Voices of the Chronically Ill

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Broken Words

By

Mary Kalfoss

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This book is dedicated to all those who are chronically sick, their families, and their carers.

This book is also dedicated to my beloved husband, Frank, who is struggling with his own life–threatening illness.

Reading lives educates us how certain naivetes about what it is to be a human being.
—WILLIAM MATTHEWS

Literature not only illuminated another's experience, it provided I believed, the richest material for moral reflection. My brief forays into formal ethics felt dry as a bone, missing the messiness and weight of real human life.
—PAUL KALANITHI

How is it that at a time when fragmentation is both prominent and valorized in postmodernist writing, illness narratives tend to preserve, even strive for, coherence and continuity? Wouldn't narrative fragmentation be the most suitable form for the experience of disrupted narrative identity?
—SHLOMITH RIMMON-KEENAN

I find me, leave me, go towards me, come from me, nothing ever but me, retrieved, lost gone astray, I'm all these words, all these strangers, this dust of words, with no ground for their settling, no sky for their dispersing, coming together to say, fleeing one another to say, that I am they, all of them, those that merge those that part, those that never met, and nothing else, yes a, something else, that I am something quite different, a quite different thing.
—SAMUEL BECKETT

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PREFACE

Many years ago, as a newly graduated nurse, I chose to work in a large cancer hospital. These were some of the most gratifying years of my long nursing career. My patients taught me so much about what it is like to be a vulnerable human being struggling to survive their illness. They also taught me a lot about the hard task of having to rediscover a new sense of self when former images of whom they felt they were, gradually crumbled away. In witnessing their struggles, I kept a diary in those days, as a need to sort out and reflect upon the myriad of feelings and questions I carried within me. In one of my entries. I wrote:

> "How does one feel like a human being when one has lived through intensive pain, been operated on for cancer which hasn't been successful, taken medication over two years to find out that all nausea and vomiting and horrible side effects have not helped at all? How does one feel like a human being living together with a husband who can't accept your disease, or the seriousness of it, and asks you day after day, 'Are you better today?' You say he can't believe, or won't believe, that you will not be better. How does one feel when your two adolescent children, whom you say suspect the seriousness of your disease, won't talk about it? You comment, they bite their nails and carry out helpful tasks. but never say what they are feeling. You describe playing a game, trying to fool one another, trying to be humorous, and pretending. Now, you tell me you can't maintain this game much longer. You say the burden is mine to carry, I must carry it alone, no one who can place themselves in my position. You describe your neighbor's visiting, but it is usually 'nice-weather talk'. Here in the hospital, the patients' around you talk only of treatment side effects. Your roommate vomits all the time, so you seek refuge out in the corridor to eat and live out your life there. Nurses do their duty, you say, they come in with their medications, but if you have thoughts you would like to discuss, they remain too private to bring up yourself. You say the nurses are too busy and probably wouldn't know what to say because they feel bad that your treatment has not helped. How does one feel like a human being when you have lost all your hair, eyebrows, eyelashes, and pubic hair? How do you feel when your vagina suddenly becomes numb, you suddenly have no feeling, bleed easily, and your skin is thin as tissue paper?" (Kalfoss 1982, 52-53).

In this note, one can see two women suffering. My patient was experiencing her chaos, suffering, and loss of self, and I was suffering with and for her suffering as well as suffering over my potential vulnerability and mortality.

A couple of months after this entry, I faced and resided in my suffering in a different form. As a young mother, I was forced to witness my small son die slowly of a brain tumor over eight months. Experiencing this chaos, I again reached for my pen. Writing helped me uncover my brokenness while striving to find some coherence when I felt I was losing myself together with my child. The following entry voices a moment of my deepest anguish where my language fractured and I was thrown into the waves of the unspeakable deep.

> "I do not understand what causes one's defense mechanisms to break down. Do they tire and cannot hold out any longer? What is it that finally allows a person to suddenly empty herself and let go, to the depths, that one resembles a dog on all fours? Pawing at the ground, pawing so hard, so hard, so hard, that one falls over in a heap of pure exhaustion? You fought hard but with a sort of welcome relief, you give up. You open yourself, to your "self", to all those thoughts you have pushed into the darker chambers of your mind." (Kalfoss, 1982, 89).

As an older woman now, reading this diary entry, I have come to understand that the thought I was burying underground was the impending death of my little son whom I knew I had to meet. However, reading these words of ages past, what strikes me now is the language I used. I formed the metaphor of myself as the dog, pawing, pawing on the ground, and falling on its side in pure exhaustion. Here, my brokenness was so black I had no words to describe it. Unconsciously, only a metaphor could fill the gap in the unthinkable.

Throughout my nursing career, I have been given the gift to journey alongside many chronically ill people and bear witness to their words. I also believe I was an empathetic listener, or at least I tried to be. Sadly, I do know today, I didn't particularly listen hard for the symbolic language many of my patients used when attempting to grasp meaning in their experiences. I think If I had done so, I could have opened another door and entered into a deeper understanding of what might be hidden behind their words. I say this because some years ago, I started to read and collect narrative fragments voiced by ill people, which I found in personal reports, autobiographies, and research articles. As my collection grew, I came to a clearer realization that many people, perhaps unconsciously as well as consciously, use literary images and metaphors to describe their experiences just like I had done as a young mother.

The ideas presented in this book are ones that I have had for some time. The pages are centered on some of the voices I have collected, including some of my own experiences. The voices give words to what it is like to be thrown into the chaos of illness where one's sense of self becomes ruptured and incoherent. The voices speak of many forms of brokenness. For some, this brokenness may destroy language and isolate one in which we have no words to communicate. For others, brokenness creates language which can be shared and communicated. In the pages to come, you will find brokenness which screams and shouts, cries and calls, reveals and discloses. You will find big voices, small voices, still voices, deep and high-pitched voices, strong voices, weak voices, and of course, muted voices. All these tones vibrate in intensities conveying different images of how being ill is lived. The voices also bear witness to the intense struggle people undergo, as they attempt to gain back some wholeness of self. The voices also portray how a conglomeration of feelings, sensations, and thoughts merge into people's experiences. oftentimes threaded with symbolic language. They also shed light on the vast array of images and meanings that take form for those who find themselves in a space where they must negotiate and remake a sense of self. Importantly. I have come to believe that the major challenge of those who are chronically ill is the need to find a coherent sense of self over time when one's sense of self has been threatened and deeply wounded.

Usually, most stories are told in full voice. They are articulate and usually, as listeners, we are caught in a narrative web. However, in these pages, you will find only fragments, broken silent ruptures spoken by voices trying to find their words. Their voices speak the truth of the lived embodied experience of being ill. The fundamental aspect for all of us who are carers is our attempt to understand the ill person as being and becoming in their experience of illness. This holds that their needs or dynamisms, or whatever we want to call them, can only be understood in the context of the lived world and the existence of the unique person we see before us.

Notably. much literary discourse on chronic illness depends on a linear narrative that asserts coherence in the experience of illness by enforcing some sort of closure: either the ill person is cured or dies. As such, it fails to address the more disruptive and disjunctive experiences of many, which do not move unilaterally and unequivocally in the desired direction. By highlighting only optimistic stories of individual triumph, this discourse fails to give voice to the many continual interludes of suffering, emotional chaos, and hardship that overlap and even disturb the strictly linear pattern. Indeed, as a nurse, I have often witnessed this dark side of illness, yet sadly, there remains little written about it. Someone once said that if you can't find what you need to read in a book, then write it yourself. This has been my challenge. The fragments you find here show no closure, no linear movement in being ill. They remain as fissures, in their disruptive, yet dialogic absence of coherence. I have intended to engulf the non-linear, acknowledging both the chaos and human resiliency which encircles it.

Mostly, I have wanted the fragments to breathe and speak for themselves, to inform in their raw lonely nakedness and authenticity towards moving something in our imagination. I believe that illness fragments, voicing symbolic meanings, can give us all a unique lens to understanding more deeply how chronic illness is experienced by those afflicted. Their words and hidden meanings can *teach* us what it is to be human. At the same time, I understand well that the fragments also convey the inadequacy of written language which is bereft of the engagement, dynamism, facial and body language which are so needed in grasping any experience.

Simply said, these story fragments can also be regarded as a call to the reader, to "feel and witness with." It is my hope, therefore, that you will enter into the heartbeat and breath of the words, of the said and unsaid, and allow the said and unsaid to enter you. Can the words fire red in our feelings, thoughts, and senses and stir something deep within us? Can the words brush cold on our skins causing deepened awareness? I have intended to weave a tapestry of senses and emotions–intricate, complex, and poignant to increase our sensibility, sensitivity, and empathy toward the vulnerable ill person experiencing.

It must be remembered that the fragments presented here claimed primacy of my attention in some way. That is, they called out to me. Consequently, they claim my perspective and choice on one slice of a person's reality, excluding from consideration all other slices seen from other perspectives. Thus, the fragments represent splinters of time, which I have caught and held for a moment while reading about people's lives. They represent only slashes of reality in stories that remain ever-changing, unfolding, and unfinished. They represent one slice of a sense of self in a flow of nows.

It is also hoped that incomplete as any book on people's stories can be, the attempt to bring together various voices which are not in dialogue with the other's sense of time and space, will weave something together, creating a common essence and resonance of something shared. However, I am well aware, this can be critiqued for placing so many voices together, which drowns out the singular voice in all its deepness and complexity.

One can ask what are these fragments articulating. For me, they are attempting to voice what Arthur Frank calls suffering. “Suffering”, he says, “is the unspeakable, it is what remains concealed… beyond what is tangible even hurtful” (Frank, 2004, 335). The fragments also speak of the undoing, loss, and remaking of the self.

Without comment, I bring this Preface to a close with a poem written seven centuries ago by the Sufi poet Jalal al-Din Rumi.

Longing for the Birds of Solomon

Is this Stuff poetry? It’s what the birds sing in cages.
Where are the words spoken by the birds of Solomon?

How would you know their cries, if you heard them,
when you haven’t seen Solomon even for two seconds?

That bird lifts his wings, one tip touches East, one West.
Those who hear the note feel an intensity in their whole body.

The bird descends from the Holy One’s bedroom door to Earth.
And from earth flies among light back to the Great Seat.

Without Solomon, every bird is a bat in love with darkness
Listen, oh mischievous bat, try to become his friend.

If you go even three feet toward Solomon’s Mountain,
others will use a yardstick to measure their lives.

If your leg is gimpy, and you have to hop, what’s the difference?
Going there, even by limping, the leg grows whole.

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ONE

GROUNDING VOICES IN CONCEPTUAL VIBRATIONS

Illness rarely knocks before it enters.
—SUSAN SONTAG

Illness is huge. Illness, or more accurately, our relationship to it, threatens the way we know ourselves and how others know us.
—KAETHE WEINGARTEN.

Chronic Illness and Lived Body

All we know is mediated through the body; we receive the surrounding world through our hands, eyes, ears, and brain and it is through the body that we respond. We think and see and perceive through our bodies. Our body also mediates all our reflections and actions upon the world. For most of us who are healthy, the control, owning, and operating of our body is so automatic, so familiar that we never give it a thought, our bodies are normally beyond question, they are simply, unquestionably there. However, being chronically ill is a condition that takes away the certainty of the body and gives grounds to doubt the body. Perhaps, indeed, to lose one's entire body in total doubt on the journey.

This bodily experience of chronic illness can begin in a variety of ways. Sometimes, it originates with almost imperceptible differences in sensation or movement; at other times it emerges in the aftermath of a health crisis. Sometimes, it is characterized by rapid and frightening changes in the body; at other times, it begins with awakening to the realization that familiar symptoms may signal something serious. Some people are born with health problems that will become chronic; others have not yet experienced any bodily changes at all when they become victims of chronic disease. While there is no single sequence in which the onset and diagnosis of chronic illness occur, these events are profoundly important within the chronic illness experience. The underlying organic dysfunction–chronic disease–is only one aspect of the total reality of the chronic illness experience. An inscription, a diagnosis, marks a concrete body with an idealized notion of a specific type of body with a specific disease. Consequently, from the moment of diagnosis, most people feel differently toward their bodies. What is happening in the deep recesses of a person's biological system threatens to disrupt people's lives. One's body can no longer be trusted. Nor can it be ignored. Due to this, many chronically ill people become on guard, watching and listening to the body's rhythms, and its sensations or loss of sensations. During acute periods of illness, one's body can also intrude further into consciousnesses. This forced attention to one's body is an ongoing process for most of those who are chronically ill as described by a woman living with multiple sclerosis:

> "When I went to sleep at night, I was terrified that I might wake the next morning to find my limbs would no longer move. I interpreted every significant muscle twitch as a portent of disaster. Every sensation–pins and needles, numbness, cold, cramp-suggested to me the beginnings of abnormal and permanent sensory loss." (Toombs 1995, 6)

We can say, the chronically ill person experiences not just a breakdown of the body but a disruption of the life that is lived in the body. Living with chronic illness tears the person, often without warning, out of his daily life as the introductory quote to this chapter voices, "Illness rarely knocks before it enters." Chronic illness causes pain and unfamiliar symptoms, releases fears about further complications and premature death, and causes permanent changes in physical appearance and/ or bodily functioning. It disrupts the previous ease and everydayness of things. Additionally, it also poses an assault on self-images, and self-esteem, generates dependency and new demands for practical help, and removes feelings of control over one's self, one's life, and one's future. It forms doubts against valued past times and habits, raises or strengthens worries about family life, employment, and finances, and can generate and increase uncertainty about the appropriateness of previous activities, goals, and ways of life. Moreover, living with chronic illness also enhances distressing emotions such as anxiety, depression, resentment, and helplessness and can cause other severe psychological demands on the ill person and their significant others. As Kaethe Weingarten stated above,

> "Illness is huge. Illness, or more accurately, our relationship to it, threatens the way we know ourselves and how others know us."

Chronic illnesses also vary in their outcome. Some are brief. Some are more distressing and have prolonged courses. And some, as voiced by the chronically ill in this book, never entirely disappear. Chronic illnesses also vary greatly. Some lead to such a ravaged loss of functioning that the person is almost or entirely disabled. Others will experience a gentler journey. Still, for others, the journey will end in death. Chronic illnesses also tend to oscillate between periods of exacerbation, when symptoms worsen, to periods of greater smoothness, when symptoms and life remain on hold. Given the nature of the disorder, this life disruption will also manifest itself in different ways and at different times. But since the disorder is chronic, and the disruption is ongoing, even in periods of total remission, chronically ill people live with the disquieting knowledge that the disease is only temporarily quiescent. To live with chronic illness is to experience chaos in periods and a global sense of disorder–a disorder that incorporates a changed relationship with one's body, a transformation in the surrounding world, and a change in one's relationships with others.

Fredrik Svenaeus (2000) has described this global sense of disorder in a specific way. To be ill, he states, means to be *not at home in one's being-in-the-world.* It is to find oneself in a pattern of disorientedness, resistance, helplessness, and perhaps even despair, instead of the home–like the transparency of healthy life. We can say that illness permeates one's entire embodied being-in-the-world. This unhomelike being-in-the-world is characterized by a fatal change in the meaning structures not only of the world but of the self with illness. For ill people, Svenaeus (2000) claims, there occurs a change in their lived body through which their body is forced to the foreground. One's lived body shows up as an alien being (being me, yet not me) and this obstruction attunes one's entire being-in-the-world in an unhomelike way forcing an "otherness", an unfamiliarity and foreignness, that permeates the ill life. Illness, therefore, also disrupts one's embodied access to the world. The usual effortless and unself-conscious unity of the body and the self is disrupted, making one pay explicit attention to the body as separate or extrinsic from the self. Illness is thus recast as "a state of unselfconscious being that illness shatters." Chronic illness, therefore, can be understood as a radical transformation in the relationship between mind and body, one in which quite suddenly, a change occurs from a large taken-for-granted state characterized by a kind of bodily disappearance, shifts to varying degrees of disembodiment, and feelings of bodily betrayal and alienation.

Chronic illness has also been described as an altered state of existence arising out of an *ontological assault on the humanity of the person who is ill* (Pelligrino and Thomasa 1982, 32*).* It is an assault on the person–a wounding of their very humanity which forces a change in the structure of their human life world or “existentials.” That is, it challenges not only one’s lived body (corporeality), but also one’s lived space (spatiality), one’s lived time (temporality), and one’s lived human relations (relationality or commonality). Consequently, the perception of change in existential states also forms the central experience of illness. Pellegrino and Thomasma (1982) describe the ill person as becoming homo patiens–a patient–a person bearing a burden of distress pain, or anxiety; a person set apart; a person wounded in specific ways. They state that the uniqueness of illness among human experiences is rooted in this assault on the unity of being of the one who is ill. Those who are ill suffer the insult to their inherent humanity and whole being.

In sum, the diagnosis of chronic illness brings about a confrontation with the self, with its meaning, its slender grasp of autonomy, its obsessions, and dependencies. The transparent sense of body-self which existed before the diagnosis becomes opaque, disturbing the view, demanding detours, demanding a going-out-of-the-way. These are detours that are demanded, not chosen. It is the malfunction and mortality of the body and a fragmented sense of body-self that demands these detours. Importantly, each illness has its’ unique, valid, and poignant odyssey of detours accompanied by a myriad of new and worsening symptoms, paths of uncertainty, fear, and faith, peaks of truth, turmoil, and vulnerability, yet also triumph and hope. Importantly, despite these detours, many ill people find meaning despite being in a chronic condition that before the onset of their illness, they would have deemed intolerable and unacceptable. Such people handle the burden of chronic illness with amazing fortitude. They are also able to forge new and harmonious relationships between the self and the body with *both* serving equally as sources of guidance, knowledge, and values for living their lives.

Inner Voice: A Sense of Self

> *Where are the models for what I’m supposed to be in the situation?*
> —ANNE LORDE

In addition to the changed relationship with one’s lived body and the disruption of the surrounding world, chronic illness poses *continual threats to one’s sense of self.* I understand one’s lived body and one’s sense of self to be deeply interwoven. Living with a chronic illness involves continual shifts in self-identity. Importantly, it has been written that a major task for all those chronically ill is the need *to produce a personally valued and socially credited identity* (Charmaz 1987, 296).

As stated earlier, illness represents an ontological assault on the ill person's humanity, which includes a fundamental loss of wholeness. This loss of wholeness is related not only to one's physical status but most importantly, to one's experience of self. Living with chronic illness is the rupture "of the previous unity of self." (Toombs 1988, 223). Importantly, *illness fractures one's sense of self, momentarily and for longer durations*. Therefore, the ill person's sense of self, their feeling of intactness and integrity, feels diminished along with their body. An ill person feels what is happening to her body, is happening to *me*. This loss of self is a form of disorientation that people often express in terms of not knowing who they are, but can also be seen as a radical uncertainty of where they stand. They lack a frame or horizon within which things can take on a stable significance both within themselves and within their surroundings. This is a terribly frightening and painful experience as depicted by the introductory voice:

> "Where are the models for what I'm supposed to be in the situation? I want to write of the pain I am feeling right now, of the warm tears that will not stop coming into my eyes–for what? For my lost breast? For the lost me? And which was that again anyway? For death, I don't know how to postpone. Or how to meet elegantly? I'm so tired of all this. I want to be the person, I used to be, the real me. I feel sometimes that it's all a dream and surely, I'm afraid to wake up now" (Lorde 1980, 25).

This disorientation and uncertainty about where one stands as a person seems to spill over into a loss of a grip on one's stance in physical space. A sense of self is linked to a sense of orientation so when one loses one's orientation or has not found it, one is not to know who one is.

Consequently, learning to live with a chronic illness involves continual shifts in identity as the person grapples with the changes in one's sense of self that existed before the illness as described by the women above. Shifts in identity for the ill person and the struggle for finding a coherent sense of self involve an ongoing process of grasping images, monitoring changes, negotiating, constructing, and reconstructing. The self is described as being dynamically, continually, and progressively reconstituted throughout the prolonged experience of illness. Therefore, most of those who are ill devote much effort to preserving their sense of self. Although self and body are not the same, each informs the other. Consequently, changes in the body affect changes in the self. As new discomforting images arise from tensions between bodily feelings and views of its appearance, this prompts the ill person to struggle with preserving the self despite bodily decay. Preserving the self means maintaining essential qualities, attributes, and identities of the past self which are fundamentally reshaped in one's present self-concept. Thus, ill people will be called upon to relinquish some identities but retain others. By preserving the self, the chronically ill reconcile the identity struggles that the illness thrusts upon them. Preserving self also implies maintaining a way of being in the world and a way of relating to and knowing self, others, and social worlds. Likewise, by attempting to preserve self, the ill also maintain a sense of continuity throughout the past, present, and future.

Therefore, we can say, everyday experiences in living with chronic illness can be understood as a journey of ongoing identity work. The chronically ill person's sense of self is a subject in process, with identities constantly called into question brought on trial, and overruled. This is a process of becoming rather than of being as voiced by another woman with breast cancer, "I was in a sense, moving one from one identity to another" (Mayer 1992, 59).

In sum, we can say that maintaining and sustaining a coherent sense of self is a major task for all those who are chronically ill. This o*ngoing reshaping of a sense of self lies at the core of the lived experience of bearing a chronic illness* as the many voices in this book bear witness to.

What is a Sense of Self?

> *The self is itself a word or caught in words.*
> —AMIR ALI NOJOUMIAN

If maintaining a *coherent sense of self* is a major task for all those who are chronically ill, one can pose the question, "What is meant by a sense of self?" I believe almost everyone carries within themselves a sense of self or who I am. That is, we can look back on ourselves as both subjects and objects of the universe. However, there are probably as many notions, definitions, and theories of what a self is, as the centuries which have been used to contemplate this issue. To add to this confusion, the word "self" is also used in all sorts of ways and is used interchangeably with such words as identity, self-identity, self-concept, self-image, personhood, and ego to name a few.

In pondering over the question of what is a sense of self, perhaps the best way to grasp this idea is to focus on what we usually describe today as the question of “Who am I?” I understand one’s sense of self to be grounded in the answer to this question. We are beings of inner depth and complexity who strive to maintain a coherent picture of the question “Who am I,” which also includes images, thoughts, and feelings of who I am, how I am, what I am, as well as the “Me.”

We also experience our sense of self mainly in two senses. The first sense is that of being an active agent who acts on the world as well as is influenced by that world. This type of self is usually referred to as the “I”, and focuses on how I experience myself as a doer. The second is how I experience myself as an object of reflection and evaluation. In this type of sense, my attention is turned toward the physical and psychological attributes I use to contemplate the constellation of skills, traits, attitudes, opinions, and feelings that I have. This type of self is referred to as the “Me”, and focuses on how I observe myself from the outside looking in, much like like how I monitor and contemplate the competence and character of other people. We can understand the “I” as the doer, as being distinct from the self-as-object, or the various “me’s”. The “me” allows me to reflect on past events, analyze present perceptions, and shape future experiences. Thus, my “I” represents the processes by which my self is formed, and the actual content of these processes can be understood as that which forms me.

Erik Erikson (1997), a psychologist who developed a theory of psychosocial development, described our sense of “I” as our subjective awareness of being a sensory and thinking creature endowed with language, who can confront a self and can construct a concept of an unconscious ego. He described the “I” as including a sense of being centered, active, whole, and aware. It takes a sense of the “I” to be aware of myself, or a series of my selves, while all the variations of self-experience have in common the conscious continuity of the “I”. Thus, he regarded each person as a core of awareness in a universe of communicable experience, a center so numinous that it amounts to the sense of being alive and, more of being a vital condition of existence (Erikson 1997, 88).

Many perspectives focus on the self as being in some sense fixed and definable as Erikson proposed. According to this view, the self consists of a person's conscious and unconscious aspects, personality, cognitions or thoughts, and feelings. Additionally, it includes feelings of agency, ownership, feelings for the body, autobiographical memory, experiencing the self as a unit, or labeling of stimuli as self-referential. We can understand one’s sense of self as an integrative pattern of these characteristic features which is the anchoring unit for our self-conscious experiences and is anchored in our body.

Psychiatrist Daniel Stern (1985) argues that a crucial term to be considered is a *sense of*, as distinct from a concept of a self. The emphasis of using the term "sense of" rests on the palpable *experiential realities of substance, action, sensation, affect, and time*. According to him, a sense of self is not a cognitive construct but instead *an experiential integration* of these experiential realities. This sense of a core self, he states, will be the foundation for all the more elaborate senses of the self which we add on later in life (Stern 1985, 45).

Goffman (1963) describes one's sense of self as *being multifaceted and composed of many "selves*" which are formed through processes of self-definition and social interaction which shape an evolving self (Goffman 1963, 147). Another author, Charmaz, who has written about the chronically ill, builds on Goffman's view and describes a sense of self as an emergent structure or organization that may shift or change as the person reflectively interprets the images and identifications that self and others confer upon him or her (Charmaz 1987, 284).

Understandably, we can perceive a sense of self as representing different meanings, from fundamental and abiding sameness to fluidity, contingency, negotiation, and so on. Other perspectives, by contrast, have sought to introduce alternative concepts in an attempt to capture the dynamic and fluid qualities of human social self-expression. Still, others suggest understanding a sense of self as an emerging process, to take into account the reality of diverse and ever-changing social experiences. Some scholars have introduced the idea of identification, whereby identity is perceived as made up of different components that are "identified" and interpreted by individuals. Other scholars conceive the self as emerging out of the mind, and the mind as arising and developing out of social interaction. The mind is, therefore, regarded as the thinking part of the self, essentially, the covert action in which the person points out meanings to himself and others. The ability to point out meanings and to indicate them to others is made possible by language, which encapsulates our meanings in the form of symbols. When one's self is encapsulated as a set of symbols to which one may respond self as an object, as it responds to any other symbol, the self has emerged. One could say the trademark of this process of emerging selfhood can be understood as reflexivity. As I underlined earlier, in being human, we can see ourselves as an object. We can regard and evaluate ourselves, take account of ourselves, and plan accordingly to bring about future states.

Moreover, we can be self-aware or achieve consciousness concerning the way we are a processual entity. We formulate and reflect, and this is an ongoing process. We also search the horizons seeking ways to recognize ourselves and those who surround us, yearning to place ourselves within space and time, and infinity in confirming our beliefs that life means something. One's sense of self can also be thought of as *an unfolding story* in which we are trying to make sense of *who I am.* Making sense of our life as a story also takes place in the space of questions we continually ask, and in which only our coherent narrative can answer. Being human, we exist in a space of questions, which we answer according to our own beliefs of where we stand and what meaning things have for us. Most of us want our sense of self and lives to have meaning, weight, and substance and grow towards some fullness. We also want our future to "redeem" our past, which has a sense of purpose that can give us a coherent sense of unity.

Our narrative structure of who we are at present also has a larger role. What we are can be understood as what we are becoming. This is the essence of our narrative understanding. This notion of self is also supported philosophically, by Heidegger who posits that to have a sense of who we are, we must also have a notion of how we have become and where we are going. He described this as our inescapable temporal structure of being in the world. He means that from a sense of what we have become among a range of present possibilities, we project our future being. Thus, one's sense of self unfolds among the different opportunities we experience and how we project our lives about it.

These different notions of what constitutes a sense of self demonstrate how difficult a concept is to describe concretely. Since a sense of self is a virtual thing, it is impossible to define it empirically. However, I believe most people carry a sense of it within. And I believe this is what becomes broken and needs reshaping in the experiences of being chronically ill. I understand the ill person's sense of self as being that anchor or an integrative force in their life which is grounded in their sense of who I am and who is me. I also understand it as being grounded on the palpable experiential realities of substance, action, sensation, affect, and time as described by Stern. The ill person's sense of who I am is also grounded in their lived body, in their embodiment. Therefore, I regard a sense of self as not representing a cognitive construct. I view one's sense of self as an emerging and evolving experiential integration of the many various senses of self that have been added to a core sense of self, through time. It is this experiential integration of self that I believe becomes deeply ruptured in the plight of chronic illness.

Inhabitating Shifting Liminality

> *You stand on the threshold of the doorsill neither in one world nor another. This can be a frightening place to be.*
> —LAURENCE GALIAN

As I have previously underlined, many ill people experience forms of disorientation and uncertainty about where they stand as a person and this seems to spill over into a loss of a grip on one's stance in physical space. We can understand the ill-lived body as consisting of those lived spaces where bodies are located conceptually and corporeally, metaphorically and concretely, discursively and materially, being simultaneously part of bodily forms and their social constructions. These lived spaces inhabited by ill bodies can be apprehended as forms of liminality. Liminality is a term used to describe qualities of transitioning and the state of being in-between and ambiguity. Together with considering the importance of a sense of self, I also offer the notion of liminality as an additional lens for understanding the lived experiences of the chronically ill.

Liminality was first described from a cultural anthropologic view by Van Gennep (1960) who used the term to identify a quality of transition in rituals and rites of passage. Typical rites include life events such as pregnancy, birth, marriage, and death. He also described rites of passage as being divided into three stages: the separation, or detachment of a subject from its stabilized environment; the margin, which is an ambiguous state for the subject; and the aggregation, in which the passage has completed and the subject has crossed the threshold into a new fixed, stabilized state.

Turner, a cultural anthropologist drawing on the work of Van Gennep, described liminality as "*a movement between fixed points which is essentially ambiguous, unsettled, and unsettling*." Liminality can be discerned as a stage in the process of change, a stage of threshold *(limen)* that alludes to the possibility of moving to a new stage or reverting to the old. In Turner's words, the "coincidence of opposite processes and notions in a single representation characterizes the peculiar unity of the liminal: that which is neither this nor that and yet is both" (Turner, 967, 95). Persons fall "betwixt and between" past and future categories. The liminal person, while neither located in the departed stage nor the arrived-at, is still reliant on the presence of both stages. Consequently, this "transitional being," or "liminal being" is characterized by a series of contradictions and cannot be easily placed into a single category of existence. As having departed, but not yet arrived, he/she is at once no longer classified and not yet classified…neither one thing nor another; or maybe both; or neither here nor there (Turner, 1967, 94).

Furthermore, the liminal being is imaged as being invisible both structurally and physically. Structural invisibility is the inevitable result of losing or being without social status or what is called by some the rolelessness of persons. Liminality, thus, also refers to a social space characterized by ritualized degrees of separation from society. As such, the term liminal alludes to a *space-between, a place of ambiguity and transition*–a site of passage in which borders, boundaries, and thresholds are crossed. It is a space-between consisting of a blurring of categorical boundaries and a crossing of metaphysical thresholds, allowing for the dissolution of perceptual borders, and the dismantling of fixed identities, which include the exploration of subjective/objective dynamics within a person. Therefore, ambiguity and paradox are also described as characterizing liminal persons where inner nature is somewhat incorporeal and dissolved during liminal periods. Liminal persons are also characterized as being naked, and unranked of anything that differentiates them from others. They have temporarily fallen through the cracks, in the interstices of social structure. We can say the liminal state or liminal space is characterized by indeterminacy—one's sense of self ruptures to some extent and becomes less clearly recognized, disorientated, disembodied and fragmented. Importantly, however, liminal personae share as communitas through an interconnectedness with the unbounded, the limitless, and the infinite which also supports the powerful generativity that can occur in liminal spaces. In these spaces, the liminal person can meet other humans, outside the prescribed roles and as equals, and jointly experience a common humanity. They also hold a period of transitioning the situation which can lead to new perspectives and a reconstructed sense of self.

Importantly, liminality has also been described as a fundamental category of experience of those living with chronic illness (Little, Jordens, Paul, Montgomery et al., 1998, 1490). Based on the conceptualization of liminality described above, the chronic illness experience can also be understood as living in between and through changing liminal processes. How the chronically ill inhabit liminality can help us understand their attempts to grabble with the ambiguous nature, uncertainty, and complexity of their shifting sense of self in their illness experiences.

Chronic illness can be understood as a transitional state and a blurring of boundaries (between health, sickness, and recovery of health, between life and death) in which the ill person has been isolated from his/her familiar social context, routines, and activities and passes through a cultural realm that has few or none of the attributes of the past or coming future. Chronic illness pushes the ill person into a temporal and spatial zone which is liminal insofar as it involves the interruption of the normal course of events, segregation from the healthy, long periods of waiting, and life-changing consequences. The ill person finds oneself “betwixt and between” the normal day-to-day culture and social states. Most chronically ill also live with the possibility of recurrence which represents a blurring of the boundaries between sickness, recovery, and health. This boundary or blurring of boundaries can be understood as being liminal where one inhabits a space (at the edge, being on a threshold) suspended in time.

As one chronically ill person voiced:

> “I felt that I was in a place that was between the living world and the dying world and it was like a grey space and everything was grey and I wasn’t frightened of it but I was aware that I was in a space that other people aren’t in” (McKechnie, Jay, and Macleod, 2010, 9-29).

Another chronically ill person described her blurred boundaries as such:

> “My experience had shown me that I belonged outside of the binary. I have experienced periods of liminality, but these can only be described as such because of what happened before and afterward. Dialysis would be one example of this because it allowed me to transition from end-stage renal disease to having a healthy transplant, not having a story ritual to explain my newfound health was another. Coming to terms with my post-transplant identity forced me to confront the extent to which I had bought into the medicalized binary of well/ill. It showed me that I felt “abnormal‟ because I had not been able to see further than the binary to the unsettled and unsettling spaces that I usually occupied. These were not wrong; they were just different. My battle to preserve a veneer of normality and wellness, despite the constant reminders that I was other, took a toll on me. The monstrous cannot be confined to the place of the other; it is not simply alien but arouses the always contradictory responses of denial and recognition, disgust and empathy, exclusion and identification.”

She further stated:

> “I needed to recognize and accept parts of my experience that I had long denied. I could only do this through reframing my experience and I could only do this by writing. I wrote myself a third space alternative to being well or ill. This space was not in between the binaries along a continuum, but elsewhere. I called it the littoral zone. This is a maritime term used to describe the area of the seashore where the waves wash in and out. It is a

> messy area that contains flotsam and jetsam, tracks that are made and erased and overwritten. It is neither sea nor land. It is something else entirely and always dynamic and shifting. It is a blurred boundary. It can be a threshold to another realm, but it can also exist as a zone in itself" (Richards, 2012, 25).

As noted by these examples, the experience of liminality is closely grounded in a sense of self with the shedding of old identities accompanied by feelings of brokenness and discontinuity. The liminal challenge for the ill person is to negotiate and makes sense of their liminality. The chronically ill person's sense of self is a subject in process, with identities constantly called into question brought on trial, and overruled. This is a process of becoming rather than of being as described by a woman with breast cancer who voiced

> "The reconstructed breast retained its power as a metaphor for my whole sense of self but the symbol was becoming increasingly mixed. I was the same person–sort of until you looked closely- but my inner landscape had radically changed. I was in a sense, moving one from one identity to another" (Mayer 1993, 11).

Consequently, in this liminal space, the ill person's most important challenge is to negotiate a new self. Reassessment of identity, therefore, lies at the core of the illness narrative as epiphanies are pivotal life-changing experiences altering a person's fundamental meaning. Another chronically ill woman described the liminal space she was inhabitating as such:

> "It feels like being in a kayak in a five-class rapid. While you are going through the rapids, time and space shift so rapidly, up and down, right and left transpose so often, that one truly feels inside a vortex, the way out which is entirely unknown in any one moment. Ultimately, my chaotic narrative pitched me into silence. Unable to find any models of it, I assumed I was going mad. Shame (and rage) silences me" (Weingarten 2001, 3).

The concept of liminality has also been applicable in nursing research where I present a few scant cases. From a research point of view, Little, Jordens, Paul, Montgomery, and colleagues (1998) suggested that seriously and chronically ill people enter into a state of liminality with the first manifestation of their disease and that the state can continue for the rest of their lives. They describe liminality as a process that initially is an individual's attempt to deal with the disruption of life after the illness incidence and, later on, a continual adaption to illness by constructing its meaning through narrative. They suggest that people diagnosed with a chronic or life-threatening illness do not necessarily pass through three clear phases, as described by Van Gennep, but rather liminality is experienced as an enduring state. These authors found in their research, that the ill tend to proceed through two phases: Of acute and sustained liminality which persists until the end of life. Acute liminality begins with the first manifestation of disease and diagnosis and is characterized by disorientation, loss of control, and uncertainty. Sustained liminality follows the acute phase after an indeterminate period of time and is described as an "adaptive, enduring phase" characterized by a search for meaning and challenges to identity. Liminality was seen to reflect three narrative themes which they described as "cancer patientness", communicative alienation", and "boundedness" which have also been described by others (Blows, Bird, Seymour, and Cox, 2012, 2158). These researchers argued that, although the specific features associated with each theme change over time, liminality remains the most fundamental aspect of life with chronic illness. The notion of liminality can be understood as being composed of an inner liminality (liminal body-self and also as a body-self inhabiting exterior spaces, consequently the liminal contains both spatial and temporal dimensions of betwixt and between. Said in another way, we can say that living through chronic illness can also be understood as living in and through liminal space and in-between liminal processes. This is aptly depicted by Murphy, a social anthropologist, suffering from paralysis which he described his situation as such,

> "In the long days and nights of my recovery from spinal cord surgery, I would lie in my hospital bed and think, too weak to concentrate on reading and yet not sick enough to watch television. And what I mused upon was myself and my new and permanently altered feelings of who and what I was. Gradually my thoughts became disembodied, and I began to think of myself as if a part of me were perched over the headboard, waiting for the rest; it was as if it was happening to somebody else." (Murphy 1987, 5)

In summarizing, as these narrative fragments and research suggest, a shifting sense of body-self in liminal spaces is a major struggle among those who are chronically ill. Inhabitating liminal space is deeply interwoven with one's sense of self suspended not only in space but also in time. It is important to understand that the array of meanings and responses ill people use to make sense of their situation, can never entirely resolve the essential ambiguity which is at the center of their liminal experience. The ill must continually cross thresholds (borders) and deal with the oscillating trajectory between acute and sustained liminality. I believe that the notion of liminality has a significant contribution to make in helping us to attempt to understand an ill person's experiences because it offers insight into the ever-changing process of feeling human and broken, and thrown into illness spaces where one's sense of self is threatened and continually shifting.

Lived Time and Time-spaces

> *He never knew a single second could be expanded into something timeless and so archaic. It shook him to his core–there were no words for it.*
> —DIANNA HARDY

As I have previously written, the ill person's existence in liminal spaces is deeply interwoven with their feelings of being suspended not only in space but also in time. As captured in the quote above, a single second can be experienced as expanding so greatly into a timelessness that it can shake the very core of one's being. For the chronically ill, a very distinctive characteristic of their illness is its temporal dimension, meaning the ill person's *sense of and experience of time*. Being human, we come into being, develop a sense of time, have a relationship with time, and are, therefore, essentially temporal beings. Put another way, we can say as embodied beings, we are the consequence of time. We know that we go ahead and that we don't turn back, there will always be a packet of years that is destined for each of us. Consequently, most of us live with a linear view of time which spurs us toward our future. Although we act as if time existed objectively, it is a feature of the world we all share and experience. Shared time helps define not only our social world, action, and work but is also a fundamental orientation to our embodiment. We can describe time as being both physical and mechanical, as well as experiential and cultural. The relationship between time and our lived bodies are dictatorial yet frail, controlling yet ephemeral. Encouraged by small gains, we bargain and negotiate, obscure and reconceptualize our relationship with time, but victory is always tentative because time is inexorable. Time is also the fundamental element in the unfolding of our mortal lives and their impending termination.

Although chronic illnesses have varied physiological, biological, and pathological properties, they also share these common aspects–time and temporal aspects. The term "chronic" actually arises from the Greek word "Chronos," which at its root simply refers to the passage of time itself. Time mirrors the life of those living with chronic illness because the illness persists over time and doesn't go away.

Consequently, living with chronic illness introduces new dimensions, meanings, and relationships to time that are different from those who are healthy and those who experience acute illness. Ill people's very sense of embodiment in experiencing illness, bonds with aspects of their pasts, presents, and futures. Thus, perception of time plays a very important, yet often hidden role, in shaping ill people's sense of self. We can say that temporal continuity, or its lack, grounds one's concept of self. Consequently, the physical, mental, social, spiritual, and existential pains of chronic illness ultimately become losses of the self in the ill person's experience. These losses can also be understood as *disruptions of the self's continuity through time and space.* Time is re-embedded in a loss of self and the self is reconstituted in time. While time assumes a dictatorial role in renegotiating a sense of self, it is the re-embodiment of time in the body that points to new opportunities for a remaking of the self. Stated in another way, Charmaz (1993) writes that *control over time is a struggle to control the defining images of self.*

Chronic illness also results in a profound multi-dimensional sense of temporal disruption, one in which time has to be completely and continually re-ordered. The basic temporal problems–too much, too little time, scheduling, and timing–involve ill people in a delicately balanced game of temporal juggling. Such temporal disruption adds a further subtle layer of hindrance to the experience and challenges of living through chronic illness.

For ill people, this temporal juggling is also experienced differently. For some, time drifts very slowly and hangs heavily, for others it speeds up, while for others, one's sense of time can be completely lost. Still others will live time at the moment, existing from day to day while trying to keep past and future from totally consuming one. Likewise, others can feel warped in an alien present. Some can have a sense of being suspended in time, without feeling movement in either direction. Consequently, many forms of timelessness can occur when time falls outside the linear order. As time slips away, various ill people may feel that their existence slips away. One chronically ill person aptly described this sense of time as such:

> "I feel like it's time long before anybody else feels like it's time. It is just some kind of time warp. The time warp, in general, gives no sense of a beginning, middle or end to its structure." (Henderson 1998, 47).

Still, others will face the time of a failing body and death. Contrarily, for others, lines between past and present time can merge in a way that an intense present feels richly lived.

However, ill people's sense of time can also render their experience more comprehensible. Many ill people divide their lives into periods of illness and non-illness, crisis and quiescence, flare-ups and remissions, rigid regimes and convalescence Moreover, one's immersion into illness will