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THROUGH MY LOOKING GLASS: A WOMAN’S EXPERIENCE OF LIVING LONG-TERM WITH INVISIBLE UNDIAGNOSED CHRONIC PHYSICAL ILLNESS AND PAIN AND ITS IMPACT UPON HER SENSE OF SELF

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by

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ABSTRACT

This heuristic thesis explores the experience of a woman living for decades with invisible, undiagnosed, chronic physical illness and pain. With ethical care and respect for confidentiality, the researcher recalls incidents of trauma in her early life that informed the development of her self. The paper describes the complex effects of living with symptoms of undiagnosed illness for many years. Complicating factors include the lack of a support network, and revisions of services in the local health care system. The author discusses her experience of the prevailing attitudes that disempower women who advocate on their own behalf in the legal system. Concurrent disenfranchised losses, including intimate relationships and role identity, are also described. Circumstances that contribute to marginalization include unemployment, divorce, and poverty. The thesis explores insights that emerged from the period of intense heuristic inquiry. It provides ideas for potential future research as well as possible personal, community and political activism. The thesis work is complemented by a set of five piano compositions.

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Abstract

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Chapter One: Introduction

First reflections

When I was a child, I reversed the Sunday School lessons about loving one's neighbours as one's self. I tried to comprehend how to love myself in the way that I felt devotion to others. I was not very successful. To others, I probably appeared to be self-contained and capable. I was adept at suppressing emerging values that differed from those of adults. I was stringently loyal to the persons upon whom I depended. I was obedient and thorough despite often overexerting my body. I routinely attempted to dismiss my intuition. When relationships grew intolerable I felt shame and guilt. I rigidly attempted to control a persistent fear that I might vanish. There was no language yet acquired to describe the tumultuous feelings.

I was captivated by colour, form, design, sounds and language, and by science and nature; I was interested in the study of cultures, history, political events and human rights issues. Though I was innately curious and had the desire to devour new ideas and experiences, I felt simultaneously a need to suppress the value and the expression of these passions. When exuberance could not be stifled, the words tumbled forth and I was consequently filled with embarrassment. Anticipating interruptions from a busy household, I could not concentrate and did not excel in school after the elementary grades. My sense of advocacy for others was high, but I felt I did not deserve to speak on my own behalf. I empathized with others in times of stress, loss, and pain, yet could not identify my own unresolved and disenfranchised grief. Frequent crises provided a focus on activity that released the valve on personal and household tensions.

I have heard that in the not-so distant past some medical procedures for babies did not always include the administration of anesthesia. It was believed that the patient had not yet developed pain sensitivity. Similarly, I imagine that during my infancy I was exposed to severe stresses; I surmise that my infant senses were dismissed as undeveloped. It now seems evident that my current daylight vigilance and erratic sleeping habits stem from a time when I sought security through acute attention to persons and events in my external world. My little-girl needs raised irritability and annoyance; my ordinary bodily emissions evoked expressions of distaste. My appearance and behavior were always under scrutiny. In a home that was defined by a parent who lived with mental illness, I developed awareness that my emotions could undermine the fragile stability that existed. Similar to a roofing structure, the power of negative experiences dominated over every other.

I was alert to potential dangers and to the needs of others. I disciplined myself to silence persistent feelings of illness, lethargy, allergies and pain. I ignored feelings of intolerance to stimulants such as caffeine and adverse reactions to medications. I thought others bore these same sensations more successfully by means of stronger personal fortitude. When I independently sought out medical professionals, I presented my needs gently, minimizing the symptoms’ impacts upon my everyday life. Frightened by debilitating physical issues and by how I was received in the medical environment, I withdrew from my self.

As a young adult, I made critical choices using all the rationality I possessed but I was conscious that something was lacking. Many actions resulted in feelings of culpability and shame. When I articulated doubts they were dismissed by the persons I heard most audibly.

I developed an understanding that invisible physiological and the emotional disturbances were intertwined, and eventually I engaged in pastoral therapy when unidentified physical pain and illness became extreme. At that time, therapy sessions were the only regular commitments I could manage to maintain beyond trying to fulfill my responsibilities to my child and my spouse. Like a frightened animal in the therapy space, I tentatively approached and retreated. Over and over, I tested my voice that spoke of the pent-up sadness and pain. I tested the constancy and presence of the pastoral counsellor. Nervously, I returned each subsequent week; somewhere within was the desire to persevere.

Years passed with devastating alterations to my life. I groped toward an inner self who had some trust in her own resources and values; who, though trembling, could advocate on her own behalf. The cost was high. I confronted difficult choices, critical losses and unanswerable questions. Gradually, I became aware of the transference and codependency that surrounded me. I desired greater security with my developing sense of self, and more ease for life's passage. I confronted inexplicable uncertainty and emotions that confused me.

Later yet, I found the invaluable support of college faculty to embark upon this heuristic research. And so it began.

This heuristic research

Heuristic research touches on a phenomenon that has significant meaning for the researcher. The study involves deep immersion into the research question; it demands the researcher to remain with a question for an undetermined duration of time and effort. Sufficiently engaged, the researcher cannot predict or hypothesize where the work will lead, or when and where the research will be complete. It requires commitment and energy that can be compared to groping, blindfolded, through a house where walls and doors are constantly in flux. Indeed, even the destination provides apertures that open onto more questions.

The following chapters of this thesis describe the search I undertook to find meaning behind my experience of living with long term, invisible, undiagnosed, chronic physical illness and pain, and its impact upon my sense of self.

Chapter Two explains the heuristic method with reference to significant resources that make use of it in the phenomenological research field. The description of my methodological process includes an explanation of the ethical standards necessary in my approach to gathering the research data. I emphasize that my predominant caution was to write the document from my perspective. I endeavour to repeatedly ensure the reader knows that the observations of my experience are solely my own. I take care to prevent recognition of any individuals, institutions, or agencies. To the best of my ability, I endeavour to protect from censure vulnerable persons, including myself. I avoid attributing specific actions to specific individuals. I intend to respect the perspectives of others who shared in these events.

Most incidents that were deemed necessary for data have been modified to prevent individuals from being identified. It is stressed that the heuristic research paradigm is not dependent upon details of events. It does not aim to attribute blame to any persons. My focus is the experience of an individual researcher during years of living with undiagnosed chronic illness and pain.

Before I present the literature that supports and affirms my research, Chapter Three takes the reader into the data of my early life. I recall my childhood, adolescence and young adulthood. Preparing this section was the primary challenge for the researcher; it stretched my patience and honed my resolve. It brought up long suppressed memories and emotions, and it provided new assurance of the self that has been affirmed through my years of therapy work. This chapter presents the background through my eyes so the reader may grasp my early development with its pain and illness. It is hoped that this chapter will inform the reader of the sense of separation and anxiety I felt in seemingly safe environments.

Chapter Four presents some of the literature that affirmed my experience, the data and explication. Heuristic work requires immersion in a personal experience in order to raise new meaning of the experience upon the self. This method of research demands a state of indwelling with the self. Its primary focus is not with the related literature until the insights from the data are clear. The value of the literature then reinforces the explication of the researcher's experience and ultimately enhances understanding of the self.

The insights I have gleaned in the research process are expressed in Chapter Five. I share my thoughts about the meaning of the music compositions that form a part of this thesis. I address paths for further study from both the personal and the professional perspective. I briefly discuss the issue of political activism, which I believe is imperative for women’s health and spiritual care. I respect the wounded woman’s ability to know and abide with her truth.

As mentioned above, this heuristic thesis is supplemented by creative expression in the form of five piano compositions. In Chapter Five I describe what these selections presently mean to me. Called *Neologisms*, these selections are expressions of experience, of words “...used in a new sense” (Webster’s Universal College Dictionary, 1997). I invite the reader to listen to the music at any point to find one’s own unique experience of it. The music manuscript can be found in Appendix A. The compact disc is attached on the inside of the back cover.

The question

When others heard my choice of research topic and method, I anticipated their skeptical thoughts: “Write about yourself? Sure. No other participants? Mm hmm...”

Of course, I also had doubts. During one period this past winter, my cries woke me from dreams in the night feeling as though I had been physically assaulted. Being confronted with that visceral terror, I can defend the value of this extensive research immersion. Even after years of committed therapy, I could still confront periods of debilitating uncertainty and anxiety. One restless day I wrote about a feeling of transition in my journal:

> The barrier: It feels as though I am awaiting something. Expecting it to emerge. Meaningful. Purposeful. I feel I have been at a station perched expectantly for this vehicle to carry me with momentum, acceleration, vision, revelation, creativity. My truth. (personal journal, September, 2010)

That note exemplifies an aspect of the immersion process during which I felt both helplessness and anticipation. It was not clear where the thesis was headed; I was suspended in a phase of waiting, but I was compelled to go to the depths of my inner self where there is no language. This recurring incident affirmed my research question: what has the experience of living for years with invisible, undiagnosed chronic illness and pain had on the development of my self? I suggest that incubating and waiting for inspiration, imagination and insight test the patience of any heuristic researcher, her relationships, as well as the resolve of a student's academic faculty members.

The narrative and explication contain inconsistencies and contradictions; my writing process has been tangential, circular, and awkward. My hope is that the product is adequate for the reader to follow and that the thesis may benefit other women who share my experience. The thesis might also inform persons in the health care and counselling professions.

Chapter Two: Heuristic Research Method

Introduction

Heuristic research differs from other phenomenological research methods because it places the researcher at the centre of the process. The researcher becomes the internal focus and the instrument of inquiry. Clark E. Moustakas (1990) developed this method while researching his experience of loneliness. He was influenced by the work of humanistic and existential psychologists and philosophers including Maslow, Polanyi, Buber, Rogers, as well as Kierkegaard, Troisfontaines, and Tillich. While understanding the phenomenon with increasing depth, he concluded that, "...the researcher also experiences growing self-awareness and self-knowledge" (Moustakas, 1990, p. 9).

Through the discovery process, new images, meanings, and realizations emerge. MacIntyre (1982) wrote that the steps in the emergent phenomenological methodology must be flexible:

> [T]hey emerge from the developing study. Only upon reflection, in the clarity of a backward glance, do they seem clear and logical. Therefore, the heuristic researcher must be open to the unique and unfolding nature of this particular form of inquiry." (p. 97)

In pursuit of my thesis question, personal immersion led deeply within to the seat of knowing. This "...internal frame of reference..." is the singular base of an individual's own knowing (Moustakas, 1990, p. 26). The essence of the phenomena is deepened by the researcher's persistence in the heuristic process, searching for the qualities, conditions, and relationships that underlie a fundamental question or concern (Moustakas, 1990, p 263).

Over an extended period of time, the researcher observes the relationship to the question with sustained curiosity, involvement and participation. Explication of the experience may be further illuminated through creative synthesis in the form of metaphoric tale, artwork, story, lyric poem, or song (Moustakas, 2001, p. 270). I found composing for the piano was a means of expressing the essence of my past experience. Music themes emanated unbidden over a period of months while I was intently focused on the research question. Previously, this researcher had never composed any music; the melodic ideas that emerged were a surprise and called upon long-buried music skills expressed in a new format.

Sela-Smith (2002) critiqued that many heuristic researchers claim to be doing heuristic research though the methodology appears to disorient the researcher, shifting observation from that of experience and self-search to that of observing experience of self and of others. She notes that the heuristic research method should be focused on self-searching, inner dialoguing, and entering the tacit dimension. She proposes that heuristic research be more narrowly defined as heuristic self-inquiry (Sela-Smith, 2002, p. 79).

Sela-Smith (2002) observed that Moustakas' research had a second unacknowledged question: the first was heuristic, a commitment to the "leashless" (sic) exploration of the feeling of loneliness" (p. 75). The second question was based on the dissociated phenomena of the experience of loneliness as articulated by other participants. She also perceives a paradox in which Moustakas seeks an inquiry free of definition, while aiming to define it for positivist scientists expecting external validation (Sela-Smith, 2002, p. 76). In response, MacIntyre (personal communication, 2010), a former student of Moustakas, contended that Moustakas was motivated to find acceptance of the method in the contentious qualitative research milieu of that era. His focus was on a longer-term goal.

Moustakas (1990) advised:

> Heuristic research is an extremely demanding process, not only in terms of continual questioning and checking to ensure full explication of one's own experience, . . . but also in the challenges of thinking and creating, and in the requirements of authentic self-dialogue, self-honesty, and unwavering diligence to an understanding of both obvious and subtle elements of meaning and essence inherent in human issues, problems, questions, and concerns. (p. 37)

The heuristic researcher, as instrument, is immersed in the experience of a phenomenon and engages more than intellectual capacities. The question arises from an interest in the essence of a personal phenomenon of human experience that grows in intensity. Without predetermining or predicting causal relationships, the researcher must imagine, empathize, feel, intuit, dialogue, and encounter the interior self in order to understand the phenomenon (Moustakas, 1990, pp. 41-42). Creative synthesis is "...the peak moment when the researcher recognizes the universal nature of what something is and means, and at the same time grows in self-understanding and as a self" (Moustakas, 1990, p. 90).

Gathering themes from the emerging data, the mysteries, miracles and discoveries can be explicated (MacIntyre, personal communication, 2010). Heuristic research is a discovery process where intellect and intuition coalesce; it is without pre-conceptualization. One is urged to let go, to allow emergence of truth; one must be accepting, open-minded, engaged, non-judgmental. As in person-centered therapy, the researcher recognizes the significance of honesty, authenticity, human presence, and mutuality as catalysts for self-discovery and self-renewal which provide "...[the] unfolding sense of truth, explication of experience to deeper levels of meaning, and expansion of consciousness" (Moustakas, 1990, p.105).

One looks inward first to find an integration of facts that make a clear pattern. Moustakas (1990) describes that the formulation of the inquiry method is accomplished through thoughtful reflection, meditation, self-searching, intuitive and mystical reaching, and hours of silent midnight walking (Moustakas, 1990, p.102). One sifts and assimilates data, gathering and clarifying in an effort to find patterns which will lead to an integrated understanding of the phenomenon (MacIntyre, 1982, p. 95).

Methodology

The heuristic researcher seeks to understand and distinguish between the essence of the lived experience and the nature of that experience. "[T]he depicted is always the same as the depicter" (Moustakas, 2001, p. 264). This research involves self-search, self-dialogue, self-discovery into the feelings beneath the experience and an explication of the effect that this crucial sense of invisibility has had upon one's sense of self. The question and methodology, "...flow out of inner awareness, meaning and inspiration" (Moustakas, 1990, p. 11).

The researcher places value on the inner experience, or initial data, and identifies spontaneous meaning that may lead to awakening and transformation. Intently abiding with the question, writing and rewriting, the researcher lives inside the focus of the research. For this researcher, almost everything in everyday life subtly or profoundly related back to the thesis work. Memories arose. Present events were highlighted by past remembrances, and vice versa, while I rhythmically moved "...through periods of active involvement and of quiet reflection" (MacIntyre, 1982, p. 104).

This critical self-dialogue, attuned to all facets of the experience of a phenomenon, moves the researcher from the whole of the experience to parts or facets, and back again; it moves between feeling and language, unifying "...intellect, emotion and spirit" (Moustakas, 1990, p. 16). Honest self-disclosure in the tacit dimension invites others to openness in their own disclosure. "It is I who sees and understands something, freshly, as if for the first time and I who comes to know essential meanings inherent in my experience" (Moustakas, 2001, p. 264).

In Chapter Three, I provide the initial data, through recollections of my early life and environment. Connecting to this young, pre-verbal self, the *I-who-feels,* and the physical sensations, the researcher enters the tacit dimension and subjective experience (Sela-Smith, 2002, p. 26).

Moustakas (1990) explained that his primary research task is:

> ...[to] recognize whatever exists in my consciousness as a fundamental awareness, to receive and accept it, and then to dwell on its nature and possible meanings. With full and unqualified interest, I am determined to extend my understanding and knowledge of an experience. (p. 11)

The heuristic experience is my truth. The conclusion is another beginning; the research invites further exploration.

Six Phases of the heuristic research method

During the research process, I challenged my self-awareness by exploring problems and questions in order to "...throw light onto a critical human experience"

(Moustakas, 1990, p. 11). Immersed in the phenomenon, I moved through the six phases of research: initial engagement, immersion, incubation, illumination, explication, and creative synthesis, to transformation. It is not a linear one-dimensional route that transports from a point of departure to a designated destination. It is an intuitive exploratory process that reveals, enlightens, and expands. Sela-Smith (2002) stressed that "...[t]he feeling response as experienced is valid as it stands" (p. 79).

Sela-Smith (2002) proposed that Moustakas' six phases are mechanistic formulations. She comments that the research must be based upon a steady gaze toward new understanding; a person must encounter each phase as an opportunity for *free fall* into the data where awareness, personal growth, and personal transformation may emerge (Sela-Smith, 2002, p. 64). During my research I sometimes observed a sense of losing control. I would then remind myself of the inherent reality of research which delves into the truth of lived experience where there is complexity in ebb and flow, ease and struggle.

The first phase of research, *initial engagement*, is intense. It demands consciously encountering the self, one's historical lexicon, and significant relationships. But intuition facilitates creativity and originality and intuitive judgment becomes concrete and decisive as the researcher develops trust in her means of insight. By successfully defining what is potentially a painful topic or question nothing is swept aside; the research comes into sharp focus (MacIntyre, personal communication, 2010). I sat with the potential question posited by this thesis for several months before it solidified and became certain.

Immersion is a natural state in which everything is "...crystallized around the question" (Sela-Smith, 2002, p. 65). The researcher is intimately involved with the question in self-dialogue. Sela-Smith (2002) cautioned that the researcher may not truly be practicing heuristic research when bound by the preoccupation of incorporating the experiences of others and/or the requirement of timelines (p. 66). This became a critical consideration in my decision to base the research solely on my own experience. The depth of the topic, its timeline, plus the potential demands upon my physical health were all concerns I had to address in preparation of the thesis proposal. I allowed that further projects may include the response to my work, and the input of the related stories others have to tell.

Retaining a singularity of focus has proven invaluable while existing physical issues have regularly, unpredictably, interfered. *Indwelling* is the term Moustakas (1990) used to describe the deliberate attunement to the deeper meaning of a theme or a quality of experience; in time it provides the fundamental weight of the phenomenon (p. 24). It was profitable for me when musical themes arose from an unconscious realm during the indwelling and immersion period. The creative outlet of composing for piano helped to provide impetus to remain with the process of indwelling, a grounding for the discomfiture that sometimes ensued. As I perused literature or encountered stories in the media that related to the research question, I was challenged to hold onto my personal recollection and imagination. Staying with the question required rigorous inward focus.

Phase three of the heuristic process is *Incubation*. The researcher puts action on hold, surrendering, retreating from the concentrated process in order to provide space for emergence of "...new ways of thinking, being, seeing, and understanding" (Sela-Smith, 2002, p. 67). New insight and understanding of the research question arise. This difficult phase challenges the researcher's urge to direct or advance one's efforts which would prevent a true revelatory state. Self-doubt crept in as I held onto the question and the elusive potential for revelation. Clarity and resolve developed during contemplative movement facilitated by the phases of research.

The fourth phase, *Illumination*, occurs naturally through tacit knowledge and intuition. This is the “Aha” experience of insight; the self and one’s world are experienced in entirely new ways. “It may take place in a single moment or it may take place in waves of awareness over time” (Sela-Smith, 2002, p. 67). I would describe these moments of insight as similar to branches of a tall hedgerow along a rural Irish road that suddenly open to reveal the green mountains beyond. Also at this time, musical phrases began to gel in my mind with development of harmony and rhythm.

Explication entails a full examination of all dimensions of that which rises to consciousness, providing new understanding and meaning. Through focusing, indwelling, self-searching and self-disclosure, one recognizes that meanings are unique and distinctive to one’s experience and one’s internal frames of reference (Sela-Smith, 2002, p. 68). Transformation in consciousness is then expressed and explicated. Just as medical researchers and diagnosticians will inevitably arrive at more clarity about autoimmune diseases, I expect some personal insights will continue to arise for as long as my senses and intellect endure.

Creative Synthesis, the sixth phase, is the naturally occurring story that comprises the “new whole”, the union of the deep-unconscious with the waking consciousness. This is “...an amazing synchronicity, harmony, connection, and integration . . . [B]e it in the form of a painting, a book, a piece of music, a dance, a lecture, or anything else creative, there will be something that resonates deep agreement within the observer" (Sela-Smith, 2002, p. 69).

With the researcher as mid-wife, the mutuality between the researcher and the experience of transformation cannot be falsely manufactured. For my research process, culmination of the music component reflected the illumination of my narrative. The music is simple in form yet it assisted me to know my authentic self at a new depth.

I remind the reader that these six phases intersect and flow along together like clouds in formation. Often evading the grasp of the researcher, major themes eventually coalesce. Chapter Five contains the illumination and explication, including spiritual reflection and creative synthesis. I hope the accompanying music will complement the experience of transcendence for the reader. The concluding chapter also provides my insights and presents opportunity for readers to carry this question forward.

Tacit Knowledge

The concept of *tacit knowledge* is applicable to my experience of undiagnosed chronic physical illness. Michael Polanyi (1966) defined the phenomenological tool, tacit knowledge, as "something a person knows but cannot tell" (p. 5). There is no language to explain how a mother knows the meaning of her baby's cry. Nor can we describe how a few persons are able to identify the auditory pitch of musical tones.

Living with inexplicable pain, words are often insufficient, yet the *knowing* remains. I delve into the pre-reflective consciousness. The mystery of a lived experience is recaptured not as an entity, a behavior, a feeling, or an emotion but *through* them. I strive to explicate elements of the mystery of my younger self who lived within invisible barriers to physiological wellbeing and a sense of wholeness. From here, new understanding of the present self is derived.

Moustakas (1990) conisdered Polanyi's facets of tacit knowledge, *subsidiary* and *focal*. Subsidiary facets of knowledge are in *conscious* awareness. This level of awareness captures the context (Chapter Three) of my thesis. I describe my world, relationships, and the period of time which concerns my thesis. Focal facets are subliminal, the core of heuristic research, in which the researcher experiences doubts, concerns and challenges. Subsidiary and focal facets form the essence of a phenomenon, guiding the researcher into untapped directions and sources of meaning (Moustakas, 1990, p.22).

Intuition–sensing clues and making shifts–leads the researcher to form patterns, relationships and inferences that provide essential material for deepening and extending scientific knowledge (Moustakas, 1990, p. 24). This period of indwelling is not logical or linear in degree. Moustakas (1990) referred to Gendlin's study of *focusing* as both a concept and a process of sustained systematic contact with the central meanings of an experience (p. 25). Through the focusing process, the researcher is able to determine the core themes that constitute an experience, identify and assess connecting feelings and thoughts, and achieve cognitive knowledge that includes "refinements of meaning and perception that register as internal shifts and alterations of behavior" (Moustakas, 1990, p. 25).

Sela-Smith (2002) defined heuristic research as a process of "trial and error," or a process of problem solving that is almost entirely unconscious (p. 58). This state of subliminal pondering houses the structures that contain perception, feeling, intuition, beliefs, and judgment. They govern behavior and determine how we interpret experience by drawing together images, beliefs, values, priorities, memories and emotions. This accumulated data becomes affixed onto our world-view and undergirds all personal knowing.

A person's embedded world-view may be poorly understood; it may alienate what is known from what is spoken. It may divide parts of the self (Sela-Smith, 2002, p. 62). In Chapter Five I refer to this observation as it pertains to my lasting sense of being inauthentic. Moustakas (1990) wrote that self-dialogue with the phenomenon, open, receptive and attuned, moves the researcher from the whole of the experience to parts or facets, and back to the whole again in unity of intellect, emotion and spirit (p.16). The researcher must be honest with self-disclosure in the tacit dimension so that others can perceive and be encouraged in their own disclosure.

The thesis question raises the keen researcher's awareness in daily life. One consciously selects compassionate immersion in situations that will facilitate the exploratory process and increase awareness of common patterns and relationships beyond what is intellectually available. Insights and thoughts, recorded in memos, enrich understanding. The methodology is flexible and emergent as insights and perceptions deepen. The researcher concentrates on the demands of the explicative process, reflecting upon and elucidating the parameters and details of the experience. One moves toward creative synthesis, an illumination of essential qualities and meanings of an experience.

Validation

I recall the phenomenon of living with undiagnosed long-term chronic physical illness as it impacted my being. This is not autoethnography, narrative research, or memory research, all of which Ellis (2009) described as a traveling back and forth between dramatic plotlines, scenes, dialogues and character development (p. 15). Through sustained curiosity, personal passionate involvement, energy, and resourcefulness over a long period of time, heuristic research retains the *essence of the person* in experience, rather than the phenomenological conclusion of the *essence of the experience* (Moustakas, 2001, p. 264).

Sela-Smith (2002) suggested that a new depth of self-understanding and transformation arises best from the single feeling response of the researcher in surrender to the process. She continued:

> I remain committed to the understanding that without surrender to one's own non-projected feelings, the tacit level will not be reached and brought into consciousness. Change will not occur at the tacit level; whatever change does occur in spite of the external focus, will be limited in comparison to what might have been with internal feeling orientation. (p. 81)

The timeless, universal humanness of the individual researcher's experience is sufficient as a validation, like the forty-day wander in the wilderness (Sela-Smith, 2002, p. 81). Further, she contended "...heuristic inquiry that results in self-transformation and the creation of a story that generates potential for transformation in others and in society is the strength of the self-inquiry method" (pp. 82-83).

MacIntyre (1982) described the passion of the creative scientist who is inspired by humanistic researchers such as Moustakas, Polanyi, and Craig. This inner conviction is the crucial element in validation of heuristic research. She quoted Craig as saying, "...no one can know better the depths and nuances of a particular research experience than the researcher . . . motivated by clarity . . . who conducts research responsibly and accurately” (p. 98). The fruits of discovery change a researcher’s personality and deepen the understanding of one’s world. They culminate from the intuitive rhythm of active and passive phases of the research, and seem to emerge effortlessly (MacIntyre, 1982, pp.101, 103). The heuristic experience is one’s truth. The conclusion is another beginning. “The feeling response as experienced is valid as it stands” (Sela-Smith, 2002, p. 79).

Research goal

Sela-Smith (2002) saw the goal of heuristic research as social transformation, a new world view. The appropriate application of the heuristic research method, in its original uncontrolled nascence, is through “...surrender into feeling-the-feelings and experiencing-the-experience. [This] allows the self-as-researcher to enter heuristic self-search psychological inquiry” (p. 83). The researcher must frankly acknowledge any resistance to feeling and must surrender to transformation with its potential to impact the individual, society and all of humankind. The intention to search internally will inform one to “...discover what caused me to create the external experience.” It serves to transform the inside experience and the outside world (Sela-Smith, 2002, pp. 85-86).

The researcher’s “...intellectual, intuitive and imaginative powers have the stamp of individuality. Research designs flow from one’s own experiences, perceptions and insights and they are therefore unique” (MacIntyre, 1982, p. 100). Progressive, flexible, and deepening insights, and an open state of mind bring clarity and logic.

> The call of humanistic research is for innovative and original models that are adequate to questions related to the individual human person and these methods

> can only be developed by researchers who are committed through a heuristic passion towards discovery. (MacIntyre, 1982, p. 101)

My research process

Sela-Smith (2002) wrote that the “feeling response” is the final frontier of being to which true subjective researchers must transport themselves. Through recollection of a frightening dream she realized that her feeling-self had long ago dissociated from her thinking-self, hiding the solution to a major problem in her life. This acknowledgment precipitated the intimate observation of the *I-who-feels* and of the resultant transformation which she describes in her thesis (Sela-Smith, 2002, p. 57). In my own research I discovered my unconscious awareness of the contrast between my childhood development and that of my peers; it was a clue to recognizing my experiences of neglect and the impact of physical illness.

Students who contemplate heuristic research inquiry need space in their lives, plus the energy to shuffle and rearrange what is current while inhaling that which emanates from within. As researcher, present with the feelings that had been previously suppressed or denied, there were moments when the help of a therapist was important. I found the relationship with an empathic, supportive thesis supervisor imperative in my heuristic research because the unpredictable nature of the methodology means confronting issues that can seriously compromise trust in the process.

The recounting of early experiences, in Chapter Three, provides opportunity for the reader to recognise feeling responses that words alone cannot clarify. Chapter Five presents my reflections upon the feelings, and the transformative insights that arise from the periods of immersion and incubation as well as from the literature review.

Chapter Four presents the literature review. My earliest study of the research question investigated the depth of peer-reviewed literature on the topic of living with undiagnosed chronic illness. I found articles written primarily by nurses in Scandinavia and Australia about experiences of persons living with diagnosed chronic illnesses. There was material about the impact of illness upon the individual and her family members. A few articles were specifically about children coping with chronic illnesses in their lives. Some literature explored the experience of chronically-ill women who were also isolated by circumstances such as age and poverty. Articles described the critical necessity to work alongside the patient, assisting them to function to the best of their ability.

Initially I found no literature written from the personal viewpoint of a woman living with *undiagnosed* chronic illness; nor did I find material that discussed the experience of living specifically with undiagnosed chronic physical illness over an *extensive period* of time.

Continuing, I studied the concept of *self* as defined by respected authorities in psychology and philosophy. Bubbles of memories arose and I wrote copious notes, attempting to express my remembered sense of who I was in earlier years. Many of the recollections remain at the non-verbal level. I tried to discern when and how the symptoms of chronic illness influenced my experience of my self in my childhood world. I was challenged to summarize the early years in a way that would provide the reader with an understanding of the privileges and the vulnerabilities that defined my life. Everyday events occurred that highlighted early sensitivities and alerted me to the formation of beliefs and views in my present self. I learned more about the effects of trauma on the development of one’s self and physiology.

Major themes became clear as I worked to illustrate a confluence of lived experiences during my development. To abide with the essence of an experience as its truth emerged, I endeavored to stay with my recollections and trust the clarity of the backward glance. “Since intuition plays such an important role in heuristic inquiry, researchers need to develop their intuitive powers and trust their own intuitive insights” (MacIntyre, 1982, p. 104). At times overwhelmed, I paused to allow synthesis of thoughts and feelings. Upon reflection, it occurred to me that this research inquiry began at the onset of critically deteriorating health more than thirty years ago when I first actively sought understanding, support, and resolution. The determination I had was derived solely from fear; it required immense expenditure of energy and resultant isolation. The thesis presents some of the effects upon my life, my views and beliefs, ending with insights, transformation and creative expression.

Through the looking glass of the heuristic research process, which transports me more deeply than mere remembering, I sought to identify the lived data and the nature of that experience upon the vulnerable self. Delving into the pre-reflective consciousness, one is cautioned that “...the critical moments of inquiry are ultimately elusive to systematic explication” (Van Manen, 2003, p. 34). It is my hope that Chapter Three, which recalls incidents from a cumulative period of time, will enhance the reader’s perception of my circumstance of undiagnosed chronic physical illness when external validation seemed dependent upon a biomedical diagnosis. The literature review in Chapter Four will amplify, clarify and refine the experiential findings (MacIntyre, 1982, p. 96).

Fixed on the research question, writing and rewriting, the researcher lives inside the focus of the research. Throughout the period of this research, much of everyday life seemed to relate to the thesis question, sometimes subtly, sometimes profoundly. The explication, Chapter Five, focuses on the feelings beneath the experience, and the effects that the invisibility has had upon my sense of self. I express the insights and implications for the development of an authentic self.

Research ethics

While I investigate my past and explore my transition, I honour other persons' rights to their privacy and truth. The focus of my research is the essence of my own experience; it entails rigorous immersion, incubation, reflection, imagining and creative expression of a powerful personal experience. Where Chapter Three provides background recollections, Chapter Five draws together the themes and insights that have arisen from these.

The experiential piece, Chapter Three, makes reference to incidents that took place more than a decade ago. Time and geography create distance from events and from individuals; some persons are now deceased. Amalgamation of individuals and events create more anonymity and disguise. My surname has changed. I am no longer involved with communities or professions that I had been in the past. Gender-neutral nouns and pronouns are used as much as possible to further erase identification. Regarding members of my immediate family, the experiences of my siblings coincide with mine but are obviously perceived from unique perspectives. I respect the dignity of members of my family of origin and their right to their own personal awareness of past and future experiences and relationships. I honour the sanctity of my deceased parents, my only child, my extended family and all other persons with whom I have been connected.

To state it plainly, this heuristic project is based on *my* inner experience. Past events serve as data to illustrate the experience of my self. For instance, the authoritarian roles are a construct of a patriarchal society, and as such they relate to the topic in question. I am a product of this cultural environment; masking identities does not erase the sense of powerlessness and invisibility I experienced within my community.

Feminist philosopher Virginia Held (2006) wrote that the feminist ethics of care call for the empowerment of those who seek restraint of an imperialistic ideology.

> ...[T]hey will depend heavily on citizens caring about potential victims, wanting to prevent their suffering, and understanding what needs to be done. And this factor of relatedness to other human beings may be more important than a mere rational recognition of abstract liberal rights, though progress in understanding and respecting human rights is surely important also. (p. 151)

Similarities can be highlighted between my story and that of journalist and author, James FitzGerald (2010). In his forthright book he revealed having lived with the insidiously secret legacy of mental illness and suicides in his prominent Canadian family during the first decades of the twentieth century. This history of illness effectively penetrated and silently manipulated the lives of descendents. Among other things, he and I share a diagnosed chronic physical disease which is often associated with the effects of long-term trauma. His family is notable in the history of Canadian medicine; he could not possibly conceal their identities while telling his important story.

Health care professionals whom I encountered during the relevant time period are no longer acquainted with me. Some have retired. Some are deceased. Some practices were transferred. Bureaucratic agencies and faith communities to whom I indirectly refer are not attributed sufficient particulars to make them recognizable. Modified examples of events that incited feelings of condescension, estrangement, neglect, stigmatization or misogyny now serve as catalysts to awareness.

Rollo May (1975), the existential psychologist, wrote about the emergence of a new kind of power through truth expressed creatively:

> Commitment is healthiest when it is not *without* doubt, but *in spite* of doubt. To believe fully and at the same moment to have doubts is not at all a contradiction: it presupposes a greater respect for truth, an awareness that truth always goes beyond anything that can be said or done at any given moment. To every thesis there is an antithesis, and to this there is a synthesis. Truth is thus a never-dying process . . . [quoting Leibnitz] "I would walk twenty miles to listen to my worst enemy if I could learn something." (p. 21)

Creative courage involves the discovery of new forms, symbols, and patterns upon which to build a new society. The reader's appreciation of a creative work is itself a creative act. It is this heuristic researcher's aim that she and the reader may find transformation through the synthesis of my heuristic thesis work, the written explication in Chapter Five, as well as in the music compositions. When an image is highlighted by direct sunlight, it is the shadow that defines the sculpted nuance. In like fashion, I hope allusion to strokes of darkness in a pain-filled past will serve to reveal the *essence* in my creative heuristic work.

To reiterate: specific details of events are not the focus of the heuristic thesis. It is in the explication, Chapter Five, that feelings, observations, awareness, insights, knowledge and purpose are synthesized from the experiences of the events. Creative expression helps to reveal the essence of the inner experience. I believe the benefits of writing this thesis with discernment, care and respect, outweigh the risk of harm to myself, my immediate relationships, or to others with whom I presently have no contact. I approach this heuristic research with the purpose of bringing enlightenment to my self, to others who share my experience, as well as to those in the field of caring, and in health care research.

Moustakas (1990), contended that "... heuristic inquiry that results in self-transformation and the creation of a story that generates potential for transformation in others and in society is the strength of the self-inquiry method" (p. 36).

Protecting the researcher

Carolyn Ellis (2009) advised research students to "...try to show the dust and clutter without saying they're 'dirty' " (p. 312). She stresses that students take responsibility for their perceptions. I am conscious that the care with which one's thesis is created reflects upon the writer, the research, the institution and the effectiveness of its purpose. For inquiry that is close to personal life, she suggests: "When possible, research from an ethics of care. That's the best we can do" (Ellis, 2009, p. 316).

It is not my intent to expose myself or anyone else to harm. I intentionally refrain from writing about some of the most personally devastating events in order to preserve dignity and safety for me and/ or vulnerable other persons and relationships. Years ago, I took formal actions to separate my identity from certain persons. Two sites a click away on the Internet sabotage my privacy; government records and a genealogy program both reveal past relationships. Consequently, in writing this thesis I worked diligently to protect the safety and privacy of others and myself.

Rollo May (2007) likened an inner struggle to a conflict with the daimonic, the essence of our own unconscious. He drew comparison to the biblical story of Jacob, whose battle with Esau evolved into an interminable entanglement with God (May, 2007, p. 168). He wrote that one can choose to shut out the world, as do the New York subway riders, or we can choose to see and create it (May, 2007, p. 234). He also states:

> For consciousness surprises the meaning in our otherwise absurd acts. . . . And the daimonic . . . leads us into life if we do not kill these daimonic experiences but accept them with a sense of the preciousness of what we are and what life is. Intentionality, itself consisting of the deepened awareness of one's self, is our means of putting the meaning surprised by consciousness into action. (pp. 324-325)

It would appear that heuristic research provides essential knowledge to the broader context of the wounded self in community, and in a world torn by dissention and conflict.

Illness was accompanied by a sense of deep humiliation, powerlessness and isolation as my heuristic journey began decades ago. I have striven to honour and gently embrace the child, adolescent and young adult person, the *"I"* who is the focus of this thesis. I am confident that expressing my truth will contribute to the health and wholeness of other persons and communities.

Ellis (2009) noted that some topics are not "nice topics". She continued:

> ...[T]he question of how to honor and respect our relationships with intimate others while being faithful to what we perceive to be the truth of our story is a difficult ethical issue with which researchers must grapple. . . . I have come to believe that the well-being of the researcher is not always less important than the well-being of the other, especially others who have behaved badly. (pp. 306-307, 317)

In his article about ethics in research, Clifford G. Christians (2005) depicted an evolving moral order and the current crises of creating, and meeting, ethical standards. He describes a "...hierarchy biased toward patriarchy . . .[There] is no sustained questioning of expertise itself in democratic societies that belong in principle to citizens who do not share this specialized knowledge" (p. 148). Part of my purpose is to contribute awareness to those in health care fields where my lived experience was minimized by others, where my anecdotal experience contradicted the biomedical tests which revealed no remarkable physical evidence of disease.

The feminist model of ethics of care influenced Christians (2005) to say:

> Compassion and nurturance resolve conflicting responsibilities among people, and as such these standards are totally the opposite of merely avoiding harm. . . . Accumulated wisdom, moral meaning from our own choices of decency, and the ongoing summons of the Other [*sic*] together reintroduce love, happiness, sympathy, and beauty in a modern, nonabsolutist [*sic*], but principled theory of morals. (p. 149)

This thesis aims to provide me the opportunity to remember and emerge from a time of fear, pain and confusion. Rita Charon (2006) wrote about her practice of narrative bioethics within narrative medicine. She insisted that *narrative bioethics*, a term she coined, surpasses what she calls the more pragmatic practice of bioethics. The former embraces literary studies, liberation theology, cultural studies, feminist studies, post-colonial studies, humanistic psychology, pastoral care, and phenomenology. She emphasized the value of story, and the participation of an entire community of care-providers, in the treatment of every individual.

> [T]raining in health law and knowledge of moral principles do not suffice to fulfill ethical duties toward the sick. . . . Echoing its transformative force in other disciplines and professions, narrative practice has renewed and redefined the very enterprise of what used to be called bioethics. These [narrative] methods seek congress among human beings limitted by mortality, identified by culture, revealed in language, and marked by suffering. (Charon, 2006, pp. 203, 209)

I am inspired by the relevance of the story in my witness to suffering; it is grounded in singularity, temporality, and inter-subjectivity. Charon (2006) quoted a poignant comment made by her colleague, Micah Hester:

> The more complex and threatening the experience [of ailment] for the patient, the more it tears at the fabric of that person’s life. And conversely, the more an ailment tears at the fabric of our relationships, the more severely it is experienced. (p. 211)

Attention is a gifting of the presence of the self; it begins with welcome, and opens the self to the promise of consolation. With compassion and respect for my self and others, I present my heuristic experience so that it might “...[fuel] another turn in the spiral toward fresh attention, new sightings, new duties, and new stories” (Charon, 2006,

p. 211). I have been motivated by hope and belief in a potential health care milieu that affirms the dignity and wholeness of all people.

As previously stated, my third chapter provides some experiences of my past. I use events to draw generalizations about their impact upon my sense of self. I strive to express my experience of the ineffable, inviolate–the sacred union of body, mind and spirit–as the potential of living presence unfolds. I find that there is irony in marginalization and invisibility: it frees one to be with the self intimately to seek meaning through the act of "creative discovery" (Moustakas, 2001, p. 264). Chapter Five provides reflection based on the inspiration and transformation of the authentic self that this heuristic research has presently provided.

The thesis inquiry has been greatly inspired by the founder of humanistic psychology, Carl Rogers. I am encouraged to trust my experience as the highest authority for my truth which provides a means of converging on a greater truth. Kirschenbaum (1979) quoted Rogers who said that, "what is most personal is most general" (p. 27).

Final thought

Martin Buber (Friedman, 1988) recounted that an academy of like-minded men planned to develop a community for creating, "...words of spiritual value for the speech of Western peoples." They approached Buber for advice. Friedman (1988) quoted Buber's careful response, including the following:

> The coming into being of words is a mystery that is consummated in the enkindled, open soul of the world-producing, world-discovering man. Only such a word engendered in the spirit can become creative in man. . . . What is needed is

> not teaching the use of new words but fighting the misuse of the great old words. (p. 311)

I am conscious that words can be elusive, misinterpreted, or ineffective. Occasionally however, verbal expression can provide much good. I pray this project brings forth worthwhile meaning for an aspect of an issue that I found compelling and that, I suggest, certain other women confront. The issue is a woman's experience of living long term with invisible, undiagnosed, chronic physical illness and pain, and its impact on her sense of self.

Sorrow bears a lasting legacy. As the next chapter will illustrate, I was a child determined to secure a sense of personal safety by dissociating from painful incidents and memories. The research experience with the thesis question revived memories. It demanded confrontation with uncomfortable truths. To capture these truths in words required discretion where there is reluctance to undermine my fragile security. I have erred on the side of under-reporting incidents of anguish, pain and heartache though the reader is assured that the effects have been constant companions. At times the reader's own intuition is called upon.

Chapter Three: Early Life

Introduction

To provide background and context for the thesis question, and in order to illustrate my development as it affected my inner resources, I introduce the writer and report her memories from childhood, adolescence and young adulthood.

The heuristic research methodology is a deeply personal work, “...ineffable and unspecifiable...” in nature (Moustakas, 1990, p. 23) but, “[i]ntuition makes immediate knowledge possible, without the intervening steps of logic and reasoning” (p. 23). I mention here that the habit of incubation and immersion developed in the process of this research will most certainly continue to bear seeds of new awareness, cultivating a more intensely introspective and creative stance. Formulating this chapter occupied my daily life; it insinuated into thoughts, at times intrusive, distracting, elevating, and annoying. This chapter highlights aspects of self in present experiences as I take my handy notebook and jot down words for contemplation.

As indicated in Chapter Two, any background circumstances that involve other persons have been written with care, observing the right to dignity and privacy for every perspective. Events and persons are disguised wherever possible. The passage of time further diminishes identifiable factors. Some most devastating incidents are underreported with the hope that sufficient context will remain for the reader.

In recounting passed time, I resist interpretation of incidents. I study intricacies and details like the fractals of a snowflake, taking care to preserve the delicate essence. I gaze at the child with awe and respectfully assimilate experiences in an exploration of initial data. I trust that I empathically honour her despite the lapse of time and the use of terms that were then inaccessible.

I don’t have idyllic memories. Many details are lost while sensations are recalled vividly. Intention is focused upon witness to my early development without desire to discredit any persons, living or dead. This heuristic document is a solo production. By that I mean I respect the sanctity of the experience of individuals whose voices are not included here.

Childhood

I know how to hold confidences. Before I was five years old I kept big secrets on a dramatic stage. In the back seat of the car one day, at three-and-half years old, I stared at the large rural brick hospital where my father had been suddenly admitted. Adults who were with me came and went to visit my father as he lay inside. They said things like “...the pain is so bad, he just wants to die.” He died over that Thanksgiving weekend. In the space of a few months I had a new father and different surname. The relationship with my birth-father’s parents, my grandparents, ceased. Subsumed into another family unit, I didn’t know how to love this new dad. Even his teasing felt inappropriately personal. There was much I could not comprehend.

After his death, a package of picture books arrived from my father’s former store in the town where we no longer lived. As I learned to read the books it seemed that he was with me. I thought I could remember the feeling of him and the town. The books were worn with much use and discarded. When I had the opportunity to drive myself there many years later, I found that the layout of buildings and streets matched my recollection, coinciding with and validating cherished memories of him.

As an adult I had the opportunity to meet again my paternal grandfather. I was surprised by his account of joy at my birth. I had concluded as a child that the years of absence were my fault: I was bad and therefore his love was denied, or, more difficult to contemplate, he was bad, and by association so was I. Adult attempts to rekindle our relationship were hindered by inexpressible awkwardness, though my aged grandfather and my child had a brief time to know each other.

I lived in eight homes before I was ten years old, and felt uncertain about new friends, faith communities, schools. I was earnestly attentive in my environs, treading lightly, moving inconspicuously, speaking softly. When I was involved in anything that contributed to turbulence in the home I heard the message that I should have known better. It was a pattern for me to anticipate consequences, to be thwarted by unintended results and stymied by mistakes.

I had a capacity to listen carefully. I could intuit the needs of others. I watched over my shoulder lest anyone should just vanish. My mother was beautiful, artistic, sophisticated, passionate, brave; her eyes spoke of cycles of depression, hallucination, narcissism, phobia, paranoia and mania. Subtle mood changes, a certain facial expression often signaled the calm before a tsunami. She dominated my daily thoughts and actions even when we were apart. I perpetually focused upon unattainable expectations. Anticipating rebuke, it seemed I only mimicked stability and confidence. I doubted my sincerity. I reserved expressions of insight and maintained a sense of foreboding, irony, and disappointment.

Yet I clung to my mother during frequent bouts of discord. Her unpredictable mood changes and medical treatments that dulled her mind and eyes all frightened me. It was evident after her hospitalizations that she was aware of her behavior and bore a lingering shame which complicated fragility and imbalance. I knew she needed protection.

Affection was transient. I heard stories of the fawn whose mother is killed by the hunter. He is then rescued and nurtured. There was the spunky orphan who finds herself embraced in a surprisingly warm family unit. A child-super-sleuth finds fulfillment helping her father solve urban crimes. Myths of adventure, trial and resolution led me to wonder about the fantasy of forgiveness, reunion, enduring grace. I sometimes dared to crave that same comfort and protection.

Life was full of contradictions. It was due to popular children’s movies and television cartoons that I was first enthralled by great music compositions. In an indescribably intimate way I treasured these as well as some of the sacred music I heard in the church sanctuary. The inestimable legacy my father left was money invested with the Public Trustee, because he had not prepared a will. Amongst other things such as winter coats, my mother wisely used the money to pay for hundreds of music lessons. Practicing the piano transported me. This means of expression was so intense it was jarring to be expected to make music for others to hear.

It was hard to discern for myself when it was appropriate to note my discomforts**.** A parent remarked that on the occasions when I did complain, it was a sign that something indeed was very wrong. Rubella, with high fever, skin rash and horrid aches, required lying in the dark to prevent damaged eyesight. I remember terrific loneliness while the illness took its course. When I was nine a lingering cough in my lungs was thought to be tuberculosis, and the whispered tones of adults unraveled me as my health was regularly monitored at the sanatorium in subsequent years. The toe-picks on new ice-skates tripped me at every glide the first day I wore them at the rink. After I removed the skates my legs would not straighten; I crawled down the street and went to bed believing I would not walk again.

I believed I was not a good playmate because common childhood past-times such as “playing house” held no interest. I liked to surreptitiously mould mud into fanciful creations, aware I would be punished for soiling my clothes. I wanted to climb trees, to play with boys’ mechanical and construction toys, model cars and trains, but that was clearly unacceptable. Once when playing outdoors I became firmly stuck in a drift of snow, and another time my heavy winter clothing caught on a barbed fence. These incidents brought visceral fear that I would never go home again. In a recurring dream I was thrown into a deep shaft without a means of escape.

I heeded admonitions to stand tall, sit still, maintain a brisk pace and pleasant demeanor. I depended upon others to make me aware of my physical appearance. Critical comments reflected negatively on my developing self-image. I was confused by the sense that I was not who I saw in the mirror. I felt nondescript, malleable and afraid. I was included in adult settings but denied the opportunity for personal assertiveness. My younger siblings’ welfare was in my charge. Friends my age were seldom invited to my home and I found it unsettling to visit theirs. I nervously observed other children who were permitted to be rambunctious, challenge authority, explore their innate sense of wonderment and curiosity while their security seemed assured and a night’s rest came peacefully.

At night I kept a tally of my guilt and humiliation.

Adolescence

I remind the reader that the historical section is painted with a diluted articulation of time past and additional hues of more present language.

The years between eleven and twenty cover a broad span of development. In my perception, there had always been physical pain. I remember the consternation of wishing away extreme bouts of pain without knowing an acceptable threshold. Reticence to respond to my sensations was normal. Emerging beliefs, passions, opinions, hopes and dreams were secured away from the anticipated glare of judgment and failure. As I proved my dependability, responsibility increased beyond the proportion appropriate for my age.

Dysfunction of the digestive tract made outdoor activities problematic. I noted a correlation between certain foods in my diet and the exacerbation of symptoms, but as the eldest in the family I was expected to gratefully eat the nutritious meals provided. Especially at celebratory events, disturbed digestion and lethargy felt isolating. I recall sensitivity to fabrics and scents; my feet blistered and bled in my shoes and I bruised more often than my peers. I frequently dealt with seasonal congestion, weakness, vertigo, headaches, fever and nausea. During summer, I desired the quiet solace and coolness of basement retreats. I knew the phrases “seeing stars”, and “blacking out” but never perceived these as defining what resulted for me from exertion and heat. My lassitude was perceived as disinterest or laziness. In social settings, I clung to the periphery, averting my eyes and stammering the occasional frozen response.

During the first two school years I shared one strong bond of friendship. We walked to school together and were active and inventive in free time. My friend’s family warmly included me in their activities. My parents however were suspicious of the cultural difference between our families. When my friend moved far away we wrote to each other weekly for more than six years. Later, in a remote rural setting, her family created a faith sect and they began to send newsletters full of condemnation of people in mainstream churches. They called for my repentance and submission. My resistance was evident. Our long friendship ended. I was saddened and confused.

At twelve years old, I resigned from the struggle against untenable forces that I could not identify. Incorrect inference had been so often drawn from what I said and did that I had no confidence in my own thoughts and intentions, and allowed others to speak for me. I battled my intuition, tentative and avoidant with one parent while determinedly responding to the demands of the other. Emotional distance was my safe zone. I ignored the need for personal identity because it felt undeserved. I wiped and tidied any space from which I departed in order to conceal evidence of my presence. I perpetually apologized.

I existed in a chasm between internal and external identity. It was beyond my comprehension to accept that I was by nature introspective, curious and contemplative, and intimidated by the perpetual waves of activity surrounding me. The fragile family structure seemed to shift from crisis to crisis while I endeavored to be circumspect. It was almost a kind of game: daring to endure any eventuality. Unable to absorb gestures of kindness, I was confused as to whether my own compassionate actions were authentic or simply derived from obedience. I was told my face was serene. News stories and movies telling of abuse, oppression, and torture struck me powerfully.

School days

When I was a professional teacher in later life, I came to understand that, without my knowledge, I had been part of a research study on childhood academic development during my public school years. I recalled that I was embarrassed each year when I was removed from class to write the formal exams that were required for the study. My teachers were irritable that I was withdrawn from class; their assessment was that I was a privileged, intelligent child who was not meeting my academic potential. No one knew why that was, except to say that I should apply myself more. School had been a place of refuge but by the middle grades it no longer provided a feeling of security.

Looking back, I remember scarce affirmation of unique values and personal boundaries. Assumed to all have the same needs, interests, thoughts and beliefs, my siblings and I were expected to present a cohesive family firmament against erosion from within and without.

Chronic pain, extended periods of intestinal disturbance, infections, numbness, edema, headaches, sinus congestion, loss of fine motor dexterity and coordination, lack of vigor, injuries, menstrual problems, vertigo, all interfered with exuberance in extra curricular activities. Thus my involvement in music lessons and sports, ensembles and committees in school and faith communities, plus work in the family business were all compromised. I enjoyed playing piano and viola, but could barely withstand the repetitive, focused exertion and posture. Rather than developing expertise, my skill deteriorated. A friend of my mother’s, a music instructor, assured me I would never be as good as my mother. This perplexed me. I did not understand perceived rivalries with my mother or with classmates, and I shrank naively when peers suggested I threatened their successes. I was only aware of challenging myself to make it through the day.

Most social activities were connected to my family's faith community. I eked out passing grades from high school, from a coed Christian campus for lay leaders, and a university degree. These were accompanied by long bouts of bronchitis and repeated injuries that included a sprained neck. I learned to be ambidextrous to compensate for numbness and pain in my dominant hand. I did my homework late at night when household intrusions decreased although my parents assumed I stayed awake late because of my curiosity. I knew it was vigilance. I was confused and world-weary, insecure but attached by powerful external expectations.

Young adult

The irony of developing skills and deteriorating physical acuity continued as my agile body complained more and more. I did not recognise the unique challenge this presented me. Affirmation arose solely through the ability to listen, discern and contribute support to others. I continued to perform heavy household work. I developed some meaningful relationships, was a dedicated school teacher. I made a home of my own. In total, I studied music and performed in the field for over thirty-five years.

Approaching my fourth decade, inflammation and other physiological anomalies became more pronounced. Numbness and pain in my hands disrupted normal use; I was prone to injuries through loss of equilibrium. I noted that teaching in the classroom was a profession with plenty of movement that would prevent my proclivity to fall asleep. The pace of life slowed significantly. Though I was enthralled with teaching, with the opportunity to invest in young learners, I contracted contagious illnesses and incurred injuries more frequently than the children.

A significant photo of my wedding day captures me slouched in a chair in my borrowed vintage satin gown amidst a whirl of family members preparing themselves for the ceremony. On that important day it was all I could do to keep going.

In my fourth year of teaching a speech therapist advised me not to use my voice for six months. In the sixth year, defeated by constant illnesses, I left the school system. My spouse and I hoped to be able to finally start a family, and I thought I could focus more energy on my music profession. Because development of my piano technique had stalled, I chose to focus on vocal technique and repertoire. I entered the Department of Fine Arts as a voice student, and was accepted by internationally renowned coaches for summer programs. Ironically, immersed in the voice program at university, I discovered I was pregnant, and nausea followed me through the entire term. Being a mother was my great desire; we both had waited a few years to conceive. I was enthralled with being a mother after our child’s birth and my husband and I decided that I would continue my studies of music repertoire and vocal technique privately. I taught voice technique and repertoire privately to young adult musicians. Opportunities arose to perform before dignitaries and royalty, to study and present challenging compositions and work with admirable colleagues.

A singer needs the physical health and fitness of an athlete. A professional singer requires sufficient stamina to stand and steadily expand and contract the lungs for long periods of time; control of air flow from the diaphragm past the vocal cords creates a smooth vibrato and agility that span the range in pitch and the duration of phrasing. The best sound is produced by resonance in the chest, throat, facial and sinus cavities. Long rehearsals demand physical and mental concentration in order to quickly learn repertoire, produce musical nuances and create the cohesive sound with accompanist or other participants. The reputation of the prima donna is partially based upon fact; dryness of climate, smoke, alcohol or the overuse of the larynx have a deleterious effect upon the tiny organ. It is a specialized instrument one cannot take to a shop for repairs. Uninformed use of medications can also affect the instrument.

When I returned to my music I experienced constant abdominal pain, chest pain, throat disorders and infections, migraine headaches, fevers and chills. Medications impaired the voice. Energy levels did not match those of my colleagues. Despite setbacks, my professional music reputation grew for a time, which perplexed me. A singer of the classical genre from the western provinces with professional aspirations would generally go abroad to establish a career. This was not something my music-loving spouse would contemplate.

Household tasks, grasping utensils, tending the needs of a small child, and gardening were impaired. I employed my physical size to compensate for grasp of weak hands, thumbs and fingers. I modified tasks whenever possible. Personal grooming habits were dictated by the diminished tolerance of my hands. I chose clothing, jewelry, gloves, shoes on the basis of preventing irritation, friction and pressure upon sensitive tissue. I avoided fasteners such as shoelaces, small buttons and zippers whenever possible. Fashionable high boots and shoes with heels were not tolerable.

Over time, embarrassing clumsiness and injuries called for concentrated prevention and avoidance. During the first year of married life we saved our resources by house-sitting for a wealthy couple who wintered in Arizona. The living room in the house was cluttered with irreplaceable fragile ornaments; I mapped out the room, and carefully boxed all the pieces to prevent bringing them harm with my proclivity to inadvertently drop or knock into things. A foam mattress reduced pressure at night. I resisted physical activities and even exercise that required impact with such things as handlebars, bicycle seats, even the floor. Often breathless, I sighed heavily; oxygen did not seem to reinvigorate muscles. I was able to perform some exercise at times to maintain muscle tone and prevent further injury.

Pregnancy was fraught with illness. After delivery, I slept with undetected hemorrhaging into the womb. The first day of my child's life was spent receiving multiple transfusions to save mine. An extended recovery period followed with an agonizing infection contracted at the hospital. Irritable and weak for several months, I made parenting and spousal roles my primary focus.

As time went on, I sometimes appeared to be intoxicated; rubbery legs staggered as I grasped for a stable object. I broke toes and bruised legs, arms and shoulders by walking into such things as furniture and door jambs. Perplexed, anticipating slights, I whittled away at commitments, eager to find balance. Rest was not recuperative. It appeared to me that my spouse was disgusted by my symptoms. I complied with prescribed physical therapy and medications, but good health did not resume.

There were other difficult dilemmas to confront. Unpredictable episodes of positive health deepened confusion and disappointment for myself and others. Skepticism was rampant. By my late thirties, my personal life entailed tending physiological anomalies, meeting with medical professionals, submitting to invasive exams, and monitoring numerous adverse effects of treatments and medications.

For most people, young adulthood is accompanied by the richness of good health. For me, investment in education and the development of skills, cultivating interests and relationships, and creating a family life, could not stave off my abnormal decline. As I descended further into a world defined by physical incapacities, I shared very little commonality with peers. I felt relegated to the margins. Efforts to explain were often fruitless. Months and years passed; youth passed also.

Only metaphors effectively describe my common experience of everyday movement: I walked through dense mud and moved my arms through mud, trying to breathe with a weight of mud pressed upon me. When I put my feet to the floor my body screamed. Every tissue, tendon, muscle that should be flexible and expandable felt altogether like an ancient sheet of dry parchment paper that was certain to break apart even with small gestures.

Confronting the dilemma

Through my looking glass I saw futility. I was impatient and easily annoyed as the pain grew increasingly intolerable. Often reduced to discouragement and a level of irritability that I could not comprehend, I was ashamed that I had lost capacity in every role. My young child demonstrated anxiety and a need for attention. My peers eagerly shared stories of their accomplishments and joys while I focused more and more upon inexplicable illness and pain.

At the same time, my mother, now a widow, was hospitalized once more with uncontrolled symptoms of severe mental illness. My spouse’s parents developed emergency health issues that also required our advocacy. A friend was recovering from a serious motor vehicle accident; another was confronting the onset of debilitating rheumatoid arthritis. I resigned my membership in a world-renowned professional music ensemble, and weakly performed what was to be a final solo recital honouring a respected contemporary composer.

I was losing my way. Our joint unemployment brought financial concerns to our home. If my spouse could not see my physical illness, then I had to be losing my mind. A relevant note in my medical file indicated a history of mental illness in my family of origin. I expected this inevitable diagnosis but I did not receive it except through many inferences.

When one physician left her practice to a male partner, she provided me with a list of women doctors who were taking new patients. On the basis of a few minutes conversation, one prescribed a highly promoted antidepressant. “You’ll be amazed,” she said to me. Within a week, in profound agitation, I contemplated suicide. I tried the next physician on the list whose investigation quickly confirmed my experience. Research later brought to the public the inherent danger in the medication I had been prescribed for a significant number of people.

I judiciously reached out to complementary health care options. I attended a voice workshop featuring an internationally renowned physician, who was also an operatic baritone and choral conductor. Dr. Robert Thayer Sataloff is Professor and Chairman of the Department of Otolaryngology (head and neck surgery) at Drexal University, Senior Assistant Dean for Clinical Academic Specialties, and adjunct professor in Vocal Arts with particular qualifications in the treatment of the voice, and especially of singers. His presentations were meaningful but the potential help he offered was beyond my geographic and monetary reach.

I read self-help books. These provided some emotional and spiritual affirmation, but I had the need for someone to be with me in this confusion. A search for solace led me to a pastoral agency and a counsellor. I was also accepted to participate in a support group for abused women sponsored by a faith community. My head swirled with losses, shame and confusion. I had no personal support system. The world and everyone in it seemed muted by a dense fog of cacophony I could not dispel.

Medical treatments

Medications were easily accessed in my family of origin. I was reluctant to swallow anything unfamiliar. I irritated my parents when I enquired what a pill would do to me but I always obediently swallowed it. In my teen years, I was breathless and soaked with perspiration from menstrual pain (dysmenorrhea). A medication eased the pain after further wringing me out with headaches and vomiting. My low desire to ingest medication is an instinct that was confirmed time and again. As a university student, a specialist told me that dysmenorrhea would cease when I had a pregnancy. I found this proclamation profoundly unhelpful and embarrassing. Furthermore, in my experience he was not correct.

Some physiological symptoms were eventually identified as osteopenia, severe anemia, migraines, arthritis, bursitis, fibroids, Meniere’s (inner ear disorder with dizziness, tinnitus, eventual hearing loss), Reynaud’s syndrome (sensitivity to cold in the extremities), and allergies (and multiple chemical sensitivities) to elements ingested, inhaled, and applied. There were countless solitary trips to Emergency units, to specialists, with additional hospital stays; I was given many painful treatments, therapies and procedures. At one point, housebound with paralyzing pain and digestive disorder, I lost over thirty pounds (13.6 kg), almost twenty-five percent of my body mass, in a period of two months. Permanent hair loss also altered my features.

I responded to my body's intuition through investigative medical literature. I was the patient who did not willingly comply with recommended medical advice because some procedures that were meant to alleviate one symptom might complicate another. I asked many questions. This attitude was not well received.

Unfortunate events with the health care system

Practitioners and treatments within the health care system can have adverse effects upon patients. Unwittingly, a negative reaction further complicates the ongoing relationship with the entire structure. Such reactions with medical practitioners and events are called iatrogenic. For background purposes, I will briefly describe some iatrogenic experiences I had.

As a veteran client of the health care system, I knew well that exploratory procedures can be painful: the preparation can be difficult; the execution of the exam can be invasive. The medical technicians (who know the potential pain involved) maintained a degree of professional distance while I lay alone in significant pain, wearing a drafty garment on a cold, hard table. Alert, attentive, curious and admittedly distrustful, I realized that my attitude signaled a problem patient as I monitored what was undertaken even as I was seated in a dental chair.

The first critical medical incident in my adulthood followed the night I delivered my baby. Moments after birth, our healthy child was rushed to the neonatal unit. I was cleaned and wheeled to a ward; my spouse departed and the staff turned out the lights. Several hours later, at shift-change, various personnel with furrowed brows attempted to record my blood pressure by several machines. I could not lift my head; my heart pressed sluggishly in my chest. I had “flat-lined” due to concealed, heavy blood loss into the distended uterus.

New mothers dressed to go home with their babes, excited to start their new lives. I was wheeled to a case room for a day of transfusions. Shaking and cold, the joy of my child’s birth was dulled by physiological and emotional shock. The night nurse told me that they should have seen the signs earlier. Genetic factors (skin and hair colour) can indicate proclivity for atypical postpartum reactions. There was no official explanation or apology for the delayed attention, but I did receive an invitation from the physician in obstetrics and gynecology to return the next year for my second pregnancy. I would have appreciated more assurance. Postpartum complications, following delivery and transfusions, included a severe malodorous infection that I contracted in the hospital. The infection compromised recovery and seeded more consciousness of my body’s undependable nature.

I once sought treatment for a joint injury. The nurse’s hands settled on my breasts. Mustering the courage to report this to another medical professional, the nurse’s professional intentions and conduct were defended and my complaint was dismissed.

Another time, a friend and former music colleague was in town for the day. My world had become so isolated that I was exhilarated to meet her for a brief lunch. Afterward, I had a medical appointment. Still uplifted by the visit with my friend, I could not erase my smile while I described the extent of the pain I was experiencing. The doctor dismissed my complaint, and departed the exam room with annoyance.

My first CAT scan (computerized axial tomography) used a new expensive machine; the technicians were effusive with pride. While waiting alone in a dimly lit room, stripped of my possessions, a video provided explanation of the imminent procedure. It concluded with a passing comment that the preliminary injection caused no more deaths than did farm accidents. No one had advised me there would be any danger involved. In fact, I had been assured CAT scans were benign, other than the "minimal radiation." Knowing farm accidents occurred not infrequently, I wondered how many resulted in death. The ensuing bustle of hospital technicians did not invite conversation. I was soon mortified by the effects of the injection which was intended to highlight the lower abdomen, but also caused a strong sense of sexual arousal. I had not been forewarned about this, but the technician matter-of-factly confirmed my surprised reaction. "Sometimes people feel like they are going to pee." This was of little assurance.

Similarly, an MRI exam (magnetic resonance imaging) began with negligible human discourse. In the crowded anti-room, a nurse approached me with a syringe. My family physician had assured me there was nothing invasive with MRIs. To my query the brisk explanation was that the injection would improve clarity for the technicians "and," she said, "it only has adverse effects for people allergic to seafood." "I *am* allergic to seafood," I said. I was astounded that no one had even enquired about this. Clearly, I was holding up the schedule; I consented to the injection and was then swallowed into the loudly vibrating machine trying to keep claustrophobia and anxiety at bay. Fortunately, I did not experience an allergic reaction.

Over the years, through a process of trial and error, I had determined many foods that contributed to intestinal inflammation. On one occasion when hospitalized for routine surgery I described my dietary needs to a hospital dietician who responded agreeably. Post surgery pain was intolerable; the medication (with caffeine and codeine) caused continual sleeplessness, agitation and spasms. Due to the other undiagnosed complications, I could not find a comfortable position on the hospital bed. Inconsolable when indigestible food was delivered, I was chastised for not eating, and repeatedly scolded that I could not leave the hospital until I was able to demonstrate that the digestive tract was fully functioning. Because of the pain, it took time to immerse myself into a medically prescribed bath. A male nurse ordered me to open the door immediately and take an analgesic. I responded (appropriately, I believed) that I would do so when I was finished. The balance of a week passed without any staff coming near my bedside. At a later date in the same hospital for day-surgery, a nurse told me that my file indicated I was prone to hysteria; she remarked that I seemed just fine.

I have had several colonoscopies. Familiarity with this exam only increased my anxiety. Both the preparation and the procedure cause insidious problems for me that extend into the following weeks.

These and many other encounters with health care practitioners have served to undermine trust. There were numerous situations where more respectful information, courtesy, and dignity would have been appropriate. I generally comply with professionally advised treatments and interventions though I do want to discuss them. I hold no one accountable for exploratory and corrective procedures which feel perfunctory. I believe an exam or treatment is performed to meet an effective standard. It seems though that a patient can be relegated to feeling invisible, only a trivial bystander to the procedure.

Myriad symptoms mounted while no comprehensive over-reaching diagnosis was found. It was evident our precious innocent child was deeply affected by home events. I was unemployable; the new normal was intolerable. Suppressed and discouraged, I knew I had to find some explanation for my illness and try to rebuild our family's stability. I searched many sources (this was a pre-Internet time) about women's health, complementary health modalities, dietary advice, etc. while my life passions and relationships disintegrated. Most suggestions were out of reach financially or geographically. The infamous Canadian tainted-blood scandal of the early 1980's coincided with blood plasma transfusions I received after childbirth. When I became aware of this and when no encompassing diagnosis was found, I desperately requested an HIV (human immunodeficiency virus) test. It was reluctantly granted along with advice to see a "good Christian psychiatrist" despite my avowal that I had a secure relationship with a pastoral counsellor.

As I learned that adverse side effects were normal for me, consultation on this topic was negligible even with pharmacists. It was empowering to recently hear my insight confirmed by my physician and my gastroenterologist. Whether medications are administered by mouth or injection, or topically, to highlight a scan, to anesthetize, to sedate, to accelerate blood flow, to relieve pain, to control hormonal levels, I take home symptoms that compromise physiological systems, and/or exacerbate underlying physical anomalies and cognitive ability. I was also told that lengthy recovery from some procedures might be the result of irritation of connective tissue between organs.

The more that I was immersed in the world of the “chronically ill” and subjected to invasive exams, the clearer it became that my informed protestations were an inconvenience to the machinery that is the Health Care System. It remains a challenge for me to submit to medical procedures and treatments.

Chloe G. K. Atkins (2010) described her recent difficulty with obtaining appropriate diagnosis of life threatening symptoms through health care services in Canada and the United States. Conclusions of “conversion reaction” (another euphemism for hysteria) were inevitable when standard tests indicated nothing remarkable (Atkins, 2010, p. 21). Now an associate professor at the University of Calgary, her experiences validate my own. It is clear that finding understanding professional care and support for women’s physical maladies is not an uncommon problem and the significant responsibility for finding such care lies with the patient. One way in which Atkins’s story and mine differ is that she had a loyal partner, an advocate who worked in the medical profession, in addition to having an esteemed reputation of her own. That is, she possessed credibility that had not dissipated with the passage of time.

Reforms to health care policies in the 1990’s permanently reduced access and availability to physiotherapy; consolidation of clinics and labs demanded more transit time–a stress for compromised health and stamina. Many physicians with whom I was engaged became unavailable. One chose early retirement. A specialist I regularly consulted moved his practice to the United States without informing his patients. A physician I valued chose to enter the research field. A fourth moved back to her home province.

The solitary walk

Immersed in a mire of symptoms which were difficult to explain, I felt increasingly alone. One Father's Day weekend, my extended family, including spouses and children, united at a campground. I remember panting with the effort required to lift one foot after the other. Later, I was told I had been the topic of a private conversation in which it was recommended that I should be ignored.

A social worker said with admiration that my extreme weight loss was the envy of many women while I gasped for air as a consequence of minimal activity. When I told people I was exhausted, the response was often that they were tired too. I sympathized. It took a long time for me to admit to myself that the exhaustion I experienced was significant; it was not something a holiday or a good rest would correct. It was hard to understand.

I sought support and comfort from an ordained clergyperson in my faith community to express my illness and sense of spousal abandonment. I found the person's bias threatening. Within a couple of weeks, my partner accepted an invitation from the same person to take a leadership position in our faith community involving many hours of commitment away from home. This led to further feelings of dejection.

Understandably, societal attitudes carried over into my faith community where I could not change my identity. I did not find sanctuary that permitted me to retire from a conspicuous role as choir member and reader to a more passive role as worshipful congregant. Someone always noted that my offerings were missed. That which had previously defined me was a barrier to being accepted as I currently was. Misunderstandings abounded. After I resigned my membership from that community, certain members privately recalled their observation that my physical deterioration indicated terminal illness. Out of respect for my family’s privacy, they chose to say nothing.

As in my marriage, many confusing incidents surrounded my relationship with the faith community. I needed distance to clarify what was going on for me. It is important to note that some members of that congregation continue to bless my life.

Severance of the marriage

After discussions with my spouse, I took responsibility to remove myself from an increasingly volatile relationship that negatively impacted my health. Though I was familiar with my former spouse’s temperament, and had nervously considered the move for many months, I could not have predicted the extent of the consequences of this choice. I found temporary sanctuary and left the marital home with my child. I hoped the distance would bring clarity to heal the situation for our small family. But the perception of that goal was not mutual. I still had no encompassing medical diagnostic evidence to verify my testimony of illness and need for spousal support. The impression I got from my spouse was that it was my fault and mine alone to repair. What then ensued made coping nearly impossible.

Devastated, I could barely move, and needed perpetual access to washroom facilities. With unreliable cognitive and memory function, I left notes everywhere to remind myself of responsibilities and appointments. I curtailed making commitments because energy and health were unreliable. Everywhere I went, I carried a bag that contained essential toiletries, telephone numbers and pieces of identification. When I had to leave the house, I moved with great concentration in order to avoid incurring injuries. I had not yet determined the deleterious effects of some medications I was ingesting.

The rapid heart rate and remorse are still present for me when I recount the divorce process. The marriage devolved into indescribable misery with both of us accountable for moments of inappropriate behavior. Feminist law practitioners seemed persuaded that I was stuck in the fictitious era of entitled dependency. Mediators, one from a municipal social service agency, another from a prestigious law firm, were not helpful to me. I was undermined by the feeling that I was still not heard, and I attempted to make sense of my partner’s inability to acknowledge the physiological symptoms that had been present for years.

I was intimidated by the formal law office setting. Its professional structure appeared to empower my spouse which separated us further. The theme of these engagements focused upon division of property and assets though my overwhelming concern was for my child and for my health. The procedure drew cruel outbursts. I read in my spouse’s manner a sense of insult and shame at the exposure of our personal lives. A psychologist engaged by the legal firm observed the interactions between my child and me; she assessed my intelligence, mental health and parental stability. My responses were nervous and terse. The psychologist’s interviews took place in her environs which, I respectfully suggest, placed undue pressure on a perceptive child immersed in a fractious process. My compromised health was not considered a factor in her assessment and recommendations. The records remain sealed leaving me with primarily the emotional recollections of fear and misunderstanding.

I foresaw the relationship with my child would be undermined by the depth of resentment and retaliation within the marriage. There was no recognition of the inequities inherent in the divorce process. When my personal savings had been exhausted on legal fees, I obtained the assistance of Legal Aid Services to complete a divorce decree in order that my former spouse could remarry. In a crowded waiting area I witnessed the flailing arms of a few angry clients. It was a threatening environment.

The divorce contract did not define the two issues that were critical to me: formalized parental rights and my need for financial support. The process was profoundly hampered by inadequate concrete evidence of my medical condition which I was unequipped to defend. Mediators and attorneys had no verification that I was anything other than a malingering and bitter partner. I attended the recommended (now required) parenting-after-divorce sessions. To the best of my knowledge, my estranged husband did not. I cannot know how my persona was represented in his new home especially to my child. I found his inability to compromise made co-parenting impossible. Our child grew increasingly unwilling to disturb the routines and conveniences in the comparatively lavish paternal home to ever reside at my apartment.

My former spouse appeared unwilling to communicate with me to arrange visits with my teenaged child. Our child was given the choice to maintain contact with me on a private telephone. Oft times when an arrangement to meet was made, it would be forgotten or cancelled. I could not express the degree of my inconvenience and disappointment. My pleas to my former spouse were fruitless. Under the circumstances it felt dishonest to identify myself a parent. After unsettling occasions when I was called upon to act as a mother, I would not be informed of the resolution or denouement. As my child grew up, the distance created between us expanded. Often, celebrations or family events were wrenching for me because I could not engage in the conviviality. For several years my child and I spent only a few hours together. I could not identify with those who were active in their offspring's lives on a consistent basis. Looking back, the agony of those lost years remains vivid in my soul. I no longer could instinctively respond to the voiced appellation of "Mom".

Surrounding everything was extreme poverty that disempowered and marginalized me. My savings, including life insurance, were spent. I could not afford to stock food, clothing, entertainment items and toiletries, or rent space with the prospect of ever cohabitating with my child. I could no longer schedule my commitments based on parental responsibilities and care which were not called upon. Eventually, items that were tokens of the absent child I loved were sent to the other home; furniture was disposed of elsewhere. There was no choice but to let go of my former parenting role and I was acutely aware of what this would symbolize to a sensitive adolescent. On a purely material basis, I could not compete with the space, privacy, and privilege of the other home. My grief was palpable, though incomprehensible to many others.

I lived on the income from a disability pension for which I qualified with the help of a hired physician who was familiar with the application process. We spent an exhaustive ten hours recording my reported health issues to create a twenty-five page document. He concluded by saying that I knew how to care for others but not how to care for myself. My family physician complemented a five-page document that I compiled which listed every physician, treatment and procedure I had undergone in the previous ten years. Her report concluded by saying:

> I believe Janis has basically attempted to deal with this disease for a long time through whatever means she had available. . . . Limited income, and often lack of understanding both by medical professionals, and personal friends as well as family have been added stressors. . . . She is a highly motivated individual and could, with assistance, make a greater contribution to her [child's] life, her own life and that of her surrounding community. (personal medical file; 1996)

Rereading this paragraph recently I realize I had previously been so overwhelmed with my circumstances that I was not able to absorb these words of affirmation. Upon the basis of these reports, with my sketchy employment earnings (plus a fraction of that of my former spouse), I qualified to receive the small federal government pension and a provincial supplement. I often hear comments that illustrate the stigma toward persons who are dependent upon disability pensions and I remain quiet.

The provincial supplement was so entwined in contradictions that, when I reported having used some gift money for education, I was threatened with fraud charges. I discontinued the supplement and I repaid what the agency had provided using a cancelled life insurance policy. (The primary benefit of the provincial pension was funding for medical treatments, plus dental and optical fees. Because at the time I had no primary physiological diagnosis and most medications were counter-effective, it seemed illogical to continue to be penalized for being honest, and to be prevented from pursuing education which stimulated my mind, offered a modicum of self-esteem, and provided hope of possible employment.) Later, I was blessed with a benefactor who financially supported the college program I chose. The program provided flexibility in course load and schedule that was moderately tolerable for my body. This part time arrangement did not fit the paradigm of government-funded student loan schedules.

A clearer picture develops

In my forties it was concluded that my body manifests symptoms of FM (Fibromyalgia) and ME (Myalgic encephalomyelitis or chronic fatigue syndrome). These two related diagnoses remain controversial, with stigma in the medical community and in society. Research is slow and underfunded, even though, in reported cases in 1995, it affected as many as 2.6% of Canadian women under the age of 50 (Bested, 2008, p. 17). There are three specialists in our nation. One is a psychiatrist who lives with ME and is employed only part-time. There is no definitive diagnostic tool as yet. Some investigations hypothesize an autoimmune system disorder or a basis in bacterial flora, and some studies support neuro-physiological abnormalities.

It is suggested that Florence Nightingale returned from the Crimea with ME, spending the balance of her influential life in bed. The annual ME Day is May 12, Nightingale’s birthday. Expressions such as “yuppie flu” and “gulf war syndrome” linger and cloud public attitudes. At the time of my diagnosis, these syndromes were viewed with overt skepticism in the health care profession. If the syndromes were substantiated, some doctors whom I saw believed patients would recover completely within a few months. My observations belied that impression. Records indicate that 5% recover and 32% live on an income of less than $15,000 per year (Stein, 2009).

In my sixth decade, the digestive disorder which has flared and waned for most of my life was diagnosed as Crohn’s disease/ colitis (or inflammable bowel disease, IBD) and PBS (painful bladder syndrome, formerly called chronic cystitis) each of which have symptoms that are unpredictable in severity and can be elusive with present exploratory procedures. It has been proposed that one inflamed region refers inflammation to another, leading to exacerbation of pain in hips, pelvis, and spine. I am convinced that one day science will draw upon diagnoses of myriad and confusing symptoms, and discern much about the body-mind continuum that will provide knowledge and help prevent the alterations to life such as I have endured.

Summary

During the years when contiguous difficult events were unfolding, I depended upon radio for company. I was fond of the CBC (Canadian Broadcasting Corporation) program, Morningside, hosted by the late Peter Gzowsky. Some of his guests were survivors of trauma and abuse for whom he compassionately provided a venue to be heard. I found myself identifying with the courage and inner spark of the divine that kept them going. I found comfort in Mr. Gzowsky's gentle acceptance. There were also documentaries and interviews with people such as Dr. Helen Hayes who treated persons with chronic pain with dignity. Her insight gave me a bit of hope in my solitary daily life.

I participated in support and advocacy groups for those with ME**.** On one occasion I was invited to speak to a group of health care workers. I expressed how this elusive illness had affected my life. A sponsoring physician commented that I was too emotionally involved, as though a woman should be detached when describing her experience of deteriorating health. I sent letters to government officials and to a local newspaper. I joined a national citizen's advocacy group and a provincial citizens' health care advocacy group. When I could I participated in public protests.

Promotion of government budget cuts included the use of negative images of persons abusing the health care system. It was said such citizens behaved irresponsibly, exacerbated personal health problems and overextended the general cost of health care for the electorate. (It is interesting to note that presently the federal government is again focused on the increased cost of health care services, vilifying senior citizens and those with chronic illness.) I observed that the revisions to the system such as de-insuring critical services (optical, dental care, and physical therapy), centralizing of services, increasing user fees (such as parking at major facilities) all contributed to marginalizing and compromising the health of those concerned. With limited energy, minimized duration of travel and of waiting times is critical.

Amendments to health care services also impacted my ability to provide advocacy for loved ones. (For example, my mother developed dementia and lived her final years in long-term care. I was a primary caregiver, advocate and chauffeur.) In addition, the omission of rent-control policies in a fluctuating market-driven economy accentuate the divide between those who have and those who have not. Landlords can increase rent at an unregulated rate which places the lives of the most vulnerable on a precipitous plane. I have downsized and made five costly difficult moves in the past twenty years based on the increasing cost of rental accommodations that I wanted to call my home.

My current engagement with others is selectively planned in order to have energy to participate in some social occasions, drive myself to meet appointments or attend classes. I have learned that by honing the expectations of others and making fewer demands upon my time and energy, I can tend to the basics of life. The greater balance of my time is spent at home where rest and quiet supply adequate energy.

Having prepared this chapter I am reminded of the idiosyncrasies of my lifestyle. I monitor priorities and make adjustments to create the most potential for a fulfilling life. Events requiring unexpected exertions of energy are problematic. Life is slow; my schedule is light. I resist attempts to explain or apologize. I do my best to contain irritability arising from exhaustion. I make every effort to be with people who accept me and who do not see limitations as defining who I am. I am reliable in keeping the commitments I make to those who have more complex lifestyles than my own. When I have to excuse myself, some well-intended comments resonate as pity, leaving me feeling disempowered.

Our society has a distance to go to achieve equality for all citizens. It is my hope that those who can identify with my experience will find some assurance. I endeavour to pass on knowledge, avoid prejudice, and look at others as complementary in the exploration of wholeness, mindfulness and new resources.

Chapter Four: Literature Review

Introduction

The heuristic researcher is urged to know one's personal experience, unique perceptions, and responses as distinct from the attitudes and theories of others (MacIntyre, 1982, p. 97). The review of associated relevant literature is primarily done near the end of the process in order to avoid any influence or predisposition that might sway the outcome of the data. MacIntyre (1982) wrote that the literature review should "...amplify, clarify and refine experiential findings" (p. 98). Therefore, in contrast with the normal thesis layout, this literature review follows after Chapter Three that describes the data from my early life. The reader is introduced to the data and then encounters the literature which informed and affirmed my insights.

Max Van Manen (2003) stressed the need for constant reflexivity, insight, sensitivity, and open-mindedness while writing about a lived experience. The hermeneutics of discovery, of *being and becoming,* are the essence of the experience. He urged constant mindfulness of the original question, and a steadfast orientation to the lived experience, to make present what is pre-linguistic (Van Manen, 2003, p. 50). This speaks powerfully of my research which has sought the non-verbal *feelings* behind the phenomenon.

My research topic has lingered in my thoughts alongside daily life; it has filtered into activities and relationships and has provoked hours of quiet reflection. Romanyshyn (2007) described a Jungian view of research; it is the work of the "Unanswered, Unresolved, and Unredeemed" (p. 85). The shadow lingers in collective thoughts and dreams waiting to be addressed using the “imaginal approach”, or “reverie” (Romanyshyn, 2007, p. 87).

I found three primary sources for information on the field of heuristic research. Each of their contributions is discussed, in depth, in the second chapter. Moustakas (1990) was the founder of heuristic research; his thesis work delved into the experience of loneliness. Sela-Smith (2002) elaborated and critiqued Moustakas’ method. She emphasized the importance of self-transformation in the research process with its potential for social change. MacIntyre (1982) stressed that the heuristic researcher must be open to one’s senses and to the unique and unfolding, spontaneous nature of this form of inquiry (p. 97).

Two articles in phenomenological research further described the study of personal essence in researching a lived experience. Eatough and Smith (2008) wrote about interpretive phenomenological analysis (IPA) which seeks to define the essential phenomenon. Janesick (2003), a dancer and researcher, encouraged the use of Moustakas’ inductive discipline in qualitative analysis. Janesick coined the word “methodolatry” to describe rigidity that discourages flex and movement in research methodology. Creativity has been the muse in my work; I express the literature that has informed this process by breaking them into four sections:

- The girl child; development of the self;
- Trauma, illness, medicalization, listening;
- Spirituality;
- Transformation, self-advocacy, empathy, political action.

It will be evident to the reader that these categories overlay each other. However, they will provide us with some grounding.

Literature about personal relationships, loss, disempowerment, pain, illness, and spiritual life have challenged and expanded upon my experience. Literature written by women particularly provided assurance while I confronted issues of illness and asked the existential question: What makes this life worth living while so many factors seemed to marginalize and suppress my being? Some people wrote of their personal experiences of abuse, trauma, or physical illness. Some wrote from the position of health care professional. Some shared their clinical observations of the self in transition. I found very little about a woman's experience of living for many years without an encompassing medical diagnosis.

The girl child: development of the self

"I think I've met you before." This was said to me so frequently that I usually responded by saying something self-deprecating: I am a generic design; the divine creator didn't break the mould that formed me. These moments reflected my impression that I was indistinct; I had not acquired a personal character and I bore significant similarities with other women of my generation. Some persons later suggested the reason I seemed familiar was that my face was open and receptive, which made others feel comfortable. Yet I never felt assured that my uniquely independent feelings and beliefs were acceptable. Intent on not inflicting offense, I focused on the sensibilities of others. My sensations mingled with those belonging to others.

At the beginning of life, a child's self is not yet defined. Wolf (1988) explored the theory of self-psychology, describing the initial phases of development of self through selfobject experiences. A new infant must receive assurance from the caregiver. “The self cannot exist as a cohesive structure–that is, it cannot generate an experience of well-being–apart from the contextual surround of appropriate selfobject experiences (Wolf, 1988, p. 14). My means of being in my world was less than sufficient to provide for adequate development of the young self. Selfobject experiences evoke, maintain and give cohesion to the self structure. Essential aspects of the cohesive self experience are acquired through the achievement of intimacy in attachment and affiliation, and through the experience of efficacy. “It is as if the infant were able to say . . . (with apologies to Rene Descartes): ‘I can elicit a response, therefore I am somebody’ ”(Wolf, 1988, p. 62).

Wolf (1988) described the significant psychological trauma that can result from disruption of a selfobject. He called this *selfobject transference* and writes that, “The self of one or both of the participants has become dependent upon the other for the needed self object support to its self” (p. 64). This observation helped me to understand what was experienced in my family of origin, and in experiences with some music teachers. I recall it in ties with some friends, colleagues, my former spouse, and with some health care providers. As a child I sensed something was wrong. Similar selfobject experiences were repeated until, with therapy, I was able to discern the codependence and make changes. There were tremors of self-doubt; I anticipated responses of confusion or of volatile resentment.

Authors Lee and Martin (1991) discussed the concept of *self* in the development of the *person* through the work of Kohut and others. Lee and Martin (1991) quote from Stern saying there are “...recall ‘systems’ in an infant that are not language-based and that operate very early” (p. 184). The study of human development helps to explain the non-verbal roots of confusing patterns of thought and behavior. It contributed to my understanding of how difficult the challenge has been to develop a new awareness of self. Lee and Martin (1991) recommended that, "[whatever] the process of development of the core self, access to it, in psychotherapy is through exploration of its organizing principles. These organizing principles are uncovered through the intersubjective context of the psychotherapeutic relationship" (p. 189). I placed my trust in the long-term therapy relationship which modeled a new form of connection. This trust itself had no words.

Llewellyn and Osborne (1990) wrote a series of essays about women's development; they describe circumstances and expectations that bring women to therapy. A young woman's autonomous development can be hindered by issues such as the mother who identifies strongly with her daughter, or one who may off-load her own emotional burdens onto the child (Llewellyn & Osborne, 1990, p. 28). When an adolescent daughter progresses toward separation from family, the girl may feel conflicted and curb her desire for separation (Llewellyn & Osborne, 1990, p. 29). While relating with peers, she may encounter "...a sense of confusion and inability to answer the question 'Who am I?' " as she struggles to integrate the influences of parents, peers, and other community expectations and aspirations (Llewelyn & Osborne, 1990, p. 31). Her beliefs about the meaning of sexuality are most affected by, "... pre-existing experiences and by what she has been told both overtly and through example by her parents" (Llewelyn & Osborne, 1990, p. 33). She may find that the adult world does not meet, and may dismiss, her passionate ideals.

Llewelyn and Osborne (1990) further suggest that the adolescent woman may feel intense anger and self doubt about her political protestations and intolerances, as well as

“...disgust with herself and her own impulses toward warmth and comfort from others, since, as far as she can see, this has led to the moral failure of others” (p. 35). The egocentric adolescent girl may doubt her own personality. Extremely unhelpful advice, though well-intentioned, may further establish a sense of inadequacy and injured self-esteem (Llewelyn & Osborne, 1990, pp. 36, 37). While expected to meet domestic responsibilities, the adolescent woman must work on development of social and physical attractiveness and on caring skills, “...all of which takes time and energy and distracts her from academic achievement” (Llewelyn & Osborne, 1990, p. 38).

Given these observations, I realize that with the added presence of a parent whose narcissism dominated the home atmosphere, I floundered through my teen years. Much later, I discovered that I could identify persons who are related to someone living with substance-dependence. I recognized the entrapment in the emotional chaos of enablement and concealment, of love, hate and fear. This insight contributed worthwhile knowledge into my search for my invisible self, as well as the relational and professional choices that I had to make.

Llewelyn and Osborne (1990) discussed the diminished value placed upon the role of nurturer in the care of children and husbands. They describe the stereotypical concept of the workplace as masculine; it suggests an environment “...[of] control, competitiveness, ruthlessness and physical strength” (p. 109). Increasingly, a good manager is seen as one who can listen, empathize and respond well to people, skills that many women possess. When women lose employment they can have feelings of desolation:

> [T]his ignores the capacity of many women for creativity, commitment to political, social or organizational ideals, and activity outside the home. It also ignores the personal issues that may have inspired many women to choose their particular sphere of work, and which give energy and purpose to their daily activities. (Llewelyn & Osborne, 1990, p. 114)

My health issues insidiously crept into my life until most of my identity was consumed and relationships were severed. I lacked the resilience for what lay ahead. Income for persons with disabilities or chronic illness is based on previous employment contributions to the federal pension plan. During the time I have lived with debilitating illness, I have been unemployable; even the concentration required for academic studies was sporadic. My focus was affected by erratic parenting responsibilities and the choice to advocate on behalf of a parent with encroaching symptoms of dementia. The government does not adequately recognise the status of stay-at-home parents. Similarly, it does not identify or compensate for the time and energy that unemployed persons devote to dependent adult family members. My position has little impact on the broader societal structure and statistics.

In 1997, four female psychology professors and authors, Field Belenky, McVicker Clinchy, Rule Goldberger, and Mattuck Tarule (1997) recounted the study of young female students. “[As] a woman becomes more aware of the existence of inner resources for knowing and valuing, as she begins to listen to the ‘still small voice’ within her, she finds an inner source of strength” (Field Belenky et al. 1997, p. 54). They stated that this transition, from dependence on an external authority to reliance on the authority within, has important repercussions on a woman’s self-esteem, relationships, self-concept, morality and behavior. The intuitive process serves to protect the self, and provide self-assertion, and self-definition of a truly autonomous personality. This type of maturity is a step toward subjectivist epistemology which “...we call connected knowing, an orientation toward understanding and truth that emphasizes not autonomy and independence of judgment but a joining of minds” (Field Belenky et al., 1997, p. 55).

Field Belenky et al. (1997) stressed that many of the young women threw themselves into their new autonomous life structure without considering the consequences (p. 80). Women who achieve the most have learned strategies for a new means of knowing that grows “...out of their very embeddedness in human relationships and their alertness to the details of everyday life, during the period of subjective knowing,” and they are gaining a voice through “really listening” and “really talking” (Field Belenky et al., 1997, pp. 85, 86).

Women “... reveal in the way they speak and live their lives their moral conviction that ideas and values, like children, must be nurtured, cared for, placed in environments that help them grow” (Field Belenky, et al, 1997, p. 152). The preparation of this heuristic thesis has provided me an opportunity to contribute to my world.

Trauma, illness, medicalization, listening

Years ago, desperate to understand what was happening to my body and my self, I looked to self-help literature. Before the Internet connected us to a world of information, I subscribed to a newsletter about the health issues of women. At the time that doctors speculated I had ME (chronic fatigue syndrome; also known as ME) I joined a local support group that had regular newsletters offering information about international research on the subject. It provided resources for individuals and for medical professionals. Three Canadian medical specialists treat persons with ME**.** Eleanor (Ellie) Stein of Calgary referred me to articles containing statistics of the prevalence of ME in Canada, and about ongoing ME research in which she is active.

I found excellent women's health resources written by physicians like Northrup (1998) who had a spiritual dedication to her practice in women's health care. I found quiet motivation even from a distant connection to women who encouraged other women to know their bodies and instincts.

Northrup (1998) quoted Martin Buber who said "...freedom and fate embrace each other to form meaning; . . . with meaning, fate may look like grace" (p. 410). Preceding each in-depth chapter about women's physiology, Northrup spoke about the attitudinal difference between healing and curing: "The external treatment doesn't necessarily address the factors that contributed to the symptoms in the first place" (p. 41). Northrup can be viewed on PBS (Public Broadcasting System) television. Her book was a valued companion. The following words rose off of the page, as if directed to me:

> *No matter what has happened in her life, a woman has the power to change what that experience means to her and thus change her experience, both emotionally and physically. Therein lies her healing.* [author's emphasis] (Northrup, 1998, p. 40)

I live in a country that has publicly funded health care. Many of the holistic and medical services that Northrup (1998) recommends are not readily accessible to all women, particularly those restricted in their financial and travel resources. This is not an underprivileged nation; however, accessibility and choice remain an issue. It must be mentioned that in this era of instant access to information, one’s awareness of the tantalizing health care options that are beyond reach can increase frustration.

Today, praise is poured on the independent woman; even wealth is said to follow empowered individuals who demonstrate feisty determination to fight against the odds. I knew that people in my faith community and beyond believed and prayed that this personal revival would be possible for me; but with my resources the obstacles were insurmountable. I was ashamed that I had not successfully conquered the pain and exhaustion, and the external hurdles. Sometimes I chose to conceal this failure by avoiding others. It was less taxing to leave others to conclude I was not interested in being involved with them. Looking back, I think this was one means of self-empowerment.

As previously mentioned, the home of my family-of-origin was impacted by the presence of serious mental illness. Managing this illness was problematic; during my early years, the household was controlled by my mother’s erratic behavior. Jamison (1993), a psychiatrist and professor, wrote in depth about her experience of living with manic depression (also known as bipolar disorder). She opts to use the term manic depression because it more vividly illustrates the extensive wave of symptoms. Her book included reports of many renowned artists who lived with manic depression. Jamison (1993) described what my family encountered:

> The fiery aspects of thought and feeling that initially compel the artistic voyage– fierce energy, high mood, and quick intelligence; a sense of the visionary and the grand; a restless and feverish temperament–commonly carry with them the

> capacity for vastly darker moods, grimmer energies, and, occasionally, bouts of "madness". (p. 2)

Jamison (1993) helped me concretize and externalize my recollections of childhood. There were times of high exuberance when we swirled in attractive adventures. I could not trust this revelry. My family and the house we lived in were the creative palette for the inconsistent hands of a grandiose designer. She organized fantastic events, purchased extravagant items, demanded that I help rearranged the furniture perpetually in our home, outfitted us elaborately, and she directed us to rehearse and perform brilliant music. She could go for days without sleep, keeping me awake as well. At times her bizarre behavior exposed her to the astonishment and censure of people in the community. Despite the help of recruits to her cause, some projects were impossible to fulfill. I frequently fixed on her frightening eyes, eyes that signaled the fall into grim hallucination, paranoia, rage, and dark depression. Like a tsunami, the radically shifting forces drew me in and tossed me out. My commitment was to keep my siblings and me afloat, in the calm and in the storm. My vigilance could never cease.

I was intrigued by a volume recently published by journalist and author James FitzGerald (2010). Using his investigative skills, he found validation for his instinctive awareness of untold ancestral secrets that he suspected were the undercurrent of his generation. He was convinced that something sinister lay in his genetic history. The FitzGerald men were prominent in the field of medical research, establishing the famous Connaught Labs. They were instrumental in the development of immunological vaccines that increased human survival rates around the world. When FitzGerald (2010) discovered some of his grandfather’s letters, he found the answer to his puzzle about his father and grandfather. He wrote:

> The pair of drowning voices thrashed inside my head, fusing and confusing, making no distinction between the separate identities . . . father and son. In fact, as the voices drilled and swirled and lashed, they awakened a third voice–the sound of my primal dread. . . . I felt part of some weird trinity of father, son, and unholy ghost; it was falling to me, the third-generation eldest son, to stand and fight. (p. 147)

I, too, have wondered about the dearth of facts in one prominent branch of my family. Certain relations were seldom mentioned, though some were publicly recognized for their contributions to the broader community. I heard incomplete stories about illnesses, depression, and suspicious deaths that occurred. I believe a particular individual’s activities brought shame upon family members and were therefore kept concealed. I even wondered about the closeting of certain individuals and the disconnection and codependence that lingered into my generation. As well, I heard whispered stories from two elderly aunts (now deceased) about their vigilance to avoid being alone with their grandfather when they were young.

As well, FitzGerald and I share a physical illness that can be linked to the experience of emotional trauma (Neparstek, 2004, p. 66). It has always been evident to me that there was a connection between the lived experience and the pain and extreme exhaustion I experienced.

My parents were born when many governments enacted legislation to curb the reproduction of so-called “mental defectives” (FitzGerald, 2010, p. 301) because some people were deemed to have a potentially negative moral influence on the populace. FitzGerald (2010) recounted the work of those whose moral authority aimed to "... aggressively champion the hereditary origins of all psychiatric illness . . . through eugenics and euthanasia" (p. 300). As a student I was aware of this history in my province. Perhaps that attitude affected my grandparents and their descendents. It may have contributed to fear, shame and secrecy.

As a child I knew that her incidents of hospitalization and medical treatments had a powerful effect upon my mother's sense of herself in her world. I suspect that this destructive patriarchal attitude toward persons living with mental illness was threaded into the fabric of my family. Though only somewhat conscious of the searing experiences persons must have undergone, the issue invaded my existence. FitzGerald (2010) brought it to the forefront for me. Along with the witness of my mother's experiences, these political attitudes informed my fear of listening to my body and contributed to my reluctance to share my thoughts or seek help for invisible symptoms. Understandably, I did not trust that I would be heard; without hope, my voice was barely audible.

Before being diagnosed, I found inspiration from the courage of women who live with chronic illness and/or disabilities. Years ago I was referred to a little book written by several Saskatchewan women who call themselves The Barb Wire Collective (1997). They gathered their spiritual thoughts and conversations about experiences of living with disability or chronic illness. Their honesty and wisdom buoyed me even when I could not allow that I might be an affiliate. They accepted life on the margins; they found solace in the spirit within. One expressed the difficulty in maintaining relationships because of her compromised energy. Christy (The Barb Wire Collective, 1997), said:

> When I describe how I am feeling on any given day, I am not complaining, not pleading for sympathy, and not expecting you to fix things. I am saying that these are my parameters today and it is given as information for our relating. (pp. 133 - 134)

Without a diagnosis I always tried to push past the pain. Without diagnosis I was on my own. I tried to meet commitments to family, community, and students. Commonly, I resisted looking in the mirror: would my reflection be full of rebuke or would it plead with me to run away? My search continued to find validation for my observations and the words I could speak. In a documented discussion amongst the women, Richards (The Barb Wire Collective, 1997) expressed:

> If both the fields of medicine and psychology/counselling/therapy would see disability or illness as part of the reality of the human condition rather than a symptom of people/families overcome by the stress of living, then wisdom could be shared with no judgment or humiliation. . . . Lost is the wisdom of experience for all concerned. (p. 161)

I concur with this premise. My sense of invisibility increases when some people attribute my enduring symptoms to irresponsible or inappropriate activity or lack of faith.

Neuroplasticity, the contemporary study of the brain, recognizes the impact of psychological trauma on its physiological development. There is growing evidence that the physiology of the human body is affected by emotional trauma, beginning with changes in brain chemistry. Neuroplasticity provides hope that the brain can change how it holds trauma, and how the physiology can respond to the energy of meditation and prayer.

A 2007 New York Times best-seller by physician Norman Doidge contained fascinating insights that challenge the Cartesian theory of the brain's rigid, inert, machine-like quality. "While we have yet to understand exactly *how* thoughts actually change brain structure, it is now clear that they do, and the firm line that Descartes drew between mind and brain is increasingly a dotted line" (Doidge, 2007, p. 214). He also wrote that, with psychotherapy, we can turn ghosts into ancestors, diffusing their emotional charge:

> [We] can transform implicit memories–which we are often not aware exist until they are evoked and thus seem to come at us "out of the blue"–into declarative memories that now have a clear context, which makes them easier to recollect and experience as parts of the past. (p. 243)

Neuroplasticity contributes both to human rigidity and flexibility, "...depending upon how it is cultivated" (Doidge, 2007, p. 318). The theory of the brain's neuroplasticity complements my research by providing confirmation that the brain, like other organs, responds to changes in input; we can influence the functioning of our mind. He described the impact of childhood trauma upon the hippocampus, which shrinks so that new, long-term memories are unable to form (Doidge, 2007, p. 240). Antidepressant medications can stimulate stem cells to become new neurons in the hippocampus. Persons in psychotherapy can also find that memories become more clear. This suggests that psychotherapy "...also stimulates neuronal growth in their hippocampi" (Doidge, 2007, p. 241). The study of neuroplasticity is an exciting field of research that may lead us further from the strictly medical response to trauma and illness.

A consequence of a child’s long-term trauma can be the development of symptoms of PTSD (Post Traumatic Stress Disorder). Physicians Naparstek (2004) and Scaer (2001) both elaborate on the effects of psychological trauma on brain development and brain chemistry. The reader may find a thorough anatomical discourse from both writers. A consequence of trauma is that one’s belief in a predicable world and a sense of influence upon that world are lost. Neparstek (2004) wrote that trauma “ ...by its very nature is a situation of feeling an outsized helplessness and a paralysis in our ability to affect a situation” (p. 40). I realize how the complexity of confronting many physical anomalies played on my deep-seated symptoms of trauma. I experienced episodes of dissociation at very critical moments. Such episodes can shatter one’s self identity and personal meaning (Neparstek, 2004, pp. 43- 44).

Many of the physiological symptoms and diagnoses I have received can be the consequence of constant activation of the alarm system in the body.

> [Trauma] leads to an accumulation of metabolic waste products in the muscle fibers, and the release of kinins and other chemical pain-generators in the tissue, resulting in myofascial pain and the appearance of those seemingly intractable chronic conditions. (Neparstek, 2004, p. 78)

Information about trauma and its effect on anatomy validates the questions I had during the years when I sought to unravel complex issues. I share the experience of having frequently witnessed or confronted “...an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others” (Scaer, 2001, p. 1). I believe my fearful adaptation to my worlds has shaped my physical being.

Scaer (2001) explained that the effect of childhood trauma on brain physiology and chemistry may result in symptoms of PTSD arising later in life. As an adult, I observed that both pleasant and unpleasant activities (such as formal presentations, social engagements, or the stress of class attendance and completion of assignments) all serve to maintain an unremitting high degree of anxiety after the initial trigger has disappeared. Like a faulty automobile engine, my heart and mind would continue to race even after the stimulus (or accelerator pedal) is eliminated. Stimulation cannot be regulated. In my efforts to diminish rapid thoughts, trembling, exhaustion, and over-vigilance, I exercise, rest and seek mental distractions.

More recently, as resources permit, I have found help in the practices of tai chi, acupressure, yoga, body talk, and energy psychology, all of which focus on the body's flow of energy in relationship to health. The trauma I experienced extended over a long period of time; the remediation requires time and care. I am fortunate to have had the help of generous professionals whose fees are on a sliding scale. As a result of all of this work I am more present, grounded, and connected to others. I am gaining confidence in my creativity. I am better able to trust my intuition and am more at ease with the pace my body needs to take.

In Neparstek's book (2004), a survivor of trauma said: "I am an excellent brainstormer . . . I am used to having to find multiple solutions and easily think 'outside the box'. . . . [W]hen some solutions don't work, I just keep looking for more" (Neparstek, 2004, p. 342). After a time, survivors of trauma gain a sense of joy, generosity, and compassion. They discover a renewed connection with the divine, including a "...profound and palpable peaceful centeredness . . . acceptance . . . [and]

intuitive understanding” (Neparstek, 2004; p. 343). For more detail about their work with PTSD, and with clients, the reader is encouraged to read Naparstek (2004) and Scaer (2001).

Bolte Taylor (2006) reviewed her experience of a brain aneurism that occurred when she was a young neuro-anatomist. Her professional witness to the invasion of the left sector of her brain is incredibly specific. She also shared her extensive course of redevelopment of brain and physical functions with the endless support from family and colleagues. For me, most significant is Bolte Taylor’s (2006) description of her choice to reframe how she experienced her self:

> I have been very fussy . . . about which emotional programs I am interested in retaining and which ones I have no interest in giving voice to again (impatience, criticism, unkindness) . . . Since the hemorrhage, my eyes have been opened to how much choice I actually have. (p. 122)

Bolte Taylor (2006) was diligent and disciplined for her rebirth. Her spiritual life became primary as her body redeveloped movement and control. “From my perspective, the focused human mind is the most powerful instrument in the universe, and through the use of language, our left brain is capable of directing (or impeding) our physical healing and recovery” (Bolte Taylor, 2006, p. 157). She observed herself as part of a greater structure, “...an internal flow of energy and molecules from which I cannot be separated...” that provided an assurance of safety, and an acknowledgement that the essence of her being has eternal life (p. 160).

Dossey (2009), a physician, poet and speaker, was convinced of the correlation between an individual’s spirituality and one’s physiology. He believes in intuition, premonition, and the concept of the *numinous*, a word coined by Rudolf Otto, in 1917, to describe the "...nonrational, nonsensory experience of feeling whose primary and immediate object is outside the self" (Dossey, 2009, p. 35). Scientific tests measuring electrodermal response suggested that a physical response at the emotional level precedes the fight or flight action of persons under stress (Dossey, 2009, p. 66). He proposed that the poets are correct: the autonomic nervous system may be capable of apprehending future events; the heart responds before the brain (Dossey, 2009, p. 76). "We see what we *can* see, and what we can see is largely determined by our beliefs" (Dossey, 2009, p. 89). This thought provided some certainty in my pursuit of understanding about the relationship between my body's symptoms and my self.

Dossey (2009) introduced me to the term *nocebo response*, an "inhibition of therapeutic effect resulting from negative attitudes or disbelief toward a particular treatment," (p. 134), which explained in part my reticence toward medical interventions. He supported a sense of comfort in the heart where one's spirit can "...dabble in poetry; play with metaphors; shun literalism. Avoid habits, ruts and routines. Make a place for variety, risk, novelty, playfulness, generosity, and mystery in your life" (Dossey, 2009, p. 137). Perhaps the isolation of chronic illness combined with the heuristic inquiry allowed my bewildered senses to connect to the innate creativity that defines my self. Senses tuned to high alert were a means of survival, but to constantly function at this level creates lasting anxiety.

Burns, Busby and Sawchuk (1999) collected a series of articles about pain. These articles commented on the negative biomedical view that portrayed the body-in-pain as empty space, devoid of an environment or social context. This schematic rendering of the body indicated “...a standardized, androgynous, corporeal form that must fit everyone and hence fits no one” (Burns et al., 1999, p. xvii). The biomedical attitude is that pain must be knocked out, either by surgical or chemical intervention. “[The] physical and psychological recovery industry is built on long and complicated pain careers, which, except for those in graveyards, are perhaps the most striking example of the failures of Western medicine” (Burns et al., 1999, p. xix).

The experience of pain does not mean a declaration of victimhood or self-pity, “...but an acknowledgement that we are not independent agents in absolute control. We inhabit pain-filled environments” (Burns et al., 1999, p. xx). There is no easy remedy. My efforts to present my pain were initially dismissed with pills that rendered me dull both mentally and physically while the pain and exhaustion remained. Surgeries removed pieces of my body but not the encompassing pain. When surgery was deemed successful, the specialist’s responsibility was complete. The problem of pain was one that professional health care providers found most elusive. I felt accountable for the predicament.

Receiving advice or referral to seek assistance elsewhere, the focus would shift to another part of the body. It was my experience that I presented overwhelming complaints. Currently, overtaxed health care workers are forced to limit the number of issues that a patient may bring to an exam appointment as well as the duration of each appointment itself. Some clinics post signs saying that only one issue per visit will be addressed. Particularly in its early stages, symptoms of chronic illnesses (such as ME) can be difficult to distinguish from other potential concerns. IBD can flare, travel throughout the intestinal tract and for some it can temporarily vanish. A patient might be confused; there has to be a means of providing the care these persons deserve.

Physician Rita Charon (2006) described the benefits of the practice of *narrative medicine* in the healing process. Recounting experiences with patients and her medical students, she emphasized the value of relationship, attunement, and presence in the process of examination and diagnosis. Sadly, the practice of medicine that I and my friends and family members have observed seldom draws upon the luxury of narrative. The course can be solitary and destructive before acknowledgement and diagnosis. In its wake, the relational divide feeds into the patient's sense of isolation and marginalization (Charon, 2006, pp.197, 198).

> Bearing witness to suffering helps us to overcome some of illness's pernicious divides. . . . Recognizing, hearing out, receiving, and honoring the stories of illness may give doctors and nurses and social workers new tools with which to make contact with patients and to ease the suffering of disease. (Charon, 2006, p. 199)

My invisible physical symptoms were (and remain) unpredictable in severity and duration. Physician appointments did not always coincide with symptoms at their worst. I attempted to follow others' advice to be hopeful, to be positive, and to have faith that things would improve. Other persons who doubted my sanity reinforced my own doubts and the more impoverished my physical life became, the more critical the emotional betrayal became. However, I was aware that everyone could become as overwhelmed as I was. As the years passed, the external world seemed so averse that I grew discouraged with making efforts to connect to others.

Like a trek in the wilderness, all that I could do was attempt to stay present to what I was experiencing within my body and spirit. In an article by Delmar et al. (2005), she and her nursing colleagues in Scandinavia reported on their research into the lives of persons who live with chronic illness. They highlighted many points that confirm my experience. Loss of control over one's body leads to loss of one's perception of self. In order to cope one must invest energy and emotion to find harmony, peace, with oneself (Delmar et al., 2005, p. 205).

Delmar et al. (2005) continued: "[Patients] constantly move between hope and doubt, . . . the need for a clarification of their fundamentally existential situation" (p. 206). Living with a condition that is not visible to others can make it difficult for the individual to ask for help (Delmar et al., 2005, pp. 208-209). For those who have a diagnosis, denying the realities can hinder "...the process of getting in harmony with oneself. . . . There is a pendulum that swings between hope and doubt leading to continuous powerlessness, . . . during regular outpatient visits" (Delmar et al., 2005, p. 209). An irony with which I am familiar is that "...if one attempts to transcend the limitations on personal development by cheating oneself, one risks not obtaining the help that one needs" (Delmar et al., 2005, p. 210). Being stalwart and keeping a brave front can be counter-productive.

Yet, I felt that in the absence of anyone to acknowledge the truth of my pain and physical dysfunctions I faced a stalemate. This was affirmed by Delmar et al. (2005): "[There] remains considerable uncertainty about what these patients need in order to manage their lives in accord with oneself and one's surroundings" (p. 211). The authors advise nurses to be attentive to the patient's existential dimension. Even without visible signs of illness or pain, they suggest nurses respect the patient's reported restrictions, and their suffering, and be attentive to the pressure of doubt:

> Hope is the source of energy for a spirit of life/life courage and towards self-realization. . . . and doubt can shake the hope to such a degree that instead of the movement toward reconciling oneself with the chronic conditions and acceptance, the patient will drift towards hopelessness, despondency and despair. (Delmar et al., 2005, p. 211)

Spirituality

For decades, I was washed by waves of illness, insight and despair. I determinedly strove to understand and trust my outside world and inner knowing. Ashbrook (1996) provided a look into the pastoral practice of "minding the soul," through presence and compassion, expanding the meaning of the human family (p. 21). He stated that the creative unconscious works to find "optimal environmental adaptation," which shapes conscious intention. "In the language of neurotheology, creative unconsciousness is the work of the Holy Spirit in its whole-making activity" (Ashbrook, 1996, p. 21). He further states that the adrenal arousal system can take over for the parasympathetic adaptation system because "...all systems are on alert to defend against attack" (p. 20). With the help of the pastoral counsellor, one may shift the body from defensive mode to growth, turning dysfunctional autonomic tuning back to the service of enhancement (Ashbrook, 1996, p. 20).

Minding the soul, one's unique personhood, is preferable to focus merely upon survival. In Ashbrook's (1996) understanding of therapy (as well as of life) we need to acknowledge and embody the feminist theological theory of shared humanity: "We are in this world together, as partners, as friends" (p. 38). He refers to Tillich's belief that under stress we need to know we are accepted (p. 39). This affirms the soul's knowing that we are acceptable.

In childhood, through attending the needs of family members, I had developed sensitivity, intuition and compassion for the needs of others, and pushed awareness of my pain deeply below the surface. Duerk (1989) wrote to women who seek a new way of being, of the self, that is cultivated within a supportive group of like-minded women. She asked questions that I once found unbearable to absorb. All the queries contained the format: "How would your life be different if there had been a place for you to . . . ?" One that caught my breath was:

> How might it have been different for you, if, early in your life, the first time you as a tiny child felt your anger coming together inside yourself, someone . . . had said, 'Bravo! Yes, that's it! You're feeling it!' (Duerk, 1989, p. 30)

Of all the personal expressions that were not acceptable, when I was a child and a spouse, anger certainly was at the top of the list. I wanted to belong to a non-judgmental community of women who benefit from the giftedness and wisdom we all shared. Somewhere in my heart, I believed it was possible to give and to receive and be acceptable, whole, as I am. It had to start with me.

Feminist theologian Brock (1988) described the term *heart* as the source of all spiritual relationships. *Sacred erotic power* provides sensuous, transformative whole-making wisdom. Her courage to believe carried me forward. "When power is seen as something possessed by an individual who uses it causally, connecting power will be thought to diminish those involved because vulnerability and connectedness will be seen as threats, rather than as enhancements of selves" (Brock, 1988, p. 33). Through Brock and others, I began to comprehend more clearly the disconnect I experienced from patriarchal constructs and the way in which my heart responded to that denial of our collective selves.

I often wondered if I would have been more visible had I been a man or if I had had a strong male advocate, and I was riled by the reality. My credibility had become negligible. For many years I had been unemployed, primarily defined as a homemaker, then merely a single dependent. There were many environments where my perceptions were not acknowledged. Wahlberg (1986) immersed herself in the gospel stories about Jesus' encounters with women. As a "Christian Feminist" (p. 1) she struggled to unify the stereotypical, negative, view of women in Scripture with the belief that women are created in the image of God. Wahlberg (1986) recognized that the Scripture's content may have a patriarchic historical slant, but:

> ...Jesus knew what he was doing. He affirmed women in ways his contemporaries and later followers did not recognize. What this view offers is a new insight – a new perception of a reality of wholeness which was there all the time. (p. 97)

It is exciting to imagine the recognition that Jesus might have provided intelligent women who spoke when they observed a need, even to the disregard of protocol. Wahlberg (1986) summarized by saying that women are persistently vocal when they need to be; they can share their wisdom forcefully without being judged as hysterical (p. 97).

Anderson and Hopkins (1992) met women from many walks of life in their research. They found that relationship is the necessary connection for women who seek mature spiritual lives. The authors' mantra became, "...what you need to know is not written in any book. You already contain that knowledge. It is to be unfolded from within you" (Anderson & Hopkins, 1992, p. 3). Women's stories of trust in *the sacred within* have provided support for my quiet heuristic research project. The connection with other women by means of their literature and spiritual quests has empowered my own search for the centre of the self. Their creativity and devotion were invaluable even in my solitude.

Indwelling with the research to find the meaning of my suffering self, I was informed by the wisdom of many prominent thinkers. Psychologist Carl Rogers (1961) passionately explained that his person-centered approach engendered trust that one's experience is the highest authority; what is most personal is most general (p. 23). In the heuristic research process, there is an opportunity to create a means of making one's personal truth available for others. Theologian Jean Vanier (1998) wrote of the paradox that accompanies loneliness: "[As] humans we are caught between competing drives, the drive to belong, to find in and be part of something bigger than ourselves, and the drive to let our deepest selves rise up, to walk alone," (p. 18) and to ultimately find relationship with the divine.

May (1983), an existential psychologist, inspired my wounded spirit to find the path for newness of life through creativity. He wrote, "We have stated that the condition of the individual when confronted with the issue of fulfilling his [*sic*] potentialities is *anxiety*. We now move on to state that when the person denies these potentialities, fails to fulfill them, his [*sic*] condition is *guilt*" (p. 112). He drew upon the work of Paul Tillich in describing the individual's courage to create.

May (1975) posited that creativity is at the essence of the mature self; it emerges from the imagination to threaten the ordered structures and presuppositions of society and way of life (p. 71). Creativity is “...the process . . . the expression of this passion for form. It is the struggle against disintegration, the struggle to bring into existence new kinds of being that give harmony and integration” (May, 1975, pp. 139-140). The mind is actively forming and re-forming the world (May, 1975, p. 133). Existential philosophy affirms my course of inquiry, an inquiry that is driven from an instinctive, indefinable source. It comforts me in my response to the desire to resist condescension and marginalization, and to be unconventionally proactive in my life, in the care for my body’s health, and in my spiritual knowing.

Buford (2008) specifically referred to her experience as a pastoral counsellor who lives with a disability. She shed light on aspects of the wounded healer, of both the physical and emotional state from which she embarks in life. “A woman who lives in the strange land of disability rebuilds her life by listening to that still small voice inside of her. Spirituality is not a luxury; it is essential for survival” (Buford, 2008, p. 346). Often, in the course of this work there has been reference to that inner voice, that tacit knowing or belief in the unfathomable. Living with “... loss, terrified and alone...” (Buford, 2008, p. 335) one searches for life’s meaning and purpose.

Buford (2008) posited that because of “...the mystery and tenacity of chronic illness, grief is ongoing ...” (p. 339). Some feel guilty and selfish about their needs and the renegotiation of their lives can be difficult and costly (Buford, 2008, p. 341). Women with disabilities have to revise goals; full or part-time work is not feasible because “they cannot work under a superimposed schedule” (Buford, 2008, p. 345). She observed that the preoccupation with illness, which is necessary for survival, can move women to depression (p. 343).

Women living with chronic illness are constantly in survival mode. I see a correlation between the stress of illness and the rekindled trauma I experienced in adulthood. Buford (2008) quoted one woman who said “...if you don’t address this disruptiveness in your personal life, you are never going to get better” (p. 342). I concur with her that while reworking old relationships and finding new ones, one must also develop whole new networks of support (Buford, 2008, p. 343). In my circumstance, the creation of a small, secure, network has been a lengthy task. Even within a spiritual community, the well-intentioned may be fearful, run away, patronize, or engulf the person they are trying to help (Buford, 2008, p. 344). Misunderstanding and miscommunication became intolerable while I lived with undiagnosed, invisible illness and pain. As Buford (2008) advised, one must simplify one’s lifestyle and constantly reassess it (p. 346). Complicating my experience was the effect of reduced financial resources, dissolution of primary relationships, and several relocations to new homes and communities at each market fluctuation. I found that illness accompanied by a quiet lifestyle, and further fueled by poverty, brings its own invisibility.

People who minister to women living with chronic illness may expect to be overwhelmed. “Living with limited energy, resources, and often fragile egos in a complex world that moves at a breakneck speed is the task put before women with acquired disabilities” (Buford, 2008, p. 347). I would add that the issue is heightened by the fact that such women cannot define or teach others how to provide support in the critical moments. It has been an indescribable challenge to find equitable understanding;

it has necessitated patience and acceptance with myriad consequences. I was not always congenial in my behavior and knew that this response was interpreted as derived from illness rather than an intellectual or emotional source. It felt dismissive. In Buford's (2008) article, the reader can find further elaboration on pastoral ministry to women with disabilities.

Borg (1997) wrote that the monarchical model in the form of "…legal metaphors and legal logic shapes Christian life into a 'performance model' " (p. 65). Other issues such as repentance, redemption, liberation and salvation are distorted. This leads to the internal dynamic that one is a sinner, bad and guilt-ridden. God is seen as the superego to whom we humans may never be acceptable. Consequently, the dynamic of the Christian life becomes meeting some unattainable acceptability (Borg, 1997, p 37). Our destiny is wholly dependent upon how we perform. My religious background (as well as that of some companions) diluted my spiritual confidence by saying that my physical disabilities reflected a divine disconnect. Borg (1997) proposed the spirit model, *ruach*, in which the central dynamic becomes relationship with the creator of life who always loves and journeys with us (p. 83). The resurrection need not be the resuscitation of a corpse but rather involves the presence of spiritual embodiment (Borg, 1997, p. 92). Jesus taught unconventional wisdom that required relationship instead of obedience, performance and punishment (Borg, pp. 99, 100). As I broke from the bonds of understanding of the religion in which I was raised, affirmation was found in literature written by persons such as Borg.

Maley (1995) defines the transition of the self as psychospiritual change, a period of creativity when something emotional, physical or spiritual is transitioning and changing “...with a whimper or a bang” (p. 94). I faced overwhelming emotions and feelings of anxiety that provided an internal inconstancy when I wanted it all to settle to a smooth plane. “It is not a process one is always in control of; it takes a serious commitment to ‘the work’ ”(Maley, 1995, p. 97). One must release the desire to cling to old structures that prevent connection to a greater “spiritual reality” (Maley,1995, p. 98). Creativity can be a process that blends with the self experience. Confronted by unpredictability and formlessness, we can respond by polarizing further, or we can embrace “formlessness . . . learning how to question, accept others, and blend. . . . [T]he self grows by including the world in its structure” (Maley, 1995, p. 188), and living with the question about life’s outcome. In order to be effective in a world in transition, I understood that I must focus on my spirit.

Transformation, self advocacy, empathy, political activism

The literature reviewed in this section served to provoke and affirm in me my right to dignity and wholeness of self, though the odds remain great. “[Equality] is not the empirical claim that all groups of humans are interchangeable; it is the moral principle that individuals should not be judged or constrained by the average properties of their group” (Holland, 2006; p. 282).

Atkins (2010) wrote about her experience of critical illness that was difficult to diagnose. As a young woman, she found herself rushed to the emergency department and then into intensive care wards for life saving treatment. Medical interventions were often withdrawn when her medical records were retrieved. She was terrified by obfuscation in the reasoning of health care personnel. “[A] patient may be psychosomatic, and so she should see a psychiatrist; and, since she sees a psychiatrist, she must be psychosomatic. . .

. As the object of their bewilderment, I grew afraid" (Atkins, 2010, p. 33). She did not have the financial resources to find, "...some hotshot specialist" at the Mayo Clinic in Rochester, Minnesota, or at Harvard. (Atkins, 2010, p. 129) I, too, considered that someone somewhere might have the expertise to diagnose and to treat me. Atkins's experience, and her feelings of abandonment were familiar to me and aroused my own anger and futility.

In theory, evidence-based medicine looks like a good idea. However by only treating those who have substantive evidence or data proving the factuality of their claims, many are left abandoned. "[Patients] who are statistical outliers, or who do not meet diagnostically normative models, are potentially overlooked and cannot have their needs met because there is no evidence to back up nonstandard therapies" (Atkins, 2010, p. 145). Her compliance in obtaining psychotherapy provided voice for past familial injuries and she was then able to vent frustrations. "However, it also exposed me to a myriad of assumptions and techniques that I found belittling" (Atkins, 2010, p. 33). She reported that psychotherapy used broad generalizing theories that did not clearly reflect an "...individual's lived experience" (p. 34). Accused of playing an intellectual game with her physicians, the "... psychogenic diagnosis seemed to be a maze from which I could not extricate myself" (p. 35). Like me, she did not have the one critical feature of psychosomatic patients: susceptibility to suggestion. This deficiency reinforced my timid resolve to believe that there was real disease even though that was an unhappy and marginalizing thought. When my symptoms were paralyzing, I was resigned to facing death. "Dying was lonely and painful . . . All I could hope was that my apprehension would disappear as I encountered increased and sustained health" (Atkins, 2010, p. 123).

Her book was a raw witness to an experience of illness with which I could strongly identify, even though she had a partner and children, and a professional reputation to help sustain her. I was moved by her intellect and persistence. Atkins's work provided affirmation of my research phenomenon and a solemn recognition of the validity of our experience. Indeed, it must be an experience shared by countless silent women. One of Atkins (2010) statements remains critically relevant: "[There] may be new psychological discourses about illness, but the actual arrangement of specialties means that physicians are really ill-equipped to respond to patients in a truly holistic manner" (p. 128).

Atkins's (2010) book is part of a series from Cornell University providing perspectives on health care issues. A clinical commentary at the conclusion was written by University of Toronto physician Brian David Hodges. He ended with the observation:

> Atkins's moving work helps to remind us that it is a road better traveled when we are all facing in the same direction, with the same goal – the reduction of suffering in a context of curiosity, engagement, and trust. (Atkins, 2010, p. 192)

The consequence of this marginalization, I would unhappily suggest, was the duration and exacerbation of my solitary passage through increasingly debilitating symptoms that proved destructive to my self, my body, my reputation and my relationships. Olds and Schwartz (2009), practicing psychiatrists, proposed that three factors contribute to increasing aloneness and consequent depression and illness in our current western society. These are the contemporary Christian attitudes of self-sufficiency and accountability, the cultural striving for self-improvement and self-reliance, and technological advances in communication. Social connection is fundamental to neurobiological health and the need for attachment; it provides an alternative to prescription drugs.

> Social support and human connection are a little like sunlight: they are so ordinary that their miraculous powers barely get any attention. . . . Socially connected people live longer, respond better to stress, have more robust immune systems, and do better at fighting a variety of specific illnesses. (Olds & Schwartz, 2009, p. 2)

Frenetic, overworked people push away from others while striving to stand apart as self-made heroes (Olds & Schwartz, 2009, p. 17). As one who cannot meet the common pace of life, I perceive isolation as necessary for maintenance of self. In the concluding chapter I write about the manageable means of connection and the comfort with being alone.

Feminist author Virginia Held (2006) described the factor of relatedness that comes through assertion of alternative values to the political adversarial democracy. She identified it as "...care and trust and human solidarity" (p. 151). My pursuit has not been for justice or reparation, but for a self who is prepared to live more fully in this world. Held's (2006) words conclude this chapter:

> Beyond the traditional public and political philosophy, . . . [images] and narratives appealing to the moral emotions of empathy and caring would also contribute. The values of the ethics of care could incorporate traditional ones, such as justice, and go beyond them . . . to seek cooperatively to provide for children and care for their global environment. (p. 153)

Chapter Five: Reflection on a Changing Life

I now have perspective to see what was once concealed. The heuristic blend of stillness, consternation and receptivity with the phenomenon have proved invaluable. I have been intrigued with the opportunity to do this research, which juxtaposed the past in the context of my present life and broader world events. It would have been impossible to have foreseen the effect of indwelling with the thesis question. One year ago I could not have written a hypothesis or structured a method of inquiry that would have predicted the insights I have since acquired from the essence of my self.

During the thesis process I encountered a PBS documentary titled *Fractals: Hunting the Hidden Dimension*, produced by Schwarz and Jersey (2008). Fractals are patterns that, with close scrutiny, reveal exquisite infinite detail. The program's motto was "...[making] the invisible visible; hunting for order in disorder." It explored the work of Benoit Mandelbrot who searched for an understanding of nature, a frontier of science.

Designs in the creation of snowflakes, leaves and trees, clouds, coastlines, mountain ranges and heart rhythms are all more comprehensible when perceived through the concept of fractals. With computer technology, the science of fractals provided the knowledge necessary to create film animation and design the capacious wireless network. It further promises detection of the initial growth of some cancers in the recesses of the circulatory system (Schwarz & Jersey, 2008).

The concept of fractals confirmed my awareness that the more closely we examine our question, the more we reveal. However, the depth of the unknown expands ad infinitum. This confirms the divine in all the complexities of creation. In my mind, it links me to the affinity that women have had with the sacred in nature (Anderson & Hopkins, 1992, p.19). As well, it appears there is precision and a rationale even for fear and pain.

My curiosity has led me to trust in the divine formlessness that remains beyond our comprehension. When everything has been sheared away, by leaving old security, or confronting pain, “...we are presented with a great opportunity for spiritual growth. At such times we are likely to examine ourselves more deeply than we ever have before and be asked to trust far beyond our understanding” (Anderson & Hopkins, 1992, p. 63). The phenomenon I confronted seemed unfathomable; the compulsion to seek my authentic self beyond the physical symptoms had intense value. I went forth, informed by a whispered faith and trust in something greater than anything I could articulate.

I am a fraud

Looking into the mirror or being the focus of attention has always been difficult for me. By confronting my health crisis and the consequent fractures to old structures, my body and emotions were exposed, yet there remained a barrier which prevented something more. I could not verbalize what it was that I experienced. I chose to put myself under the less-than benign examination of the heuristic gaze. In preparing Chapter Three–the recollection of early experiences–sensations of the younger woman were defined more clearly. While doing so I sometimes doubted my instincts; the story seemed laden with a sense of fraudulence.

Contrasts and ironies have been rampant throughout my life. I feared my story would appear overlain with middle-class privileges and values that concealed the undercurrent of trauma. When physical symptoms of illness and pain were at their peak, I separated from my spouse, without certainty for my child's future or for my own. My pastoral counsellor continually challenged me to listen to my body, and to stay with myself. Sensations had overwhelming power. Unknowingly, I had cultivated a way of being that was characterized by accommodation and compromise accompanied by resentment that could engender paralyzing fear. I over-functioned which gave allowance for others to do the opposite. In consternation I would shut down.

I did not like myself. I did not like the effect I had on others. I was frightened and muzzled by the apparent rancor and envy I saw in others. I did not know how to define what I needed and I suppressed the instinct to try. At first, I justified the therapeutic process by saying it was for the sake of the mother of my child. Eventually it became evident that the therapy was also for the woman-child in me. When a confluence of crises arose, my body's inability to maintain function was threatened even more. I was terrified by the invisible symptoms; their denial by others forced me to persevere with incredibly disabling results.

To find my self I had to look to my early life. At twelve years old, my means of survival entailed submission to unpredictable forces that were beyond my control. I excised the expressive self who might consciously open doors and look beyond the present. The inquisitive mind was oppressed, permitting no significant expansion beyond what served the context of my external milieu. It was important not to draw attention, not to be attractive, not to be unique in thought or action. I attempted to silence passions and personal desires and expectations. I accepted failure as inevitable. I was confused by praise. I took constructive comments as rebukes. I focused on the tasks that needed to be accomplished each day. For my own safety, I resisted intimacy and sabotaged pleasure and fulfillment. I knew that the chaotic home-life could reverse its course in a moment.

At three years old, and not accompanied by an adult, I averted my eyes from strangers on the street and would regularly push a doll's carriage full of clean linens, necessary for my father's business, to his shop. At ten, I accompanied my four younger siblings to the dentist on the bus; listening to their cries, I held myself distant as I awaited my turn. At thirteen, my mother planned for me to fly alone across the continent to visit a friend. En route, the airplane was diverted to Chicago and passengers were discharged without further services. I located assistance to help me arrive at my destination; I recall I was comfortable with responsibility for only me. In the last month of the third year of high school I wrote seven matriculation exams, a music theory exam, and I did two performance exams. The following month I was evicted from my home because I had not found summer employment. I accomplished countless obligations while suppressing perpetual fear. I had no concept of the need for a support system. My primary expectation was to accept the inevitable, to let the environment carry me where it would. I was malleable, equipped for external trauma, and completely frozen within.

My stammering speech, memory losses and inability to concentrate on intellectual pursuits had rational cause. The fluid current of external responsibilities, which defined my beliefs and behavior, was fraught with weakened connections. It is a challenging commitment to work to retool the unconscious. New awareness leads to the ability to choose to make change and to flex the emotional muscle enough to instill new responses.

Sins of the ancestors

I was the first child of a very young woman who was born into a strict religious/ social/ political environment. The predominant goal of moral order led to unconscionable government legislation (FitzGerald, 2010, p. 301). My mother would not have articulated her fears, but I surmise these were manifest in a stringent duty to cleanliness in body and mind and appearance. Without access to her thoughts, I conjecture that she attempted to meet these aspirations through the creation and control of her little family. Given her sensitivity, it is not difficult to extrapolate the meaning of the events which unfolded. As her first baby, I was vulnerable to her unspoken anxiety, paranoia, and delusions. I was scrubbed, soaped, dressed and disciplined obsessively. I was fed more than I desired. Her actions were aimed at molding a perfect child to reflect a perfect mother. It would seem that her fear of censure was absorbed into me.

Then, inconceivably, her world imploded. Shortly after her father died, her spouse, my father, succumbed to polio. The two males upon whom she completely relied were taken from her before she was twenty-five years old. Referring to the epidemic, Taylor (1990) wrote that it seemed "...this vibrant, optimistic city had been smitten by a medieval plague; it engendered the same fear and helplessness" (p. 15). At the time, we lived outside the city but no one was protected. The disease did not emerge from any particular place, finding "... its way into the most remote areas and even up into the far north" (Taylor, p. 17). My father was dead two days after his diagnosis. My mother remarried quickly. I believe she imagined that stability might ensue once more. The sinister polio scare lurked in the community until an effective immunization was discovered. Relatives, particularly children of the victims were potential carriers and thus our family was somewhat isolated for the safety of others. No class or age was spared. “After a short silent incubation period, victims developed a headache, followed by rapidly progressive paralysis and sometimes death within three or four days” (Taylor, 1990, p. 16). I was haunted by stories about the respirators called iron lungs that permanently engulfed the survivors’ entire bodies and provided strength for their own lungs to inhale and exhale. I never spoke about my fears of these sci-fi machines.

My mother’s instability lurked in the mist. Stories that others might have shrugged off lingered in my consciousness. For example, in a hallucination or a dream, my mother believed she had been told to choose between her two babies or her husband. She told me that she chose us children and soon afterward my father fell ill and died. I felt I carried an ominous responsibility akin to survivor’s guilt. Many of the stories that she shared with me had similar eerie impact. Perhaps absurdly, I tried to incorporate them into my life. I attempted to have the strength that my mother required but lacked. Of course my false courage too had bizarre repercussions. One consequence is that my self-control during times of stress can be perceived as emotional detachment.

From this beginning, I suppose my mother believed no one could be sufficiently prepared to meet the elusive expectations or dangers she perceived. I did not succumb to polio though the inexplicable distress lived on in me. For instance, the basic Christian tenet of the crucifixion raised memories of death and this hushed awareness separated me from my childhood faith community. In time, when the fears overshadowed the light of being, I had to extricate the feelings, verbalize the questions, and climb down from the oppressive *Zacchaeus tree* of shame and guilt.

Creative spirit and wholeness

My pursuit to find my authentic self could not be achieved in the looking glass. It was not found in any gift with which I had been endowed nor through any personal accomplishment. I was not appeased by sacred text or thoughtful word. I was compelled to attend to the essence within, in order to unite with my self. There is no sufficient consolation for the loss of opportunity to demonstrate my love for my child. The evidence that reinforced my authentic self emerged in fragments.

During one of the academic courses we learned to enter into our creative selves by drawing mandalas. I found affinity with this new form of expression. In meditation, quieting the censure, my arm moved in large sweeps of line and colour. That which emerged was a surprise. In drawing my archetype, I had anticipated a bird with extended wings to appear, soaring beyond the inconstant landmass. Instead, there was a very large polar bear standing firm and resolute in her formidable environment. Her great shoulders and broad flanks manifest resilience. She is alert, grounded, and present. Researching the meaning of this symbol, I discovered that the solitary female bear resolutely protects the vulnerable of her species.

A mandala depicting my soul’s purpose revealed the face of an ageless woman. In my journal I wrote:

> She is powerful, outward facing. Simple boldly shaped. She has her eyes and ears open. Her mouth is sensual and yet not prominent. Her mouth can open but is not at this time. She listens, looks, takes in what is happening. She is inspired and inspiring. She glows with life force. Red. (Stewart, personal journal, 2006)
>
> The images are found in Appendix B.

I observed the contradiction between these images and my prevailing sense of vulnerability. I resisted emotional blows and the bizarre quakes of instability. My passions were susceptible to eradication and my life experiences were viewed through secreted anguish.

After completing Chapter Three, I visited my present physician, whose discernment, empathy and intelligence I trust. My substantial medical file contains reports and summaries going back to the point of hospitalization and delivery of my child. One report, prepared for application to a government benefits program, especially validates my recollections. The dense compilation confirms my memory of frequent inflammations, pain, injuries, unremitting exhaustion, and numerous examinations. Alongside the then-current political scene, with its reformation of the health care structure, physicians were quietly planning their exit strategies. These were accomplished through early retirement, a career in medical research, returning to one's home town, or to a more lucrative, independent practice south of the border. As a patient, I was disempowered by their retreat. My health grew increasingly compromised as I repeatedly felt forced to explain and defend my circumstances. The fear of being disposable was my reality.

Relationships with self, with others

Over many decades, I attempted to wait out the storm, to minimize problems. When extremes in my situation became intolerable, a pastoral psychologist became my only constant tether.

Working as a counsellor in a community support agency I encountered women who presented with concerns about issues of relationships, parenting, addictions, employment, grief, and poverty. In the therapy environment, several disclosed the hopelessness of non-specific health issues. The circumstance of inaccessibility to a receptive health care system was often mentioned. My empathy and compassion for these clients challenged me to revisit my experiences and recognize transference. The importance of this topic is prominent.

I have tried to relinquish my affinity for music over the past two decades. I did not find comfort in meditative music. I could not hear performers without primarily listening as a professional to details of the composition, its instrumentation, and quality. There was no solace or pleasure in singing and playing because the physical demands were painful and aptitude is lost. In writing Chapter Three, it was problematic to find expression for what music means to me. Then themes began to play in my inner ear and music emerged from my imaginative mind, through my fingers.

To visually document the suppressed losses in my life, I drew out my loss-line a few years ago, under the auspices of a psychologist. Beginning with the death of my father and the illness of my mother, it is compacted with the events that bore personal loss in my young world. I remember mourning the deaths of extended family members and friends that I could not comprehend, when I was required to behave with impossible formality, sometimes expected to sing a solo anthem. When I was still a youth, pain existed constantly. My simmering anger confused me and annoyed my parents. I was conscious of the inevitability of end of life narratives but did not know how to be with the pain. In my work and relationships I had ability to be with another individual’s reality. I recognized the discrepancy presented in the compassion I felt toward others.

I recall how difficult it was to bring forth the words to describe the anguish in the sense of obligation to compromise my values and beliefs, to suppress my voice. I was drawn to persons whose sensibilities were easily offended, who could be volatile and enraged by innocent slights, and who could maneuver the truth to suit their needs. I attempted to immerse myself in their values with a consequent moral abandonment of my being. From early years, my personal essence was visible to me only in the peripheral glance. The thesis process provided a prescient focus for cultivation of clarity with my self. My heuristic work has been supported by a therapeutic relationship. There were days, even weeks, when the physical body and mind were unable to remain present to the work. There were periods when the soul seemed to ask for time to capture the emerging awareness, to mull upon, incorporate, and explicate all that was presented in the unconscious. Sometimes the anxiety increased; nightmares came; restlessness and confusion strode with me everywhere.

And one day, I simply saw differently. “I must have the right to just *be*.” The soul had fought to be recognized in my self, to deserve comfort, to expect like-minded relationships, to rest in the unknown. Here was the apex of my search. After that day, I felt a union within that gave me access to my authentic self. I have no words to describe the value I experience in music, literature, art, nature, and relationships. I still seem to wrestle with language and stumble with diction.

As silence is an unacceptable form of thesis, I grasp for words to describe what my essential self was attempting when my music compositions emerged. I recognize what the authors of heuristic research promoted when encouraging creative expression. How else could the power of my life’s essence be adequately expressed? Creativity is the divine expression of the essence in each person. I believe that human nature is at its zenith when in the act of invention, imagination, or inspiration to connect with one's self and the world.

I understand that life's temporariness demands physical compromises. For example, my siblings and I know that dementia is prominent in my family background. Aging brings more timely deterioration, uncertainty, impermanence, and loss. In focusing on the tacit knowing beneath the disguise, I face the potential for the unexpected or for the unconscious to manifest itself in life. Negative experiences and beliefs that invaded and controlled life are illuminated differently now; I hold them as revelations stemming predominantly from a precious girl's anxiety and her sacred desire for survival. Her precocious courage and stubbornness are unified with the crone's wisdom and imagination.

To end a thesis inquiry that was often contrary and confusing, I contemplate the thought that the initial research question could be asked in the opposite way: What is the impact of woman's sense of self upon her experience of invisible, long term, undiagnosed chronic physical illness and pain? The choices that others made before me which affected my development are not my responsibility. I carry new mindfulness and discernment to measure every day choices to live and love. I choose the potential to *be* in wholeness and unity of body, mind and spirit.

Piano compositions put into words

The musical themes in the accompanying piano compositions appeared first and harmonies arose, preceding contrivance or language. While indwelling with the thesis question, music expressed the presence of the unarticulated inner spirit, the tacit knowing. Tentatively, my fingers felt both the pencil and music simultaneously in my grasp. The heuristic research process, open and receptive to the data that is my recollection of my life, allowed these musical themes to emerge. It was an experience I have never had previously and I was awed.

I must still confront aging and imminent health issues, life and death. There will be occasions when present courage will be called upon to respond to contemporary experiences. Physical losses exist; sadness has a source. But the self can prevail. The expressive essence of my self provides an avenue for my body, mind and spirit to create meaning. The underlying personal meaning in the compositions, for me, is derived from the knowing that cannot be told.

I urge the reader to listen to the music before reading the following annotations. The listener’s response is itself another form of divine creativity.

Neologisms:

1. The low voice is exposed and alone. In this piece I hear lament. The minor key reflects substantial and sustained grief. Yet there is a melodic thread comprised of energy and structure. Other voices interact and conclude as one.
2. This piece moves me with its grace, as if I am skimming on ice. The air is cold and crisply alive. I am free to circle around and around. Listening and moving my whole body undeterred, all the senses are alive. Snowflakes and frost from my breath melt on my eyelids and cheeks, running down my reddened face like tears.
3. At first there is lightheartedness in a major key and a steady dance-like rhythm, rising and descending. I chuckle. Then hesitation; the key changes. It rewinds. The bass has a

voice; the soprano enters. It is frenetic, a hurly-burly, and it ends like an unanswered question.

4. They all rolled into each other, days and nights. Pain. Incomprehension. No sense of peace. The minor key, the wide chord spans hint of possibility, of arising hope, but in the final phrase it seems resigned to a present cautious reality.

5. Perhaps it is a lullaby sung to a restless child who struggles against sleep. Gently, steadily rocking, the watercraft's sustained tones soothe and still. They invite the breath to calm and eyelashes to meet together. A little activity, a little more wakefulness, interrupts the rhythm, but inevitably, soundlessly, my dear child enters safely into a dream. Through the child's innocent eyes we share the wonders of the world; I do my utmost to provide a secure vessel for the shoals ahead.

While recording this CD, I found myself embraced in a phenomenon, the creative energy, that I had felt departed from me long ago. The performer and the recording technician are musicians of high caliber. Working with them, the compositions came alive; it thrilled me to hear my compositions, the notes, the phrasing, lifted off the pages, interpreted by a pianist on a finely crafted instrument. Produced in a professional recording studio, the selections are imprinted upon compact disc. My intimate expressions are now available, through the help of others, just as each person's existence composes the external world. As with any creative expression, my compositions are open to interpretation and augmentation. And so I engage, evolve, migrate, hibernate and create. The music manuscript can be found in Appendix A; the CD is also attached.

With increased affirmation and mindfulness, I am more capable of respecting my authentic self. From that knowing, I approach each day with the desire to acknowledge my body and self, engage my resources and explore my world.

Extending the question further

Rollo May (1981) wrote about a client who had experienced a destructive early life. The only means of finding freedom for new potential, he said, was in acceptance that the injustice would never be reconciled. “It can be absorbed and mitigated by new experiences, but it cannot be changed or erased” (May, 1981, p. 35). If you trade your freedom for a “...mess of emotional pottage,” you never use your anger constructively, and “...[you] lose a tremendous amount of power, energy, and possibility. In short you lose your freedom” (May, 1981, p. 35). The purpose of psychotherapy is to help one get to the stage where one is free to choose a way of life, “...as far as that is realistically possible...” and to accept one’s situation, “...as far as that is unavoidable” (May, 1981, p. 210). This observation aptly applies to the life with chronic illness. I am aware that there will likely be more issues that touch on early wounds, and there will be more encounters with the health care system that accelerate my heart rate and quicken my breath with fear.

During the years when I was extremely ill and immersed in the protracted divorce process, I had no income, no trust of security, no credibility, and no safety net. Indeed, the sense of abandonment was devastating. I cannot minimize the importance of individuals who were there for me even for moments at a time. I may have been unable to fully acknowledge it then, but their gestures of love were critical. I am cognizant that many persons were not able to stay with my drama for long periods. I found some who served needs that could not fit with my gestating sense of self and, learning to trust my intuition, I chose to disengage. It is not my purview nor certainly my right to know and express another person’s thoughts. I do however understand the sway of personal limitations and commitments. I hope to use my experience and insights to cultivate and extend my abilities in service to others and our world.

It would be tidy to close with the words, “She lived happily ever after. Amen.” However, I speak to my listening ear: “Listen: how critical is this inexplicable experience of the heuristic process in your life. Listen: how intensely you press to find resolution. Listen: there is turbulence remaining. Listen: to the meaning. Listen to what may be created tomorrow. Listen...”

Future research inquiries

It has been mentioned earlier that this research might lead to inquiries of relevant issues. The following paragraphs describe a few of the topics I would be curious to study.

I am interested in studying the phenomenon of the eldest daughter in a family who is subsumed into the role of surrogate mother. What effect does that role have on her sense of self? And how is her sense of self impacted as the other children reach adolescence and adulthood? She confronts a revision of her role as sibling. As well, I recognize that there is a sense of grief (such as mothers experience) in the undefined abandonment, and in the opportunities of youth that she was not able to fully experience.

It would be informative to investigate the experience of a mother, distanced by uncontrollable circumstances, whose sense of irrelevance contributes to the increased divide with an adolescent child. In my observation, the inexpressible helplessness and devastation of suppressed love and intuition impact the issues of self esteem and the declaration of life passions.

The changes in our health care delivery system will impact persons with chronic illness. I will be interested in how those who are “undiagnosed” will find support and fit into this fast-paced society. I have experienced vociferous bias against those perceived to be taking advantage of our social safety net. Such attacks hit the mark and exacerbate existing injuries.

With the blessing of continued life, I confront the likelihood of remaining below the poverty line. I have personal experience of unscrupulous landlords who use government legislation that opposes rent control and supports developers, as sanction to gouge the most vulnerable residents. (In Alberta the landlord is superficially restricted regarding the frequency of rent increases, but not in the amount.) This provides a stress that, again, contributes to illness, isolation, and it damages self-esteem. I am in financial debt even with the assistance of friends and loved ones. Dependence too has its own insidious implications. Rapid technological developments lead to obsolescence which guarantees that the marginalized fall further behind. With respect, I suggest that unemployment statistics do not report the economic reality and marginalization of those who remain uncaptured by such statistics.

I often hear the comment that something is low-cost or affordable. This is often irrelevant for many persons who live on low fixed incomes. When speaking from the position of poverty, one’s credibility is covertly questioned.

There is quick judgment and a stigma directed toward people who have invisible disabilities. In my case, I often choose not to engage. However keeping silent comes at a cost. There is a stereotype of the “quitter” as a person who is dependent upon society. Housing and seniors care for those on minimum income remains woefully inadequate. Development of big-box stores and large suburban shopping centres serve those who own sizeable vehicles and bank accounts. The invisible, the majority of whom are women, grow less visible. Economic fluctuations in the market, a predominant topic for political conversation, dictates the awareness of the populace. Many of us, in quietness, continue to reduce, reuse, and recycle as a necessary everyday practice.

My recent academic experience provoked curiosity about how the needs of persons with invisible disabilities are met by learning institutions. I made every effort to eliminate obligations in my life that would prevent focus, especially during weeks of condensed class schedules: meals were pre-prepared, and solitude and silence reigned in my home. Most instructors were lenient with my requests for extensions of deadlines for term assignments. Yet I found little comprehension for the barriers that I confronted both during classes and during one of the requisite online courses. My strengths were most seriously compromised by requisite oral presentations and peer-group work. Instructors commented that I was not engaging the class. I was unable to describe to peers why I could not meet the expectations of an informal thesis support group. Just as my physical limitations are not understood, some persons did not comprehend the idiosyncrasies of an heuristic research inquiry. I was sensitive to the academic ethics review committee’s cautious consent to my thesis ethics proposal.

To my regret, our joint lack of knowledge about, and abilities to express, the barriers prevented an optimum learning environment and camaraderie throughout the graduate program. I must emphasize the important benefits along the way: a college bursary funded the laptop computer that I used to produce my academic work for the past several years, and friends and relatives helped to finance my extended academic period which the college allowed. Individuals encouraged me during my lengthy journey. Unfortunately, many people with invisible disabilities could meaningfully contribute to this discourse; they do not receive the opportunity.

Political activism is one means of expressing one's vision. I wonder at the endurance of those dedicated few who work for change in any conservative constituency. Certainly my own efforts are easily dismissed by legislators, but my awareness of those who continue to be marginalized, disempowered and underprivileged raises my ire.

I am interested in researching disabled women's access to equitable legal services. From what I have heard, the cost for divorce remains prohibitive, especially for the under-employed and those living on low fixed incomes. The legal structure and fees undermine a woman's health and energy. Rightful attention to issues of long-term health and stability for her children and herself are inaccessible; dissemination of her options is also weak. Wounded and silenced, women and children are marginalized by imbalances in the legal system, access to community resources, and inequities of health care services. Family ties are forever compromised. From a purely capitalist standpoint, this results in a less qualified workforce.

Conclusion

"[Insights] emerge not chiefly because they are 'intellectually true' or even because they are helpful, but because they have a certain *form*, . . . that is beautiful" (May, 1975, p. 132). Such insights complete what is incomplete in us. On the basis of wish and intentionality, human beings make form in their world. "Genuine creativity is a passion for form; it is involved in every experience, . . . as we try to make meaning in our self-world relationship” (May, 1975, p. 133). I once heard a popular music performer describe her work as fulfilling because it was creative and not craft; it was integral to her being. This stuck me as relevant to that which I was attempting in the heuristic research. The search for an inexpressible unique knowledge of the self has no template; it has no mass-produced or readily available destination. The explication of the acquired insights is only as effective as language allows. The benefit of the heuristic reflection is garnered in the self that is now more visible–the creative self now more present. This is the validation of the heuristic process.

From the start of the thesis process I bore the awareness that the filigree of one’s life is delicately created and we capture the past only in glimpses. Kierkegaard’s (1952) poignant words whispered to me:

> It is perfectly true, as philosophers say, that life must be understood backwards. But they forget the other propositions, that it must be lived forwards. And if one thinks over the proposition it becomes more and more evident that life can never really be understood in time simply because at no particular moment can I find the necessary resting place from which to understand it–backwards. (p. 3)

The passion to create is the passion to be present with and to the self. When I am grounded in my self I am connected to the energy that desires creative expression. I am in love with the self who feels emotions and is not afraid to encounter the fog of formlessness, meaninglessness, and unanswered questions. I hold sacred the opportunity to be present with other persons within the fractals of our creation. I empathize with those who feel cloaked in the irony of invisibility. We can be empowered by the courage to create, infused by the ruach that encircles us, embraces us, and celebrates our truth.

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APPENDIX A

NEOLOGISMS

Five Pieces for Piano

Janis Louise Stewart
2011

Supplement to Thesis

Through My Looking Glass:
A woman’s experience of living long-term with invisible undiagnosed chronic physical illness and pain and its impact upon her sense of self

Partial fulfillment of the degree of
Master of Psychotherapy and Spirituality
St. Stephen’s College, Edmonton, Canada
2011

NEOLOGISM #1

© Janis Louise Stewart

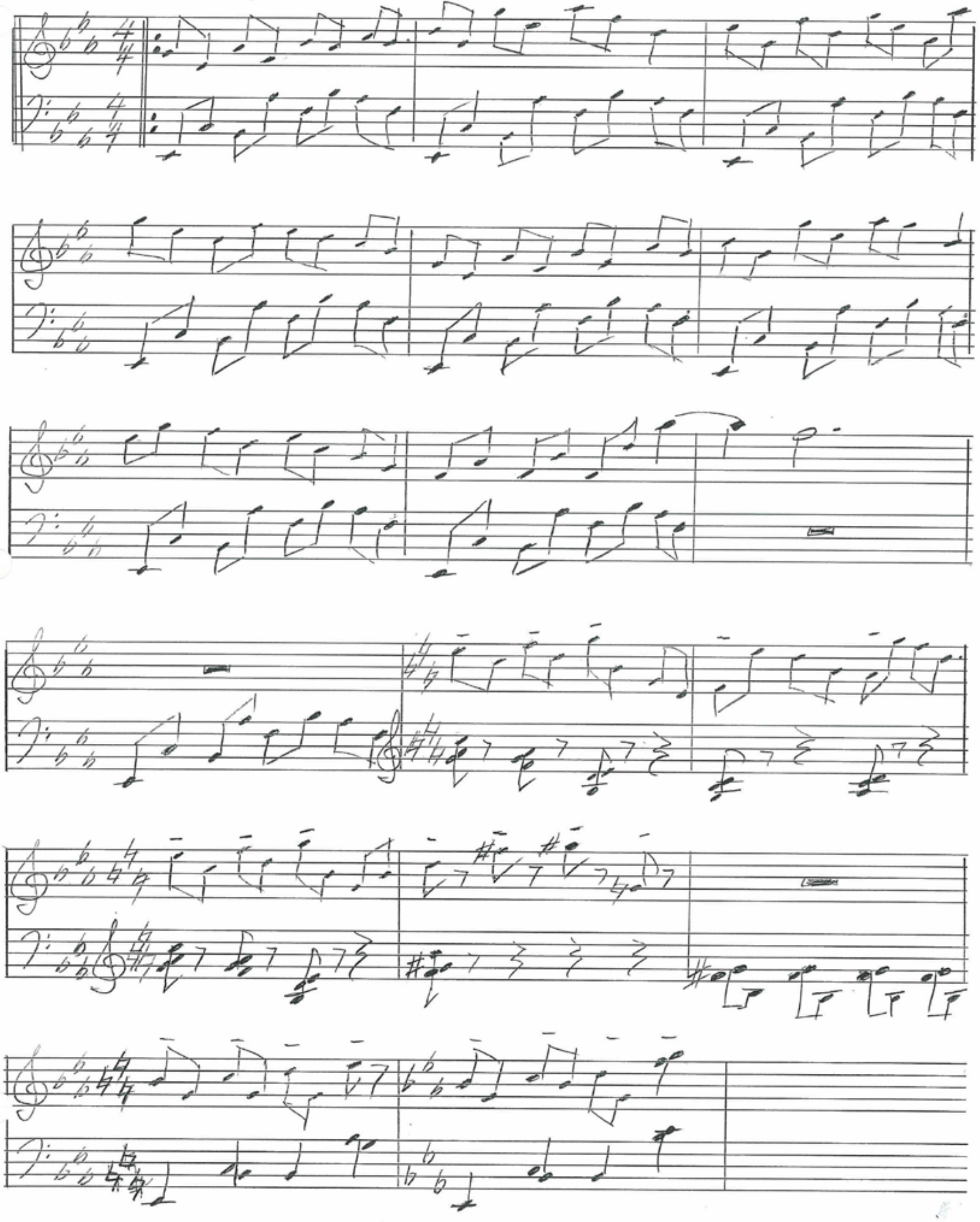
NEOLOGISM #2

grace, glide, strokes

©Janis Louise Stewart

NEOLOGISM #3

fast, agitated,



© Janis Louise Stewart

NEOLOGISM #4

© Janis Louise Stewart

NEOLOGISM #5

slow rocking
mp

©Janis Louise Stewart

© Janis Louise Stewart


pp
slower
ppp
rit.

APPENDIX B

MANDALAS

Archetype

Soul's Purpose