TOWARD AN UNDERSTANDING OF MY TRANSFORMATIONAL EXPERIENCE WITH CANCER

by

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ABSTRACT

The phenomenological research process is one in which a systematic attempt is made to uncover and describe the deeper meanings underlying the particulars of a lived experience. Phenomenology aims to make explicit that which is implicit; to uncover the essential meaning structures inherent in an experience. This hermeneutic phenomenological study examined the researcher's lived experience of having cancer. The overriding task of the project was to construct a reflective-interpretive text that mirrored the essential nature of this particular lived experience.

The research question chosen was in line with phenomenological tradition which directs us to ask "What is it like" to live a particular experience. In this case, the question asked was: What is it like to have cancer? Or more specifically, what was it like for the researcher to have experienced cancer?

A journal written by the researcher during the cancer experience provided the initial text for the hermenuetic work. Anecdotes were developed that reflected important meanings embedded in each particular aspect of the experience. The anecdotes served to give substance or concrete counterweight to the thematic formulation and analysis that comprised the remainder of the final text.

Through thematic formulation and analysis, an attempt was made to explicate the underlying meanings, to mirror the essential nature of the experience.

Following the first two chapters, which establish the ground for the research question and delineate the research methods, the remaining chapters in the thesis each examine a question which represents a piece in the understanding of the overriding research question. These questions and themes are:

What is it like to await a potentially serious medical diagnosis? The primary theme examined in relation to this question is the concept of waiting. In trying to come to an understanding of waiting in the context of awaiting a diagnosis, the text examines the body in-between; desperate waiting; waiting with hope; and waiting with uncertainty.

What is it like to know you have cancer? The themes examined in relation to this question are: a new reality of self; the body/mind; cancer victim as leper; lived spaces of safety and threat; and cancer as intruder.

What is it like to decide on a course of treatment when the "wrong" choice could be life-threatening? The themes examined in relation to this question include: choice; body/mind partnership; and the difficulty with which one achieves efficacy within the medical system.

What is it like to experience cancer treatments which entail harm to the body? The themes examined in relation to this question are: exposing the body to destruction; relationships that sustain; rediscovering a future; and dwelling.

What are some of the lessons to be learned from having a life-threatening disease? The themes examined in relation to this question include: suffering; sensitivity to beauty; body as friend; and being cared for.

What transformations occur as a result of the crisis of having cancer? The themes examined in relation to this question are: evolution and transformation; loss of certitude; connectedness and unity.

The final chapter of the thesis looks at the experience of conducting the research through an examination of the following themes: theorizing as edifying activity; evolving tactfulness; and personal integration.

Selected quotes from literature and poetry are used throughout the study to add strength and richness to the text and to give a broader perspective to the interpretive work.

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CONTENTS

A gem is not polished without
friction, nor man perfected
without trials.

Chinese Proverb

CHAPTER I

ESTABLISHING THE GROUND FOR THE QUESTION

Introduction to My Experiential Context

Today it happened. The thing everyone dreads and fears.
I have a malignancy. I have cancer.

With these words, on December 29, 1987, I commenced the writing of a journal which was to document my journey with cancer. I'm not a person who normally keeps a journal. But it seemed an important thing to do. The desire to write the journal came from a strong intuitive urge, an inner "knowing" that I was being launched into a profound and difficult life experience. There was, also, a sense that the documentation of the experience would, ultimately, contribute to my understanding of it.

My journey with cancer had a profound influence on my "being-in-the-world". I am not the same person I was on that fateful day, and yet I *am* the same person. It is the nature and depth of my transformation that interests me and is the focus of my present research focus.

Cancer. It is the most dreaded of diseases. Cancer is feared, I think, for three reasons: (1.) it can produce great pain and suffering; (2.) the treatments for the disease are often as painful and debilitating as the disease itself; and (3.) many people still die of cancer.

I am no different from any other Canadian when it comes to cancer. I fear it. I would have preferred almost any other diagnosis. As a nurse, I have cared for people dying of cancer and I know, too well, how terrible it can be. Like most people my age, I have had friends and colleagues who have contracted cancer. Some of them died within months of the diagnosis, others lasted for years, but all seemed to succumb eventually. If I have known people who have been "cured" of cancer, I couldn't remember them when I received my diagnosis.

Having cancer was, perhaps, the most profound experience of my life. As time distanced me somewhat from the experience, I began to realize that it was the stuff of which evocative phenomenological research is made.

"Phenomenological researchers, if they are sensible, don't choose topics about which they know nothing. . .. Most commonly, they study an experience because of its special significance for them. They have become deeply involved with the phenomenon, it is something at the very center of their personal or professional interests. . .."(Tesch, 1987, p.6)

There is no doubt that my experience with cancer had, and continues to have, a deep significance for me, both personally and professionally. In fact, I felt a certain need or drive to undertake a disciplined study of the experience in order to better understand its significance in my life. In so doing, of course, my hope was that such understandings will be useful to others. Although I dealt specifically with *my* experience, the underlying potential of my research is to shed light on, or at least make us wonder about, how we can create a world that supports and encourages people with cancer to have hope, to experience growth, to truly live.

Phenomenological Research: The Study of Lived Experience

Because I was concerned with the meaning of a particular lived experience, I chose to approach the study of my experience with cancer using a phenomenological methodology. It seems appropriate, then, to discuss phenomenological research as a particular form of disciplined inquiry.

In conducting my research, I have primarily followed the hermeneutic phenomenological approach to human science research and writing advocated by Van Manen (1982, 1984, 1986 & 1989). This approach draws from the European schools of phenomenological philosophy and methodology, with particular emphasis on the contributions of the founding philosophers of the phenomenological movement, namely: Husserl, Heidegger, Gadamer , Dilthey and Merleau-Ponty. The Van Manen approach strongly advocates the linking, within the text, of lived experience descriptions (anecdotes) with reflective-interpretive theorizing. This seemed a most appropriate method for my purposes.

Phenomenological research, as the reflective study of lived experience, aims at gaining a deeper understanding of the nature or meaning of our everyday lifeworld. As a consequence, phenomenological research does not strive to produce theory or "results" with which we can better explain or control the world. It offers, instead, the possibility of insights that bring us into more direct contact with the world of human experience.

According to Van Manen (1989), phenomenological research is the study of essences. It asks for the very nature of a lived experience, for those components that make an experience uniquely what it is. Through phenomenological research, we systematically attempt to uncover and describe the deeper meanings or structures underlying the particulars of a lived experience. Phenomenological research does not ask questions such as: What elements of lifestyle contribute to development of cancer? or What are the most effective methods of coping with cancer? Phenomenological research is more concerned with questions such as: What is the nature of the experience of having cancer? What is it like to have cancer? Of course, even as we seek after that which is essential, it is with the knowledge that the "essence" will never completely show itself. It is more the nature of a quest than an achievable destination.

The doing of phenomenological research requires the attentive practice of thoughtfulness - a minding, a heeding, a caring attunement to some aspect of lived experience. It engages the researcher in a mindful wondering about what it means to be a human being absorbed in the project of living.

Phenomenological research is unlike other forms of research in many ways. As noted above, one way in which it differs is in its orientation, the question(s) being asked. Another important way it differs is in relation to "results". In phenomenological research, there are no results, no conclusions, no punchlines. As in poetry or good literature, it is inappropriate to ask for a conclusion or summary of a phenomenological study. Such a summary would destroy the result because the whole itself is the result.

While phenomenological research is, in a way, an attempt to poetize human experience, to find language that reverberates the lifeworld, it differs from poetry, story or art in the epistemological end for which it strives. Phenomenology aims at making *explicit* that which is implicit. It seeks for *essential meanings* within the particular lived experience. It is "self-disclosure and self-commitment, personal witnessing and contributing to the shared world of meanings... the explicit, historical, ongoing accumulation of perspectives and knowledge on already known issues, the building of a multi-dimensional house of language in which the issue dwells and has its changeable being" (Von Eckartsberg, 1986, p.194)

Hermeneutic phenomenology has generally been recognized as that arm of phenomenological research that focuses on works of literature, autobiography, and works of art (film, theatre, etc.) as appropriate texts for reflective-interpretive activity. It is possible, however, to see that all phenomenological enquiry is essentially hermeneutic since the fundamental model of the approach is textual reflection on lived experience (Smith, 1990). Writing, the production of text, is central to the research process. In my case, the research is textual in two respects: firstly, I have used my journal to trigger remembrances of my lived experience with cancer; secondly, I have produced the present text which seeks to reflect on and interprete the meaning structures of that experience.

Writing: The Critical Process

Hermenuetic phenomenological research is fundamentally an activity of writing and rewriting. In essence, the research and the writing are aspects of the same process. Through writing, we fix thought on paper; it distances us from the lived experience and objectifies our thinking. "The object of human science research is essentially a linguistic project: to make some aspect of our lived world, of our lived experience, reflectively understandable and intelligible." (Van Manen, 1989, p.130)

If writing is the process, we must ask how is writing research? The writer produces more than text, the writer produces him/herself. Paradoxically, the process of writing separates us from what we experience while uniting us more closely with it. As we commit ourselves to paper, we can see ourselves mirrored back. We now have something upon which to focus our reflective awareness. We can look at the text we have produced and ask: "Is that really it? Would other words get at the essential meanings more effectively?"

Writing distances us from the lifeworld we wish to understand, it abstracts and objectifies our lived understandings from our concrete involvements while, at the same time, it reunites us with what we know and draws us more closely to living relations and experiences. As well, it exposes us to others in a very intimate manner. "Writing exercises and makes empirically demonstrable our ability to 'see'. Writing shows that we can now see something and at the same time it shows the limits or boundaries of our sightedness" (Van Manen, 1989, p.134).

Phenomenological writing empowers us with new understanding, new "sightedness". So, the way I am in the world can never be the same. My writing has allowed me to see things I have never seen before; in some way my existence is mediated by my new understanding. Through the process of writing, I have come to a deepened understanding which now reflects itself in my practical action in the world.

Even as I undertake to come to new knowledge, broadened understandings of lived experience through writing, reflection and rewriting, I am uncomfortably aware that lived human experience is always more complex than any description or reflection I can generate. There is always an element of the ineffable to life. So, in reality, to do phenomenological research is to attempt the impossible. However, it *is* possible to come to an understanding of a lived experience that brings forth a comprehension that was previously unseen. Phenomenological inquiry is a creative attempt to capture a certain phenomenon or life experience in a linguistic description that is analytical, precise and unique while also being evocative and sensitive. "The writing, as interpretation, strives for a poetic (disclosing) quality in that it attempts to bring to language the thematic moments in such a way that the essence, or lived-through meaning of the experience shows itself" (Bergum, 1986, p.49).

Because the use of language is so central to phenomenological writing, it is important that words and language structures be selected with care. Phenomenological writing requires that we not take language at face value. It requires an attunement to the deeper meanings not always readily apparent. Going back to definitions of words we think we know may sometimes cause us to reaffirm our understanding of meanings. Tracing etymological origins may sometimes put us in touch with the original lived experiences from which the words themselves sprang. Being attuned to idiomatic phrases can also prove useful as such phrases generally have their genesis in the life world.

Even the word "re-search" suggests the elements involved in this attunement process. According to Webster(1989), "search" means "to look into or over carefully or thoroughly in an effort to find or discover something; to read thoroughly; to look at as if to discover or penetrate intention or nature; to uncover, find, or come to know by inquiry or scrutiny; to make painstaking investigation or examination" Attuning oneself to the deeper meanings, then, requires searching, and re-searching, accompanied by writing and rewriting.

The Nature of the Question

To do phenomenological research, one must first, even tentatively, evolve a question that guides one to the essence of a lived experience.

Burch (1986) has given a clear description of the difference between a question in the phenomenological sense and a problem. The primary differences are as follows:

1. Problems tend to concern objects whereas a question concerns a matter in which we are involved essentially. We do not so much have a question as we are in it.

2. One attacks a problem with a goal of closure, of a "solution". The outcome of questioning is greater understanding. Questions serve to expose to view, to call forth in a way that leads one to greater understanding.

3. Problems, generally, are matters of cognition and control. We strive for "correct" results. Questions, on the other hand, concern the elucidation of that which is essential. There are no correct answers to such questions.

4. The answer to a problem concerns what we do. The response to a question concerns who we are as human beings. The principal matters in all questions are our being, doing, thinking, and experiencing.

Through phenomenological research we are not dealing with a problem in need of a solution but a mystery in need of greater understanding. Gadamer says the questioning "is more a 'passion' than an action. A question presses itself on us; we can no longer avoid it and persist in our accustomed opinion" (Gadamer, 1975, p.330). Likewise, the task of the researcher/writer is to "pull" the reader into the question in such a way that the reader begins to wonder, to question, to desire greater understanding.

The phenomenological attitude compels us constantly to raise the question: What is it like to be? And, so, I may ask: What is it like to be an educator, a healthcare provider, a woman? What is it like to be a person with cancer? Such questions challenge us to define the essential elements that separate this particular human experience from all other human experiences.

Thematic Analysis

The essence of a phenomenon is never straightforward or one-dimensional. The essence of any human experience is multi-dimensional and multi-layered. In order to come to grips with the complex structure of meaning in a phenomenlogical inquiry, it is helpful to organize the text according to meaning units or themes. In human science, themes are not referential to some frequency count or coding of selected terms as might be found in other forms of research. In phenomenology, themes are the structures of experience. Through thematic analysis the researcher tries to unearth the focus, the point, the meaning of the experience

"Themes are the stars that make up the universes of meaning we live through. By the light of these themes we can navigate and explore such universes" (Van Manen, 1989, p.95). Themes serve to point at, to allude to or hint at some important aspect of the phenomenon.

Not all meanings that may be encountered in reflecting on a certain lived experience are specific to that experience. A most difficult aspect, then, of phenomenological inquiry is to differentiate between those themes that are fundamental and those that are more incidentally related to the experience. In determining which themes are fundamental, our concern is to discover those aspects or qualities of the experience that make it uniquely what it is and without which the experience would not be the same.

To determine fundamental or essential themes, the phenomenological researcher uses a method of free imaginative variation. Using this method, the researcher asks: Is the experience still the same if I imaginatively change or delete this theme? Without this theme, does the experience lose its fundamental meaning? This same process may also be used to generate themes.

CHAPTER II

A WAY TO UNDERSTAND ONE WOMAN'S EXPERIENCE

Autobiographical Method

"We are not mere smudges on the mirror. Our life-histories are not liabilities to be exorcised but are the very precondition for knowing" (Pinar, 1988, p.148). Through autobiography, we seek to understand ourselves in relation to situation. Through understanding of self we come to better understand others: "To understand is to rediscover you in me; the spirit retrieves itself on ever higher levels of configuration; identity of Spirit in me, in you, in every subject of our community. . ."(Bauman, 1978, p.35)

This spirit of autobiographical method, may speak to the criticism sometimes levelled at phenomenological enquiry, namely that it "leans in the direction of a purely descriptive exercise and one that is both normatively and politically 'neutral,' thus shading over into quasi-positivism" (Dallmayr, 1981, p. 4). Or, as suggested by Smith (1990): "Interpretation easily lapses into a dalliance of interpretations rather than lead to a renewed embrace of the Other and the world in the service of a fuller appreciation of the human prospect" (p.9). Through my reflection and interpretive efforts, I have continually sought to understand how *my* experience could be *our* experience. In this way, I find myself being continally drawn to "a renewed embrace of the Other" that is surprising in its strength and invigorating in its effect.

Cancer is a very common diagnosis. Every year, one million North Americans learn that they have cancer (Woods, 1989, p.51). The type, extent and severity of the disease varies enormously, of course, but there is a commonality nevertheless. On my post-treatment visit to my family doctor, he said to me: "Whether you like it or not, you are different now. You are one of those people who knows they can have cancer."

The ways in which the experience of having cancer made me different, transformed who I am, was the focus of my reflective inquiry. Through reading the documentation of events, physical sensations, feelings, and emotions in my journal I have "relived" my journey with cancer and come to better understand the "meaning" of this experience. It is not the particular events themselves, nor the physical sensations, nor even the feelings or emotions that provided the fundamental meanings. The essence is glimpsed not as any of these elements, but through them.

Because my journal provided the initial text for my reflective work I have been, in this sense, involved in a dialectical self-self relationship aimed at developing a deeper level of knowing. Within this dialectic relationship there exists an orientation, a station or vantage point in life that influenced my seeing and, therefore, my understanding. The fact that I am a woman living in Canada in the 1990's strongly shapes my orientation. I am also a wife and a mother. I am a college instructor and administrator, a curriculum developer and a Registered Nurse. As a health educator, I have valued health and striven to maintain a lifestyle that fosters health. I have always viewed myself as a healthy person. These roles and self-concepts that define "who I am" are integral to my particular experience of having cancer.

Being aware of "who I am" reflects an occasionally voiced criticism of phenomenological method, namely, that it well may be extremely difficult, if not impossible, to repress one's inevitable prejudices and everyday ways of seeing and thinking. This inability to completely stand outside of self could "have the effect of foreclosing on the phenomenon and of obstructing the view of it" (Roche, 1973, p. 35). This is a very serious consideration, as we do tend to take things such as rules, values, social organizations, social roles and responsibilities for granted. The danger is that we accept this "reality" as given and not requiring of further probing and understanding. There is no doubt that the person I am reflects my history and my culture. In conducting my phenomenological reflection I have attempted to be continually cognizant of this fact while, also, actively questioning these "realities" in an effort to not only to better understand my own prejudices but also those of my culture and my community.

The Research Question

Phenomenological research asks the question, what is it like to have a certain experience? A seemingly simple question. Yet, paradoxically, that which seems, at first blush to be simple often is most complex. Human experience is shot full with complexity and, as a consequence, any effort to understand the essential nature of a human experience is, indeed, a daunting task.

An important aspect of the phenomenological process is to be constantly mindful of one's original question and thereby steadfastly oriented to the lived experience that produced the question in the first place. Gadamer

(1975) said that "the essence of the question is the opening up, and keeping open, of possibilities" (p.266). Van Manen (1989) tells us that "to truly question something is to interrogate something from the heart of our existence, from the center of our being" (p.45). Consequently, in deciding on an overall question to guide my inquiry, I was challenged to orient myself to that which would involve me in a profoundly meaningful way.

Phenomenological research asks: What is it like? So, my research asked, basically, What is it like to have cancer? Or, more precisely, What was it like *for me* to have cancer? What was *my* experience of cancer like?

Through these questions, I have been guided to construct a reflective-interpretive text that mirrored the fundamental nature of my own unique experience with cancer.

Searching for Essential Themes

Basically, theme is the tool we use for getting at the meaning of an experience. Theme gives shape to that which might seem ineffable. While no theme can completely unlock the full meaning, the deep mystery, of human experience, through thematic formulation and analysis, we can hope at least to touch on the core of the experience.

There are a number of approaches to working with a text to uncover or isolate thematic aspects of a phenomenon. One way would be to "pan" the text looking for those major dimensions that seem to be at the center of the experience, those that seem to address the very nature or essence of the phenomenon. Another approach may involve the "survey" method whereby the researcher examines the text in a painstaking line-by-line effort to capture all that is there. "The result of the process is a list of themes, some of them more tentatively formulated than others, and some more revelatory of the experience than others" (Tesch, 1987, p.3) I have undertaken both approaches to working with my initial text, i.e. my journal. The same approaches were used in working with my secondary text, that which flowed out of the review of the journal.

Because the lifeworld is so complex, I felt the need for some guiding order in identifying themes. I needed a fundamental structure that would guide my reflection without unduly limiting my scope. I chose the four fundamental existentials of spatiality, corporeality, temporality and relationality (Van Manen, 1989, pp 106-111) as guides for my relection. Spatiality (lived space) is concerned with the way that the space in which we find ourselves affects the way we feel, think and act. Corporeality (lived body) refers to our bodily presence in the world and the ways in which an experience influences or is influenced by our physical being. Temporality (lived time) is our subjective experience of time as influenced by the situation we find outselves in. It is also our temporal way of being in the world - as a young, middle-aged or old person. The temporal dimensions of past, present, and future constitute the horizons of our lives. Relationality (lived other) is the relationship we maintain with others, the interpersonal, communal aspects of our lives.

These four existentials of spatiality, corporeality, temporality and relationality form an intricate unity which we call our lifeworld. While in a research study we can temporarily differentiate the existentials, it soon becomes apparent that one existential calls forth the others. In reality, these four existentials are never separate. Nevertheless, they provide a useful tool for guiding reflection and eliciting themes.

Once themes were identified, they became objects of reflection in formal and informal collaborative hermeneutic conversations. Van Manen (1989) states that ". . .conversation lends itself especially well to the task of reflecting on the themes of the notion or phenomenon under study" (p. 103). In my case, regular meetings with my thesis advisor was a formal way I gathered interpretive insights to the text that flowed from my reflective activity. Less formal methods included sharing the text with my husband, select colleagues and certain friends. The primary purpose of these conversations was to strengthen the text by bringing to awareness the limits of my vision. Also, by encouraging others to reflect on their own experiences that were similar to mine, it was possible to get a better sense of the generalizability of meanings inherent in the text.

Literature and poetry have been used in an effort to add strength and richness to the final text. The literature of illness - chronic illness, cancer, and others - allowed me to explore the experience in a wider perspective (see Beisser, 1989; Dosdall & Broatch, 1986; Epstein, 1989; Radner, 1989; Van den Berg, 1980) . Sometimes passages from literature or poetry contributed to the essential understanding which the text struggles to expound. And, often, the most useful thoughts came from surprising sources, i.e. not necessarily scholarly works nor those concerned with health/illness. Again, I was reminded that human experience reverberates with common meaning.

Anecdote as a Methodological Device

A common rhetorical device used in phenomenological research is the use of anecdote. This form of short narrative is used as a methodological device to make comprehensible some notion that might otherwise elude us. Anecdote can give substance or concrete counterweight to abstract theoretical musings. The anecdote can provide the lived experience from which the layers of meaning can be extricated. Anecdotes, then, force us to search out the relation between situation and reflection.

In my reflective work, I have developed anecdotes of my various experiences with cancer. These anecdotes are not necessarily direct quotes from my original journal but flow from that source. The anecdotes that have been selected for this research are those that most effectively reflect the meanings embedded in the particular aspect of the cancer experience. In selecting appropriate anecdotes, I used the following criteria: the anecdote: (1.) invites a reflective search for meaning; (2.) may involve the reader in a personal way; (3.) has a certain emotional power; (4.) effectively reflects the meanings discussed in the text.

Throughout my research text, I have changed the names of all individuals other than myself.

Living the Research Experience

The original text, my journal, though written by me, was written at a different time and place. The distance of time provided a certain perspective that I feel was helpful in the reflective-interpretive activity. Gadamer (1975) suggests that time distance lets the true meaning emerge fully. "The temporal distance which performs the filtering process is not a closed dimension, but is itself undergoing constant movement and extension. ...It not only lets those prejudices that are of a particular and limited nature die away, but causes those that bring about genuine understanding to emerge clearly as such" (p.266). The optimum temporal distance, I feel, is one which offers a sound perspective on the true meanings while not being so removed from the experience that some of the vividness of memory is lost. The time period in which I worked seemed to meet these criteria quite well.

Throughout the reflective process, I have had to struggle against forcing results or jumping on themes that might not actually reflect an essential element. Sometimes, through conversation with others or through reading of others' experiences, I have been made aware of an interesting meaning or theme. I have had to discipline myself to use the method of free imaginative variation to search for those themes that were truly an essential part of *my* experience.

I have had, on occasion, to "step back" from the reflective process. Yet, not surprising, a part of my brain always remained in tune with it, even when I was engaged in other things. Insights came at unusual times, not always when I was directly working with the ideas - during a walk on the beach, whilst I was preparing a meal, in the middle of the night.

Doing phenomenological research is a fully engrossing human activity fraught with a certain amount of difficulty and toil. "We know from Heraclitus and Parmenides that the unconcealment of being is not simply given. Unconcealment occurs only when it is achieved by work: the work of the word in poetry, the work of stone in temple and statue, the work of the word in thought. . ." (Heidegger, quoted in Pinar, 1988, p.147)

Organization Of The Thesis

Chapter I has established the ground for the research question by explicating the phenomenological approach to human science research and writing. Chapter II introduced this particular study more specfically by delineating the research question and the methods used to reflect on the question.

In Chapter III, the journey begins. In deciding where to start, I came to the conclusion that it is best to begin at the beginning - awaiting the diagnosis. From here my experience with cancer evolves. With each aspect or component of the overall experience, there is a question. These questions, of course, are pieces in the understanding of the overriding research question. I have chosen to break down my experience with cancer as follows:

Chapter III Awaiting the Diagnosis: What is it like to await a potentially serious medical diagnosis?

Chapter IV Living the diagnosis: What is it like to know you have cancer?

Chapter V Searching for the Way: What is it like to decide on a course of treatment when the "wrong" choice could be life-threatening?

Chapter VI Experiencing Cancer Treatment: What is it like to expose one's body to destruction in order to be "saved"?

Chapter VII Cancer as Teacher: What are some of the lessons to be learned from having a life-threatening disease?

Chapter VIII The Different Me: What transformations occur as a result of the crisis of serious disease? In what ways do one's perceptions, meanings and values change or shift as a result of having cancer?

Chapter IX Toward Thoughtfulness and Tact : In what ways does the reflective-interpretive experience lead to edifying theory, thoughtfulness and tact? How doe the experience encourage a greater sense of personal integation?

CHAPTER III

AWAITING THE DIAGNOSIS

It's a long walk, these five blocks to the doctor's office and yet, not really long enough. My feet are moving and the surroundings are passing but I have little awareness. My mind is numb with fear. I am aware of little else than the lump in my neck and the appointment I am about to keep.

Three months ago, my dentist noticed the lump and advised me to mention it to my physician "next time you see him". There was a studied naturalness about the remark. I remember contemplating it and saying to him: "You know, I'm a very healthy person, I seldom have need to see my doctor. Is this thing worthy of a special appointment?" His response was my first inkling that this might become serious: "Yes, you should see him as quickly as you can. In fact, I'll be phoning and talking with him today."

My family physician, Dr. Whitney, has an informal demeanor. I have always appreciated this about him. He palpated the lump and told me it didn't feel like a malignant lump but we'd do a number of investigations to find out just what it is. I had a blood test taken that very day. The results were back quickly, showing I did not have leukemia.

The next test was a C.T. Scan. This was my first real contact with the technology of illness. I was alone in the room, lying on the hard surface while the machine groaned and hissed. Now and then a disembodied voice came through an intercom to tell me what I was supposed to do. I remember my heart thumping wildly and I wondered at my anxiety.

Waiting on the results of the C.T. Scan was my first taste of real fear. The day I phoned about the results, Dr. Whitney's receptionist told me the results were back, then said: "Well. . .he'll want to talk with you about this". The panic struck me like a punch in the gut and my brain was full of horrible thoughts. The three hours I waited to hear from Dr. Whitney seemed like an eternity. I was completely preoccupied with my terror. I filled the time with mindless activity. Driving home from work, I began to weep inconsolably because I was sure I'd not survive to see my son grow up!

As it turned out, the C.T. Scan showed nothing. My relief was enormous, yet there was still no answer. Just what is this lump anyway?

I'd been aware of the lump for about a month now. It had not changed in any way (even though I daily willed it to disappear). Dr. Whitney now suggested I go see an Ear Nose and Throat specialist, Dr. Robb.

My experience with Dr. Robb reaffirmed my fear and the continuing *difficulty with "not knowing". He looked in my ears, nose and down my throat. He palpated the lump and said it did not feel like a "bad customer". Then he performed a needle biopsy.*

I recall lying on the table in Dr. Robb's examination room awaiting the procedure. During his examination, Dr. Robb had said the lump felt like a cyst and as I lay on the table, I desired with every part of my being that the syringe would draw back fluid: "Oh God, let this be over. Let it be finished right here, today!"

But the syringe did not draw back fluid. In fact, I remember seeing the clump of tissue in the bottle as I left Dr. Robb's office. It was red and angry. Or maybe it was I who was angry. My neck hurt from the procedure. I felt invaded. And I knew I was not yet finished with the "unknowing".

I had seen Dr. Robb in mid-December, therefore the earliest I could call for the results was after the holidays, December 29. Over Christmas, I tried to forget the lump in my neck but I could not resist feeling it daily just to assure myself it had not changed.

When I called Dr. Robb's office on December 29, the receptionist said: "Oh, yes, Mrs. Ferguson, just a moment." She obviously went off to talk with Dr. Robb returning to the phone to say: "Dr. Robb wants to see you. Could you come to the office today?"

At that moment I knew.

All the fear I'd been struggling to hold at bay over the Christmas season came tumbling down upon me. My mind raced. I felt panic, dread, terror. I ran immediately to my husband who tried to calm me by persuading me there might be many reasons why Dr. Robb would want to see me. But I wouldn't be persuaded.

And now as I walk to my appointment, I hope upon hope that I am wrong, that my husband is correct. Once I reach the doctor's office, I am ushered in to see Dr. Robb almost immediately. He , once again , examines my nose, ears and throat. Then he tells me he wants me to have an x-ray. He is filling out the necessary forms for the x-ray and telling me to return to see him afterwards. He's avoiding my eye contact. Finally I say: "Before I go for the x-ray, please tell me what the biopsy results have shown".

Dr. Robb takes a deep breath and sits in a chair facing me. The lump is malignant.

Waiting

I sit silently in the restaurant. I gaze about the room, noting the decor and the other diners. I think of the friend who will soon be joining me and I remind myself to ask her about her new job. I begin to read the menu. My friend arrives and smiles when she sees me. As she approaches the table, she says : "I hope you haven't been waiting too long." This experience of waiting has been in accord with the common definition of waiting : to stay in place, pause, remain stationary in expectation or readiness. We all live this kind of waiting - we wait for the bus, the doctor, the bank teller, the movie. In all these we have an expectation of a particular outcome and a certain sense of a reasonable amount of time for the waiting.

But waiting isn't always a passive experience. In December, my seven-year-old son asks me daily: "How many days until Christmas, Mom?" When he hears the answer, he invariably responds: "Oh, I can't wait. I just *can't* wait!" It's such an exquisite anguish this excited anticipatory waiting. And it is seldom passive. Much activity, talking, and thinking are brought to bear as we project ourselves into the longed for future.

In all these situations we have a definite expectation of the outcome of our pausing in time. There is even a fairly certain sense of the time that will be entailed in the waiting. The waiting allows us to prepare for the expected outcome. As I wait for my friend, I think of things I'd like to ask her. As my son waits for Christmas, he anticipates the joys of that special day.

What is it like to wait when the expected outcome is uncertain? How is waiting experienced when the outcome has the potential to plunge the individual into the depths of despair? I remember one lonely night in the middle of a prairie winter waiting for my husband to return from a journey. As the hours ticked by in the darkness, long after his expected arrival time, I recall the desperation of my waiting. I envisioned him bloody and broken by the side of the highway, yet I struggled to convince myself that I was overreacting. When he finally arrived, safe and tired from battling the icy roads, my relief was a balm to my whole being. Because of the outcome, my life was not markedly changed by this experience. If the outcome had been different, the whole course of my life from that point onwards might well have been altered.

Waiting on a potentially serious medical diagnosis is replete with uncertainty. The outcome is unknown. The length of time required to "discover" the diagnosis may also be indefinite. What is it like to live this particular experience of waiting?

The Body In Between

Waiting on a medical diagnosis engages the body in a manner that is quite different from other experiences of uncertain waiting. Awaiting a potentially drastic diagnosis puts the body in limbo, a time of in between. Does one begin to view the body as sick, or is it still well? This was especially dramatic for me since I had experienced little, if any, symptoms of disease. I felt the same as I had before. The only difference is the possibility of a frightening medical label being applied to me. It is that *possibility* that initiates changes in the body, or perhaps more accurately, how the self perceives the body.

During this in between time, there are many aspects of life that reflect a healthy state. After all, in every way my embodied capacities are functioning as well as ever. I'm not limited or impeded in any discernable way. But, there are increasing aspects that reflect illness. It seems that the mere possibility of a serious threat to my normal embodiment has the power to take over my life in a manner similar to the experience of illness.

Holohan (1977) referred to this time as a "rite de passage". Rites de passage are those experiences and rituals which accompany change of place, state, social position and age. Is waiting for the diagnosis a rite de passage from the place, state, social position of well person to that of sick person? Is it a preparation, a dress-rehearsal, for the changed person one may soon become?

One's body is so integral to self. It is the way in which we encounter the world. In a state of wellness, we are not particularly aware of our body and its functions, yet, our embodiment is so intimate a thing that when it is at issue all other concerns become secondary. This worried attention to the body diminishes the easiness of day-to-day life. Life goes on, tasks are done, but continually bodily concerns invade.

The lived body is not the
instrument
with which I act; it is my acting.
On the other hand,
it is the conscious vulnerability
of the self in the world,
the felt capacity to be affected,
injured.

(Gadow, 1982, p.87)

Awareness of the bodily sign or symptom which originated the concern becomes acute. This unwelcome small lump has become me - it has taken over my life. Other bodily sensations now take on new dimensions. Does that cramp, that headache, that tiredness mean something sinister?

There is also the reaction to the "violence" of medical intervention. Is this necessary? I want to protect my body, protect myself from this invasion.

I'm not ready to be labelled as diseased. I'm not ready to take on the stigma of illness (see Sontag, 1978, pp 26-36). Therefore, I try to carry on with others in my life as though nothing has changed. While this allows a certain measure of normalcy, it requires more energy than previously because something *has* changed. I have a dark secret which isolates me from most others in my life.

Desperate Waiting

Perhaps the most dramatic aspect of waiting for an uncertain outcome is the desperation. This desperation may only last a few hours, or even a few minutes, but it is so totally consuming that all else pales.

Despair comes from the Latin desperare (*de* - without and *sperare* - to hope). Despair, then, means the loss of hope, the state of being without hope. Being desperate means being led, overcome or directed by despair.

When faced with uncertainty that contains the seeds of darkness, the mind tries to make meaning. The emotions can easily hold sway, carrying one away with thoughts of disaster. During these moments or hours one feels trapped, captive to the terror of what might be possible. Nothing matters but the moment. The future is non-existent. All of life is now.

Despair
is in a certain sense
the consciousness of time as closed
or, more exactly still,
of time as a prison.

(Marcel, 1962, p.53)

During desperate waiting, one does not sit idle, one *cannot* assume a pausing, stationary stance. The emotions flare and the body answers. There is need for physical action.

As I walked to the doctor's office, I was unaware of the walking. I saw only the grey sidewalk passing beneath my feet. A friend could have passed by and I would not have known. I felt totally isolated in my fear and dread. It took over my whole world. It was, for those moments, my only reality. I felt so small and vulnerable and alone.

But, even as the scenes of destruction tumble over themselves, there is a germ of rationality that begs to be heard. The little voice in my head insistently intrudes on my panic: "You silly woman! Get yourself together. There is no reason for you to despair just yet!" The rationality struggles to calm the emotions enough that hope may find an entrance.

The soul always turns towards a light

which it does not yet perceive,
a light yet to be born,
in the hope of being delivered from its present darkness,
the darkness of waiting.

(Marcel, 1966, p.31)

Waiting with Hope

Between the moments of despair, the self opens itself to hope. Sometimes this is just a getting on with day-to-day life, almost (but never quite) forgetting the question that is hanging there with no answer. Many times the mind reiterates the hopeful signs.

The lump hasn't changed, in fact isn't it a bit smaller today? Both doctors have said it doesn't *feel* like a malignant lump. I'm certainly not in a high risk group for getting cancer. There are so many reasons to feel optimistic. I listen eagerly as my husband reiterates the reasons for hope (is he trying to convince me or himself?).

At this stage, though, my hope lies in the outcome being "positive". This means, that the lump is NOT malignant. I have not gotten to the point of seeing the possibility of hope even if the lump *is* malignant. So, one could say, that this is a somewhat limited hope, it hasn't yet become a part of my whole being - body, mind and spirit. Perhaps that explains its fragility.

In so far as I make my hope conditional
I myself put up limits to the process
by which I could triumph

(Marcel, 1966, p.46)

Waiting with Uncertainty

Perhaps the theme that most poignantly flows through all aspects of waiting for a diagnosis is the unrelenting uncertainty. We human beings constantly project ourselves into our futures. I have a lunch appointment for tomorrow, there is a project I'd like to have completed for next year, I pay into a pension fund. In big and little ways we plan and visualize the forward thrust of our lives. We *need* to expect and be ready.

Waiting for an uncertain diagnosis immediately creates an uncertain future. Suddenly, all the future projections we've made and are making are called into question. Rawlinson (1982) suggests: " ...illness confounds our capacity to expect. The future, either short-term or long-range, takes on a brittle quality. One finds one's plans disrupted and possibilities withheld." (p. 75) But I'm still not sure that I'm ill. To what degree is my future in doubt? In what ways should I be altering my future visions?

The "not knowing" creates a disequilibrium borne not only of fear for my present well-being, but also for the future I cherish. In the definition of the word *wait*, (Webster, 1989) one of the alternatives is "to be temporarily neglected or unrealized". Waiting, especially if it drags on, can have this effect. In the case of an uncertain outcome, perhaps the effect is even more encompassing for it is one's future as well as the present that must be set aside.

As time passes, the need to know grows stronger. I am reminded of the many stories I've heard of people who have spent years of their lives going from doctor to doctor trying to find a label for a disturbing symptom. These people become increasingly desperate for an answer.

Yet there is an ambivalence - wanting it over, yet not wanting it over. The diagnosis marks the end of the waiting. Hope and fear are strongly intermingled as the diagnosis is contemplated. When the phone rings announcing the physician's call, I hesitate. But I do answer it. When it's time to go to the doctor's office, finally to get the word, I choose to walk rather than drive.

The diagnosis, the label, I've been awaiting promises to bring with it a relief, and release from these months of uncertainty. In so doing it may also present me with a challenge for which I am not sure I'm prepared. I go forth in dread. Yet the diagnosis must be known. My future must be decided.

PRESENTIMENT

I am like a flag by far spaces surrounded.
I sense the winds that are coming, I must live them
while things down below are not yet moving:
the doors are still shutting gently, and in the chimneys is silence;
the windows are not yet trembling, and the dust is still heavy.

Then already I know the storms and am stirred like the sea.
And spread myself out and fall back into myself
and fling myself off and am all alone
in the great storm.

(Rainer Maria Rilke in Norton, 1938, p.79)

CHAPTER IV

LIVING THE DIAGNOSIS

> **Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.**
>
> (Sontag, 1977, p. 3)

A New Reality

Dr Robb sits facing me. His shoulders are slumped slightly as he takes a deep breath and explains that he had spoken with Dr. Whitney about me. "Because Dr. Whitney is out of town this week, we felt it best that I tell you. The biopsy came back malignant."

So there it is, what I had feared most. I have cancer. As I contemplate this verdict, I notice the strangest sensation. The fear and anxiety of the past two months seem to just dissolve I feel an enormous calm. I am surprised at my composure.

I talk at length with Dr. Robb and I hear the hopeful things he is saying. He tells me that the type of cancer I have usually responds well to radiation. It generally occurs in people much older than I, so my age is in my favor. Unfortunately, this lump is not the primary tumor, so we will need to do some exploration to find the primary site. Dr. Robb speaks in such a kind voice and seems to have all the time in the world for me.

Dr. Robb sends me elsewhere in the building for another test. Upon return to his office, I overhear him talking with another patient, an elderly man I had noticed in the waiting room. Dr. Robb is telling this man that there is nothing more that can be done for the cancer in his jaw. I think: "God, it must be hard to tell someone that." And then it strikes me that I can trust this doctor. He isn't holding out false hope to me - he would tell me if *there was no basis for optimism.*

Walking home from Dr. Robb's office, I begin to cry.

With a few words, a doctor I hardly know has confirmed my new status as an inhabitant of the "Kingdom of the Sick". Not only that, but the label I now bear is that of "person with cancer". What is this new reality? What does it mean to suddenly "know" you are a person who has cancer? What will it mean to me, to my understanding of self?

Being diagnosed with a terrible disease alters one's present and one's future in profound ways. But disease is not simply dis-ease. Each one comes with a particular portent and meaning. Being diagnosed with cancer is different from being diagnosed with diabetes or pneumonia. Our technological, scientific society has prescribed many of the meanings we attach to cancer (or diabetes or pneumonia). As well, every illness also carries a set of specific, person-centered meanings.

medical background

Part of the physician's task in introducing a person to their illness is to help that person to alter his/her life-world in terms of the *doctor's* understanding of the disease. The manner in which the physician approaches this task can greatly influence the way the person perceives his/her new status in the world.

> **It is our duty as physicians to estimate probabilities**
> **and to discipline expectations.**
> **But leading away from probabilities**
> **there are paths of possibility,**
> **towards which it is also our duty to hold aloft the light.**
> **And the name of that light**
> **is Hope.**
>
> (Menninger, 1963, p. 400)

As I listened to Dr. Robb, I realized that I was now different, my life had been altered forever. He did not spare me the gravity of my situation, yet the significance being ascribed to the diagnosis was not as dreadful as I might have imagined. Through offering me his own perceptions, Dr. Robb helped me to have some optimism. He was not handing me a death sentence. In his presence, calmness overtook me and I saw the possibility of realistic hope.

The Body/Mind

> **When that focus changes, turns inward, that is, when the self-body experiences itself as acting upon or being acted upon, not by the world but by *a part of itself,* the immediacy of the lived body gives way to self-distinction.**
>
> (Gadow, 1982, p.88)

One's body is an integral part of total self (body/mind/spirit). Through our bodies we affect our world and are affected by it, so, in essence, we can say that our bodies are our connection with the world. The body is of the self and of the world.

In situations of optimum health, the body and mind function as a harmonious whole. An obvious example of this is the elite athlete. But even for those of us who are not athletes, there are many times that we function with little or no awareness of the complimentary unity between body and mind. I talk with my friend, using my hands and facial expressions to complement my word. As I sit at the computer my fingers fly across the keyboard, typing out my thoughts almost as quickly as they are produced.

In illness, the mind-body unity breaks down and divides into mind and body. The mind reflects on the body. The body gives signals to the mind. There is a loss of ease (dis-ease), a tensionality between mind and body. Suddenly, one cannot take one's embodiment for granted anymore.

My conscious mind focuses on the lump in my neck. I touch it often. I measure it. Has it gotten bigger? In my mind's eye it is a huge repulsive thing, hanging out on my shoulder for all the world to see. In reality it is no bigger that a quarter, tucked silently, invisibly under my jaw line.

My body seems removed from this threat. Certainly my body gave me a "warning" by producing this lump, but beyond that there seems to be no bodily "knowing" of the disease - certainly nothing that reflects the enormity of the threat. There is no unusual sensation, no pain, no pressure. My physical abilities are unaltered.

It seems so strange. Apparently, I have cancer. But I don't feel different. I don't look different. I'm still doing the things I normally do. Yet, lurking in my body is an unfelt enemy.

For several weeks immediately following the diagnosis, the chaotic fear that intermittently grips my consciousness is "spoken" through bodily symptoms. I lose my appetite, I experience "butterflies" in my stomach, I have occasional diarrhea and heart palpitations. These symptoms are annoying and distracting. They remind me again of the potential danger that stalks me.

I notice, also, that I experience a number of "phantom" symptoms, strange sensations that last only a day or two then depart. These, are the products of my conscious concern - my mind "producing" symptoms to fit what it knows - a feeling of fullness in the throat, a tenderness in the region of the offending lump, difficulty swallowing. But the body, in it's wisdom, quickly rejects these phantoms and, so, I come to know that they are not real.

My mind responds to my body with protectiveness. I'm surprised at this. I had always thought that if I were to contract a serious disease that I'd feel let down or foresaken by my body. I'd see my body as culpable. Much of the literature in chronic illness suggests that this response is common, at least initially. Yet, I could find no blame, no condemnation of my body for this silent intruder that was now ruling my life.

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The relationship between mind and body that evolved for me was more like a parent and child. My mind became a guardian, a protector of my body.

I must give my body its due, must take care of it,. . .and must not therefore despise it or treat it as an enemy. It is just by neglecting or even ill-treating my body that I would bring myself into subjection to it . . . for in this way I would make it into something - despite its identity with me - negative towards me and consequently hostile and would force it to rise up against me.

(Hegel quoted in Gadow, 1982, p.89)

I wonder at my reaction towards my body. Why did I not feel blame? Why did I experience this diagnosis of cancer so differently from others, and from what I had previously expected? Perhaps the fact that I experienced no symptoms contributed to my reaction. If I had experienced pain, diminished function, physical deterioration, would my perception of my body have been different?

Also, another contributing factor in my reaction is likely my particular view of mind/body interractions in illness. My background as a nurse and health educator has given me knowledge of the exquisite interaction between the body and mind. I know that the mind and body are not separate entities. Each affects the other in complex ways that medical science is only beginning to understand (see Borysenko, 1988; Cousins, 1983; Pelletier, 1977; Rossi, 1986; Siegel, 1989). I knew my body could not get sick without the intimate involvement of my mind. Body and mind had gotten into this predicament together, and would need to work together to get out of it.

Cancer Victim as Leper

As I ventured out into the world with this new label, this new reality, I was concerned about how other people would react. In what ways will my friends, family, colleagues see me differently now that I have cancer?

In our society (and likely others...) cancer has become a metaphor for ugliness, suffering, disorganization, and death. We use terms like "It was a cancer on the landscape" to describe something repulsive, perverse and disgusting.

> **Cancer . . . is felt to be obscene--in the original meaning of that word: ill-omened, abominable, repugnant to the senses. Cardiac disease implies a weakness, trouble, failure that is mechanical; there is no disgrace, nothing of the taboo that . . . surrounds those who have cancer. The metaphors attached to cancer imply living processes of a particularly resonant and horrid kind.**
>
> (Sontag, 1977, p.9)

We all fear death, pain, disfigurment, thus we want to separate ourselves from those who have cancer. Separating is a way of saying "I'm not like that person, therefore, it won't happen to me." The separation can take many forms. It may simply be an avoidance. Or it may be a looking for those aspects of personality or life style that make one different from the person labelled with cancer. He's a smoker, so he got lung cancer. I don't smoke. She's 85 years old and has skin cancer. I still have many years before I need to worry. In some vital way, we assure ourselves, we differ from that person; therefore, we are "safe".

One of my colleagues at work told me how hard it was for her to accept my cancer: "You're so much like *me!*"

Perhaps, too, we are trying to protect our emotional stability by separating from the person with cancer. In many minds, cancer equals death. It may also mean suffering, both emotionally and physically. When someone is labelled with cancer, we may distance ourselves in order to detach, almost a form of anticipatory grieving.

Before I had been diagnosed with cancer, I had felt all these things. I had distanced myself, in one way or another, from people I knew (or heard about) who had cancer. I recall, at my first visit to Dr. Robb's office, noticing literature describing services for cancer victims. I felt an emotion boardering on anger as I gazed on those pamphlets. I didnt want to see them, they told me too bluntly that this doctor has many patients with cancer. I turned away and told myself I did not need any of that literature. People with cancer were still "other", separate from me.

When I joined the ranks of "people with cancer", my prevous avoidance and denial assured me that I would be met with a similar response from others once my new status was known. I *knew* that I would be treated like a leper, isolated, made to feel like a failure. After all, didn't I now embody the very thing people most fear?

Dreading this anticipated isolation, I was unsure how, or if, I should tell people about my diagnosis. Should I keep it secret? But, I knew I couldn't keep it secret. That would only add to my emotional burden. I needed friends to help me with this burden. I had to share and, yet, in the sharing I feared that I would engender isolation. I was in a quandary.

I phoned Thea today to tell her of the situation. When I told her of the diagnosis, there was a momentary silence on the other end of the phone.

When she spoke, she said she felt like she had been socked in the stomach. It's funny how cancer does that to people. If I'd been diagnosed with arthritis or even heart disease, I'm sure the reaction would have been different. But, cancer. . . .

So, carefully at first, I began to share my dark secret. But even as I did so, I made sure to confirm the many ways in which I was still well. I reiterated every scrap of hopefulness: "The doctor says this kind of cancer responds well to radiation"; "It seems that we've caught it very early". Partly, such statements were ways in which I maintained my own hope. But, they were also messages to the others in my life that I wasn't so different from them and I intended to rejoin the Kingdom of the Well as soon as possible. I was telling them: "Please don't expect me to be one of those people who are eaten up by this disease. Please don't expect me to die."

The need to exert some kind of control over the irrational forces that we imagine are loose in our bodies also results in what I have come to recognize as the "brave act" put on by people who have cancer. . . Our brave act is important. It is . . the way that we convince those who live in "The Land of the Well People" that we aren't all that different from them.

(Trillin, 1884, p.135)

Lived Spaces of Safety and Threat

My first visit to the Cancer Clinic. I've actually been looking forward to this. I'm anticipating that I will get some answers. I'm sure there will be treatment protocols for my type of cancer and today I will hear about them. I'll know where I'm going.

I carefully select clothes that I feel express my self-determination, that give me an aura of strength. I want to portray an image of intelligence.

As I walk into the Cancer Clinic building, I'm struck by the cold, clinical nature of it. I'm ushered into a small room where a woman sits behind a computer terminal. She asks me questions in a matter-of-fact manner, then takes a polaroid picture of me "for the files".

Following this, I am taken to an examining room where I change into a paper gown. A female doctor, whom I've never met before, enters and proceeds to conduct a thorough physical examination, culminating in a rectal examination (What has this to do with my neck?!)

After the physical exam, I put my clothes back on and wait. The examining room has no windows and the fluorescent lights bother my eyes. The chair I'm sitting on is hard. I feel very much alone in this confining room.

Finally, the oncologist, Dr. Alistair, arrives. He has my file in his hands. He sits on the edge of the examining table and looks down on me. He seems to study me for a few seconds as though I am an interesting specimen. He tells me that the pathology report shows that I have a metastatic squamous cell tumor. So there it is - that's the label. The precise, emotionless nature of those words shock me. I particularly hate that word metastatic. My God, the cancer has ***spread****! Is there any chance of survival once the cancer begins to spread?*

After a very few questions, Dr. Alistair comes over and palpates the lump in my neck. His hands are cold. He touches my neck carefully, almost gingerly. He looks puzzled and asks if I mind if he has a colleague examine me. I agree.

Dr. Alistair leaves and returns shortly with a serious looking young man. He, too, palpates the lump. Then the two men stand over me discussing my "case"in long medical terms. I don't understand all of what's said but I hear phrases such as "radical neck surgery" and "lung involvement".

Both doctors leave and I know they are discussing me further in some other room. Dr. Alistair returns and tells me that there isn't enough information upon which to base a treatment regimen. He tells me I'll need to have more tests.

As I am about to leave, a nurse I have never seen before approaches me: "Mrs. Ferguson?"

"Yes?"

"Before you go, would you like to see the Social Worker?"

"Why would I want to see the Social Worker?"

"Oh, some people just like to see her on their first visit."

"No thank you."

As I leave the Cancer Clinc, I feel weepy, discouraged and despondent. I phone my husband: "I need you, please come home".

The space in which we find ourselves greatly influences how we feel and how we react, perhaps even how we perceive ourselves.

As I struggle with the new reality of my illness, certain spaces have considerable bearing on the experience. At the Cancer Clinic, I feel a part of the processing machinery of cancer treatment. There is nothing in the physical and interpersonal environment that recognizes my individuality or offers comfort. There is no space, no place to be a person. Here I am an object, a case. I have to be very strong, very brave in this environment because my humanity, my individuality is certainly threatened. If I break down, lose my composure I will lose what little dignity I have.

In the environment of the Cancer Clinic, I become timid, accepting and weak. I'm surprised how quickly I have taken on the mantle of "good patient". But I am aware of how weighty and uncomfortable the cloak is upon my shoulders. A voice inside me screams: "I don't *want* to be this timid, accepting person. I want to be a warrior. I want to be strong, sure, in control." Where is that self-assured determination that accompanied me to this place? When did it desert me?

I come away from my first visit to the Cancer Clinic feeling small, dejected, threatened. I need solace, I need hope. I flee immediately to my home.

The home reserves a very special space experience which has something to do with the fundamental sense of our being. Home has been described as that secure inner sanctity where we can feel protected and by ourselves. Home is where we can *be* what *we are.*

(Van Manen, 1989, p.107)

Home is where the heart is; home is where I lay my head; home sweet home. In idiomatic phrases such as these we try to describe the meaning of home. Home is the place where we love and are loved. It is the place we go to rest, the place where we can feel secure enough to lower our guard and lie down to sleep. Home is synonymous with safety and comfort - "He felt at home in the new place."

My home is my sanctuary from the fray. It is where I am *me* in all my complexities and frailties. I don't have to be brave there. I can cry, I can rant and rave, I can be quiet and find courage. At home, I put on the clothes and take on the posture of comfort.

Home is inseparable from family. Within the fold of my family, I am nourished. I don't need to explain who I am. It is also through being important in someone elses's world that I define my own importance and feel a sense of purpose and belonging. There comfort, security, identity enfold me and I can once again feel whole.

The experience of the Cancer Clinic stands out in stark relief from the experience of home. There I found only threat and discomfort. I was not a person, I was a "case". I felt out of control, weak, timid, unsure. I am not comfortable with the loss of personhood I suffer there. Leaving that environment is an escape.

At no time before my diagnosis had the sanctuary of my home been so important, so necessary to my strength and sanity. The experience of becoming an inhabitant of the "Kingdom of the Sick" had given me a new sensitivity and awareness, a new appreciation for the importance of home.

My special place
It's a place no amount of
hurt and anger
Can deface.
I put things back together
there
It all falls right in place -
In my special space
My special place.

(Joni Mitchell, quoted in McWilliams & Roger, 1989, p.538)

Cancer as Intruder

In the first few days and weeks following my diagnosis, my cancer seems to constantly intrude on my awareness.

Being back to work (after Christmas holidays) has been good . It's a busy time and it's good to focus my thoughts on something other than "The Cancer". But I do feel distracted a good deal of the time. A part of my attention is always elsewhere.

The cancer has become an ever present, oppressive reality. My life, perhaps my death, is round and small and located in a small pocket in my neck. It takes up too much of my thoughts, plans, energies. I resent its continual intrusion.

This small lump with its dire possibilities holds me firmly in the now. Only the very immediate future seems certain. The struggle to regain my position in the Land of the Well must be my primary focus. My concern for my own welfare absorbs me and limits my ability to be open or available to other possibilities and opportunities. I cannot invest in my future beyond this immediate circumstance. I don't *know* if I will have a future beyond this struggle.

I want the doctors at the Cancer Clinic to outline a protocol of treatment that will assure my cure. But I soon find out that no such protocol exists, that there still exists considerable unsureness about how to proceed. As a consequence, I don't know exactly what the struggle will entail. How can I begin to prepare for it? How can I even project myself into that limited future?

I search for my future when I search for hope. I desperately want my doctors to give me statistics that indicate that thousands of people survive and have long lives after cancer. I want them to guarantee me a future. But I receive no such guarantee, therefore I am held in worried servitude to my present.

This cancer befell me. It happened despite my considerable effort to lead a healthy, circumspect life. That knowledge signifies, more strongly than anything else I've ever experienced, the limits of my ability to direct my own future. The rude reality of my mortality has abruptly been put before me. Finding this lump and having it labelled as cancer have suddenly, unequivocally forced me to acknowledge the vulnerability of my body, its temporal nature. I am *not* going to live forever. Like all human beings, my horizons are limited.

We are not always aware
of our having to die,
but in the light of the experience of our having to die
our whole life is experienced differently.

(Tillich, 1952, p.56)

CHAPTER V

SEARCHING FOR THE WAY

Choice

> **Everything can be taken from a man but one thing:**
> **the last of the human freedoms:**
> **to choose one's attitude in any given set of circumstances,**
> **to choose one's own way.**
>
> (Frankl, 1963, p. 104)

CHOICE: To choose, to decide, to select. Everyday of our lives, we make choices and we live with the results. The choices we make and how we make them reflect who and what we are as individual human beings. Through our choices we show the world our underlying motives, we reflect the influences of our culture and, hopefully, we affirm our values. We cannot NOT choose, for even when we give our choices over to someone else, we have, in fact made a choice.

For good or bad, we are defined and molded by our choices.

(Sinetar, 1988, p.25)

How often are we truly attuned to the choices we make?

A student feels ill-at-ease for not having read a journal article that is being discussed in class. This student may feel she made a stupid choice not to read the article. But was the choice merely to read the article or not read the article? More likely, the choice was between reading the article or working on a paper, preparing dinner for her family, or taking a few minutes of much-needed rest. When we are mindful of our choices and attune ourselves to the process, we are less likely to feel unhappy with the outcome. We understand the alternatives, we realize the reasons for choosing one alternative over another. Being mindful of the choice-making process, being aware that we *do* have choices, contributes a sense of personal control, a sense of efficacy in our lives. Life becomes more meaningful, less of a buzzing confusion, when we are attuned to the vast possibilities of personal choice.

Yet another definition of "choice" is : of high quality, exquisite, elegant, rare. We speak of a choice comment, a choice gemstone, a choice cut of meat. This concept of choice reflects merit, excellence, desirability. Should the choices we make, especially the important ones, not reflect this idea of excellence and worth?

> **Then there is another thing: my use of the word *elegant.* I chose that word because it precisely describes that inner refinement, that personal grace, that effortlessness, that lovely naturalness commonly embodied by supremely well-developed persons. . . The elegant choice enables us to become increasingly individuated: more of what we know ourselves to be, on the inside, at the core of our most noble self. . .**
>
> (Sinetar, 1988, p.1)

Having cancer is not a straightforward thing. There is no set course. There are many choices. In deciding on a specific course of treatment, the choice of action must be made by the person who has the cancer - even if that choice is to let others decide. What is it like to make such a choice? What is it like to decide on a course of treatment when one knows that the "wrong" course could mean greater suffering and, possibly, death?

The person with cancer must also choose how to "frame" the disease and the happenings that surround the disease, to choose one's attitude. What is it like to make choices about how one will *perceive* a life-threatening disease? How do such choices influence the experience of having cancer? How does one's viewpoint influence the choices for treatment of the disease?

The Body/Mind Partnership

An important aspect of the way a person views a disease experience is related to one's philosophy of mind and body interractions.

In Western society, we are taught, subtly and not so subtly, that mind and body are separate. If something is wrong with our body we go to a physician - sometimes a physician specializing in a particular *part* of the body. If we have a "mental problem" we seek out a psychologist or psychiatrist. Through such dualistic thinking, we see the body as material, while the mind is nonmaterial. Only the body is subject to physical laws, therefore a bodily disfunction or disease can be traced to a physical "cause" and can be treated in some appropriate physical manner. But is this so?

Every year, thousands of Canadians experience measurable physical alterations, such as stomach ulcers and high blood pressure, traceable directly to psychological stress. Many therapists have had considerable success in helping people modify autonomic nervous system processes through the use of biofeedback. Hypnosis has been used as an effective analgesic in dental procedures, childbirth and even during major surgery. It has been recognized for hundreds of years that certain Eastern yogis are able to modify their bodily processes to a remarkable degree during meditation. All healthcare providers are aware of the potent effects of placebos in providing relief from pain and in other aspects of disease treatment. How does one explain these phenomena within a dualistic framework?

As I face the reality of cancer and the need to make choices about my perception of the disease and its treatment, I must come to terms with my beliefs about the relationship of mind and body. If I am truly dualistic in my thinking, then the course seems clear. If, however, I honestly believe that mind and body are not separate, then the course I will choose must recognize this.

Prior to contracting cancer, I had been exposed to a great deal of research and theoretical writing that indicated that physical and psychological functioning are inextricably intertwined. In choosing to conduct research for a Master's degree in Educational Psychology in 1978, I chose to look at the effects of preparatory information on the course of surgery and hospitalization in young children. This was a relatively new field of enquiry at the time (see Boyd, et al, 1973; Epstein, 1970; Ferguson, 1979; Janis, 1958; Johnson, 1971; Vernon & Bigelow, 1974) Through this research and much subsequent reading, I know that there is plenty of evidence that attitudes, knowledge and emotions play a significant role in the development of and recovery from illness (see Engel, 1968; Schmale, 1972; Schmale & Iker, 1971; Seligman, 1975; Sklar & Anisman, 1979).

My heritage and enculturation is most vividly displayed in my need for "hard data" before I can allow myself to abandon a purely dualistic mode of thinking. It says something about our Western culture, too, that we feel we must research, must *question* this aspect of being. It reflects the strength of the dualistic position in our society, that we must see the body/mind linkages "proved" through research before it is "real".

Through scientific enquiry we are beginning to discover what Eastern traditions have accepted for centuries (see Borysenko, 1988; Cousins, 1979, 1983 & 1980; Langer, 1989; LeShan, 1980 &1989; Pelletier, 1977; Rossi, 1986; Siegel, 1986 & 1989). Body and mind are both intimately involved in the whole that is the human individual. They form a crucial partnership, one influencing the other in the most essential ways. Yet, as partners, body and mind each contribute specific characteristics and functions to the whole. In this way, they are separate, whilst being intimately entwined one with the other.

This is the most important teaching:
not two, not one.
Our body and mind are not two
and not one.
If you think your body and mind are two,
that is wrong;
if you think that they are one,
that is also wrong.
Our body and mind are both two <u>and</u> one.

(Suzuki, 1970, p. 25)

Today I read Bernie Seigel's book (<u>Love, Medicine and Miracles</u>) once again. I notice he says that most cancer victims he has encountered have experienced some serious crisis in their lives two years or so before the diagnosis. These desperate life situations very often involve feelings of powerlessness, hopelessness and helplessness.

I cast my mind back about two years and I see myself very much in crisis. It was a professional crisis. I suppose I was in burnout (what a trite phrase *that has become!). I had no harmony in my working life. There was no joy or creative excitment in my labors, only numbing fatigue. I felt my contribution was not valued by others in my work environment. And I, in turn, felt I had little to offer. I was trapped and desperate, yet I had no energy to find a way out. I could envision no alternatives. I seemed to be caught in a hopeless situation. It was a very painful time.*

Doctor Thomas sat over his dinner,
Though his wife was waiting to ring
Rolling his bread into pellets;
Said, "Cancer's a funny thing.

"Nobody knows what the cause is,
Though some pretend they do;
It's like some hidden assassin
Waiting to strike at you.

"Childless women get it,
And men when they retire,
It's as if there had to be some outlet
For their foiled creative fire."

(W.H. Auden, 1979, pp 57 & 58)

When faced with a significant loss or serious calamity, it is human nature to ask "Why?". It's as though we have to have some reason, some understanding to counteract the arbitrary nature of such happenings. Through understanding "why" we strive for some order in the chaos, some predictability in the unpredictable.

Based on the belief that mind and body are intimately linked, I now construct an understanding of how I have come to contract this cancer in the first place. By selecting an identifiable time in my life in which I had experienced a crisis in that part of my existence that is profoundly tied to my creative expression, I am able to pinpoint the start of my cancer. Of course, I will never know if, indeed, that this time of distress lead to the depression in immune function that offered the opportunity for cancer to grow in my body. It doesn't matter. What does matter, is my *choice* of an explanation for my cancer.

I might have chosen to explain my cancer in a purely physical way. For example, I may have decided that the cancer resulted from exposure to secondhand cigarette smoke during childhood. Perhaps I was exposed to a virus that produced a vulnerability to cancer. Perhaps the electromagnetic fields that surround me daily are responsible.

The choice I made, with a fair degree of certainty, clearly reflected my belief in the mind/body partnership. In choosing a cause, I define the way in which I will experience the disease. Because I do not believe that my disease was caused by something purely physical, I can not believe that a purely physical treatment will suffice in its cure.

Since I believe that mental processes contributed to the advent of my cancer, then it follows that I believe that other sorts of mental processes will contribute to regaining health. If feelings of discouragement, hopelessness, helplessness and lack of efficacy contributed to my getting cancer, then hopefulness, optimism, control and personal efficacy must be a part of the recovery process.

> ***Most*** **of the time illness is not a premeditated act;** ***all*** **of the time there is some relationship between an illness and our thoughts. Nothing happens onto us;** ***we*** **are the happeners. The mind and body work together, with the body being the screen where the movie is shown.**
>
> (Siegel, 1989, p. 83)

Struggling for Efficacy Within the Medical System

Having choices, taking responsibility, feeling in control can be frightening. This is especially so when the outcome of one's choice is critical to one's well-being. Often we try to avoid such decisions. Often we continue in situations that are non-productive, growth-retarding, even destructive rather than taking the risk of chosing another course.

Sometimes, in an effort to avoid the responsibility, we allow others to make our choices for us. We allow our parents to select our career path. We let our social group dictate how we spend our leisure time. We let our spouse make all the major decisions about the family finances. We ask the counsellor to tell us how to live our lives. We leave the decision about disease treatment entirely to the physician.

By allowing others to decide for us, we are relieved of the burden of choice. In this way, if the outcomes are less than perfect, we don't have to blame ourselves. But, what is the cost of this abdication? Perhaps the most obvious is the mindless way in which we go through life, never questionning, never seeking better alternatives, never feeling fully involved in the process of life. Gradually, as we take less and less opportunity to make choices, we lose the ability to do so. Things seem to happen *to* us without any apparent link to our needs or desires. Eventually, we feel ineffective and out of control, perhaps even helpless, lost.

Ineffective people are not prized in our society. Most of us do not like to view ourselves as ineffective nor do we want others to see us this way. When personal efficacy is diminished, self-esteem is diminished. Unfortunately, this can lead to a viscious downward cycle as diminished self-esteem leads to doubt about one's ability to make wise decisions.

As I approach a decision about my cancer treatment, I know I have to be intimately involved. I know that I, and I alone, can determine what is "right" for me. Yet my resolve is not always strong. After all, I am not an "expert" on cancer. It would be so easy to abdicate my responsibility, to simply let the physicians decide. And, who knows, perhaps the outcome would be the same. But the process would be different and, therein, lies the crux of the matter.

In choice-making, the outcome is important, of course. In my case, it is very important. I want the outcome to be as positive as possible. Foremost, I want to be rid of this cancer. This is a goal I know I share with all the physicians involved in my care. But I have other goals which they may not share. I feel a desperate commitment to protect my healthy body from unnecessary damage. As well, any approach to my treatment *must* recognize my philosophy of mind/body partnership. I want this difficult experience to contribute to my growth as a whole human being, not just be a momentary bump in the path of my life. I want to learn and grow from this experience. If my goals are to be met, then, the process becomes as important as the outcome.

Whenever we try to heal ourselves, and not abdicate this responsibility completely to doctors, each step is mindful. For example, we question destructive categories of disease (such

> **as the image of cancer as a death sentence). We welcome new information, whether from our bodies or from books. We look at our illness from more than a single perspective (the medical one). We work on changing contexts, whether it is a stressful workplace or a depressing rather than a positive view of the hospital. Finally, the attempt to stay healthy rather than to be "made well" necessarily involves us with process rather than outcome.**
>
> (Langer, 1989, pp 193-194)

Since I am the only one who can decide what is right for me, it is I who must seek out the sources of information I need. It is I who must form the questions. I must do all this with fair dispatch as time plays a crucial role in the cancer/cure equation. And though I am tired, frightened and often unsure, I must ultimately decide and commit myself to my decision.

The lump in my neck has been surgically removed. Today I meet with Dr. Alistair to discuss the lab findings and plans for my further treatment.

Dr. Alistair talks with me in a small examining room at the Cancer Clinic. This time I choose to sit on the examining table so he cannot look down on me. He stands and talks to me. He tells me the pathology report has confirmed that the neck lump was a metastatic squamous cell tumor. The fact that the primary tumor has not been found may well indicate that my body has "taken care of it".

He now comes over and sits beside me on the examining table. He sits very erect, tight. He begins to outline the course of treatment he has planned for me.

"We will radiate from here to here", he says, as he touches me lightly on both cheekbones and moves to the base of my neck on both sides. "You will have a treatment everyday for five weeks".

I ask him if it's necessary to radiate so broadly and he informs me that it is the wisest course of action: "Ninety percent of neck tumors exist within the direct vacinity of the metatastic site. This way we'll be most apt to get it. If we miss it, you could be faced with radical neck surgery, or removal of your larynx. You wouldn't want that, would you?"

When I ask about side effects of the radiation, Dr. Alistair tells me I'll have a severe sore throat and a very dry mouth. "For some people, the dry mouth never disappears."

When I ask him if there might be damage to my thyroid, he responds that it "will be watched". He tells me that I will be followed closely for three years after the radiation, as much to moniter the adverse effects of the radiation as to check for the reoccurence of the cancer.

Dr. Alistair's manner is cool and matter-of-fact. He presents the "facts" as though there is no alternative. This is the way it is. This is what must be done.

At the Cancer Clinic, my involvement in the choices about my care is not fostered. In many subtle ways I am invited to be apathetic and docile, to become the "easy" patient, to accept what the doctors have decided. Information is not voluntarily nor readily given, my questions are answered purfunctorily. It becomes difficult for me to feel "in charge" or even involved in choices about my treatment.

At no time, during my visits to the Cancer Clinic, do I feel I am viewed as anything other than a "cancer patient". I am aware of no recognition of me as an educated person, as a self-directed adult with life experience. I never feel involved, in any honest way, in a collaborative venture. It seems evident that these doctors view it as *their* responsibility, and their's alone, to battle my cancer. My role is not to decide, it is to abide.

As we circle the block for the second time, I'm aware of the tightness in my shoulders and the flutters in my stomach. I look at my watch. If we don't find a parking space soon, I'll be late for my appointment. Finally, my husband pulls into a large parking structure and we find a spot.

We walk quickly into the large building. This cancer clinic is certainly big compaired to the one at home. As we enter the building, we find ourselves in a maze of corridors and offices. There seem to be people everywhere, rushing and milling. We ask directions to the Head and Neck clinic.

We find our way to the correct floor and are directed to a large waiting area. The place is full of people. There are people of every age and size, all sitting, waiting. I glance around and try to determine which of this multitude are cancer victims and which are friends or family. Several are *smoking. Many look ill-at-ease. The room is hot.*

Every few minutes, a nurse appears in the waiting room, chart in hand and calls out a name. It seems to me that we'll have to wait a long time. There are so many others ahead of us. But, very shortly, the nurse appears and calls out loudly: "Mrs. Ferguson!" With some relief, I follow her to the examining area.

The examining room is very small, bare and bright. There is one chair and an examining table. There is no place for my husband to sit as we wait.

A physician enters and introduces himself as Dr. Fleur, the chief of the Head and Neck clinic. I sense the irony of his name in this barren place. Dr. Fleur is soft-spoken with the hunched stature of a man who has carried too many sorrows. He reads over my chart and asks me a few questions. "So, the primary tumor hasn't been located. . ." He seems almost to be thinking out loud.

"Well" He says as his eyes meet mine, "let's have a look."

"Do you think you can find it?"

"Yes, we'll find it." He seems so matter-of-fact.

Dr. Fleur commences to examine my throat and naso-pharynx with mirrors and a fiber optic scope. He chats easily as the examination proceeds. He answers questions from myself and my husband with a calm assuredness. He informs me that there is a tiny spot at the base of my tongue on the left side that looks a bit abnormal.

I ask him, in his experience, what is the prognosis for someone like me. He responds: "Well, we must remain positive. The fact that it has metastisized is not a good sign, but it would have been far worse had the lump appeared lower in the neck region."

As my husband and I leave this huge complex, we feel a sense of relief. We both comment on the discomfort we felt with the crowded, impersonal nature of the place. As we drive home, I'm aware that I feel discouraged, oppressed by this seemingly endless quandary.

In our culture, the physician is seen as an authority. This person has knowledge and experience that we desperately need when we are ill. It is easy to become docile, childlike in the presence of such authority. Yet, authority is assigned, people only have authority because we give it to them. Is this yet another manifestation of choice?

I was trained to be a nurse two decades ago. At that time, we learned in no uncertain terms that the physician was the unquestioned authority. He (it was seldom she in those days) was to be given subserviant respect at all times. The effects of that early indoctrination are still strongly entrenched in my psyche. Within the physical and interpersonal environment of the Cancer Clinic, I find it is too easy to snap back into the old roles. I have to struggle mightily with myself to overcome the inclination to accept without question or understanding the directions of the "expert".

My husband and I wait in the lobby of the office building. A youthful dark-haired man comes out of an office and introduces himself to us. This is Dr. Brighton. We are all a bit stiff and formal as we walk to the nearby cafeteria.

Once seated in the comfortable cafeteria, we order tea and I launch into the reason for our meeting: "Dr. Brighton, thanks for agreeing to see us today. I've heard your name so many times in relation to cancer treatment, that I just thought it would help if my husband and I could speak with you. When I discovered you were a friend of Ellen's, well I just asked her if she'd arrange for us to meet with you."

Dr. Brighton seems a bit shy as he responds: "No problem. I'm glad to do it, if it'll help in anyway. . ."

I knew that Dr. Brighton had training as an oncologist and haematologist. Until recently he worked at the Cancer Clinic, but had left the clinic to pursue his haematological interests. I wonder if there were other reasons why he'd chosen to leave, but that isn't the purpose of our time together.

I outline my concerns regarding the aggressiveness of the radiation being offered me at the Cancer Clinic. Almost immediately, Dr. Brighton suggests that I request a consultation with the Vancouver Cancer Clinic. "They just deal with so many more people that they have more experience. It would be worth your while to go."

I tell Dr. Brighton that I am thinking of consulting with an oncologist in Los Angeles who happens to be related to a good friend. He encourages me to follow through on this plan and tells me that the Cancer Clinic will foreward my documents to California if I make a request.

As my husband and I chat with Dr. Brighton, I feel myself relaxing. This "expert" has validated my concerns and helped me develop a plan of action. We talk of many things - radiation, diet, vitamin supplements, exercise, stress management, visualization. I feel I am a full partner in this discussion. Dr. Brighton refers to my background often, finally saying: "Just because you've lead a healthy lifestyle and still contracted cancer doesn't mean that the same lifestyle won't help you to overcome the disease." There is an optimism in this conversation that buoys me with hope.

As we discuss the choices about traditional cancer treatment, I mention that I see one choice I have is to NOT undergo any treatment at all and hope for the best. Dr Brighton, I believe in a gentle effort to encourage me to seek some form of traditional treatment, makes an interesting analogy. He says: "Cancer treatment is like being in the middle of a hurricane - everything in your life seems so focused on surviving the storm, yet a year or two later, looking back, it doesn't seem so bad."

In my search for the "right" treatment for my disease, I encounter many physicians. Some of these encounters weaken my sense of efficacy, my sense of self. Others strengthen me and give me hope, courage.

Words, when used by the doctor, can be gate-openers or gate-slammers. They can open the way to recovery, or they can make a patient dependent, tremulous, fearful, resistant. The right words can potentiate a patient, mobilize the will to live, and provide a congenial environmnet for heroic response. The wrong words can produce despair and defeat or hinder the usefulness of whatever treatment is prescribed.

(Cousins, 1986, p.110)

Why are there such differences in my experiences with various physicians? Dr. Alistair creates a very clear role differentiation - I am patient, he is medical authority. Dr. Fleur maintains that status but adds an element of calmness and sharing that adds to my sense of self. His diagnostic skills provide me with new alternatives. Dr. Brighton does not erect barriers, meets me on common ground, shares his expertise. He encourages my active involvement in the healing process.

When physicians erect barriers by creating very clear role expectations within the medical treatment situation, does this evolve solely from their strong scientific/medical ethic? Or is this a reflection of their dualistic view of the mind/body? Is this merely a difference in value structures? Or, are the barriers a way a physician can protect himself from the pain of the suffering before him? What must it be like to be a physician caring for a steady stream of people with cancer? How does one deal with the unending desperation? How does one deal with the continuous uncertainty about outcome?

There is much in this situation that will create discomfort, even psychological pain, for a committed physician. Dealing with people on the level of roles provides a psychological insulation. We each play our roles, we don't become real, we don't get too close. We remain strangers in this fight for life, this most intimate of struggles. The physician can, thereby, remain objective, scientific, unbiased, unaffected by the grubby realities of my humanity.

He, also, can remain untouched by my suffering. And, in so doing, the basic humanity of caring is lost.

"You see, medicine is supposed to be an objective science. It avoids making moral judgments, and it avoids dealing with philosophical and existential issues. But by not addressing itself to such issues, medicine implies that they are not important."

(Simonton quoted in Capra, 1988, p.189)

What characterizes the encounters with physicians that sustain my sense of efficacy and hopefulness? It's not a lot, really. I don't need my physician to be a trained counsellor, I just need some indication of respect for me as a unique human being, some feeling that this person cares about my welfare. I need to feel I've made contact with another human being.

I talk with my family physician, Dr. Whitney. He makes me laugh by relating the many positive and sometimes funny experiences he has had with people who've had my particular type of cancer. I always feel better after I've talked with him.

I visit Dr. Robb often. I have a real sense that this physician knows me and cares about me as a person. How do I know this? When I visit him, he always seems genuinely happy to see me. He calls me by my first name. He expresses interest in my life outside of the "cancer patient" role. He occasionally even shares bits of information about himself outside of his role as doctor. He seems genuinely sorry for the unpleasant procedures that I am exposed to in the search for the primary tumor. He gathers information on my behalf that will assist me in my decision making, and encourages me in my efforts to do the same. He is unfailingly positive in his view of my future. My visits to his office are short, yet I always come away feeling better for having been there.

As I contemplate those physicians who sustain my sense of self, who connect with me on a human level, I can't help but suspect that they have benefited as well. Respect begets respect, caring fosters caring.

Approaching the Decision

Ultimately, a decision must be made about my treatment. Dr. Fleur is successful in finding the primary tumor. It is tiny and localized. This means radiation treatment can be more localized and, hopefully, less damaging to healthy tissues. But I wonder if I need the radiation. The primary site is so small, perhaps my body can deal with it.

I am caring for my body with great nurturance. I am religious about getting regular exercise, eating properly and getting enough rest. I take supplements of the micronutrients which have been implicated in strengthening the immune system. Beyond these body-care practices, I am enlisting my mind in the fight for health. I am actively involved in meditation and visualization, using the approaches recommended by Dr.Carl O. Simonton (see Matthews-Simonton, et al, 1978). I play taped affirmations on my car tape deck as I drive back and forth to work. I seek out beauty in all its forms to attune myself to its healing effects.

Isn't this enough? Do I *have* to have the radiation? For awhile, I feel that more information will make the answer clear. But, gradually I become aware that collecting more and more information doesn't necessarily lead to the answer. Because, there isn't one answer, there is only that choice that best fits me. Eventually I have to come back to *my* values, *my* beliefs. I struggle to make the elegant choice. I waver on the brink of the decision.

Life ultimately means taking responsibility to find the right answer to its problems and to fulfill the tasks which it constantly sets for each individual.

(Frankl, 1963, p. 122)

CHAPTER VI

LIVING THE TREATMENT

Exposing the Body to Destruction

The time for uncertainty has passed. I have made the choice, for better or for worse. I have committed myself to a course of treatment. I am told by the doctors that this part of my journey will be arduous. I am told, but don't want to hear, that the radiation therapy I will receive will have many adverse effects on my body. I'm not ready to acknowledge that the choice I have made in order to avoid suffering may, in fact, be a choice for destruction. What is it like to live this paradox of suffering in order to avoid suffering? What is it like to expose oneself to physical destruction in order to be "saved"?

It is May and the sun is shining. I carry a giftwrapped box of chocolates for the technicians at the Cancer Clinic. This is an occasion. Today is my last treatment.

Twenty-four times I have entered the doors of the Cancer Clinic, walked to the area labelled "Radiation Therapy" and exposed my body to the destruction of those silent rays. Today, the twenty-fifth time, will be my last.

This treatment is no different than all those that have gone before. I enter the room that houses that huge impersonal machine and I lay down on the hard, narrow table. The technician places the clear plastic mold over my face and neck - the mold that was specially made for me. The mold is bolted to the table so I may not move even a millimeter. I can hear my breath inside the plastic. The technicians check the coordinates of the machine for the twenty-fifth time, then they leave me alone. The room is still as a tomb.

A disembodied voice comes through the ceiling: "Okay, Mrs. Ferguson, stay very still." The big machine begins to groan as it moves slowly into position. With a grinding sound it stops. Momentarily a red light appears and I know the radiation is hitting my body. The light stays on for a few *seconds, then the machine groans again as it repositions itself. The red light appears again, this time for a few seconds longer.*

Once the light goes off, the technicians come in and unbolt the plastic mold and free me from my restraint. One of them says: "Dr. Peters wants to see you." Another one of the technicians, an attractive young woman, says: "Good luck. Drop by to see us when you are back for your check-ups." I thank them and walk to the now-familiar examining room.

As I wait to see Dr. Peters, I take stock of the damage. My throat is so sore - like razor blades cutting and tearing. It is an excruciating pain just to swallow my saliva. How can something be so raw and not bleed? I've not been able to eat anything other than liquids for the past three weeks. My tastebuds have been rendered useless by the radiation and I taste nothing. As a consequence, eating has no appeal even though I am hungry all the time. I now weigh 97 pounds. I have dreams of hamburgers!

Part of the radiation hits my lower jaw on the right side. Consequently, the inside of my mouth on that side is very sore. My tongue has three viscious welts on it. There are several pus-filled lumps on the mucuous membrane. My gums are swollen and very tender - I can't brush my teeth on that side.

My mouth is dry because of the effects of the radiation on my salivary glands. My voice is hoarse and my larynx feels like a raw little ball in my throat. It hurts to talk.

I'm tired all the time. I sleep 11-12 hours every day and still have no energy. I feel like a decrepit old woman. Sometimes I feel such sorrow at the destruction that has been wrought upon my body.

Dr. Peters enters the small examining room. He is not particularly concerned about my physical decline over these few weeks. I have responded as expected. I ask him what will happen if the cancer isn't all gone. He says: "You'll not be having anymore radiation, you've had the maximum. Any further treatment would be surgical. But, you won't need surgery. this will have gotten it." Dr. Peters, the perpetual pessimist, has actually said something hopeful! There is even a hint of a smile. . .

As I leave the Cancer Clinic, walking out into the May sunshine, I suddenly feel such a marvelous sense of release. The destruction is over. Now is the time for healing.

There is nothing men will not do, there is nothing they have not done, to recover their health and save their lives. They have submitted to be half drowned in water, and half choked with gases, to be buried up to their chins in earth, to be seared with hot irons like galley slaves, to be crimped with knives, like codfish, to have needles thrust into their flesh, and bonfires kindled on thir skin, to swallow all sorts of abominations, and to pay for all this, as if blisters were a blessing and leeches were a luxury. What more can be asked to prove their sincerity?

(Oliver Wendell Holmes, quoted in Menninger, 1963, p.303)

Prior to starting my radiation treatments, a fragile bravado overlays my anticipation of the trial that awaits me. I tell myself that I will be different, I will NOT experience adverse effects from the radiation. There is even a certain cavalier humor (gallows humor?) in my anticipation.

Today I went to the Cancer Clinic to have a plaster impression of my head and neck made. This is necessary for the plastic mould that will be used in my therapy. When I returned, I told my work colleagues that I'd gone to the Clinic, taken off all my clothes and gotten plastered!

During the first couple of weeks of daily radiation, I discern no particular effects. I am jubilant. Maybe I will be different. Perhaps I won't have any effects, or perhaps they'll be minimal. Then halfway into the course of treatment, the adverse effects are suddenly there. One day I am eating as usual, the next day my sense of taste is gone and I can swallow only liquids. Blisters appear on my tongue and my gums are swollen. My denial can no longer sustain me. The reality is here. My body cries out in its alarm and my mind is filled with sorrow. How can I *allow* this?

Why would any sane person, especially one with no discernible symptoms of disease, expose herself to the destructive influences of surgery and powerful radiation? Many times throughout my treatment for cancer this question disturbs my thoughts. As my body begins increasingly to display the effects of the damaging assaults upon it, my anguish and uncertainty grow. Is it really necessary to do *this* amount of harm?

My embodiment is now very much before me. There is a bodily "knowing" of this ideopathic dis-ease that enters all my awareness. My whole body cries out with the knowing of it. My mouth and throat are under immediate attack, yet all parts of my body are involved. Bodily functions I once took for granted become focuses of concern. I am constantly tired, weak, sore. I wonder, is this what it's like to be old and infirm? Yet this is different. This did not come about as a result of the ravages of a long life. This came about by choice, my choice.

Knowingly exposing my body to noxious influences goes against everything I have ever done or believed in. I value health and healthy living. I study and try to practice lifestyle choices that foster physical well-being. To see the irrefutable effects of my choice to expose my body to destruction is undeniably difficult for me.

I had been told by my surgeon that the actual cancer was a very tiny, superficial lesion on the inside of my throat. As I progress with the radiation treatments, it seems to me that medical science is, indeed, imprecise. We are using a sledge hammer to kill a fly. The treatment is far worse than my experience of the disease. But is it worse than the threat of what that disease *might* become?

This destructive radiation was the treatment of choice offered me by traditional western medicine. My physicians offer me nothing else. I am a product of my culture. I am also a product of the North American medical care system. How could I not accept this treatment? If I were to travel a completely alternate route, I would not be able to live with my uncertainty and fear. For, in the final analysis, I do believe in the efficacy of modern Western medical practice.

Throughout the course of treatment, I continually try to convince myself that this was a wise decision. The physicians at the Cancer Clinic consider it the *only* wise decision. By accepting the radiation, I have bowed to their combined wisdom and experience. But they have no apparent awareness of my experience, of my struggle to accept the necessity of this harmful action. Only Dr. Robb, at my follow-up visit, says: "I'm sorry you had to go through this." I appreciate his acknowledgement of my pain - a pain as much psychic as it is physical.

I continually seek reassurance from my surgeon, my oncologist, my dentist that my body will return to normal once the radiation is over. But each one tells me something a little bit different than the others. Yes, the tastebuds will regenerate, probably your mouth will be a bit dry for some years, your gums will be fine. . . .How can I believe that my body will be "normal" again after such an assault? Who can I believe? Are they just humoring me or does each patient respond so differently that they just don't know? The oncologist's affirmation that I was given "the maximum" radiation does not make me feel any better. A terrible war has been waged upon the battlefield of my body. Hopefully the enemy has been vanquished, but at what cost to the "good guys"?

Relationships that Sustain

Today is Mother's Day. As I sit in bed listening to the busy noises emanating from the kitchen, I reflect of how frail I have become. I'm almost at the end of my radiation treatments and I feel tired and sore most of the time.

My husband and son burst into the bedroom. They have brought me gifts and breakfast in bed.

Six-year-old Alexander carries the gifts, he dumps them in my lap with excitment and offers to assist with the unwrapping. He advises me that the "best" gift (and, therefore, the one to leave until last) is the picture he has drawn specially for this occasion. Quickly the gifts are opened and I express my surprise and appreciation. Finally, the special picture is presented. It is a drawing of a fine ship with a smokestack from which a series of smiling faces roll across the sky. Beside the boat is a figure with one arm held high. Alexander informs me that this figure is "Super Mom". I smile as I look at that figure. How special of him to draw me as a hero!

Sometimes in the heat of the battle, I lose track of the reason, the meaning of the effort. As my radiation treatments progress, the physical effects leave me weak and frail. Sometimes I feel discouraged and unsure. Then a 6-year-old child gives me courage and strength. He sees in me the hero I need to be. He reminds me why the effort is important.

By the spiritual act of love (a person) is enabled to see the essential traits and features in the beloved person; and even more, he sees that which is potential in him, that which is not yet actualized but yet ought to be actualized. Furthermore, by his love, the loving person enables the beloved person to actualize these potentialities. By making him aware of what he can be and of what he should become, he makes these

potentialities come true.

(Frankl, 1963, p. 177)

I am reminded of a time, during my wait for the diagnosis, when I feared my life would soon end. I remember crying in great anguish, not for myself but because I thought I might not live to see my son grow up. I don't feel, at my age, *ready* to die but I think I could become so if the necessity were there. I've lived a full life and been fortunate in many ways. I could leave this life with few regrets. But, how could I leave this special little person who draws me pictures and is excited when he can give me gifts? The love of this child pulls me back into the battle and makes me aware of a very serious responsibility I bear.

A man who becomes conscious
of the responsibility he bears
toward a human being
who affectionately waits for him. . .
will never be able
to throw away his life.
He knows the "why" for his existence,
and will be able to bear almost any "how".

(Frankl, 1963, p. 127)

A friend of mine, Sam, is a taxicab driver. I recall a story Sam told me just as I was starting my radiation treatments. Recently, Sam had a direct experience with another person who was receiving radiation for cancer of the throat. This person, an older man, lived alone in a run-down inner city hotel. Everyday, Sam would pick him up at the hotel and drive him to the clinic for his treatments. Everyday the man smelled of alcohol. He smoked several cigarettes on the way to his treatment and several more on the return trip. Sam wondered: "Why do they bother?! Wouldn't it be kinder just to give the man all the booze and cigarettes he wants and just leave him alone to die in peace?"

I think of this man as I struggle with the adverse effects of the radiation treatments. Although he and I have not and will never meet, we have a bond of common suffering. Yet, I can't help but think that his suffering is much worse. Who was there to care for and care about this man? Who was there to give his struggle purpose?

Rediscovering a Future

As the course of radiation treatment proceeds, my cancer becomes less of an intruder in my temporal existence. Even though the treatments focus my attention on my body in a very dramatic way, my mind already reaches out to the future. In this way I reflect my faith in the efficacy of this terrible treatment. There *will* be a future beyond this experience.

I notice, just in the past few days, that my thoughts are straying away from my cancer and its treatment. I am becoming much more future-oriented. I'm thinking about what courses I'll take at University in the fall. I'm busily planning our family holiday for the summer. We are thinking about a trip to Hawaii next Christmas. And I'm beginning to think about future goals I might want to pursue in my career.

I no longer contemplate my future as an uncertain possibility, I now plan for it as a reality. For the first time since my diagnosis, the chains of that diagnosis are falling away. Even though I am tired, weak and physically drained, my mind can see a future of activity and growth. At a very basic level, I feel assured that I am on my way to reentering the Land of the Well.

There is a certain sweetness in being able to contemplate a future once again. I can plan for it, nurture it and look foreward. The landscape of my life is opening up once more. I am no longer trapped solely in an unpleasant or uncertain now.

As my future becomes a more palpable part of my being, I realize that the intrusion of the cancer in my thoughts has diminished. Odd that this should be so, under the circumstances. Here I am tired, weak, and thin, experiencing considerable discomfort and disquiet, yet more and more my thoughts range to interests and challenges that do not in any way encompass my experience with cancer.

It is a peculiarity of man
that he can only live
by looking to the future -

sub specie aeternitatis.
And this is his salvation
in the most difficult moments
of his existence. . .

(Frankl, 1963, p. 115)

During the final weeks of my radiation treatments, I stay home from work so I might rest. Nevertheless, I spend three to four hours each day at the computer writing learning materials for a new course I will be teaching in the fall. The work is therapeutic, it taps my creativity, it makes me feel a part of the foreward motion of my life. It carries me away from the arduous struggle that has encompassed my existence these past months.

A Place to Dwell

During the six weeks of my treatments, my world rapidly shrinks until my life is primarily lived in two environments - the Cancer Clinic and my home. I am at the Clinic for only a short period each day. The rest of my life is spent at home. Yet, though my lived spaces are diminished, I do not chafe against the limitations.

For the first time in my journey with cancer, I am visibly sick. I am a person experiencing a short acute illness. I welcome the opportunity to rest and care for my body. I do not see this shrinking world as a long-term change in my life. This is a transitory time between my immediate past and my future. There is a pleasantness about this interlude. A time to rest, a time to seek comfort, a time to contemplate and search for meaning. A time to dwell.

Dwelling.
The sound of the word attracts. The meaning of the word comforts.
Dwelling.
To pause, to rest, to linger.
To abide. To stay for a while. To inhabit.
Dwelling.
To let things remain as they are for a time, to let be, to let go.
To stop, and to let ourselves be surrounded by the joys - the healing joys - of rest, of contentment, of doing nothing.

Dwelling.
To give ourselves permission simply to *be*.

(Harris, 1989, p. 87)

When we contemplate the concept of dwelling, we immediately think of place. A dwelling place, the spaces in which we dwell. It is true that all dwelling, at least initially, has to do with place. However, the concept of dwelling is equally important to the mind and spirit. Our minds and spirits as well as our bodies periodically need to be rested, enfolded, warmed and comforted.

Rest, which is necessary for dwelling, is a humanly attractive aspect of life. How often do we hear people say :"I need a rest" or "I had a wonderful rest on my holiday"? Amongst the definitions for "rest" in Webster's dictionary (1989), is: "to cease from action or motion; refrain from labor or exertion; to be free from anxiety or disturbance". The word also refers to a rhythmic silence in music - as important to the melody as the notes of the music. In the same way, rest is important to the melody of our lives yet how often do we recognize this?

I am not unlike many women of my culture and my age. For me, rest has a particular allure and often seems elusive as I try to balance the demands of my many roles - mother, wife, teacher, administrator, friend, neighbor, etc. Our culture values productiveness so greatly and I am, without doubt, a product of that ethic. To rest, to dwell, to do no-thing is slothful, unproductive, unacceptable. I feel guilty for my desire for rest.

Yet, when I am sick, I don't need to feel guilty. I have permission to rest. And it is a wonderful gift. The surroundings of my home, both physically and interpersonally, are relaxed and undemanding. I feel sheltered and secure in this place. There are no schedules to meet. I can do what I want, when I want. When I tire, I sleep. My bed is snug, cozy and warm. And sleep comes as a blissful friend. My body, mind and spirit find solace in the luxury of unlimited rest.

I wonder. . . is it necessary to get sick before I can allow myself the serenity and tranquility of rest? Is there no space in an illness-free life to pause, to linger, to abide? Is it necessary, is it wise, to value productiveness above all else?

CHAPTER VII

CANCER AS TEACHER

> **Your pain is the breaking of the shell that encloses your understanding.**
>
> **Even as the stone of the fruit must break, that its heart may stand in the sun, so must you know pain.**
>
> **And could you keep your heart in wonder at the daily miracles of your life, your pain would not seem less wondrous than your joy;**
>
> **And you would accept the seasons of your heart, even as you have always accepted the seasons that pass over your fields.**
>
> **And you would watch with serenity through the winters of your grief.**
>
> **Much of your pain is self-chosen.**
>
> **It is the bitter potion by which the physician within you heals your sick self.**
>
> (Gibran, 1964, p. 58)

Suffering

Sometimes the most difficult experiences of our lives give us the greatest gifts. Through adversity, we may find strength, clarity of purpose, greater understanding. Suffering may, in fact, be life's challenge to grow beyond ourselves.

The two meanings of the word suffer, to allow and to endure pain or distress are joined in the origin of the word (Shipley, 1982). The Latin *sufferire*, to bear, means both to carry and to "bear up". Suffering calls upon us to carry a heavy burden, yet to endure.

There is a certain irony in viewing suffering as opportunity. There seems to be a commonly held view that adversity is undesirable and, therefore, should be eliminated. We see it in advertisements - the quest for the comfortable, the easy life. We try to protect our children from too much difficulty. We take courses on problem-solving or time management which promise to give us the tools for an existence that is untroubled, calm, happy.

Sometimes, we are even reluctant to admit to difficulty or distress in fear that it will be seen as a reflection of our inability to cope adequately with our lives, and thereby seen as personal weakness or inadequacy.

Yet, through suffering we are challenged. The most meaningful personal growth is often preceeded by struggle, hardship or misfortune. But we all know that suffering can also demoralize, devastate, even destroy. And herein lies our aversion to suffering. When it gets too heavy, too strong to bear, we may experience a pain so terrible that it can threaten our very being. Suffering can overwhelm us, cause us to lose control. It can ultimately result in our total extinction. And so we try to avoid suffering and those who suffer.

What we often forget, is that suffering has many degrees, many weights. When we look upon the suffering of others, we cannot assume they are suffering in the way that we would be in a similar situation. In the face of adversity or affliction, it is often the context, framework or disposition of mind that determines the extent of the suffering. In choosing how we will perceive or "frame" the experience, we may choose for growth or choose for destruction.

Suffering is a hard teacher. It challenges us to learn important lessons, to go beyond our present selves, to become what we are not yet. Adversity hones us in a way that ease and comfort never will.

> **The world breaks everyone and afterward many are strong at the broken places. . .**
>
> (Hemingway, quoted in Siegel, 1989, p. 188)

My journey with cancer was one of the most difficult experiences of my life. Cancer is certainly not something any of us would wish for ourselves. Even now, I would not wish to contract cancer again. Yet, I realize the experience taught me some of the most important lessons I have ever learned. For this reason, I am thankful for the opportunity to have been involved in this struggle. What are some of the lessons to be learned from suffering a life-threatening disease? In what ways did I grow as a result of the cancer experience?

An Exquisite Sensitivity

Three years ago, I was graced with cancer. I looked my whole life for a teacher, and it wasn't until I got cancer that I really started to pay attention to the preciousness of each breath, to the momentum of each thought, till I saw that this moment is all. All my other teachers gave me ideas. This caused me to directly experience my life.

(Cancer survivor, quoted in Siegel, 1989, p. 193)

As I move along my journey with cancer, I am acutely aware of the heightened sensitivity I have developed. Sometimes I feel emotionally raw and exposed. I am so much more attuned to the beauty and wonder of small things. I find myself often on the verge of tears as I contemplate my son's angelic face or my dog's trusting old eyes. I am moved by the delicate perfection of a flower or the drama of a sunset over the ocean. These things have always been there, why am I now just beginning to see?

Beauty: "the quality or aggregate of qualities in a person or thing that gives pleasure to the senses or pleasurably exalts the mind or spirit." (Webster, 1989)

It is the greatest of ironies that I find myself, in the midst of my struggle with cancer, becoming increasingly attuned to that which is beautiful, graceful, and elegant. I experience a sensitivity, an openness to beauty that borders on the poetic in its intensity. I am enthralled by the smallest, most commonplace things. I live with serendipity. It is as though I am now just discovering the magnitude of the beauty that surrounds me.

It seems my mind has chosen to focus me on those things in life that make life most precious, most meaningful. Is this my mind's way of attuning me to the reasons for the struggle, making me aware of the importance of life? Is this the spiritual side of self asserting itself in the service of my need for hope and strength?

I have read much of the increasing research evidence that the positive emotions - love, hope, joy, humor - have positive physiological consequences. I wonder, is my increased sensitivity to the beauty around me, a reflection of my mind focusing on positive awarenesses in the service of my body's need?

Whatever the reason, my refined attunement to beauty gives me great pleasure. I rejoice in the wonder of so many things. In the midst of my daily struggle, this sensitivity provides me with moments of supreme joy. In some ways, it's almost as if I am really experiencing life for the first time.

And the moment we let ourselves be touched by beauty, that
part of us which has been badly bruised
or even shattered
by the events of life
may begin to be revitalized.
At that moment a true victory takes place -
a victory over discouragement, a positive affirmation
against resigning ourselves to the process of crystallization
and death.

(Ferrucci, 1982, p. 188)

A New Relationship Between Body And Mind

It's late March as I walk beside the ocean enjoying the sounds and scents of springtime. I love my walks, it seems to be almost a meditative time for me - a time to be alone with myself.

Today, as I walk, I begin to think about my attitude towards my body. It's ironic that only now, as I am faced with possible physical annihilation, that I am coming to truly appreciate and love my body.

Like most North American women, I have spent most of my life attuned to my body's deficiencies. I have always accented what wasn't "perfect" about my physical self. I can recall the inordinate efforts I expended as a young woman to become thinner. Being slim is a goal I've certainly spent much mental and physical energy attaining!

Now that this insidious silent invader is threatening my body, my concerns *of the past seem petty and foolish. What does it matter if I don't have a "perfect" female form? What does matter is that my body is strong, healthy and able to cope with this terrible disease and the almost more terrible treatment.*

I now see my body differently. I rejoice in my recuperative powers. This crisis has made me cherish my body.

As the threat of serious, life-threatening illness enters my life, my relationship with my body is markedly changed. And, surprisingly, the change is for the better.

I've never hated my body, as I know many women do. Yet, I've never been truly *satisfied* with it either. There is much in our social fabric to perpetuate dissatisfaction with our physical selves, especially if one happens to be a woman. We are constantly inundated, through billboards, catalogues and glossy magazines, with irrefutable evidence of what the "perfect" female form should be.

It is through our body that we connect with the world. Our bodies are our conscious vulnerability of self in the world, "the felt capacity to be affected, injured" (Gadow, 1982, p.87) Doesn't this "injury" also include the assaults of advertisers, dress designers, and the general dictates of our social milieu? Women, in particular, are affected and often injured, both physically and emotionally, by our narrow social concepts of what is physically perfect.

All my life I've had a healthy, strong body. Until the advent of this cancer, I have never had a serious illness. I've never required surgery. Yet I've not been satisfied with my body. It's not "perfect". In this way, my mind and body were at odds. My mind struggled with my body to become more "perfect". My mind struggled to control. In this way, I viewed my body as object, as instrument. When I was unsuccessful in becoming more physically perfect, then my body was seen as recalcitrant. The solution, of course, was more mastery on the part of mind. I must get in *control* of my appetites and my activities. Little thought was given to the messages that emanated from my body, unless, of course, they were extremely insistent.

Often in illness, body is viewed as an increasing obstacle to the other components of self (intellect, emotion, spirit). Illness can also represent a failure of mind - an inability to maintain mastery. Perhaps, however, what is happening in illness is that the body is insisting that its own reality, complexity and needs be acknowledged. By seeing body as subject rather than object, it can be experienced as a legitimate, equal part of self.

It is only by complementing the mastery of the object body
with equal attentiveness to the subject body
that an enduring and dialectically complete unity
can be achieved,
one which does not require continuing conformity of body to self.

(Gadow, 1982, p. 94)

Illness brings me in tune with my body in ways I've never experienced before. Because of my illness, my body has established itself in the foreground of attention. It is vulnerable, yet it is also strong. The slow but sure recovery of my body following the assaults waged against it is a symbol of its quiet strength. During illness, my body is more clear than I've ever experienced in explicating its needs e.g. which foods to eat, how much rest to get. I attune myself to the messages of my body and a new harmony evolves. No longer is the relationship between mind and body one of master/servant, it now becomes one of friend/friend. And in the process, my mind *sees* my body as friend "one attached to another by affection or esteem" (Webster, 1989).

There is a hint of a new way of being here. By experiencing body as subject rather than object, it becomes an integral part of self. As such, it should have equal billing. My body gives me very clear messages of its needs during illness. I attend to those messages and they prove wise. How many times have I ignored those messages in the past, and at what cost?

My body has its own reality, complexity and needs which are communicated in a multitude of ways. Tiredness, for example, may be seen as an expression of the body's own perspective on the busy-ness of one's life at the moment. Illness, itself, may be the body's way of communicating its need for attention or rest or balance.

At various times during my struggle with cancer, I become very thin. Being thin is a goal I've striven for all my adult life, yet when I finally achieve it, I don't like it. I feel frail, small, woundable - *not* sleek and svelt as the diet ads promise. My body transmits messages of vulnerability and weakness.

I know this is not a healthy state of affairs. In unison, body and mind work to correct the situation, slowly and surely. I eat when and what my body dictates. The foods I crave are nutritious, not necessarily fattening. The weight gain, therefore, is slow but the healing is rapid.

My body and mind have become friends, colleagues, in an important endeavour. One is not more important than the other, both are critical to the well-being of the whole.

This body of mine is not something to be revered or despised, feared or controlled. It is, simply, part of *me*, as worthy and important as all other aspects of my being. Through this suffering, I have learned to appreciate this important fact. My body is *me.* And it is fine.

Being Cared For

This is my last trip to day surgery. Dr. Robb is going to biopsy the site of the primary tumor to see if it has been eradicated.

Arriving at the day surgery area is rather like coming to visit old friends. I've been here four times in the past six months. I know the nurses and the routines. It's hard to believe this place was once frightening to me.

I change into the hospital gown and housecoat (always a size extra-large) and am sitting on my assigned stretcher when Dr. Robb enters the room. He is dressed in his O.R. garb. His face is relaxed and kind as he speaks with me. He tells me he expects to find no remnants of the cancer.

I gulp down my pre-surgical "cocktail", screwing up my face at the vile taste, just as Dr. Brown, the anesthesiologist, arrives. Dr. Brown is a friendly, chatty fellow. This is my third encounter with him. He remembers me, calls me by name and talks with me about the radiation treatments and how they affected me.

The time has come. I'm wheeled into the operating theatre. The room is cool. With my diminished weight, I seem to be continually cold and, now, in this cool room I begin to shiver. I shift myself onto the operating table, extending my left arm outward to receive the intravenous infusion. The nurse places a mound of blankets over my shivering body and tucks them in around me.

Dr. Brown is chatting amicably with me when Dr. Robb enters the room. Dr. Robb smiles at me, then he reaches for my right hand and holds it firmly. His hand feels warm. Dr. Browns's voice sounds friendly as he *says: "You'll be drifting off now, Faye. See you soon . . ." As unconsciousness overtakes me, I am aware of the warm hand holding mine. I feel thoroughly relaxed, calm and safe.*

I awake in the Post-Anesthetic Recovery Room and am immediately aware that I am hungry. Dr. Brown breezes past pushing an unconscious patient. When he sees me observing him, he says: "Hi Faye, from what I could hear in there, it sounded good!"

I am returned to the Day Surgery area. After awhile, Dr. Robb comes in and tells me that visually there is no evidence of any remaining cancer. He's confident that the biopsies will also prove negative.

My husband comes to get me. I am dressed and ready. I hold his arm as we walk out of the hospital. When I get to the car, I find two of my son's favorite stuffed animals smiling at me. On my seat lies one perfect long-stemmed red rose.

Sometimes it seems that we live in an extremely careless society. Daily, we are confronted with systematization, bureaucracy, and violence which seem to tell us that there is no place for caring. But, quietly sometimes and without fanfare, human connectedness and genuine acts of caring do take place.

Caring is "the capacity to grasp the lived reality of other living persons, to help those others grow in their own authentic fashions, or to attain a well-being of which they may be deprived" (Green, 1990, p. 30). It involves the ability to regard the other person's reality as possible for oneself. Once we care for others, we can no longer objectify them. We cannot look at them as "cases" or as if their realities were defined by a diagnostic label or social role. Caring is attending to living persons in their particularity.

They can only begin over and over,
pay heed,
open themselves to one another.
In an atmosphere of intensity and care,
music no one could precisely anticipate
will come to be.

(Green, 1990, p.33)

Day by day, in a multitude of big and small ways, I receive messages of caring. Just as I am sensitive to the physical beautiful in my world, I am exquisitely aware of the beauty that exists in the caring responses of those around me.

I find myself at the center of concentric circles of caring. In the innermost circle is my family who care because they love me. My husband, with his expertise in psychology, encourages me to enlist my mind in the treatment process. He teaches me relaxation exercises that help me cope with some of the initial stresses and provide beginning skills for my meditations. He is constantly there to listen to my fears and concerns, to help me sort out my needs and values. He also helps dispel the boogie man of despair that constantly threatens to overtake me.

My son, sweet child, is my most direct contact with pure trust and love. He is so unfettered in his expressions of caring. He knows I am sick, but I do not share the potential seriousness of the illness with him. At six years of age, he does not need to carry such a burden of knowledge. Besides, his unworried innocence contributes to a normalcy in his actions and reactions that are lovely and welcomed. Through him, I am reminded of the ongoing flow of normal existence, the many small triumphs and joys of daily life.

As I move outward in the circles of caring people, I encounter those who are friends or colleagues. An old school friend, who is now a farm wife in the prairies, phones me weekly during my radiation treatments just to see how I am doing. Another woman , who has been a colleague for years, tells me for the first time about her father's successful battle with cancer.

The women with whom I work quietly arrange for replacements for me when I'm unable to make it to work. I know that many times, my precarious health causes them inconvenience, yet I am never aware of any resentments. Another colleague tells me of her mother's ongoing, but seemingly successful, struggle with breast cancer. My immediate superior at work sends me a celebratory bouquet of flowers on my last day of radiation.

On the outermost layers of the concentric circles of caring are the people I barely know who come into my life during my hour of need and open themselves to my suffering in kind and helpful ways. A woman who chairs a college committee on which I sit takes time after each meeting to talk with me. The wife of a colleague of my husband's sends me notes of encouragement. The receptionist at my dentist's office takes time to ask how I'm doing and actually sheds a few tears the day I tell her the cancer is gone.

As I assess this wonderful network, I become aware of the inordinate number of women who have taken up roles of supportive caring in my life. The outpouring of care and encouragement comes with ease and understanding. There is concern but no discernible discomfort. In comparison, several men who inhabit my world are visibly uncomfortable with me, unsure, I suspect, of what to say or do. I do not doubt the concern these male friends and colleagues are feeling, but they seem to have no repertoire of caring responses to offer me. Likewise, when I think of that outermost circle, made up of people I hardly know, there is not one man.

I am reminded of the basic nature of women to nurture and to care. Are we, as women, just more comfortable with expressions of caring? Have we learned in our upbringing to be more sensitive, more adept at the everyday tools of caring?

Julia and I leave the building and begin our walk across the college parking lot. We have just finished our committee meeting.

Julia teaches in an area of the college with which I have little contact. Had it not been for this particular committee, our paths would likely never have crossed.

Julia is a handsome woman in her early fifties. She is dressed in an attractive, stylish emerald green suit. She knows I am struggling with cancer and has often expressed her concern. As we walk, she tells me a story.

"When I was first married, I had a very bad skiing accident. My feet and legs were so badly crushed that the doctors thought I might never walk again. It was terrible. There I was, newly married and facing such a prospect."

"Well, my husband, Ben, was wonderful. There were times when I looked awful and behaved worse. I was pretty discouraged at times. But Ben was always there. He never gave up on me. I'm not sure I'd have done it without him. . ."

"At any rate, we've been married for 32 years now, raised two boys. Sometimes when I get annoyed at something Ben has said or done and I'm tempted to respond in anger, I remember that time when he was there when I most needed him. Then, whatever it is that's made me annoyed

suddenly doesn't seem so important anymore."

I nod as she speaks.

Women have long been concerned with relationships. Gilligan (1982) has suggested that women evolve differently from men. In contrast to the male vision of a "hierarchy of power," women view the world as a "web of relationships." For women, then, it is less important to be "on top" and separate than to be a part of a fabric of interconnectness.

The difference between gender qualities and values is probably related to the discrepancies in the kinds of worlds in which men and women have traditionally been expected to function. The systematized, bureaucratic worlds of business, industry and government, have long been the domain of men. In these domains, classification and control for the sake of efficiency, impartiality, and profit are the norm. Compliance with the nonpersonal and the objective have, over the years, become recognized as masculine traits. Such traits have been prized within our society for they represent the tools of power.

Women, on the other hand, have traditionally inhabited the world of relationships. Women have been the caregivers - the ones who tended to the young, the sick and the infirm. As a consequence, we have tended to be much more concerned with personal attachment, for the *particularity* of other people. This has not only influenced the way in which we act in the world, it influences the way we view the world.

An ethic built on caring is, I think, characteristically and essentially feminine - which is not to say, of course, that it cannot be shared by men. . .But an ethic of caring arises, I believe, out of our experience as women. . .

(Noddings, 1984, p.8)

Traditionally, because the people who held power in our society were men and because men tended to prize objectivity, impartiality and impersonal control, the "feminine" ethic of caring has been undervalued, even looked down upon as soft and weak. It is as though that which cannot be measured, quantified, and classified is unworthy of respect.

On one level, I cannot refute that technical rationality and the objective research methods of "hard" science have given rise to some very important sources of knowledge. Some of these may affect my very chance for life. I am encouraged, for example, that the advances in cancer treatment have meant new hope, new possibilities that did not exist even five years ago. Yet, on another level, I am aware that the honest caring responses of those around me are absolutely critical to my sense of wholeness and well-being. Without them, something critical in my being would be lost. Yes, I *do* have cancer. But I cannot survive by becoming a "case". I must be cared for as a person, a very particular unique person, who happens to be dwelling with cancer.

As I ponder the feminine ethic of caring, I discover a joyous sense of self-discovery and self-affirmation as a woman. I am delighted to recognize that women's "ways of knowing", so long derided as soft and unworthy, are important beyond measure.

Of course, I also know from firsthand experience, that men *can* and *do* express caring. It is not only the domain of women. There is no need, in reflecting on the feminine imperative to care, that we must create another dualism. As women and men come together to pursue the give and take of equality, it will be important that we all learn the instincts and gain the tools of caring. It is, in the final analysis, an awareness of the human condition, a reflection of our common heritage of suffering.

The expressions of caring and support that bolster me in my distress are not necessarily big things. A warm hand in a cold operating theatre. The knowledge that someone is always there to hear my most outlandish fears. A hug, a smile, a touch on the shoulder. A few minutes spent truly *listening*. These small actions confirm my sense of individuality while replenishing my strength and hope.

Caring, ultimately, is sharing our common humanity, our common need for connectedness and nurturance. This sort of sharing does not require training, it merely requires a recognition of the importance of care in all our lives. Through caring, others give us the courage to make of our suffering an opportunity for growth.

Helping out is not some special skill.
It is not the domain of rare individuals.
It is not confined to a single part or time of our lives.

We simply heed the call of that natural caring impulse within, and follow where it leads us.

(Dass & Gorman, 1988, p.237)

CHAPTER VIII

THE DIFFERENT ME

A butterfly is not better than a caterpillar.
It is a development, an unfoldment.
The view we have from the valley is not worse
than the one we can enjoy on top of the mountain.
It is simply narrower,
and that is the order of things.
There would be no top without a valley,
no butterfly without a caterpillar. . .

(Ferrucci, 1982, p. 139)

Evolution and Transformation

When I was a child, I viewed the world from the perspective of a child. To me, the adults in my childish world represented paragons of understanding and knowledge. They had reached the mountain top. They had gained the wisdom of the ages. And, I felt assured, that once I reached adulthood, I too would be privy to this wisdom. With this grand wisdom would come clarity of understanding and certainty of purpose.

But, as I moved closer to adulthood, it became apparent that the mountain top was not so easily attained. Unlike the static vision I had of adulthood when I was a child, I now realize that our evolution as growing, unfolding, developing human creatures does not stop when we become adults. The person we are at 45 is decidedly different from the person we were at 25. And, so it will be at 65 and 85. The evolution may not seem as dramatic as in childhood, but it is no less real.

Evolution is defined as " a process of change in a certain direction: Unfolding" (Webster, 1989). Within this concept, then, is the sense of gradual, relatively gentle change in an expected direction. To a large extent, the normal developmental processes of childhood and youth can be seen as evolution. In adulthood, too, we experience this gradual unfolding and change. And, as many developmental theorists have shown us, the direction and nature of the evolutionary changes of adulthood can often be anticipated.

. . .most personal growth is organic,
continuous, gradual.
Humans grow, like oaks,
in silence and almost imperceptibly.

(Novak, 1971, p.44)

How is the relatively gentle, predictable evolutionary process of human development related to the concept of transformation? Transformation "implies a major change in form, nature, or function" (Webster, 1989) Transformation often is thought of as a dramatic, wrenching change: "I was transformed by the experience, I was never the same after that."

But, are we not transformed by the evolutionary processes of development? Don't the experiences of a life result in some fairly dramatic changes? When we look back at the person we were twenty years ago, do we not see that we have changed in decidedly significant ways?

transformation is natural
and part of the process of life
and its evolution.

(Lindbergh, 1955, p. 66)

We do transform throughout our lives, as we progress along our life path. And, perhaps that which is most profoundly transformed is the way in which we *perceive* our world. We are, each of us, situated in a particular place and time. We each live through a multitude of experiences. From these elements of place, time and lived experience, we evolve our perspective. From our individual perspective, we constitute our reality. Perception is the conscious awareness of what it is one lives through in experience. "Perception presents us with evidence of the world not as it is thought, but as it is lived." (Boyd, 1988, p. 69) Consequently, our viewpoint on the world, our perception, is intimately intertwined with time, place and lived experience. I no longer see through the eyes of a child, therefore I no longer live in the same world. As my perception changes, so does my reality.

The key struggle of life is that of psychic transformation: of breakthroughs in the way one perceives events, imagines oneself, understands others, grasps the world, acts

(Novak, 1971, p. 53)

Our individual journeys take many twists and turns. There are times when we rest or "mark time", when it seems that our perspective changes very little. During such times, the transformational process may seem to be stopped, or at very least, slowed. Perhaps these are the times when our lives are progressing relatively smoothly, when there is little to disrupt or challenge our habitual day-to-day existence.

At other times the circumstances of our lives are such that we are "pushed" to examine our values and meanings, to question assumptions, to develop new structures for understanding. A crisis can often precipitate such a push. A crisis is a particular kind of lived experience, "an emotionally significant event or radical change of status in a person's life" (Webster, 1989). The direction and rapidity of personal transformation can be profoundly influenced by crisis. For this reason, we may be more *aware* and expectant of transformation during and following crisis. We may be more apt to question the ways in which the crisis has changed us.

There is no doubt that being diagnosed with cancer was an emotionally significant event that heralded, for me, a dramatic personal struggle. In what ways did this struggle give direction and/or rapidity to my transformational evolution? In what ways are my perceptions now changed?

As before,
but differently and better than before.

It is never a simple return
to the status quo,
a simple return to our being,
it is that and much more.

(Marcel, 1966, p. 67)

Loss Of Certitude

The ringing of the telephone interrupts our supper conversation. My husband leaves the table to answer it. I can hear him talking. It's obviously not a friend, there is no warmth of familiarity in his voice.

I hear him say: "Just a moment please", then he calls me to the phone.

I take the receiver and say: "Hello"

"Mrs. Ferguson?"

"Yes"

"It's the Cancer Clinic calling"

As I hear the words, a flood of panic overtakes me. My whole body feels numb while my mind races with thoughts of doom. It's been six months since I completed my radiation, why would they be calling me now and at this time of the day? Maybe they've found a forgotten lab result that shows I have more cancer. Maybe they've realized the radiation didn't do the job after all. For this brief few moments, the crushing weight of terror controls my whole being.

"Mrs. Ferguson, we need to change the date of your next check-up."

"Oh. . ."

When we are young, we tend to feel invincible. During youth, we can rely on our bodies to serve us, even when we abuse them. Youthful bodies are remarkably resilient and forgiving. If we are even the least bit careful in our lifestyle choices, we can usually be assured of fairly robust health.

As a young adult, I led a relatively circumspect life and my body rewarded me with stamina, energy and resistance to illness. I felt impervious. Nothing could touch me. I was young and very much alive. Disease, especially of the life-threatening or chronic type, was for old people or people saddled with abusive habits. I was not one of those.

Suddenly, rudely, my invincibility is taken from me. I am no longer invulnerable. This cancer has shown me, in no uncertain terms, that I have no particular protection, no magic against disease and suffering. I can no longer take my physical health for granted. I am one of "those people", those who have been on the margin, who have experienced life-threatening disease. I now know that the end is not necessarily so very far away. Life is not endless.

Even months and years after my struggle with cancer has culminated, the threat of it still brings foreward the most crushing dread and panic. This disease has made me an intimate of terror. But the moments of panic and terror are just that, moments. Yet they are so vivid that they effect my being in very profound ways. I am no longer cavalier about my physical well-being. I am aware of every little bodily symptom. Any persistent ache or bump creates a worry.

Cancer has robbed me of my trust in my physical well-being. It has introduced a very real element of uncertainty into my life. As a consequence, I perceive my body differently, I perceive my self differently. I cannot be assured of uninterrupted physical well-being. I cannot be sure that I will live to an advanced old age. I cannot be certain.

And with this loss of assuredness, I am aware of another loss. As I confront my vulnerability and potential for disintegration, I realize I have lost something I had held to be very dear. I have lost my youth. I am no longer young. At least not in the way I was before - blighthly assured of an unlimited future filled with unlimited possibilities.

But, perhaps it is not so great a loss after all. Perhaps it is no greater a loss than the loss of my childish perception of the perfect wisdom of adulthood. Only when I let go of that delusionary perception was I able to continue with the ongoing evolution of self. Maybe the losses associated with my lived experience with cancer are inviting me towards another critical change of perception equally pertinent to my continued evolution.

We insist on permanency, on duration, on continuity; when the only continuity possible, in life as in love, is in growth, in

fluidity - in freedom, in the sense that the dancers are free,
barely touching as they pass, but partners in the same pattern.

(Lindbergh, 1955, p. 108)

Connectedness and Unity

Cancer, even as it robs me of certainty about my future life, instills in me a reverance for the life I now have. Suffering a life-threatening illness is a very potent way to bring home the realization that this is all there is. The past is done, the future unknown. Now is what we have been given.

My journey with cancer allows me a space in my life. Being "ill" gives me permission to step back from my hectic, sometimes tumultuous day to day life. There is time for solitude and contemplation. From my place apart, I begin to grasp, ever so tentatively at first, the important role of connectedness and unity in the pursuit of health and wholeness.

Connectedness refers to things, people, elements being joined or linked together, bound in some way. Unity connotes the quality or state of oneness, wholeness. The word is from the Latin *unus*, one. Interestingly, the word onion comes from the same Latin root - from many, many layers, comes one sphere. Unity also is used to suggest a condition of harmony and accord.

Our experience of being,
within the time and spaces of the eternal process
which we find to be our own,
such experiences are *connected* to the others,
to their experience of being *connected*
also to the unfolding of nature's experience of itself -
and all is *connected*,
in quite profound ways,
to the evolution of being itself.

(Moccia, 1990, p.209)

Separateness, division, disunity, discordance. Why do we choose to see ourselves and our world through these concepts of reality? Einstein once called our assertions of separateness an "optical delusion" (Moccia, 1990, p. 209). For, in the most meaningful and sometimes mysterious ways, we are connected, within ourselves, with others, with nature.

As I ponder my lived experience with cancer, I realize that the delusion of separateness may well have contributed to my getting the disease in the first place.

Today I was reading about Marie Curie
she must have known she suffered from radiation sickness
her body bombarded for years by the element
she had purified
It seems she denied to the end
the source of the cataracts on her eyes
the cracked and suppurating skin of her finger-ends
till she could no longer hold a test tube or a pencil
She died a famous woman denying
her wounds
denying
her wounds came from the same source as her power.

(Rich, 1974, p.225)

I must look to the source of my wounds for the source of my healing. And, in the looking, I see a time when my reality was one of separation, alienation, distancing of self from others and from self. During this time, as connectedness and unity broke down, I became confused about my worth, unsure of possibilities, discouraged, disheartened. The life energy was rapidly draining from me. My body became a ready haven for disease.

Conversely, my healing process has and will continue to enlist my growing perceptions of connectedness and unity.

Firstly, there is the unity of self. I have experienced the mysterious ways in which body, mind and spirit interrelate and I know this is a touchstone for the wholeness of being I wish to pursue. But how to do it? How to achieve continuing unity of self? I have only intimations to guide me, inklings harvested from the experience of illness.

I know my future evolution must include a balanced awareness of the divergent realities, complexities and needs of each aspect of self. And I also know that balance is not a static state. Like many other aspects of life, balance is an alternating rhythm, an easy ebb and flow of energies and priorities.

An important part of the attentiveness to self is an attunement to the complexities of life. If I am to continue to become a more whole, more unified being, I must recognize the multiplicity of my life - those demands on my time and energies that often detract from awareness. I need the stimulation and excitment, and opportunities for creative thought which evolve from my complex life, but, I realize, this must be balanced with moments of solitude. Permission must be given for "time apart" without requiring illness.

My journey with cancer has provided me with an exquisite sensitivity to the beauty, harmony and unity of nature - and I know firsthand the healing benefits of this awareness. Attunement to the natural world brings a peaceful sense of connectedness with that which is much greater than self. The tumult of the day does not lend itself to such attunement. Again, my evolution depends on a balance within my life.

> **Work without pressure.**
> **Space for significance and beauty.**
> **Time for solitude and sharing.**
> **Closeness to nature to strengthen understanding**
> **and faith in the intermittency of life:**
> **life of the spirit, creative life,**
> **and the life of human relationships.**
>
> (Lindbergh, 1955, p. 120)

We divide ourselves from others on the basis of so many things - class, race, religion, creed, economics, age, sex, state of health. For most of my life, I deluded myself into believing that the lives of sick people were separate from my own. I was on the other side. Not only was I young and healthy, but I was the designated caregiver.

I deluded myself until one night, early in my journey with cancer, I awoke to discover blood flowing down my throat and out my nose. I was hemorrhaging from a biopsy site. That night and the whole of the next day, I spent on a stretcher in the hallway outside the emergency room because there were no beds in the hospital. I lay there stripped of any identity beyond the small wristband that proclaimed my name and number. Suddenly, I am no longer separate from "those people" who are sick and in need of help. Suddenly, I am not so different from "those people" who are nameless and homeless - for a few hours I experience a kinship with those people on the fringe who exist in the public places - the streets and hallways - of our cities. Are we, any of us, really so different?

The waiting room is crowded today. I find an empty seat and begin to leaf through a magazine. But the magazine is old and not too interesting, so I put it down and begin to observe my fellow "waiters".

There is an older man in the corner who looks like he's been a farmer - sunburned face and big tough hands still harboring vestiges of the earth. His wife sits beside him, knitting. They both seem calm and unworried.

Across the room is a middle-aged lady, talking animately with a volunteer. I can overhear some of the conversation, and I realize that it is her husband who is ill. Momentarily a man in a wheelchair is wheeled in and the lady leans over to kiss him. He is very thin, like a skeleton with skin, and his color is ashen. He hardly responds to his wife's cheery greeting. The volunteer says: "Hello Dr. Rowman, it's nice to see you. You're looking much better today."

In the other corner, I notice a young woman sitting alone. She is holding her body very stiff and straight, her hands clenching the arms of the chair. She is staring straight ahead and I am immediately aware of her eyes. I have never seen eyes so full of fear.

The nurse appears and calls out my name. It's time for my treatment. As I get up, I smile and say to the young woman: "Guess it's my turn."

Those frightened eyes dart towards me, almost in surprise. She follows me with her gaze as I leave the room.

When my treatment is finished, I walk past the waiting room. All the chairs are empty. I am haunted by those eyes.

Being connected creates concern, a common bond. When I see myself as connected with the other, the "otherness" is diminished. We are united in a common bond of humanness. We are sisters and brothers in the battle. Suddenly the differences aren't so relevant.

Verna sits in front of me wearing jeans and a T-shirt. Tendrils of grey-blond hair curl around her face. She slumps slightly in the chair. I am aware that she looks older and smaller than last time I saw her.

I had been dreading this occasion. Verna had called me two days earlier requesting yet another session with me. We'd met twice before and had had numerous telephone conversations. A few months previously, Verna had registered to take a challenge examination in one of my courses. The subject of our many conversations was the fact that she had been unsuccessful in the exam.

In my initial contacts with Verna, I was aware of her extreme pain. She seemed to have equated her failure in this one exam to her failure as a human being. In our first few conversations, Verna railed against the exam, the college, the "system". Her anger and hurt were palpable. I wanted desperately to fix things for her, to take her suffering away. But I could not. In fact, in essence, I was the cause of her distress because I was the one who had prepared and marked the exam. I was the one who had failed her. And, by not assuaging her pain, I was continuing to fail her. Or so I feel.

When she had phoned to make this present appointment, I groaned inside. I've had enough of this! What more can I do?

But now, as she sits before me, I decide I will try as best I can to hold my own defenses at bay. As much as I don't want to share her suffering yet again, I struggle to tune in to her concerns one more time.

She tells me about the many accomplishments she has had in her life. She has brought certificates and letters and other documents that "prove" her worth. I acknowledge them all.

And as I listen to her talk, I am startled to realize that I honestly like this person. I know what she is experiencing. I know how hard it is to have one's self-confidence shaken at its very roots. And, gradually but surely, the tension between us seems to melt. We have become two women who have both known pain. We begin to talk about families and goals and hopes. For a few special minutes we connect as two fragile yet resilient human beings.

Finally Verna says: "Well, then, what are my options now?" I look at her with real respect as I discern that she has begun to move on, to put the hurtful experience behind her.

Later, as she arises to leave, she says: "Well, I guess this is it. You won't be seeing me again."

I touch her shoulder as we move towards the door and say: "I hope I <u>will</u> see you again, Verna." I'm surprised to realize that I mean it.

Each time we drop our masks
and meet heart-to-heart,
reassuring one another simply by the quality of our presence,
we experience a profound bond which we intuitively understand
is nourishing everyone.
Each time we quiet our mind,
our listening becomes sharp and clear,
deep and perceptive;
we realize that we know more than we thought we knew,
and can reach out and hear,
as if from inside,
the heart of someone's pain.

(Dass & Gorman, 1988, p. 223)

We have so much suffering of our own, why take on that of someone else? Like so many other people, I am very good at insulating, separating myself from the pain of others. It is easy to rationalize why I have no responsibility for the suffering of others. After all, I have my own problems.

Frequently, however, as I strive to protect myself, I notice that I tend to treat others as objects to be manipulated toward my own ends. When this happens, I don't really listen. I don't really see. And the interraction between us is bereft of true human contact. We do not connect. We remain separate.

But occasionally I remember those times when others dwelt with me in honest caring. I remember and try to put aside my protective barriers in the service of connectedness.

Common to all those moments and actions
which truly seem to help
is the experience of unity;
the mind and the heart work in harmony
and barriers between us dissolve.

(Dass & Gorman, 1988, p.223)

Separateness and unity. It's interesting that these are root concepts of many of the spiritual traditions of mankind. In peeling back the layers of meaning, have I stumbled upon a spiritual imperative? There is much to ponder here, to give direction to future contemplations and reflection.

In the final analysis, then, the different me that has emerged from the spectre of the lived experience with cancer is not so different a person from before. At least, so it would seem if you were to see me on the street or talk with me over lunch. I probably don't behave in a manner too changed from before - a little calmer, perhaps, or less open to pretense. But not so different, really.

Yet, at a very core level of my being I *am* different. I no longer see with the same eyes, therefore I no longer live in the same world. My reality has been changed forever.

Nothing is different, yet all is transformed. It is *seen* differently. In that change of perspective, in the transformation of meaning lies the meaning of transformation. Our old life is still there, but its meaning has profoundly changed because we have left home, seen it from afar, and been transformed by that vision. You can't go home again.

(Doloz, 1986, p. 26)

CHAPTER IX

TOWARDS THOUGHTFULNESS AND TACT

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.

(T.S. Eliot, 1944, p.43)

Bringing to speech my understanding of the meaning structures of my lived experience with cancer has been the central focus of this study. In so doing, I have attempted to be thoughtfully aware of the consequential in the inconsequential, the significant in the mundane. A walk to a doctor's office, a casual discussion with a colleague, a few minutes sitting in a waiting room - ordinary experiences that made up my extraordinary journey with cancer. Ordinary happenings that seem, in themselves, to be void of importance, yet the meanings are there.

In "re-living" my experience with cancer, I have attempted an attentive thoughtfulness, a mindful attunement to what it meant for me to live such an experience. I knew at the outset that I was attempting the impossible, for I was treading on the ground of that which is most mysterious. But, I was also treading on the ground of that which is most human. The reflective journey has been arduous at times, frustrating when it seemed that the essences, those aspects of the experience that were most important, were just beyond my grasp, just beyond my ability to verbalize.

We are impelled to speak;
yet that whereof we are obliged to speak
we find ineffable.

(St. Augustine, quoted in Novak, 1971,p. 75)

Experience is always richer than our capacity to verbalize or analyze it, therefore my efforts always fell short. Yet. . . there have been moments when, through the reflective process, I have "discovered" insights which have gifted me with a certain inspiration and enlightenment. There is within me a new respect, an admiration, for ordinary life, for the wisdom to be gained from reflection on the daily experiences of living.

Action is the starting place of inquiry.
Action reveals being.
In action we declare our cosmology, our politics, our convictions,
our identity.
Who am I?
I am what I do.

(Novak, 1971, p. 46)

Novak (1971) suggests that the two fundamental, indispensable questions are: Who am I? Who are we, we human beings under these stars? Through reflecting on our own stories, our own experiences, we come to a better understanding of the first question. And, ultimately, in so doing, we gain insight into the second. Through understanding of self, we come to better understand others.

Theorizing

As I struggled to give voice to that which was central to my experience, I realize that I have been moving from action or lived experience to beginning theory.

Theorizing as edifying activity is the conversational transformation of flesh into word, lived experience into language.

(Van Manen, 1986, p. 48)

The Greek word *theoria* connotes "wakefulness of mind" in the "contemplation" or "pure viewing" of truth. Van Manen (1986) tells us that truth, in the Greek sense is not equivalent to our present notion of it as a property of consensus or a correspondence between a proposition and things described. "Truth in the Greek sense refers us to the disclosure of the essential nature, the essence, or the good of things" (VanManen, 1986, p. 44)

The word edify comes from the Latin *aedificare*:: " to instruct or improve spiritually", and the French, *aedes* : "temple, house". Edifying theory, then, is that wakefulness of mind or pure viewing of truth which instructs or improves morally or spiritually. It is the building of a structure in which enlightenment can occur.

> **The theoretical. . . is a place where in the midst of everyday life we find the possibility of contemplating, beholding, and presenting the good; and the possibility of thus having a transforming experience - in the edifying sense of "inspiring," "making pure," enlightening," and "uplifting spiritually".**
>
> (Van Manen, 1986, p. 44)

Traditionally, we have developed theory as a means of informing in ways that allow us more rationally to regulate the practice of living. We seek to set up principles, norms, or guidelines which direct our action. Theory, then, becomes a tool. I recall a comment, attributed to Abraham Maslow, that when the only tool you have is a hammer, everything looks like a nail. Are there times when our theoretical maps do not reflect the true experience of those with whom we live and act? Do our principles and guidelines always point us in the direction of that which is most edifying in human experience?

Van Manen suggests that theory, as a form of edifying discourse, is a bringing to speech of our orientation to that which praises the meaningful, excellent and good in our lives. The good is the end, the end in itself, from which we gain all our hope, love, and inspiration. From this source comes our insight and enlightenment. The person who can bring to consciousness the wisdom of this understanding is a theorist in a most profound sense.

Rather than a body of knowledge, . . .theory is a poetic bundle of illuminations, an edifying display of discourse to be sung rather than mathematized into hypothesizing relationships.

(Van Manen, 1986, p. 47)

The outcome of this type of theorizing is a quality of self that Van Manen has referred to as tactfulness. The word tact comes from the Latin *tactus*, to touch, (the same root as tactile). Tact involves a sensitive or aesthetic perception from which evolves a keen sense of right action. Tactfulness involves knowing *and* doing. Action based on insight and understanding, thoughtful action that emanates from "being in touch" with that which is real, true, and essential. It is a knowledge that issues from the heart as much as from the head.

Evolving Tactfulness

The phenomenological writing process I undertook in this research was an effort to write myself toward greater tactfulness - constantly writing and rewriting - attempting to "see" the deeper significance or meaning-structures of the lived experience. Through the writing, the "conversing" with self, I found out what I know. And sometimes it surprised me.

The writing has produced a new "sightedness" and the way I am in the world can never be the same. Living the questions of this research has invited me to reassess my relationships with my family, my friends, my colleagues and my students. It has caused me to ask questions like : What does it mean to be a parent? a wife? an educator? an administrator? What does it mean to care for and nurture another? None of these specifically attend to the experience of having cancer, yet they fall out of my reflections. For, reflecting on lived experience, in a phenomenological sense, puts us in tune with that which is most meaningful in human actions. It is not surprising that these meaning structures have broad applications.

A grasp of one's own basic story
offers some guidelines for the future.
One becomes quicker to discern,
in new and surprising situations,
which suddenly assumed roles are "out of character."
One gets a sense of being more "together"
with oneself,
more "connected,"
more able to be "present" to others.

(Novak, 1971, p. 64)

No person's life is exactly like anyone else's. Each person is individual and each person's lived experience is particular. Yet, herein lies an interesting paradox, for in that which is particular also lie the seeds of universality. My individual experience made it possible to see the importance of broader human issues that apply not only to situations of illness, but to a multitude of other human realities.

As I reflect on my experience with cancer, I note the words that I often use to describe that time: adversity, affliction, struggle, crisis, suffering. In my role as an adult educator, I am aware that I often encounter learners who are also experiencing adversity and/or crisis, who are struggling and suffering. Sometimes, these experiences are related to happenings in their lives outside of the educational environment - a failed marriage, poverty, a death in the family, illness. Sometimes my students find the educational experience itself to be a struggle and, when the struggle is lost, the result can be a serious crisis with considerable suffering.

Shelley enters the reception area looking apprehensive.

"You wanted to see me?" she says.

"Yes, Shelley. Thanks for coming. Let's go into my office."

Shelley and I enter my office. I motion to her to sit in a chair beside my desk. I sit facing her.

"Shelley, I wanted to talk with you. I hear you had some problems in your

clinical practicum and I thought it would be a good idea for us to discuss them so you'll have a better time of it in your next practicum."

"What do you mean?" Shelley is looking at me out of the corner of her eyes, her face set in a frown.

"Well, I think your instructor talked with you about some of the communication difficulties that arose between yourself and the staff in the facility?"

Suddenly, Shelley breaks into tears, sobbing almost uncontrollably. "Why are you doing this to me? " She yells, "I've never done anything to you! Why are you picking on me?"

I'm a bit surprised by the magnitude of Shelley's emotional response. I'm not sure what to do. Should I touch her? Should I try to console her? Should I try to explain? I decide to sit quietly, to dwell with her in silence during this time of pain.

In a few moments, the sobbing lessens, her voice becomes a bit calmer.

"I didn't want to come talk with you. I thought you were going to tell me I'm failing. I know I'm going to fail this course, just like I've failed everything else in my life. How am I going to tell my family that I've failed again?"

Now, I touch her, and explain that she has not failed, although we are concerned about her. And, thus, gradually, we approach the core of the problem that has plagued her from the moment she arrived in our program. Her manner, her communication style, her words - have continually had the effect of creating anger and defensiveness in others. Even her fellow students avoid her. Several of the instructors have commented on her "attitude".

As I talk with her, I am aware of Shelley's youthful attractiveness. I know that she is bright - her marks prove it. Yet, this attractive, intelligent young woman has very effectively pushed everyone away. No one wants to be the brunt of her sarcasm or her criticism. What's happened to this person that she is so angry?

Slowly, she begins to talk and I hear of a childhood of criticism, a father who continually told her she was no good. I hear of her struggle with bulemia. I hear of a marriage to a man who tells her that she"trapped" him into commitment. I feel her desperate pain, and suddenly she seems like such a child. How can we expect this child to care for others when she *herself has never experienced caring?*

After a long time, our conversation draws to an end. As she arises to leave, Shelley notices the bank of family pictures I have scattered over my desk.

"Is that your family?"

"Yes."

"You have a nice family. You have a good job. Why do you care about me?"

When Van Manen talks about the particular thoughtfulness and tact that educators of children need to pursue, he speaks of "pedagogic tact" (Van Manen, 1986, p. 48). Pedagogy is "the art, science, or profession of teaching; education". It is also an orientation, a standpoint from which to see the world.

As an adult educator, I have a somewhat different standpoint than the teacher of children, yet the orientation is still pedagogic i.e. geared to that which celebrates the art and science of education. In the development of tact, I must be oriented to the meanings of educating and supporting adults who are engaged in a formal learning experience.

Thoughtfulness and tact are not simply a set of skills to be gained in a workshop. True tact requires an attentive attunement of one's whole being to the experience of the other. Having attuned myself to similar experiences in my own life helps me to recognize and orient to that which is most essential in the experience of the other. But, if I am to become a caring educator, I must observe my students with the eyes of a caring educator. I must believe that there is a way of being with another adult that sets a teacher-learner relationship apart from any other kind of adult-adult connection. And I must always seek to better understand what makes a certain situation or action with the learner pedagogic rather than something else.

What I glean from my own experiences of crisis, struggle and suffering has provided me with a new sensitivity that provides furtile soil in which pedagogic tact may grow. I appreciate, now more than ever, that I must be attuned to the small things. A perceptive teacher knows when to be silent and when to speak, when to touch and when to refrain from touching. Tactfulness shows itself in little things. "The big things are always in the small" (Van Manen, 1986, p. 48)

When I set about to conduct a reflective study of my experience with cancer, I expected to gain an expanded understanding of that particular experience. I thought, at the outset, that the awarenesses gained in this pursuit might have usefulness to others suffering with cancer. I did not anticipate that my understandings would be transferrable to my role as educator or, for that matter, to my role as parent, spouse, friend, colleague, neighbor. But such is the case. That which is most human touches all aspects of human being.

And, so it seems, as I have worked to peel away, layer by layer, the meanings inherent in each aspect of my cancer experience, I have become more attuned to some very basic meanings of what it is to be human. With this new awareness, I have noticed myself becoming just a little more attuned, a little more tactful in my interractions with others.

> **We can, of course, help through all that we *do*.**
> **But at the deepest level we help through who we *are*.**
> **We help, that is by appreciating the connection between service**
> **and our own progress on the journey of awakening**
> **into a fuller sense of unity.**
>
> (Dass & Gorman, 1988, p.227)

But sometimes my new sensitivity deserts me and I am left with a gnawing sense of failure. Too often I am aware of times when I do not practice tactfulness, when I opt for separateness rather than connection. I fall short of what an "adult educator" or a "caring person" should be. But even the awareness of failure reflects a growing wisdom.

If wisdom is the ability to go to the heart of the matter, then it is fruitful and valuable to discipline oneself to become more reflective, to grow in understanding through the contemplation of the lessons of day-to-day living. Experience preceeds understanding. From experience and understanding we evolve and are transformed.

To grow in wisdom, then,
is to have undergone many transformations.
It is to have known joy often.
For joy is the taste of reality.
And each transformation of one's horizon
is for the sake of a profounder,
more comprehensive penetration
into the mystery of one's own existence,
into the reality of the world in whch we live.
We are never directly in touch with reality.
We proceed,
little by little,
into an ever more tutored, more accurate grasp
of what it is to be a human being under these stars.

(Novak, 1971, p. 58)

Integration

As I ponder the experience of conducting this research, I am aware that the reflective-interpretive process has allowed me, in a very meaningful way, to integrate my experience with cancer into the fabric of my life. The word integrate is from the Latin *integer,* "whole". It means: "to form, coordinate, or blend into a functioning or unified whole: unite" (Webster, 1989). Having cancer was not just an unfortunate bump in an otherwise fairly smooth life journey. It was not just a "difficulty" to be overcome and put aside. It was an integral part of my life. It is an integral part of me.

When I started the reflective-interpretive process, I questioned: "What was that experience about? What did it mean?" At the time, my experience with cancer had the character, in my mind, of a crisis which was definitely segregated from the rest of my life, before and after. Yet, the mere fact that I questioned its meaning suggests that I was not totally satisfied to leave it as an isolated event in my life.

The reflective process has allowed me to re-live the experience of having cancer in a way that puts me in touch with many of the meaning structures inherent in that experience. And, with some surprise, I find that these same structures of meaning have broad application throughout my life. My experience with cancer has become less and less an entity unto itself, the "edges" of the experience have become blurred, and it now flows into the rest of my life story. I have become united with it in familiarity and thankfulness.

It is not true that faith, creed, convictions come first
and then action.
It is rather true that we are already acting long before we are clear about our ultimate convictions.
More important still:
our actions, reflected on, reveal what it is we really care about,
more accurately than our words or aspirations
about what we would like to care about.

(Novak, 1971, p. 45)

If good education is a series of new births, new understandings, then my reflective-interpretive journey has been good eduation, indeed.

REFERENCES

Auden, W.H. (1979). *Selected poems: New edition.* New York: Vintage Books.

Bauman, Z. (1978). *Hermeneutics and social science.* New York: Columbia University Press.

Bergum, V. (1986).*The phenomenology of woman to mother: The transformative experience of childbirth.* Unpublished Thesis: University of Alberta.

Beisser, A.R. (1989). *Flying without wngs.* New York: Doubleday.

Borysenko, J. (1988). *Minding the body, mending the mind.* New York: Bantam Books.

Boyd, C. (1988). Phenomenology: A foundation for nursing curriculum. In *Curriculum revolution: Mandate for change* (pp 65-88). New York: National League for Nursing.

Boyd, I., Yeager, M. & McMillan, M. (1973). Personality styles in the post-operative course. *Psychosomatic Medicine, 35*, 23-40.

Burch, R. (1986). Confronting technophobia: A topology. *Phenomenology and Pedagogy, 4*, 3-21.

Capra, F. (1988). *Uncommon wisdom : Conversations with remarkable people.* Toronto: Bantam Books.

Cousins, N. (1979). *Anatomy of an illness.* New York: W.W. Norton & Co.

Cousins, N. (1983). *The healing heart.* New York: W.W.Norton & Co.

Cousins, N. (1989). *Head first the biology of hope.* New York: E.P. Dutton.

Dallmayr, F. R. (1981). *Beyond dogma and despair.* London: University of Notre Dame Press.

Daloz, L. (1986). *Effective teaching and mentoring realizing the transformational power of adult learning experiences.* San Francisco: Jossey-Bass.

Dass, R. & Gorman, P. (1988). *How can I help?* New York: Alfred A. Knopf.

Earle, W. (1977). *Autobiographical consciousness: A philosophical inquiry into existence.* Chicago: Quadrangle Books.

Eliot, T.S. (1944). *Four quartets.* London: Faber & Faber.

Engel G.L. (1968). A life-setting conducive to illness. The giving-up, given-up complex. *Annals of Internal Medicine, 69*, 293-300.

Epstein, A.H. (1989). *Mind, fantasy and healing.* New York: Delacorte Press.

Ferguson, B.F. (1979). Preparing young children for hospitalization: A comparison of two methods. *Pediatrics, 64,* 656-664.

Ferrucci, P. (1982). *What we may be.* Los Angeles: Jeremy P. Tarcher, Inc.

Frankl, V. (1959). *Man's search for meaning.* New York: Simon & Schuster.

Gadamer, H.G. (1975). *Truth and method.* New York: The Seabury Press.

Gadow, S. (1982). Body and self: A dialectic. In V. Kestenbaus (Ed.), *The humanity of the Ill phenomenological perspectives* (pp. 86-100). Knoxville: The University of Tennessee Press.

Gibran, K. (1964). *The prophet.* New York: Alfred A. Knopf.

Gilligan, C. (1982). *In a different voice.* Cambridge, Mass., Harvard University Press.

Green, M. (1990). The tensions and passions of caring. In M. Leininger &J. Watson (Ed.s), *The caring imperative in education* (pp. 29-43). New York: National League for Nursing.

Harris, M. (1989). *Dance of the spirit.* New York: Bantam Books.

Holohan, A. (1977). Diagnosis: The end of transition. In A. Davis & G. Horobin (Ed.s), *Medical encounters the experience of illness and treatment* (pp. 87-97). London: Croom Helm.

James J. (1983). *Success is the quality of your journey.* New York: Newmarket Press

Janis, I.L. (1958). *Psychological Stress: Psychoanalytic and behavioral studies of surgical patients.* New York: John Wiley and Sons.

Johnson, J.E. (1971). Effects of structuring patient's expectations on their reactions to threatening events. *Nursing research, 21*, 499-507.

Langer, E.J. (1989). *Mindfulness.* Reading, Massachusetts: Addison-Wesley.

LeShan, L. (1980). *You can fight for your life: Emotional factors in the treatment of cancer.* New York: M. Evans.

LeShan, L. (1989). *Cancer as a turning point.* New York: E.P. Dutton.

Lindbergh, A.M. (1955). *Gift from the sea.* New York: Pantheon Books.

Marcel, G. (1962). *Homo viator : Introduction to a metaphysic of hope.* New York: Harper & Brothers.

Matthews-Simonton, S., Simonton, O.C. & Creighton, J.L. (1978). *Getting well again.* New York: Bantam Books.

Mayeroff, M. (1971). *On caring.* New York: Harper & Row.

McWilliams, P. & Roger, J. (1989). *You can't afford the luxury of a negative thought.* Los Angeles: Prelude Press.

Menninger, K. (1963). *The vital balance.* New York: Viking Press.

Moccia, P. (1990). Deciding to care: A way to knowledge. In M. Leininger & J. Watson (Ed.s). *The caring imperative in education* (pp. 207-216). New York: National League for Nursing.

Noddings, N. (1984). *Caring.* Berkeley, Calif.: University of California Press.

Norton, H.M.D. (1938). *Translations from the poetry of Rainer Maria Rilke.* New York: W.W. Norton & Company.

Novak, M. (1971). *Ascent of the mountain, flight of the dove.* New York: Harper & Row.

Pelletier, K. (1977). *Mind as healer, mind as slayer.* New York: Delta.

Pinar, W. (1988). Whole, bright, deep with understanding: Issues in qualitative research and autobiographical method. In W. Pinar (Ed.), *Contemporary curriculum discourses* (pp. 134-153). Scottsdale, Arizona: Gorsuch Scarisbrick Publishers.

Radner, G. (1989). *It's always something.* New York:Simon & Schuster.

Rawlinson, M.C. (1982). Medicine's discourse and practice of medicine. In V. Kestenbaum (Ed.), *The humanity of the ill phenomenological perspectives* (pp. 69-85). Knoxville: The University of Tennessee Press.

Rich, A. (1984). *The facts of a doorframe.* New York: Norton.

Robinson, J.A & Hawpe, L. (1986). Narrative thinking as a heuristic Process. In T.R. Sarbin (Ed.), *Narrative psychology :The storied nature of human conduct* (pp. 111-125). New York: Praeger.

Roche, M. (1973). *Phenomenology, language and the social sciences.* London: Routledge & Kegan Paul.

Rossi, E. (1986). *The psychobiology of mind-body healing.* New York: W.W. Norton.

Sartre, J. P. (1968). *Search for Method.* New York: Vintage.

Schmale, A.H. (1972). Giving up as a final common pathway to changes in health. *Advances in Psychosomatic Medicine, 8* , 20-40.

Schmale, A.H. & Iker, H. (1971). Hopelessness as a prediction of cervical cancer. *Social Science Medicine, 5* , 95-100.

Seligman, M.E.P. (1975). *Helplessness: On depression, development and death.* San Francisco: Freeman.

Shipley, J.T. (1982). *Dictionary of word origins.* Totowa, New Jersey: Rowman & Allanheld.

Siegel, B. (1986). *Love, medicine & miracles.* New York: Harper & Row.

Siegel, B. (1989). *Peace, love and healing.* New York: Harper & Row.

Sinetar, M. (1988). *Elegant choices, healing choices.* New York: Paulist Press.

Sklar, L.S. & Anisman, H. (1979). Stress and coping factors influence tumor growth. *Science, 205* , 513-515.

Smith, D.G. (1990). *The hermeneutic imagination and the pedagogic text.* Unpublished paper: University of Lethbridge.

Sontag, S. (1978). *Illness as metaphor.* New York: Farrar, Straus and Giroux.

Tesch, R. (1987).*Emerging themes: How researchers discover them.* Paper presented at the Sixth International Human Science Research Conference, Ottawa, Ontario.

Tillich, P. (1952). *The courage to be.* New Haven: Yale University Press.

Van den Berg, J.H. (1980). *The psychology of the sickbed.* New York: Humanities Press.

Van Manen, M. (1982). Edifying theory: Serving the good. *Theory into Practice, XXI* (1), Winter, pp. 44-49.

Van Manen, M. (1984). Practicing phenomenological writing. *Phenomenology and Pedagogy, 2* (1), pp. 36-69.

Van Manen, M. (1986). *The tone of teaching.* Richmond Hill, Ont. : Scholastic.

Van Manen, M. (1989). *Researching lived experience human science for an action sensitive pedagogy.* London, Ont.:The Althouse Press.

Von Eckartsberg, R. (1986). *Life-world experience existential-phenomenological research approaches in psychology.* Lanham, MD: University Press of America.

Webster's new collegiate dictionary (1989). Toronto: Thomas Allen & Son Ltd.

Wood, D. (1989, August/September). The search for a cancer cure is heating up. *Today's Health, 7* (4), pp.51-53.

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Ferguson, Faye (1987). *Activity Aide provincial curriculum.* Province of British Columbia: Ministry of Advanced Education.

Ferguson, Faye (1986). *Gerontology: Footcare.* University of Victoria: University Extension and Community Relations.

Ferguson, Faye (1985). A clinical preceptorship: Nursing students in transition. *RNABC News,* July/August.

Ferguson, Faye (1979). Making hospital preparation child-centred. *Journal of the Association for the Care of Children in Hospitals,* Vol. 8, No. 2.

Ferguson, Barbara Faye (1979.) Preparing young children for hospitalization: A comparison of two methods. *Pediatrics,* Vol. 6, No. 5.

Ferguson, Barbara Faye (1978). *Preparing young children for hospitalization: A comparison of two methods.* Unpublished Thesis: University of Calgary.

Ferguson, Faye (1978). Children's cognitive discovery of death. *Journal of the Association for the Care of Children in Hospitals,* Vol.4, No. 2.

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TOWARD AN UNDERSTANDING OF MY TRANSFORMATIONAL EXPERIENCE WITH CANCER

Autho[redacted]________________

BARBARA FAYE FERGUSON

July 20, 1990

(Date)