STORIES OF OUR LIVES
Living with a life-threatening illness

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PROJECT DEMONSTRATING EXCELLENCE (DISSERTATION)

ABSTRACT

STORIES OF OUR LIVES

Living with a life-threatening illness

This project demonstrating excellence, entitled **stories of our lives: living with a life-threatening illness,** is a phenomenological and ethnographic study of health and illness. It investigates the meaning people attribute to their illness experiences. The central hypotheses state that experiencing a life-threatening illness can be a catalyst for change and personal growth. The meaning of an illness experience can be discovered by bringing awareness to irrational and seemingly weird fantasies connected to the illness experience. Awareness of the body states accompanying the illness as well as the memories and fantasies around crucial moments connected to the illness are clues to necessary life changes.

In ten in-depth interviews with people who experienced a life-threatening illness, their irrational thoughts and fantasies regarding memories around the illness onset, the reasons and explanations for the illness, life changes triggered by the illness experience, and valuable lessons and teachings they gained from the illness experiences for themselves as well as for society are elicited. The interview questions are based on the philosophy and theoretical framework of process-oriented psychology.

The study further investigates cultural views on health and illness, living and dying. It examines the implications the general attitude towards illness has for whomever gets seriously ill. Illness itself is looked at as a potentially meaningful experience not only for the individual affected by it, but also for society. Seeing illness and death as an integral part of life rather than as disturbances that need to be eradicated, reflects a shift in attitude towards unpredictable life events which focuses on awareness rather than control.

People who had been affected by a life-threatening illness found meaning in their illness experience which was valuable for themselves and the world around them. Illness took on different roles. It served as a reminder to listen to, value and appreciate the body and inner experiences. Illness was experienced as an important change agent and push for personal growth. Illness became a spiritual teacher where it made people become more aware of the interrelatedness and interdependence of human beings and the world.

To be ill is an odd mixture of
pathos and bathos, comedy and terror,
with intervals of surprise.

- Anatole Broyard, "Intoxicated by My Illness"

CHAPTER I: INTRODUCTION

In the earliest dream I remember, a witch entices me to come up to her, step through a door in a hill into her realm, down some stone steps into the fire of the earth.

My curiosity led the way in the dream. The prospect of getting a peek at what is inside the earth helped me overcome the fear of the witch and started me on the journey into other realms. It is my passion to discover life's mysteries and to get a glimpse of what their meaning might be. The witch's calling is still with me. Like she did with me in my early dream, I want to entice other people to get a closer look at their inner nature and get in contact with the richness underneath the surface.

I believe that there is meaning to our existence and that we all are searching to be in contact with our deepest nature. I remember as a teenager discussing the meaning of life with my girlfriend on the way home from school. We both went to Catholic school where religious beliefs were present every day and confrontation with these beliefs and the resulting ethical code unavoidable. My metaphor for how I saw my place and task in life was the litmus paper I knew from chemistry class. Similar to the different chemical elements crawling up the paper in different colors and heights, I figured people had different paths in life. I was convinced though that everybody fit in somewhere in the global scene and helped create the whole.

As long as things follow the course we have in mind, we might be less inclined to ponder life's meaning. It is more often a crisis that brings up the need for entering places in ourselves we have not touched upon. Unpredictable and uncontrollable events, like accidents, illnesses, and other life crises, disrupt our usual way of being, challenge beliefs about who we think we are and question the reason for our existence. We feel victimized by processes which happen to us, seemingly out of nowhere. In those moments, we might get a glimpse of life's force. Being open to the unexpected might lead us to enriching information about ourselves to help us grow closer to our true natures and the potential inside.

Whenever a person experiences a severe life crisis, a rupture takes place. The old identity is not prepared to deal with the new demands; no tools or patterns are available; they need to be developed.

My interest in exploring personal experiences of dealing with a life-threatening illness emerged unexpectedly during a gathering where three women were telling each other their life stories. One of us had survived cancer of the colon in her late twenties and has been without any symptoms for the past five years. I could not take my eyes and ears off her and asked her all kinds of questions. She finally told us this amazing story of how she explained the beginning of her disease.

Her first reaction when her doctor told her about her physical condition was that she connected it with the stress in her life at that time. She admitted though that she also instantly remembered an incident which happened about three years prior to the doctor's consultation. She drove on the highway over some black waste a truck in front of her had spilled over the lanes. That same evening she heard on the news that anybody who happened to drive on that particular freeway should get their car detoxified. It took her about a week to get an appointment. The potential danger to which she was exposed she only realized when she brought the car in. "It seemed as if I entered a space station," she said. Two men completely protected by special suits thoroughly cleaned the inside and outside of her car. Somehow she figures that driving over the toxic waste on the freeway was the beginning of her cancer, although her rational mind discards that notion as irrational and therefore impossible.

What intrigued me most about her fantasized onset of the illness -- I also call it the beginning myth -- was that she was embarrassed about her explanation, telling us that it was completely irrational and did not really make any sense. This started my thinking in a new direction. I realized that I wanted to do a project that used an interactional style, where I delved into the mysteries of the mind and the body, together with people whose lives had been seriously threatened at one point. My passion lies in learning more about people and life. I want to engage other people in the quest of finding meaning out of difficult life experiences by focusing on irrational and unexpected fantasies and exploring together how the discarded thoughts and feelings might be connected to the myths of their lives.

From the beginning of this research project, it was clear that personal contact was important. I wanted to use a true beginner's mind. I also wanted to let myself be guided by the unknown as it would reveal itself throughout the research process.

So far I have not experienced a life-threatening illness myself. I still feel like a real novice when it comes to dealing with body symptoms and illnesses. While I was in the middle of my research I had the following dream:

I did an interview with an old friend of mine. He told me that he had cancer six times in his life. The first time was as a six-month-old baby living with his teenage mother under a bridge. In the course of the interview, I find out that my friend had already died. He had come back from the dead to do an interview with me because he had an important message for other people. He needed to tell his story.

The dream revealed that some part of me -- represented by my old friend -- must have a lot of experience with life-threatening illnesses. It had survived cancer six times already and came back from the dead because it had an important message! Where in my life did I experience traumatic events that killed off a vital part in me? The strongest body memories are around temper tantrums I used to have as a young child. I would scream until my face turned blue. My inner nature came up against restrictions on the outside.

Arny Mindell (1985, 1989) -- whose work is centered around developing a comprehensive and positive approach towards body symptoms -- connects this kind of process with the Grimm's fairy tale called "the spirit in the bottle." According to his expertise, body symptoms and illnesses are bottled up experiences of our true inner nature. In the bottle lies the totality of our human potential: the healer, creativity, magic, anger, etc. The bottle represents all the reasons we are not able to live our wholeness: parents, school, church, country, environment, etc. The spirit inside the bottle shows itself in cramps, body symptoms, lumps, anger; it tries to find loopholes where it can get out and live.

Interviewing people who had experience with a life-threatening illness was a format for me to start an "Auseinandersetzung" with health and illness, life and death. It offered a starting point from where to philosophize about the meaning of life and change.

I started out pretty naively without much knowledge and understanding of what it is like to have your life threatened by an illness. In the course of my research I met some remarkable people. They helped me to gain an understanding of the struggles and mysteries of life and death matters. Their stories touched me emotionally and started to work on me internally. I began to think more deeply about my life and my own mortality. I caught a glimpse of what it is like to feel your own body's decay and to lose control over its basic physical abilities. I imagined my life becoming totally unpredictable, not being able to plan ahead because I might be too tired or feel too sick. I also wondered which friends would be able to tolerate my anger at God and the world, who would stick with me when I became dependent and could not return favors anymore, who would be willing to share closeness and intimacy when I might leave them soon for another world.

My life has been enriched by the people I met and the stories I was told. While I encouraged and supported their discarded and unappreciated fantasies, they in turn taught me to look closely at my life, to remember that I am not in control of it and to therefore appreciate life while it lasts. I hope that the reader will have a similar experience; that he or she will be guided by the stories and open up to the other side of life which seems to lie close to the abyss from which new life and meaning sprout.

Not everybody survives. For some people it is time to make that ultimate transformation and face death at a seemingly young age. The first person I interviewed has died since. I only met her once for the interview. I am grateful that we had that time together. She encouraged me with her enthusiasm and openness to believe in my project when I was still at the very beginning. It was a relief to her to be able to talk about her excitement about death and what she imagined might lie ahead. She had not shared this fantasy with anybody before because she feared that she would not be understood and supported.

Writing about illness cannot happen in a purely scientific form. An atmosphere needs to be created where mystery and magic have a place. I believe that insight and understanding can slowly seep into all of our lives and I hope that this work will strike a cord inside the heart of the reader. Illness takes us beyond our known ways of being. Being struck by a life-threatening illness will sooner or later stretch one's identity. It means looking at the meaning of life and death, facing one's mortality, discovering what it is that is worth living for. Living the message inherent in an illness implies stepping out of the known patterns of behavior.

CHAPTER II: TOWARDS AN UNDERSTANDING OF ILLNESS PROCESSES

This work is an attempt to understand more about the mystery of illness. It is based on the philosophy of process-oriented psychology developed by Dr. Arnold Mindell (1982, 1985, 1989, 1993), with a particular focus on the ideas and attitudes regarding illness processes. My intent is to add to the existing body of literature in this area a study that investigates the discarded fantasies and irrational ideas regarding the onset of a serious illness and explanations for the illness. Memories of the actual physical experience and changes triggered by the illness will be explored. This study will also focus on possible teachings for the larger society which emerged from the personal illness experiences.

This research attempts to show that, even though an illness is usually seen as something one wants to avoid or cure, it can become an important and meaningful life experience. Illness can become a resting point for reflection and growth, an opportunity to look at one's inner truth.

In the following literature review I will present works from different fields of study including medicine, psychology, and religion. The focus of this review will be on the connections of body, mind and soul, health and illness, living and dying, and healing. I will also look to writers, poets and artists for inspirations and answers to questions of life and death matters.

Towards a holistic medicine

A serious illness involves the totality of a person's being. For healing to occur, the person needs to be addressed not only from the standpoint of his or her physiology; the emotional and spiritual well-being of the person need to be included as well. A holistic medicine understands a person's illness in the context of his or her life as a whole. This more holistic approach reconnects to ancient wisdom and finds support in recent research in medical science[1].

Medical technology has dramatically improved over the past hundred years. Many of the known infectious diseases which could wipe out large percentages of a region's population are under control in the Western world; they can be prevented by immunization and treated by administering medication. Although medicine has greatly advanced its knowledge of the biology and chemistry of the human body and is skilled in intervening and treating disease processes, illness is still prevalent and almost everyone will be affected by it at one time or another. Many illnesses are not fully understood and cure is not available yet. New and unknown diseases afflict the human body -- environmental diseases, AIDS -- and challenge the medical profession. It has become apparent that in order to find a comprehensive model of illness and health, some prevalent ideas in Western medicine need to be revised[2].

Western medicine usually approaches illness from a causal perspective and focuses locally, onto the area affected by the illness. Doctors and medical researchers search for agents that interfere with proper functioning of the human body on the chemical or physiological level. Medical interventions are used that directly influence the chemistry (by administering drugs) or the structure of the body (by surgery). I would think that where neglect (if not denial) of social, psychological, and religious factors happens in medical research as well as practice, it is in order to stay "scientific" and only deal with variables that are controllable. Although this approach has influenced and furthered general knowledge of the human body a great deal, it shows limitations when it comes to assisting people with their illness experiences.

Since around the turn of this century when psychology became a separate field of study, some researchers started to explore the influence of the mind on physiological processes, thereby creating the field of psychosomatic medicine[3]. An understanding developed that certain illnesses are predominantly influenced by the psychology of the person and seem to be a physical reaction to certain life experiences. According to Zimpfer (1992) the interest in psychosomatic medicine declined because its overgeneralized claims (e.g., the "ulcer" personality) could not be supported. In more recent years, people who survive so-called incurable and terminal physical conditions and patients whose bodies do not seem to follow the expected outcome of medical treatment triggered physicians and medical researchers to look more closely at the relationship of body, mind and the soul[4].

Lawrence LeShan, a clinical psychologist, has worked with cancer patients and researched the link between cancer and the patient's emotional life since the 1950s. LeShan (1990) found that before 1900 the relationship between cancer and psychological factors was commonly accepted in medical circles. Without any sophisticated instruments at hand, a physician needed to listen carefully to the patients in order to come up with the right diagnosis. During this process people would also talk about their emotional well-being. "The factors of great emotional loss and of hopelessness occurring before the first signs of the cancer were so repetitive and frequent that they could not be ignored." (p.7) It seems that with the advancements of medical technology, the improvement of surgical procedures, and with the availability of radiation, cancer became a local disease of a specific part of the body rather than being seen as an aspect of a total human being's functioning.

LeShan, in his psychotherapeutic work with cancer patients, came to the same conclusion as the physicians a century before him. In a large majority of the people he saw, some overwhelming personal loss had happened as a precursor of the disease. They often lacked meaning in their lives and felt hopeless about ever achieving what they really wanted from life.

Hans Selye (1956) originated the concept of "psychological stress" and its effect upon the general well-being of human beings. His work influenced and changed the prevalent attitudes in Western medicine at that time; the image of the human body as a machine with independently working parts slowly transformed into the concept that the human body works as a an intricate information system. As medical research gains more and more understanding of the different systems in the human body, causal and mechanistic explanations about the nature of the human body become too limiting. Below, different books and articles, published over the past decade, will be presented which focus on the interface between and the connection of body and mind. The traditional field of psychosomatic medicine is being expanded, and is newly referred to as psychoneuro-immunology[5].

Psychoneuro-immunology describes the complex interactions among the nervous system, the immune system and the endocrine system. It focuses on how actions or events -- on the level of the body as well as the mind -- have an effect on the totality of the being. Findings in the field of psychoneuro-immunology contradict the dualist separation of body and mind which has been prevalent in Western medicine. The focus in medical research has thus shifted from studying the mechanics of the body to exploring the communication system inherent in the body's physiology.

Locke and Colligan's book The Healer Within (1986) presents an extensive study of the new science of psychoneuro-immunology. They include: a brief history of psychosomatic medicine and how it developed into psychoneuro-immunology, a thorough description of the immune system, and a compilation of studies supporting the premises of psychoneuro-immunology. These premises state that the immune system is sensitive to outside influences and that there is communication between the nervous system and the immune system. In addition, Locke and Colligan explore ways in which emotions and attitudes, both negative and positive, can affect ones health and the treatment of illness. The authors state that "appreciating the role the mind plays in these disease processes is the first step to developing a new body of medicine." (p.132) A new body of medicine would include more of the natural healing mechanisms inherent in all of us and support a more holistic approach of healing.

Justice's book Who Gets Sick? (1988) is very informative on the topic of how mind and body interrelate and work together. By doing an extensive literature review, the author finds evidence that beliefs, moods and thoughts affect the body on a physiological level and vice versa. He believes that "disease is not so much the effect of noxious, external forces ... as it is the faulty efforts of our minds and bodies to deal with them." (p.28) "How we look at a stressful situation, the attitudes and beliefs we bring to the problem, influences what chemical messages the brain sends the body." (p.55) The author stresses the biopsychosocial risk-factor concept over the germ-theory. In other words, being exposed to certain germs does not make everybody sick; there are biological, psychological and social influences that may spare people from becoming ill. Life situations which are perceived as stressful and cannot be resolved effectively lead to feelings of helplessness and hopelessness and therefore to an increase in ones vulnerability to disease. Whatever provides an increased sense of control -- optimism, happiness, hope, love, humor -- seems to mobilize the self-healing systems.

In her book Deceits of the Mind Goldberg (1991) defends an interesting hypothesis: she assumes that there is a parallel process happening on a physiological and a psychological level. Her notion of disease is that it ".. reflect[s] a condition of too much response, or not enough. Diseases are the organism's being out of touch with reality; the reaction to the stimulus reflects an incorrect evaluation of the danger or innocuousness of the stimulus." (p.79) In cases of cancer, the body fails on the physiological level to recognize that an unwanted and potentially destructive intruder is in its midst; and, in spite of profound changes taking place within the organism, there may be no signs or symptoms for a long time. On a psychological level, Goldberg postulates, cancer patients have a tendency to unrealistically assume that the world is "cotton-candy" and are underresponsive to hurtful experiences.

> The mind of the cancer patient seems to be in stark contradistinction to the functionings of the body. Cancer within the body is a state of wild expansiveness, growth unchecked by any normal control apparatus. The mind of the cancer patient is, in contrast, characterized by constriction - a control too tightly held... It looks as though mind and body are operating in some compensatory fashion. (p.167)

The pioneering research in the area of mind/body medicine supports the concept that in order to successfully treat serious and life-threatening illnesses not only medical but also psychological, sociological and spiritual aspects of the person suffering from the illness need to be considered. Looking also at the social and environmental impact of diseases such as AIDS and environmental diseases, I believe that a comprehensive theory of disease will need to incorporate knowledge of the body, the mind, the soul, and the world around us. The findings also show that the body has inherent wisdom and intelligence to convert a destructive, disease-producing process into a constructive, healthy end.

Carl Simonton and Stephanie Matthews-Simonton (1978) have devoted their lives to the discovery of ways the psyche can assist the healing of the body. They are pioneers in the field of researching the psychological causes of cancer and finding ways to treat cancer with psychosocial means. Their studies explored how an individual's reaction to stress and other emotional factors might have contributed to the onset and progress or the recurrence of a disease. They developed detailed instructions to help patients recognize and deal with these elements in their lives. The Simontons found visualization to be an effective tool for influencing the immune system and reducing stress. The goal of their work was to encourage people's participation in their own healing processes by using the powerful therapeutic tools of mental imagery combined with relaxation and self-hypnosis.

Jeanne Achterberg (1985) offers a comprehensive survey of the impact of imagery in the healing arts, past and present.

> Imagery has always played a key role in medicine.. Imagery is the thought process that invokes and uses the senses: vision, audition, smell, taste, the senses of movement, position, and touch. It is the communication mechanism between perception, emotion and bodily change. (p.3)

The human mind has an incredible capability to use imagery, fantasy and memory to evoke a diverse range of states of consciousness. Access to these states can mean access to healing.

For Norman Cousins (1989) hope is the crucial aspect in summoning a person's inner healing resources. Any person who is suffering from a serious illness needs reassurance. A serious illness is a terrifying experience; anybody afflicted by it, reaches out not only for medical attention but also for ways of thinking about illness. Cousins sees the relationship between doctor and patient as very important. A good physician carefully listens to patients, knowing that the stories people tell may contain valuable clues that can assist in healing. The author points out that a doctor needs to respect people, be sensitive towards them, establish good communication and have an understanding of the overall impact a serious illness can have on a person's life. In his own recovery from a serious illness, Cousins found "laughter-therapy" very useful. Laughing releases endorphines, the body's own pain medication. Therefore, watching funny movies or reading books that make you laugh can have positive therapeutic effects.

Cousins' work is mainly associated with promoting laughter as a healing tool and with stressing the need for hope for anybody who experiences a serious illness. I particularly value his contribution regarding the doctor - patient relationship. Doctors have a powerful role and can be the main source of hope or despair. Their expertise lies in treating the physical body; yet the success of treatment seems to depend a lot on a doctor's ability to establish a good rapport and an observant relationship with the person in need of treatment.

Deepak Chopra, in his book Quantum Healing (1989), focuses on the untapped potential in all of us. His experience as a medical doctor treating people with serious illnesses led him to believe that deep within us lies a network of intelligence which can change the basic patterns that design our physiology. He also suggests that our mind has the potential to defeat serious illnesses like cancer. "Consciousness is a force that most of us undervalue. Generally we do not focus on our inner awareness or use its real power even in the most difficult moments of crisis" (p. 18). Chopra found that people spontaneously healing from a lethal cancer appeared to have gone through a dramatic shift in awareness just before their illness took a magic turn. The dramatic shift usually meant finding some way to become hopeful, courageous and positive. Chopra's book stresses self-awareness as a way to find healing.

Siegel (1989) believes that people can use illness to help them redirect their lives. In his book Peace, Love and Healing he states: "I suppose, in the broadest sense, my book shows how illness or suffering can heal not just the individual but society." (p.5) Like Chopra (1989) he refers to studies on people who recovered from incurable diseases. He is convinced that an existential shift occurs prior to the healing where the person for the first time in his or her life is truly living. Siegel learned from the studies of the placebo effects that a change of mind can alter what takes place in the body. People have access to healing states when they are able to open up to experiences and perceptions that lie outside their current identity and everyday reality. Siegel suggests mind-altering techniques and experiences (for example, meditation, visualization, love, or the mere experience of being close to death) to help a person get in contact with the possibility of change and healing. Finding peace of mind and happiness through acceptance of one's core being might be the ultimate way to truly live until we die.

LeShan (1990), a pioneer in researching psychological therapeutic techniques for people with cancer, believes that if people are able to truly live their own lives, the immune system recovers its strength. In his therapy he helps people to rediscover zest and enthusiasm in their lives. His methods focus on the positive aspects of a person; he is interested in what is right about the person, and what is the person's most natural way of being, relating, and creating. The emphasis is on individual approaches and solutions.

Dossey (1991), a physician who recently broke with conventional scientific medical thought, recognizes the connection between mind, meaning and illness. His book Meaning & Medicine is a collection of stories from his medical practice. The stories demonstrate that the meaning people attribute to their physical state has a crucial impact on their health and well being. This often unconscious meaning might determine whether a person lives or dies. He saw people unexpectedly die as well as recover because of the meaning they attributed to certain circumstances or the hope that was instilled through a meaningful coincidence.

Arnold Mindell (1982, 1985, 1989, 1993) comes from a Jungian tradition. C.G. Jung's basic philosophical thinking about human beings and the world is still very present in Mindell's works[6]. As a theorist as well as a practitioner he goes beyond Jungian analytical practice, especially in regards to the significance of the body. Mindell has generalized and extended the importance of "dreaming." According to Mindell dreams not only happen at night while we sleep; they also pattern body processes.

> Dreams are snapshots of body experiences that are trying to happen, and body experiences mirror dreams. I call this symmetrical connection between snapshots of dreams and the body the dreambody. (Mindell 1993, p.22)

The dreambody can be understood as a unifying principle which sends information; it reveals itself in dreams, body symptoms, fantasies, attractions, relationship problems, conflict, and other unusual experiences that are trying to reach everyday awareness. The information of the dreambody is often experienced as a disturbance and has a "not-me-quality" to it.

> The essence of the dreambody can only be approximated through symbols, just as the essence of matter is only vaguely described in terms of theoretical physics. Uncertainty guards a secret from intellectual formulation and forces each individual to experience the world personally, as if nothing were known. (Mindell 1982, p.174)

According to Mindell, body symptoms and illnesses are significant and meaningful biological processes, rather than chaotic, destructive or pathological states. With the help of amplification the information within body symptoms can be accessed. Thus, the meaning of an illness is processed and can be used to enrich a person's life. Bringing awareness and appreciation to the dreambody's information is the main goal of Mindell's work. (A thorough description of process-oriented therapeutic techniques developed by Mindell which help to access information in body processes will follow in the chapter "theoretical framework.")

The implications of Mindell's work are far-reaching. He not only suggests a way of working with symptoms and finding the meaning in an illness, he also focuses on a necessary shift in thinking about illness and disturbances. Acknowledging and appreciating whatever we experience as potentially useful and meaningful information of a larger unifying principle, demands the life attitude of a warrior.

Philosophical implications come out strongly in Mindell's latest book The shaman's body (1993), where he states the following:

> The body wants to dream. It needs to reduce stress and also to become the creator of trouble. It wants to live at the edge of the unknown and gets weak if it is only protected or "healthy." The dreamingbody requires more than wellness; it wants challenge, risk, personal power, and freedom... The dreamingbody will never be healed through healthy living alone, because it seeks the uncanny, at the edge, through dreaming. (p.153)

Mindell invites us to be full of heart and courageous with ourselves and the world around us. His approach urges people to take their own perceptions seriously and to be willing to unfold their experiences whatever they may be. Symptoms and troubles are understood to be disturbing and problematic only from an ego-perspective. We all have access to states where different rules govern and symptoms survive.

There are many more books available that focus on the psychosocial treatment of serious illnesses (e.g., Hay, 1987; Pearsall, 1987; Roud, 1990; Pelletier 1991). The following is a brief summary of the different approaches suggested:

- usage of relaxation and mental imaging to reduce stress and enhance medical treatment
- educating a person regarding their beliefs about the disease progress and treatment
- eating healthy food and getting enough exercise

- using different types of therapy in order to find a well-balanced, satisfying and interesting life on personal, interpersonal and spiritual levels.

The goal generally is to access the person's inherent healing potential, to reduce destructive attitudes, assumptions, beliefs, and behaviors and therefore to restore health.

Personal illness experiences

In order to understand more about illness processes, I started to look at works describing people's first-hand experiences of serious illness.

Epstein's (1989) book describes her journey from conflict and illness to wholeness and health. It is a personal account of her experience with kidney cancer. The author talked mostly about the psychological aspects she saw as self-negating aspects of her personality. She described how she learned of herself as a cancer prone personality and how she detected over time that she lived most of her life with a "hollow self." Traumas in early childhood were seen as responsible for "splitting off" certain parts of her personality. She became painfully aware that her focus in life was wanting to please other people. She discovered that she was not able to be happy with her successes and to do things for her own enjoyment, independent of other people's needs. In addition to the necessary medical treatments, the author used meditation, self-affirmation techniques, Simonton's visualization techniques and psychosynthesis. Her physical recovery was accompanied by deep changes in her personality.

> My battle with cancer was one of the most significant experiences of my life... Its most lasting effect is a dramatic change in my attitude toward living... Now I celebrate each birthday as a triumph that I have lived to experience another year. It is a shame that it took a life-threatening illness to bring about this change, but I am grateful that I have learned at last to appreciate the gift of life. (p.204)

Dealing with a life-threatening illness can be a long-term process which not only impacts the person directly affected by the illness but also their environment. Adjustment and change needs to happen on a physical, psychological, spiritual and social level.

Kleinman's (1988) book The Illness Narratives focuses on the psychological and social aspects of chronic illness. In a collection of detailed personal accounts of chronic illness experiences, Kleinman provided examples of how a chronic illness can change people's lives: some individuals had to give up their jobs while others had to live under strict limitations due to their extreme sensitivity to sound and light. The author points out some of the positive sides of an illness experience as well. These included the opportunity to focus more on the body and to take time to grieve past and current losses. The stories are written from the perspective of a compassionate physician who emphasizes the need for a more holistic approach in medicine. Kleinman states that a good doctor needs to listen to all aspects of the person's life and to take the stories seriously. A good doctor will also pay attention to the "not-being-able-to-heal" and acknowledge the suffering that goes with the seriousness and chronicity of certain illnesses.

Kleinman comes to the conclusion that there is a fundamental teaching in chronic illness about the human condition, with its universal suffering and death and the inevitable process of mourning losses.

> The moral lesson illness teaches is that there are undesired and undeserved pains that must be lived through, that beneath the facade of bland optimism regarding the natural order of things, there is a deeper apprehension of a dark, hurtful stream of negative events and troubles. Change, caprice, and chaos, experienced in the body, challenge what order we are led to believe - need to believe - exists. (p.54)

The illness narratives are very detailed and self-explanatory; they speak for themselves. Kleinman's main purpose seems to be to show the person behind a physical condition. Illness is often accompanied by psychological suffering, feelings of shame, failure, and alienation on the side of the ill person due to the way the world of the healthy deals with illness. Kleinman appeals to the healthy people to show compassion and understanding for the ill person to avoid additional hardship caused by society's attitudes.

Kleinman points out that illness introduces change, caprice, and chaos on a body level; the belief that we can stay healthy and youthful forever is disturbed. The author feels that those interferences are part of the human condition, even though we try to ignore them while we are healthy. People who have to live through chronic illness need support and understanding for their suffering. In my research I want to go a step further and explore the individual process of a serious illness. I suggest ways to use fantasy in order to unravel the caprices of nature which show up in troubling body experiences. My hope is that a certain awareness of the body symptoms will help the person experience and live with the physical condition in a way that is -- at least on an emotional and spiritual level -- life-enriching rather than life-confining.

Hunt, Jordan & Irwin (1989) approached the subject of how people explain their illness experiences from an anthropologist's angle. The purpose of their study was to discover how people utilized their doctor's information to explain what was going on in their bodies. The authors were primarily concerned with two issues: 1) the resources which individuals bring to bear when making sense out of what they experience, and 2) the process of finding an explanation for their illness experience.

The women they interviewed (four times over a time span of about six months) were experiencing very common but nonspecific and indefinite physical symptoms. The authors made the following discoveries. The women's explanations of what was wrong with them fluctuated over time. The interaction with the medical profession was not central to how they explained their physical experiences. People tenaciously held onto their own explanations even if they did not coincide with the doctor's explanation. Diagnoses were interpreted, changed and integrated into prior concepts of their illnesses. The authors found that illness explanations ".. were used to give meaning to important life stages, to exonerate socially unacceptable behaviors, and as justification for certain social action." (p.955)

These findings are interesting. The authors only describe the phenomenon; they do not offer any answers as to why the women's own opinions about their illnesses would be more relevant than the doctor's advice or medical evidence. If we assume that there is such a thing as a "disease process," that is, a meaning of a life course of an illness, then we might see that the women's illness did not respond to the treatment of an authority, if the possible meaning was overlooked.

In her book The Power Within (1990), Wendy Williams relates personal stories people told her about their experiences with life-threatening illnesses. The stories are documentary reports, covering the whole span of the course of the illness experience, from the first discovery of a lump to magnificent life changes and to death in some cases. She had people describe the different medical treatments they underwent, the impact the illness had on them physically, emotionally, professionally and socially. The stories are very touching and powerful. In each case, the person seemed to go through various stages. In a beginning stage, a person would usually experience shock, a sense of terror and being overwhelmed by the diagnosis. Various medical treatments would then fill the person either with hope or despair. Gradually a person would learn that there was life after cancer. A process of slowly confronting fear would allow unexpected and special resources to emerge and to transform the terrifying experience of having looked into death's eye.

One person experienced her illness in the following way:

> This sense of the disintegration of physical limitations was a key experience in shaping my future, an experience which would return in future crises. Life, I learned, is something different from my usual, everyday, three-dimensional perception. The essence of life is not the human body, but an integration of body, mind, and spirit. (p.97)

Pepper (1984) and Shook (1983) fall into the same category of books whose central topic revolves around personal stories of men and women who survived cancer and beat the odds. Beliefs are offered on what seemed crucial to recovery and how the illness changed people's lives. These are books that can give hope to anyone afflicted by a so called incurable physical condition. Pepper (1984) wants to convey another important message.

> These survivors possess an innate sense for beauty, for goodness, and for truth or perfection... It may be hidden within them, it may alternate with extreme cruelty, cowardice, or treachery. Yet it is inevitably there, and we observe it most clearly in these men and women as they emerge from their crises, after facing the possibility of dying. (p.2)

The author points out a certain moral sensibility, reverence towards life and humanity that people seem to gain from their illness experience. Impending death can be a driving force for change as it dismantles the protective structures people have built around themselves. Pepper (1984) comes to the conclusion that five factors appeared to be determinant in eventual survival: love (being loved or loving), self (being able to hold onto a sense of self-determination and control), need (being needed by others for their survival), luck, and getting the best treatment possible. The first three criteria are mentioned by various healers as essential to healing. I will go more into the topic of healing at a later point.

Relative to their importance in our lives, illness experiences have not been widely addressed as a literary subject. Recently, there are more and more authors telling their stories. I have come across some wonderful books in which the authors shared their own trauma and struggles with a life-threatening illness and communicate their experiences with the larger public. In these personal accounts I often found a different approach to illness than in the literature where doctors or psychologists presented their views on what helps in dealing with an illness. Some people who had lived through a serious illness described how the illness that first appeared as the "enemy" to be eradicated, transformed into a useful advisor. Illness was given - or, more so, had to be given - space and time to express itself, thus transforming its meaning for the person.

Broyard (1992), a journalist and author before he fell terminally ill with cancer, stated: "My intention is to show people who are ill - and we will all be ill someday - that it's not the end of their world as they know it, that they can go on being themselves, perhaps even more so than before." (p.61) His book reflects a great sense of humor, artistic talent and a lot of soul. It shows how the man valued his own experiences and let them be his guide. "A critical illness is like a great permission, an authorization or absolving. It's all right for a threatened man to be romantic, even crazy, if he feels like it. All your life you think you have to hold back your craziness, but when you're sick you can let it out in all its garish colors." (p.23) For the author, the illness opened the door to another side of himself. He could let go of social conventions and experience a new sense of freedom. It seems that his illness brought him in touch with another reality in which the rules of society no longer applied.

Kat Duff fell ill with chronic fatigue and immune dysfunction syndrome in her thirties. Her book The alchemy of illness (1993) is a woman's pondering of the internal states triggered by a chronic illness. She suspects that illness is an attempt to embody the whole truth and to remember all of ourselves. The author comes to the conclusion that illness represents a part of who we are all the time.

> Sometimes I think we would lose ourselves altogether if it were not for our stubborn, irrepressible symptoms, calling us, requiring us, to re-collect ourselves and re-orient ourselves to life. The longer I am sick the more I realize that illness is to health what dreams are to waking life - the reminder of what is forgotten, the bigger picture working toward resolution. (p.33)

Duff proposed that a serious illness follows the stages and requirements of traditional initiation ceremonies - separation, submergence, metamorphosis, and reemergence. By comparing an illness experience with an initiation ceremony Duff brings a spiritual component to the experience of a serious illness. Illness could be seen as a powerful introduction into the spiritual realm, where the person encounters the central challenge in her life and finds the necessary wisdom and strength to follow her path of heart.

Laura Chester (1987) movingly writes about her experiences with lupus erythematosus, a chronic connective tissue disease involving the immune system. Years pass by while she is trying different healing approaches, which are more or less successful. It becomes apparent that dealing with a serious chronic illness means dealing with the unpredictable. The body becomes unreliable. The present and the future become uncertain. There are no guaranties, no securities left. Fear has crept into life: the fear of pain, wasting away, losing control, and facing death. The illness made her aware that the body has its own ways, its own rhythms.

Another literary jewel on illness experience and the effect it has on family and friends is Refuge, written by Terry Tempest Williams (1992). Her mother's dealing with ovarian cancer coincides with the process of the disappearing Bear River Migratory Bird Refuge at the Great Salt Lake in Utah. An avid bird watcher, poet and naturalist, the author parallels the experience of seeing a familiar, soothing place in nature change drastically with the experience of witnessing her mother's dying process. She beautifully interweaves narratives of her mother's dying process, the accommodation of the whole family to what is happening and transforms tragedy into a document of renewal and spiritual grace.

Bryce Courtenay (1993) makes his son's living and dying process the center of his moving book April Fool's Day. Damon dies at age 24 from medically acquired AIDS. As a hemophiliac, he was in need of blood transfusions on a regular basis since birth. Most of his childhood was spent in pain. A slight knock could cause severe internal bleeding that needed to be attended to in the hospital. At an early age, arthritis in his joints made it difficult for Damon to walk. Despite all the difficulties related to his severe medical condition, Damon hardly ever complained. He is described as a very courageous, brilliant and humorous person, who early on discovered and experimented with the power of his mind. He deals with the AIDS-diagnosis as he dealt with hemophilia: quietly and with a lot of courage and self-determination to fully live until the end.

Shortly before his death Damon noted the following in his "diary of the mind:"

> Love is the most powerful force of all. It is an energy, it is a power. I must use it constructively. I must stop listening to the negative forces in my head that tell me that it is beginning to end. I want to give so much to this world to the people that I love. (p.413)

The book addresses the rage the family felt towards the Australian government that ignored international warnings regarding infected blood donations in the early and mid-80s. The lack of government ruling and the unavailability of testing for the HIV-virus until 1984 was responsible for a large percentage of hemophiliacs' infection with the HIV-virus. Ultimately many of these individuals died from AIDS.

Positive Women (1993) is an international anthology of works presented by women who are living with the HIV-virus or are suffering from AIDS. The editors Andrea Rudd and Darien Taylor, both HIV-positive themselves, collected women's responses to their illness and offered these women a place to tell their stories. The editors included a broad range of submissions. Visual as well as written material is presented. Through their worldwide networking, the editors realized that HIV-affected women were often living in profound isolation, deep fear and loneliness.

Despite the struggles and difficulties associated with AIDS, these stories are not about despair. They are a broad spectrum of writing from women all over the world and from all walks of life. They are emotionally moving accounts of women who talk about their feelings, struggles, their love and the personal growth triggered by the illness. They also talk about the social stigma associated with AIDS and the lack of information especially in some of the poor countries on this planet. One woman noted that it was important to her to convey that women living with AIDS are daughters, mothers, wives, lovers and activists. "We have moments of joy and ecstasy and also sadness and fear. We have moments of strength and moments of vulnerability. We laugh, we cry, we live - just like everyone else." (p.215)

Some of these stories shatter myths. Lori Lynn Ayers is one of the women one would not expect to be living with AIDS. Before she found out that she was HIV-positive, she was pursuing money, career, possessions: the Great American Dream, as she calls it.

> No one was more shocked than I when I received my diagnosis... I didn't realize then what is so wonderfully clear now: that this diagnosis would turn out to be an incredibly positive force for change in my life. I'm not saying I'd prefer to carry this virus around in my body. But it's there and I appreciate the life lessons and changes that have happened because of it and am deeply grateful. I've learned and grown more this year than I ever would have, left to the complacency of my old life. (p.22)

These personal illness experiences speak for themselves. They help to bridge the gap between the world of the healthy and the world of the ill. Sharing brings us closer together. Some of the myths the culture has about certain illnesses are shattered. Illness is prevalent; it can happen to anyone.

Illness and creativity

Art has been enriched by musicians, poets, and painters who have used their illness experiences for creative expression. Sandblom (1992), a medical doctor with an interest in the arts, studied the connection between artists' suffering of a physical or mental illness and their works of art. He portrays a large number of famous artists who suffered from an illness and includes their own statements on what their illness meant to them and how it affected their works. He found different kinds of connections between illness and creativity: for several artists it seemed that their work of art was a way to express how they saw their own illness. An example was the surrealist Mexican painter Frida Kahlo. Kahlo suffered from an anomaly of the spine called spina bifida. She also had polio as a child and later was badly injured in a traffic accident. Several of her self-portraits represent her ailments in artistic form. She painted her injured spine as a broken pillar holding up her head (The broken column, 1944). Her feet in the bathtub show the typical lesions due to her illness (What the water gave me, 1938).

Renoir continued to paint although his hands were severely deformed by arthritis. The severely affected hands are noticeable in a self-portrait painted in 1914. Matisse witnessed him and spoke the following: "A lengthy martyrdom -- his finger-joints were swollen and horribly distorted -- yet he now painted his best works! While his body wasted away, his soul seemed to gain strength and he expressed himself with increasing ease." (Jack, D. 1973, Matisse on art. Quoted in: Sandblom 1992, p.4)

Creativity can be a solitary activity. For some artists their illness provided them with a refuge from worldly activities. Matisse's life was changed when he became ill with appendicitis -- which at that time could not be surgically treated --: he had to refrain from his legal profession. As a diversion he started to paint and became obsessed with it. The necessary idleness due to ill health gave room for a dormant talent to be awakened and developed. An illness had brought on a pioneer in modern art.

It is said that Gustave Flaubert's disgust and boredom at law school, combined with the solace he sought in the bottle, promoted the onset of epilepsy. His illness secured his return home where he could engage in his favorite activities of dreaming, reading and writing.

Tuberculosis affected numerous famous writers of the past. Anton Chekhov suffered from tuberculosis. Novalis, a German poet of the romantic period, died of tuberculosis at age twenty-eight. These are his thoughts on illness: "Could disease not be a means of higher synthesis, a phenomenon into higher powers?" (p.24)

In rare circumstances, illness provided the artist with "a special talent." Paganini, the famous violin virtuoso, benefited from the effects of a congenital disease. He had hyperflexible joints, which made it possible for him to bend his fingers in a way that helped his playing of the violin. Sandblom comes to the following conclusion about the way artists dealt with their illnesses:

> Realizing that some of the greatest art has been born of suffering, one is led to conclude that illness sometimes enriches the artist, his fellow men and posterity... One reaction is consistently present in the majority of artists, whatever their illness, namely a remarkable stoicism, even heroism, when confronted with this sort of ill fate. The urge and endeavor to achieve an original creation, to immortalize a personal conception, may overcome even extreme suffering. (p.180)

There is a body of literature from psychotherapeutic practice in which dreams and creative expressions are used to help with the illness process. The focus is on illustrating the psyche's coping mechanisms in view of the possible fragmentation of the personality as the mind watches the body deteriorate. Wheelright (1981), a Jungian therapist, recorded her work with a young woman named Sally who was dying of cancer. The author presents Sally's dreams and her own interpretations of them, thus showing a remarkable transformation that could take place. Many of the dreams had ancient mythical images and symbols in them. A recurrent theme was the cat, which showed Sally's struggle to come to terms with all parts of her feminine nature. The therapist's careful dream work and her commitment and compassion not only helped Sally deal with her suffering and her illness, but also helped her find fulfillment and a sense of completion in her life.

Bosnak (1989), also a Jungian analyst, assumed a similar task. He describes his experiences in working with a young man dying of AIDS. The book presents the man's dreams and his analyst's interpretation. The dreams reflect the man's conflict between his fundamentalist Christian upbringing and his gay life. They bring up feelings of self-blame, guilt, and fears of isolation.

Both books use Jungian dream work to access the healing power of the imagination. It is interesting to see that in the dreams the dreamer is rarely represented with an ill body. In the "dreamworld" physical reality can be transcended. This seems to be another confirmation that there are parts in us that are not concerned with questions of health and illness. Physical illness and health might be of importance for our everyday consciousness. It would be very limiting, however, to believe that happiness, transformation and growth are only possible when we feel physically well.

The personal illness accounts seem to be a link between the scientific/ psychological approach and the more philosophical and religious questions.

Philosophical and spiritual aspects of illness

Hauerwas (1990), a professor of theological ethics, investigated why illness and death are so troubling to us. He criticizes the medical approach that treats the human body as a sort of machine, where all "real" diseases have specific causal mechanisms which can ultimately be identified and treated. This attitude rules out the centrality and importance of experience, feeling, emotion and interpretation in the phenomenology of sickness and disease. The author states the following:

> The ideology that is institutionalized in medicine requires that we interpret all illness as pointless. By "pointless" I mean that it can play no role in helping us live our lives well. Illness is an absurdity in a history formed by the commitment to overcome all evils that potentially we can control. (p.62)

According to Hauerwas, illness creates silence. From that silence may emerge deep lying suspicions that our lives are subject to arbitrary, capricious powers of destruction and that suffering is meaningless and absurd. We fear that we might lack a life story which would give the illness meaning and make us capable of responding to illness in a manner that would enable us to go on as individuals, as friends, as parents, and as a community. In his words, "To the extent that we think of our lives as a series of discrete events which are open to manipulation by ourselves and others, we invite the assumption that our lives, and our suffering, have no point." (p.123)

Dossey (1985) reminds us that "suffering has always been part of the maturation process of the saint and the mystic... There is a collective statement from mystics of diverse sources that affirms the place in life for difficult, painful experience. Perfection of the spirit is, in fact, impossible to attain without it, we are told." (p.43) Suffering does not only mean experiencing physical pain. Kramer (1993) states that "the worst pain is not of the body but of the mind, emotions, and spirit -- the pain of loneliness, the fear of abandonment, the pain of loss, feelings of guilt or doubt -- these cause the worst suffering, now that palliative care and pain control have become so effective in most cases." (p.39)

On healing

Although medical science has advanced a lot over the last century, when it comes to illness and healing, many mysteries remain. Dossey (1985) reflects in depth on the experience of health and illness in his book Beyond Illness. One of his important statements is that health cannot be possessed, only experienced. Dossey also stresses that health and illness are like two sides of one coin. Illness helps us to become aware of some of nature's and our bodies' functionings.

> Suffering, ill-health, and pain are not so much grotesque facts of life as they are prerequisites for the opening of the doors of perception. Without the conjoined fact of the good and the bad, of health and illness, there is no advance of the spirit, only stasis and stagnation. (p.44)

Dossey thinks that good health places demands on us. It extends to the level of feeling, emotion, behavior, thus challenging the roots of our being. It seems as though we sabotage our healthiness -- by smoking, poor eating habits, sedentary life style. Health not only includes proper body function. It is a way of being that demands our attention and awareness. For Dossey the search for health is a search for wholeness, for the intrinsic oneness that unites the opposites; it becomes a spiritual pursuit which transcends the body and the mind. "Health and illness, when illuminated by spiritual light, are beheld for what they are: the moving principles of each other." (p.179)

Recently I saw an article in the local newspaper where Bernie Siegel was portrayed as "the guy who wrote the book that says people get cancer because they didn't love themselves enough." Dr. Siegel explained that through his own experiences and by listening he found that healing your life is very separate from curing disease. "If someone is loving, they're not sick. That doesn't mean there's no disease." In his mind, exceptional people are those willing to confront whatever is going on in their lives - and try to find their path home. "The point is to live happily. And when the time comes to die, to do it peacefully, surrounded by love - not feelings of failure." (The Oregonian, June 1, 1993)

This article reminded me to be cautious in promoting health and optimism; it is too one-sided. Today's society supports eternal youth and well-being, as well as raising oneself by one's own bootstraps. It makes sense that we favor concepts of health that mainly support optimism, life and growth. With this attitude, though, we cast out the hopeless and unmotivated and deprive the frail of personal power. Healing approaches which teach that you can heal yourself may put personal blame and guilt onto the person who is still ill after trying different approaches. Getting well becomes a chore, a consuming pursuit, work that has to be done in order to belong. It possibly feeds into the very same attitude that made the person sick in the first place. Getting well is not a necessity of the ill person anymore but rather of society's need for the status quo.

Health needs to stay a reasonable goal rather than a transcendent value. Up to a certain point, it lies in our hands to stay healthy: how we listen to the signals of our bodies, the kind of food we eat, how stressful we allow our lives to be, etc. Pursuing ultimate health, however, is an unrealistic goal. Illness is a part of life which cannot and should not be eradicated. Illness and health are like night and day; natural cycles of youth and age, growth and decay.

In cultures that are more in touch with nature the belief is prevalent that healing involves not only the human level but needs to include an experience of the spiritual realm as well. The ill person needs to deal with his or her connection to nature and the divine in order to get well.

Krippner and Villoldo (1987) state in their book Healing states that we each need our own unique healing. The authors find psychiatrist E.F. Torrey's four fundamental principles in effective psychotherapy relevant to successful healing as well. They are: a shared world view that makes the diagnosis and naming process possible; positive personal qualities of the healer that facilitate the client's recovery; client expectations of recovery that assist the healing process; specific techniques, materials, and healing procedures that are appropriate to the illness and conducive to recovery. (p.192)

Their book is an attempt to merge ancient wisdom on healing with the knowledge of modern medicine. The authors visited different shamans and spiritual healers in North and South America and witnessed some of their healing sessions. "The healing traditions of shamanism and spiritism can teach us that as important as healing the sick is learning to maintain our health -- indeed, learning to discover increasingly higher levels of health." (p.200) In other words, we need to be concerned with our overall well-being before we get sick. This would include living a healthy life style, being in contact with our spiritual nature and respecting others as well as the planet we live on.

Carlson and Shield (1989) collected essays from different well-known nontraditional healers. The contributors to their anthology Healers on healing explore the complex nature of healing from many viewpoints. In the following section I will share statements directly from the authors regarding the question of what is healing.

Levine (1987) defines healing as follows: "Healing is the growth that each person seeks. Healing is what happens when we come to our edge, to the unexplored territory of mind and body, and take a single step beyond into the unknown, the space in which all growth occurs. Healing is discovery." (p.4) Levine also notes that "the very question 'What is healing?' is not something that should be answered too quickly; it is only something in which one can participate with a sense of wonder and questioning that is never fully resolved. Like the truth, healing is not something to be known but something to be." (1989, p.201)

Moss (1989) defines true healing as a process of drawing the circle of our being larger and becoming more inclusive, more capable of loving. In this sense, healing is not for the sick alone, but for all humankind. (p.36) Moss understands that all healing is in essence spiritual. It ".. brings each person and humanity as a whole toward a more inclusive, more unobstructed relatedness to all that is emerging in this adventure of life." (p.37) The key to healing is paying attention to the moment.

Kaptchuk (1989) states that "healing is not something we only do when we are sick; it is part of the process and journey of life." (p.105) According to Borysenko

(1989), "we are healed when we can grow from our suffering, when we can reframe it as an act of grace that leads us back to who we truly are." (p.195)

Other important aspects which define healing are: gaining inner peace and letting go of fear, achieving a balance between the physical, emotional, intellectual, and spiritual dimension, rediscovering who we are and who we have always been.

An ill person usually relies on the wisdom and skills of a doctor or healer in order to heal. The following are characteristics a healer should have in order to be most helpful (Carlson & Shield, 1989). A healer needs to be loving. He must have no goal but innocence. She has no judgment against illness and death. A healer needs to be humble and open. She knows about her own mortality. He is aware that the true healer is within everybody. Positive client expectations and a powerful sense of mastery aid the healer in his or her work.

It is stated by many authors from their experience with patients as well as from the personal accounts that healing from a serious illness involves the whole person with all aspects of his or her personality. Therefore the descriptions of what healing means and how it can come about will vary widely. The following is by no means an inclusive set of criteria:

Physical healing can happen when the person truly wants to live and has enough motivation to go on. This includes finding what is most essential to the person and recognizing the part that is really living. There needs to be a willingness and a kind of open relationship to the conditions the person is experiencing. Learning to let go and meet life in a fuller way can be crucial to healing. It seemed to help the healing process if the person found some way of embracing the illness with loving kindness rather than seeing it as an enemy. People who had an attitude of "I am going to beat this thing!" took longer or were not as likely to recover. (This was a surprise to me in view of all the antagonistic vocabulary that is used: "fight cancer," "kill cancer cells," "bombard cells with toxic rays.")

Developing a sense of enjoyment in life, overcoming negative blocks, and developing positive, life-affirming attitudes are conducive to healing. When the patient can perceive and accept his or her own truth, healing can occur. A trusting and honest relationship can be very important. To feel love and be loved are essential for every human being. Time and patience, trust and faith in the process and experiences of silence and solitude further healing as well.

Modern medicine does not have all the answers when it comes to healing physical conditions -- and I want to add: it should not. True healing is an act of grace. When it happens, it does not merely address the physical body; it rather involves the person as a whole. To foster the myth that human nature can overcome any obstacle increases our sense of mastery and control into unnatural proportion. Life and death are not and hopefully will never be fully in our control. Human beings are only one little part of the whole universe.

Living and dying

The topic of experiencing a life-threatening illness cannot be discussed without looking at death and dying. From the moment of the diagnosis of a serious illness, a battle seems to start between the person's survival instinct and despair. The mind begins to watch the deterioration of the body, its vital seat. The longer the illness lingers or the smaller the chances for survival given by the medical establishment, the harder it is to keep hoping for recovery and survival. Depression becomes a steady companion lurking in the background.

Impending death makes one aware of all the unlived dreams, the parts of oneself that have not yet found expression. One of the challenging tasks is to not become bitter in the face of unlived potential and missed opportunities. A process of mourning the losses accompanies any experience of a serious illness. Spiritual concerns might come closer to the surface. Knowing that life could end sooner than expected and that there is only a limited time left, a shift in values occurs. All of a sudden consciousness has a different focus. It is oriented beyond the physical existence and wants to discover and explore the internal world of the spirit.

In the book Conversations at Midnight, Herbert and Kay Kramer (1993) write with great sensitivity and honesty about their personal experiences with impending death. Herbert is dying from metastasized prostate cancer. Kay is a therapist who has helped hundreds of patients and their loved ones cope with dying and death. The book is set up in dialogues between Kay and her husband Herb. Together they try to understand themes that come up in the face of death: What is death? How and when do we give in? What about spirituality? The couple address worries around unresolved business, the question of what it means to be personally responsible of one's health, and offer thoughts on feelings of confusion and denial. Their conversations are very personal and universal at the same time.

Herb had gone through a dying experience before with his previous wife Karyl. He remembers that hardly anyone was willing to openly talk about death. The doctors were not understanding when Karyl felt that she wanted to surrender to death and no longer be dragged back to life.

> It was as if her failure to be cured was an affront to their profession, the result of some moral weakness in her. This almost universal inability to come to terms with the blunt fact of her death forced her to be the comforter, to get them off the hook by demonstrating her acceptance of the presence of death. (p.33)

In the books I read where someone's terminal illness was described up to the death of that person -- for example: Bosnak (1989); Wheelwright (1981); Kramer et al. (1993) -- I noticed that the authors mentioned a surprising peacefulness settling in during the last stage just before death. Even though the person had been struggling with the illness and the thought of approaching death and had been frightened during the months before, when death was close, they all seemed to come to terms with something inside of them. (Possibly this fact is also due to the person writing about the experience. For the person surviving the need for a positive and meaningful ending of the relationship could be a part of his or her own mourning process.)

Wheelwright (1981) describes the last stages of the dying process of a young woman suffering from cancer from her point of view as a Jungian analyst, believing in individuation, personal development until we die.

> Her unconscious had taken up the process of preparing for death and brought her life to completion in the last dream. I feel that during her final weeks, when she was living so quietly, she could have been living close to the unconscious in the realm of the archetypes, where all was prepared for her death... In her last days she was serene and peaceful, as though she had at last come to a full acceptance of herself and was ready to die. (p.271)

Von Franz (1987) notes that: "All of the dreams of people who are facing death indicate that the unconscious, that is, our instinct world, prepares consciousness not for a definite end but for a profound transformation and for a kind of continuation of the life process which, however, is unimaginable to everyday consciousness." (p.156)

In the last stage of life, death seems to become a positive force. Why is it so difficult for us to look at death while we are in the midst of life? Elisabeth Kuebler-Ross (1975), a renowned authority on death and dying, thinks that our fears are there partly because death is unfamiliar to this society.

> If we can learn... to reintroduce it [death] into our lives so that it comes not as a dreaded stranger but as an expected companion to our life, then we can also learn to live our lives with meaning - with full appreciation of our finiteness, of the limits on our time here. (p.6)

Becker (1973) speculates that our fear of death is related to the wish and need to be immortal. Since as a culture we no longer believe in death as the final ritual elevation to a higher form of life and to the enjoyment of eternity in some form, the fear of death becomes a part of our internal psychology.

> It is still a mythical hero-system in which people serve in order to earn a feeling of primary value, of cosmic specialness, of ultimate usefulness to creation, of unshakable meaning. They earn this feeling by carving out a place in nature, by building an edifice that reflects human value.. The hope and belief is that the things that man creates in society are of lasting worth and meaning, that they outlive or outshine death and decay, that man and his products count. (p.5)

Becker talks about the impossible forces human beings are faced with. On the one hand, human beings have a body, which belongs to the earth and dies. Man is out of nature and hopelessly in it. On the other hand, as Becker points out, human beings have this incredible capacity of self-consciousness, an expansive mind that makes them "godlike" and gives human beings a special status of a small god in nature. It seems an impossible task to reconcile with this paradox.

The Buddhists focus very much on dying. In their tradition death is not something to avoid but rather something to prepare for. They recommend that we all meditate on our death every day in order to remind ourselves of the impermanence of things. It is truly a way to avoid getting too attached to things and helps us not to take ourselves too seriously.

In the following paragraph I will offer some Buddhist thoughts on death from Sogyal Rinpoche (1992). According to Tibetan Buddhist tradition, life and death are seen as one whole, where death is the beginning of another chapter of life. Death is a mirror in which the entire meaning of life is reflected. A close encounter with death is believed to be able to bring a real awakening, a transformation in our whole approach to life. It is when we accept death, transform our attitude toward life, and discover the fundamental connection between life and death, that a dramatic possibility for healing can occur. It is only when we believe things to be permanent that we shut off the possibility of learning from change.

Illness and health within the context of culture/ society

Holistic medicine mostly deals with helping the seriously ill cope with their new lives. The final goal is to heal the person on a physical, psychological and spiritual level. It is rarely mentioned that illnesses for which medicine does not have any conclusive answers might be a challenge not only for the individual, but for society as a whole. The point of society needing to change is raised in books where authors talk about their personal illness experiences (Frank 1991; Broyard 1992; Duff 1993). Going through an illness, living the isolation, coming to terms with not being able to be a productive member of society, inevitably pushes the individual to question society's rules and wonder which social and cultural norms and expectations are "sickening." Duff (1993, p.37) says that "a serious illness, especially one that cannot be readily explained or remedied within a given world view, poses such a threat; it cracks the cultural trance and reveals the limitations of those shared assumptions we take for granted." Frank (1991) states the same idea more sharply: "The healthy can begin to value illness by doubting the standard of productivity by which they measure their lives." (p.118)

In workshops I attended in which people with serious illnesses worked on finding the meaning behind their illness experiences, I noticed that interpersonal problems and problems with society's expectations surfaced frequently.
I remember a man who was dealing with prostate cancer. When he started to focus on the physical experience of his illness and was encouraged to follow its way, he realized that the illness was connected to his sexuality. Being a gentle and loving man, he had difficulties living his more forceful and masculine side. In his profession as a therapist as well as in his relationships, he will most likely encounter little support for his new discovery.

Another common theme was "nature" expressing herself in physical symptoms. I recall a woman who visualized the lump in her breast as a slimy green blob that was reminding her to connect with her vegetative system and live life more intuitively. I saw her process as a symptom of a society in which rational thinking, achievement and progress are generally favored over being concerned with nature and living more intuitively.

Illich's (1976) provocative book Medical nemesis is a critical study of what Western medicine really does, as opposed to the myth that has been built around it. His topic is the close examination of "iatrogenesis:" diseases caused by the process of medical examination or treatment. He distinguishes between three types of iatrogenesis: clinical, social and cultural iatrogenesis. Clinical iatrogenesis includes side-effects of medication and damage inflicted by doctors. He understands social iatrogenesis as the fact that people are encouraged to become consumers of curative, preventive, industrial and environmental medicine.

> Social iatrogenesis is at work when health care is turned into a standardized item, a staple; when all suffering is "hospitalized" and homes become inhospitable to birth, sickness, and death; when the language in which people could experience their bodies is turned into bureaucratic gobbledegook; or when suffering, mourning, and healing outside the patient role are labeled a form of deviance. (p.41)

Cultural iatrogenesis explains the effect modern medicine has insofar as it "destroy[s] the potential of people to deal with their human weakness, vulnerability, and uniqueness in a personal and autonomous way." (p.33) Healthy responses to suffering, impairment and death seem to be paralyzed by the possibilities offered by medicine. People come to believe that health care technology can be used to change the human condition according to almost any design.

We are all influenced by the myths of our time. Therefore personal explanations and fantasies of illness experiences also need to be seen in reference to the public opinion of a particular illness. Susan Sontag focuses her book <u>Illness as metaphor</u> (1978) on the metaphors around cancer and compares them with myths about tuberculosis before it was understood to be medically curable. She says:

> Our views about cancer, and the metaphors we have imposed on it, are so much a vehicle for the large insufficiencies of this culture: for our shallow attitude toward death, for our anxieties about feeling, for our reckless improvident responses to our real "problems of growth," for our inability to construct an advanced industrial society that properly regulates consumption, and for our justified fears of the increasingly violent course of history. (p. 87)

She states that: "Although the way in which disease mystifies is set against a backdrop of new expectations, the disease itself arouses thoroughly old-fashioned kinds of dread. Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious." (p.6)

In the following paragraph I will list the metaphors around cancer that Sontag collected. Although the book was written sixteen years ago, the metaphors are still circulating and very present in today's world. The author found that cancer is seen as a disease of growth, of abnormal, ultimately lethal growth; it is associated with affluence and excess. Cancer is thought to cripple vitality, make eating an ordeal, and deaden desire. Cancer is considered to be de-sexualizing. Cancer has also been referred to as a demonic pregnancy. Metaphorically, cancer is a disease of pathology of space, which is indicated by the following notions: cancer "spreads," "proliferates," is "diffused." In the literature, the author found that the person dying of cancer is portrayed as robbed of all capacities of self-transcendence, humiliated by fear and agony. "Today many people believe that cancer is a disease of insufficient passion, afflicting those who are sexually repressed, inhibited, unspontaneous, incapable of expressing anger." (p.21)

It becomes apparent how society projects its own crises and struggles onto an illness: overpopulation and growth, overindulgence in the Western world, a general attitude that prefers rational decisions, predictable outcomes and controllable events over irrational and spontaneous behavior and uncontrollable occurrences. It seems that the metaphors of the illness represent the fears of what we have created.

Summarizing statement of the research topic

The findings in the field of psychoimmuno-neurology support ancient and popular wisdom that feelings, beliefs, attitudes towards life, the environment we live in, and many other factors influence our physical well-being. Health is multi-determined; it includes physical, psychological, social and spiritual aspects. The research in psychoimmuno-neurology discovered an interconnectedness of systems within the body which, up until recent times, seemed to work separately from each other. If we extrapolate and translate this information onto a philosophical and spiritual level, we might understand that human beings are similarly interconnected with each other and the larger world. This assumption might also get us closer to an understanding that what happens to us is not solely determined by our own individual personality.

The literature on personal illness accounts shows that an illness happens within the context of a person's life, i.e., no part of a person's life remains untouched. People's personal experiences bear out that, although illness is rarely welcomed, it can transform into an opportunity for personal growth. Self-awareness can be an important key in how healthy we stay or how readily recovery happens.

The use of fantasy, play and creativity is a common tool in psychotherapeutic practice as a way to access more unconscious material[7]. In the treatment of a serious illness, visualization and imagery have proven to be very effective tools to assist healing and to complement medical treatment (see for example: Simonton & Simonton 1978, Achterberg 1985). The techniques are used as a way to activate a person's inner healing resources and to prepare the person mentally for medical treatment. In this research I focused on irrational fantasies and discarded thoughts regarding specific aspects of the illness experience. Discarded thoughts seemed to be furthest away from a person's normal (thinking) awareness, thus containing the most "not-me" quality. My assumption was that by eliciting and appreciating an unacknowledged aspect of the illness, a thought experienced as weird or foreign, a fantasy that seemed unacceptable to the person (although it had entered her mind), could open a new way of thinking about the illness experience.

This study offers a perspective from people who have been at the brink of death from a physical illness. It tries to bridge the gap between the healthy and the ill. The basic assumptions of this work in regard to illness were based on the work of Arnold Mindell (1982, 1985, 1989, 1993) (Mindell's work is also referred to as "process-oriented psychology" or "process work.") The following hypotheses were explored:

1. Experiencing a life-threatening illness can be a catalyst for change and personal growth.

2. The meaning of an illness experience can be discovered by bringing awareness to irrational, discarded and seemingly weird fantasies connected to the illness.

3. People have very personal explanations for their illness experiences which are connected to their larger life patterns.

4. Experiences people have while they are ill and dealing with a life-threatening illness contain valuable information that could make everybody's lives - healthy or ill - easier, better understood, and more balanced.

I applied process-oriented therapeutic techniques[8] in the interviews to explore people's thoughts, attitudes, and symbols about their life-threatening illnesses and to help them discover the vivid images and fantasies about their experiences. My contribution lies in the attitude I used towards illness, rather than in offering another technique. I understood illness as a part of the person's life myth which encapsulated the wisdom for future personal development. Therefore the fantasies connected to different aspects of the illness contained the key for transformation.

I was not primarily focusing on healing people, nor on merely collecting people's story. My interest was to gain more understanding of the illness process by encouraging people to focus on irrational thoughts about the illness and remembering early fantasies about where the illness came from. This discovery process was set up to lead to new insights into the meaning of life and could therefore have a secondary healing effect.

Through exploring the irrational, obscure, forbidden, seemingly stupid and disavowed fantasies about serious illness, I hoped to stimulate a new corner of awareness around the illness process and to offer the people I interviewed a beginning from which to spin further their lives' thread. I was also interested in finding patterns in their current lives that connected to the meaning of the illness and to see if and how the story continued and the myth lived on after the symptoms disappeared. My intention was to create a vessel in which the interviewees could express their more irrational ideas of the origins, meanings and myths of their life-threatening illnesses. In that sense, this work adds to the literature focusing on personal accounts of illness experiences. It goes beyond the existing literature through including more unconscious and discarded thoughts and feelings about illness elicited by a specially focused interviewing technique. The interview process used process-oriented therapeutic techniques to access unintentional information about the illness. It did not, though, fully follow and unfold the material brought forth in the process. By stimulating creativity and fantasy the person was assisted in going beyond the current experience. I hoped to raise awareness of discarded aspects around the experience of the disease and of explanations that were forgotten or discredited because they seemed too fantastic and farfetched.

I wanted to listen to the message of the illness, which usually is the foreign and unknown entity, the change agent, the mystery. It is the part that never seems to belong to the person, the family or the community afflicted by its presence. I believe it contains information important to all of us. Lerner (1990) wrote about and meditated on his own "wrestling with the angel," as he calls his experience with a life-threatening illness. He had a sense of the general "bad reputation" of illness when he wrote the following: "Understandably there is the smell of taboo around life-threatening maladies, since a society tribally tries to protect its integrity and sees a stricken person as a threat to the well-being of all." (p.38)

CHAPTER III: METHODOLOGY

Theoretical framework

The main theoretical framework of this research was based on process work. In his book Working with the Dreaming Body Mindell (1985) introduced a single theoretical framework which promised to integrate the immense variety of human psychology. He called this framework process work, "...because it is based upon discovering the exact mode or channel in which the person is moving" (Mindell 1985, p. 2). The underlying belief of process work is that things which happen to people are potentially meaningful and, when unraveled and experienced with awareness, can enrich their lives.

Physical symptoms or potentially life threatening illnesses, such as cancer for example, are viewed from this perspective. They "... can be the beginning of fantastic phases of life or bring one amazingly close to the center of existence. They can also be a trip into another world as well as be a royal road into the development of the personality" (Mindell 1985, p.3). The key lies in experiencing the reality of the symptoms rather than in trying to eliminate them.

The way to access the process behind an illness varies depending upon the individual's perception of his or her disease. Staying as close as possible to the person's immediate experience is an attempt to discover the exact mode of perception or the channel in which the symptom is experienced. The person may feel pain (proprioceptive channel), be disturbed by changes in his or her physical appearance (visual channel), experience a tumor as pushing against another part of the body (movement channel), be forced to depend on others for care (relationship channel), or experience himself alienated from society (world channel). Possible interventions are structured by following the information coming through the different channels.

The next step in becoming aware of the process is to amplify the experience in its channel. For instance, if the experience was in the proprioceptive or feeling channel, then bodywork may be used to help the person feel the symptom more exactly and gain more information about it. At this point, a channel change may occur, in which the information is translated into a picture, for instance. Perceiving the same information in various channels serves to fill out the process and helps the client learn more about it.

Amplification usually reveals an aspect of the individual's personality which is not a part of his or her normal identity. The person will come to a momentary crisis point, the "edge." A new way of being is not acceptable yet; the person will need to process the pros and cons, discover the value of the edge and finally make a decision to explore the new pattern step by step in different channels. Any new way of being, any change challenges the most basic beliefs we have. As a result, living the background "spirit" which is trying to express itself in the symptom, for example, may demand big life changes. Integration can be difficult or impossible. Sometimes the gap between the normal identity and a new way of being and looking at the world is so big that the person would rather die than change. For others, however, the prospect of dying becomes a powerful impetus for personal growth.

Process work is not only a therapeutic method of intervening and unfolding a disease process, but contains beliefs about people and life. By training and using our awareness we have a choice to be the victims of things happening to us or to use the message of disturbances and integrate their energy into our lives. In this sense we are the creators of our lives and have the opportunity to grow beyond the limits of a set identity, experimenting with, using and unfolding the rich potential inside.

Experiencing a life-threatening illness means change in a person's life and implies a severe life crisis. The illness intrudes into and disrupts everyday life and demands intense focus. The person is confronted with the unexpected, the uncontrollable and the unknown. People who experience or have survived cancer, for example, will have lived with or through extreme life circumstances: closeness of death, loss of control over their bodies, worries around family members, etc. The closeness of death and the awareness of life's limitation usually shakes a person at the core of his or her being. I believe that people who go through such intense life experiences will get in touch with their true natures, their basic fears and doubts, their courage and strength.

Someone living with a life-threatening illness might want to use process work as a way to find healing. Healing in the sense of getting in touch with the life governing process does not necessarily mean that there will be physical improvement. The symptoms might persist although the person is in touch with the illness process and is living life more and more fully. The impersonal part of the person's process stays wrapped up in the body as a reminder and ally for the individual as well as the larger society. Increased awareness of one's body and a glimpse of one's wholeness most likely increase overall well-being and happiness, which is an essential part of healing. Sometimes the time has come where the person is meant to surrender. As hard as it is to accept that a loved one is dying, death is as real and valuable as life. Process work's philosophy supports living as it does dying, since they are both essential parts of the eternal flow.

Arny Mindell mentioned in a course on dreams he taught at the Process Work Center in Portland, OR at the time of this project that process work does not primarily offer another healing method. It fills the need for an alternative way of thinking. He sees process work stepping out of a dualistic way of thinking where being sick opposes being healthy, a long life means success and a short life is associated with personal failure, where living is in contrast to dying. A non-dualistic or unifying way of thinking is furthered by following the actual experience and discovering the ancient Chinese concept of the Tao as the governing principle behind life.

Any process can be looked at from a short-term or acute, as well as from a more long-term or developmental viewpoint. The two viewpoints are interconnected. Acute body symptoms, like headaches and cramps, are more readily accessible to one's awareness because they are more disturbing in the moment. Their message points towards a part, state or atmosphere that is not appreciated and valued enough in the current life. Chronic body problems are more difficult to work with. The signs of a life-threatening illness often develop over a certain period of time. Cells can grow into tumors inside of the body without being noticed by their host person. They might not cause any pain for a long time and therefore go unnoticed. Also, chronic physical problems may have been around for an extended period of time and have become part of one's identity. They might not even be recognized as a disturbance anymore. The person has learned to live with a particular physical condition. Often there is also a certain mood that accompanies long-term problems. Hopelessness and disbelief that anything could ever change has seeped into the person's life. Unfolding the process of long-term body problems will get a person in touch with his or her life myth.

Process work is unique in its approach to illness insofar as its focus is primarily on the experience of the illness. How does a person know that he or she is ill? What is the actual body experience? This physical experience is translated into a psychological and spiritual experience by means of amplification. In a figurative sense the person can then adapt the quality of the illness and give it expression in everyday life.

Research design

The primary purpose of this study was to investigate the meaning people attribute to their illnesses, to explore with them how the illness experience fit into a larger life pattern, and how the meaning of the illness experience could be integrated into everyday life. I used assumptions and world views based on the philosophy of process-oriented psychology to investigate these questions.

Early on in the process of this project I sensed that I needed to be a servant to the process and to the people who went through a big life-crisis. The methodology needed to reflect and integrate this attitude. My interest in the topic of exploring experiences around life-threatening illnesses surfaced by witnessing friends working on their illness experiences in specific seminars and in their everyday lives. I have been very touched and impressed by the courage and wisdom people seem to gain out of very difficult experiences when awareness is brought to the experience and a connection with the person's life pattern is discovered.

The nature of my study was qualitative. "Qualitative methods permit the evaluator to study selected issues in depth and detail ... without being constrained by predetermined categories of analysis..." (Patton [1980] 1990, p.13). The purpose of the study was to record how individuals perceived their illnesses and how they attributed meaning to these experiences. Rather than quantitative research, which refers to distribution, frequency and prevalence of a phenomenon, a qualitative research approach allowed me to explore the meaning and perceptual experience of the phenomenon at hand and to obtain detailed information about it from a small number of people.

One type of a qualitative approach is the heuristic study. "In heuristic methodology one seeks to obtain qualitative depictions that are at the heart and depths of a person's experience.." (Moustakas 1990, p. 39). Heuristic inquiry seeks to discover the nature and meaning of the phenomenon itself. It allows one to get to a holistic description of the phenomenon's essential meaning -- in this work a life-threatening illness -- and to portray the personal significance of specific events or questions.

Heuristic research includes the experiences of the researcher as well; it emphasizes connectedness and relationship (Moustakas 1990, p. 38). I have not experienced a life-threatening illness myself, which made me stand outside of the group of people I interviewed. I was aware that I could not fully comprehend what it means for a person to go through such extreme life circumstances. The personal involvement happened in the sense that my listening to and my absorbing of what people related to me about their life-threatening illness experiences impacted and changed me and my views about life and death a great deal. For the past year, I have been living with a close friend who is dealing with AIDS. Interacting with him on a daily basis, witnessing his struggles with his health and the changes they brought about for him and the world around him gave me an even closer look into the world of the seriously ill. (He was not one of my interviewees.)

Moustakas (1990) proposed a sequence of steps to follow when analyzing data in a heuristic study. After recording and transcribing the data, the researcher needs to immerse herself or himself into it, until it is understood. A next step is to construct, as fully as possible, an individual description of each participant's experience. From the totality of these individual descriptions he suggested that the researcher constructs a composite picture of the experience and then develops few exemplary portraits. A creative synthesis reflects the original data as well as the researcher's intuition and personal knowledge.

Again, due to my lack of a direct personal experience with a life-threatening illness, I could not draw upon personal knowledge to compare with my findings from the interviews and engage in a critical disputation between my subjective experience and the collected data. A prolonged immersion into the subject happened in the sense of my living situation and my dealing with illness on a daily basis. I used an interpretative style in order to generate themes and patterns that crystallized over time.

Since I could not strictly follow the guidelines of heuristic research, I looked at. using the ethnographic research approach. The goal of ethnography is to tell the whole story of a defined group's daily life, to identify the meaning, patterns and passions of a bounded cultural group. Agar (1986) called ethnography "the social research style that emphasizes encountering alien worlds and making sense of them." (p.12) Ethnographic research tries to make sense out of human differences and mediate between frames of meaning. By using an ethnographic research approach, I needed to determine evidence for the specific culture of the seriously ill.

Looking back at personal illness accounts from the relevant literature and remembering some of my own illness experiences, I learned that being ill changes everyday life drastically. Experiencing a strong headache or backache, being bound to bed for a day, impacts the ability to follow the rules and expectations of the surrounding culture. Behavior patterns change. In case of a chronic physical condition or a life-threatening illness, differences relative to the world of the healthy become even more evident. The goal of this project was to investigate those differences and to create a bridge of understanding between the two worlds.

I complemented the ethnographic research approach by using a phenomenological viewpoint as well. The phenomenological approach attempts to grasp the essential meaning of a phenomenon and therefore goes beyond merely describing behavior and differences of two cultures. According to Manen (1990) "the insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience." (p.77)

I believe that illness is a very personal experience and that its core meaning can best be expressed in stories told by the individual living and struggling with it on a daily basis. As Sacks mentioned, "the scientific and the romantic ... cry out to come together at the intersection of fact and fable, the intersection which characterizes the lives of the patients.." ([1985] 1986, p. xi) I have enjoyed Sacks' work a lot. He managed to combine the scientific and the romantic, to observe illness with the necessary accuracy of a physician while at the same time presenting the material in a beautiful literary form.

Selection of participants

Ten participants were selected for a two hour in-depth interview session. Their ages ranged between 27 and 52. I interviewed seven women and three men, all of them Caucasian. Out of the ten people I interviewed, seven experienced some form of cancer, one person suffered from lupus, one person from a congenital heart disease and one person from hydrocephalus.

The relevant criterion for selection was that the person was either living with or had survived a serious, life-threatening disease. The illnesses included different forms of cancer, congenital heart disease, hydrocephalus and lupus. Except for one person whose illness struck him when he was 37 years old, the first discovery of the illness happened when the people were in their late teens or in their twenties. One person has died since the time of the interview. Half of the participants continue to struggle with their illnesses and live on insurance and disability payments, three people are fully recovered and working full-time, and two of the participants are working towards a degree.

I chose subjects whose first diagnosis of their illness occurred between three and fortyfour years to the interview. I felt that in order for a participant to be open and interested enough in this in-depth research, the person needed to be able to detach somewhat from the initial feelings of shock, anger and victimization.

Other important criteria for the selection of the participants included their willingness to share very personal experiences, their interest in experimenting with their own creativity and some curiosity about their inner life. I primarily selected participants (seven out of ten) who were not familiar with process work since I wanted to reduce the bias that might result from shared philosophical beliefs. Six of the participants were recruited through referral from friends, and four of the subjects answered ads in the local newspaper. In a first telephone contact the people interested learned that I was engaged in a research project exploring the psychological experiences and meanings people attributed to their illnesses. The logistics of the interview were presented. I let the participants know that the interview would be audio-taped and that I would handle their information confidentially and anonymously. I sent them a brief letter in which I introduced myself and explained that the information gathered during the interview session would belong to me afterwards. I also asked each participant to grant me permission to use their interviews in my research project.

In return for their time and energy, I offered each participant a free follow-up session to further process issues triggered by the interview. None of the participants requested this. They all received a copy of the transcribed interview and were encouraged to contact me with any further comments or ideas.

Set-up of the interview

Interviews took place either at the participant's or my own home. They took an average of two hours, were tape-recorded and later transcribed.

For the interview I combined a guided approach with a conversational approach (Patton [1980] 1990, 281ff.). The guided interview approach allowed me to gather basic information on the person and his or her illness. The second part of the interview was informal and conversational to allow a high degree of flexibility in following the process of the person in the moment.

Interview questions

The interview questions were based on process work philosophy and formulated to allow access to the illness process. The questions reflected a stronger focus on the long-term or mythical level of symptom work.

During the first part of the interview I tried to cover the following questions:

- What is the illness that you survived or are suffering from?
- When did you first find out that you had this illness and how old were you at the time?
- How did you learn about it?
- Did you have any indications that something was going on with you before you knew what the illness was?
- Why do you think you got the disease?
- How did your illness change you, your life, your relationships?
- Do you find any meaning in the experience of your illness?

I was interested in the history of the illness and the development of the illness process. The earliest memories associated with the illness were evoked to get the person in touch with the beginning of the illness myth. I was interested in finding possible connections with the overall life pattern of the person. The time around the diagnosis gave information about the moment of crisis and chaos. It possibly marked a big edge in the person's life. The illness would be a way to "dream" around the edge; it allowed the person to leave everyday reality and gave time for a new pattern to arise. The changes brought about by the illness showed the person's way of integrating formerly discarded information into his or her life. By asking for future changes the person would like to see for society, I intended to go beyond the personal aspect of the illness and introduce some awareness of the usefulness of the experience for society.

In the course of the interview, I also focused on the actual physical experience of the illness. The people I interviewed did not necessarily experience any body symptoms related to their illness at the time of the interview. I asked them to go back in time and to give me a detailed description from their memory of the first physical symptoms. I used these descriptions to engage the interviewees in a dialogue between the world of the symptom and the world of their usual reality.

The purpose of the second part of the interview was to lead the person into the more unknown territory of his or her illness. I was interested to discover the fantasies of the illness rather than the facts, to help the interviewee get in contact with the irrational, forbidden and mythical aspects of the illness, to connect the illness with other aspects of life, and to have the participants create stories of their illnesses.

With the following questions I intended to set the stage for the participants to contact the more irrational and numinous aspects of their illness experiences. I hoped to appeal to their more irrational side and worded the questions accordingly.

- Do you remember an explanation of your illness that you had at one point that seemed just too far-fetched to be realistic, but you thought it anyway?
- What do you think was happening in your body at that time, using your own intuition rather than a medical explanation?
- If you imagined being a kid again, how would you explain from a kid's perspective what happened to you and your body?
- If you could be in charge of giving people certain experiences, why do you think somebody might have to experience ..... (the person's illness)?
- What would be important about that experience?
- Let's create a story about such a person and his or her rival/ ally/ or whatever term they associate with the illness: "Once upon a time....."

As a note on my general interview style, I want to stress again that I did not intend to do therapy with the people I interviewed. My goal was to see if the participants could get in contact with a background illness process that would relate the illness experience to a larger life pattern. Since my focus was to elicit irrational ideas and explanations about the illness experiences, as well as to encourage people to take the memory of their direct physical experiences a step further and create a story around those original symptoms, my questioning style became very leading at times. I felt the need to hold people to certain statements. I realized that it was far more difficult than I expected for most people to experiment with irrational and weird ideas. Leaving causal reality and entering the unknown, believing in the potential meaningfulness of random events, seemed to be an unfamiliar and possibly anxiety provoking task for most people.

Analysis and interpretation of the interviews

For the analysis of the interviews I used an editing-style approach (Crabtree & Miller 1992). In a first step, I carefully read the interviews several times in order to detect meaningful segments which would stand on their own and also relate to the purpose of the study. In a second part, I explored the different categories addressed by the structured part of the interview -- memories around the illness onset, personal explanations for the life-threatening illness, life changes triggered by the illness experience and possible learnings or teachings -- and determined patterns and themes. The presentation of the material reflects the two approaches.

I selected five interviews which were edited, pasted, and rearranged. Whenever dots (...) appear, there was a pause in the interview. I interspersed the interview segments with interpretative comments. Each interview includes an "afterthought"-section where I express my reflections and comments. The names of the participants were changed and some personal comments left out in order to ensure confidentiality. Since I was interested in very personal explanations of illness experiences, a general summary could not illustrate the spontaneity, the interesting twists and the depth of the experiences these people went through. I therefore decided to let the interviewees speak for themselves. The reader is able to get a little taste of the intensity of the experiences, the struggles and pains these people went through and how they managed to come out of the illness as different people.

The second part of the analysis is a summary of general themes I found. Excerpts from interviews are used to illustrate certain points. I want the reader to be aware that I derived these themes from a very limited pool of information, data gathered during ten in-depth interviews.

In addition to the conclusions I draw from the material, the reader is invited to come up with his or her own theories. I want the reader to listen to the experiences people present since the person directly affected is the only one who knows what message the illness comprised. I hope to transmit ways people can access more unknown parts of themselves and stimulate the reader's curiosity about the wonders and mysteries of life.

CHAPTER IV: PAT, A WARRIOR IN A WAR ZONE

Pat is a young woman in her late twenties who was diagnosed with hydrocephalus at age 13. It was found accidentally, when she needed an operation for a knee injury. The orthopedic surgeon, whom she describes as really cool, noticed that her hands were large, as well as her feet and her head. He consulted with a neurosurgeon. After several painful tests, they diagnosed her with hydrocephalus, a condition that is usually discovered at birth or after a serious head injury.

Pat remembers symptoms of nausea and headaches during her childhood, which she now believes were effects of her medical condition. Her pediatrician would minimize the symptoms, say that it was fatigue, and not do any further testing.

When her hydrocephalus was discovered, Pat was told that unless she had a shunt placed, she was going to end up retarded and probably die at a young age. Pat's professional dream at that time was to either become a medical doctor or go into engineering. Of course, she was going to allow the only medical treatment available, follow instructions and have a shunt placed, which drains any excess fluid from the head and channels it into the rest of the body.

Pat has experienced severe problems with her shunt. She had several infections, suffered from meningitis and spent, at age of 16, four months in the hospital in a semi-comatose state. At this time, she lives on her own with the help of Social Security Insurance and is able to more or less manage with her disability. When her shunt is not functioning properly, she experiences the following symptoms: severe headaches, double vision, spontaneous vomiting, feeling sluggish and lethargic.

Pat relates the onset of her illness to her childhood. She states that she was dropped on her head from her father's shoulders. In addition she hit her head really hard on the floor a couple of times and experienced several concussions. Her personal explanations coincide with what she knows about the causal explanations of modern medicine: hydrocephalus is either the result of a head injury suffered in an accident or is congenitally caused.

Renata: "What would happen if the hydrocephalus were not treated medically?"

How does Pat explain what is going on in her body? She uses a medical explanation, which is infiltrated by her own imagination and pictures of what is happening in her body. The words and pictures used hint at the process in the background.

Pat: "There is too much ribospinal fluid surrounding the brain. And it causes pressure and when it is left unabated it would .. I don't have good words, it exerts pressure on the brain. Between the skull and the brain and .. I would guess, it cuts off nutrients to the brain, oxygen and whatever else the brain needs to function. It would work to suffocate the brain, whatever concept of fluid that would stop the brain from being able to function and lead to lethargy or retardation and death."

There is too much fluid surrounding the brain. A river that swelled out of control. The brain is drowning. In my own fantasy, I connect the liquid with emotions being left unabated. An imbalance stops the rational mind from functioning. Pat relates the beginning of the illness to early abuse: she was dropped from her father's shoulders and hit her head several times on the floor.

Renata: "Is there a more irrational explanation that you have ever thought of? An explanation that doesn't make any sense, but it has crossed your mind?"

Pat: "No, no."

Renata: "No?"

Pat: "No. I am a scientific minded person who has gotten more into emotions and stuff in the last three and a half years. I have been healing from abuse stuff. But no, I haven't..."

Pat identifies with being a scientific minded person. She is reluctant to talk about feelings. There is a connection to past abuse that makes it difficult for her to step out of medical terminology and try a more child-like or irrational approach. The abuse is two-fold: she hints at abuse in her family. Her medical condition might not have been taken seriously enough as a child; her father dropped her off his shoulders. At a later point, Pat mentions that she is not used to being supported or having an ally; growing up in her family she felt she was always on her own.

Pat also suffered abuse by the medical system. She states that she is dealing with post-traumatic stress from traumas experienced while she was in hospital care.

Pat: "All the staff that I remember from being in the hospital and being treated like a stroke patient. I guess nurses think stroke patients have to do things right now for themselves or they will never do them. I wasn't that way. I was being forced to feed myself when I was really unable to. No one knew what to do with me anyway, because I wasn't responding to the medical treatment that I was getting. You know, they did some drastic measures finally to stop bleeding inside my skull. I was made to sit up. It was extremely uncomfortable for me. Certainly if having a person sitting up is going to have the body function better than lying down, that makes sense. It would have been a hell lot nicer to have someone sitting next to me holding a hand, saying you are doing wonderful, any of this, the caring stuff. I didn't grow up with any caring or nurturing or affection or love or protection. It sure would have been nice to have that when I was going through horrible traumatic stuff either then in the hospital or before or after. But things weren't like that."

Abuse from her childhood is repeated. During a time when she is very vulnerable and dependent, Pat finds herself again without caring and love. Where did she find the strength to get through?

Pat: "I guess my family is really determined and so am I. So it was just something that was done. I have never looked at anything as: why me? I think it is silly when people do... I am dealing with post-traumatic stress. I felt like a war vet. I felt like I went through combat." ..

Renata: "It takes a lot of strength to live with your medical condition..."

Pat: "Yeah. it's a pretty fucked up thing to have to mess with. It would be really easy to give up. With the problems that I have had, it is really easy to give up."

Several times, Pat has been close to the threshold of living and dying. Something has kept her from giving up, although enormous physical difficulties had to be overcome. After four months in a semi-comatose state, she had to relearn the most basic functions: how to swallow, how to talk, all the physical movements. To live against odds, to find strength and resilience inside was a big challenge for a teenager. Going through the necessary medical treatment left Pat feeling like a war veteran. Her emotional side was left untreated; the caring "stuff" was missing.

Pat: "I sure was sensitive to touch and the warmth from touch and the warmth from caring people. I know that now. I never had it growing up. But I know it now. It would have been beneficial to have caring along with the hospital experience rather than - I don't want to say automation - but rather than just work. But that part is seen as of no medical consequence or incident or anything. It's like: this person is not going to remember this, she has a whole lot of pressure on her head. She is semi-conscious. She is not going to remember any of this."

What is Pat's relationship to her illness? How does she perceive the illness?

Pat: "It has a life of its own, you live with it and it's that little thing on your shoulders, like: fuck off!"

Renata: "Right. You are at war with it. You are enemies. If you would personify it.., who is this little thing sitting our your shoulders?"

Pat: "I don't personify it, because that's giving. I don't think of the hydrocephalus; I don't want to. You know, I have done visualization to try to help me deal better in life. But it has nothing to do with giving more to the hydrocephalus then what it has. And it's just sort of an ethereal thing now. It comes up. I work with it. I work on it. And then I work on healing again. It's not something that I... As far as I am concerned, it's only around when I am having problems with it. Otherwise, it's not in my life."

Renata: "So the way that you manage is by trying to give it the smallest place possible in your life."

Pat: "Yeah, which is usually non existent."

Renata: "I understand that, because it must be completely overwhelming. It's really being at its mercy, or at least to some extent."

Pat: "Yeah, I guess, yeah. When it comes up, it's in control. And I work to gain the control back."

Pat experiences the power of the illness when the shunt gives her problems. Then she is at its mercy. To see the illness as an expression of a part of herself and to establish a relationship with that part means acknowledging its existence. Pat does not want to know more about her illness at this point in her life. She is working on finding a way to go on living despite her medical condition.

Renata: "What would it be like to think of your illness as an ally? I mean that's a bit far out.."

Pat: "You asked something similar on the phone. Thinking of it as an ally.. o.k., it is leading me towards a better place in life. My life wouldn't be like it is now if it hadn't come up. I am thinking from 13 years ago, if I were thirteen now. My life is dramatically different than it would have been if it hadn't come up because the whole perspective changed. I ... wouldn't say I'd change anything that has been in my life. There is some really awful stuff there, but I wouldn't be here if I hadn't been through all of that. And, I have got so much done in the last 3 and a half years, and I have some really neat people in my life now. And I am continuing to work on getting things better. Ally.. I don't, I still can't pull that concept in."

The illness forced Pat into experiences that changed her life. She can accept that fact and even find something positive about her past. To look at the illness as an ally is too far fetched for her. - The casualties of the war were too high.

In the course of the following dialogue, I am trying to help Pat access the background process of her illness. I appeal to her creativity and fantasy by asking her to tell the story of her illness in the form of a fairy tale.

Renata: "I'd like to use your creativity and play around with your illness experience. How about making up a a fairy tale: Once upon a time, there was a thirteen year old and she met this.."

Pat: ".. hideous monster."

Renata: ".. hideous monster, right. She met this hideous monster and for some reason..."

Pat: ".. and they lived together happily ever after. No way!"

Renata: "No, no, they didn't live happily ever after, but they found themselves locked into the same house."

Pat: "Oh, cooperation versus competition. Gee.."

Renata: "I don't know, I don't know what will happen with them. If that could be a beginning. There they were. For some reason they got locked into the same house. Imagine the thirteen year old.."

Pat: "They had to learn to coexist.."

Renata: "Now, one had, imagine that the thirteen year old was sort of in a .. probably more scared position than the monster that came along and then it probably had the upper hand.."

Pat: "The thirteen year old said: well, gee, what are we doing here? What can we do? O.k."

Renata: "Well, the monster probably didn't care and said: I am just going to eat you up, no question. I am going to push you out the door and you will be gone. I am not interested in you."

(there is a moment of silence)

Pat: (laughs)

Renata: "I am going to put so much pressure on you, it won't be.."

Pat: ".. and the kid kept living.."

Renata: ".. kept living? How did the kid keep living? I am going to pressure you and pressure you and pressure you.. I am much more powerful than you think I am.. I am going to squeeze the last drop out of you."

Pat: "Oh well, I am not leaving."

Renata: "You are not leaving? What are you going to do about me?"

Pat: "Hey, if you can't hang, you can leave!"

Renata: "I should leave?"

Pat: "The monster."

Renata: "I have lived here for hundreds and hundreds of years."

Pat: "Oh, well. I am trying to get into your fairy tale.."

Renata: "Maybe it's not the right one. But sort of.."

Pat: "No, no. It's going off into all different directions and I don't know how to fit in. Because it would be nice if it were really simple. It would be really nice. Now go in, fix them up, take them out, great. It's not. It's having, having a cannon at the front door, guided missiles outside, a bazooka in the back, a bomb underneath the house, soldiers coming to the door. You don't know what's going to go off, when it is going to go off, you know. Those are bad, silly metaphors, whatever they are."

Renata: "That was sort of.."

Pat: "..It's just like a time bomb. I guess. Putting it into something. When it comes up, deal with it."

Renata: "It's really war.."

Pat: ".. but you don't know when.."

Renata: "It's really war that is the best metaphor for you."

Pat: "Yeah, and it's the easiest not to think about it. Last night on TV they showed the movie "Queen," after Alex Haley's book. It was really cool to see, the slaves, the women were inside the mansion, singing. And outside the bombs were going off. I think it's cool to connect, to understand, to get the feelings, because I don't get feelings really well. But these women were singing so they wouldn't hear the bombs going off outside. The cannon fire. They didn't hear that. And that's what my life is doing. In a way it's spent keeping busy. Doing things to keep myself going, rather than thinking about medical problems, having to think about that. They are really overwhelming when they come up. So I am working on not having pain. I am working on connecting with people."

It is difficult for Pat to get into a fairy tale around her illness. At first she jokes about the idea - there won't be a happy ending in her story! Then she tries to find out what concepts I could be looking for. Her comment about cooperation versus competition gets closer to the mood of a smart teenager, outwitting the teacher's line of thinking. Pat laughs when the monster becomes powerful in the story. There is a pause. The story has taken an unexpected turn. Pat reacts with her own strength, resisting, ready to fight for her life.

She comes to the next impasse when the weight of the past is brought into play. The monster, which identifies the illness, is not ready to leave. It is not that simple. Pat knows the reality of living with a life-threatening physical condition. Her situation has been very unpredictable. She literally lives with a time bomb that could go off any moment.

Pat remembers a scene from the movie "Queen," set in the time of the civil war. She identifies with the black women singing inside the mansion while outside a war is taking place. Though it is not really their war, it is a war about them. Their way of participating is to connect with each other, to find strength and solace within their community and within themselves. It is a way to not give up and lose hope, but to continue to live for a world where the connection among people creates a vessel for all the suffering and pain.

What were the changes brought about by the hydrocephalus?

At a time when her peers enjoyed being teenagers and having fun, Pat went through traumatic medical treatment, spent months in a semi-comatose state and ended up having to relearn all her physical movements: how to swallow, how to talk, how to walk. She worked hard to keep up with her school work. She worked hard against her own fate: the possibility of retardation. Keeping up with school work was important. Her determination got her through high-school and through college.

Pat: "I went through all this hydrocephalus stuff so far. But I don't have a sense of future. I am working on today. I am working on life. I didn't have any focus in life before this stuff came up and after it. Since the hydrocephalus came up, I have been working on living, making things better for myself. And by giving back to the world."

Pat tells me that she felt drawn towards the community of street kids. In their midst she found caring and a connection with people. Hardship and trauma brought them together. This was a group of people with which Pat empathized and identified to a certain extent. It was a place to give something back. Pat spent a few years doing volunteer work and giving out syringes and condoms. She experienced giving to others as a great way to contribute to make the world a better place.

Pat: "Living life on the edge of chronic medical stuff certainly pushes one towards self-realization. Like: well, future, I don't have that. What can I do now to make things better for me and thus the world, or vice versa."

I was curious to hear what Pat learned from her illness experience and what teachings she has for others.

Pat: "The five things that I have figured out, I need to keep living are: nutrition, pain relief, intellectual stimulation, fun, and there is another.. sleep. Because if I lose any of those, things start getting worse for me. Those are the basic things I need for life. I tend not to eat, I tend not to sleep. I have pain that I don't necessarily take care of. I tend to isolate myself. It's hard to keep in contact with good, safe people who aren't going to be hurtful. And so, positive, positive outlook and positive things in life are needed for me. I need them to keep going, to give me desire to keep taking chances. And I am out to make the world a better place... I can work on healing from the past, but I can't change the past. I can change the future by what I am doing now. I can make the future. I can make things better. And that's what's important, because I have been screwed over in life... My dad laughs when I tell him about the bumper sticker that says: 'recycle or die.' The earth is a living thing. We have got to take care of it or we are going to blow it."

Renata: "It seems like your body has experienced a lot of stuff."

Pat: "Yeah."

Renata: "All those war wounds."

Pat: "Life."

Renata: "Life wounds."

Pat: "Life, life."

Afterthoughts

I remember noticing Pat's clothes when I first met her. She was wearing army pants and boots. Little did I know at that point that her outfit matched the experience of her illness so well. She stated in the interview that her illness could best be described with living in a war-zone in which you never know where the bombs are hidden and when they will go off.

Pat used strong pictures to describe her illness experience. She reminded me of the incredible resilience human beings sometimes have to go on despite the impossibility of their everyday situation. Pat's strength also showed in her way of relating to me. She would resist my way of thinking about illness and a few times outsmart me with a great sparkle in her eyes.

Pat is a true warrior. She has found her spiritual task. From her own position of pain and hardship arose the need to help create a saner and more positive future. The caring has extended beyond her own self.

Pat's experience illustrated that healing does not come through sophisticated medical treatment alone; physical contact, emotional support and respect for the person's state of consciousness are as essential. Pat's biggest teaching is directed towards the medical system. Her own experience of being semi-comatose for a few months made her realize how important human contact and caring is. Although she was seemingly unresponsive to and disinterested in external stimuli due to her altered state of consciousness, she remembers missing physical contact and emotional support. Her experience is a plea to anybody who takes care of very ill people. We should not forget the human being; we need to show respect, care and love also at times when the ill person is no longer able to use the communication system we are used to.

CHAPTER V: DRIVE THROUGH CANCER

Anthony: "I had drive-through cancer. That's what I have told people."

Renata: "Drive through cancer.."

Anthony: "Would you like fries with that Mr. James? .. "

Anthony is a man in his early thirties. During a routine eye exam at age 19, a malignant melanoma tumor was detected within his left eyeball. At the time, the safest form of treatment was considered to be the removal of the eyeball. Within 27 days of the diagnosis, Anthony had the eye removed. The doctors followed up with routine blood tests to make sure no cancer returned. On a physical level things were taken care of quickly, however, emotionally Anthony was left to himself to deal with the traumatic experience.

Anthony: "Sometimes I feel a little bit guilty because I didn't do the cancer thing right. Because I didn't have to go through chemo or radiation treatment or anything like that... But some of it did catch up with me later. At that time, nobody tried to ask me where my head was at or checked in with anything. I was just kind of told to go on about doing what I was doing. You know, when you are 19, you don't think too much about getting cancer or your mortality. It kind of came as a surprise and .. a shock. Actually, I didn't allow it to be a shock when it happened. I just figured that it was one more thing to take care of and to step over. Looking back on it, there were times when I really didn't make sense of what had happened. I felt like I had been picked up by the system and thrown back into it. I felt like I had to do a lot of it on my own."

Anthony remembers very vividly a comment he made before he knew on a conscious level that a tumor was growing inside of his head: *"I was at work and I* *just told somebody, you know, feeling kind of dizzy and just really strung out and kind of crazy: "I think I have a tumor in my head." Just kind of like this: there is something inside of me that needs to be worked out, just aggression or anger or something. Something that I don't want to own is in there and growing. It seemed kind of ironic to me then. But I wasn't thinking cancer at all, you know."*

Anthony calls this statement a landmark, looking back on his experience with cancer. Neither Anthony nor his co-worker paid any real attention to that statement at the time. *"It was kind of a throw-in statement,"* Anthony says. *"We were probably pissing and moaning and commiserating, you know."*

There were other signals trying to get Anthony's attention:

"I had symptoms like dizziness. And I would run into things. You know, dizziness is one of the most common symptoms of anything. But running into things. I would run into walls. I mean, basically if I was walking down a court I would bump in and brush the wall. Or I would hit a street sign as I was walking down a sidewalk and not see it. But I felt: well, I am tired, I am preoccupied. Just feeling basically out of whack."

One day while playing the piano he noticed that he could see the sheet music better out of one eye than out of the other. This visual disturbance led him to go into the ophthalmologist where they discovered the tumor in his eye.

How does Anthony think he got cancer?

Anthony: "There is all kinds of questions and explanations that go through your mind. Was it the high-school physics class when we studied lasers? Did I look into the laser, blast some cells into cancer mode? And I thought for a long time, *well it was probably just the schedule that I was keeping. And if anything, that's what's easiest now for me to reconcile. That I was just really burning the candle at both ends. It is easy for me to accept that the potential for cancer is out there for everybody. It can happen. That's pretty much the way I see it now."*

Renata: "What do you think made you live that way? Or, why would you..?"

Anthony: ".. trying to live up to other people's expectations. Just trying to be the bright boy and do whatever people wanted me to do, so that they would like me or that they accept me or whatever. And also that you never get anywhere in life if you just kind of went with the flow. So you always had to struggle, you know. .. I guess, for me at least, that was part of being in my late teens, it was like trying to make a mark."

Renata: "Did that attitude change in any way?"

Anthony: "Oh yeah! Yeah. It took a while. About two years after that, all the stress culminated in a really good case of mononucleosis. I just hit the brick wall. I pushed it until my body just said: "Stop!" I went to the doctors and asked what was wrong with me. They said: "Well, you are sick. You have to lie in bed for about six weeks to recuperate." That was the next step. I had an authority figure, somebody in a white coat tell me: "You have to take it easy." Then I had an excuse to say: "O.k., now I am going to take care of myself." So I cut back my hours at school. I had already started to transition from the science based classes. I had taken them because I felt that studying things that were difficult for me was a character builder and something that I should try to do. As opposed to doing something that was easy for me. I slowly started to make a transition back into the liberal arts. Late at night, when I was studying chemistry, the book was there and I was also drawing in my notebook and stuff like that. I gave myself the permission to start exploring that a little bit. In addition to the science classes, I would take an art class at night or something like that. After I recovered from the mono and went back to school, I took seven hours of art classes. I remember the point when I was sitting in an analytical chemistry class, and they were talking about balancing equations on the board. I wasn't interested at all! Although I was *a little intimidated, I got up, closed my book, threw everything in my pack and walked out of the class, in the middle of the class. And that was it. I went and I dropped every bit of the chemistry and the calculus and everything else and signed up for some art classes. And that felt really rooting. I was doing it for myself."*

Late at night, Anthony discovers that while one part of him is studying chemistry, another part of him is more interested in drawing. He allows himself to explore that side more. It is after a second illness experience that he gains the courage to give his artistic side more room. He drops the science based classes he saw as "character builders" and follows his natural interests. It was a hero's act to walk out in the middle of a class and therefore make a public statement that he is done adapting to outside expectations. How liberating it must have felt!

Anthony finished with a liberal arts education and started showing his art with some success. He found people calling him and saying: "We like your work. Now, we want more of these. But can you get them in red?" An old struggle had resurfaced in a new disguise.

Anthony: "It was the same story that you hear from other artists. I just didn't want to put up with it. So I guess in that trail, it was another sense of: I don't want to live up to expectations. I'd like to continue to draw and print and paint. It's just that I am not sitting down at the table every night for three hours because somebody who is serious about, has to. When I don't have the time or when I am not feeling compelled to do it, I don't feel I have to be apologetic to anybody."

Using art as a business does not work for Anthony. Producing art that is in demand seems to defeat the original purpose. Earlier, exploring his artistic side had been connected to following his natural talents rather than following outside expectations. Now he only draws and paints when he feels like it. He sees and collects things, stores art projects in a folder for later. At this point, all he wants is a regular 40 hour job so that he could fulfill a long-term dream and own his own home.

Experiencing an illness inevitably puts focus on the body and on the person's relationship to his or her physical being.

Anthony: "I felt a real separation of body and head. In fact, it is still difficult to think of this as being me (points to his chest). This is me up here (points to his head). But feeling the connection isn't really easy. I guess when you are young you can get away with some of that. But you do catch up, living that way. My body was trying to struggle and work through a lot of that stuff till I got both my mind and body in sync. I don't think I originally was really settled on what had happened. And for me that was a long drawn out period. And sure, it wasn't chemotherapy but it was Anthony's therapy."

Renata: "Right. Did you ever feel that your life was threatened by what was going on?"

Anthony: ".. I had always felt that other people didn't consider it life-threatening enough. Yeah, I always considered it to be quite a shock. Maybe just the stigma of cancer. Even ten years ago, the idea of survival and cancer together wasn't as clear as it is now. So I am sure that my impression of cancer was closely tied with the last ailment or death. I did have this longing sense that nobody was taking this seriously. Here is this life-threatening thing that happened to me and I really can't get any recognition from anybody that this happened. And yet I shunned any kind of sympathy. When people would ask if I needed any help or anything like that, I would turn them away.. "

Renata: "You didn't get support from the outside for the seriousness, which then probably in turn made it a little more difficult to take it as seriously inside. That would be my guess."

Anthony: "I kind of wanted to take it seriously inside but I couldn't take that seriousness that I felt to anybody. Nobody really wants to hear much about your cancer. I guess it is kind of a threat? A threat to your friendship or a threat to their security, to how they feel about themselves. And the doctors were basically saying: "well, you know, get on with your life." And I guess I just kind of expected to do what they told me to do or how to feel or something. It seemed like a real contradiction with what I felt cancer was and what I felt I had just gone through. But yet it was easy to just buy into that and because it had only been such a short period of time. Just pick up and keep going."

Without any encouragement to see the physical experience as an expression of his whole being, and without the acknowledgment that a strong process had interfered with his usual identity, Anthony felt the gap between the outside reactions and his inner longing. Something had swept him up, had taken him away from the usual environment and then pulled him back in. Life went on.

Anthony: "I think I felt the impact until it felt too stressful and then I put it away. For the last ten years, I was checking in with it when I could and allowing as much of the impact to be a part of my life as I could handle at the time. I integrated it into my life over a period of years. It was just easier for me to kind of work with it for a while, see how it felt and then work with it for a while and see how I felt."

The above seems to be a description of what Anthony earlier called "Anthony's therapy": learning to be gentle with himself; finding and following an inner guide who knows the importance of going on with life as well as the need to acknowledge the strength of the experience and gain more understanding of its impact over time.

Renata: "You lost your eye, an important body part, especially since you say that you are a visual person, interested in art. It got you at the core there..."

Anthony: "Mmh. Yeah, I suppose so. And I am a bit vain, too. So my appearance is pretty important to me and it always bugged me a bit that the two eyes weren't the same. But yeah, the loss has been a struggle. I had a friend whose father is from Hamburg and they were over here visiting. He lost his eye in World War II. He was full of things like: "Well, what doesn't cure you, makes you stronger." I said to him: "Isn't it a nuisance to go reaching for a cup and knock it over instead of picking it up?" But even him: "We don't have to deal with things like that." It's a physical thing that I have never been able to drop. I have one eye that sees and I have grey over here. And when I close my eye, the grey disappears."

This German man from Hamburg who lost an eye during the war represents a toughness which is also in Anthony. Maybe a certain Germanic attitude? Anthony wonders: How come this man is so hard on himself? How can he only want to suppress any emotion connected to the loss, any grief, ignore that side of himself? -- You just have to go on with your life. Pick up the pieces and go on. That is what it is all about. It was only one eye. It could have been a lot worse.

Anthony: "A sense of loss is almost always there with me. There are times when my concentration is away from the visual and I am thinking or not concentrating on that. But that's always been something that I have been very aware of and wondering will this ever change. Why is that screen in my brain still grey?"

The lethal tumor was removed. Nature gave in. Unfortunately the eye had to go with it. Now there is a "grey-zone" to deal with. Something between black and white, between life and death. It stays as a constant reminder.

Anthony: "I think for the longest time, there was the feeling: the blindness will go away and the sight will come back. Almost like a lizard grows another tail, I'll grow another eye. This scar will go away and there will be fresh skin underneath and everything will be fine. I think at the core, that's how I felt for a long time. I am slowly learning to deal with it. And it's not such a let-down anymore. I am learning how to reach for cups and not knock them over and learning when it's comfortable for me to drive and not to drive and things like that. .. And I have learned to live with it. I don't really have any regrets about where I am at right now. I am happy with my life the way it is. And so, whatever has happened to me to get to this point, I can't regret that either. I might be equally as happy if I'd never had cancer. I am not bitter at all about it."

Mourning the loss of his eye has been a long process. The belief in and hope for renewal slowly turned into the realization and acceptance that the loss will be permanent. Regrets and bitterness are not part of Anthony's identity at this point. He alludes to them by denying them. I could empathize with feeling angry and bitter. The body let him down. Growth happened in an unexpected and unwanted place. It deprived Anthony of his normal sensory awareness, left him with only one eye.

Renata: "Certain things can be forgotten. But what you said, there is a scar there. There is something there that says.."

Anthony: "..I am different. That's what came to my mind. That's how I wanted your sentence to end anyway."

My question was intended to hear more about the scars of the illness that stay as a reminder of the forcefulness of the process in the background of Anthony's life. He in turn tells me that his illness experience sets him apart, makes him different.

Renata: "There is something forceful that has crossed your path or your life. A certain intensity that struck you. And then .. living with the aftermath of it for the rest of your life."

Anthony: "That is pretty much what one would have to do on any scale. To pick up the pieces. Since I talked to you on the phone, I have been thinking: what do I have to say about cancer anymore? What do I have to say about illnesses or experiences? It's just how you pick up the pieces and go on, you know. The whole thing is about how you just go on with it from day to day. I am still alive and how do I go on with things. And every decision is just: how do I keep going?"

For Anthony surviving cancer meant learning to pick up the pieces, to go on with life on a day to day basis. It is also about making decisions for himself which might go against what other people have in mind for him. I asked Anthony next why he thought cancer existed. Here is his answer:

"Why does cancer exist? Basically because we are an organization of cells. We have evolved and we continue to evolve and the mechanism isn't perfect yet and we have a constant bombardment of things that want to reduce us back down to, you know, to the dust that we were. Or whatever terms you want to use. Cancer is just one of them."

Renata: "So, cancer is a force that is adversary towards human beings..."

Anthony: "Well, I think I define everything about being kind of an optimum human being. And it seems to me that is really what the human organism is trying to be all the time. It's constantly struggling to be healthy, to continue to do the reproductive thing, or the eating thing, or whatever. And cancer interferes with that. And the body has to fight all kinds of things that want to interfere with that. And cancer is just one them."

Renata: "Could you imagine that there could be a world without cancer? How would that world be different from ours in terms of how would it function differently or what kinds of criteria.."

Anthony: "I guess, it basically comes down to what then would limit population, what would regulate society and other things. I don't know. That's a very difficult question. I guess, my belief in human nature is that if there weren't disease to .. rally around or to ignore or to however we chose to deal with it, there would be something else that would basically take its place that would be unpredictable."

Renata: "Going back to the actual experience of the cancer you had, what were the body sensations? There was the dizziness that you said and the .."

Anthony: ".. bumping into things and apparent lack of vision."

Renata: ".. Let's say that you could not have the tumor removed. You would have to go on living with the dizziness and the bumping into things, and stuff like that. Can you imagine, what kind of life you would have to live to integrate that? What would you be like?"

Anthony explained in the beginning that the first indications that something was happening in his body were disturbances of his equilibrium and his vision. I am trying to have Anthony experiment with the idea that the symptoms were giving him an experience worth exploring. They changed his usual way of being in the world. A new life-style might have been needed at the time for his overall well-being.

Anthony: ".. This is a great question. If I bumped into things and felt dizzy... This is not much different than how I feel now all the time. I still bump into things and the lack of depth perception sometimes sets me off a little bit. You learn to live with it. I see that as a process of life and death. We are born with genetic material that might predestine how we live. But from that point on, all those things that we talked about that bombard us in the world and try to change us and try to reduce us down into life matter, that doesn't consume a lot of energy. We start dying as soon as we are born."

Renata: "It's interesting, you still have the same symptoms that you had before. You have learned to cope with it and you have learned to do certain things to cover it up.. If you would be a person that actually goes the other way, and the symptoms would be more and more exaggerated. What would you be like if you couldn't cover up?"

Anthony: "If I couldn't cover up? I keep wanting to meet you and say: I would always adapt, somehow, I would always find some way to adapt. I am pretty sure. It's easier to adapt than curl up and die. That's the way I see it. It's black and white for me."

Taking on another identity, another way of being can be seen as curling up and dying. - This would not be me anymore. I would always adapt to the situation, go along on my path and integrate this new limitation to the best of my ability. It is still me, just a little bit different. Anthony's "new" eye sees gray, although it is not supposed to see anything. Does it want to tell him that there could be another way? What would change for him if he would follow the symptoms' lead?

Renata: "I have this picture of a person that would tumble through life..."

Anthony: "Just going with it?"

Renata: "Doing it more extremely even. Like: you bump into this and then you bump into that. Basically, you would be living your symptoms. "

Anthony: "These people outside of the main stream, the ones that we feel that need to be channeled back into society, if we just allowed them to continue to bump around and do the things they like? I'd go crazy! No, I am part of the main stream society."

A switch happened. It went from a personal experience - what would Anthony's life be like if he lived his symptoms - to "these people out of the main stream." Anthony does not consider himself part of that group. He could not tolerate being that way. It is threatening to live parts of yourself that set you apart, that do not go along with who you think you are and who you want to be.

Renata: "You would go crazy if you had to accept people who just kind of..."

Anthony: ".. yeah, to accept things like that. I have never been one really to like change. Wait a second! I was pretty happy with the way it was. It has taken me a while to adapt to that course. But now I am adapted to it and don't just expect me to turn on a dime now. I don't like that. Kind of like I did with the cancer. It's like: o.k. the hell with the fact that I had cancer! I am not going to change. I keep going the way I want. But change is inevitable, I guess, you will eventually have to flex with it."

Afterthoughts

The interview begins with a joke. "Drive-through cancer. Would you like some fries with that?" What is that about? Fast food, fast treatment. Medicine as an industry where you get snubbed. You are done and finished, no hurt feelings about anything. Be happy that you are still alive! It was only an eye. Don't perseverate! Forget about it.

I wonder if Anthony's cynicism is a disguise for some intense feelings that were not expressed; possibly some bitterness about his fate. He explained cancer as a force that works against the optimism and the striving of humanity. A force that tries to reduce us down to dust and therefore reminds us of our impermanence. Having experienced a life-threatening illness at a very young age, the dichotomy between society's expectations to be ambitious, to "make a mark," to be tough, and the reality of the symptom that pointed more towards going with the flow must have been very confusing. The interview shows clearly that there was not much support from the environment for a process of living more in a "grey-zone" and letting things evolve as they come up. The need for the unpredictable seems to be as inherent in human nature as the need for safety and certainty. We help create both sides.

Anthony's treatment and recovery only lasted for about two weeks. He soon was out and about and enjoying his life again. The illness process took a lot longer to unfold its pattern on a psychological level. For many years, Anthony was haunted by the "quick solution approach." He slowly learned to ask for help and take the cancer experience more seriously. Anthony just now feels he is coming to a resting place with his experience. He mentioned to me that he felt ready to let go. Doing this interview was his way of saying good-bye, accepting his fate and going on.

It was fascinating to learn that the loss of his eye left Anthony with the same awkwardness in movement he had experienced before due to the tumor. Taking away the disturbance, so to speak, did not discard of the process in the background. The message of the illness could be seen as pointing away from following intent or will. Living life by following unpredictable movements (and impulses) rather than a laid-out plan would be a way to integrate the message of the original symptom created by the tumor. Anthony naturally picked up some of this "life-style" by the way he chose his career. Anthony's illness process is also related to society. I believe that we all could benefit from valuing momentary awareness and appreciating impulses that challenge us to change and grow.

CHAPTER VI: CANCER, THE LONG AWAITED CRISIS

One of the people I interviewed was a woman in her late thirties. At age 30 she was diagnosed with Hodgkin's disease. (Hodgkin's disease is a cancer of the lymphatic system.)

Celia: "Well, my healing came in a way I couldn't possibly have predicted. Cancer lifted me into the process of finding how to work with the doctors. I knew I had to make this connection with the doctors and with the staff and with chemotherapy and with radiation. I went into it as a spiritual experience. That was my healing: how to connect with Western medicine."

It was a long way to get to the healing. Dealing with doctors brought up the most fundamental fears for Celia. She had to overcome her phobias about doctors, needles and nausea. She also had to deal with her family myth, with abuse suffered early on as a child and with abuse handed down from generations.

Celia: "Most of my life I felt something was wrong with me physically. It started around the first grades in school. I had felt really strong and healthy and then I went through this period where I got sickly and I wasn't eating properly. And it got to a point where I just stopped growing. And so I had a tremendous sense of guilt around this. I thought something was wrong with me. I looked sickly. I was undernourished. I was little."

She developed an eating disorder.

Celia: "If I was nervous, I'd start to be afraid that I was going to throw up. I wanted to eat, but I thought that my body wouldn't let me. I would feel nauseous."

The sense of not feeling well physically stayed with her all through her twenties.

Celia: "In my twenties I had basically dropped out of life. I wasn't working and I was unhappy. I am moving along in life and I am feeling that something isn't right with me. Not able to really work, because I couldn't get along with people that well. You know, when you don't feel you are right, you are whole or you are healthy, you interact in a particular way with people."

Celia searched for answers with psychics. They predicted that something was seriously wrong with her physically and urged her to go and see a doctor. She also had a dream telling her that her river was going in the wrong direction.

A routine medical check-up did not show anything abnormal. The doctor minimized her symptoms of a cough that did not get better and a general body experience of not feeling well. His answers to her dream was that it must have something to do with sex. A year later, she came back with a swollen neck. This time x-rays showed several masses growing in her chest area. After the biopsy of a lymph node, the doctor said to her: "Well, I have good news for you. It's Hodgkin's."

For Celia it was a shock to hear that it was cancer.

Celia: "When I was diagnosed with cancer I just knew, it was this total stopping point in my life. Like this is the final edict .. that your life is not working. Something isn't right and you need to heal. Period. Everything. Within a few days somebody sent me a Bernie Siegel article. And that was like this huge shift for me. He said that cancer is a wake-up call from God. And I just got it immediately. I just thought, well, it's not bad. This is a good thing and it is meant to save me; it's *meant to heal me. And so at that point, I knew that that was the biggest thing in my life and I was going to put everything into it."*

Celia understood that her life had come to a total stopping point. She needed and wanted to turn her life around. The process of healing needed to start where emotional trauma, she believes, stifled her and made her unable to live a happy and satisfying life. She ignored medical advice and started her own healing program: getting in touch with her emotional being, dealing with grief, and pursuing personal growth. Celia's decision to pursue emotional healing rather than standard medical treatment at that critical point in her life was strongly influenced by her view of medical doctors, which in turn was tainted by her relationship to her father, a medical doctor himself. About a year before Celia was diagnosed with cancer, he had committed suicide.

Celia: "See, my dad was a doctor, and that's why I didn't trust doctors. I didn't trust the medical community because I had seen not only the way that I had been treated as a child, but my father was addicted to drugs and the medical community didn't deal with it. And so I thought: trust them with my life? No way! I thought that would be death. So it was really deep seated. I felt if I just went ahead like anybody, trusted the doctors and treated it like it was nothing, then I would die. Because I was after total healing."

Celia needed to deal with the emotional abuse first, to strongly follow her own path before she would be ready to surrender to her biggest enemy. For three years Celia focused intensely on emotional healing. It meant opening herself up to grief, abuse, pain and whatever emerged from the depths of her being. The path she chose shows her courage, strength and stubbornness.

Celia: "After three years I started to die physically. I was getting more in touch with myself all over the place, but I was physically dying. I would periodically check in with the doctors and they would be horrified. We can cure this, why don't you take treatment? And I was all the time resisting. It got to the point where I was dying. I couldn't walk across the room, I was so weak. I would have these huge sweats at night because my lymph system was all clogged up. I couldn't eat and I was really emaciated. I had this grief process where I was just crying and grieving my life. Like I thought that I was going to make it and I wasn't making it. And then I had a dream. And the dream said: there was an indoor swimming pool. And there was a bulletin board with a notice on the board which said: Celia will be facilitating encounters between cancer patients and dolphins. I didn't have any conscious desire to be with dolphins and I had never even seen one in real life. I thought: it means that I am going to live. It was an assurance that I was meant to live, that life wanted me. And I thought I should do anything I possibly can. And I just made the leap into the willingness to do chemotherapy. Because I was so stubborn, I would have died without this faith that I was meant to live."

Celia believed that God had sent her a wake-up call with cancer. The way the message of an article had started her on the journey to emotional healing three years before, the faith in a dream gave her the strength to comply with the doctors and work towards physical healing. Her struggle with the medical community turned into a spiritual quest.

Celia: "I learned to bring my emotional body to the office. And I wouldn't do anything unless I was treated right. I would cry when I needed to. Every day I went into radiation, I made a deal with God. Every day I would reach out in some way. (She sniffs.) .. All I needed to do was have a sign of where I should be or how I should reach out. I had one incredible experience: .. It's really scary this radiation because you have all these associations that radiation kills you, you know. And you are in this room with these huge doors and they set you up and *say: "Don't move!" And you are on this table. They have these blocks that are put on these shelves above your lungs so that the radiation doesn't hit your lungs. And this larynx one that is like a pencil. And you know if you move.. And then everybody runs out of the room and they say: "Don't move!" And they are watching through a control panel and they are working these computers and stuff. It's this tunnel, this huge thing, this exhilarating processor, this nuclear thing that they built up to kill your cancer. And so I knew after the first time that I had to connect with the people doing it. And I went in and I just chose the right technician. A woman that seemed more friendly. She had this cross on. So I said to her: "Will you please say something nice to me before you leave?" Just like a child. And she comes over and she puts her hand on me. I'll never forget this; it was so beautiful. She put her hand on me and she said: "Christ be with you."*

...

I learned how to relate to people like that. I figured while the doctors would take care of the medical things, I would take care of what I needed and I would ask for it."

The life-threatening illness brought different parts of her life together: dealing with the medical community reconnected her with her father and what he represented. Early emotional abuse in the form of harsh criticisms, threats and carelessness made her afraid of him and pushed her into silence and hiding. Her feelings and needs became unacknowledged and unimportant. The illness amplified the process of separation and even alienation from people. The turning point came about through believing in another realm. Celia got in touch with her own spirituality and started a deep belief in herself, love and other people. The healing process included learning to connect with people, expressing needs and being open and vulnerable while trusting that someone would be responsive.

Surviving cancer meant more to Celia than coping with an illness and getting back to normal, the way she had been living life up to that point. For her this was a last chance to turn her life around and discover the lust for and meaning of life from within. Faith in herself, her dreams and a supreme being she calls God fostered true transformation. At the edge of life critical mass was reached and radical change started to happen.

Celia: "Everything I went through was just so precious. It was so incredible. I was so dysfunctional. I couldn't deal with people. And there I had to trust people to put needles into me. So I would come out of these things like it was a blessing. I would have to interact with people so strongly and so primitively, so fundamentally. You know, people would hold my hand. I just became a little child. I let myself be that little child. And that is so precious to let yourself do that. And it's o.k. And if they can't deal with it then you find someone that can. And they usually can. I mean, I have been blessed. The people that I have opened up to, they were able to be there for me. You learn a lot about connection and relationship."

Dealing with the medical community meant carefully balancing strength and sensitivity. It meant rising out of passivity and taking on responsibility for her own life in the face of death. On a physical level, Celia recovered completely from her illness. She believes though that there is a long-term psychological process in the background, a life myth with which she came in touch through the illness experience.

Celia: "Well, .. sometimes I think I need cancer in order to grow. (laughs) I really do fear that if I get stuck, I'll just get cancer and then I'll be able to access change and growth. It's kind of an uncomfortable way to live. But also I really know what it is to live as opposed to a lot of people who don't. Because every day I think about *it. I try to think like that. It is hard to take the steps in your life. It's hard for me. Since I know what it is like to be close to death, I don't think I have life forever."*

During the following interview sequence I attempted to get Celia in touch with the background psychological process of her illness by using verbal cues. The starting point was her actual experience of the original symptoms.

Renata: "I would like to go back to the original experience of your symptom. You mentioned that you had a swollen neck and they discovered a mass in your chest. Do you remember what that was like physically? I remember that you said you saw it in the mirror. So that was a visual experience. Do you remember any other way you noticed that?"

Celia: "Well, ..you can kind of feel it. It's just kind of swollen and you are not quite as mobile. Then I remember I would feel a little bit sluggish. .."

Renata: "So you would be a little less mobile and feel sluggish.."

Celia: "Yeah. And like there is this pressure here, kind of like a pressure... And that is really what it is. Because it is like being clogged up. Your system is backed up. Oh, you know what? I have to tell you. Last night I dreamt that I was at a school. And I went to use the restroom and I flushed the toilet. It flushed o.k., but I noticed that there was all of this toweling. Not like toilet paper which flushes easily but these paper towels that don't. People had been using that instead of toilet paper because there wasn't enough toilet paper. And I was indignant. It wasn't flushing down. The water was changing but that stuff was staying. So I know somebody has to go in there and get that stuff out. So I am a little bit backed up right now."

Renata: "There is some stuff in there somewhere."

Celia: "Yeah, there is some stuff in there. That has become one of my feedback mechanisms. And that is my whole cancer thing. If my system doesn't get flushed or things don't go down, I have to pay attention because that leads to masses growing."

Celia associates her original symptom of the swollen neck with being clogged up. Remembering the physical experience reminds her of a dream she had the night before the interview where the same theme came up: a backed-up toilet. The dreaming process behind the original symptom seems to still be hanging around although physically she considers herself recovered. It is apparent that Celia uses her dreams as well as her body symptoms as messages from another world to which she needs and wants to pay attention. She calls them "feedback mechanisms." I want to see if we can go somewhat deeper into the dreaming process by going back in time and using a kid's mind as a way to allow more irrational answers to come forward.

Renata: "So let's see. Since you are such an expert in being a kid, how about if you go back in your mind and try to explain to me what was happening in your body at that time when you discovered it from a kid's perspective."

Celia: "At the time that I got it kind of?"

Renata: "Yeah, when you sensed that something was going on."

Celia: "Well, I think, I think.., I mean I think like this naturally!"

Renata: "You are doing this naturally. Go ahead."

Celia: "I think that all this stuff in my childhood, I just couldn't swallow anymore. I think that all that stuff had been building and building and it made this thing inside here and it clogged me up. It clogs me up!"

Renata: "So what kind of things were stuffed in there?"

Celia: "What kinds of things? Things like not being able to take care of myself, not being able to stand up for what I wanted. Like when my father died. I had a family member who blamed me for his suicide. Not being able to say: "I didn't do it. I am not the fault. You can't treat me like that!" I was tremendously angry at that, I think, and I never let that out."

Renata: "Now probably with a real kid's mind, you wouldn't say things like: I didn't stand up for myself, or I wasn't assertive. A kid would probably have different things that they would mention. It's more on a fantasy level. They might talk about certain animals that would be in there or toys that got stuck, or, who knows what they would say. They might use different kinds of metaphors."

Celia: "Oh, when I was sick, I went into the hospital, I had some kind of a food poisoning. And you know what, I thought it was the cottage cheese I had eaten, that it was really animal poop. So I would say that this was a clogged mass of poop."

Renata: "Poop, from some kind of an animal."

Celia: "Well, from me."

Renata: "Your own."

Celia: "Yeah, my own that didn't go out."

Renata: "It didn't go out, it went up and it got stuck. Poop got stuck in your chest and your throat."

Celia: ".. Or maybe I ate it. Maybe I ate poop by mistake. Somebody fed me that."

Renata: "Somebody fed you poop and it didn't go down."

Celia: "It couldn't. It sort of is part of a normal process. But if it doesn't go out then it's not. You have got to get rid of it."

Renata: "I see. Who could that somebody be that fed you that?"

Celia: "Who fed me that? I think it was my family. Yeah, it was all throughout. It started to be my family and then when I got older it was my extended family, my aunt and my dad and to a certain degree my .. well, a little bit my sister. But we were getting along pretty good then."

Renata: "They were all feeding you poop. Gross!"

Celia: "It might have looked like food at first.."

Renata: "They disguised it. "

Celia: "Right. I thought I should eat it probably. Well, that sounds so gross."

Renata: "No, that sounds like a good one."

Celia: "Maybe it wasn't poop when it started out. Like the cottage cheese. It was by accident that poop got into it. ... So it was something that I ate became poisonous."

Renata: "So somebody wasn't watching out what you were eating or what she was feeding."

Celia: "Right. "

Renata: "They were kind of careless about that. Whatever could go in, could go in. Undifferentiated."

Celia: "Yes! Undifferentiated. That is a really big part of my process. Differentiating things, articulating things, expressing things. "

Renata: "Spitting it back out if it doesn't taste good rather than swallowing it."

Celia: "Right. .. "

Renata: "You are thinking something.."

Celia: "There was something about.. Do you want that now?"

Renata: "Yeah.."

Celia: "Well, when I was first diagnosed, I went to this transformational psychiatrist. He thought he was hot shit. (laughs) And I actually had a crush on him right from the start. But I went in for the first time and it was really incredible. I laid down on the couch and I went into this altered state. And that was unlike me. I never really had this happen before. And I just went into this altered state and it felt like pins and needles all over, pins and needles so help me God. And I let something out, I regurgitated it. And I said: "I caused my cancer. I know I did. I did it." And he was totally not expecting this huge thing to come out. So he tried to say: "No, we don't really do that." But it was the truth. It was the greatest thing I could have come to him with, you know. And all of these years of not feeling healthy and thinking I stunted my growth and feeling guilty and ashamed and then getting cancer. And I knew, you see, it was me, that something unconscious or whatever was causing this process. And I had to let it out. But anyway, I felt these pins and needles. There was something about bees, about bees not going to sting me now because that had happened. So periodically I would dream of bees as the symbol for cancer."

Renata: "Isn't there a whole mythological thing around transformation with bees?"

Celia: "I don't know, I have never heard that about bees.. Well, with me it was more the fear that they would sting me. So stinging started to mean... You know, when I felt the pins and needles, it was that all my life I had been stung without ever really feeling it, letting myself feel it. And so once I felt it, it went out. And so if the bee would sting me, it would be like being stung by somebody saying something, a stinging remark. And so I had to get that out of my system, get that poison out. Since then I had a couple of experiences where I had a really deep experience and I'd notice my hands would be like pins and needles."

Renata: "You said before that you think you caused your cancer. How do you think you did that?"

Celia: "How did I do that? I think it was my digestion."

Renata: "What do you mean, your digestion?"

Celia: "My digestion. I think I don't digest things properly and it creates poisons in my systems and then they clog me up."

Renata: "So how would you digest it right then or better?"

Celia: "..If it is something not digestible then I have to spit it out. If it is something digestible, then I have to let it in."

Renata: "Kind of differentiating the poop from the food."

Celia: "Yes, right. Learning how to differentiate my needs and seeing what fits and what doesn't. Seeing what fits where and when to use what.. Yeah. It's really tough."

Afterthoughts

After the interview was done, we went to have lunch and chatted about this and that. As with other people I interviewed, I noticed that the fact that the tape recorder was shut off relaxed Celia and allowed her to more freely relate some ideas and opinions about the illness she experienced. I want to include her theory about Hodgkin's disease, why she thinks people get afflicted by this particular illness.

Celia has participated in different cancer support groups over the years. Her opinions and theories about Hodgkin's disease are based on her own as well as other people's experiences. Hodgkin's disease generally strikes people in their early life -- children and adolescents -- or as older adults. Celia firmly believes that Hodgkin's disease has to do with a certain developmental passage in life. She stated that she met people with Hodgkin's that were at a passage point towards developing as an adult and got stopped for some reason. She saw that the illness was often related to a psychological conflict around taking adult responsibilities.

I interviewed a man who was diagnosed with Hodgkin's disease in his late thirties. When we focused on his illness experience he went back to a school experience that happened when he was in sixth grade.

My personal experience with Hodgkin's disease is far too limited to make any generalizations. I feel strongly that it is important to be careful when categorizing illnesses and connecting certain physical processes with psychological ones. I am concerned that general categories rather steer a person away from going into the actual physical experience than encourage him or her to let meaning develop unbiased by a preexisting idea about where the process needs to go.

CHAPTER VII: FINDING TRUE LOVE, A DO-OR-DIE SITUATION

Carol: "I have been dealing with ovarian cancer for four years. Right after I turned 30, I had a little birthday present. I found out that I had cancer."

Carol's first symptoms were pains much like menstrual cramps, back pains and a feeling of fullness in her lower abdomen and pelvis area around the time that she would be ovulating. Her gynecologist thought that the symptoms were related to an ovarian cyst and calmed her worries. The pains persisted. A few months later grapefruit sized masses on each ovary were discovered. She had surgery and woke up to the bad news that she had ovarian cancer which had spread pretty extensively.

It was a big surprise. After six months of chemotherapy, a minor exploratory surgery and follow-up blood tests showed that the cancer was gone. Three years later, she had a recurrence. This time the treatment was more radical: an eight hour surgery to remove the tumor and extensive and severe chemotherapy to eradicate the numerous tiny nodules of cancerous tissue. Carol developed an allergic reaction to the drugs and, against medical advice, decided to follow her body's reaction and stop treatment a month early. Statistically her decision reduced her chance for survival from 5% to 0%.

Carol: "I get overwhelmed a lot. There is a strange dichotomy... I am coming to terms with the possibility that I might die. You know, really facing that possibility. Yet, I still often feel that it is not going to happen to me, that I am going to find a way to beat it. Statistics are one thing but there is still, even just the smallest chance. Someone in this situation has survived, so there is a chance that I can, *too. So I feel like I haven't given up completely. I feel there is still hope, but not as much as before. I also feel a big responsibility and sometimes that feels overwhelming. If there is an answer to this, I have got it somewhere, but I don't know what it is. I have got to find it if I am going to survive. So that's pretty hard sometimes."*

Renata: "How are you feeling these days in your body?"

Carol: "My energy level is still lower than it was. It's been shocking to me how long it's taken to recover from the chemotherapy. And digestive problems, I don't digest food well. Still I get a lot of diarrhea and problems associated with just moving things through and digesting. It makes it hard to be in the world a lot of times... I have been depressed a lot. You know, that has been a big part of the whole thing, fighting a lot of depression. I get pretty scared a lot of the times about a recurrence. I don't know what my future is. It's really changed my outlook on what I do with my time.

The awareness of her mortality pushes Carol to focus more on the remaining time in this life. What dreams would she want to come true? What would fulfill her? What is really important and essential to her?

Carol: "It seems that the important thing for me is connection. I got this answer from asking myself: how would I spend my last day? What I would want to do is be with my cat. That's all. That's what matters the most."

Renata: "The cat is really important."

Carol: "Yeah, yeah. (some tears) He is probably the only creature that I know that I really, really love. So, I think it's love and I think it's connecting. - There is a hopelessness around really being able to connect and love and be loved by people. There is a hopelessness that that's not really possible. That's kind of like a core thing for me in there."

The cat is the only living creature that can be fully trusted. What makes Carol so mistrustful of people? I found a first connection when I asked her about the time of the illness onset.

Carol: "There was something around relationships. I was actually feeling kind of suicidal about a relationship ending. Some friends of mine were getting married, and I was really depressed because my relationship was ending. I had put a lot of hopes on this relationship, I guess. I had thought that if I can't have a relationship with this man, I won't be able to have one with anyone. Because he is just the ideal, you know, that I have had in mind. This really loving and really giving person, communicative. I really just felt if I can't have a relationship with this guy, if I can't have what I want, I might as well give up. So I think there was that beginning of a hopelessness."

There is something absolute in Carol's pursuit of relationships. For Carol not getting what she wants on a relationship level means becoming hopeless and giving up on life.

Renata: "And that was shortly before you .."

Carol: "It was about .. I don't know, about a year before. - The one thing that was most important in my life was the relationship that I had with a man. That is what I was living for. And I began to become aware of that right around that time. That there was something wrong with just always living for a relationship. And yet .. what I really want to do is to really, really connect with someone."

At this point, Carol's cat jumps onto her lap.

Carol: "This cat is so wonderful. He is just a really lovable creature. And he is very, very connected with me on subtle levels. When I came home from the hospital.., he knew that I was hurt. He stayed right beside me in bed every second. If I'd stir or wake up or move at all, he would immediately stand up and go "meow" and look at me. He was concerned about me. I mean, all night he was like that. He understood somehow. He wouldn't leave.. I don't have to explain to him, you know, he just knows. "

Renata: ".. that's the kind of connection you are looking for in relationships. If only people could also be that way..."

Carol: "It is a fantasy, I guess. I don't want to have to explain myself to everybody all the time. I want you to understand me without me having to explain everything. But we can't all be as psychic as Ziggy is, I guess." (laughs)

Renata: "He has a special intuitive cat nature."

Carol: "He does." (laughs)

The cat offers psychic understanding. He embodies the ideal qualities of a mate: a soul connection beyond all doubts, someone with whom you can be yourself, where understanding happens without words and connection exists on an instinctive level. Carol's relationship fantasy is very idealistic as well as romantic. She would rather die than not find true love in her life.

Knowing about her cancer started a process of self-discovery. Carol remembers telling a friend of hers just before undergoing her initial surgery that if it did turn out to be cancer, she would not be thinking about anything else for a long time. There was a sense that a big life change was about to happen. She quit her job as a nurse in a hospital because she found the hospital setting to be like "a dysfunctional family."

Carol: "I needed to find meaning in life and somehow a reason to live. It seemed like I was just kind of going through the motions of life, in a way. I didn't have real connections with people. I also needed to find out who is this self that I need to be true to. Because that is probably a core part of it. You have got to be true to yourself. How can you be true to yourself if you don't even know who that self is."

Renata: "So the illness has helped you kind of shed the parts that may be superfluous, that.."

Carol: "Yeah, parts of you need to die, you know. Let them die! And spend your energy and time on what needs to live, what needs to be developed. I guess that's it. And that's been the big task. I almost feel I had to get really sick in order to be woken up to that fact. Nothing else really would have woken me up to really looking at what is here in front of me. I was too preoccupied with the facade that I was building up."

Renata: "That's a strong statement. "

Carol: "Yeah, yeah.. It's weird to think about it that way. But I can see that's really the truth for me."

Renata: "Well, I am sure that you have thought, at one point or another, why you got the illness..."

Carol: "Oh yeah, oh yeah. I have many different hypotheses on that one... It seems that it is about relating and connecting with people and with the world... And being who I really am and really finding a way of being in the world where I can be who I am and be accepted for that and loved for that. I think there is also something about being a woman. Just really loving myself as a woman and really being a woman in the world. And my creative side, that's another thing. I made *this connection with some help. In some book, I read about the significance of ovaries on a psychic level. It is creation and creativity. And I am beginning to see how I really stifle my creativity a lot. That is something I need to explore a lot more. My creative side, my relatedness to others, my self as a woman. That's probably most of it, in there. And it is something about generations of abuse and unconsciousness and non-connectedness, another area of hopelessness. I can trace it back for generations and see what it has been. There is a part of me that does not want to continue in this extreme. I was always kind of afraid of having kids. I don't think I could cope with all the realities around having children. So it is also about reproducing myself and allowing that to go on."*

Renata: "You need a new and different way of reproducing yourself. A way that does not reproduce and propagate the same pattern, but starts a new pattern. And it has something to do with a new way of relating. It's exciting!"

Carol: "It is exciting. I get all choked up when I think about this... I feel like this is my last chance. I really am on the verge of discovering what it is that I need to live. That somehow if I can get a hold of that, you know, and really do it, then .."

Renata: "So it seems almost like your life started over when you got your illness. You got a second chance.. to somehow rethink your life."

Carol: "Yeah. In a sense, what point was there in going on the way I was going on, really? So I guess, finding a way to make it have some point for me is the answer. It does feel like there is a lot of pressure around and that makes it really hard, you know. At the same time, I probably wouldn't do it any other way. There are so many pressures in life keeping you from really making the strides in the direction you need to do."

Renata: "What would you say is the most mysterious aspect of this experience as a whole?"

Carol: "Mmh... There is a big unknown quantity about how we get in touch with what our own answers are, you know. That has been pretty mysterious. And what *is our soul, our spirit and our true self. That's kind of mysterious to me. The illness is pushing for a discovery of that."*

Renata: "If you could be the creator of the world, coming from where you are now, what would need to be different in other people, in the world and in society as a whole in order for you to have it easier? What would relieve you? Do you have a sense of that?"

Carol: "Boy,.. I don't know. Maybe just for people to accept each other's differences. Just to accept ... I am just thinking of how hard it is to discover who we are in this world because we all think we have to be something else. If we could accept our intuitive inclinations and just go with those and have our natural selves accepted... You know, we grow up thinking that we are not o.k. the way we are. You have somebody else as an ideal instead of yourself. If as children you were taught that you are unique and special the way you are, to have the encouragement to unfold..."

Renata: "It also sounds like you in your personal life have not had that too much growing up."

Carol: "Yeah. I remember as a little kid all the time finding stray animals and wanting to take care of them, wanting to connect with them. That was forbidden. I remember one time finding this little cat. It was a black and white cat. It followed me home. It was just this tiny, tiny kitten. It was lost. My mom made me take it to the pound and leave it in this cage to be killed. I always wanted to be around animals a lot and that was discouraged. My mother didn't want to take the responsibility for pets, I guess. There also were all these horses around that I went to see every day. The man who owned them was a dentist. There was a colt born and he offered to let me show it if I wanted. He had daughters that were showing his horses. As they grew up, they moved away. He knew how much I loved this little colt and he offered to let me go to the show and show it. And my mother wouldn't let me do it. She forbid me to ever go there again. Her idea was that this guy was a dirty old man and that he had some kind of intention towards me, or something..."

Renata: It sounds like your mother did not support your love for animals or trust your intuitions about people very much..."

Carol: "Yeah. I never thought about this in that way, Renata, but I can really see that where every intuition and probably like the connection with the animals, too, like the natural stuff, the intuitive stuff is kind of along that line. It was always: don't trust that!"

Renata: "I would like to dig a little bit on the creative end of things. In my head, I am stuck with the picture of your symptom you mentioned in the beginning, the grapefruit sized growth and all the tiny modules. I visualize space, a mother planet with satellites. What actually is your relationship to your symptoms?"

Carol: "I have a story that came to me yesterday. It came out of some work I did around the symptoms... It goes back to the generational thing. Last week I bought some tulips. I had them in the sun, and in the sunlight you can just see them opening up. I realized that's what I need to learn: to really open myself up to life; and to just explore life and to be here; to not be afraid to really open up and to really bloom and blossom into myself. So the story that came to me yesterday afternoon was: I was thinking about my grandmother. What a flower she must have been! She still is so beautiful. There seems to be some myth in our family that it is too dangerous to really blossom and to be a beautiful flower. You are going to get picked and cut down! When my grandmother was sixteen, she basically was abducted by her husband. She didn't know him. She was this beautiful little flower, you know. Just beginning to blossom. And someone came along and saw that and just.. He was an abusive man and I think that started some kind of myth in our family that it was dangerous to really open up and be yourself. It was dangerous to be a woman, to be .. attractive, to be.. to really open up."

Renata: "It's kind of like hiding the treasures.."

Carol: "Yeah, hide them away or you end up getting hurt! And I can see that with the ovarian cancer, too. It is a very hidden, very insidious disease. It usually progresses pretty extensively by the time it is found because it is so hidden."

Renata: "So you could look at the tumors as treasures that you have in there, which have been growing and growing and getting bigger.. They might want to be seen."

Carol: "I also feel that there is some connection between my illness and my father dying. He died when I was nine. And it's actually, it's around having something hidden again, something secret. He was a diabetic. My mother was taking care of him all the time, giving him his insulin shots and making sure that he didn't eat the wrong things and always policing him. When she left him for another man, he basically was just really in despair. He died within a year of her leaving him. His family blamed my mother for his death. I know when I was growing up I was really ashamed of that. I remember always telling people that he died when I was little. And that it was no big deal to me because it happened so long ago and I hardly even remembered it. The secret in it was that my mother took on the blame for my father's death. I don't know how that relates, but somehow it seems an important part to me... I thought of it because I was thinking of abandoning the kitties, you know."

Renata: "Probably some of it was true. Her leaving him surely had a big effect on him. The reason for him to keep on living was gone. And as a kid to understand all those things, I mean.."

Carol: "Yeah. And we never talked about it. Until I was about twenty, I didn't even know how he died. I always assumed that he died in a car accident. It was this big hidden secret."

Renata: "Is there also something about hiding frailty, that some of that needs to be hidden in order for you not to be abandoned? If I think of him, in a sense to be unhealthy, to be difficult or dependent puts you in a spot that if you really show *that and if it's really out, you can be left for it. You can be abandoned for it. These are just some guesses."*

Carol: "I think there is a lot of.., I haven't really looked at this very much. I just have a sense that it is important. And sometimes I get a flash and I feel like this is something concrete. I mean, my father, I think he was 30 when he died. And there is something about that, about moving on at that time of crisis into a new existence and a new way of being versus not being able to handle it and succumbing."

Renata: "So he was the same age actually, that you were when you got your diagnosis."

Carol: "Yeah, I thought about that for a long time. That seems almost eerie. And he also died out of a sense of hopelessness and despair. He lost his family and this connection with relationship and meaning in life through relationship. So maybe that is the deeper sense of that."

Renata: "Kind of like the same story that you had. It also was a relationship that didn't work out for you..."

Carol: "Why didn't I ever connect that before? And I know that his family was really important for him. I have lots of memories of him that he was a really good father. He wanted to have lots of kids and he was just really loving as a parent. He never hit us as kids. It seemed that we were always really respected and that his family was really important to him. And losing that just threw him into despair and killed him. And so in a sense the same thing happened to me."

Renata: "He put a similar importance on relationships as you: that it is not worth living if you cannot connect with people in a really deep sense. That is really crucial and important."

Carol: "Yeah. I have tried to remember what it was like as a small child. The only memories I have as a small child were memories with my father. I don't remember *my mother. I don't remember ever running to her for comfort or any memories of her really. When I was little, there was my father. I guess there is a new connection to him for me. This father aspect is something I pushed aside most of the time."*

Renata: "The stray intuitions.."

A week later, Carol calls me up. I am trying to catch her words as she speaks on the phone.

Carol: "I was sitting and meditating on a tulip and puzzling over what the message is of my illness. What it means. My ovaries just won't quit! Different memories. The ovaries are telling me that I need to be a mother. Your words helped me, the way you described the cancer. I remember that you described them as little babies. That stuck with me. I thought about it a lot. And the connection with my father. That family was so important to him. I always struggled with kids. I had two abortions, was pregnant at the wrong time. I thought it would be too hard to be a mother. I was always involved with men who didn't want to have children. One guy would tell me that he thought I was born to be a mother."

Afterthoughts

Carol calls her cancer "a little birthday present." I am reminded of a pregnancy. Something mysterious is growing inside of her, unknown, yet made of her own tissue. A process of separation has started. The cancer becomes an entity of its own.

It is only a week after the interview, during a phone conversation, when Carol tells me that she had two unwanted pregnancies. I am strongly reminded of the stray kittens her mother made Carol bring to the pound. Maybe life is stronger; maybe her ovaries just won't quit producing growth until someone will mother it.

During the interview I probe to find out what the tumors represent. Carol mentions at one point that the illness is pushing for a discovery of who she really is. She is engaged in the quest of the self to be true to; to fully blossom into herself. She has realized that the answers lie inside.

For me this interview reflects a lot of idealism, which if the ideals cannot be lived, ends in complete hopelessness and despair. The illness is forcing Carol to find out if she really wants to live. She is not only searching for answers on a personal level. Her life story and her illness process seem connected to generations before her who were not supported or able to live out their dreams. Abusive patterns in relationships might be related to Carol's own despair in this area. Hopelessness is part of the family myth as well. The father who is left for someone else is not able to take care of himself. He dies shortly after his big loss.

If I were to go on working with Carol, I might ask her how I could help her realize her ideal world. I would encourage her to create "an ideal animal kingdom." She naturally started this by using her cat. A certain playfulness might help balance the seriousness of her inner quest and bring forth unexpected solutions.

CHAPTER VIII: LUPUS, A TEACHER IN COMPASSION

Sara: "I was diagnosed with lupus four years ago [at age 26]. *Lupus is an auto-immune illness that affects your immune system. I basically have too much immune system and when I experience what is called a flare, which comes and goes, my immune system attacks my healthy body. At the time, I was experiencing a lot of fatigue and low grade fever. I would have severe joint pains and the joint pains would just kind of roam my body from day to day. I thought I got the flu that I couldn't get rid of. It started bothering me mentally because I found that I was taking a lot of naps. I just didn't have the energy and the zest that I normally did. I started feeling that I was just lazy."*

Sara goes on explaining the course of her illness:

Sara: "There is no cure for lupus. They can basically just treat the symptoms. For about the first year, I did o.k. I just had one incident where I got hospitalized with pleurisy for like three or four days. Other then that, the doctor was able to maintain my health. And then finally last year it really hit the worst. I could tell that my kidneys weren't really functioning because I had really bad edema. I was swollen and my blood pressure was really high. At that point, I had problems with my intestines, and then from there it went into my lungs. I couldn't breathe and they put me into intensive care and I was on a ventilator. Finally they put me in intensive care and then I was on a respirator for a month. In the meantime my kidneys had shut down, so they put me on dialysis. Then I was finally released three months later."

Renata: "So it sounds like it is a disease that shows up in various diseases, in various forms."

Sara: "Exactly. That's the thing that is really frustrating for the patient and really challenging for the doctors. Because it is an illness where everybody's case *varies so much. No two patients are the same. And all the doctors can do is sort of hit and miss. Let's give this a try and see how it works and if not.."*

Renata: "What do you think brought your illness on?

Sara: "Well, .. as far as .. medically I think what caused it could have been a drug reaction. I had an allergic reaction to sulfa. Of course, they don't really know what causes it. They say that stress could be a big part of it. When I was diagnosed, I was in a real high stress job. I was a sales representative. Plus my folks were going through a divorce. Now, I didn't really think it bothered me. But you know, sometimes things bother you and you just don't realize it. Then I bought a house. And then I was scared that maybe I made too big of a financial commitment. I mean, all these major things were going on in my life.. Personally though, you know, I look back on where I was, you know, kind of the perspective where I was personally. I considered myself pretty much on top of the world. 26 years old, had a college degree, was a sales representative, making really good money, you know. Just like I said, on the top of the world. Not a care... But I think at the same time, you know, looking back, I think I kind of have this .., kind of looked at the world through rose colored glasses."

Renata: "It wasn't very realistic what you were expecting from the world?"

Sara: "Well, more like: I am so perfect why can't everybody else be." (laughs)

Renata: "Oh, being critical of other people?"

Sara: "Oh, yes! .. I don't know, I have always been the kind of person that had really high goals and expectations. I mean: I am going to college and I am going to have this really good job, I am going to support myself, nobody else is going to take care of me. And I did it! You know, and I think at that period in my life, I don't think I was very empathetic to other people... I used to kind of feel like: we control our own destiny. If people wanted to, they could be anything."

Sara was living up to her expectations of leading a successful life, which mainly focused around establishing a career and guaranteeing financial independence. She felt that she was the creator of her own destiny; that she could be and do anything she wanted. And then, all of a sudden, things changed. The illness interrupted her plans. It brought her in contact with her own weakness, her need for support and opened her eyes and her heart towards less fortunate people. Sara got to the point where she had to admit to herself that she was not in control; the illness was leading the way and she had to go with it. Her first reaction to the diagnosis was denial; later came fear and depression. It was a hard lesson to learn to be out of control and to rely on other people.

Sara: "I think one of the things I realized through all that was that the worst happened and I was still able to survive. I think the scariest thing about an illness is the fear of the worst that can happen... I also learned with having the illness that I was not going to let little things get me down. Before I got sick, everything in my life had to be perfect. I mean, I was the kind of person that had everything clean. I just had to be my personal best. And if I didn't, my life got me down. After being sick, I realized: hey, life isn't going to be like that! I am not in control anymore. Yeah, my house isn't exactly like I want it. But you know what? There is another day tomorrow. And it comes and it goes. And I guess, I have just so much more inner peace now. Because those things aren't important. What's important, you know, is the people I love and who love me and who I care about and the happiness. Not these materialistic things."

Renata: "You have become a Buddhist.."

Sara: (laughs) "My brother is a Buddhist. In fact he was a big part of my healing, too. I even chanted with him sometimes. Whatever, just help me, God! Because I mean, I believe in God. I wouldn't say that I am a religious person, but I am a spiritual person. I was really mad and disappointed in God at first. Why had he *done that to me, you know? I felt like I was just suffering. I couldn't believe it. Fortunately they had a priest that would come and see me. And we would pray. I think that was a big part of it. And my mom and I, we would just pray every day. And she did the rosary. I mean, it really brought us closer... Yeah, I think (sighs).. I feel more inner peace now."*

Renata: "Do you have any future plans? Do you have any idea how you might or will integrate these experiences into a future life or a profession? Do you ever think about that?"

Sara: "Well, we talked about writing a book, my mom and I. But we haven't really done much of that. We were going to call it: we are survivors. About our experiences with lupus and stuff. But I wanted to write all about how awful it was to be at the hospital.. (laughs) and everything."

Renata: "So you feel the world could learn something from your experience?"

Sara: "Yeah. Well, I am a volunteer now at the hospital. I take my little dog up there. It's called pet therapy. We are working with mental patients and depressed people. I am hoping that I could help other people in that way. I just want to kind of get involved in that nurturing part. And then I talked in my doctors' class a couple of times, to those medical students. I am also in a support group. I haven't really been able to help anybody else, I don't feel. But that doesn't necessarily mean it won't happen."

Renata: "So you might want to go more into the helping professions?"

Sara: "Yeah, I thought about it. Go into counseling or something. I want to help as many people as I can. I think, if nothing else, to encourage people when they are really bad. Because I know when I was really sick, it meant a lot to me for people to say: you can get better. I think when you hear that people have been really bad and they did get better, that helps you feel more encouraged... I really thought I was going to die there for a while. In fact, I wanted to die. (laughs) And I think I would have if it wasn't for my family and my friends. I couldn't leave them.

Because they said: "We are not going to let you go." And it was like I had to do it for them."

Renata: "You couldn't do it for yourself, but you could do it for them?"

Sara: "Yeah. Kind of. Because I just wanted to die so that I could get out of that pain. But my mom wouldn't let me." (laughs)

Renata: "She kept you here..."

Sara: "Yeah, she did. I remember when I called the priest and I asked him: "If I don't get on this respirator, is that suicide?" Because I wanted to go to heaven. And he goes: "No, that's not suicide." I asked: "Why is God making me have all this pain?" And he said: "Remember how much pain Jesus had when he was on the cross?" And so that really helped me. Every time I would think about that, you know, how much he suffered. Maybe I could just suffer a little bit more and than it would be better. And I remember later on, just to be able to drink water, just to be able to eat, just to be able to talk. I mean, that was a gift! Because for a month, I couldn't eat or drink or talk or anything. I remember coming home and I had to be carried into the house. I couldn't walk. It was about six weeks before I could walk again. I remember my roommate. Once in a while, she'd go wild and she'd go dancing and go swimming. If only I could just do that! I mean now I am just so lucky to be able to do that!"

Renata: "So you started to appreciate the simple, basic things. It's amazing how many things we take for granted!"

Sara: "Oh yes! And you don't realize that till they are taken away. You know, now I am not nearly as goal-oriented as I used to be. I think I am happier. I mean, I don't have to prove anything."

Renata: "I asked you at the beginning what you thought the cause or the reason for your illness was. I wonder if you ever had an idea that was completely *irrational. Something you never told anybody, or maybe don't even quite admit to yourself, but it crossed your mind at one point..."*

Sara: "Well, I think.., I don't know. For a while I thought that God wanted me to have it... But then there was also: he did not. He didn't want me to have it."

Renata: "But you thought that at one point. And that is the important part to me. Now why do you think God would want you to have lupus?"

Sara: "To teach me to be a better person."

Renata: "To teach you to be a better person. So one day, he was up there, he was looking down and he saw Sara and then he said: "..." What would he say?"

Sara: "You need to be more considerate of other people... I can only guess that it is a way of keeping me in line."

Renata: "Keeping you in line?"

Sara: "Yeah, as I get comfortable thinking that my illness is doing just fine and I am on top of the world: (claps her hands) All right Sara, better settle down and be a good person now! Or the illness is going to start flaring up."

Renata: "What do you mean by that "good person?" It's hard for me to imagine that you are ever not a good person."

Sara: "I don't know.... Well, maybe, I don't know.... getting too greedy or too materialistic..

Renata: "You said in the beginning that lupus is an auto-immune disease. Do you have some kind of an idea or a picture of how that works in your body?"

Sara: "Yeah. I never really thought much about it, which really, you could think a lot about it, I mean. There is this disease inside of you and how is it working. Yeah, why does it act up sometimes when other times it doesn't?"

Renata: "How does it act up? What is it doing in there? What do you picture or fantasize?"

Sara: "I would say, just kind of imagine that .. I never really thought about it. Something is attacking my joints and making them swollen."

Renata: "You are doing something with your hands there. Two hands, one is the joint and the other one is..."

Sara: "Attacking it like that. (One hand grabs the other one.) Like little somethings or other."

Renata: "What kinds of things are in there? Little creatures?"

Sara: "Yeah, like little bugs or something. I don't know what would make me tired and what would make me nauseated and feverish and just feel blah. Just feel awful."

Renata: "There are little bugs in there. They go after certain parts of Sara and say: mmh, she is a tasty one!"

Sara: (laughs) "...Yeah, I don't ... I don't know what makes it do that or not. It's weird."

Renata: "Something on those joints there. There is something happening with them. And you probably feel it when it's happening. What is it like?"

Sara: "They just hurt. Like kind of your elbow would hurt if you bumped it. Or your wrist would hurt if you would sprain it. Kind of swollen. Kind of a warm type hurt. I have been lucky; I haven't really had it for a long time that the joints would swell *up and it would hurt to bend them. They would get really tight because they are swollen. And my feet and ankles get that way, too. Especially with the high blood pressure. When my kidneys aren't working really good ... I don't know. I imagine when my kidneys aren't working really good that it spills out this protein."*

Renata: "It spills stuff out.."

Sara: "It's water coming out and then it stays in your tissue in your legs and that's what makes it swell up."

Renata: "Somehow it just stays in there and bloats you and you get almost to a point where you burst... Actually, that's the kind of person you are! Just talking to you, I get the sense that you are bursting out of your seams, in a way."

Sara: (laughs)

Renata: "You are very sparkling. There is a lot of energy in there."

Sara: "Yeah." (both laugh)

Renata: "There is a lot of energy just waiting to pop out. Like all stored up in there. And every now and then it pops out. So there is something that wants out and something that holds it in, if we would talk about a relationship between two parts. The water in there that is filling up and something that holds it in. And the two sides are in a conflict. ...It makes you look thoughtful."

Sara: "Yeah, I am thinking about it. Maybe that's what really wanted to come out before I got sick."

Renata: "I see. What was that that really wanted to come out?"

Sara: "The good person in me. And now it did. All that bad stuff would eat me up inside. I think I am a caring person. I care about other people and I try to make *others feel good and be happy .. and feel good about themselves. Because that's what I have been taught and I'd like to teach other people."*

Renata: "So somehow the good person was trying to burst out of it. And in the situation that you were at that time, not enough of you could come out. Although you were on top of the world, it seems like you were still limited in certain expressions of yourself that didn't have room there."

Sara: "Yeah."

Renata: "Not enough of your activity or energy could come out, it seems."

Sara: "I think maybe too much of my energies were focused on things that were going to benefit me, like working hard and bringing in money. But that didn't get me the opportunity maybe to be the kind of person that could help others, maybe?"

Renata: "Isn't that amazing! It sounded like you were in a high power position, using a lot of energy. But actually there might have been a lot of energy that couldn't come out in that particular place. Whereas now, where you are tired sometimes much more can come out of who you are and of what is really important to you in your life. It's such a paradox..."

Sara: "It is. .."

Renata: "Seeing you and meeting you, I get this impression of a really sparkling person, ready to burst. (both laugh) Telling the world that there is a lot to do."

Sara: "Definitely."

Renata: ".. A person that has probably a lot of ideas about the world, too."

Sara: "Yeah, actually I find myself.., I don't know. Before I felt I am going to do this and I am going to do that. Now it is not so important, I don't know. "

Renata: "Maybe it's thinking in a different way, you know. It sounds like you are actively making good connections with people. And that sort of just happens because you are being yourself. And being in the moment just has this effect on people."

Sara: "Right. I find that .. I don't have to plan so much. Things just work out. Even though maybe I have unconscious control, it's not black-and-white control. Like you say. And if you just kind of do the best you can and then sit back, things will work out. I used to always worry: what is going to happen? And you know, half the time you don't have any control over it anyway."

Renata: "Becoming comfortable with being..."

Sara: "... who I am."

Afterthoughts

At the very beginning of the interview, Sara summarizes what she understands to be the process of her illness with the statement that she has "too much immune system" and that the "immune system attacks her healthy body." I am carefully listening to her description because I assume that it will contain useful information about her psychological process. Sara tells me that two parts of herself are in conflict and battling each other. She is understanding her explanation of the illness not only as a physiological, but also as a psychological and spiritual experience.

The questions that came up for me based on my psychological orientation in process work were: Where is/was she too "immune" to herself, towards her needs, in her relationships, in regard to the world around her? Does her body react when Sara is not sensitive enough to herself? Is she a person meant to learn for herself as well as to tell other people, her community, and the larger society where we all are not sensitive enough and therefore go against our nature?

Sara's illness process taught her about compassion for people. God wants her to be considerate of other people. That is the area where she needed more sensitivity. In her pursuit of a career and a successful, independent life-style she could not express her love for other people who needed her and were less fortunate.

The mentioning of being a Buddhist within the interview happened spontaneously. Looking back, it seems to summarize Sara's life-change. The Western goal-oriented outlook on life, where materialistic thinking, advancement, worldly success and "doing" are ideals is contrasted by the demands of the illness where the ego needs to surrender. She learns about suffering, about the impermanence of things, about compassion and simple "being."

CHAPTER IX: GENERAL FINDINGS

The purpose of the interviews was to investigate the experience of a life-threatening illness as a catalyst for change, to explore the personal meaning attributed to the experience of a serious illness, to see how the personal explanation connected to a larger life pattern and to discover teachings that arose from the illness experience which could be useful for society. The questions were geared towards exploring discarded fantasies and seemingly weird ideas about certain aspects of the illness experience.

The research focused on the following questions:

- How did the person first discover that she or he was suffering from a life-threatening illness and what were the memories and circumstances around the illness onset?
- What was the person's medical as well as personal explanation for the illness?
- How did the person actually experience the illness; how was she or he aware of it?
- How did the illness experience change the person's life?
- What did the person learn from the illness experience for her or himself and for the larger society?

Some topics were not specifically addressed by my questions but came up spontaneously. My interview style allowed for some flexibility in following the person's lead. People going through a life-threatening illness shared some experiences and concerns which were not the primary focus of this research. An example of such spontaneous information was dealing with the medical system and medical abuse. The information surfacing on the periphery expanded and deepened my knowledge and understanding of a life shaken by a serious illness.

The intent of this research was to get people in touch with their fantasies and more "irrational" explanations of their illness. Most people were aware of an explanation they considered at one point, but did not regard as highly since the idea was "irrational," impossible or stupid for their normal mind. I expected the participants to create stories, "illness myths," which would further elaborate their irrational explanations. This task proved to be more difficult than I anticipated. My explanation for that fact is that there was a lot of information people wanted to share. They needed to tell their stories before they would engage in anything new and unfamiliar. Since I did not know most of the people and did not already have a therapeutic relationship established, I did not push too hard. I felt that I got so much valuable information that needed a forum without having the original intentions of my research fully met. The research focus shifted somewhat from having the "illness myths" be the central point to having the actual illness experiences be the center piece. My dream came true in the sense that people's experiences were very rich and deep and that there is a lot of teaching for everybody in them.

Memories around illness onset

When asked how they remembered first knowing about their illness and what the circumstances were around the illness onset, people usually mentioned the time when a doctor gave them the particular diagnosis. The onset of the illness was often set around a time of intense personal stress or loss (for example, the death of a close family member), a time of dissatisfaction with life in general (for example, feelings of being at a dead end), a transition point in life from a developmental viewpoint (for example, the transition from childhood to adolescence). One person's rather surprising connection to her illness onset was the fact that she was doing so well.

The findings go along with the results from the field of psychosomatic medicine where stressful life events are clearly seen as connected to illness processes, involving both psychiatric and somatic disorders. Around developmental transition points -- early childhood, adolescence, adulthood, around middle age, retirement -- as well as during major personal changes -- getting married, divorced, birth of a child, death of a parent or partner -- human beings appear to be more fragile and therefore vulnerable. A change of identity can be viewed as an opportunity and challenge or as a crisis that threatens one's core being.

I was interested in the individual psychological connections people make and the fantasies that come up spontaneously as well as the connections to life events. Some of the participants responded to my prodding for further, possibly discarded and irrational connections they made to their illness onset. Some people remembered that they had a hunch about a dormant illness process long before they ever got a medical diagnosis. One person set the "irrational" beginning of an illness process 25 years prior to being diagnosed with cancer. Since early childhood she had felt somewhat "off-center," a vague but consistent underlying feeling, which was finally confirmed when she got the cancer diagnosis.

Another person who experienced himself as a very healthy person all his life remembered during the interview that the first time he thought about cancer was as a fifth grader watching a teaching video on cancer. His fantasy of what the cancer was doing in his body brought back a long forgotten memory. A friend of mine I casually interviewed about her arthritis admitted that she felt it started when she was born although the symptoms did not manifest until she was in her twenties.

I was somewhat surprised that most people remembered very specific moments when they first discovered their illness, although, in some cases, a lot of years had since passed. One person mentioned that, of all places, she detected a malignant melanoma behind her ear while being in a tanning booth. In the course of the interview she mentioned that focusing on appearance and outside expectations rather than on her inner feelings had been an on-going struggle for her. Another woman remembered that she noticed a swollen neck, the first sign of Hodgkin's disease, while checking herself out in the mirror. She was just getting ready to go shopping and to treat herself with some new clothes, at a time where a lot of stress was happening in her life. That look in the mirror might have been a first glimpse of the enormous changes she would undergo in the next few years. Wanting to buy new clothes might have been an indicator that a process of transformation had already started.

The following story I found particularly ironic and also funny. A man in his fifties (Jack) remembered that his first symptom indicating a more serious illness, a heart condition called Epstein's anomaly, happened as a teenager in health class.

> *I happen to pass out in a health class, in fact, during sex education. And the rather amusing aspect of it was that this was a class that had been scheduled just for a bunch of us jocks. I was supposed to take notes this one day and, all of a sudden, I passed out.*

In his life, Larry continued to work with two extremes: a great weakness and vulnerability and an incredible strength which showed in his will to survive. Again and again, I found that with some encouragement people come up with fantasies that connect situations with the onset of their illness in, to them, surprising ways. Those are the precious therapeutic moments where something unexpected comes up and offers information that goes beyond the known identity. Here the research could go on and further explore these glimpses. If I were to process the information together with the person within a therapeutic context, I would encourage the person to fill out the memories and "stage" the scene and work with the memory as if it were an important beginning dream of their illness process.

Explanations for a life-threatening illness

The explanations people came up with for their illnesses fell into two categories: the more "logical" -- meaning generally accepted and supported by medical and scientific research -- and the more personal, "unreasonable" reasons for getting ill.

There is a vast body of scientific literature available in the area of cancer research. I came across over one hundred recent (since 1990) articles by checking citations under "causes for cancer" at the Oregon Health Science University on-line medical catalog. The following list is meant to give a general impression of what medical science considers possible cancer producing agents:

- The environment we live in: due to air, water and soil pollution, the disappearing of the ozone layer, fallout from nuclear testing, radar, low-level radiation.
- The food we eat: in the form of pesticide residues, certain additives and chemicals used to preserve and create food.
- Unhealthy habits and life styles we entertain: active and passive smoking, unnecessary x-rays, stressful life styles.
- Some characteristics or deficiencies of the human body: defective genes, hereditary weakness in a certain area of the body, dormant cancer cells, characterological predisposition.

Most people's responses regarding what caused their illness followed explanations supported by the current medical research: environmental factors, passive smoking, immunological weakness due to a drug allergy, stress, not eating properly, dormant cancer cells, genetic predisposition, toxic fumes. One person specifically mentioned that he did not find a medically sound explanation for his illness (Hodgkin's disease), which caused him a great deal of anxiety. Not knowing what causes the illness means that he cannot prevent it from happening again.

It is generally agreed upon that cancer is multi-determined. This fact makes it difficult to determine what caused the particular cancer in a person, to prevent cancer and to find a cure for it. According to the above list of carcinogenic agents, it is almost a miracle for people to live a long life in today's world without getting cancer in the course of their lifetime. Sontag (1978) noted that an illness seen as multi-determined indicates that the illness is medically not understood yet and that its causes are basically a mystery to the science of the particular time.

So far, I have only mentioned cancer as an illness that is still somewhat of a mystery to today's medical science. In my research, I came across people with other life-threatening physical conditions, like lupus erythematosus (lupus, for short) and AIDS, which, similar to cancer, have an unpredictable and mysterious flair. There is no cure available for AIDS or lupus; the length of survival is unknown. A variety of symptoms are associated with both illnesses, and it is unpredictable which symptoms a person will experience in the course of AIDS or lupus, as well as which symptoms will be lethal.

Since Western medicine does not have conclusive answers to certain illnesses, it seems sound to include people's own explanations for their illnesses and to take that information as seriously for diagnosis and healing as the medically accepted causes. With some prying, most people mentioned more irrational explanations for their illnesses. Those surfaced more out of magical thinking. They were often connected with spiritual beliefs, like a punishment or sign from God or a twist of fate. Here is Melanie's "irrational" belief of why she got a sarcoma in her early twenties:

> *I think the only thing that could have crossed my mind was, could this be a punishment from God. I did go through a time where I felt like I had to apologize for every bad thing I had ever done in my life. It was a desire to make sure, to clear up lose ends, I guess.*

For Melanie the idea of a punishment from God was fed by a moralistic attitude. Her growth happened in the sense that she learned to stand up against judgment and distance herself from it. She pointed out to me during the interview how prevalent moralistic explanations are when it comes to life-threatening illnesses. *"You know, like with the AIDS crisis now; you hear that people are getting punished for their homosexual activities. God would never be so cruel."* Sara, a woman suffering from lupus, also thought that her illness was a sign from God. In contrast to Melanie, Sara understood God's sign as a positive push rather than a punishment. God wanted her to become a better person and to be more considerate of others. The same belief, that the illness was a message from God, had a very personal meaning for each one of these two women.

Jack, a man in his forties who survived Hodgkin's disease, thoroughly researched different explanations for why he happened to get what he called a "teenage disease" in his late thirties. Years later he concluded that *"it was just bad luck, a bad fate sort of thing, my misfortune,"* something over which he did not have any control. The illness was an important change agent in Jack's life. This might be one of the reasons why he could finally come to terms with not knowing what caused his illness and see it as a mere twist of fate.

Life changes triggered by the illness

> Critical illness leaves no aspect of life untouched. .. Your relationships, your work, your sense of who you are and who you might become, your sense of what life is and ought to be - these all change, and the change is terrifying. (Frank 1991, p.6)

A life-threatening illness has a big impact on a person's life. There are two kinds of changes people are faced with. First, the immediate change, which includes adapting to the new situation of being ill, becoming dependent and needing treatment, making choices about what kind of treatment to get, and becoming a consumer of medical services. In addition, there are the more long-term changes. They include changes in attitude and values, change in professional goals, changes towards people and life in general. Change includes discovery of new possibilities and opportunities; it also means grieving what has been lost.

Being diagnosed with a serious illness often starts with having to make decisions about medical treatment, i.e., changes might include moving to an area where treatment is more accessible. For one person it meant leaving her husband and moving back in with her parents, hundreds of miles away. This decision had a big impact on everybody. The young couple's relationship was tested by the separation. The parents needed to find a relationship with their daughter on the basis of her being an adult woman and to accept the fact that her husband was her primary relationship at that point in her life.

Several people stated that one of the first things they did after they heard their diagnosis was to get as much information as possible about their particular illness and the kinds of treatments available. They became wise consumers in a system unfamiliar to them up to that point. I heard from several people how important it would be to have more patient advocates, people who are familiar with different treatment approaches and facilities and are able to give comprehensive and sensitive advice. Connections with people who have experienced a particular illness themselves could be especially helpful in this advocate role.

For most people their diagnosis was the first confrontation with the medical establishment in a life and death matter. They found that it often was difficult to deal with doctors and they learned over time to be more assertive and not only be "good" patients. One person who was treated in a teaching hospital learned to demand that only her attending physician check in with her and that she no longer answered to any of the various residents who came by and wanted her attention. Another person quit her treatment prematurely against medical advice because she felt that further treatment would be toxic rather than helpful. She could only do that after learning that medical doctors were not as omnipotent as they appeared in the beginning and after seeing the aspect of medicine that was a business.

The difficulties in dealing with the medical establishment were often connected to a lack of communication and a lack of common sense. One person told the story that while she was on oxygen, the staff planned to transport her to a different room. Instead of hooking her up to another oxygen tank, they fumbled around with her and asked her to hold her breath. Another person remembered how threatened she felt when the head nurse did not want to give her a booklet explaining the radiation treatment out of fear that the patient was too worried already.

Making changes and adapting to the new situation was not an easy task for most interviewees. A first stage of shock and denial was very common. Melanie commented: *"I remember being in the hospital. You primp yourself all up, you got your make-up on, you have your hair all fluffed up, and you act like nothing is wrong. I call it the Jacky-Onassis-syndrome."* The reality of the situation started to sink in after the treatment started and she was all worn down. Getting through a day was a major ordeal. *"It was just a primal existence."*

Sometimes treatment meant disfigurement. Where once a tumor bulged, there is now a hole, scars. The body image changed and beauty took on a new meaning. Several people mentioned the impact their illness had on their self-image and self-esteem due to changes in their appearance. Most people are very attached to a particular image; it is an important part of their identity. One person reported the following:

> *I don't think I was major vain. But you know, I was 26 years old, I had long blond hair, suntan, lots of dates and this and that. So the fear of losing my hair was a big thing. If anybody would say: Vicki with the long blond hair? That's who I was. So the prospect of change in my physical appearance was really scary to me.*

Melanie had a sarcoma which was located in the jawbone on the right side of her face. Her following statement made me aware again that in our society good looks are portrayed as crucial for happiness and success, especially for women. An illness can change a person's looks drastically. How frightening!

> *I just felt I could never get beyond having my face .. being kind of deformed or permanently changed. I have come a long way. Still, there are times when... every Halloween I have someone ask me if I made my face look like that for the occasion. It is very, very hurtful. You wonder if you will ever be able to do anything because of how you look.*

Larry mentioned that he loves to show the big scars he has on his chest from the different surgeries. He found a certain pride in them.

Fear and anger were two emotions often associated with the beginning stage of a serious illness. For Jennifer, who was dealing with malignant melanoma and tumors that had spread throughout her body, overwhelming fear of the unknown, of her prognosis and of her future took hold of her. Larry expressed his emotional reaction the following way:

> *I was very angry, incredibly angry at everybody, at the world. I was like: hell, this can't happen to me, I mean, I am me! I was angry at God as anybody. I remember at least once or twice standing up in front of the mirror and looking at my own face and challenging God: You cannot kill me!*

The very definition of a life-threatening illness includes death. Life has come close to an end, to a transformational stage. The person is faced with his or her mortality. To be confronted with death is a shocking experience. The seemingly unavoidable end of one's existence is a powerful transformational force. It puts things into perspective. Another level of reality has been introduced and shifts the importance attributed to things, relationships, work and many other areas.

Frank's (1991) statement echoes what several people told me: "Once the body has known death, it never lives the same again." (p. 16) I found with all the people I interviewed that the closeness to death was a major catalyst for change. Jack expressed it in the following way:

> *When your life is threatened, you focus more on the question of what is going to happen. Because your own mortality really gets brought home. It really makes you analyze your own life. You just.. there is not enough of a real push to change until something like this happens.*

Death can not be dealt with on a merely rational level. The imminence of life's ending brings forth a crisis on every level: physically, emotionally, spiritually. People told me that experiencing death so closely changed their outlook on life. Death became more integrated into their lives. It has become a constant companion, reminder and ally. The person may recover fully on a physical level; the memory stays.

Another change brought on by the closeness of death was the experience as well as the value of time. Time took on a new meaning for most of the participants. They addressed the fact that time became more precious; they now favor living in the moment over always looking ahead and planning for the future.

Experiencing the body becoming unreliable, losing physical abilities that were taken for granted and then regaining control again deeply influenced people's attitudes towards their bodies. Health is no longer taken for granted, but valued as a precious gift. One person expressed that she feels more caring towards herself. She tries to pay closer attention to her body's needs and permits herself to take a nap in the afternoon. Relaxing has become as important as working and being successful used to be. Another person mentioned that she enjoys basic things more. Remembering that she could not eat most foods at one point and was limited as to how much fluid she could take in during the course of one day, she now savors meals and takes pleasure simply from a glass of water.

For Larry it was particularly difficult to become physically weak in his late teens. He was a very active child and mourned the loss of his physical functioning deeply. He remembers savoring the moments after his first heart operation when he could get out of bed again and walk around the block. Jack stated that the relationship to his body changed in the way that his body seemed no longer a friend to him. His body became something that he had to put up with, something he had to maintain, something that was out of his control.

Some people felt that their illness experience increased a feeling of strength. The experience reassured them that they were really meant to live and that they had a task in this world. For another person, her illness taught her to become more courageous and take more risks.

Several people I interviewed mentioned the loneliness, isolation and exclusion from the rest of the world that accompanies an illness. (This came up in the literature as well where authors wrote about their personal illness experiences. See for example, Frank 1991, Broyard 1992, Duff 1993.) I am reminded of Larry whose heart condition sent him on a long journey into another world where, at times, he could hardly tell anymore if he was dead or alive. Days, weeks and months seemed to blur together almost inseparable in their monotony. He missed human contact. Larry is still hurt by how little effort was made in his family to acknowledge his presence in everyday life and to ensure continuous contact with friends and peers. Larry mentioned how difficult it was for him to come back to normal life. He felt so different from his peers.

> *There was a tremendous loneliness. I was like someone from a different country. Maybe even somebody who didn't understand their language. It was as if there was a whole alien kind of aspect that had been created. It was hard to try to figure out how to go about things. My issues were so different than everybody else's.*

Partly the isolation creates the time and space that is needed in order to deal with the illness. Exclusion adds additional pain for the ill person when the separateness can mostly be attributed to the unwillingness and unawareness of the world of the healthy to learn more about the states of the body, the mind and the spirit which accompany the experience of a serious illness.

Relationships, friends and family became a vital and important part in an ill person's life. Illness changed some of the assumptions and expectations upon which relationships were originally built. Being house bound, having a different daily rhythm, and many other changes that accompanied the illness interfered with a "normal" relationship life. It took the openness and willingness of everybody to adapt to the new situation. Many of the people I interviewed mentioned that they valued their family and friends in a different way after having gone through intense states with them. They appreciated a friend or family member staying with them through some of the intrusive medical treatments. The personal contact gave them a sense of familiarity and security in a rather cool and professional environment. Some interviewees also stated that they became more selective around relationships. At this point in time, they prefer to spend quality time with close friends and are more likely to avoid social gatherings experienced as a mere convention or obligation. One person became painfully aware how unsupported and emotionally neglected she felt when she was in a semi-comatose state at the hospital for several months. She found that building close friendships, helping underprivileged people and caring for the environment became the main purposes of her life.

Several people mentioned that their illness experience made them more empathetic towards others in need. For one person this meant changing her political party; she went from being a republican to being a democrat. These were her words:

> *I feel you have to be a socialist type person. Well, look at me! I mean I had to be on social security and disability! I used to feel that we control our own destiny. If people wanted to be, they could be, you know. Whereas now I realize there are a lot of people's hands that are dealt that just don't have any control over.*

Another woman stated that she opened up towards diversity. She feels more accepting of people with disabilities and people with different life styles. She would now go out of her way to make friends with someone who is more disadvantaged than herself, whereas before she might not even have noticed their needs.

Money and success generally became less important after a serious illness demanded focus on what was really important in life. Priorities changed. Most people became more aware of their spiritual needs. They learned to pray and surrender to a higher power, which helped them to develop more of a sense of inner peace. They learned first hand that they ultimately were not in control of their lives.

Some of the changes people went through were accompanied by immense losses. Larry, who got seriously ill early on in his life, stated the following:

> *One of the things I was incredibly angry about was that I felt I would never be an adult. I wouldn't have a chance to have a girlfriend, to know what sex was about, to have children, those kinds of things. I felt a tremendous sense of loss.*

What the illness survivors could teach society

Several people I interviewed mentioned that they had been thinking about writing a book. In some cases, it was to give an avenue to the creative impulses they discovered in the illness. For other people it was to communicate to others what one goes through with a life-threatening illness. One woman already contacted Oprah Winfrey, a famous TV host. She felt it would be important for the general public to see that one can survive cancer and live happily ever after. For her this message seemed particularly important. Her illness left her with a severely scarred face, a mirror reflecting trauma and pain. Her husband stood by her at a very young age when the illness disrupted their lives. Their love has grown through the hardship they went through together. Melanie's story challenges society's myth that you can only be happy and loved if you are beautiful. At the time of the interview, she was six months pregnant and looking forward to being a mother. An old dream of hers was finally coming true.

A lot of the changes people wanted to see in society were the changes into which they were challenged by their illness: to appreciate life, to pay more attention to basic things that often seem unimportant, to value friendship, family and community more, to be less materialistic and ambitious.

One person talked about the need to educate people about death and dying.

> *I think there is that incredible fear of dying because it's an unknown, because death hasn't been brought out into public consciousness. We need to take away the mystique of dying. Death is simply a passing of what was. It doesn't have to be in any way bad or painful or terrible.*

Another person specifically mentioned that she would like to see changes within the medical establishment. From her own experience of being in a comatose state, she knows how important body contact is even if the person looks like she is only "vegetating." People are very much human beings in those states, needing affection and contact.

Advice I often heard from these people was to follow your interests and take risks. *"One of the things that did come out of all of this was the understanding that you need to do the things in life that you need to do or want to do. If you don't do them, you pay a heavy price."* Pursuing one's passion and dreams seems more likely to create happiness than following expectations and materialistic goals.

There clearly is a need to bridge the gap between the two worlds, the world of the healthy and the world of the ill. The messages which are wrapped up in illness experiences are often controversial; they imply the need for change in all of us. Are the healthy people ready to listen and open enough to hear them? The attitudes you encounter with your partner, your family, your circle of friends and your community once you get sick will have a big impact on how well you will be able to deal with yourself. Illness is a personal affair; it is also a mirror in which we all see our own mortality and fragility as human beings.

CHAPTER X: CONCLUSION

The purpose of this study was two-fold. A first intent was to explore personal aspects of illness experiences. I used the philosophical framework of process-oriented psychology in order to help people who have experienced a serious illness get in touch with their own explanations for the illness. Together we explored their memories of the actual body experiences the illness created, changes they had to undergo because of the illness, and the lessons and teachings that emerged out of the illness experience for themselves and for society. My hope was to encourage people to take fleeting thoughts and fantasies, "weird" inclinations about their fate, seriously and to enrich their lives by using the messages they find in them.

A second intent of this study was to investigate cultural views on living and dying, as well as to examine the implications the general attitude towards illness has for whomever gets seriously ill. I wanted to give illness and the people affected by it a voice in order to break the silence and the awkwardness between the world of the healthy and the world of the ill, thus transcending the separation.

My attempt to help people get in contact with the background process of their illness experience and learn more about their life myth was rather ambitious. Considering the complexity of the task, it was astonishing, though, how much information could be elicited within a two-hour interview by merely focusing on discarded, seemingly "stupid" fantasies related to different phases of the illness process. (On a side-line, this also showed the effectiveness of process-oriented techniques not only for doing psychotherapy but for any situation where attentive listening and understanding is important.) People were eager to talk about their situations. An illness experience and its meaning within the context of a person's life never fully reveals itself.

The themes connected to the illness experiences were usually reflected in the fantasies around the illness onset as well as in the memories regarding the body experiences brought up by the illness. A common theme triggered by an illness experience was a rising awareness about the need to follow body sensations, inner experiences, feelings, and dreams versus living by outside standards and expectations. Illness is a major adventure in proprioception. It calls for experiencing and accepting certain body states, e.g., fatigue, pain, dizziness. Ideas of how we should be and behave or how we should look are no longer viable or important. A process of reclaiming the body, appreciating and following body signals occurs. Illness reminds us that the body is important for our survival and needs to be treated with respect, love and care. Illness also forces a person to go inside and to focus on inner experiences. With life being threatened, questions concerning the very personal meaning of one's life come into the foreground. An understanding grows that finding one's individual life purpose is a priority. Illness served as a reminder to listen to, value and appreciate the body and inner experiences.

It was not surprising to me that an increasing awareness of the tension between inside needs and outside expectations was the main discovery for half of the women I interviewed. Our culture still encourages women to adapt rather than to follow their own needs. It is still seen as an especially feminine trait to serve others and be there for them, an understanding that often goes along with learning to put one's own needs aside. Epstein's (1989) personal illness account refers to this particular aspect of what she calls the "cancer-prone personality." For her, pleasing other people was the main purpose in her life until her illness started her on a process of self-discovery. I need to state again, though, that my sample was very small and no conclusive evidence could be drawn regarding gender differences.

There are many books available where people's experiences of being physically ill is the central theme (e.g., Chester 1987, Duff 1993). (Several works were presented in the chapter "personal illness experiences.") These illness narratives describe how body experiences change because of an illness, the anxiety and fear that is connected to every new symptom that appears, and how the person is forced to learn to live according to the body's energies rather than according to a schedule or any kinds of "shoulds." This work tried to not only describe changes that happened because of an illness experience, but also take a step further and understand the potential usefulness of illness and get a sense of where illness itself has a message. Where the meaning of the illness experience was mainly seen as a push to focus on one's own body and inner life, the illness can be understood as a healthy regulatory system that prevented a person from distancing himself or herself too far from the physical reality of the body and true personhood.

The tension of weakness and vulnerability versus strength came up strongly for one man whose interview was not selected for a previous chapter. The weakness created by his heart condition forced him to be a "pioneer" in the area of gender expectations. He was a househusband, taking care of domestic affairs and child raising while his wife was the main provider of the family. In the 60s, this life-style was not as common and did not go along with his own expectations about his life or the expectations of his family of origin. In this case, the illness pushed an individual to learn about and question role and gender stereotypes. Illness can be understood as a healthy regulatory system which, through an individual's life experience, brings awareness to human diversity and gender equality and encourages society to grow and change.

Another big topic brought up by the experience of a serious illness was the tension between pursuing ambition, success and money versus leading a life-style which would foster compassion and love for other people and the world around us. Illness took the role of a spiritual teacher and of a reminder that each individual needs to also be aware of the interrelatedness and interdependence of human beings and the world. Where the meaning of illness was discovered as a reminder to consider not only individual needs but to also be aware of a larger web that we all weave together, illness can be seen as a healthy regulatory system that takes care of humanity and the world as a whole.

Another theme which emerged in the interviews was where the illness clearly turned into an ally and wise advisor in life. Two people stated that their illness pushed them to follow a path of personal growth. For one of them, the message of the illness went even further to include other people. He realized that the best prevention from having a recurrence would be to take over some of his illness' quality. In retrospect, he appreciated his illness as a necessary push and a "wake-up call" which got him out of a stuck place in his professional life. He had felt impulses before to push his friends towards change and growth and learned that his being more assertive and tough with his friends would not only benefit them but also himself. Illness seen as an ally is one of the themes in Mindell's (1993) work. In order to find the ally (or wisdom) in the body the author suggests to ask oneself what drives one's body, what does the push or fatigue feel like, what does it look like. In the role of an ally, illness becomes a "healthy" response. It reminds a person to focus and to follow the signals of the body, thereby storing rather than dissipating vitality and energy. It can also advise a person about her true path in life.

We can derive the following lessons from these people's illness experiences. Healthy living includes an openness to expanding one's identity to include previously rejected parts or aspects of one's personality. An illness can temporarily take a person away from the daily routine and help her to get in touch with a bigger purpose, thus giving more meaning to her life. A serious illness can bring a person to look at where he is already dead and dying, in the sense of not really wanting to live or cutting himself off from his life force. Probably the biggest challenge any life-threatening illness poses is to find an answer to the question: Do I really want to live? Do I have something that is worth living for, do I have a reason to survive? As described in an earlier chapter, truly wanting to live is a crucial element for healing to occur (Carlson & Shield 1989). I wonder why we often wait for a serious crisis to ask ourselves these questions. Being in contact with one's life purpose could be seen as preventative medicine.

The majority of the people I interviewed found meaning in their illness experience and saw the changes they made -- or, had to make -- in a positive light. Looking back, they could honor the self-growth that was triggered by the experience. This does not by any means imply that they would want to go through the suffering again. Some people went so far as to say that they experienced their illness as a gift. These are the voices of people who survived and learned a lot for themselves. The optimism, joy and happiness is at the end of usually a long process with a lot of fears, suffering and pain. The changes did not come easily; it took a lot of courage, perseverance and will to live to get through.

Dying can be as welcome an experience as surviving. I learned this from one young woman I interviewed who died about two months later. Her suffering was partially attributed to the fact that she felt that her yearning to leave this world and join some loved ones who were already dead was seen as a psychological weakness she needed to overcome. Yet, I experienced her as most vibrant when I shared her excitement for life after death.

Researching illness experiences has stretched my own thinking a lot. Many assumptions, expectations and seemingly helpful ideas of mine needed to be revised. One of the most persistent and also insidious attitudes towards ill people is that they are in need of not only medical, but especially psychological and spiritual help. I find this attitude in myself and I also noticed it being very prevalent in the literature where holistic well-being is promoted. As Guggenbuhl-Craig (1988) pointed out, we seldom hear that someone falls ill because she is psychologically well-balanced or able to express feelings well. Yet, the opposite is stated rather frequently. Guggenbuhl-Craig sees the attempt to understand the body as a symbolic expression of the life of the psyche and as a language of the soul as very fruitful. His warning addresses the potential moralism that is fostered by seeing illness as a personality flaw or individual failure. The significance of illness can only be appreciated when it is lived like good health according to its dictates.

One way to move away from moralizing illness would be that we as a society take more responsibility for what we create together. The people I interviewed all belonged to American white culture. I believe in their illness experience they were also victims of culture. In the Western world -- my own Central European background is very similar in regards to cultural attitudes discussed here -- there is a strong interest in dissociating oneself from "polluting" elements, i.e., illness, death, conflict. We think that by eliminating undesirable elements of life from our immediate view, we can stay "clean" and lead a life as if disturbances were only other people's problems. I feel strongly about bringing some of these disturbances back into public awareness. I see the need for building a bridge between the world of the healthy and the world of the ill for two reasons. A first reason is the fragility of health. Nobody is spared from illness experiences. Knowing more about illness experiences, thinking about death and dying before one is directly confronted with them, is an important preparation for living more consciously and more fully. Second, people's illness experiences have shown that being ill does not mean one's life is on hold, so to speak, until health is established again. Meaningful experiences happen in the course of an illness process that need to be brought back into the life of the healthy. Putting them aside and leaving them unacknowledged and unappreciated deprives us all from an incredible gift.

I want to add a note on "meaning." Dossey (1991) used "meaning" either in the sense of a person's interpretation of an event and the significance it holds for the person, or in the sense of how perceived meanings and experiences of a lifetime have the capacity to affect the body. When I talk about the meaning of an illness experience, I am not trying to find the cause for why someone became ill, nor how one could reverse illness back into health. I am interested in illness experiences because they are, as Kaptchuk (1989) stated, an opportunity to encounter the source of our being in our worst time. It is a time when the genuine and potentially intact response to chaos, anguish, and suffering can reveal itself. In my understanding, finding meaning goes beyond healing and does not guarantee health. I see illness as a necessary component to life, which transcends the individual.

It is important to not become moralistic or judgmental around the meaning of an illness. Any process that reveals itself in an illness, a dream, a relationship conflict, is equally valuable, important, and necessary. Sara, for example, whose illness brought her in contact with her compassion and love for other people, gained this insight by following her body signals. It is therefore her individual truth.

In another scenario, the illness might urge a person to become more ambitious, to become a politician, etc. Awareness will lead the way.

The personal aspects of illness experiences brought forth in the interviews all have implications that go beyond the individual, connecting the individual processes to society and the environment. In that sense, the individual stories are windows for teachings for the culture. One of the additions of this work to the literature on illness is its bringing forth how individual illness experiences reflect problems of the cultural attitudes towards illness, health, death and dying. Culture tends to try to exclude these "disturbances" from its awareness. Individuals with illnesses are carrying lessons for the society -- if we extrapolate from the lessons the individuals learned, there are messages for society as well. With death looming at the door, one becomes more conscious of one's attitude towards life and how precious life can be. From the many illness experiences I have heard and read, there remains no doubt in my mind that people who have been very ill and at the brink of death have important information to share with all of us.

I believe that illness shows us where we repress our nature. Symptoms break the barriers of culture by bringing up experiences and parts of our personalities that have been forbidden and needed to be kept out of public view. They leave us naked and out of control. Working with them rather than against them will be the way to go in order to find the gold hidden inside. As life is lived, so illness is lived. We cannot separate ourselves from a body that is ill; it affects every bit of who we are.

Working with illness and staying healthy means taking risks and challenging society's rules. Certain rules and expectations need to be broken. Illness is where the individual meets the collective. Socialization works against us being our true selves. We learn early on that certain characteristics are not acceptable in particular surroundings. We learn to survive and adapt. I mentioned gender roles earlier and how illness seemed to push some of the people to question those roles. For some of the women it was important to move away from mostly focusing on the well-being of their loved ones and start focusing on their own inner experiences more. Adaptation has its price. Nature is forgiving and patient, but it has its limits and it works in very unpredictable and surprising ways. As humans we are very much at the mercy of earthquakes or floods, we are also at the mercy of our own natures, stored in the body.

Illness cannot be dealt with on a totally impersonal level. It is intricately connected with a person's life. Illness is impersonal insofar as there is a general explanation for it (cell growth, poisoning, etc.). When illness enters the body of a particular person, however, it takes on a very individual meaning. Therefore, there is no one ultimate explanation for illness, like there is no one explanation to life. We need many different theories of illness as well as healing methods. Illness is a very personal affair; the person who is affected by an illness needs to find healing in a way that supports his or her very own being. Healing needs to be integrated into his or her life process and become an integral part of life.

Theories that say you can stay healthy by exercising and eating the right foods speak to a certain aspect of illness, and therefore to a certain aspect in all of us.

We want to believe that it is possible to stay healthy all the time. We are eager to work towards that goal. There is also another side in all of us that likes junk food and pollutes the environment, even though we know that these habits work against health. We think that we can have it all, that we will find treatments that will counteract unhealthy behavior. Or, maybe we know deep down that where there is light, there is also a shadow; where there is health there is also illness. We are not superhuman, only human.

With many of the people I talked to in the course of this project, the connection between physical and emotional abuse during childhood and some disease process later in life was brought up. When working on illness experiences, people often remember a specific incident where some abusive person stopped them from expressing a certain part of their being. It seems that we can ignore or repress parts of ourselves only for so long. There comes a time where old wounds need to be revisited. We do not want to have our daily lives disturbed by pain and suffering, nor do we want to be reminded of our own mortality. We feel the need to keep our lives safe, to guard ourselves from the uncertainty of fate. The nature of illness is ruthless. It does not ask you first: "Would I be welcomed into your life?" Illness comes as a powerful agent of change. Illness has its own rules and demands. Could those demands be wisely placed?

Many of the people presented in this work got close to their own truth or essence through their illness experience. They often mentioned that it took the intensity of their fate to make the changes which would enable them to live that essence in everyday life. This makes me wonder how we lose contact with the essence of our life in the first place. Why do we seem to need a severe crisis in our lives in order to search for what we are about? What would the world be like if we all would live our essence more fully?

On a spiritual level, illness could be seen as a protection for the soul. When ambition, etc. gets us too far off the path or our truth, illness forces us to be quiet, to reconsider who we are. This is clear in Sara's interview. Sara was living what looked like a successful life: she was young, educated, had a good job where she felt challenged and made good money. She felt like she was on top of the world. This was the moment when her illness broke out. Over time she came to the realization that her compassion and love for other human beings did not have enough space to express itself. Being a successful businesswoman did not fulfill the needs of her soul.

During the time of researching the topic of how people deal with a life-threatening illness, I was in a continuous inside struggle which would fluctuate between optimism and despair. An optimistic phase, in which I had answers to offer, would be followed by a time of crisis where I was very doubtful and self-critical, feeling that I could never come even close to an answer to these all-encompassing questions of life and death. I imagine this is a process very familiar to anyone who has been severely ill.

There are no simple answers or remedies when a person's life has been threatened by illness. I have read and listened to numerous personal accounts of illness experiences. These were lives shared with me; lives that would be totally different without this experience. It involved and often transformed the person on a physical, emotional, relationship, communal and spiritual level.

I concur with Carol, one of the characters in DeVries novel The Blood of the Lamb (1969). She is an eleven-year-old girl dying from leukemia. Just before she dies, she writes a note to her father, in which she states the following: "I don't understand it all, but I think I get the drift." (p.241) Although we will never fully unveil the mystery of life and death, there are ways to get in touch with the "drift," which can lift the phenomena of illness from an absurd occurrence into a meaningful life experience.

NOTES

1 Locke, S. & Colligan, D. (1986) and Justice S. (1988) offer comprehensive summaries.

2 Examples are: "The body works like a machine." Or: "Body, mind and soul are discrete entities and need to be studied by separate disciplines."

3 Franz Alexander and Georg Groddeck were two of the pioneers in researching and creating the field of psychosomatic medicine in the late 1930s. Their ideas emerged from Freudian psychoanalytic thinking.

4 Examples would be Lawrence LeShan, Carl and Stephanie Simonton.

5 Robert Ader's book Psychoneuroimmunology (1981) is regarded a seminal text on the field.

6 The following are some examples of how Jungian thought is integrated into Mindell's work: Jung's finalistic point of view, the notion that we are all growing and engaged in a process of continuous self-discovery, the meaningfulness of synchronistic events, the basic assumption of dreams as meaningful events which contain their own solution, the use of symbols and fairy tales to amplify and explain individual experiences, seeing a unifying principle in the background of all life.

7 Examples are: "active imagination" in Jungian therapy, art therapy, sandplay.

8 Process-oriented therapeutic techniques will be presented in the methodology chapter under "theoretical framework."

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