequent treatments created. 

**Developing a Psychosocial Specialty**

At its inception psychosocial oncology was heavily influenced by the medically based psychiatric profession, though, over the years, there have been a number of important changes in the practice of psychotherapy with people living with cancer (Cassileth, 1995). Growing up in the shadow of medicine, psychosocial oncology has endeavored (like medicine) to "diagnose" the psychological sequelae of living with cancer and (again like medicine) to mitigate the worst effects through therapeutic "treatments" usually labeled "psychosocial interventions". Many early psychosocial programs
emphasized the need to reduce people's anxiety and depression, the assumed normal reactions to the stress of a cancer diagnosis (Greer, 1995).

As psychosocial oncology was becoming an established subspecialty, there was a growing interest in the psychobiological correlates of illness, most notably in questioning which mental and emotional states might cause cancerous tumors. Early on, it was believed that a direct causal link between mental/emotional states and tumor etiology would be found. The influences of behavioral medicine and PNI research prompted a rash of studies considering how a person's psychological functioning and interaction with their social environment might impact on the disease. Research in this area has looked at various possible causal factors, such as grief and loss, social isolation, depression, and emotional expression (Fox, 1982; Temoshok & Heller, 1984). But increasingly in recent years, a simplistic cause and effect perspective of tumor etiology has given way to a "systems model involving interactions among events that occur on various levels from genes to the environment" (Cassileth, 1995, p. 264). This change reflects our growing understanding of cancer's complexity.

The turn toward etiological complexity mitigated the difficulties involved in looking for causes at the level of individual psychological events. Susan Sontag (1978/1990) expressed these concerns well when she decried the damage inflicted on a person who is already suffering, by psychologizing the causes and continuance of the disease. Assuming that anger or withheld frustration "causes" cancer, neglects the whole person in favor of one aspect. Just as physicians tend to elide mental and social aspects of the person by focusing solely on the diseased body, psychosocial practitioners were in
danger of focusing solely on the individual psyche, while ignoring the social and physical environments in which the person is embedded.

The major emphasis in psychosocial oncology over the past decade, has been on the psychological and social issues involved in living with cancer as a chronic illness. As more people survive the initial diagnosis and treatments, long term effects of the illness experience have come to the fore and quality of life studies have become increasingly important (Stenstrup, 1996; Cull, 1997; Cella & Bonomi, 1997). A study by Stam, Bultz, and Pittman (1989) provided evidence that people living with cancer report post-diagnosis and treatment related problems across a number of psychosocial domains. These domains include: impaired relationships and consequent isolation, familial role problems, sexual dysfunction, bereavement, cognitive impairment, anticipatory grief, body image issues, denial, adjustment reaction, instrumental problems, and medical system concerns. Taking these as areas for intervention, psychosocial oncology has developed programming which provides people experiencing cancer with educational information, social support, and cognitive control strategies to enhance their coping abilities (Fawzy et al., 1995). Cognitive coping strategies such as disputing negative self-talk, discussing causal attributions, and enhancing evaluative perceptions, are meant to mitigate against the depression or anxiety that arises from maladaptive cognitions. These cognitions, it is assumed, dwell within the individual (Mathieson, 1992). Such cognitive approaches echo the reverberations of cognitive psychology, which have been felt throughout the field of psychotherapy. Currently, individual counselling, and peer or professionally led support groups are used to encourage a whole variety of self-help strategies such as biofeedback, imagery, exercise, relaxation, and meditation.
The following consensus statement was issued after an international conference on psychosocial interventions in 1995, in an attempt to outline exactly what psychosocial interventions can realistically be expected to achieve. The participants of this conference concluded that psychosocial programming should:

- Improve the quality of life of the patient and their family members
- By enhancing coping skills, reducing psychological distress,
- Increasing sense of control and social support, by enhancing the interaction between patients and healthcare providers and by
- Encouraging a better utilization of the medical system (i.e. compliance and risk management) (Kiss, 1995, p. 270 - emphasis added)

Are we, as psychosocial practitioners, only to concern ourselves with such things as "adjustment", "coping", "patient compliance", "service utilization", "risk assessment and management"...? As I have labored to become a good psychosocial counsellor, I have often wondered whether our "interventions" get in the way of simply caring for and being with people who are living with the disruption of cancer. I swing between: seeing my job as allowing people a nurturing and safe place in which to explore and vent their fears, frustrations, and sorrows; offering simply a sense of support, understanding, and guidance through a difficult period; and the feeling that I should be able to provide something more concrete. I wonder if sometimes our "interventions" are an attempt to distance ourselves from others by finding a recipe for "How To Get Through Cancer".
Research Efforts

Research into the effectiveness of psychosocial "therapeutic interventions" has also followed the lead of medical science. "[Q]uantitative research...using psychometric instruments..[in] prospective controlled intervention studies [and].published in leading (and therefore English-language) medical journals" is the gold standard for assessing programs (Stiefel, 1995, p. 215). Stiefel, a leading psychosocial oncology researcher in Europe, questions whether this method of assessment in itself does a disservice to what he believes should be the ultimate goal of psychosocial oncology, that of trying to truly understand "the complex situation of an individual cancer patient" (p. 215). He also wonders whether there are perhaps other viable therapeutic strategies that are not easily amenable to quantitative evaluation.

The proponents of medical science often call the effectiveness of psychosocial interventions into question, and research efforts are stymied by the myriad influences at play in every encounter between psychosocial workers and people living with cancer. There are scores of uncontrollable factors in each attempt to "quantify" the evidence that psychosocial programs do make a difference in peoples' lives. Experimental confounds include such things as: sample populations unmatched for level of social support, stage, and site of tumor; influences from self-care efforts such as increased exercise, dietary changes, and complementary therapies used; differences due to the same program being offered by different therapists; and differing levels of support, which develop in various group settings.
Bernard Fox, a psychiatrist and psychosocial researcher (1995) states that:

...confidence in experimental results may be diminished by interference of possible confounders.

A large number of these exist, both physical, perhaps more easily measurable, and psychological or psychosocial. (p. 257)

He demonstrates the difficulties faced by psychosocial researchers with an example of a highly publicized study of a support group for women living with metastasized breast cancer, which showed a measurable effect on survival time. This particular study has been criticized by the contention that: "people in the control group felt badly about not being randomized to the treatment group and, because of their disappointment, feelings of depression, and giving up of hope, died earlier" (Fox, 1995, p. 262). Other criticisms of psychosocial research include: a lack of definable intervention procedures; an inability to produce specific and measurable changes in "adjustment" during diagnosis, treatment, and follow-up care for various types of cancer; lack of control groups; few objective evaluations of the intervention; inadequate statistical analyses; and too small of samples to show significant change. It has also been suggested that: "age, race, gender, education, income, genetic predisposition to cancer, and receptivity of cancer to treatment have not been sufficiently accounted for in intervention studies aimed at improving patients' adjustment and adaptation" (Iacovino & Reesor, 1997, p. 48).

Taking all of these confounding factors into account seems too daunting a task for any serious researcher. In my experience, working in a caring way with groups made up of
unique individuals makes a poor fit with "definable intervention procedures" or "specific and measurable changes" or control groups matched for "age, race, gender, education, etc....". While the above mentioned researcher suggests that: "With a large enough cohort one hopes to equalize the two groups in regard to the most potent of the confounders." (Fox, 1995, p. 258); I wonder if our whole approach is missing the mark. By ascribing to scientism, has psychosocial oncology simply re-enforced the forgetting which began with the scientization of the art of healing? Is there a place for the complexity of the human experience in our psychosocial efforts and investigations? - a place for the humanity of the experience of illness? Perhaps interpretive human science approaches to investigation would more effectively support us in developing compelling "evidence" that psychosocial care is useful for people living with cancer.

Psychosocial Discourse Positions the Patient

Although there is merit in the fact that psychosocial approaches broaden the narrow biomedical perspective, beyond the acute phase of the physical disease, to consider the long-term impact of the cancer experience on people's lives, the psychosocial model remains problematic in several ways. This model often views the psychological and social struggles which attend a cancer experience as negative, pathological symptoms to be subdued and resisted - another technical problem to be "cured" through a more appropriate (less physical) form of treatment. The psychosocial model continues to assess any distress around the experience of cancer as caused by some personal failing, internal to the individual, such as an inability to cope with stress or the retention of anger. This perspective reinforces the myth that we are isolated individuals who have control over our health, and it detracts us from considering how institutional treatment procedures might be maladapted and in need of change to better meet the requirements of people living with
cancer (Frank, 1997a; Matheison, 1992). Perhaps most problematic is the
complicit intertwining of the psychosocial approach into the medical model.

For medicine, psychosocial programming is often a way of simply
"placating the patient" into compliance with the medical protocol. Acceptance of
the diagnosis and treatment procedures, and "adjustment" to suffering, pain,
and losses, are the expected results of psychosocial efforts (Frank, 1997a).
The psychosocial literature is rife with "psychological adjustment" and
"psychosocial adaptation" as the preferred "outcome measurements" (for a
recent example see Holland's, 1998, Psycho-oncology). Cassileth (1995b)
describes an important goal for psychosocial care as:

Enhancing adjustment and helping patients to regain ability
to lead a normal life. This major goal involves eliminating
patients' preoccupation with illness so that the cancer is put
in its place. Whether working towards cure or palliation
patients need to lead as normal a life as possible. This
requires keeping the disease in proper perspective so that
it does not expand to fill up the patient's entire existence (p.
269, my emphasis)

The goal seems to be to supply the medical establishment with "good patients" who ask
few questions and cause little disturbance to the smooth running of the medical
machinery. I applaud psychosocial efforts that have grown beyond keeping people
passive, helpless, and dependent by educating them in coping with the exigencies of the
medical establishment and acknowledging the challenges of living with a serious illness.
Yet, I wonder if there is something more we are not attending to. Could we perhaps be
doing people struggling with cancer a disservice, by pushing them prematurely toward
forgetting, with our emphasis on being "well-adjusted"? What if "preoccupation with illness" is actually a survival instinct - a pathway towards healing? Are we so sure that "normal life" (as suggested in the above quote) is living well?

**Pressure for Change**

Due to the mounting evidence that health should encompass the whole person, there is increasing public awareness of, and consequent pressure on the medical establishment to sanction, alternative or complementary approaches that take into account the ability of the mind to mediate in immune functioning (Cousins, 1994; Jerry, 1996). This pressure is especially strong among people diagnosed with cancer. For many, the question of the relationship between the mind and body in illness is no longer "if", the focus is on "how" to tap into this connection and use it to our advantage. Numerous authors have begun to provide self-help books predicated on the interrelationship between mind and body (see for example: Benson & Stuart, 1992; Borysenko, 1987; Chopra, 1989, 1993; Dossey, 1982; Kabat-Zinn, 1990; Lerner, 1994; LeShan, 1989; Seigal, 1986, 1989; 1993; 1996; Simonton & Sherman, 1988; Speigel, 1993; Pert, 1991 & 1997; Weil, 1995). Increasing numbers of psychosocial programs are being created, which address the need for people living with a cancer diagnosis to attend to their healing on more than just the physiological level (see Cunningham, Lockwood, & Edmonds, 1993; and Lerner, 1994; for reviews of multimodal cancer-help programs).

*Such approaches can seem like a breath of fresh air in a musty room. But mixing self-responsibility and consciousness with illness can also produce fumes of control, whiffs of causation, and the heady possibility of blame - as posed by the question; "If you created this illness why can’t you cure it?" As I facilitate meditation and yoga classes for people*
living with cancer, teaching breathing, deep relaxation, and mindful being, I am aware of how assuming self-responsibility after the diagnosis can lead to unhelpful regrets about what came before. How do we engage with the "lessons" illness can offer without being overwhelmed by self-reproach? Perhaps the views of health growing out of anthropological and sociological studies can help us...

Viewing Health from Anthropology and Sociology

Social anthropology has turned an increasingly critical eye on the workings of medicine over the years. In doing so it has followed the movement in much of the social sciences and humanities to find some "middle ground between grand theory and attempts at universal explanations on the one hand, and the context specific empiricism and relativistic accounts...on the other" (Lock, 1988, p. 3). The reification of "scientific fact" allowed for a lengthy period of blindness to the need for social analysis of the dominant ideology within biomedicine, even as anthropologists located exotic healing ceremonies and rituals within "other cultures" of medicine, describing healing systems based on non-scientific standards as "primitive". At the same time sociological analyses only went as far as explicating the roles and mores resulting from modern medicine, without considering biomedicine a "culture of healing" in its own right. Frank (1995) describes these approaches as "medicocentrist" - akin to the ethnocentrism of early socioanthropological studies of culture - a stance that upheld biomedicine as the standard of comparison for all other health systems. Studies such as Talcott Parson's description of the sick role (see Frank, 1995) and Erving Goffman's (1963) treatise on the stigmatization of illness and disability, although important works in their own right, did little to question the hegemony of modern biomedicine.

According to Frank (1997a), Parson's theory of illness:
...requires a person to act according to the normative expectations of the sick role, and among those expectations is the obligation to seek and comply with medical treatment. The Parsonian tradition thus reduces the ill person to the patient, and this patient's agency is limited to compliance; the physician becomes the active agent in the illness process. (p. 131)

Though Parson's and Goffman's models both problematize the blaming of people who are ill, early sociological models rarely questioned the Cartesian mind-body dualism or the authority of the physician expert. The unquestioned societal goal of rational mastery reinforced the precarious position of the ill person, requiring a "patient" to remain within the purview of the sick role, never wondering about the doctors' directives or refusing treatment (Kirmayer, 1988). Those who transgressed this role risked being labeled "noncompliant," "difficult," irrational," or "uncooperative" and the authority behind this naming went unquestioned as well. Our tendency to view illness as something we can be held personally responsible for, blaming the individual experiencing distress, and relieving the physician from any need to relate to their "patient's" human suffering, were problematic positions supported by these early theories. These models even supported the physician in blaming the individual for treatment failure, preserving as they did what the expected moral order with "the physician, rationality and health on one side and the patient, irrationality and sickness on the other" (Kirmayer, 1988, p. 64).

The issue of blaming points to a quandary that continues to plague us in the on-going conversation of health. What is our personal responsibility for health maintenance? If I
abuse my body and develop an illness as a consequence, who should pay for my
treatment? These questions become increasingly crucial in an already overburdened,
publicly supported healthcare system. If I develop lung cancer from smoking should the
tobacco company pay? Should I pay? And should “our” healthcare dollars support my
continuing abusive behavior, if, for example, I continue smoking after surgery for lung
cancer? And who gets to say? (I raise these as “neglected” questions, even though they
are beyond the scope of this study).

The early sick-role models have not transferred well into the “morally
ambiguous realm” occupied by the numerous chronic and stress related
illnesses of today (Kirmayer, 1988, p. 62). More recent sociological and
anthropological analyses have provided a framework which allows us to see
how a “metamedical philosophy... guides the basic features of medical
knowledge, its organization and practice” (Lock, 1988, p. 4). Recent studies
reveal the socially constructed nature of the modern “health-care complex”,
including as it does hospitals, clinics, laboratories and medical personnel
(Hunter, 1991). The institutions of modern biomedicine are viewed, in these
studies, as specific by-products of modernist, techno-industrial society and we
are made increasingly aware of the subsystems of bio-technical medicine
which influence our experiences of illness (Frank, 1997a).

Sociological and anthropological studies of modern medicine have
helped show us that biomedicine is not the monolithic structure that we often
assume it to be (Lerner, 1994; Hunter, 1991; Lock, 1988). There is increasing
evidence that individual physicians have varying opinions about appropriate
treatments and that the various specialists and sub-specialists tend,
unsurprisingly, to favor their own procedures. Cross-cultural differences in the
formation of standard treatment protocols, also indicate the constructed nature
of the biomedical enterprise. For instance, European approaches to medicine depend much less on technological and pharmacological interventions than North American biomedicine, with cancer treatments in European countries seldom including the second- and third-line chemotherapy treatments which are often administered on this side of the Atlantic.

Postmodern influences have motivated sociology and anthropology to pay much more attention to issues of social control within the institution of medicine. Studies now describe the use of science and technology as strategies which, in concert with the reification of science in our society, place biomedical discourse beyond the reach of most critics (Lock, 1988). Socioanthropology has expanded the analysis of science as an interpretive project to include the discourse of medicine. Medicine, like all of science, is increasingly being located within a nexus of social, cultural, and historical forces (see Bernstein, 1985; and Kuhn, 1970 for these arguments). The linking of power and knowledge within medicine was strongly influenced by Foucault's (1973) analysis of how medical language constructs a particular way of looking at illness. Medical diagnoses and prognoses are predicated on the belief that diseases will act in accordance with statistical norms, with little regard for the context of the individual who has been diagnosed with the disease. "The belief that diseases are real entities and that their elimination crystallizes the essence of what medicine is all about" are increasingly seen as culturally constructed notions which can be questioned (Lock, 1988, p. 4, emphasis in original). Cassell (1990) argues that medicine should be returned to its original concern of alleviating human suffering. This move would require that medical practitioners confront decisions about how to best deal with each individual's illness experience, rather than simply treating diseased bodies.
Medicine, from this perspective, no longer inhabits a value free realm and issues of moral responsibility in the provision of care can be opened up.

Questioning the authoritative stance of biomedicine is the hallmark of postmodern analyses of medicine. Frank (1991) points out that: "When a person becomes a patient, physicians take over her body, and their understanding of the body separates it from the rest of her life" and he questions the legitimacy of this separation (p. 52). The existential fact of embodied experiences of vulnerability and suffering are missing in the biomedical discourse and many theorists are questioning this lack (Cassell, 1990; Kleinman, 1992 & 1996; Lock, 1988). Kirmayer suggests that the entrenched dualistic schism between mind and body may be re-paired by "shifting from a preoccupation with causes to an emphasis on care" (p. 82). This emphasis foregrounds the voice and needs of the ill person. Others have echoed this need for a fundamental shift in perspective, promoting one that moves beyond "the objective stance of the cure paradigm of Western medicine and embraces a care paradigm where the subjective experience of the person is of central concern" (Lindsey, 1995, p. 287).

Socio-anthropological analyses point out how medicine has distanced us from the unavoidable human experiences of suffering, vulnerability, and death; and how, in reconnecting with these inescapable aspects of our humanity, we might begin to redirect medical practices to more humane avenues (Frank, 1992, 1997a & b). Baron (1985), a practicing physician with a bent for phenomenology, proposes that: "Nonmedical descriptions of illness show how we can reorient our thinking to encompass both our traditional paradigm and one that takes human experience as seriously as it takes
anatomy" (p. 606). Frank (1997a) suggests that illness experiences are fundamentally phenomenological, narrative, and hermeneutic:

The morality of illness is inherently phenomenological since the moral issues of care and mutual obligation are one aspect of the ill person's construction of an intersubjective reality. It is narrative, since ill people sort out their reality and its moral issues through the exchange of stories. It is hermeneutic since these stories require ongoing interpretation by those who tell them. (p. 135).

By paying attention to people's stories of illness we have an opportunity to realize the ways in which institutional medicine can support or disrupt the healing needs of people who are experiencing illness.

How would our views of healthcare, our understanding of what it means to experience illness, be transformed if we really listened to the 'nonmedical descriptions of illness'? Can we expand on the medical paradigm by considering what individuals have to say about their experience? What might we learn about ourselves as healthcare providers (or as human beings?) if we expanded our understanding of health to include phenomenological and hermeneutic perspectives?

A Hermeneutic-Phenomenology of Illness

Since Husserl, the philosophical approach of phenomenology has questioned the ascendancy of scientific objectivity as the only valid way to "know" the world and us in it. A hermeneutic phenomenological perspective views science as "one particular way in which humans tell stories and refigure the world of lived experience, and the rules of this particular narrative genre or
language game are determined not by nature but by culture" (p 46, Madison, 1988). By positing that human beings are inextricable from the world in which they find themselves, that consciousness is immutably embodied, and that all human experience is embedded in a context comprised of language and history - a hermeneutic phenomenological perspective may help us out of the dualistic quandaries which modern medicine and its off-shoots tend to mire us in. Conscious "being", from a phenomenological perspective, is simply (and complexly) our on-going experiential involvement with the world; something which is "opaque and ambiguous, and lived bodily" (Valle & King, 1978, p. 17). This continually changing embodied, enlanguaged, and intersubjective existence contrasts dramatically with the modernist perspective of a rational, central, controlling mind or will which is assumed to be distinct from the body and separated from some objective reality - the individual self on which modern biomedicine is predicated.

A hermeneutic-phenomenology of illness requires the description of, and serious reflection on, personal experiences of sickness in order to bring subjective meanings to the level of intersubjective or shared understandings. Through conversational interaction we can create new possibilities for action. This approach allows us to recognize the suffering of the subjective being at the center of every medical drama - a recognition which encompasses the ill person's intersubjective context as well; the web of meanings, understandings, and relationships which situates their very being-in-the-world (Heidegger, 1962). In the words of one recent theorist: "...phenomenology discloses the manner in which the individual actively constitutes the meaning of his (sic) experience" helping us to understand that "there exists a decisive gap between the patient's experience of illness and the way in which physicians think about it
in terms of disease", thus allowing us to develop an "expanded paradigm of illness" (Toombs, 1987, p. 220). This expanded paradigm can educate us to consider our bodily selves, and our enlanguaged and contextualized nature, moving us toward a practical wisdom of the illness experience.

Enlanguaging the Experience of Health

Hermeneutic-phenomenology also requires that we pay attention to how language is used, because our relationship with the world and others is "enlanguaged". All understanding is achieved through language and "the conversation that we ourselves are" (Gadamer, 1994, p. 378). Language plays a significant role in the negotiation and interpretation of the local worlds of meaning contained within any given discourse (Kleinman, 1992). As Maturana (1988) describes: "we have no way of referring to ourselves or to anything else outside of language", we create ourselves and our world through our cooperative use of language, our conversations involve a "consensual braiding of language and emotions" and those conversations conserve and reflect our worldview (p. 43). We express the coherences of our world through our language and in turn our language provides coherence to what otherwise might occur to us as, in William James' apt phrase, a "blooming, buzzing confusion". Our every experience is organized and interpreted through language.

From both the phenomenological and hermeneutic perspectives then, words carry much more weight than we usually concede to them. Because language informs our very ability to think, care should be taken not to prejudice (pre-judge) our shared understandings by using words that carry implicit meanings which differ from our present needs. Baron, the medical doctor turned phenomenologist, describes the concern for language this way:
"Phenomenologists are acutely aware that words, especially everyday words, carry with them whole universes of philosophic presuppositions" (p. 608, 1985). For example, the word "embodiment" or "lived-body" is used in phenomenology, instead of the word "body", in an attempt to draw attention to our experience of the bodily-self as center of all thought, action, and existence. This is done to emphasize our bodiliness as something that cannot easily be separated from our thinking selves. Using language carefully is a difficult prospect, especially when we are attempting to negotiate new territory, as our habitual word usage often leads us unconsciously back on the same old paths.

Hermeneuticists have long used etymological investigation to bring forgotten meanings and lost sensitivities, which may have been hidden by our everyday understandings of words, back into play. For example, "invalid" and "patient" are fairly explicit examples of words which, if we consider their underlying meaning, "show" our commonly held belief that people experiencing illness are no longer considered able to act on their own behalf. But what do we make of the fact that: "diagnosis" comes from a combination of the Latin gnosis meaning "knowledge" and dia meaning "opposed to" - What type of knowledge might a diagnosis be opposed to?; or that "cure" has its roots in the Latin word cura which carries the meanings "care", "concern" and "attention" - words which have little connection with our present usage of "cure" to designate the elimination of disease; or that tumors are described as either "malignant" or "benign", words which are respectively associated with "spiteful, mean, stingy, or bad" and "kind, affable, friendly, or beneficial"? There is a recollection of meaning in our every word.
It has also been suggested that the words of poets and novelists resonate with the lived-meanings of experience in ways well beyond the abilities of the researcher or the spoken word of research participants (Frank, 1997a & b). Hermeneutics in particular, carries expectations that the inquiry of a topic would do well to include the investigation of appropriate written texts. Perhaps the well crafted words of poets or authors can better “train our ear to hear what is expressed in action and in speech in the most daily of everyday encounters” than the efforts of researchers (Frank, 1997a, p. 142).

**Bringing The Body Back In: Embodiment in Illness**

Phenomenology particularly, addresses the issue of our bodily experience of illness. The phenomenological notion of the sensuous, experiencing, lived-body:

...is very different from the objectified body diagrammed in physiology textbooks, with its various "separable systems"... very different from that complex machine whose broken parts or stuck systems are diagnosed by our medical doctors and "repaired" by our medical technologies. Underneath the anatomized and mechanical body that we have learned to conceive, prior indeed to all our conceptions, dwells the body as it actually experiences things, this poised and animate power that initiates all our projects and suffers all our passions. (Abrams, 1996, p.45-6)

The approach of modern medicine has been to treat human beings as bodies - divorced from consciousness and interconnectedness. Phenomenology opens us to a practical wisdom derived from our sensing, emotional "poised
and animate power"; a bodily knowing which cannot be separated or disconnected from our mental/emotional selves, nor from our involvement with others.

The conjoining of mind, body, and context through phenomenology and hermeneutics requires new perceptions of mental and physical illness, and illness related behavior, that go beyond traditional theories of physical treatments or psychosocial interventions. Our theories and practices must begin to account for the interpolation of mind, body, and context in human health, necessitating a dissolving of the boundaries between medicine, psychology, and sociology (Radley, 1996; Frank, 1996). As Hank Stam describes it: "...body talk crosses disciplinary lines; it is not interdisciplinary so much as it is transdisciplinary. Bodies resist boundary maintenance" (1996, p. 555). An understanding of how meaning and biography play a role in the disruption of physical functioning and its restoration, is crucial to an embodied perspective (Radley, 1991). The following has been suggested as a possibility for reconfiguring our understanding, for educating our perceptions, of illness:

*Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication - the language of the organs - through which nature, society, and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle.* (Schepet-Hughes & Lock, 1987, p. 31)

An embodied perspective of illness requires that we consider: how the body might also be a site for resistance to the constraints of society; how seemingly disturbed behaviors
may be the result of resisting untenable positioning; how individual illness experiences reflect society’s ills. Perhaps we could depathologize our therapeutic theories and view all human acts as meaningfully related to contextualized lived-experience.

There is a common ethical dimension that runs through the numerous discussions of embodied illness (Frank, 1996; Stam, 1996). As healthcare providers, we need to take care that our models and our "expertise" do not get in the way of our ability to connect with those who come for help. John Shotter (1995) suggests that the over-riding moral implication of situating our understandings and explanations within the lived experience of the self is to move: "people’s lives out of the technocratic, bureaucratic control of experts, and to place the responsibility for their own forms of life back into the hands of the people in relation to each other" (p. 387, my emphasis). The prevailing ethic of embodiment requires a commitment to holding our models and concepts lightly. Embodiment thus becomes a guideline for how we should carrying on in the world; judged by its usefulness in solving practical problems (Pile & Thrift, 1995). Our theories and practices, our treatment protocols, procedures, and interventions must stand ready to be adjusted by the lived experiences of each new individual we meet.

An embodied sense of self allows us to appreciate more fully how threats due to serious illness can have a dramatically disorganizing effect, requiring a major reappraisal of the self in relation to the world and others (Charmaz, 1987, 1995; Corbin & Strauss, 1987; Mathieson, 1992; Zegans, 1987). If we know ourselves, others, and the world essentially through our bodies, as phenomenology suggests, then threats to the body imperil the very ground of our being and the true dis-ease created by an experience of illness cannot be understood in more restrictive terms (Radley, 1991).
From this perspective psychosocial approaches which emphasize compliance and acceptance have the effect of compounding the medical control of the body, which uses "diagnosis and pathology" to discount and replace "experience and biography" (Radley, 1991, p. 39). A hermeneutic-phenomenology of illness would have us pay close attention to the narratives (Frank, 1993, 1996), discourses (Ussher, 1989), or stories of the people experiencing illness. The emphasis in psychosocial efforts would be to aid people in connecting with their own knowing and with what they believe they need to heal, rather than reinforcing the authority of the medical experts. The experience of illness, viewed from a phenomenological perspective, brings us to a dramatic understanding of our fundamental embodiment: to a true understanding of how we are our bodies; that bodies are not just one aspect of ourselves which can be, for the most part, ignored or set aside; and that as bodily beings we are vulnerable to pain, suffering, and death, both our own and that of others.

An emphasis on embodiment also necessitates a consideration of gender - a questioning of the impact that being female or male has on our experience of illness. Audre Lorde contends that women seem to be subjected to a myth of cancer as a "cosmetic problem" (p. 55), which is in keeping with the societal stereotype of woman as visual object. This myth portrays that all women need really worry about during illness is their physical appearance and it can be seen in the emphasis on breast prostheses, wigs, and cosmetics for women who have cancer. "Reach for Recovery", the volunteer support program for women with breast cancer, and the "Look Good...Feel Better" campaign, programs which are endorsed by the Canadian Cancer Society, both entertain these myths. Particularly the latter claims that it is: "dedicated to helping
Canadians living with cancer cope with the appearance-related side effects of chemotherapy and radiation treatments" (Canadian Cosmetics and Toiletries Foundation, 1996).

The "Look good - Feel Better" program promotes women's health and well-being by encouraging them to accept cheerfully rendered "tips on skin-care, make-up, wigs, headwraps and much more" (CCTFA Foundation, 1996). While it may be very helpful for some women to "look good" during their cancer treatment, I have misgivings that this "take" on cancer glosses over much more pressing issues such as: What are the best treatment choices? Does the wearing of wigs and breast prostheses disguise the prevalence of female cancers? Are environmental pollutants a major factor in the disease? and, Are these well turned-out women going to be alive next year?

Bringing the Context Back In: The Social Arena

Along with reconsidering issues of language and embodiment in our experience of illness, a hermeneutic-phenomenological perspective brings the social context of each person back into play. Shared attitudes and assumptions about health and illness have evolved historically to create a context that influences all of our experiences. This perspective elicits the awareness that we live within a social milieu or discourse which views illness as an individual failure, a shortcoming in our presumed ability to control or master our bodies with our minds. This perspective helps us to see how those experiencing illness may require support to disengage from societal messages of blame and guilt.
One phenomenological sociologist who struggles personally with a serious illness, Kathy Charmaz (1987, 1995), describes how chronic and progressively debilitating illnesses require on-going reappraisals of the self in relation to the world. She takes a very positive view of this process, suggesting that as people struggle to create valued lives and selves during illness, they do so “with a strength and vitality that is seldom ascribed to them”, which “has much to teach us about the human capacity for ‘courage in the face of adversity’” (p. 284). Corbin and Strauss (1987), also using a phenomenological approach, see this self-appraisal as continuous “biographical work” and suggest that it can create unnecessary challenges at an already difficult time in people’s lives. Regardless of the conclusions reached, a hermeneutic phenomenology of health provides a perspective which expands our present horizon of understanding (Gadamer, 1994), calling us to listen carefully to people’s lived experiences, to the language used, and to the prevailing social discourses in order to hear what is missing.

A hermeneutic-phenomenological approach creates a space in which to search for new ways of understanding human experiences of health, illness, and well-being? It seems important to recognize that the basic question from this perspective is - not "why" things are as we find them, or even "how" we came to be in this present state - the fundamental question asks: "So what now?"...or; Given the present state of affairs, how best might we carry on from here? Using a Zen perspective, Nan Shin (1986) puts it succinctly:

In everyday living, why is irrelevant. The question, how to proceed this being the case, remains. (p. 65, author's emphasis)
Given that biomedicine continues to ignore some very important aspects of human health and healing, how can we best support those who struggle to engage their whole being, rather than just their bodies, in the illness experience? - and - How might we transform the limited biomedical interpretations of our illnesses?
CHAPTER FOUR
WAYFINDING

If the responsibility of the ill is to tell, 
the responsibility of the healthy is to listen. 
(Arthur Frank, 1997a, p. 42)

Pathways to Living Well During Illness

As I made my way through the reams of transcripts from my conversations with women who were entertaining a sense of well-being during illness and the various texts authored by people about their own illness experiences, I found myself following pathways which often wound back on themselves. My interpretation, it seemed, would have to encompass something very non-linear and non-logical that is inherent to the process of taking up illness in a way that promotes well-being. As outlined earlier, I have framed my interpretation of the experience as a series of paradoxes. The last chapter explored the various discourses of illness at play in our society. This chapter traces a number of paradoxical pathways to living well after a life-threatening cancer diagnosis. It also provides a reflection on how a person’s approach to living well with cancer can be helped or hindered. Both of these sections are illustrated through the voices and words of the twelve women who conversed with me and the numerous first person accounts of illness outlined earlier. As each new voice is introduced, I will briefly describe their story. A more detailed narrative of each participant’s experience can be found in Appendix B. The chapter begins with an exploration of the notion of paradox and the ways in which paradoxes bring meaning to this interpretation of well-
being during illness. Throughout the chapter I continue to weave into the
cornerstone my own wonderings, the connections I have made, and the
questions which continue to puzzle me.

The voices and stories presented here are meant to expand the area of
wellness into the territory of illness, through mapping the pathways of what it
means to live well after a life-threatening diagnosis. Currently, as noted, our
predominant maps of health, illness, and well-being tend to derive meaning
from the biomedical model, marking out disease as a concrete state of the
physiological body, requiring physical intervention and perhaps a period of
convalescence (literally - from the Latin convalescere - to grow strong or
vigorously). But if we take into account some of the other, less well
established, discourses on health we find that a simple physical interpretation
does not do justice to the experience of illness. A serious illness is not just a
physical event, it encompasses all aspects of our being, influencing the
complex webs of meanings and relations which support each of our lives.
Illness does not simply require regaining one’s bodily vigor after a period of
physical treatment, although that may be part of the process. If fully embraced,
the illness experience seems to hold some important understandings about
what it means to live well - at any time. This interpretive mapping of the territory
of illness emphasizes the possibilities of living well after a cancer diagnosis.

As with all maps and models, there is a potential for these pathways to
become entrenched in another attempt to create certainty or develop universal
truths about how to live well with illness. But, having grown out of the rich soil
of our everyday interactions and engagements in the "lifeworld", the truths
derived from this foray into the topic remain open to continuous renegotiation.
The paradoxes described here are not intended to provide the complete or final
map of this territory, rather they are an invitation to wend our way through the thorny thickets, and into some surprising clearings, which the crisis of a life-threatening illness presents.

Paradoxical Explorations

The Oxford Dictionary defines paradox as a "self-contradictory, essentially absurd statement; a person or thing conflicting with preconceived notions of what is reasonable or possible" (1989). This leads to thinking of paradoxes as unexpected refutations of our taken-for-granted assumptions; as straight forward logical contradictions of our common-sense beliefs. But paradoxes, as I have come to understand them, are not usually that simple. Historically, a sage from the island of Crete named Epimenides was credited with espousing the paradoxical statement: "All Cretans are liars". The paradox herein, lies in the twist that if the statement is true it would make Epimenides (being himself a Cretan) a liar, rendering his statement false, which in turn restores Epimenides' status as a truth teller, thereby rendering his statement true, which sends us back to repeat the quandary again and again. It is this continuous, reiterative association of disparate notions that I want to emphasize through the use of paradoxes.

The image of the mobius strip provides a particularly appropriate metaphor for this dynamic integrative process, which joins dualistic opposites into contiguous wholes. The paradoxes of living well during illness presented here are not static, binary oppositions that can be laid out on a two dimensional continuum. Rather, they are seemingly opposing possibilities, which are at play in the lives of people who attempt to live well after a cancer diagnosis. People who are facing their mortality through illness are engaged in a process of integrating a number of disparate or dichotomous issues into their lives.
Rather than viewing these as stationary, "either-or", oppositions connected by linear pathways, imagine them in a dynamic interplay, in a "both-and" integration wherein one enfolds or leads into the other - which in turn doubles back into or enfolds the former. Each informs and thereby transforms the other, in a process that resembles a good conversation weaving to and fro, one person's point of view calling up and informing the other's.

Perhaps paradoxes are an integral part of our worldly experience, a part which scientific rationalism has attempted to deny. If, in fact, "the observer and the observed are part of the same continuum" (Greenwood & Nunn, 1994, p. 214), then all of our attempts to understand the world are paradoxically engaged in this reiterative process. A process of knowing ourselves through learning about the other and knowing the other through learning about ourselves. I find myself wondering: How much of my ability to understand those I have spoken to depends upon my own self-understanding? And I realize how much I have I learned about myself and my own struggles to live well, as I have listened to these stories.

Typically, as we categorize our understanding of things in our usual linear, logical manner, we infer dichotomous, polar oppositions setting one
term above the other in a hierarchy of preferences. In our usual process of
categorizing, defining, and abstracting in order to clarify and explain our world,
we build innumerable hierarchical, oppositional dualisms. Elizabeth Grosz
(1994) describes this process:

Dichotomous thinking necessarily hierarchizes and ranks the two
polarized terms so that one becomes the privileged term and the
other its suppressed, subordinated, negative counterpart. The
subordinated term is merely the negation or denial, the absence
or privation of the primary term, its fall from grace; the primary
term defines itself in expelling its other and in this process
establishes its own boundaries and borders to create an identity
for itself. (p. 3)

The dualisms that under gird much of our thinking restrict our ability to
remain open to combinatory possibilities. Take illness and wellness for
example. Illness is dualistically opposed to good health as the negative
absence of well being. Just as the Old Norse origins of the word connote:
"illness" gets placed at the "bad" end of the spectrum, an evil to be avoided and
fought against; whereas "health", at the positive end of the spectrum, is idolized
and sought after. One "falls ill", as in falling from the blessed grace of "good
health" into the evil pit of sickness and suffering. One becomes "invalid" and
"infirm": as if only good health imbues validity and solidness; while sickness
incurs faultiness, worthlessness, and weakness. Similarly, pain, suffering,
and death are all placed at the negative, devalued ends of the dichotomous
continuums on which they rest. We are thus proscribed from finding strength
and validity in illness, or worthiness in suffering and dying.
I want to consider what possibilities arise if we turn the ends of these linear dichotimous poles, twisting and rejoining them in the middle again, as the mobius does; re(pairing) the "either well-being/or illness" into a both/and proposition - combining the linear separation of the two into a contiguous, seamless whole.

Is it possible that "explanations" depend upon such hierarchical oppositions and categorical truths, but that "understandings" require something less starkly black and white, something more infused with shades of colour? Is the back and forth of a good conversation (like the to and fro of the mobius) perhaps a more appropriate way to come to an understanding? Could we better understand our world in both/and configurations like the Taoist yin/yang notion? If we embrace the either/or's we live with as dynamic interconnections would our need to oppose dissolve? - as "self/other" "us/them" begin to co-respond (to dialogue) could we develop a more compassionate acceptance of otherness and ambiguity?

Because paradoxes encompass a "both/and" logic, they engage, transform, and create combinatory possibilities where hierarchical oppositions might otherwise impose their authority (J.W. Garrison, personal communication, March 1, 1998). Yet, our natural tendency when faced with a paradox is to "deny its existence by denying one half of its self-contradictory proposition" (Greenwood & Nunn, 1994, p. 2). This denial allows us to continue living as if we have some rational/linear/logical control over the world and our lives. Accepting paradoxes opens us up to the ambiguities and difficulties, to the mysteries of life that are not easily controlled or solved. There is a consequence to this acceptance of paradoxes. Simple, dogmatic either/or answers to the questions life poses no longer suffice. We are left with the
need to trust our inner (non-logical, intuitive) knowing about what next step to take.

As I mused on the idea of using paradoxes in conversation with one of the women I spoke to, Jazz, she had this to say:

*Life's magic hides in a paradox. ...It's a subtle process of facing oneself, not running away from demons or undesired states - like seeking happiness by trying to run from unhappiness - that seems to be our linear thinking. Reality is not running anywhere, just staying there and facing it.* (Jazz2, p. 40).

Jazz's experience has led her to a much deeper connection with herself, others, and the world around her. The story of her illness journey is very dramatic. She survived high dose chemotherapy, total body irradiation, and a harrowing bone-marrow transplant after months of misdiagnoses. By the time her illness was "recognized", Jazz had grapefruit sized lymphoma tumors in her throat, breasts, and abdomen. Although the difficulty in obtaining a diagnosis left Jazz reeling with anger, she has transformed her close brush with death into a totally new awareness of life. As demonstrated by this quote, she is less likely to rail against or run from the difficulties her life presents and more likely to face them squarely searching for the deeper meanings involved. She feels it has been healing for her to understand and work with the paradoxes that arise in her life.

*Perhaps the idea of paradox can also help us to 'disarm' the battle metaphor so commonly applied to illness. If illness is no longer an evil opposite to well-being, if wellness can be experienced during illness, then we may not need to fight against it so hard. Could we possibly "befriend" illness, perhaps even "cultivate" it for the opportunities it provides using metaphors of growth and gardening rather than war and*
strife? Could we see it as a journey, one in which the destination is not as important as what happens along the way - considering ourselves travelers, intent on the journey, rather than tourists (temporary visitors)?

Those who wrote and spoke of their experiences gave evidence of negotiating numerous contradictory pathways. They gave examples such as feeling that the life threat of the illness, while incurring physical and psychological limitations and losses, at the same time gave them an unprecedented freedom, a sense of permission to make changes, a release from the banality and grind of everyday life. They described that living well with a serious illness requires the consideration of self-responsibility alongside the rejection of any sense of blame. Their stories of well-being during illness show that it requires the establishment of trust in those whose expertise is needed, at the same time as it calls people to trust themselves more explicitly. Negotiating wellness during a life-threatening illness also results in some surprisingly close connections with people who had been strangers, and sometimes discordant distance from intimate loved ones. These are a few examples of the paradoxical pathways that will be shown in detail in what follows. While no two of the illness stories I was exposed to were exactly alike, many described traveling the mobius routes of these, or similar, paradoxes. But let us look to the words of those who participated in conversations with me and those who wrote of their illness experiences.

While "mapping" and "pathways" might incline one to expect some linear progression from illness to a sense of well-being, a journey with a beginning, middle, and an end, this is not what I experienced as I investigated the topic. I felt myself to be following clues through a labyrinthine forest, much as the origins of the word "investigator" would
lead us to expect, coming as it does from the Latin investigare, meaning "to track" or "search after footprints" (footprints are vestigium in Latin). In seeking for the vestiges of what it means to live well during illness, I gathered clues wherever I could find them. (Clues from clew - the Latin word for the ball of string that was unwound through a labyrinth to mark the way.) I searched less for the substance - the essence of the thing - and more for the heart of the matter - from the Anglo-Saxon heart, meaning the essence of life. Please be aware that a separate mapping of each paradox is an attempt to delineate with some clarity experiences that overlap and intertwine. Quotes used in one paradox often point as well to another. I suggest we would do well to remember that a map is never an exact replica of the territory.

Paradoxes

The Paradox of Living with Dying

The first and perhaps over-arching paradox is the process of coming to a deeper appreciation of one's life by fully facing, even embracing, one's approaching mortality. Everyone I spoke to and every autobiographical account I came across had something to say about the experience of finding an increased significance in living by being present to the fact that one might die sooner rather than later. This recognition of life's preciousness seems to be a predominant aspect of the phenomenon of living well after a terminal diagnosis. A serious cancer diagnosis brings the awareness of death close. As one of the first women I spoke to said: "It's right there in your face! It's not an option anymore, it's an option that got really close." (Carole1, p. 26). For Carole, death came much sooner than she or I imagined - coming as it did before we had a chance for a second conversation. Perhaps her exuberance and zest for life belied the severity of her disease. She certainly engaged
enthusiastically in conversation with me, describing how she lived each day with an abundance of enthusiasm and apparent well-being, even as she was under-going treatment. Carole never returned from a long anticipated holiday to her birthplace in the Maritimes.

Illness in our society is commonly held to be a negative experience, and yet the women I spoke to often described being blessed by illness in their new found ability to truly grasp and feel a sense of gratitude for every passing day. There was a great variety in the preferences people had for how best to apply the learnings that illness initiated. But, all expressed a similar feeling, that perhaps they had come to an acknowledgment which was tragically missing in most people’s lives, that perhaps most of us not faced with a life-threatening illness, in fact, - "live less than well" (Frank, 1993).

Another one of the participants, Ginger, who has lived 13 years after the metastatic recurrence of breast cancer, stated emphatically that even if she was given a guarantee of a cancer free life, on the condition that she returned to her former (pre-cancer diagnosis) way of being, she would not do it. The awareness and growth, which the threat of cancer had demanded of her, felt too important to give up, not even for the guarantee of an extended life. She describes her experience this way:

*The greatest pain and the greatest pleasure that I have known has been since my cancer. Cancer has forced me to go...to go deep,*

*but it has also allowed me to soar and I am still doing both.*

(Ginger1)

For her, cancer was a "wonderful teacher" providing her with an important opportunity to explore a new way of being in the world. Ginger has engaged in a complete change of life, with a significant emphasis on meditation.
diaphragmatic breathing, and yoga postures. She has spent many years teaching others how to engage in this mind-body process of healing and growth. Her HOPE groups encourage people living with a cancer diagnosis to slow down the usual pace of life in order to allow themselves time for exploration of, and reflection on, what they most value in their lives.

Living well after a serious diagnosis involves reframing the experience of illness and reorganizing one's life to make each day more meaningful. Cancer, while it threatens people's lives, also allows them to live with a new awareness of the importance of each day. A woman who chose the pseudonym Inspiration, and who competed as a master's athlete in a marathon within weeks of surgery for bowel cancer, told me:

"It's not as normal anymore just to be healthy, you know. You really appreciate that you can do this. Yes, you really appreciate life. It makes you very aware of your fragility too, you know, and also of the time - in a way - that you have left. You want to do certain things, so you make better use of the time." (Inspiration1, p. 11)

Inspiration has made better use of the time she has left, by engaging more fervently in her preferred pastime of training for races with a mixed-age group of other competitors. Unlike before the diagnosis, she now rarely hesitates to take an opportunity to race, traveling extensively to compete at the international level. She hopes the way she has chosen to live after her diagnosis will be seen as inspirational to others, hence the pseudonym she chose.

Many of the women I spoke to expressed the idea that the diagnosis of cancer, painful as it was, brought them to a sudden new awareness of the world and their place in it. There is a new or renewed sense of the significance their individual life makes in the world. For these women living well entails a
sense of gratitude in simply being alive. Jazz, the woman who made the spectacular recovery from fast spreading lymphoma, described this gratitude in a variety of ways:

The cancer experience... - cancer wasn't the best thing that ever happened to me - but the "cancer experience", the wake-up call,...I'm thankful for that. (Jazz1, p.13);

One day I looked up at the sky and suddenly felt this immense gratitude. ...suddenly I became aware of the beauty of the sky and the sun. It was always there, but something shifted, that channel opened and since then I really try to be aware of what's happening in my life and be in a thankful mode. (Jazz1, p. 19);

and

I have to remind myself - on my death bed, will this moment count, will this day count, will this month count. I mean every moment obviously cannot be, but it's in a context. ...as long as I feel overall a sense that, "Yes, it was worth staying alive today", I feel good - and that for me is good living. (Jazz1, p. 21);

Another woman, Beth, claimed:

I haven't come as far as some people do, you know, they look at their cancer as a gift...(laughter)...I just can't go there, but definitely what I have found is that some of the most amazing things in my life, some of the best things in my life, have come through this cancer journey of mine. So that's pretty remarkable. (Beth1, p. 6)

Like Jazz, Beth underwent the frightening and painful trials of an autologous bone marrow transplant, a newly recommended "conventional" treatment for the late stage breast cancer diagnosis she was given. The biomedical hope
was to give Beth more time than expected with less rigorous treatment approaches, as her disease was so far advanced having been misdiagnosed over a several year period. But, for Beth as well, the consequence of such an imminently life-threatening diagnosis seems to be a renewed appreciation of life's gifts.

Many authors of illness stories, such as Arthur Frank (1991), Kat Duff (1993), and Oliver Sacks (1994), write of their lives being beneficially informed by facing their mortality as well. Audre Lorde (1980), a black feminist activist who had a mastectomy for breast cancer, describes her experience of facing her mortality as follows:

*Living a self-conscious life, under the pressure of time, I work with the consciousness of death at my shoulder, not constantly, but often enough to leave a mark upon all of my life's decisions and actions. And it does not matter whether death comes next week or thirty years from now; this consciousness gives my life another breadth. It helps me to shape the words I speak, the ways I love, my politic of action, the strength of my vision and purpose, the depth of my appreciation of living. (Lorde, 1980, p. 16)*

Sharon Batt, a Canadian journalist who wrote of the politics of breast cancer as she went through treatment for it herself, explained that: "*Having breast cancer meant enlarging my view of life - specifically, it meant allowing an awareness of life's finiteness to be a part of my everyday existence*" (1994, p. 150).

Treya Killam Wilber, who died peacefully in her home after living three years with late stage breast cancer, contended that cancer taught her the ongoing lesson of: "*balancing the will to live with the acceptance of death*" and finding a place of "*passionate equanimity*" within herself - a place which
allowed her to make the most of how ever much time she had left (Wilber, 1991). Living well after a life-threatening diagnosis seems to entail an attitude of dwelling with full awareness on life - even in the face of death. An attitude that Nan Shin (1986) described for herself as follows: "...as long as I'm living I'll live. When I'm dying I'll die." (p. 97). Nan Shin is an ordained Zen Buddhist nun who wrote about her experiences of "everyday living" after receiving a diagnosis of uterine cancer. Her small book questions the usual approach to illness, braiding her own feelings and understandings about illness together with simple descriptions of her everyday life. With this straight-forward simplicity, she describes many of the difficulties people who are mortally ill face, as they try to just carry on living.

Another aspect that seems inherent to this life-death paradox is that illness grants a certain permission; one is allowed to be more fervently who they are, to do what they really want to do, with less concern or regard for what others might think. It is as if the societal restrictions which normally keep us from acting too boldly or making radical changes are suddenly stripped away - and living one's life to its fullest, expressing one's innermost desires, become much more crucial as the criticisms of others become less inhibiting. Anatole Broyard, a literary critic who wrote throughout his experience of living with and dying from prostate cancer, claimed:

A critical illness is like a great permission, an authorization or absolving. It is all right for a threatened man to be romantic, even crazy, if he feels like it. All your life you think you have to hold back your craziness, but when you're sick you can let it out in all its garish colors. (1992, p. 23);

And Audre Lorde wrote:
I am learning to speak my pieces, to inject into the living world my convictions of what is necessary and what I think is important without concern (of the enervating kind) for whether or not it is understood, tolerated, correct or heard before. (Lorde, 1980, p. 48)

There is a sense in which living well requires that each of us do what we need to do for ourselves, not in a selfish way, but in an authentic way which does not concern itself with the external judgments of correct behaviour.

Another example of this sense of permission comes from Inspiration. She describes her experience of moving from a place of choosing on the basis of other’s needs to one of making her choices based on her own needs, in this way:

...but it was the cancer experience that made me say - that’s what I want to do and I’m going to do it! ...that was the very best thing of it, because that was important. Well, you know, your whole life you mediate and you’re in between and you give a lot... (Inspiration1, p. 7)

And Linda, a woman who had a breast cancer diagnosis several years earlier and who displays a wonderful sense of humor, said...

Well my kids say that I’m a lot goofier than I used to be...I seem to be more so now, because I really don’t care what people think. If they want to think I’m stupid or silly that’s OK, you know. I know where I’m coming from and I know why I’m coming from there. What people think of me just doesn’t mean as much anymore.

(Linda1, p. 7)
It is hard to imagine that Linda ever cared much about how other's judged her, she exudes irreverence and delights in teasing anyone who gets too serious, but she claims to have become much less inhibited, and better able to make good decisions for herself, since receiving a cancer diagnosis. She describes leaving the position she held at the time of her diagnosis because her supervisor was uncomfortable with the fact of Linda's experience with cancer and unable to accept the changes she had made.

Other women also told me of quitting jobs in which they were unhappy. One woman proposed a completely new position for herself and had it accepted, and another radically rearranged her life plans, quitting her doctoral program and getting divorced. As a culture we seem to sanction the increased latitude of choices made by those who are seriously ill. This approval is evident in such charitable organizations such as the Children's Wish Foundation, which raises funds to fulfill the "last wishes" of children who are dying.

*Perhaps the occasion of "breakdown" that illness provides becomes a "clearing" (Dreyfus, 1991; Heidegger, 1962): a space in which to live with an exuberance and freedom we generally deny ourselves; room for dancing out all the many colors/feelings of our life; time in which to recollect our unique abilities and sense of purpose. Many religious and mystic writers have suggested that living well requires a life informed by the constant awareness of death. Buddhist practitioners engage in meditations visualizing their own death in order to become mindful of the ephemeral quality of all living things, to develop compassion for the fears we all harbor - fears which keep us from acknowledging pain, suffering, and death as inevitable aspects of life. Jean Vanier (1999) says that those who come to face their own fears and vulnerabilities:*
...begin to realize that to become fully human is not a question of following what everyone else does, or of conforming to social norms, or of being admired and honored in a hierarchical society; it is to become free to be more fully oneself, to follow one's deepest conscience, to seek truth, and to love people as they are. (p. 95)

I wonder if living well requires that each of us face up to our mortality, to our vulnerability and fears, regardless of whether we have a life-threatening diagnosis.

These attitudes - that each day is precious and that there is little time to waste, least of all to waste it on worrying about how other's might judge one - seem to provide some very important pathways towards well-being in lives that may be foreshortened by illness. But I was often told that these pathways are easily lost as the sense of imminent threat diminishes. Dianne, who is currently living with a recurrence of ovarian cancer, explains this loss:

*When I started feeling better some of those little habits slipped back. What I'm trying to say here is - it comes and goes and it's a fine line and you slip off it very easily. And even though you think you've got it figured out, you might for that small amount of time but...* (Dianne2, p. 2)

After her diagnosis Dianne worked very hard on her relationships with those around her. She journaled and read, used meditation and visualization, and also reconnected with her passion for artistic creation in an effort to get to know herself better. She describes the fragility of this reestablished connection:

"So my cancer experience has helped me clarify that [sense of who I am and where I stand] and stay there...stay closer longer, but I can feel it kind of getting wobbly, you know, the more I get out in the world." (Dianne2, p. 15)
Linda also felt this concern:

"But it's easy to slide back into getting-through-the-day kind of thing and forgetting..." (Linda2, p. 4)

There is also a feeling that regaining one's footing on the well-trodden pathway of those who have not lived with a life-threatening diagnosis is something welcomed, even reveled in, but which carries its own complications. Christina Middlebrook, who has written poignantly of her life with late stage breast cancer, says that: "The increase in denial that remission brings - feels nice. It makes me strive to belong again." (1996, p. 172) And yet, paradoxically, she also feels: "To my horror, I find the self-assured and determined ideas healthy people have, ideas about what it means to be sick - about the right way to be sick - returning to me." (p. 172, her emphasis). Many people who are ill find that those who are not wending their way on the precarious pathways of illness seem to have particular ways of looking at the experience, ways which translate into a sense of guilt and self-blame for many of the people I engaged with in conversation.

The Meaning-Blame Paradox

Those of us who are undiagnosed and living life with a minimum of suffering tend to (quite "determinedly", as Christina Middlebrook describes it) equate "falling sick" with being blameworthy. We suppose that those who are ill have done, or not done, something crucial and, therefore, have brought the illness on themselves. Even our language suggests that "recovery" or getting well again requires that we make efforts to find the good health we have lost. But those who work at living well during illness are equally determined that, while there may be important messages to be found, falling ill "just happens" and it should not carry any added burden of guilt, shame, or blame. For many,
the awareness that they had accepted society's blaming attitudes comes as a surprise. Nan Shin (1986) records the shock she felt when an old friend and fellow Zen practitioner greeted her by commenting on the "good karma" creating her illness which was bringing her "close to the Way" (the Way - denotes the positive spiritual "life path" in the Zen Buddhist tradition). She wrote:

The jolt I felt then showed me very clearly that I had been thinking, Bad karma. Within a fraction of a second the molecules turned themselves round and reorganized. I am flatly grateful to him forever. (p. 79)

Without realizing it, she had internalized the societally endorsed notion that she had done something bad and therefore "deserved" the cancer diagnosis and its attendant suffering and threat. It was not until someone else suggested otherwise (wisely-other?) that she could shift her sense of guilt and embody whole-heartedly the opportunities presented by the illness.

While it is unlikely that we would engage in this process of blaming consciously, if we look beneath our civilized veneer I suggest that many of us harbor this sentiment - it being so much a part of the social discourse which surrounds us. We live in a society that collectively assumes each person is a rational agent acting on his or her own behalf. "Our commitment to rational mastery means that we would like to believe that if we do everything right, that is act sensibly, we will not get sick" (Kirmayer, 1988, p.62). As a result, most of us tend to blame those who get sick for their own misfortune (like women are often blamed for being raped) assuming that they must have done something wrong. Remaining secure in the knowledge that we have acted more sensibly and therefore will not get sick, we allow ourselves to retain our illusion of
rational control. This way of thinking protects us from the need to face our own fears of illness and death. We can continue to assume that we are doing everything right and therefore have no need to worry that we might someday find ourselves in the same position. By blaming we avoid the very conversations which might transform our understandings of illness.

Living well with illness seems to involve a deep, bodily-felt understanding that dis-ease can happen to anyone; that, in fact, those of us who don't die of an accident will likely die from some form of illness, and therefore there is no need to inculcate blame (Frank, 1991). Susan Sontag (1990), writing about societal attitudes toward cancer as she herself was undergoing treatment for a diagnosis of breast cancer, did much to warn of the dangers of guilt and shame which result from blaming individuals for having caused their illnesses. She argued that this blaming was a product of anxiety over the unknown causes of complex diseases. Guilt and shame, from the perspective of those living with a serious illness - questions such as "Why me?" and "What did I do to deserve this?" - seem only to get in the way of well-being; while blaming allows the undiagnosed to distance themselves from those who are ill.

Possibly the only good answer to the question "Why me?" is "Why not me?" Kat Duff, who suffers from chronic fatigue syndrome suggests that, for her, the only answer to the suffering and injustices of illness is to "...come to see the universality of [the illness] experience" and, in doing so, allowing the thread of one's own life to be "woven back into the web of our world" (Duff, 1993, p. 132). Viewing her illness as something that is integral to the human experience, something that can happen to anyone at anytime, is a form of resistance to the culturally held notion of blame. This is a resistance that is
often enacted by those who are living well with illness. Dwelling on the reasons for one's own possible guilt seems to decreases one's sense of well-being.

Ginger suggests that guilt is a way of thinking which is induced by our culture. It is something "we do in our heads"; she says, whereas true healing and well-being entails a loving and compassionate relationship with the self, which can only "come from the heart" (Ginger). Sharon Batt (1994) also struggled with this notion of blaming as she engaged with her experience of breast cancer. She wrote that:

*Like Sontag, I was offended by the underlying implication...that some personal failing of my character had caused me to get cancer and that - if I really wanted to live - I would quickly perform the necessary major surgery on my life, if not my basic essence. The prospect was exhausting, even demoralizing* (p. 144).

Yet she, like many others I heard from, was not willing to reject the idea that there might be a connection between the way she lived her life and the cancer in her body. She describes herself as yearning for an answer to the question her diagnosis posed to her. "*Something had caused me to get cancer; understanding it might help me survive*" (p. 144). Paradoxically, resisting the culture of guilt and blame does not equate to a negation of all sense of responsibility to the illness.

This is a quandary that I heard voiced repeatedly. People's stories of living well with a life-threatening diagnosis were rife with the need to consider the meaning of their illness, and at the same time expiate themselves from any sense of guilt or shame for having become ill in the first place. This is a difficult process of negotiation when one is surrounded by those who, often with little
awareness, impart blame. Beth describes her experience of the quandary this way:

I think the whole positive attitude thing...there is certainly something there. The mind-body connection, there really really is. But I tend to think that could be a little bit over-rated because I always think, ...well okay, well how about those people who don't survive, what about them...Did they not want to live enough? I don't think so! ...It's all about living with cancer....disease can happen to anybody, this is not something I brought on myself.

(Beth1, p.8)

Life, according to Beth, should not be defined by longevity; rather it should be defined by how well it has been lived, regardless of its length.

The oldest woman to participate in the study, a woman who has far outlived the predictions of an earlier gynecological cancer diagnosed in her thirties, as well as a more recent diagnosis of metastasized breast cancer, Alice, considered that:

Maybe subconsciously I've wondered [what I might have done to bring cancer into my life], but it's not something that I've really given thought to. Because I look around me and I see young parents that have had cancer and they've died very quickly and they so needed to continue to live, to take care of their families. There really is no rhyme or reason. You see it happening to what we consider good people and you see it happening to people who haven't looked after themselves, who don't really give a damn about anybody. Cancer especially, affects anyone and everyone.

(Alice2, p. 8)
Alice volunteered to participate because she often wonders why she has lived so well for so long, when other's, with perhaps more reason to live, have not been so lucky. She has also participated in several drug trials, believing that by offering herself up for these trials she may contribute to knowledge that could help others in the future.

Alice explained her sentiments on blame further, describing a letter to the editor published in a local newspaper that she found disturbing. The correspondent suggested, that "justice was served" when a person, who they thought had been mistakenly exonerated by the courts, had subsequently been diagnosed with cancer. The implication was clear, cancer (like many suggest of AIDS) is a punishment meted out to those who deserve it. Alice reacted this way:

_I thought, what a terrible statement for anybody to make, no matter who you are directing it at!...nobody deserves to have cancer, or any other life-threatening disease, no matter what they have done....to me that was a terrible, terrible statement ..._ (Alice2, p. 9)

And Linda, in her forthright manner, placed blame in its place very bluntly saying: "Ya, and these babies...babies get cancer you know....nobody can be blamed for getting their own cancer. Some people feel that they should be - but no, they can't" (Linda1, p.17).

Perhaps those of us without a diagnosis would do well to engage our own fears of vulnerability in order to open our hearts compassionately towards those who are ill or otherwise suffering, rather than distancing ourselves self-protectively, if subconsciously, by inculcating blame. But, it is possible that the very engagement with ourselves that
facing our fears requires would cause us to rethink the everyday banality of our lives, making us mindful of each encounter in ways which are too painful for us to consider.

Yet, even as they want to avoid the sticky path of blaming themselves, those who cultivate well-being during illness are, curiously, quite willing to look for the significance of the illness in their own life pattern. It seems as if accepting serious illness as a meaningless event, as something inconsequential to be borne stoically and as quickly as possible left behind, is not a pathway towards living well with illness. Wellness requires making meaning of illness regardless of our societal penchant for wanting "to banish illnesses from our world" (Kat Duff, 1993, p. 46).

Many people I have conversed with, who are living with cancer, have expressed the need to understand the meaning of cancer in their lives and the desire to use that message as a catalyst for change. Jazz describes it this way: "I really felt this was a wake up call and I've been trying to listen to what the experience wanted to teach me." (Jazz1, p.6) Another woman I spoke with, Lynn, who is living with a diagnosis of uterine cancer echoed this sentiment:

Part of what I was trying to do was get reoriented, as well as dig back into who I was as a person that might've...precipitated the fact that cancer cells in my body could've taken hold....Ya, that made good sense to me and I had said right from the beginning, my words were, "This is a wake-up call" and I didn't know what I was saying about it being a wake up call until I started to delve in, I just knew it was. (Lynn1, p.11)

Like Dianne, Lynn has worked hard at sorting out her relationships with others and coming to a deeper appreciation of, and comfort with, herself. Having an intuitive sense that she may have created the conditions for cancer to establish
itself in her body, she has tried to understand herself better by delving into her past and seeing how it constrains her present ways of being.

There seems to be a need to move from a place of blaming the self to a place of caring for and loving the self. My colleague and friend Helen MacRae embodies this notion for the people she counsels. She does this by contrasting the motions of the full fist breast-beating of the Catholic "mea culpa" (I am culpable, guilty and punishable), which I was taught as a schoolgirl, with an open-handed stroking of one’s own chest in a loving, caring motion. In an experiment with embodiment I suggest you try this on yourself. It is interesting to note that this breast beating or stroking occurs at the thymus, the seat of the immune system, and at the heart chakra of the Ayurvedic energetic medical system - the chakra most responsible for healing.

Problematically, many of the early, popular, self-help books on illness promote the sentiment that the growing acceptance of the body-mind link can be directly translated into the New Age dictum "you create your own reality" (Wilber, 1991). The Simonton's (1978) approach to visualization, Louise Hay's (1995) positive attitude philosophy, and Bernie Siegel's (1986; 1989; 1993) early works on exceptional cancer patients, have all been accused of making promises that can turn into a serious pitfalls for the unwary (Batt, 1994; Handler, 1996; Lerner, 1994). Evan Handler (1996), a young New York actor who was diagnosed with leukemia is openly critical of these approaches in his book *Time on Fire*. He used Simonton's visualization approaches extensively in his first go around with cancer, even spending two weeks in California at one of their costly retreats and attending a private session with Louise Hay. But, he felt the full brunt of failure, guilt, and self-blame when his illness returned after
a brief remission, requiring him to undergo a second grueling bone marrow transplant. Treya Killam Wilber (Wilber, 1991) was asked to appear on Oprah opposite Bernie Siegel to voice her understanding that the New Age "logic" of karmic lessons to be learned violates the person who is experiencing illness. While Treya declined the invitation, she wrote in her journal that this sort of logic interferes with a person's ability to see that: "While we can control how we respond to what happens to us, we can't control everything that happens to us" (Wilber, 1991, p. 220, my emphasis).

Numerous, more recent authors have tried to mitigate the damage that such guilt inducing approaches can do in the lives of people who are already suffering (See for example Michael Lerner, 1994 and Lawrence LeShan, 1990). While many of the people I had contact with used body-mind techniques such as meditation, yoga, deep relaxation, and visualization - or simply improved their self-care through exercise, diet, and getting sufficient rest - none ascribed to a sense of conscious control over having caused, or being capable of curing, their illness. Many assiduously avoided accepting any sense of blame or shame, they were not "despairing victims" of cancer - they were "hopeful survivors" living with a conscious awareness of possible remission. Illness presented them with an opportunity to find deeper meaning in life and their goal is to find ways of making whatever time remains to them a richer, more fulfilling experience. Lynn suggests that even a recurrence can be taken up with this attitude, pushing one to seek further and develop a deeper, richer engagement with life.

This interplay between meaning and blame represents a delicate balancing act between taking up an active and responsible role, by acknowledging that there is some meaning in the symptoms of the dis-ease
one is experiencing and using that meaning as the impetus for making changes in one's life, while, at the same time, retaining a sense of not being responsible for having caused the illness. Perhaps the difference is between being "responsible to" (as in able to respond) and "responsible for" (as in blameworthy). This might seem a minor distinction, but it appears to be a significant one for the cultivation of well-being during illness.

Arthur Frank (1997a) calls the need to make sense of being sick the "potential consciousness of illness" (p. 136). He suggests that this drive to find meaning in illness should not be dismissed as unproductive, magical, or superstitious thinking. For him it is an "uniquely human capacity to grasp suffering as a moral opening, as occasion for witness and change" - it is a "potent human magic", which allows people to make the best of the difficult times illness presents (Frank, 1997a, p.143). Without this "potent human magic" despair, depression, and hopelessness can never be far away.

In The Alchemy of Illness Kat Duff (1993) suggests "...we would lose ourselves altogether if it were not for our stubborn, irrepressible symptoms, calling us, requiring us, to recollect ourselves and reorient ourselves to life." (p. 33). She worries that biomedicine, or as she calls it...

Cosmopolitan medicine banishes that knowledge by insisting that suffering is without meaning, and unnecessary, because pain can be technically eliminated. Symptoms are divorced from the person who has them and the situations that surround them, secularized as mechanical mishaps, and so stripped of their stories, the spiritual ramifications and missing pieces of history that make meaning. (pp. 45-46)
The interruption of illness provides an opening, which our self-reflexive nature can use as an opportunity to reconnect with self and renegotiate one's way in the world.

Ginger, in the groups she facilitates for people living with cancer, emphasizes the need to take responsibility for making healing changes in one's relationship to self and then to others. Those who attend her sessions are encouraged to use meditative practices to become a mindful witness of their own feelings and self-criticism, with the expressed goal of deepening their self-understanding and replacing the harsh, judging side of themselves with something much more nurturing and nourishing. Illness, as Ginger sees it, provides the impetus and opportunity to engage one's whole being in this healing process, a process for which she believes we all took birth. She describes the mind as an energy field that ranges well beyond the brain, viewing healing as an increase in vital energy and as something that goes well beyond (and does not necessarily include) curing the physical disease. For Ginger, healing is something that can continue up to a person's "very last breath" (Ginger2). Although she wants to understand how she might have allowed cancer cells to take hold in her body, she makes it clear that she does not accept any blame for having "consciously" created it. She states very strongly that: "Some of the healthiest people I know are people with cancer" (Ginger1) because they are living a life fully dedicated to increasing their own, and others', well-being.

Living well after a serious diagnosis requires making sense of the disease to the self, reconnecting with the self in a more loving manner, and caring for the self in new ways. But taking up these self-conscious responses to illness presents further paradoxical quandaries to be negotiated, such as
the difficulties which arise as one's own story of illness clashes with that of the biomedical experts.

The Trust Paradox

Living well after a life-threatening diagnosis means walking a fine line between trusting one's own inner knowing about what is life giving (what is healing, as opposed to what will cure) and needing to trust the expert's advice on treatment choices. The initial difficulty presented by this paradox is the conflict between the need to authorize one's own experience while negotiating with the physicians about which treatment route to follow. The quandary is: trusting the medical expert's judgment and undergoing invasive medical treatment while, simultaneously, trying to tune into one's own intuition and emotional needs for healing - needs that are generally not worthy of consideration from the biomedical point of view.

Lynn, a nurse who has made a living training other nurses, questioned the advice of her doctors repeatedly. She describes the conflict as follows: "...there's the medical paradigm, having to depend on that and yet the patient saying, I think there is something different here." (Lynn1, p.4). Linda describes her similar experience of the problem this way:

Well, the thing is, you have to become your own advocate....you have to trust your doctors because they have the medical knowledge behind them. But, on the other hand, you have to trust yourself too and you have to learn to be pushy and say - "Well, okay, that's what you want to do, that's what you think; but I'm not comfortable with that and I want you to take more tests". If it's for your own peace of mind if nothing else, well that's worth a lot!

(Linda2, p. 3, her emphasis)
Marie also felt the need not to be excluded from the decision making process when it was her own health that was at risk. For her:

*the physicians that I see are wonderful people, I am happy to have been referred to them, I have every confidence in their abilities. But in terms of...(pause - thinking)...I feel I should be in charge of my own well-being and be responsible and so forth, to a degree. I think there is a need for a structure that allows me to do that.*

(Marie1, p. 19)

Marie is a professional who, after a breast cancer diagnosis and two surgeries (one as treatment and the other prophylactic, in consideration of the extensive genetic patterns of breast and gynecological cancers in her family line), has engaged in an administrative position to investigate and promote well-being within the institution which employs her. People living well after a serious diagnosis often seem to be drawn to work involving the well-being of others, be it directly supporting those experiencing cancer through various volunteer associations or, as with Marie, dedicating their professional life to improving the lives of others. Marie believes that all organizational systems should promote wellness by developing structures that facilitate people’s ability to make choices appropriate for furthering their own well-being.

The difficulty of staying in touch with one’s own needs while engaged with biomedical authorities is complicated by our society’s faith in the redemptive ability of science and technology. We have accepted “scientific expertise” as prophetic in many areas of our lives. Especially in healthcare, technological advancement is imbued with the capacity to save us from the vulnerability and capriciousness of illness. As a society, we continue to ignore, as outlined in the last chapter, the evidence that medical technology is fast
outstripping its moral response-ability. Biomedical approaches to illness tend to efface the consideration of a person's quality of life by focusing only on extending its length. This unquestioned faith in medicine prompted Canadian Health Minister, Monique Begin, in a discussion of how to re-vision healthcare practices, to ask: "To what extent have we erased from our consciences the meaning of suffering, aging and dying - that is, the meaning of vulnerability" (as cited in Batt, 1994, p. 309).

The technology of science has given us some miracle "cures" (in the biomedical sense of the irradication of disease) and it continues to increase biomedicine's effectiveness in acute phases of illness. But this same technology has also created a distance between doctors and "patients" which can inhibit the doctor's ability to connect with the complex reality of the ill person's life. Doctors are often more interested in the results of the diagnostic tests, the readouts and images produced by advanced medical technologies, than in learning about the individual who is experiencing illness. This dependence on technology continues to grow, even though there is evidence that suffering has more to do with the individual's interpretation than with any objective measurement of pathology (Cassell, 1990; Adams & Mylander, 1998). For example, productively interpreted pain such as the contractions of giving birth are experienced very differently than the pain one suffers after surgery, although the relief of that pain can be increased by interpreting it hopefully as a healing response.

It is interesting to note that some of those who most passionately challenge our usual approach to illness are often "experts" in medicine who have had a close personal brush with the suffering and struggle of a serious illness. (Examples include Sacks, 1994; Remen, 1996, their own illness; and
Campo, 1997; Groopman, 1997, illnesses of others). A medical pathologist specializing in the diagnosis and staging of cancer through tumor biopsies, writes of his realization that there is much more to life than his microscope offers:

*By confining myself to cells, I stay clear of the fiery trials of illness. I remain detached; I render my diagnoses with a cool eye. My fascination with the microscopic form, color, and disposition of cells drives me like a critic to interpret, to applaud or decry for the rest of us. Paradoxically, observing so much of life through a microscope has left me feeling that I've sampled too little, that I have missed the very warp and woof of it.* (Nadler, 1997, p. 71).

Having become involved with a young woman's struggles around the recurrence of breast cancer he wrote:

*I begin to see that the diagnosis of a disease plays little part in the healing process; nor, for that matter, does the treatment strategy. Help attuned to individual needs is what heals. Disease seems to be more than a set of facts, and illness more than a diminished way of life. They are a strange tandem that plays out differently in every host - despair terror, agony, a call to arms, newfound clarity, transcendence, metamorphosis.* (p. 71)

Healing, as he begins to understand it through his encounters with this woman, takes many forms and requires an attunement to the needs of each individual. The treatment offered by modern medicine is too much of a one-size-fits-all approach, and the diagnoses and prognoses he renders through microscopic tissue samples have little to do with the complex and unique realities of lives well-lived.
At the same time, people who are ill must walk down pathways dependent on the specialists who treat them. The trick seems to be in learning to depend without acquiescing all power, a delicate balancing act as Arthur Frank (1991) describes it:

*It is difficult to accept the realities of what physicians can do for you without subordinating yourself to their power. The power is real, but it need not be total. You can find places for yourself in the cracks.* (p. 56)

There is a danger when people side only with the authoritative power of the doctors and externally witness (see as if from the outside), rather than internally encounter (in a subjectively embodied manner), their own illness experience. Medical objectification distances the ill person from their own "tastes and preferences" and they lose the capacity to make their own choices (Frank, 1991). In siding with the medical staff a person can lose even the ability to attend to their own needs for pain relief or care as Lynn informed me. She spoke of the double-edged sword that her training as a surgical nurse lends to her experience of illness. Being a nurse sometimes gives her an insider status. For example she had very informed discussions with her surgeon and, when the team in the operating theatre were apprised by the surgeon of her professional status, they all had a lively discussion with her until the anesthetic took hold. But later, on the ward, "flipping into nurse-mode" caused her to ignore her own needs as empathic understanding translated into a desire to avoid troubling the nurses, who she felt were already overburdened (Lynn1, p. 13).

Another factor that makes the trust issue more difficult, is the tendency for people who are doctors to avoid developing a respectful and reciprocal
relationship with people who are ill. Occasionally this avoidance was acted-out in cavalier attitudes or flippancy, but mostly it played out in subtle things such as only showing interest in the diseased body and through not making the eye contact that allows each of us to feel recognized by another person. Dianne was appalled by the following experience:

He walks in and I've never seen this man before and I'm supposed to be examined by him and be happy about it. Anyway the first thing he says is, "So how are you doing with all the poisons they're giving you?" This is my twelfth chemo treatment and I was having a lot of trouble with the fact that they were poisons. I was trying to do the best for my body and its healing energy and, lets face it, it wasn't working and I was petrified... So that's the first thing he says to me, so that ticked me off. (Dianne1, p. 2)

She also felt both patronized by the medical system and threatened by her need to trust in it:

They ask you to do things and you have to play by their rules. I felt like a child at that time. I'm not blaming that on them. I was overwhelmed. I was scared - what this resulted in, and still does with me, is a kind of passivity. Just a "point me in the right direction" - kind of....And then this notion that you're basically called upon to trust them, you have to, the doctors, the nurses, the whole system...you don't know the particulars but still you have to trust...basically its your job to figure out how to do it right. And not only that but the stakes are high. (Dianne1, p. 5-6)
Dianne was also angered by the way doctors would come into her hospital room and view her only as an object/body, a puzzle to be solved, and ignore her as a person:

Anyway at one point one of them came in and he had five residents with him and I was feeling feisty by now. He looked at me, but they [the residents] would not look me in the eye - and I made them. I said "Hello. Hello. Hello. Hello. Hello!" (gesturing as if to look directly at each person) And the doctor was kind of irritated with me, but here I am, lying in this bed and these six people, one of them is looking at me, but the others are not.

(Dianne, p. 6)

Arthur Frank complained of this lack of humane interaction as well, a condition that increased as his disease progressed:

The more critical my diagnosis became, the more reluctant physicians were to talk to me. I had trouble getting them to make eye contact; most came only to see my disease. This "it" within the body was their field of investigation; "I" seemed to exist beyond the horizon of their interest. (Frank, 1991, p. 54)

He goes on to state that: "The active roles in the drama of illness all go to physicians" (p. 56). Those who are ill are supposed to wait "patient-ly" for the physicians’ pronouncements, the nurses' care, the labs' results; a frustrating and belittling experience, which conspires against a sense of well-being.

This expectation of passivity in the face of medical authority can result in a sense of self-doubt that needs to be mitigated if one is to retain or regain a feeling of wellness. For example, after arguing with numerous doctors over several months that she was ill and had "something growing" in her, Jazz
wonders, "how long can you persist until you start doubting yourself" (Jazz1, p.10). She states emphatically: "I still have issues around it - that I wasn't taken seriously and I was ridiculed for actually paying attention!" (Jazz1, p.3). But, having survived a grim prognosis and difficult treatments, she finds that:

the wonderful part of this is that I started listening to myself. Before that I was like this little fly or leaf in the wind - and something happened, something changed - that even when this woman [doctor] was accusing me, I could sense kind of saying, "that's what she thinks!" Like just to notice the limitations of a doctor, or anyone else, and to actually become aware of the healing powers we have in ourselves and the wisdom all of us carry, we just don't tap into it.....Ya, it's been a wonderful gift and it's getting reinforced the more I live. (Jazz1, p.17, her emphasis)

and,

I feel stronger now to say - just because they say doesn't mean I have to believe or follow them. There is a stronger sense of who I am that's coming to me... It feels more like my soul is starting to feel at home in my body. (Jazz1, p. 23)

Viewing ourselves as more than just bodies, as bodies, minds, and souls, and finding ways to listen to one's own inner voice, seems to be a very important pathway towards well-being. But if it is necessary, it is not easy to stand up to the medical establishment.

Difficulties and conflict arise when people experiencing illness choose to follow their own intuitions about healing and go against the wishes of their doctor(s), though there may also be a sense of payoff in the effort. For
example, having deliberated over the biomedical recommendations and possible alternatives Audre Lorde claims that:

*When it came right down to deciding...I felt inside myself for what I really felt I wanted, and that was to live and to love and to do my work, as hard as I could for as long as I could. So I simply chose the course that I felt most likely to achieve my desire...* (1980, p. 32).

Her choice was to have a modified radical mastectomy without the recommended options of radiation and chemotherapy because of their, in her view, inherently carcinogenic qualities. At the time this choice felt like the wisest course, though in retrospect she says:

*I think now what was most important was not what I chose to do so much as that I was conscious of being able to choose, and having chosen, was empowered from having made a decision, done a strike for myself, moved.* (1980, p. 33)

It wasn’t the specific choices, so much as the ability to make a choice that left her with a renewed sense of well-being.

The pathway towards living well during illness that hinges on making choices for oneself, is often problematized by the overwhelming number of options for treatment, as well as by the rush to treatment immediately upon receiving a diagnosis. For example Jazz, having spent months being accused of hypochondriacal tendencies, found herself under enormous pressure to decide on life-threatening treatments within hours of finally being believed and receiving a diagnosis. She was told by the oncologist: "You don’t even have time to think about what kind of treatment you want. If the chemo works, great!"
If not - two weeks - you're dead!" (Jazz1, p.3). In the same vein, Treya Killam Wilber warns those undergoing treatment for cancer:

...to always beware of being knocked off center by what doctors say (they can be terribly convincing about what they do and terribly close-minded about non-traditional approaches), to take the quiet time to be clear about what you want and what you are intuitively drawn to, and to make a choice you feel is yours, a choice you can stand by no matter what the outcome. If I die, I have to know it is by my choices. (1991, p. 221)

Currently, the various alternative therapies available, coupled with the closed-mindedness of many biomedical experts towards complementary treatments, often puts those who try to listen to their own needs at odds with their physicians.

The continuing debate and often mutual distrust between conventional biomedical practitioners and those who practice alternative therapies, makes trusting one's own choices increasingly problematic. Deciding to abandon the standard regimes of surgery, chemotherapy and/or radiation in favor of "unorthodox" procedures is regarded by many in our society as tantamount to suicide. (Hence the court ordering of the Tyrell Dueck's treatments, as mentioned earlier.) Sharon Batt, writing in Patient No More, found her decision-making process complicated by the secrecy and separateness maintained between conventional and unconventional treatments:

In the months after my diagnosis, the illicit aura of alternative treatments added considerably to the anxiety of trying to get my bearings. ...The hush-hush atmosphere about unorthodox
treatments seemed part and parcel of the perception of cancer as a shameful and secret disease... (1994, p. 162).

She points out that the legal separation between orthodox and unorthodox treatments rests on the concern that "healthcare consumers" cannot be expected to understand the "complex science" involved in making such decisions and, thereby, need protection from possible quackery. But given the present state of affairs within the biomedical oncology establishment (the proliferation of treatment options, coupled with the indecision and debates over appropriate treatments, mentioned in the previous chapter), it seems that people experiencing cancer must be prepared to make decisions about treatment, even if they access only conventional therapies. Micheal Lerner (1994), who runs the Commonweal Cancer Help Program, a retreat-based program for cancer patients, suggests that people experiencing cancer should always take the time they need to carefully consider all their options. He believes that the invasiveness of treatments must be weighed in the light of both one's hopes for cure and one's needs for healing in all areas of their life; quantity of life, he contends, should not always win out over quality.

I believe that the need for a sense of control, which can be promoted by giving the ill person an opportunity to be involved in making decisions around treatment options, should no longer be ignored, nor should its value be underestimated. We have evidence of what hopelessness does to rats and other animals, why would we continue to induce such helplessness in human beings? I have heard the argument that some are simply unprepared to make such decisions, especially in a time of crisis. But for those who are willing and able, couldn't this be offered? Also, what are the effects of hearing the words "terminal" or "only a matter of months" on a person?
Several of the women I spoke to felt resentful that they had been positioned as invalids, as helpless victims, by the medical system. Like Dianne, they want their humanity and equality to be acknowledged in their interactions with the medical "experts". As Marie described, they want to be recognized as capable of making choices for themselves. Inspiration, for example, felt that she had no choice but to follow the path laid out by conventional medicine, even though she thought it did little more than assuaged her family's fears. She describes her own difficulties with the issue and the solace she found in complementary therapies, despite the resistance she encountered in trying to talk about these "other" therapies with her oncologists and surgeon:

You see I really had a qualm with the two doctors in a way - that they were very sure, that is - "If you don't do this, 30%, if you do this, 60% chance to live." - So you make up your mind, so you sign or you don't sign, and then you are on your own. And I really did go through all the treatments,... but I think I could've chosen not to go and take the medical treatment also, and really have relied on alternatives. But it was for my family that I really thought: "So now they know I have tried everything."- I thought it would help them....

No, the doctors weren't very communicative, and that did not help. But I sought [other]help. I went to a homeopath, and I had acupuncture on a regular basis, and I think both of those really helped me. And so I felt - "O.K. I'm a little bit in control." I felt like I couldn't do anything if I just followed the medical path, so now I could do this and do that and take
my vitamins and change my eating habits. (Inspiration, p. 11, my emphasis)

Inspiration also described a spontaneous healing which occurred for her during a week long, silent meditation retreat. She experienced both a mental and a dramatic physiological shift, which left her with a sense of peace and physical ease, a peaceful feeling that her pursuit of complementary practices was indeed helping her to heal.

When the ill person lets their own views stand in conflict with those of the conventional doctors', they can be made to suffer. I heard stories of rude dismissals and ridicule. This is a risk that many women I spoke to were unwilling to take, preferring to keep quiet about their complementary treatment choices. Nan Shin (1986) writes about facing the disapproval of her doctor when she told him she would be altering her diet, using acupuncture, taking Chinese herbs, and meditating, along with his recommended chemotherapy treatment:

_He had talked to me at some length about his responsibility, and I said, I'm forty-seven years old, if I'm not a little bit responsible for myself now I never will be. When he heard about the diet and other things he said, in tones of offense and disapproval I associate with a university professor discussing an error of reasoning in a term paper - offense and disapproval and condemnation without appeal -, your making Pascal's wager (Pascal who said, Get down on your knees and pray and faith will follow - and after all, it might be true), and I said, You bet I am._ (p. 101, author's emphasis)
She was able to withstand the doctor's attempts to dissuade her, even when he
told her to find herself another oncologist, but was left with vaguely uneasy
feelings:

*He is part of the something I felt in those clinics that I call wrong.*
*He didn't want just to be obeyed; he wanted, I think, to be trusted
or loved or forgiven. I later saw him deploying floods of
gentleness and consideration with women who were resigned and
suffering, dying, in fact. And there was trust or love or forgiveness
involved I think. But there is a hypocrisy at the bottom of it, an
evasion, that I don't put my finger on and it is terrible.* (Shin, p.
102)

What is it that promotes this sense of a need for secrecy in pursuing complementary
therapies? Are biomedical authorities so threatened by alternative practitioners? Is it
simply that people have too much at stake to risk angering their oncologist, so that
doing as one is told and remaining quiet about the rest seems like the best bet? A sense
of, keeping the waves low while riding in a leaky boat? It should also be noted that not
only do conventional doctors decry complementary therapies, this criticism also occurs
in reverse. Some complementary therapists have been known to blame their lack of
success on the fact that the person they are treating had previously undergone
chemotherapy or radiation. This is a situation that can inculcate a serious sense of failure
in a person who is already suffering. If the best interest of the person experiencing
illness was put foremost, if caring was held out as the most promising approach to
healing, wouldn't it be more appropriate if conventional and complementary therapists
could learn to appreciate each other's expertise?
Even with these risks, some chose to forego biomedical treatments altogether, or to drop out part-way through, choosing instead to enhance their general health across all aspects, mental, emotional, social, physical, and spiritual. Rather than waging war on themselves in a effort to irradiate every last cancer cell in their body, they work to build up and maintain their well-being, but the impact is dramatic. Ginger still can recall, thirteen years later, the day she told the Cancer Centre staff that chemotherapy was "killing" her and that she would not return for any more treatments. From that day on she very diligently set about the work of healing (rather than trying to cure) herself. She developed a disciplined schedule of meditation, visualization, exercise, and reformed her diet (Ginger1). Patricia, a massage therapist and healer who chose to use camphor and nitrogen injections (known as 714X therapy) to bolster her body's immune functioning, after declining chemotherapy and radiation for breast cancer, tells a poignant story of her refusal:

_I was standing up when I started to say this and I nearly had to walk over and find a bed to sit on. My knees gave out when I started to say, "I'm not going to do chemo" to this guy. ...I sat down and shook, I literally shook, my whole body shook and I said, "No, I'm not going to do chemo."

...to get that out from where it needed to come inside me, it had to come through all the layers that thought, "I should do chemo...and what are my family going to think...and what is this oncologist going to say..." And he did push it. He wasn't unkind, I'm sure he wasn't. But it felt unkind to me, just because I was so...vulnerable at that moment._ (Patricia1, p. 5)
Even after having braved making this decision against the wishes of her oncologist, Patricia recalls agonizing over whether it was the right one. She felt a little like she had gambled with her life, though she also had a deep sense that chemotherapy and radiation were not health giving treatments for her. Patricia now feels that her journey with cancer has opened her to a deeper understanding and compassion for her own fears and feelings of unworthiness, and to a more intuitive capacity in her healing work with others.

Terry Tempest Williams (1991), who watched several family members struggle with cancer and who has been diagnosed with breast cancer herself, writes that there is a way in which healing is something well beyond what medical science has to offer. She criticizes how we take for granted the biomedical interpretation that disease is a deviation to be cured by medical intervention, suggesting that illness can also, and perhaps more helpfully, be interpreted as a powerful opportunity for self-healing. In her case, self-healing has included telling her own story, a story which includes the stories of the efforts her mother, grandmother, and aunt made to live well after they were diagnosed. She says:

> Perhaps, I am telling this story in an attempt to heal myself, to confront what I do not know, to create a path for myself with the idea that "memory is the only way home." (1991, p. 4)

Paying tribute to the memory of her own and other people’s struggles, by publishing her book, helps her to continue walking her own healing path.

Healing, as in moving toward well-being rather than scrambling for a cure, is perhaps most commonly approached through self-care strategies. Strategies which range from writing about the experience, as Terry described, to changing jobs (Ginger, Marie, and Linda all did this), to increased physical
activity, to not waiting for retirement to make that longed for purchase of a vacation home (Beth), or to take that longed for trip (Dianne and Carole). Yet, even self-care is described as having its contradictory aspects. The ability to respond to what the illness represents requires a careful consideration of what will be most helpful, and an on-going assessment of whether it remains so. Dianne reminded me that not every idea that presents itself is useful or acceptable:

...for those of us who have cancer...the stakes are high. You want to learn from your illness but, on the other hand, everything that is offered isn't always pertinent or useful or valuable or...productive.

(Dianne2, p. 9)

Also, all of these strategies - finding meaning in illness, making appropriate choices, listening to and caring for oneself in a responsible manner - all carry the trap of constantly worrying about whether one has made the right choices and is doing enough.

The Paradox of Self-Care

Maintaining well-being requires that we care for ourselves, as a whole person across the various facets of our being, but I heard repeatedly how it also calls for a sense of balance or moderation. Many of the women spoke of knowing people who had become obsessed with survival, who worked so diligently at doing everything possible that they had no time left over to live their lives. It is all too easy, it seems, to allow fears and concerns about "doing everything right" to overwhelm one's sense of well-being. A person who has been diagnosed with a life-threatening illness can get so focused on eating the right things, doing the right visualizations, meditating enough, getting sufficient exercise, maintaining a social support network, etcetera, that the whole reason
for living is relegated to survival. This "survival lifestyle" does not seem to be an appropriate pathway toward living well.

Living well requires not getting hooked into constant worry about one's survival and just focusing on and enjoying each day as it comes. Beth describes this as not worrying obsessively over everything she puts in her mouth. Lynn says she tries to remind herself to pay attention to what is important for her, to the small details in her life, and to allay her fears by accepting the inevitability of death. She believes:

...it's about living until you die, not preparing to die. I mean I have one other friend who had major cancer surgery and...is in remission now....But she has oriented her whole life to staying alive. And to me that is very different than taking all the living that everyday brings. Death doesn't look so bad, it'll come and I can talk about it... (Lynn1, p. 30)

Similarly, Linda found she wasn't living well by being constantly vigilant about her survival. She describes the fears she struggled with and her later change of heart:

I was so stressed all the time - Oh, I can't eat this or I can't do this or I can't do that - and I was just stressing myself out and I find that stress is a lot more harmful to you than anything else. So I just reached a point where, if I have a cookie or if I have a piece of cake that I shouldn't have, - Oh well! There might not be a tomorrow so what difference is it? (Linda1, p. 4)

This is not complacency about taking care of herself. Linda takes care to exercise regularly and eat well. She is also aware that she lives with greater risks than most people, but she aims for a balance:
Ya, anybody can get hit by a bus, but I'm walking down the middle of the road. And that's kind of the way it is and that's kind of in the back of my mind all the time. Don't think you can ever get away from that, it becomes part of your life. It's something you have to deal with and it's not a pleasant thing to think about, but you have to be diligent about your health. ...I've tried to reach a balance and I've got a balance in my life, I'm comfortable.

(Linda1, p. 15).

Keeping this balance is not something that is done once and for all. It is an ongoing act of awareness. An act that is easily lost in the return to everyday life, as is the sense of each day being a precious gift. Inspiration describes this process:

I did a lot of alternative things, extra vitamins and things like that.

So, I kept going until July I think. And then I just wanted to be normal so I dropped those... Then in September I started teaching again, and I had a lot less time, and I guess somewhere in December I had some spotting so I thought, "Oh no! what's this?"

So, I picked up my alternatives again and really worked on my visualization too. (Inspiration, p. 2)

Having lapsed back to being "normal" again, the fear of recurrence brought Inspiration back to the path of caring for herself with increased effort. People often spoke of fear as something they have paradoxically learned to both avoid and to befriend, and normalcy, while coveted, was also problematic.

The Fear Paradox

Fearing and avoiding thoughts of one's death seems to lead to a contracted life, but fear can also be useful as the impetus to keep one centered
on a pathway of wellness. Audre Lorde writes eloquently of the contradictions fear presents in her attempts to live well after a cancer diagnosis:

_I do not forget cancer for very long, ever. That keeps me armed and on my toes, but also with a slight background noise of fear. The visualizations and deep relaxing techniques I learned ... help make me a less anxious person, which seems strange, because in other ways, I live with the constant fear of recurrence of another cancer. But fear and anxiety are not the same at all. One is an appropriate response to a real situation which I can accept and learn to work through just as I work through semi-blindness. But the other, anxiety, is an immobilizing yield to things that go bump in the night, a surrender to namelessness, formlessness, voicelessness, and silence._ (1980, p. 14)

Perhaps her distinction between anxiety and fear represents the two sides of the quandary, the required healthy amount of fear which keeps one attuned to habits of self-care and the other, to be avoided, anxious worrying over things beyond our control. Audre's solution is as follows:

_If I cannot banish fear completely, I can learn to count with it less. For then fear becomes not a tyrant against which I waste my energy fighting, but a companion, not particularly desirable, yet one whose knowledge can be useful._ (Lorde, 1980, p. 15)

Fear is helpful. If used in the proper manner it becomes another tool for finding one's way, a searchlight illuminating the path ahead. Yet, if allowed to create anxiety, it can become a blind panic, a diversion from seeing what living well can mean. I heard so often how waiting for test results is a terribly anxiety inducing experience. And the longer the waiting period, the worse one's
anxious fantasies grow. Patricia claims that "the sheer fucking terror of cancer is phenomenal" (Patricia1, p. 9). She has learned that the fear she generates by dwelling on the memories of her mother's and grandmother's painful deaths from cancer, can paralyze her. To counteract her fears she has adopted a sense of "her cancer" as something unique to her alone, different than the cancers her mother and grandmother experienced. She says:

I acknowledge this is me and so, "My Cancer" kind of became a label that I used. Because my cancer isn't the same as your cancer. And it was really interesting pulling it into a possessive place, because doing it was wanting to own it, wanting to find it, wanting to know it.... pushing it away got me into denial, it got me into bad decision making, it got me into lots of pain and lots of trouble. So I don't want to go that route. So what's another route I can try. And if it's me then why don't I try to love myself, why don't I look after myself more, why don't I find out what I need to do and take the time to do that, instead of doubting my own inside, my own intuition... (Patricia1, p. 9, her emphasis)

Patricia has come to see her cancer as the part of her that is unwilling to grow up. The tumor is made of cells which are still in a wild adolescent stage, refusing to mature and differentiate. She works to understand and provide for that part of herself.

As I was riding my bike on a steep mountain path, I came to a sense that the fear I was hearing about was similar to the fear I experience as I ride. Too little fear and I can become engrossed in the scenery, this flower, that sparkling brook, those peaks shining in the sun: I am in danger of unseating myself. But if I give in to too much fear, I
become too timid to attempt the difficult maneuvers: I have to simply get off and walk, or I get myself into trouble over steering or braking too fast. Some amount of fear keeps me focused and aware. I become mindful of each moment, of the loose rocks, tree roots, or slick mud which might unbalance me. Being aware but not anxious, is a continuous process of equilibration, both for myself and for these women - though my experience, even when occasionally life-threatening, differs radically by it being something I have chosen to participate in.

So fear can paralyze, but fear can also motivate the actions and awareness of those who have experienced the crisis of a life-threatening diagnosis. It paradoxically obstructs and encourages. It is something that must be dealt with openly, or it remains an unrecognized force. Fear also reminds people who live in remission that a return to their "normal life" carries its own ambiguities.

The Normalcy Paradox

We commonly use the word "recovery" with regard to illness to mean getting over it and returning to life-as-usual. We tend to act as if illness were a hiatus from life, something we can subsequently "cover up" and ignore. As Arthur Frank says, "Society pressures us to return to the healthy mainstream, minimizing and forgetting our losses" (Frank, 1991. p. 40). But the conversations I had suggest that "recovery" might have more to do with regaining one's joy and wonderment in life, the recovery of caring for the self, a renewed connection with what's important in one's life.

Recovery does not include a sense of "getting back to normal," nor the "minimizing of losses". In fact, returning to the way things were before the illness is associated with the risks of falling back into self-destructive and self-critical habits, of becoming overly absorbed in inconsequential matters, of
ignoring one's own needs in an effort to please others, and/or of losing the balance one had struggled to find within the illness experience. For the person who has had a life-threatening diagnosis, there is no "normal" anymore, everything has changed. Or, as Lynn noted, one learns that "normal" never did exist as a static state; that one must learn to accept and live with an ever-changing normal. The difficulty arises because people who are trying to live well after a life-threatening diagnosis are dis-inclined to return to their old habits and roles. They have often renegotiated their life in various ways. They have a need to live differently in the world, a world which others, problematically, viewed as the same as ever.

One person described this conflict using the metaphor of a hanging mobile. Our lives are so interconnected with the lives of others, that the changes wrought by cancer in one person's life can easily upset the balance of the whole structure. It's as if the tumor itself added weight to the person living with illness, causing them to settle at a new level. As a consequence, everyone's position changes. This often results in significant pressure on the diagnosed person to resume her/his former position in the scheme of things, in order to negate others' needs for adjustment. Sometimes those people the ill person is most intimate with exert the greatest pressure. This is because, as Terry Tempest Williams (1991) writes: "An individual doesn't get cancer, a family does." (p. 214). The closer someone is to the one who initiated the imbalance, the bigger the adjustment required.

Thus, illness has a long term impact on everyone whose lives connect with the person diagnosed. Particularly mothers, who so often play a daily supportive family role, feel this pressure. If they defy the pressures and avoid fulfilling all of their former roles, family members must learn to fend for
themselves in new ways. Lynn described: "...watching their reactions and their attempts to put things back to normal as fast as could be ...and me saying it can't go back to normal, normal has changed" (Lynn1, p.6). She also related this story of taking care of her own mother who had come for a visit, when Lynn herself had just returned home from surgery:

...I realized after what she wanted, what was going to keep her world in shape and safe, was to pretend that I was back to normal. [If] there was nothing wrong, she didn't have to be concerned about me. And so long as she was the one being cared for and I was able to do it, the rosy hue was still intact. (Lynn1, p. 14)

People who are trying to live well with illness often seem to struggle to find a sense of well-being and recovery that includes a stronger sense of self-in-the-world. Barbara Rothblum (Butler & Rothblum, 1991), a sociologist who journaled throughout her encounter with breast cancer until just days before she died, describes the clearer sense of self she attained as follows:

I seem to be getting simpler and simpler to myself, seem to know clearly what my essence is. Things aren't so complicated anymore. I can even pick my favorite color and favorite ethnic food. I experience my preferences as a step towards clarity, rather than a limitation. Simplification, maybe that's what this process is called. It feels more like coming to one's fullest and truest self and simply acknowledging what is. The self revealed to the self, observed by the self. Simply. Coming to the essentials. (p. 105)

This renewed sense of self seems connected to a sense of healing, but it is also a fragile thing and in need of protection, easily threatened by the pressure to return to pre-illness roles and ways of being. But the outgrown
self, the old way of being in the world, is often feared as that which precipitated
the illness experience in some way. Lynn muses on her feelings with regard to
this:

I have now confronted, and have to confront for the rest of my life,
the chance of it reoccurring. My body can produce cancer, and
although I've got it controlled now there is always the chance that I
could produce it again. And I'm having to re-look at who I am in
all my relationships, who I am to myself, where I want to go with
the rest of my life? (Lynn1, p. 15)

Ironically this need to solidify a renewed or renegotiated sense of self, which
often includes a desire to strengthen and repair close relationships, can create
yet another quandary for the ill person. While people experiencing the
transformations of illness want to share their new understandings with their
loved ones, they often find themselves protecting those closest to them,
second guessing what others can handle hearing. This is just one of several
relational paradoxes that attend the experience of living well during illness.

Relational Paradoxes

There is an opportunity, under the imminent threat of mortality, to draw
others into a greater intimacy with the self, yet many people experiencing
serious illness find themselves, at least on some occasions, protecting those
they most care about by not keeping them fully apprised of their changing
status. Inspiration speaks of her surprise at how hard it was for her adult
children to accept her illness and how, as a consequence, she chooses to
protect them from unnecessary worries:

Oh, it shocked me! My two daughters were just petrified in some
ways, they were just crushed that this could happen. ... Of course
they did their utmost best, they were very helpful, anything I wanted they would do for me. But it really disturbed [me] in a way - that they were worried about something they had no control over, right. I couldn't help them.... And you know I didn't tell them anything about the blood spotting in December, I thought I'd just wait it out. I'm just handling a lot of things...it's not that I don't tell them much, I would tell them if things were right or wrong....but I wasn't going to scare them again. (Inspiration, p. 8)

Alice also spoke about how she protects others from the bad news she gets:

where the girls are concerned, I just keep them informed about my check-ups. Sometimes I hold things back a little bit... Now I haven't shared with my friends - only one person knows about my bone problems right now. (p. 7)

Loved ones are also prone to making significant demands on the ill person to maintain a "cheerful image" or to "stay positive"; they have a tendency to gloss over all the rough edges with... "You're going to be fine". But maintaining this image can only be done at significant cost (Frank, 1991). This demand for looking on the bright side isolates the ill person in their fears and worries. They have no one to share these with. The paradox is that, while an ill person is feeling fragile and in need of greater support than ever, they are also much more vulnerable and therefore unlikely to take any risks that might threaten the support they have. Thus, people who are ill often end up shouldering the further burden of guessing what their family and close friends can handle, to protect them from the worst news. Frank (1991) describes it this way:
I needed others more than I ever have, and I was also most vulnerable to them. The behavior I worked to let others see was my most conservative estimate of what I thought they would support. (p. 70)

Similar to keeping the use of complementary therapies secret from their doctors, people who are ill are unwilling to risk alienating those who support them.

But this silencing of the self has, as noted above, the twisted consequence of shutting out those who one is closest to, leaving the ill person isolated in their fears and concerns. Beth spoke hauntingly of the existential aloneness of the illness experience. She felt that, despite being as warmly and lovingly surrounded by family and friends as she was, there was a way in which the experience threw her into a previously unacknowledged place of intense solitude. Her illness experience initiated an understanding that she really had only herself to depend upon, and that, ultimately, she alone would (or wouldn't) survive the illness. Though, again paradoxically, while this was frightening at the time, it also resulted in a new sense of self-assurance in the end. Having found the inner strength to face her mortality and to undergo the arduous procedures of a bone marrow transplant, she feels nothing else can compare. An example for Beth is that she used to be terrified of speaking up in public, but since her diagnosis she has told her story in front of an audience of several hundred without any fear.

Occasionally, in exact contradiction to what was mentioned above, the distress of the illness overrides the inhibitions to relational risk-taking. Patricia describes finding herself alone in her bedroom wrestling with her fears and concerns, while her husband and daughter watched a movie downstairs. Quite
suddenly, feeling desperate for their understanding and support, she burst in and unleashed on them. Christina Middlebrook wrote in her book, *Seeing the Crab*, of a similar experience with her mother, suggesting that: "The barriers that usually shield me from the shame I feel about being angry, these lifelong barriers, have lowered. Cancer has changed me. I take more risks" (1994, p. 113). She took the risk of upsetting her mother by speaking the truth that she may die soon, only to this end:

*Jesus God, a can of worms. Pandora's box spilling like night crawlers from a styrofoam cup. We are not meant to speak the unspeakable, that my odds are not good. The telephone wires are creepy with scary, slimy things that make us turn our backs and run from each other. She runs, I think, from the fact of my death. I run from my infantile conviction that my anger toward her will annihilate me.* (p. 113)

Her mother counters that Christina is not thinking right, that she should be focusing on the best possible outcome. Christina reacts this way:

*These words enrage me. The mere assumption that good thoughts will effect the outcome of my life or death-revealing bone scans, tums me ugly as Medusa.* (p. 114, her emphasis)

The ensuing argument ends in an impasse. Christina feels a deeper isolation and worries that her mother believes she has given-up, when her true intention was to bring them closer together, to feel supported and understood.

A serious life threat, such as cancer presents, also has the effect of weeding out one's garden of friends and acquaintances, even one's family members as Christina found out. People, who can face the threat of illness, gather round; and those who cannot tend to show themselves by their
absence. It is not that the others don't care; they perhaps get mired in caring too much, unable to face the loss of their loved one. Linda expresses the process this way:

_When you get cancer you find that there's a lot of people that were just acquaintances that become very concerned about you, and become very involved in your life, and they really want to help you. And then there's other people, that you thought were very good friends, that just can't deal with it. And that's because, when you're dealing with somebody that has an illness like that, it forces you to deal with your own mortality also - and a lot of people can't handle that. It's just too frightening._ (Linda2, p. 3)

Living well with illness seems to require the ability to figure out who is truly helpful and to distance oneself from those who are not. There was little animosity expressed about those who couldn't handle the threat of illness, simply a sense of resignation that some are not capable of looking at their own fears of illness and death. Tim Brookes, a writer who lives with asthma and has had both his parents die of cancer, points out that:

_A society that denies death silences the bereaved, who are in the same disadvantaged position as the sick: the healthy and the happy (and in America an enormous premium is placed on being healthy and happy) are emotional fascists; they don't want to hear about illness or suffering._ (Brookes, 1997, p. 93)

Despite the need for supportive and loving relationships through the illness process, many find themselves unusually distanced from those they counted on, and sometimes surrounded by willing others.
This paradox speaks clearly to the need for the sensitive social relationships that support groups provide. People experiencing serious illness can be very helpful to each other in their willingness to hear and deeply empathize with each other's difficulties and triumphs. Many spoke or wrote of their need to be truly understood. Sharon Batt describes it poignantly:

*I wished I lived in a community where women with breast cancer could meet with one another and have professional assistance as they confronted the emotional devastation of a cancer diagnosis, ranging from conflicts with medical professionals, through social stigma, to the fear of "standing at the edge of the canyon".* (1994, p. 164)

But, there are also occasions when the support of others who have experienced illness is not useful. When the other is "too other", they may be experienced as unable to relate in a helpful way. After talking to a white, middle class, Reach for Recovery volunteer who came to visit her in the hospital, Audre Lorde wonders: "...if there are any black lesbian feminists in Reach for Recovery?" (1980, p. 42) She journalled the following:

*I ached to talk to women about the experience I had just been through, and about what might be to come, and how they were doing it and how they had done it. But I needed to talk to women who shared at least some of my major concerns and beliefs and visions, who shared at least some of my language.* (Lorde, 1980, p. 42)

*Clearly, numerous connections and disconnections attend to the relationships of those who attempt to live well after a life-threatening diagnosis. What people who are*
experiencing illness seem to need most, is to have all their emotions recognized and
accepted as very human responses to a difficult period in their lives. This recognition
and acceptance requires that others see how we all share this vulnerability as human
beings. Without sharing our grief, fears, and suffering, do we all become distanced from
our own ability to recognize and engage with our feelings? Connecting with others, I
am beginning to understand, helps us in some profound way to connect with ourselves,
which in turn increases our own well-being.

Bodily Paradoxes

There are several ways in which the body becomes a paradoxical entity
in the experience of living well with illness. The foremost of these bodily
paradoxes is the (earlier mentioned) difference between our subjective
phenomenological experience of embodied being which is juxtaposed against
the object-body of medical science. It has been suggested that:

*Western scientific culture requires that we see our bodies both as
physical structures and as lived, experiential structures - in short,
as both "inner" and "outer", biological and phenomenological...we
continuously circulate back and forth between them.* (Varela,
Thompson & Rosch, 1991, p. xv)

People who are being treated by medical personnel both experience
themselves as an object and a subject. During painful procedures they may
struggle to distance themselves from their body, to feel less by being "in their
body" less, but they may also subjectively attend to every little ache or pain they
feel as they worry about a recurrence of the illness. This subject/object split is
complicated by the fact that while their object body may say one thing to the
physician through diagnostic tests or measurements, their subjective
experience can be something quite different, sometimes with confusing
results. For example, Lynn spoke of feeling extremely well during the time leading up to her recurrence and, even when the CAT scans provided sufficient rationale for undertaking a seriously invasive surgical procedure, she continued to feel just fine. Consequently, making the decision to undergo surgery was very difficult for her.

Kay Toombs, a sociological researcher who also lives with multiple sclerosis, describes the difference between how she and her doctors view her illness:

*In discussing my illness with physicians, it has often seemed to me that we have been talking at cross purposes, discussing different things, never quite reaching one another. This inability to communicate does not, for the most part, result from inattentiveness or insensitivity but from a fundamental disagreement about the nature of illness. Rather than representing a shared reality between us, illness represents in effect two quite distinct realities, the meaning of one being significantly and qualitatively different from the meaning of the other.* (1987, pp. 219-20)

She goes on:

*The physician is trained to see illness essentially as a collection of physical signs and symptoms which define a particular disease state. He (sic) thematizes the illness as a particular case of "multiple sclerosis", "diabetes", "peptic ulcer", and so forth. The patient however, focuses on a different "reality". He does not "see" his illness primarily as a disease process. Rather, he experiences*
it essentially in terms of its effects upon his everyday life. (pp. 222-3)

People who are ill and those who treat them experience the "sick body" very differently. For ill people to understand and communicate effectively with those who diagnose and treat them from the medical model, they must split their own awareness between their knowledge of their body as an entity and their lived bodiliness.

Illness resists our attempts to predict and control our bodily being. In illness our bodies change from being something passive and inert, a vehicle for our minds as Descartes' legacy would have us believe, to something active with a "will of its own" as Arthur Frank (1991) describes it. The disrupted functioning of our body during illness foregrounds how we are unconditionally embodied beings; "dysappearing bodies"- do not disappear, instead they intrude upon our taken-for-granted unawareness of bodily being (Leder, 1990, my emphasis). The breakdown of the body is experienced as a movement from bodily muteness to an exuberant outspokenness of the body. There is yet another paradox here. At the same time as we are called upon to learn the objectifying language of medicine, we also become intimately acquainted with our essential embodiment. We learn in no uncertain terms that our lives are dependent on our bodily being, that all of our well thought out projects can be negated by a body disabled through illness.

We live in a world which speaks ourselves into existence as something quite separate from our bodies. We learn to speak as if we have bodies, rather than accepting that our embodiedness is the basis of our beingness as Merleau-Ponty contended. What if Descartes had said: "I suffer, therefore I am."? or "I am, therefore I suffer"? Perhaps, if
we were more in touch with how we are an embodiment of mind, "the mind's own sensuous aspect" and if we returned to a clearer understanding of ourselves as but one aspect of the myriad realm of this planet (Abrams, 1996), we might develop a new awareness of how illness and death are also simply inevitable aspects of the whole. With this awareness we might be enabled to explore the ways in which our society creates imbalance and illness, how our community includes the "more-than-human realm" and the present need for healing at all levels (Nollman, 1994; Roszak, 1996).

Another body paradox is the irony of the betrayal by the sickly body in juxtaposition to the incredibly awe inspiring ability of the body to heal. People who find ways to live well with illness seem to move beyond a sense of disappointment to a place of reverence and gratitude for the amazing regenerative ability of their bodies. Beth describes her experience this way:

...I think the hardest thing through treatment was how betrayed I felt by my body, that it had kind of let me down you know, and it had never let me down before. And I thought - "Wow! Look what's happened to me!" - My husband took a few pictures of me in treatment and it's hard to even fathom that I was that bad. But then on the flip side of that - "God! How resilient the human body is!" You go to such a low level and then you can work your way back up...it's quite remarkable. (Beth2, p. 10)

Having spent many weeks in a hospital bed for a stem cell transplant, and still so weak a month later she was barely able to walk across a parking lot, Beth has a proud photo of herself a year later on a mountain-climbing adventure. People who are living well with a serious illness seem to have found a way to accept both the body's incredible vulnerability and its wondrous regenerative capabilities. They carry an embodied understanding that we can become as
frail and dependent as a baby, but that we can also turn that weakness into new found strength.

Perhaps frailty, dependence, and vulnerability are paradoxically our true strengths. Possibly by understanding these weaknesses, becoming close to them through illness, we can open our hearts compassionately to others. Is this the realm of wounded healers? Jean Vanier (1999) seems to suggest this:

To deny weakness as a part of life is to deny death, because weakness speaks to us of the ultimate powerlessness, of death itself. To be small, to be sick, to be dying, to be dead, are stages of powerlessness, they appear to us to be anti-life and so we deny them.

Vanier goes on:

If we deny our weakness and the reality of death, if we want to be powerful always, we deny a part of our being, we live an illusion. To be human is to accept who we are, this mixture of strength and weakness. To be human is to be bonded together, each with our weaknesses and strengths, because we need each other. (p. 40)

I also wonder how our fear of death has contributed to the reification of a modern science of medicine and to our dependency on the priesthood of medical doctors? (Andrew Weil suggested that MD. shouldn’t stand for medical deity) Has anxiety over illness and mortality been the driving force, which allowed us to negate our own knowing - to willingly give ourselves over to the medical authorities? So that now we find ourselves with no understanding of, and less trust in, our innate self-healing capacity, pawns within the functional subsystems of the modern medical machine. And
as Sogyal Rinpoche (1992) notes, the penchant for denying our interdependence and our mortality in Western society has effects which:

   go far beyond the individual: They affect the whole planet. Believing fundamentally that this life is the only one, modern people have developed no long-term vision. So there is nothing to restrain them from plundering the planet for their own immediate ends and from living in a selfish way that could prove fatal for the future. (p. 8)

Helps and Hindrances for Negotiating Illness Paradoxes

Negotiating the paradoxes of illness takes a great deal of energy and effort at a time when one's resources are already overburdened. In yet another paradox, further sources of strength, courage, and wisdom are required of people who are ill for such things as: understanding the twisted logic of avoiding blame while still taking responsibility; balancing the level of fear which keeps one aware of caring for self without becoming immobilized by anxiety; and negotiating relationships made both more poignant and more treacherous by the threat of suffering and possibility of death. Those I conversed with and whose stories I read had some very explicit ideas about what helped them through these quandaries and what hindered them. This last section considers the promises and pitfalls people have suggested are found on the pathways leading toward well-being during illness.

Supportive Others

As described in the first two paradoxes, a very important aspect of living well with illness revolves around making sense of the illness for oneself and seeing the illness as an opportunity to make changes in one's life. But drawing on illness in these ways takes some soul searching and reflection. Hearing and trusting one's own inner voice, as noted earlier, is difficult and it helps if
there are trusted others who will listen without judgment, allowing the person in
need to express fears, sort through worries and regrets, and discover what is
needed for healing to occur. Those who consider the voicing of fears and
comments to be too negative, those who would have the ill person dwell only on
the positive, serve to hinder this process. They leave the one who is suffering
alone in her or his anguish. In an example of the former, Marie feels that her
large extended family added considerably to her sense of well-being:

_I think that's one of the areas where I've been most fortunate, my
family has been just terrific. ...I've had the luxury of support from
immediate family [and from] a large extended family in terms of
cousins, aunts, uncles, whatever, all who are there for me. So I
have a good sense of the depth of support._ (Marie1, p.17-18)

Lynn also felt that it was an enormous help to be able to discuss openly and
honestly with her loved ones her fears and theirs. And Alice, too, felt supported
by her daughters. She wondered:

_I suppose when you are sharing good friendships with a lot of
people, maybe that's a very healthy thing, maybe that helps you
through some of these [problems]...I don't know._ (Alice1, p. 7)

Many expressed that those who had also, or were currently, experiencing
illness often best provided compassionate understanding. They found
themselves: "seeking out others who have had cancer because they can truly
understand" (Dianne1, p1). Linda said that the two people who were the most
helpful to her were women who had also had cancer, and she also spent time
connecting with a breast cancer support group on the internet. Brenda has
maintained close ties with a group of women that evolved from a short-term
breast cancer group facilitated by psychosocial staff at the Cancer Centre. She
stated unequivocally: "I think that's really important, to have that support, to know that others out there feel that same way - have that same fear - and when you talk it over it seems to help" (Brenda1, p. 7).

In contrast, people could be particularly burdensome when they spoke knowingly of illness, not having experienced it themselves, or gave unasked for advice. Even those who write books about illness can be experienced as troublesome. After seeing a book about how to avoid cancer by eating healthy, Linda expressed her dismay and her sense that it is just not that simple:

…it's garbage as far as I'm concerned, it's just garbage! ...You know, this person eats wrong and does all this stuff and this other person eats healthy and they still get cancer. There's too many variables, everybody's body is different. I don't believe you can prevent cancer by eating certain foods." (Linda2, p. 5, her emphasis)

Alice described hearing an acquaintance pronounce that there is too much money to be made in cancer treatment, so there is no incentive to find a cure. She feels angered and saddened, saying: "I guess I keep thinking, one of these days they're going to find something and those people are going to have to eat their words" (Alice2, p. 11). Clearly, others could be either beneficial or detrimental to the ill person's efforts to live well.

Having the ability to accept the help one is offered is another requirement in the process of well-being during illness. Dianne suggests that:

...there's opening up to other people. I was totally overwhelmed by my family and friends, but I also opened myself up to it. I never felt that I wasn't deserving of it, or that - "I don't want it".
Letting people help you heal, letting people in, that’s important.

(Dianne1, p. 15-16)

It is hard to benefit from the help and goodwill others offer if one is too proud, or too afraid, to acknowledge the need for it and accept it.

Supportive Practitioners

Particularly medical personnel, because they are involved so closely, have an impact on the well-being of those experiencing illness. If the nurse, receptionist, pharmacist, or doctor remain humane and caring in their interactions, the sense of well-being of the ill person is supported; if not, the dis-ease of the illness increased. From some of her experiences, Dianne feels that:

...they forget, in all the treatment ...and all the medical... - what it’s like to have cancer. You need to know that somebody knows about you, that somebody knows about you! That somebody at least begins to understand not only your case, but your struggle.

(Dianne1, p. 4, her emphasis)

Without humane and caring treatment, a process that includes approaching the other as a unique individual, the experience of illness becomes one of great suffering, an indignity to be endured rather than a human experience to be shared. People become isolated in their pain and fears.

Those who felt supported by their care providers were adamant that this experience improved their overall sense of well-being. Alice spoke of making jokes with her oncologist about not needing to penny pinch in her retirement, given her age and stage of cancer, after she purchased a new car. For her this was an example of his ability to empathize and engage with her as an equal. She was not just as a body to be treated. Alice notes:
I feel very comfortable with Dr. _____. I think he is wonderful, and 
the nurses who work with him. So I feel that I've got all the support 
around me, which is pretty nice to be able to say. (Alice1, p. 10)

Empathic care, it seems, is invaluable in negating the invalidity of an illness 
experience, helping the person to retain a sense of effectiveness and dignity. 

Others said they felt confused and betrayed when their physicians did 
not take the time to show compassion for them as whole persons. Dianne 
describes the discomforting feeling this gave her of being split into two parts: 

You are expected to tell them the stories that they want to hear. 
Your illness story needs to be formed in such a way that they want 
to hear it. In other words, I wouldn't be telling Dr. ____ [the 
oncologist] so much about my fear and anxiety, that would be for 
Dr. ____ [the psychologist]. I'd be telling her more physical kinds 
of symptoms and stuff, and that's made very clear. (Dianne1, p. 9)

Carole, spoke of her feeling that while she was treated very well in the 
beginning, the staff distanced themselves from her as her late stage cervical 
cancer prognosis worsened. She had a sense that she became progressively 
more a body to be treated and less of a person to be cared for - a very 
frightening and disheartening experience as she described it. She would have 
liked the following: 

What I really wish the medical people would do...is be much more 
supportive. There's not a lot of optimism. Their sort of - "If your 
disease progresses this way, well then we can be optimistic, but if 
your disease progresses this way ... it doesn't look very good" - 
and that's really hard for the patient then. You need a doctor that 
doesn't promise you you're going to get better because there's no
guarantees for any of this. But at least if you're hopeful [they should] support you in that. I find that that's not there. (Carole1, p. 26, her emphasis)

Also, it was not only physicians who distanced themselves from people's pain and suffering and thereby hindered the process of living well with illness. Marie had a mental health care worker, sent from the school board, treat her this way as well:

I was left with the feeling like you're a file, number 213 or whatever, and - "We've got to get these things done ...and one of the things we've got to get done is to get you well now!" (Marie1, p.18, said in an officious tone)

Self Support

Sometimes, making the necessary changes in one's life, or making one's needs known to others requires that you become a bit of a "rhinoceros" as Marie puts it (though she laughingly claims to have been one prior to her illness experience anyway). It seems to speed the process of coming to a place of living well if one learns how to make demands and be outspoken. But this task is perhaps more arduous for women as they have been socialized to ignore their own needs and care for others. Linda says:

I find that us, as women, we're caregivers you know. We look after everybody. We have to look after the husband, we have to look after the kids, the house, we have to work - we have to do all this and our own well being gets put on the back burner. Well, I don't do that anymore. (Linda1, p. 2)
Simplifying one's life and slowing down were also beneficial in moving the women I encountered toward a sense of well-being. For example, Alice spoke of pacing herself, being more relaxed about life, and paring down by selling her home and moving to a smaller place: "I'm tired of it, I've had it. So I'm going to look for a condo where the bathroom is on the same floor as my bedroom and where life can be a little easier" (Alice1, p. 4). She wants the least amount of hassle and complication in her life, so she can be independent for as long as possible. Of course, it also helps to have the financial resources to make such instrumental changes in one's life.

Not all of the changes made were quite so material. Many of the women spoke of needing to face up to difficult psychological and relational issues in their lives. These were issues that the busy-ness of everyday life hid from view or made it easy to ignore, but which took on new significance with the threat to one's mortality. For some, this on-going process includes paying attention to one's attitudes and values. Dianne expresses it this way:

...it's a life commitment, its a commitment in every part of your life to wrestle with your demons, to be honest with yourself, to be disciplined and work very hard at - I don't want to say controlling your thoughts but putting them in their place. Realizing for example, that your pain is not who you are and your fear is not who you are, that kind of thing....a commitment to deal with the issues in your life. (Dianne1, p. 13)

And Alice says:

I think cancer has made me more aware of so many things, when you get older maybe a lot of people do that, they reflect on their life. And perhaps I am doing this at 67, where maybe people don't
do it till they're 77, I don't know. This is probably because of the
cancer that I have these reflections [now]. (Alice1, p. 17)

Viewing disease and death as integral and acceptable parts of life is
also helpful for living well. For many, this move from denial to acceptance was
frightening, though ultimately it was very beneficial. Again, in Dianne's words:

...to know that people die and not to pretend that they don't and to
know that people suffer. So there isn't this ... trite kind of,
"Everything is going to be okay" - kind of thing. To have some
strength or ability to say: "Ya I'm afraid"; and, "Ya, I don't want to
die." But also, to go on. (Dianne1, p. 15)

Nan Shin also discussed the confusion she felt as she realized the extent to
which others denied the inevitability of death. She wrote:

...I am baffled by the evasive tactics of everybody, doctors and
patients alike. I don't know what they are being evasive about.

I don't want to be sick and die any more than the next
person, but I am so certain that knowing that there are sickness
and death - my own sickness and death - is the place to start from.

Start from in the right way. It is not minor and to be
smoothed away. It is not a planetary tragedy, it is not a matter of
course, and it is not untrue and to be kept hidden.

...I think that's where the trouble is, in a wrong or incomplete
dealing with "my own sickness and death."

For her this means: "Find out now, at once, what is the problem of life and
death, your own life and death, and solve it." (1986, p. 185).

Another writer, Andrew Schmookler describes how he found it very
helpful when he finally came to an open acceptance of his lingering illness:
I realized that those experiences I was finding so bitter and frightening were an inevitable part of human life. Ultimately, for all of us, our efforts to maintain our vitality will fail, our most treasured capabilities will slip. Even if I should find the magic bullet I had sought so long and dispel the hated cloud hovering over me, it would be a mere stay of execution. Eventually I - as well as everyone else - would lose my vital powers. If not through chronic illness, then through the inescapable process of aging and, finally, death.

As obvious as this may be, it still came to me as an important if unwelcome realization. And I felt the time had come to change my posture toward this experience.

After years of fighting against what had seemed so unacceptable a loss, I found myself pondering the possibility that perhaps there was something to be gained from accepting it, from acknowledging to myself: "This is my experience and I might as well see what I can learn from it." (1997, p xvii)

In a society in which "doing" and "succeeding" take precedence, the prospect of one's life ending before the trophy is grasped can be unendurably disappointing (Levine, 1997). Our societal emphasis on objective success can cause people to judge themselves harshly, to take the measure of their life and come up feeling less than worthy, when illness interrupts their goals and plans. Living well with illness, and coming to terms with the prospect of death, seem to entail a softening of this societal standard, an opening to, and acceptance of, the inherent worthiness of self; an emphasis on being rather than succeeding. Jazz, as noted earlier, feels that her relationship with her
bodily self changed dramatically through her illness experience, from one of criticism and only seeing the imperfections, to one of loving acceptance. Ginger believes that our inability to love ourselves, closes us off from ourselves and others, whereas learning to love ourselves opens our hearts in compassionate, non judging understanding.

This acceptance does not have to be humourless. In fact, keeping one's sense of humour seems to help the process in many ways. Beth describes wonderment at how even in the darkest moments she and her partner can make wisecracks about illness and death, but recognizes that their black humour eases them through some very dark moments in her illness. Alice laughingly described joking with her daughters as follows:

...but my girls - we kind of laugh about it. My middle daughter, a year ago, she bought a greenhouse business, so I'm very involved in that (as much as I want to be). I do her books, but I also do transplanting and mix the mud and things like that. Just the other day she said to me, "Mom, you gotta be around for a while, because I don't think I can ever handle that book work." So you know we laugh about it and that's the way you have to do it, you have to be realistic I think... (Alice1, p. 7)

There seems to be a pathway towards illness that is rendered easier to follow by an openness to and even laughter in the face of suffering and dying. **Spiritual Support**

Many of those I spoke to found that an increased sense of spirituality helped them to live well with their illness. For some, this meant renewing lapsed formal religious, or less formal spiritual, connections. For others, illness initiated a whole new sense of gratitude and reverence for life, as well
as a connection to something beyond themselves. For Jazz there was a profound shift:

*It's like I can hear music with my eyes. And that's almost how it is, that there is a new dimension of perception that I cannot reach with my eyes, ears, or mouth, or tongue, or hands yet. Ya! I think that's how I would describe it. It's a new sensor...that does the same thing an eye or ear does but in it's own dimension - giving a glimpse into the bigger picture, sensing something beyond the physical. And it's a challenging and rewarding quest for balancing the awe of all and the uniqueness of self in it.* (Jazz2 p. 24)

For Dianne, while there was a similar sense of increased gratitude, there was also a realization that the spiritual aspect of her life had been completely ignored in the busy-ness of her daily activities. Since her diagnosis she has taken the time to focus some of her energies on reading spiritual material again, working to expand her sense of contentedness and thankfulness. Brenda has returned to regular church services and feels that: "I think for maybe the first time in my life, I'm actually praying when I go to church" (Brenda1, p. 7).

For some, spiritual support comes from reconnecting with nature and thereby with the cycles of birth, death, and regrowth that occur there. Terry Tempest Williams expresses it exquisitely, first from her mother's perspective, as she describes why she went a month long paddle through the Utah Canyonlands before seeking treatment for an obvious abnormal growth:

*In the long run I didn't think one month would matter. In the short run it mattered a great deal. The heat of the sandstone penetrated my skin as I laid on the red rocks. Desert light bathed my soul.*
And travelling through the inner gorge of Vishnu schist, the oldest exposed rock in the West, gave me a perspective that will carry me through whatever I must face. Those days on the river were a meditation, a renewal. I found my strength in its solitude. It is with me now.

She looked at Dad, "Lava Falls, John. We've got some white water ahead."

And then from her own perspective:

I know the solitude my mother speaks of. It is what sustains me and protects me from my mind. It renders me fully present. I am desert. I am mountains. I am Great Salt Lake. There are other languages being spoken by wind, water, and wings. There are other lives to consider: avocets, stilts, and stones. Peace is the perspective found in patterns. When I see ring-billed gulls picking on the flesh of decaying carp, I am less afraid of death. We are no more and no less than the life that surrounds us. My fears surface in my isolation. My serenity surfaces in my solitude. (p, 29, 1991)

Einstein is credited with having suggested that the biggest question that human beings have to answer for themselves is whether the universe is benevolent. Somehow, despite all the suffering, people who are living well have maintained, or in some cases gained, a sense that the universe is a friendly place, that there is some benign force, or forces, at work, and that our experiences of living and dying make some kind of sense within a grander scheme of things. Can the sacrifices of illness convey to us a deeper understanding of sacredness of all life?
Supportive Metaphors

As has been noted several times throughout this writing, our society has a fear of death, dying, illness, pain, and suffering. Those experiencing serious mental and physical illness, the deterioration of aging, or dying are shut away in hospitals and homes which hide them from us, allowing us to go on as if we are invulnerable to these inevitable human experiences. Our families and communities no longer support the seriously or chronically ill or aging among us. No longer are there extended family relatives or community members willing or able to provide the needed care. Dying has been relegated to the hospital or hospice and death to the undertaker and the funeral home. Only medical experts are viewed as capable of dealing with those who are ill or dying and, as noted earlier, the biomedical approach they represent concerns itself with the elimination of suffering and the irradiation of illness and death; with curing rather than caring.

Not so long ago the responsibilities of caring were provided within the family or community. The person experiencing illness or facing dying was not alone, but surrounded by people who had experienced these events repeatedly over their lifetime and who had, through this repetition, come to terms with them (Brookes, 1997). Currently, few of us deal with death or illness unless it touches us very directly. We have no models to follow, no experience to fall back on. This creates a significant barrier for those who need the freedom to speak openly of their illness and the imminent possibility of death.

This ignorance of death and suffering seems to reflected in our language as well. We are unlikely to learn about accepting and living well with illness (or about dying well) when all of our language and metaphors suggest
that we should fight against illness as an evil and rail against dying. Cancer, particularly, has been "maligned" in this way.

Susan Sontag (1990) described how the military metaphor, the war against disease, gained credence when medical science developed the germ theory of illness. Since we began to understand the "causes" of illness to be microscopic invaders wreaking havoc with the body's natural balance:

*Illness [has been] seen as an invasion of alien organisms, to which the body responds by its own military operations, such as the mobilizing of immunological "defenses", and medicine becomes "aggressive", as in the language of most chemotherapies. (p. 97)

The body has become a fortress that is breached by the forces of illness. Illness is something to be fought off or struggled against, conquered in battle or irradiated in all-out warfare. The ill person is exhorted to "mobilize their defenses", to "put up a good fight", and "to never give in"; to "not go gently into that good night" in Dylan Thomas's famous words. Diagnostic tests are indications of enemy progress, and treatment plans are deliberately laid military campaigns. Radiation, and particularly chemotherapy, are treatments designed to route every last cancer cell out of the body. Unfortunately, these therapies also have a devastating effect on the rest of the body as portrayed in the following description of chemotherapy:

*These drugs act during mitosis to prevent cell reproduction, destroying the rapidly growing cancer cells, hair cells, bone-marrow cells, and cells lining the gastrointestinal tract. Hence the tumor destruction, hair loss, reduction of blood cells, nausea, and*
vomiting. It's a savage exposure, a supervised chemical warfare.
(Nadler, 1997, p. 72)

War metaphors encourage aggressive behavior and risky heroics, the goal is winning no matter what the cost (Batt, 1994). Human and monetary expenditures on treatment and research are scarcely considered; control, power, and acquisition are the paramount issues in the "war waged on cancer".

The combat metaphor of illness prods people into action, encourages candor and explicitness, sets up "victims", "survivors", and "conquerors". But it also creates winners and losers. And, as Arthur Frank (1991) suggests: "Thinking of tumors as enemies and the body as a battlefield is not a gentle attitude toward oneself, and ill persons have only enough energy for gentleness" (p. 29). The anger and aggression mobilized by the military metaphor can cause misplaced or wasted energies. Anatole Broyard (1992) in his musings on cancer wrote:

_I think sick people are more frustrated by their illness than angry and that they should think of ways to go on with their lives as much as possible, rather than proclaiming their anger....Anger is too monolithic for such a delicate situation. It's like a catheter inserted in your soul, draining your spirit._ (p. 12)

The biggest problem with a war metaphor for illness, is that it leaves people feeling like failures when they can no longer "fight the good fight". The "valiant effort" against illness turns into a "defeat" as they "lose" each small "battle" and, coming to the point of having tried every treatment option, they have "nothing left to fight with". Even the seemingly harmless metaphor of "immune defenses" leaves us open to the fault of having "let our guard down", or of not
having "shored up our defenses" well enough with an appropriately healthy lifestyle.

Also, the increasing accuracy of diagnostic tests encourages prognostic declarations of statistical survival rates, but how helpful is it to hear that you have a 50% chance of living less than three years? I have heard repeatedly that the fears which predictions of this kind engender, are themselves nearly lethal. Is increased candor and explicitness the only direction to take? If we abandon the military metaphor, must we abandon metaphor altogether, as Susan Sontag suggested?

In her book *Illness as Metaphor*, Susan Sontag (1978/1990) wanted to demystify the cancer experience by denying the limited metaphors, which blame and create more difficulties for those who are already suffering from the illness. But Anatole Broyard (1992) suggests that metaphor is in fact an important device for ill people, and worries that Susan would create an antiseptic and static experience of illness in her attempts to purify it of the dangers of metaphor. Anatole believes there are positive metaphors of illness, "which might serve as a kind of literary aspirin", as comforting as one's "own slippers and bathrobe" when one is feeling sick (p. 18). He points to Oliver Sacks' writing as an example of using metaphor in a positive way, describing him as: "a doctor who has a genius for looking around inside the patient's illness for suggestions about how the sick man can cope, how he can live parallel to, or even through, his disability" (p. 19). Metaphors, Anatole believes, can help us turn "disadvantage into advantage" and lessen our suffering by describing illness as: "not a disaster, an occasion for depression or panic, but as a narrative, a story." "Stories," he says, "are antibodies against illness and
pain" and "language, speech, stories, or narratives are the most effective ways to keep our humanity alive" (p. 20). He believed that by writing his own story of illness he would remain fully alive until he died.

Narrating his own cancer experience gave Anatole an opportunity "to demystify or deconstruct my cancer" a process which helped him realize that "there is no absolute diagnosis, no single agreed-upon text, but only the interpretation each doctor and each patient makes" (p. 21). Self-formed narratives and self-chosen metaphors can, perhaps, make a space for one's own interpretation and the possibility of choosing the best course for oneself. James Hillman (1983) also suggests that our images make demands upon us, they are compelling and annoying; and, having an agency all their own, their sensuousness and resonance calls on us to respond. Perhaps, "our imagination is what saves us" (Nadler, 1997).

If this is so then perhaps we need to develop some new metaphors for the experience of cancer. Is it possible that the military metaphors of cancer put us at war with ourselves in ways that deny us the very care and nurturing required for our well-being? Could we re-story illness using metaphors of growth, nurturance, cultivation, and transformation; metaphors which allow for an increased connection to the sacredness of life and the resilience of the human body and spirit; metaphors and stories of caring support through difficult but rewarding times?

I find myself wondering if it is possible that cancer grows like a weed in the most unattended parts of ourselves? If it is, as Lynn suggested, simply a neglected part of ourselves growing wild within us in an attempt to get our attention? What if we cultivated our whole selves and nourish all parts of our bodies and selves with health-
giving thoughts, nutritious food, clean water and fresh air... could we provide a more balanced and hospitable environment for our continued growth and development? Take breath for example - given that many types of cancer cells are anaerobic, thriving only in a lack of oxygen, and the rest of our cells require oxygenated blood to survive - could we re-inspire our lives after a cancer diagnosis by paying attention to our breathing? Learning to breath, stretch, meditate, relax, and nourish ourselves in myriad and mindful ways would at least be likely to bring us into a closer relationship with our bodies. We might learn to listen for the cues, which warn us of impending difficulties, or be better prepared to listen for the messages illness brings. These techniques, at the very least, might allow us a sense of participating constructively in the cultivation of our own healing - a sense which conventional biomedical treatments, with their emphasis on "patient compliance" tends to efface. What types of stories are we interested in telling ourselves about illness? In an organic sense life requires growth and change without these dynamic processes stagnation and death soon follow. Is control then about resisting change and growth - about trying to hold in one static position something that must, by its very nature, grow and change, or die?

Rachel Naomi Remen has written a book of healing stories drawn from her experiences as a medical doctor and a director of the Commonweal Cancer Help Program. She suggests that stories are powerful healing tools:

All stories are full of bias and uniqueness; they mix fact with meaning. This is the root of their power. Stories allow us to see something familiar through new eyes. The meaning we may draw from someone's story may be different from the meaning they themselves have drawn. No matter. Facts bring us knowledge, but stories lead to wisdom. (Remen, 1994, p. xxviii)
As human beings we live with the impulse to story our lives into meaning. We give our lives cohesion and direction through our stories, smoothing out the rough and tangled pathways of our attitudes, beliefs, and behaviors. We ease or disturb our minds through the stories we tell ourselves and others. Our narratives are a source of understanding, they have a "moral force", a "healing power" and even an "emancipatory thrust" (Sandelowski, 1991, p. 161): "Our narratives are orchestrations of meaning" (Schmookler, 1997, p. 37). The stories we tell ourselves also adjust and evolve with each retelling, our reflexive nature bears new meaning and understanding with each (re) presentation, information gathered on more recent journeys informs the paths of our memories and dreams. Narrative therapists suggest that our lives are actually transformed and/or constrained by the storied paths we tread (White, 1980).

Through the Mobius

As we began this chapter, so it ends, twisting back on itself in the manner of the mobius strip: considering, once again, how the predominant stories, the well-traveled pathways of illness in our society position us in ways which give us more or less freedom to maneuver and make choices. There are numerous interpretations or maps, which we can choose from in our experiences of illness...

Medical science positions us as: a helpless victim in a battle waged against disease; a passive, and hopefully compliant, patient relying on a medical expert; a body to be tested, treated, and hopefully cured through physical interventions; and responsible only for focusing on getting well again.

New Age theories consider us: blameworthy for having brought the illness on; responsible for having created this reality, therefore responsible for changing it;
and as a failure, if we cannot negotiate the needed changes to resolve the illness and avoid death.

Society locates us as: pitiable and stigmatized; someone who must maintain a positive attitude or be avoided so others can continue to pretend that illness won't touch them.

And a phenomenology of illness accepts each of us as a unique embodied nexus in a dynamic, shifting web of relations: as unique human beings who might die sooner than anticipated and, therefore, as people in need of facing their own particular fears and vulnerabilities in order to negotiate the paradoxes of illness; as persons who are no longer able to avail themselves of the pretense that they will live forever and thereby in need of living each moment mindfully, as if it were a precious blossom; as having permission to forgo the critical eye of others and instead focus on themselves and their own needs and destiny; as unique human beings in need of listening to their own intuitions about the messages illness gives them, of telling their own story and finding their own metaphors for the illness experience, and of avoiding any sense of causal guilt or shame; as people requiring loving, mutual relations with others which sustain and support them, and words and stories which do the same.

Which stories, what metaphors, whose language - do you prefer? Which pathways, do you choose to tread?
CHAPTER FIVE
MORAL CLAIMS ON THE WAY FORWARD

Since here the object of experience is a person, this kind of experience is a moral phenomenon - as is the knowledge acquired through experience, the understanding of the other person. (p. 358)

The claim to understand the other in advance functions to keep the other person’s claim at a distance. (p. 360)

In human relations the important thing is...to experience the Thou truly as a Thou - i.e., not to overlook his claim but to let him really say something to us. (p. 361)
(Hans-Georg Gadamer, 1994, p. 355)

Stories of illness are not stable, static things, they evolve and change with each re-telling as the emphasis and perspectives of both tellers and listeners shift. Our stories are not “accounts”, a counting up of items, they are endlessly alive and in transition, they are the re-creations, the fictions, of our lives (Hillman, 1983). The paradoxes described in this study, like everything we experience in life, are in constant fluctuation, ebbing and flowing as if through the mobius - death informing life, and life, informed by death, changing the perspective on death - weaving to and fro, back and forth, constantly unfolding through time. As we hear the stories others have to tell about themselves, the world, and, perhaps especially, about us, our own stories are influenced. The stories I relate about my own life and death have shifted and changed as I listened to the stories of those who are trying to live well while grappling with illness and mortality.
The rationale for undertaking this work lies in the need for an exploration and understanding of what it means to live well after a life-threatening diagnosis. My interpretation of these narratives of living well with illness shows their capacity to expand upon the prevailing discourses of illness in our society. Consequently, these stories make a moral claim on those of us whose "practice" puts us in relationship with people experiencing illness (Frank, 1997; Walker, 1998). The question which remains is: how would our views of health and our health care practices change if we open ourselves to these stories of illness as voicing something of value and importance?

The understandings, which have unfolded throughout the body of this text, will hopefully serve to deepen your awareness of the possibilities in this approach to illness. I am not prepared to argue that everyone who would live well after a life-threatening diagnosis must follow the pathways suggested here. In fact, by presenting the paths as paradoxical reiterations, I have tried to uncover the on-going process of negotiation and renegotiation, which occurs as a person engages with well-being during illness. I have sought to avoid developing a master narrative or recipe which might limit the possibilities of those who are experiencing illness. What I do want to argue is that through careful attention to people's stories of well-being within illness, we are called into a new conversation about health and what it means to live well.

As I open this discussion about the possibilities for health, I continue to be mindful that interpretive understandings invite dialogue. Therefore, in this chapter, I want to consider how I am finding my way through the world that I have been awakened to by the voices of those who are living well after a life-threatening diagnosis. And I invite you to consider how you might also be claimed, as you read my suggestions. I explore how I have been called by
these stories to participate differently in this unfolding conversation - as a person, a counsellor, and a researcher (as much as these can be separated out). Initially my discussion may sound somewhat too up-beat and hopeful, as I focus on the possibilities that have addressed me. But later in the chapter, I also look at the limitations of positioning people who are ill in a cage of hopefulness, the inevitable grieving caused by a foreshortened life, and the sadness which attends to an acceptance of human vulnerability and finitude.

Personal Learnings

Living Well

Wending my way on these pathways toward living well with illness, I have learned something about what it means to "live well" at any time. Living with the legacy of these stories, requires that I be mindful of the numerous paradoxes and tensions of daily living. I am more aware than ever that much of life is a shifting, chaotic process which contains both sides of all dualities - the sacred and the profane, hope as well as despair - and that I must live each day with the difficulty and necessity of choosing well. I am also claimed by an understanding that human vulnerability to illness and death is something to attend to and learn from, rather than something to be avoided and ignored, that avoidance and ignorance create a void between those who are suffering, and myself. I am more acutely aware of how my embodiment is an unpredictable, unfolding process, which I can influence but cannot control. I also have an increased sense of myself as a full participant in the rhythms and cycles of nature, with both, a dependency on them and a responsibility to them.
These awarenesses call me to be more present, to live more intentionally with a deeper appreciation of life’s contingency. In conversation Lynn asked:

...is there some way for people to get back in touch with that childlike approach to living, at least a little more, maybe not as much as you’d be forced into if you’ve got a life-threatening situation and come through it and value life differently. (Lynn1, p. 31)

Hearing these women’s stories has inspired me to be more open to the childlike wonder at the preciousness of being alive, and to live with a risk-taking that is more playful, more attuned to what brings me a sense of fulfillment and a continued enthusiasm for living. I see more clearly how attitudes of obligation and boredom inhibit my possibilities for wonder and enjoyment, or the simple pleasure of a job well done, in all the activities of my life. I find myself watching more carefully now for the passions of my life, for the experiences that bring a sense of joy and completion. I find them in the predictable (my partners loving touch, hugs from my children, finishing my degree, feeling supported or being supportive) and the, to me, curiously simple (flowers in my yard, the sound of running water, an afternoon in a beautiful setting). I also have a growing awareness that such predictable and simple experiences are my life, and I am less inclined to wait for this or that event to take place before I begin to truly live.

All of these understandings have come with a darker side as well. I have become aware that I cannot really live well, or understand the meaning of living well with illness, without grieving the loss of innocence that the acknowledgment of our human finitude opens up for me. The naïveté that
attends to my own denial of death is no longer something I can count on to protect me. I now understand that if I keep the suffering of others at a distance from myself, my ability to connect with and understand them is diminished. But in not denying the selfness of the other, I open my heart to a painful embodiment of their suffering. This is an opening, which in turn creates a larger capacity for compassion in me and, paradoxically, I find it also increases the depth of my awareness and capacity for joy and celebration. Holding my first born child in my arms was a similar experience for me, though initiated from beginnings rather than endings. Feeling my heart open and flood with love and joy in the seconds after his birth, I also came to a breath-taking awareness of our exposure to loss and heartbreak. My intimate, embodied knowledge of one side of the mobius draws me through to its opposite. This paradoxical twining of opposites expands me.

**Living Well with Illness**

Having undertaken this investigation, I cannot continue to view my own health as something over which I can exert perfect control. No longer can I subscribe to a simplistic "lifestyle pact" with good health - a logical, if less than explicit, bargaining - which suggests that if I exercise, eat right, meditate, and think only positive thoughts, then I will never get sick, age, or die. I have come to a clearer perception of the inevitability of change, both decay and renewal, in our lives. As a consequence, I can no longer blindly sanction the self-protective societal myth that illness is somehow earned through an inappropriate lifestyle. I am more aware than ever before that, despite my best efforts to live well, in all likelihood I too will one day find myself ill. But I have also been opened up to the possibility that illness can provide me with opportunities - to
reconnect with the sacredness of life, to renew my relationships with others, and to transform other aspects of my life.

I hope that when my time comes, I will find a way to explore the territory of illness. Rather than battling to manipulate and control it as something foreign and threatening, I would like to accept illness as a part of life and open up to the possibilities inherent in the experience. Although I realize I will never be sure of my reaction to a life-threatening illness until I am in the middle of it, I hope that I will have the presence of mind to allow it to unfold and to grapple with the changes and challenges it presents, rather than rejecting and fighting it off. I hope I can retain what I have come to know of the possible pathways to living well within the experience of illness: remembering that, though illness threatens the foundation of my very being-in-the-world, there are a variety of ways I can choose to perceive it; remembering that the biomedical diagnosis is but one interpretation of my illness and that I need not allow it to limit my beliefs or expectations of my own healing ability.

I have come to value an interpretive approach to illness and would look for practitioners who could see how interpretation:

...gives us a way to think about illness that allows us to take suffering as seriously as we take anatomy. It permits us to practice medicine in a way that remains faithful to the human needs that create medicine. ...we can try to enter the world of illness as lived by patients rather than confining ourselves to the world of disease as described by physicians. (Baron, 1985, p. 609)

I expect, after my conversations with these women, that in illness I will search for a "healing team" of competent people who are willing to engage in an open
dialogue with me and each other as equals - a dialogue in which their various understandings of the options for therapy, and my requirements for well-being, can influence each other. I will be looking for practitioners who are more than technical experts, who bring their humanness into relationship with me in a collaborative conversational effort, which will result in an original approach to illness that is tailored to my specific health needs. I want to be offered options and possibilities, rather than being told what "must" be done. I want to be more than a chart, full of statistics and lab reports, to those who care for me in my illness.

I would also like assistance in resisting the pressures of biomedicine, and my own initial anxiety, to decide on treatments too quickly without taking the time to reflect, deliberate, and choose from a place which keeps me centered in what I believe and value. I agree with Kirmayer that:

In the confrontation with mortality, the practice of medicine offers a unique opportunity for a true marriage of reason and feeling [mind and body]. This will occur only when both healer and sufferer are open to bodily-felt meaning and the social context of sickness and respond, not just with a flurry of technical activity, but with a human relatedness that nurtures the seeds of contemplation and compassion. (Kirmayer, 1988, p. 84)

I hope I have learned enough to have the presence of mind to take time out from my daily efforts and consider carefully what I need for healing, rather than being seduced by the quick fix approach of symptom irradication. I hope that within the chaos of illness, I will find a pathway that allows me to see the message and meaning of illness, without succumbing to the societal pressure to blame myself for having become ill in the first place. Also, having heard how
it is possible to take a creative stand within my own fears and anxieties, I hope I can use fear to motivate my actions without being overwhelmed by it. I have also heard how my relationships with self and others will be challenged and how I will be pressured to return to old patterns of behavior: perhaps understanding these pitfalls will help me negotiate the tricky pathways toward well-being in illness, and find ways to sustain myself through difficult times.

Beneficial Practices

I have pondered what I might like to encounter if I find myself in need of medical treatment. While the sterility of hospitals and clinics serves an important function, I feel it also tends to foster a barren existence for people experiencing illness, as well as for the families and friends who visit and wait with them for appointments and tests. In an effort to protect people who are ill, and to facilitate efficiency for practitioners, places of treatment have become devoid of the caring, comfort, and beauty which keeps us connected to our humanity (Brookes, 1997). I would like to see hospitals transformed into centers of well-being, places where healing, not just curing, is foregrounded. I am not suggesting here that the technological approach of our modern medical institutions is in itself problematic. What creates difficulties is our reliance on technology to cure illness, when it occurs without acknowledging our humanity and our need for healing.

There are some simple ways in which this process has begun. Hospitals are being built with an eye to providing beauty and natural views for those who have to be there long-term. A more specific example is the Art à la Carte program, at the Foothills Hospital in Calgary, Alberta. This not-for-profit organization promotes a more comfortable, home-like environment for people undergoing long-term treatments for cancer, by bringing them a selection of
artwork for their hospital rooms. The founder, Debbie Baylin, has also been instrumental in creating a "Wellness Walk", which consists of a hallway full of framed art and a sanctuary, in a quiet corner of the cancer ward, which has been painted with a beautiful wall mural and furnished with willow cane chairs. Programs such as this contribute to people's sense of dignity and worth, they send a message that illness does not invalidate our human needs and desires.

I have also heard that a few major Canadian cancer institutions keep baskets of wool in their waiting rooms, so people can crochet squares while they wait for appointments and treatments. The squares are then made into afghans by volunteers and returned to grace the waiting rooms with a little human warmth and caring. I have heard how this crocheting passes the time and also creates a sense of community, fostering supportive interaction between the people who wait there. Sadly, I also heard that this practice was discontinued in one centre when the afghans were deemed unsanitary.

In another example, the growing public acceptance that humour positively effects the immune system, has given rise to the use of good humour carts on many hospital wards. These carts supply people who are hospitalized with videos, joke books, and other humour stimulating paraphernalia. The movie, Patch Adams, has recently brought the connection between humour and health back to the fore. Patch Adams is a medical doctor who believes that humor is often the best method for establishing a connection between people; a connection that he thinks is essential in stimulating a healing response (Adams & Mylander, 1998). In his recent book, he suggests that "the projection of love, humor, empathy, tenderness, and compassion are all necessary ingredients to inspire the magic healing qualities of human body" (p. 35).
This last quote, of course, is not news to counsellors. Our training pushes us to expand our capacity for empathic interaction with those we meet in therapy. The stories of living well with illness presented in this study suggest that counsellors could play a much more significant role within medical settings. Rather than counselling being an add-on, a non-essential service to be called in when a person’s ability to cope has been overwhelmed, perhaps counsellors could play a more fundamental role. Counsellors could initiate a conversation about the ill person’s needs from the onset of their interaction with the medical establishment, facilitating the interactions and coordinating the efforts of the "healing team" (such as I suggested earlier).

Callings on My Counselling Practice

Re-educating Our Ability to Care

Moving from the concern for curing to an awareness of the needs involved in caring, is the fundamental shift that these stories point to. Those working from the cure paradigm, based in our ever increasing technological capacity to save individual lives through radical physical intervention, have little time for the unique histories and qualities of the people they diagnose and treat, or for the fundamental relational quality of their lives. Caring, on the other hand, requires that we understand how each person’s unique and evolving stories generate their particular potentials for both suffering and healing. Caring requires that illness be viewed as an acceptable and inevitable aspect of living; and that people not be detached from their biography and history through treatment which focuses only on the body.
Practical Wisdom

My involvement with this topic has made me more aware than ever that working with people who are experiencing illness is a moral enterprise, entailing a practical wisdom. As a counsellor I see that I must exercise anew my own practical reasoning and judgment in any given encounter with another. This practical wisdom, like Aristotle's "phronesis", cannot be pinned down to a rule bound method the application of which would be "simply a matter of following a procedure as one follows a recipe in cooking" (Risser, 1997, p. 107). Rather, this practical wisdom "is a matter of perceiving what is at stake" in any given situation (Risser, 1997, p. 107). I see clearly, that I am never free of the necessity of choosing how best to work with this individual, in this moment, given these particular circumstances.

Self as Counsellor

I have also learned that by bringing an attitude of openness and exploration to my encounters, I will create a space for a dialogue which may transform the understandings we both hold. Within this space there may be an opportunity to share between us, respectfully in an I-Thou relationship (Buber, 1970; Gadamer, 1994), the paradoxical possibilities of living well after a life threatening diagnosis. Encountering the other as a Thou acknowledges our shared human vulnerabilities and weaknesses, equalizing the relationship between the one cared for and the giver of care. We become two people in intimate conversation about the possibilities for living well within this encounter with illness.

Engaging in this research has also made me more aware of how I bring myself to every encounter. In counselling, as in interpretive research, there is no escape from myself, no clean slate from which I can begin, that does not
include my own accumulation of experiences and understandings. For me this reinforces the need to be clear about my own beliefs and intentions, taking care not to slip into a dependence on the "usual stories" of illness, or, perhaps worse, an expectation of some formula for living well with illness. While remaining mindful of the resistances these women have taught me - such resistances as avoiding societal blaming, or not giving in to pressure from family and friends to "get back to normal" - I must allow each person's unique needs to be voiced.

This study has taught me to see a reflection of myself in the suffering and vulnerability of each person I meet, and to know that whatever they are going through is part of the range of human possibility which encompasses myself as well. I intend to use this understanding to continually awaken my own compassion and ability to join with others without needing to fix or negate their unique experience and emotional response. Where I once viewed recovery from illness as the ultimate goal of counselling for well-being, researching this topic has allowed me to see that there are ways to be well which can encompass illness. I see illness as a human experience to be embraced and engaged with, both bodily and intellectually. This requires that I make efforts to acknowledge my own vulnerability, as well. I am aware that others' stories of chaos and disintegration rock the foundations of my own being-in-the-world, requiring me to care for myself in this process if I am going to continue to be present to those who seek help. I must continue to deal with my own woundedness, seeking support and working through my own fears, so that I can stay with others in places of weakness and suffering.
Practice Possibilities

After dwelling with these women's stories, I will remember in my work with those who are dealing with illness that: "...illness alters the very forms in which a person experiences the world" (Gadow, 1990, p.168). Kat Duff's words remind me that:

There is nothing like a serious illness to blow down our fragile houses of sticks and straw. Standing amid the rubble of their lives and thoughts, people with serious illness undertake the task of building a new house, a new way of living, one that holds closer to the ground of being, the feedback and teachings of their bodies and souls. (p. 56, 1993)

As a consequence of this investigation, I see my role as counsellor, more as a temporary shelter from the storm than as an advisor. Remembering the approaches to well-being I have heard expressed, it is my intention to provide a place where a person experiencing illness can feel free to describe and embody the emotional impact of mortal illness on their life; a place to explore the meaning of illness across the various aspects of their being; a place to begin the process of restorying a life which includes illness and vulnerability to death.

Storying Illness

Hearing the variations in these stories of living well with illness, I am called more fervently than before to listen carefully to the particular ways in which each individual frames their own illness story, watching for signs which speak of wellness and healing. As Arthur Frank suggests "The story and the life can only be one's own; each must discover his or her own terms of success" (1997, p. 137). An interpretive understanding of the human experience of
illness entails engaging with every person who walks through my door as a never before encountered being, whose experience of illness is something I can only come to know through dialogue with them.

An emphasis on story allows therapists a range of techniques for entering into the other’s world with them and exploring how their narratives limit them and how they might be refigured to expand their constricted possibilities (Freedman & Combs, 1996; Gergen & Gergen, 1988; White & Epston, 1990). I would expect to explore a range of stories with them: from the complexity and nuances of personal meaning, through past personal experiences with illness, to their expectations of the future, their relationships with others and themselves, the cultural and other roles they partake in, the losses incurred by illness, their hopes and dreams for the future, as well as the transcendent or spiritual beliefs which might provide support through the intensity of illness (this list derives from Cassell, 1990, on the aspects of “person” which should be considered in a medical history). Rewriting one’s story of illness to include well-being, suggests using narrative practices which require therapists to be aware of non-verbal cues, especially voice, posture, and gesture, as well as listening carefully for personal metaphorical language which may provide insight into each individual’s story of healing (Feinstein & Krippner, 1988).

These stories have also made me more aware that we live within a social milieu, which puts great store in success and views illness as a failure. Consequently, as a therapist, I will need to support those experiencing illness to disengage from societal messages of blame and guilt. Kathy Charmaz (1987, 1995) suggests that chronic and progressively debilitating illnesses require on-going reappraisals of the self. This continuous "biographical work" takes considerable effort and may indicate another important supportive role for
counsellors as people struggle to create valued lives and selves during illness. (Corbin & Strauss, 1987).

**Embodying Illness**

But, just as biomedicine constrains our ability to heal by paying attention only to the body, counselling can be accused of a similar limitation if it pays attention only to the mind. Counselling must embrace the whole person, considering the physical, social, and spiritual, as well as the mental. As noted at the end of Chapter Three, taking an embodied view of the person allows us to appreciate more fully how illness interrupts the very ground of our being, with a resulting disruption of our ability to feel safe in our own body. A phenomenological understanding of the self, as an integration of mind, body, and spirit within a social field, helps us to view behavior that some might call pathological as "manifestations of specialized coping behaviors for survival" (Root, 1992, p. 237). As a counsellor, I will need to be aware of how Illness experiences bring us close to our bodies. I should be aware of the grieving that might need to be done over the loss of body capacities and parts, and of the sense of awe that was described as attendant to experiences of remission and recovery.

These stories also suggest that living well with illness requires getting in touch with and learning to trust one's inner knowing, a knowing that may be preconscious, held more in the body than in the mind. But accessing this knowing may be stymied, as the chaos of illness inhibits a person's ability to give voice to their experience. Being fully engaged in the chaotic horror of a mortal illness, some people may lack the distance from which to turn a reflective gaze back on it and give it any coherence (Frank, 1995). Perhaps moving therapy into accessing a bodily felt-sense would facilitate some people
in giving voice to the emotional turmoil of illness, as well as helping some to connect with their bodily knowing.

**Embodied Knowing**

In the counselling setting, accessing this bodily knowledge often produces dramatic changes in how people consciously perceive their world (Halling & Goldfarb, 1991). Consequently, a therapeutic framework which includes a consideration of "our intimate, preconscious attunement to the world around us" (Halling & Nil, 1989, p. 187) may help those who are struggling to understand their own needs for healing. This process of attunement, also called a "feeling-judgment" (Nagatomo, 1992) or "felt-sense" (Gendlin, 1981), requires paying attention to both the other’s bodily presence and to our own bodily reaction to it, in order to access meanings carried at a physical level. This attunement connects feeling and knowing, body and mind, and subject and object into a unity.

Helping people access their inner bodily knowing may be done through a number of means (Davis, 1990; Laidlaw, Malmo & Associates, 1990; Lew, 1990). Hypnotherapy (Rossi, 1993) or guided visualization (Borysenko, 1993) approaches entail a process of deep relaxation and the suggestion that the individual get in touch with their own inner wisdom, inner guide, unconscious sensitivity, or felt sense. The terminology for this inner sense can be adjusted according to what an individual is prepared to grasp (Beutler & Consoli, 1993). For individuals who are not amenable to these approaches, writing or art work may help them express and listen to their inner self. The goal is to access an expanded awareness of how new understandings may be held in a bodily knowing.
Listening to feelings is another avenue leading towards a deeper understanding of one's embodied knowing. Rom Harré (1991, 1995) holds that emotional displays are "embodied expressions of judgment" (1995, p. 369); they are messages from our bodies. There are a number of body-focused techniques that may be used to access feelings.\(^1\) Getting the individual in touch with the messages a feeling is trying to give them can be facilitated by asking them to breathe into and focus on a feeling to get a "felt-sense" of what it is telling them (Gendlin, 1981; Halling & Goldfarb, 1991; Rosenberg & Rand, 1985). This may help people to clarify confused feelings and experience how inhibited feelings are held captive in the body, resulting in anxieties and physical tensions (Halling & Dearborn Nill, 1989). The catharsis of dis-embodying stuck feelings can often be the beginning of the healing process (Davis, 1990).

Mindfulness is another approach to helping people get in touch with their embodied self. Mindfulness has its origins in Buddhist practices and entails foregrounding one's immediate sensory and cognitive environment (Kabat-Zinn, 1990). This approach is also called "grounding" (Halling & Goldfarb, 1991) and may be as simple as paying attention to one's own breathing, feeling one's feet on the ground, or holding a solid object and being aware of its sensory presence. More extensive practices of mindfulness include deep body relaxation and meditation techniques (Kabat-Zinn, 1990). These practices help us to remember to live within the embodied experience of the present moment, rather than living out past memories or future worries.

Mindfulness practices can be important tools for people experiencing illness

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\(^1\)It should be noted that historically there have been a variety of body-focused schools of psychotherapy which predicate their practice on accessing deep levels of emotion and memories through the physical manipulation of the body. Examples include Reichian Bodywork, Alexander Technique and more recently Rolfing (Smith, 1985), as well as numerous approaches which have developed out of dance and drama (McNeely, 1987).
who feel trapped by past regrets or overwhelmed by the uncertainty of their future.

Support Groups

The illness stories presented in this study also reveal what I feel is the real value of psychosocial support groups. Support groups, beyond providing information, coping skills and the like, may serve the important and needed function of bringing together a shared interpretive community (Frank, 1995). Support groups are a community of people who have all experienced the interruption of their life through illness, and who are all similarly engaged in restoring well-being through a restorying of their lives. They are also a group of people who have been similarly subjected to the dominant stories of health and illness in our society, which influence how those around them react to their illness. These commonalties may join support group members in an intimate exchange of stories of resistance and transformation.

Retreat based programs may provide an important avenue for this work, as they provide an opportunity to take time out from one's usual roles and responsibilities, to join with a group of others who are also engaged in learning to live well with illness. Allowing a safe and nurturing space in which to contemplate the effects and meaning of illness in one's life, seems crucial if we are to make the leap from fighting illness to accepting its inevitability and opening to its transformative possibilities.

The Challenge

Engaging in this study has helped me to re-recognize that we live in a society which prizes rational, linear ways of being, and that those suffering with illness are often caught between the tensions of maintaining their rational sanity and the existential howl of coming to grips with their own mortality. Thus,
I believe that "bearing witness" may be the biggest challenge of counsellors who work with people experiencing illness. Finding in ourselves the ability to bear witness to the struggles of people experiencing illness in their lives, rather than too quickly imposing on them the need to rewrite their story, is not an easy task. Simply listening and truly being present enough to hear the stories of suffering and chaos that illness brings into people's lives is important; just being with them in their woundedness and deeply experienced vulnerability, before insisting on restitution, resolution, or a return to our everyday sense of invulnerability - this is the challenge I face having heard these stories (Frank, 1995). I am aware that moving too quickly in the direction of advice and "fixing", being unable to witness the depths of people's feelings, have all the usual counselling ramifications of denying the other's experience and agency, positioning them as helpless, dependent, and needy. These are stances which are already all too prevalent in the medical orthodoxy.

As I imagine myself through some of the experiences I heard: struggling with a medical system which denies my humanity, treats me only as a body, and expects my patience and compliance; dealing with loved ones and friends who, no matter how well-meaning, are anxious to see me armed with a positive attitude and who are unable to hear my fears; and then finding myself in a counsellors' office who also pressures me to accommodate and quickly return to my "normal" life - I find myself feeling very alone in the experience, wondering if there is any place in which to do the necessary work to rewrite my life story in a way which makes a place for the chaos and interruption of illness, or for transformative healing.

But, as noted earlier, I also know that in providing such a space for others, counsellors must also take care of themselves, aware that:
...similar needs and goals are experienced by therapists as well as by their patients. To enjoy each day to the extent possible, to avoid carrying burdens unnecessarily, to somehow give back to life the good things that life grants are aims shared by all, regardless of health or disease. (Cassileth, 1995, p. 26)

As counsellors, we have a moral and ethical responsibility to care for ourselves in this process, because only in caring for ourselves, will we be able to offer appropriate care to others.

Moral Claims on My Research Endeavors

Moral Research

This study leaves me with another sense of moral responsibility, which is to continue doing research in an interpretive manner. Having faced the complexity and paradoxical nature of the experience of well-being during illness, I will always have to question the usefulness of statistical representations of illness experiences. For example: imagining a survey on people's experience of fear in illness, I envision a neutral result due to statistically combining the results of some people assessing fear as beneficial and others assessing it as problematic. But this study has shown how fear can be both problematic and beneficial (for the same person at different times). Losing the complexity of the experience of fear, could lead to a mistaken way of viewing and working with people who are experiencing illness. This seems immoral to me.

We would do well to remember that:

*Because people and their relationships are not uniform and situations are not necessarily repeatable, moral
considersation...presses toward enrichment of detail and amplification of context. Because negotiation of our lives in moral terms is a continuing process, new situations must be mapped onto past understandings and projected into future possibilities. The greater part of moral reasoning will thus be analogical and narrative. (p. 65, Walker, 1998, my emphasis)

I believe that research in the human sciences, and particularly in the field of counselling, is an inherently moral enterprise. With many of our beliefs and activities predicated on this or that piece of research - how can we engage in less than morally informed research practices.

Sharon Batt (1994) suggests that: "Researchers, physicians and administrators, it turns out, often do not want their work complicated with our feelings" (p. 309), but I believe we need to resist the temptation to stay aloof from the brute experience of illness. Without engaging with the human condition of suffering, our research and consequent theories become incapable of touching those for whom they were developed. As with our counselling practice, I believe that every research decision we make should be tempered by an acknowledgment of our own vulnerability - by an awareness that we may find ourselves in the position of the ill person we are intending to "investigate" - and an assessment of how we would prefer to be treated.

Care-full, systematic interpretive research can help us to remain connected to our own humanness and thereby to the dignity and complexity of those we "study" in the human sciences. Attempting to divide people experiencing cancer into "control" and "intervention" groups, and thereby denying half the willing participants the opportunity to engage in what might be a useful program, is for me a morally indefensible stance. The use of waitlist
control groups is a possible alternative, but I believe the feedback we get through direct interaction with participants is far superior, in its ability to deepen our understanding, than any statistical results might be.

Lamentable Limitations

The limitations of this study present me with some moral claims as well. There are numerous ways in which this investigation may not tell the whole story of what it means to live well after a life-threatening diagnosis. Because "[e]ach reacts to the "news" of the diagnosis according to its particular relevance to his concrete situation within the world" (Toombs, 1987, p. 227), the relative uniformity of those I spoke with puts some distinct constraints on the interpretation rendered here. The most obvious constraint is the lack of male involvement, but another is the lack of diversity in the women themselves. Some important issues may have gone unconsidered because for example: none of the participants were mothers of very young children; and all were relatively middle-class women with some post-secondary education. The former leaves me wondering how fears of mortality might increase for a woman who was leaving vulnerable little children behind. Alice, the eldest woman in the study, suggested that her own reactions, especially her desire for pursuing alternative therapies, might have been different if she was at another stage in her life:

I feel that if you’re going to go to your doctor and you’re going to listen to him and do what he tells you, you can’t be fooling around with all these other things. But if I was younger and had young children, I might feel differently. I might grasp at anything. (Alice2, p. 10)
She described how much more poignant her earlier experience of cancer had been, when she was a single mom with young children and was diagnosed with cervical cancer.

The latter constraint revolves around the opportunities that wealth and education, make available. Health and socioeconomic status have long been linked, even in countries that provide universal access to healthcare (Haan, Kaplan & Syme, 1989). Is it perhaps indicative that those who volunteered to speak of wellness during illness were uniformly middle class? Does poverty in fact diminish the possibility of living well with a life threatening illness due to exposure to a more noxious physical and social environment, complicated in some cases by language and cultural differences? Is the impact of illness overwhelming for a person who is already struggling with the difficulties of poverty and does that affect survival rates? Are those who are disenfranchised economically less likely to push for their own needs when dealing with the medical establishment? These are questions which should be addressed in a further study, particularly because they have an important bearing on whether psychosocial care providers need to consider the importance of spreading their programs “among a wider segment of the population” (Cwikel, Behar & Zabora, 1997, p. 29).

Speaking about well-being during illness only to people experiencing cancer is also a limitation. Cancer is rarely cured, it is generally considered only "in remission", therefore it cannot be simply put behind one in a way that some illnesses can. Thus, there may be distinct differences in how people react to a heart attack or a life-threatening viral infection that is subsequently "cured". As Arthur Frank (1991) states: "Cancer does not allow that version of recovery" (p. 2).
Another limitation stems from that fact that most of the people who agreed to speak with me were not experiencing significant on-going pain, a situation which might have given another flavor to the conversations. Some of the women had recently experienced the pain and suffering of some form of treatment: Carole and Dianne both spoke from within the nausea and discomfort of chemotherapy treatments; and conversations with Lynn carried on just days after her surgery for metastases to her lungs. But for the most part, the women spoke from more stable, post treatment, remissions. This may have given a more hopeful and up-beat tone to the conversations and hence the interpretation.

This hopefulness is for me perhaps the most worrisome reservation. The possibility that I have painted far too Pollyanna-ish a picture of illness gives me great pause. Have I, by focusing on living well or well-being, ignored the utter and ineffable tragedy of a life cut short by illness? Where is the despair and "complex sorrow" (Paget, 1993) which attends the experience of an abbreviated life. Have I created a dangerous new precedent that those who are ill might feel the need to live up to? All of the women claimed they had shed their share of tears, and in some instances we shared some together as we spoke. I know that in doing this study I have lived with a background of sadness which some days prevents me from writing coherently, or requires that on some occasions I write through my tears. But the interpretation has focused on how the tears and fears of a serious cancer diagnosis might be transformed into a way of living, which retains a sense of hopefulness and well-being. The hope is not for cure, the hope is for finding the way to continue living well with whatever the experience of illness brings.
For all the women I spoke to, but perhaps most of all for Carole, who died before our second conversation, I would like to include this lament by Barbara Rosenblum:

_It is 11:30 P.M. and this is the second night in a row that I have taken a sleeping pill. I'm tired and exhausted, yet sleep does not take me over. I'm gripped and consumed by the fear. The fear. The fear of more cancer. The fear of going off chemotherapy. The fear of recurrence. The fear of not living because I'm afraid of dying. It's not anxiety, as in an anxiety attack, with its hot symptoms, raging away. It's fear. It's the fear of death, pure and simple. The fear of no time. Of claustrophobia. Of shrinking, shortened time. Of tragic regrets and the tragedy of a life cut short; the tragedy of missed opportunities and the tragedy of having to live at highs and lows, a roller coaster that few understand. ...

I see so clearly who I am, what I am, what I stand for, who I might have become. I have made peace with parts of myself, forgiving some parts, still angry at others. I am angry at an unfair, unjust, and incompetent random world. I am in serious heartbreak... (Butler & Rosenblum, 1991, pp. 80-81)

Well-being does not negate, perhaps it even requires, an openness to the grief of losing one's possible future.

**Research Possibilities**

Investigating this topic has motivated me to consider possibilities for facilitating well-being and it has peaked my curiosity in other areas as well. I wonder how one could present an understanding of the quandaries involved in living well with illness, in a way that would be helpful. Perhaps programs such
as the Tapestry retreats I am involved in, can provide people who are ill with a break from their everyday responsibilities and concerns in which to reflect deeply upon the experience of illness. One benefit of a retreat program is that participants get to do this reflection within a supportive circle of other participants and a nurturing circle of staff. But many questions remain: Is it the support of others, the sense of being nurtured, the time-out for reflection, or some combination of these, which makes the experience valuable?

I also wonder about the concept of time in itself, and its relationship to well-being. Paul Pearsall (1991) writes of sacred and profane time experiences, believing the former contributed to the miraculous recovery he made from a large abdominal tumor. Several of the women I spoke to expressed a sense that time changed according to the acuteness of their illness, and that their sense of moment-to-moment awareness changed radically at different periods. Shamans are credited with the belief that healing occurs outside of time. I am curious about how experiences of illness alter people’s perceptions of things like time, hope, and denial.

As noted at the outset I am fascinated by the mind body connection in health issues. I am very curious as to how people experiencing cancer make a decision to forgo standard biomedical treatment, and use complementary therapies instead, especially having met a few through facilitating groups and finding them to be remarkably well. Conversations with people who have made such choices, could facilitate our understanding of why people make such choices and what the outcome is. This last is important because many of these people drop out of the medical record system that provides the statistical information on survival rates. Questions to be considered include: What prompted the decision? Was it difficult to make? Where have they found
support? What complementary therapies have they chosen, why, and how
helpful have they been? We hear anecdotal stories of, for example, the person
who was given a four to six month prognosis, who used a number of alternative
therapies, changed careers, and moved to the country - and who is alive ten or
more years later. I think it would be valuable to explore these people's
approach to living with illness.

We are also in need of interpretive understandings of how those who
labor to care for ill people can best maintain their well-being. Professional or
otherwise, "caregivers" are often at risk of damaging their own well-being. By
studying some who have managed to live well through the arduousness
process of caring for someone who is ill, we might learn of some valuable
possibilities for caring for the one who gives care.

Turning Again

Stories of living well with illness complicate our neat theories, pushing
us to expand our present horizons. As Jazz says:

_We seem to want to oversimplify human life just the way we would
build a bridge. ... Yet ... What is it about life itself, that we can only
do that in a little controlled box? And that's what I think cancer
does, it shatters our little box. And I think that's where nobody
wants to let go...because it's so comfortable [in that little box]. Yet
that's not real, ...what is real is far bigger than that, but it's so
scary...it's like: "That's too messy...lets just stick to our little box."_

_The interesting thing is, [that box is] so out of proportion to me now,
the way I am looking at it. It's so artificially created that obviously
it's impossible for me to bring my life experiences into that_
box....before I'd usually think that I must be the one going insane because I just could not fit in those thinking patterns for some reason and now I feel that it's like a mass hypnosis that we're living in. (Jazz2 p. 5-6, her emphasis)

Perhaps the time has come for us to awaken from the mass hypnosis of our too small world, opening ourselves to the greater possibilities suggested within the stories of those who live well after a life-threatening diagnosis. Perhaps we all need times in which to rewrite our stories, and the chaos of any kind of crisis can push us in this direction. Can this understanding, that we all experience breakdowns in our stories, be a reciprocity which joins us more deeply, one with another? Can our orientation to care, be it personal or professional - caring for self, carefully listening to others, or taking up our investigations with care - be predicated on this I-Thou reciprocity? Is it possible that in finding myself, I find a reflection of the other; and in opening myself to the other, I find myself reflected in them as well? What if we made a place for disintegration and reintegration in all of our lives? Could all forms of illness, threat, or upset be viewed as harbingers of transformative and life-enhancing change? As forces which bring us to a more intense aliveness?

Studying well-being from an interpretive perspective, I have come to see that perhaps living well is living interpretively: being mindful of how our traditions and personal histories inform our present experiences; remaining open to experience as it arrives and allowing it to change and shape us without closing down on the options and choices too soon; and living always with a sense of our finitude (Gadamer, 1994). Lynn feels that living well with illness requires her to live more interpretively. She speaks here of the value of coming to terms with her mortality:
I think now that I have, I can only say to myself, "Well, let's see what happens, there's no predicting," And this is where the interpretive stuff comes in - the surprises, the happenings, those aren't predictable, and they can be lived with - and they don't have to be negative challenges, most of them can be positive challenges. It's worth trying to see if you can live this way. (Lynn1, p. 31)

Gadamer suggests that our finiteness should inform all of our experiences. "The truly experienced person is one who has taken this to heart, who knows that he is master neither of time nor the future. The experienced man knows that all foresight is limited and all plans uncertain. (Gadamer, 1994, p. 357)

With an acceptance of our finitude can we see how our very limitations guide us into a more immediate and more complete engagement with ourselves, others, and the world around us: an engagement that is constantly repeating and renewing. As in the mobius: our openness to experience changes us, we return to our relationships changed and in doing so change them, which in turn changes us once again. This conversational-relational orientation to life, both recalls us to ourselves and calls us out into the world.

While this investigation cannot decisively answer the question of what it means to live well during illness, it does show that an acceptance of our shared mortal vulnerability leads to a more conscious participation in the ongoing conversation of what it means to be fully human. Perhaps this, then, is the most basic understanding I have come to from this study: that all I know, finally, is that I too will live until I die. But the fertility of this awareness gives birth to a practical moral wisdom, a wisdom that creates more questions than answers. It is a wisdom which allows for ambiguity, puzzlement, and paradox -
for the profane and the profound, despair and hope, weakness and strength; a wisdom which, if I can only remain mindful of it, leads me to both celebrate and find refuge, in this moment as I find myself in relationship with you, with the world, and with myself.
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APPENDICES

APPENDIX A

Letter of Introduction

Hello,

I am presently a doctoral candidate at the University of Calgary in the department of Educational Psychology. I am conducting a study investigating people's experience of living well after a diagnosis of a life-threatening illness. The research is part of the requirements for my doctorate degree. This letter is to introduce you to my research project so you can make an informed decision regarding your participation. If you desire more details than this letter provides or are interested in being interviewed please feel free to call me at 282-5508.

The purpose of this research is to more fully understand how people who have been diagnosed with a serious illness attain and/or maintain a sense of well-being in their lives. My interest in the topic stems most recently from facilitating mindfulness meditation groups for cancer patients. I believe a better understanding of how people regain a sense of well-being after a serious diagnosis will enhance the ability of service providers to support others in similar circumstances. I am interested in speaking to anyone who has had a life-threatening diagnosis who would describe themselves as having attained a sense of well-being, or who feels that they are working towards this.

Your participation would entail one or more conversations of approximately one hour in length. Subsequent conversations would help me to get your feedback on my emerging understanding of the experience. All conversations will be audio-taped and transcribed. This information will be kept strictly confidential. Pseudonyms will be chosen by participants and utilized throughout the transcriptions and data analysis. You will have an opportunity to see the transcripts of your conversations and change any details you feel might identify you. You will in no way be personally identified in my dissertation or in any subsequent presentations or reports regarding this research. The audio tapes, transcriptions, consent forms and demographic information forms will be kept in a locked file cabinet accessible only to myself and my supervisor until the completion of my dissertation. After completion of the degree requirements all but the transcripts will be destroyed. Transcripts, identified only through the pseudonym you have chosen, will be retained for possible use in future presentations of the data.

As I will be asking you to discuss your personal experiences it is possible that sensitive and/or emotional material may be revealed resulting in some personal discomfort for you. As in any conversation you will have control over how much to reveal, allowing you to make choices according to your level of
comfort. If necessary I will utilize my counselling skills to provide emotional support and debriefing, as well I can arrange further counselling at your request. You may benefit from your experience as a participant through a sense of personal satisfaction that you have contributed to the growing understanding of the needs and desires of people who experience a life threatening diagnosis. You may also benefit from an increased self-awareness due to reflecting on and conversing about your own experiences.

If you are interested in participating and/or have any questions, please feel free to contact me, Maureen, at 282-5508. You may also direct inquiries about the research to my supervisor, Dr. Sharon Robertson, Department Head, Educational Psychology, at 220-3586.

Sincerely,

Maureen Angen, MSc, Ph.D. Candidate
Alice

A warm and easy going 67 year old woman, Alice gives the impression of being very comfortable with herself and her accomplishments. Although she is very humble, rarely uttering a judgmental word about another person, Alice is proud of her own hard work in single-handedly raising three children, upgrading her education, and never having relied on unemployment. She claims to have been well supported throughout her life by a faith in God and a strong church community and takes great pleasure in being helpful to those around her. Her life philosophies have been to always look forward, not back, and to find useful ways to use her God-given talents. These philosophies, along with her church and square dancing communities, have helped her weather a stage four breast cancer diagnosis in 1993, a year after her retirement, and a recurrence in the same breast in 1996. During the same time period as her initial diagnosis and treatment, Alice watched a neighbor, a mother with three young children, die from breast cancer. This experience has left her with many more questions about healing and illness, than answers.

Currently, Alice is dealing with bone metastases and is involved in a clinical research trial of the drug Tamoxifen. She feels that someone her age should participate in research efforts because she has already had a good life and her participation might provide information that will help younger women to survive longer. Alice was motivated to participate in this research study for these reasons as well.
Perhaps the most surprising thing about my conversations with Alice was that only at the very end of the first two hour discussion did she remember to tell me that she had gone through a hysterectomy at 39 years of age to treat cervical cancer. When we reconsidered what she had told me in the light of this new information, it became clear that she had adopted many self-care strategies at that earlier point in her life and had therefore not mentioned these as significant to living well with this later diagnosis. Having had more than her share of serious illness, Alice is a vibrant example of what it can mean to live well after a life-threatening diagnosis.

Beth

Beth describes herself as an optimist, as someone who has always felt very blessed and had a great enthusiasm for life. Before cancer came into her life, Beth lived a busy life as a mother and as a high school English teacher, a profession she found immensely satisfying. She has three sons, two teens and one in his early twenties, and a great relationship with her husband who she describes as having been wonderfully supportive through her illness experience. Misdiagnosed for six years after an initial biopsy left scar tissue which masked the continued growth of cancer, Beth was finally diagnosed as having late stage IV breast cancer in January, 1997. She underwent a lumpectomy and the removal of her underarm lymph nodes which turned out to be 90% cancerous. Beth was offered an autologous stem cell transplant, a procedure sometimes referred to as a "rescue mission", which she says gives an indication of the seriousness of her situation. In August of '97, Beth had her bone marrow harvested and went through three weeks of what she calls the hardest experience of her life. The treatment consisted of five days, 24 hours a
day, of high dose chemotherapy and two days of total body irradiation, then
weeks of suffering before the reintroduced bone marrow cells began to bring
her blood counts back up. She describes being as weak as a baby and is in
awe that her body was able to come back from that weakened state to a point
where she felt really well again, well enough, in fact, to go mountaineering.

Beth feels she has always been good to herself, but since the cancer
diagnosis she is really good to herself. She has included the following in her
bid for healing: Long walks by herself, vitamins, shark cartilage, acupuncture,
mediation, yoga and more frequent trips to their lakeside family cottage and
their newly purchased condominium in Hawaii. In response to an article in a
national newspaper accusing complementary therapists of preying on cancer
patients, Beth wrote describing her personal experience of the benefits of
complementary therapeutic strategies. Her opinion is that there is much to be
gained by engaging in self-care through exercise, eating well, and using dietary
supplements, yet she is careful not to live her life worrying about every little
thing she does or eats. Beth aims for a balance in her life. Expressing an
increased feeling of gratitude for each day, after having so closely faced her
mortality, she is not about to waste a moment of her precious time. Beth has
also become very involved in a volunteer program which raises funds and
supports other women through the difficulties of the stem cell rescue
procedure. Recently Beth has been diagnosed with a metastatic recurrence of
cancer.

Brenda

Brenda was the second woman I engaged with who "remember" an
earlier cancer diagnosis part way through our initial conversation. She claimed
that the experience of thyroid cancer, 13 years earlier, did not have nearly the impact on her life as has her recent encounter with breast cancer. Requiring only surgery, and not the difficult radiation and chemotherapy treatments that went along with the latter experience, she had pretty much dismissed any effects of the earlier illness. Although, with a little exploration she realized that the earlier involvement with cancer had improved her attention to self-care and motivated her to develop a regular running program that continues to this day.

Breast cancer has been a much more threatening experience for Brenda. The diagnosis and treatment left her feeling vulnerable, frightened, and unsure of herself; feelings which spurred her to join an on-going support group that has given her much solace. Since her diagnosis in September, 1997 she has faced a number of issues in her life, particularly relational concerns. She says she used to be a workaholic, running from the difficulties in her life by working longer hours, a strategy that no longer seems appropriate to her. Cancer has provided the opportunity and motivation to make some important changes. She is making efforts to connect with her large family of origin, eleven siblings and her parents. Illness has also stimulated Brenda’s spiritual life, giving her a desire to return to religious services and turn that into a prayerful experience. She has also felt motivated to reach out to others experiencing cancer. Brenda has recently trained as a Reach for Recovery volunteer and intends to support other women who are diagnosed with breast cancer.

Carole

Carole agreed to talk to me after attending a meditation and yoga based stress reduction program I was co-facilitating at the Tom Baker Cancer Centre.
She had been feeling very disillusioned with the support available at the Cancer Centre and had enjoyed the program we offered. It had been very valuable, increasing her peace of mind and her ability to live well with the seriousness of her illness. At the time we spoke, in early May of 1998, she was in the middle of a series of eight chemotherapy treatments for advanced cervical cancer. She had been diagnosed the year before, in September, and had undergone 30 radiation treatments over the fall, but follow-up investigation had revealed continued lymph node involvement which, it was hoped chemotherapy would alleviate. She was aware of the doctors discouragement over her prognosis and felt they made it too readily apparent; they should continue to treat everyone with hope, she felt, to allow the person living with the illness to retain their own sense of hope.

Despite the difficult prognosis, Carole was continuing to use her illness as the impetus to make some needed changes in her life. Her one child, a young adult daughter, had moved away to attend graduate school in another city just before Carole's diagnosis, and her husband was being very supportive of the changes she was making. She felt the illness gave her a valid excuse to quit a stressful job that had been making her unhappy for a while. She had begun to take the time and effort to attend to her bodily needs for proper rest, exercise, and improved her diet dramatically. These were self-care practicalities that had fallen by the wayside over the years, as long hours and stress at work had left her feeling drained. Carole did not expect these changes to cure her of cancer, but felt she had attained a vastly increased sense of well-being through such changes and practices such as Yoga, Tai Chi, meditation, and visualization. Ironically, she said that despite being in the
midst of a grueling treatment process, she actually looked and felt much better than she had for years.

When we last spoke, Carole said she was living her life one day at a time, trying not to "buy in" to the poor prognosis the doctors were envisioning. She was looking forward to a long awaited fall visit to her place of birth in the Maritimes and suggested we have our second conversation when she returned. Having had no contact with her husband, I only found out through the obituaries that Carole never returned home from that trip, she died there in November, 1998.

My mental images of Carole all portray her avidly expressing her feelings about living with such a serious diagnosis, the sadness and anxiety, but perhaps especially the irony of looking and feeling so well when she was being told she was so ill. During our conversation she shed many tears but also laughed heartily much of the time.

Dianne

Dianne is a thoughtful, but feisty, 49 year old woman, who has been an elementary school teacher for many years and is currently working on her Master's Degree. She agreed to be involved in this study in the hope that the results might be helpful to others, though Dianne contends that the experience of living with cancer is very difficult, if not impossible, to comprehend for those who have never had a diagnosis. Others who are living with cancer, she believes, are the only ones truly capable of understanding the struggles, and sometimes overwhelming anxieties, she has been through since her diagnosis of gynecological cancer in January, 1997. Dianne initially underwent
two rounds of surgery-plus-chemotherapy and although she has suffered some neurological damage, she feels the second surgery was something of a miracle.

The illness has motivated her to do a great deal of emotional and spiritual work through writing journals and reading, and to reconnect with her creativity. In the fall, eight months after her initial diagnosis, Dianne began attending a support group of people experiencing cancer. In retrospect she feels that the wait was important. The work she had done on her own, over the intervening months, had prepared her not to have expectations that the group could simply make everything better. In the intervening months Dianne had come to realize the impossibility of that grand expectation, and she feels she was prepared to receive the simple, but vastly important, mutual support the group could offer - as the members came together to wrestle with the reality that illness imposed on them.

Dianne has found the process of being a medical "patient" very unsettling, leaving her feeling extremely vulnerable and sometimes quite angry. She rails against the childlike passivity expected of her and the discontinuity of care that has resulted from having a surgeon, a neurologist, several different oncologists, and numerous nurses involved in her case, who seemed to have little communication between them. She feels no one professional is aware of all the difficulties she, as a whole person, has experienced throughout the treatment process, and is learning to be "appropriately inappropriate" in an effort to make her needs known. Recently, Dianne has undergone a third surgery, and is currently going through another ten weeks of chemotherapy, for a recurrence of her cancer.
Ginger

Ginger is a strong-willed and very inspirational woman, who has lived thirteen years since a recurrence of breast cancer. When she was initially diagnosed, Ginger felt she was blessed, having a loving husband, three small daughters, a full time teaching position which she was enthusiastic about, and a beautiful home which she enjoyed. Cancer interrupted all this. Cancer made Ginger aware that there was something missing in her life and she set about diligently finding what she needed to heal herself. Her husband has joined Ginger in this journey with cancer, as have her children, now young women with vibrant lives of their own.

Ginger defied the biomedical treatment of breast cancer from the outset. Initially rejecting the recommendation of a full mastectomy, she sought out and found a surgeon in another part of the country who was willing to do a lumpectomy. She also changed her diet, began to exercise more, and began to practice visualization and meditation. At the time of her recurrence, Ginger acquiesced to conventional radiation and chemotherapy treatments in her struggle to survive, but part way through the chemotherapy Ginger had a sense that the treatments themselves were killing her and she let the Cancer Centre know that she would not return. Taking her treatment into her own hands, she became very dedicated to healing herself by paying careful attention to what her body, mind, and spirit needed for well-being. This quest has led Ginger to follow the path of a Guru from India and embrace a Yoga lifestyle, including the practices of breath work (pranayama), postures (asanas), meditation (dhyana) and dietary observances.

Early in her cancer journey Ginger went looking for healing support beyond the medical treatment. When she found the HOPE cancer support
group in Vancouver, she knew that this was something she wanted for herself. Over the years she has developed her own version of that program to offer to others who are living with cancer. She now has a large following and has converted the carriage house in back of her home into a center for the HOPE program. HOPE, which stands for Helping Ourselves Psychologically Everyday, is a program that uses mutual support to encourage people to heal all aspects of the self. There are now several groups, that meet weekly and many participants who return for weekly yoga and meditation classes as well.

Ginger feels that the cancer journey has been invaluable to her. She is adamant that, even if someone could offer her a long and illness free life, she would not choose to return to her pre-cancer way of being in the world. Cancer has brought her to many important learnings.

Inspiration

Inspiration chose her name because she would like her vitality to be inspirational to others. At the age of 64, she is running marathons and cross country races, competing both nationally and internationally. An elementary school teacher for many years, Inspiration recently took early retirement from her professional life to care for her husband who has had a stroke and to dedicate more time to her running. Several years ago she was diagnosed with bowel cancer and underwent the standard treatments of surgery, chemotherapy, and radiation. Concurrently, she pursued several complementary therapies such as acupuncture, herbal supplements, and regular imagery and meditation practices. Inspiration felt quite satisfied with her medical care, though she feels she probably could have used only complementary therapies and done just as well without the biomedical
treatments. She also would have appreciated an oncologist who was interested in her use of complementary therapies.

The seriousness of her illness forced Inspiration to take stock of her life and reconnect with what was important, reinforcing her desire to continue racing and to travel to competitions as often as possible. She also felt that work and family commitments had often taken precedence over her approaches to self-care and her training in the past, it wasn't that she didn't realize the value of these practices, but the numerous other responsibilities generally won out. The cancer diagnosis was a message for her that it was time for her to take her own care seriously and to embrace her love of running.

Inspiration has also struggled with her adult daughters' anxious reactions to her diagnosis and treatment. She sometimes protects them from knowledge that she knows will worry them by not keeping them fully informed. She does not want to be coddled by them and needs her freedom if she is going to train for the next big race.

Jazz

Jazz is a thirty year old woman who came to Canada in her twenties, having excelled in her home country, to undertake post-graduate training in engineering. At the time she was diagnosed in 1994, with stage four lymphoma she had completed her candidacy papers for the doctorate degree, was married, and was considering having her first child. It took Jazz many months of increasingly serious symptoms to get an accurate diagnosis, and she was literally at death's door by the time she was sent to an oncologist.

The only treatment option she was given was an autologous bone marrow transplant, a harrowing procedure in which one's bone marrow is
harvested and stored, while the body is taken down to the lowest possible level through total body irradiation and high dose chemotherapy, before those cells are re-introduced. Jazz sailed through this procedure, in a deep state of denial as she describes it. She considered the others on the hospital ward to be in much worse shape than herself and would do little things to look after them, not allowing herself to recognize the threat to her own life.

In retrospect Jazz believes this denial was a very useful stance, helping her to get through the worst side effects and to by-pass the possibly paralyzing fears generated by the procedures she was undergoing. She remembers not even flinching as the bone marrow was harvested from her hips; wearing diapers in order to go for walks on the hospital grounds, when her whole intestinal tract was raw from the chemotherapy; and assuming that she was being treated far too well by the hospital staff. Jazz later insisted on obtaining surgery to remove the masses of scar tissue, which the tumors had left in her throat and abdomen.

It was some time before the full effects of treatment took their toll on Jazz leaving her in a state of constant exhaustion, a condition of chronic fatigue that she continues to contend with. During this time she came to realize that perhaps she had been living a life that was disconnected from her own true nature. She feels her inner knowing has grown exponentially through her illness experience, and describes how it woke her one night and alerted her to a pea sized growth on her arm which turned out to be the very early stages of another form of cancer - requiring further surgery. Listening to her own inner knowing, or gut feeling, she went through drastic changes in her personal and professional life. She has been searching to find a role for herself that
incorporates her new understandings of what it means to survive such a serious illness and to really live well.

In retrospect Jazz sees her illness as the impetus for her own spiritual growth. It has helped her to feel much more connected to the universe, a part of something that is much bigger than just herself or this life. She has felt much more in tune with, and awed by, her own body, mind, and spirit since her survival and is avidly searching for opportunities to continue learning about healing and to share her experiences with others. This study provided one such opportunity.

Jazz is etched in my mind sitting cross legged on her couch as she tries to describe with great passion what it has meant to survive such a close brush with death, and how the realizations she has come to could benefit us all in our daily attempts to live well.

**Linda**

Linda is a forty-something mother of two adult boys, who works very diligently and effectively as an administrative assistant in a busy office. She has an infectious laugh and a very charming, open manner that allows all those who come in contact with her to feel readily at ease. Since her diagnosis and treatment of Stage II breast cancer several years ago, she has become increasingly aware of the effect she has on those around her and tries to remind herself that her humor and kindness will be remembered much longer than her hard work.

During her treatment and recovery Linda found a significant support system through the internet. Going on-line at [http://www.acor.org](http://www.acor.org) to chat with a
group of other breast cancer survivors has been very helpful for her. Through this "virtual" support group she connected with a woman who was putting together a book called *Hair* (Delany, 1998) on the experience of hair loss for those undergoing chemotherapy. Linda contributed to this book and continues to support other women through the Internet Breast Cancer Listserver.

Overworking and worrying about the impression she made on others, used to be essential to Linda’s definition of herself - she now sees these traits as much less significant. Before cancer, she says, she was "so busy just getting through the day-to-day" that she paid no attention to who Linda was or to what it meant to really live. Now she tries to understand herself better and takes more pleasure in the world around her, seeking to understand what gives her joy and what is meaningful in her life. People matter a great deal to Linda, especially family. She sees herself as a caring, loyal, and playful person, as someone with a great deal of drive - "stubbornness" she would say and laugh. Now she revels in being Linda and in sharing that with others, often through her wonderfully playful sense of humor.

When I imagine Linda, I conjure up a picture of her with a sweet grin on her face and a impish gleam in her eyes, offering up some teasing comment.

**Lynn**

Lynn, 56 years old, is a partner in a 33 year marriage and the mother of two adult children. She was a nursing instructor in an earlier life and is a learner, educator, and volunteer in her current life. Shortly after being diagnosed with a rare uterine cancer, a diagnosis which happened purely by chance and demanded immediate surgery, Lynn returned to university to earn a
graduate degree in adult education. She has completed the Masters and is considering entering the doctoral program.

Lynn exudes a sense of peace with herself. The calm and cheerful exterior she presents hides a deeply inquiring mind which takes little for granted and leaves very little unquestioned. This ability to question the taken-for-granted has helped her to live well with a serious cancer diagnosis. Her first inclination, when the oncologists suggested that the surgery was successful and there was no reason to do more treatment, was to carry on the treatment process through a psychological exploration of herself. Lynn worked with a therapist for a year to unravel some of the meanings she feels cancer has presented her with. She explored some complementary therapies (meditation, Yoga, dietary and vitamin supplements). But Lynn found that work related to her graduate studies, dialogues with faculty and other students, research into a variety of literature sources, and writing about cancer was most therapeutic. These were very timely methods for Lynn. Illness has called her to so much new growth that she feels she needs "to catch up with this cancer".

Having been a nurse colors Lynn's story in a number of ways, some helpful and others not. Sometimes her training gives her the knowledge to ask intelligent and important questions. Other times it gives her too much understanding, so that, for example, she has found herself caring for others on the ward when she should be looking after her own recovery.

Lynn has recently, quite unexpectedly, been diagnosed with metastases to her right lung. Because this recurrence is very rare, there is little relevant research, and Lynn has had to make a decision to undergo hormone usage with possible long-term side effects - this being the only known prophylactic at this time. In order to clarify the diagnosis, she has undergone a second
invasive surgery on one lung, and waited seven weeks for the resulting pathology report. While Lynn is relieved that the chemotherapy, which was thought to be the next step, is not the treatment of choice, her relief is overshadowed by the unknowns of whether hormone therapy will indeed control further recurrence.

Marie

Marie is a woman who exudes confidence and capability. She agreed to participate in the research, having heard of it through a mutual colleague, because she believes there is a need for more emphasis on preventative wellness in our society. She feels there is far too little care for people's well-being, and what there is occurs far too late. Her professional life has changed considerably since her cancer diagnosis, through her own impetus she has transferred into a self-defined position with the responsibility for moving the organization she works for toward a more health enhancing culture.

After Marie was diagnosed with a lump in her right breast in 1990, and had recovered from surgery, she and a cousin pursued a genetic tracing of their family history of cancer. They discovered that the family carries the genetic markers for both breast and ovarian cancer. This knowledge, and the fact that her own mother and every living female on her father's side had a cancer diagnosis, in combination with her father receiving a prostate diagnosis, prompted Marie to make the difficult decision to undergo prophylactic surgery. In 1995 she had a second mastectomy and a full hysterectomy with the hope of putting cancer behind her. The recuperation process was not as quick or as complete as she had envisioned and it was more than six months before Marie returned to work. Meanwhile, she made the observation that, while the
organization she worked for spent large sums of money on people who were no longer able to cope, they spent almost nothing on preventing people from getting to that point. Making a presentation to her superior, she formed a new position for herself, which continues to engage her professionally. This position also constantly reminds her of the need for her own self-care, as she juggles to keep family life (with her husband, a young adult daughter, and son in his early teens) and work commitments in balance. Her advice is to live more in the present and to "give it your best instead of your all" (Marie1, p. 15).

My memories of Marie include one of her, in typically straight-forward manner, laughingly claiming to be "a bit of a rhinoceros" when she goes after something she really believes in.

**Patricia**

I heard Patricia's story in another context and felt she was describing very clearly many of the struggles and resistances to the standard discourse of illness that are required of those who want to live well after a diagnosis of cancer. So I asked her directly if she would agree to join the study. Diagnosed with stage three, infiltrating breast cancer, Patricia made numerous decisions that went against the advice of the oncologists. But these are the very decisions which she believes have helped her to heal and live with a growing sense of well-being. She had two surgeries in close succession, because the margins on the first were not clean (i.e., there may have been cancer cells remaining). In the first procedure, she had refused the removal of lymph nodes from her armpit, a procedure used for staging the cancer, but in the fear and uncertainty of the follow-up surgery she agreed to their removal, against her
own previous intuition that this was unnecessary. This decision is one which she still regrets, as the arm continues to cause her pain and swelling from trapped lymph fluid on occasion: A particularly problematic condition for a woman who makes much of her living as a massage therapist.

The recommended biomedical treatments for her diagnosis were chemotherapy and radiation, but Patricia "just knew" these were not life affirming choices for her. She procrastinated about the decision and left the option open, going on a self-development retreat and then spending a month in Mexico with her family, but finally returning with enough conviction to refuse further conventional treatment. Meanwhile, having heard of a doctor in Quebec who was using camphor and nitrogen injections called 714X to bolster the immune functioning of people diagnosed with cancer, Patricia had convinced her family doctor to help her begin this treatment program. She also undertook a rigorous three month dietary cleanse, worked with a nutrition pathologist to form a healing diet, and developed her own visualization and meditation program. She felt a sense of self-empowerment in making these choices for herself and then having the discipline to carry them out.

Perhaps the most healing work that Patricia did, involved deepening her self-understanding by paying attention to her thoughts, emotions, and physical reactions to people and events in her life. Developing an ability to discern what creates fatigue and negative energy in her life, she has learned to be kinder to, and more respectful of, herself and those around her. Her "inner knowing" has grown stronger through this process, facilitating her ability to work as a healer with others. She has a sense that cancer has provided her with an alternative to a long desired academic degree, a degree in the University of Life. As a
consequence, she has an increased belief in her own credibility as she works to heal others.

One year after her diagnosis Patricia had tests, which showed almost no cancer cells circulating in her body. But, despite the fact that she had worked to achieved this remission, she took little joy in this knowledge. In wondering about her lack of celebration, Patricia came to realize that having focused for so long and so hard on the possibility of her own death, she had little energy or enthusiasm for life. In describing this dilemma to her husband she gestured with her hands, lifting them palms up beside her shoulders, to show how if she focused on death on the right side (as she had over the months of coping so well with her serious prognosis), she could not even see life on the left hand side. At that moment she had an intuition that she had never really taken the risk of living fully, that she was trapped "between" living and dying. Suddenly, she says:

*I just kind of relaxed, and my hands started to come together, and they came together in the shape of a prayer. The living and the dying met, and I took a quantum leap in consciousness ...a quantum jump from the duality of life and death to holding them both as just part of something more....Instead of operating from either/or, just put "either" and "or" together and come up above it, and look at the world from another perspective. I have no idea what this "more" is yet, but it's feeling better everyday that I'm in it! Healing...is not about living, or dying, or getting well, or getting ill, it's something about the soul. - about just being - it's not about having to do anything. Life is just living.* (Patricia1, p. 15)
APPENDIX C

CONSENT FORM

Research Project: An Interpretive Inquiry into the Experience of Living Well During Illness
Investigator: Maureen Angen, Psychosocial Intern, Doctoral Candidate Social Sciences and Humanities Research Council of Canada.
Sponsor: 

I, ___________________________________________________, hereby give my consent to participate in a research project entitled "An Interpretive Inquiry into the Experience of Living Well During Illness."

I understand that my participation entails taking part in a number of personal conversations with the researcher, all of which will be audio-taped.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in this research project. This in no way waives my legal rights nor releases the researcher from her legal or professional responsibilities. I understand that my participation may be terminated at my request or the request of the investigator at any time. My participation in or withdrawal from this project will not affect me adversely in any way.

I understand that I will have control over the conversations in order to adjust it to my level of comfort as to what I choose to reveal. I also understand that the researcher will provide me with emotional support, debriefing and help me access a counsellor should I feel the need to speak with someone further.

I understand that the researcher and her supervisor will have access to the research information I provide and that all materials will be kept in a locked filing cabinet until after the completion of the researcher's dissertation. At that time all audio tapes, consent forms and demographic information forms will be destroyed. Transcripts, utilizing only pseudonyms, will be retained for future reports and presentations of the research. I will choose my own pseudonym and have a say in how to alter identifying information in the transcripts of my interviews.

I have been given a copy of this consent form for my own records and understand that if I have questions I can contact the researcher, Maureen
Angen, at 282-5508, or her supervisor, Dr. Sharon Robertson, at 220-3586. I can also make inquire about this research to the Office of the Chair, Faculty of Education Joint Ethics Committee at 220-5626, or the office of the Vice-President (Research) at 220-3381.

________________________
date
________________________
signature of participant
________________________
participants printed name

Demographic Information

Name_________________________________________

Address_________________________________________

Phone number
(home)_________________________(work)_________________________

Age_________________________

Occupation_________________________________________

Education_________________________________________

Pseudonym of your choice_________________________