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University of Alberta

To Be Diagnosed: The Experience of Persons With Chronic Mental Illness

by

Yvonne Marie Hayne ©

A thesis submitted to the Faculty of **Graduate Studies and Research** in partial fulfillment of the requirements for the degree of **Doctor of Philosophy**

Faculty of Nursing

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Abstract

The purpose of this study is to offer a phenomenological account of psychiatric diagnosis as experienced by persons suffering from a serious and enduring mental illness. Lived experience accounts were gathered from a variety of formal and informal sources. Fourteen participants shared their experiences of diagnosis in semi-structured interviews. Participants provided drawings as an additional source of meaning for expressing their personal experiences. Some of these drawings offer images of "self" before and after diagnosis.

Holding to a phenomenological attitude, the transcripts were edited by distilling from the interviews individual accounts and unique stories. The stories aim to provide unique and concrete experiential descriptions (phenomenological "examples") of the experience of psychiatric diagnosis. The voices of participants are situated in the text without methodological regard for their biographic identities. Rather their life stories are used as an aggregate of experiential accounts for exploring the subjectivities of diagnostic experience. Rich anecdotal detail is incorporated throughout to bring the experience of diagnosis into vivid nearness or presence. In this way, the research aims to let the phenomenon "speak" in such a way that the experience of diagnosis becomes recognizable.

What registers in this text are a variety of themes that seem to give structure and meaning to the experience. However these themes are not to be understood as empirical generalizations or theoretic findings or concepts. Rather the themes are considered possible interpretations of possible human experiences. Psychiatric diagnosis places the individual in a context of reflective self-knowledge that complicates the self-knowledge that already inheres in mental pathologies such as schizophrenia or bi-polar disorder. How aware are health science practitioners of these experiential complications? How should this awareness have consequences for their practices? Phenomenology does not offer rules for application but it aims to increase professional discretion, insight and discernment.

A conclusive portrayal of the phenomenon of "diagnosis" is offered to relate insights to the sphere of professional practice. "Discernment" noted as a primary benefit of this study, is discussed in ways that touch on major issues of nursing practice and show how phenomenological understandings are consequential to the practice of health care. The study is brought to a close with emphasis on the experience of diagnosis CMI as a relational experience with the role of the care provider as vital to healing.

Prologue

This thesis is inspired by Max Van Manen's explication of hermeneutic phenomenology (1990) which supplies the leitmotif for this exploration. It is well recognized in this human science research that the researcher needs the other (the reader) in order to validate the phenomenon in question. To set up the tenor of this "text" for the reader, it seems useful at this point to detail some of what invited my interest in the subject matter of this study and to comment up-front on how the study unfolded. In that way, a tone is established for intersubjective entry into a dialogic relation with the phenomenon of "diagnosis."

One cannot, I suppose, undertake a study such as this without being somewhat transformed in the process. Mine has been no less such an experience. Like all phenomenological reflection that is retrospective I reflect on this journey through the study, itself a "lived through" experience that has taken me from an apparent interest in *diagnosis* to a, now, deep sense of guardianship over the phenomenon of "diagnosis." Through the exercise of "doing" the research I have been brought to a honed sensitivity to meanings imbedded in *diagnosis* and to a deep respect for the "word" of those challenged by chronic mental illness (CMI). Lived-experience in the domain of mentally ill persons has remained largely in a tentative position in scientific research. Called into question in this study was the "reality" of the experience as accounted for by the participants. There was a concern centered on participants' credible recall surrounding their "diagnosis experience" that fits the uncertainty expressed by those who entirely dispute the value of personal accounts in qualitative study at all. Such accounting, they allege, may be overly subjective, or perhaps too limited in nature and of questionable reliability. I hold with Allport's (1951) assertions of personal narrative (in this case the story of persons with CMI) as a vital "gateway" to knowledge and a fundamental "touchstone of reality" (p. 184). The accounts of participants were given primacy, in full recognition that with diagnosis of CMI may be added concern with accuracy of recollections and legitimacy of story. Unreservedly, however, there is no question of legitimacy of "the experience." This, an important emphasis to be made! As with all study (qualitative in particular), there will always be question of the accuracy of "data," perhaps, a justifiable concern over disparity between "actual" versus "perceived" reality in recollections of experience. Let it be said however that though verbatim recall of "actualities" may be in question, the reality of *the experience* can never be disputed (Van den Berg, 1995). And, what is important is *that* experience! It is that which we strive to seek out, that which will serve as a cornerstone of insight. Van Manen (1990) refers to such experience as borrowed from others so that we might, ourselves, become more experienced. And so this study ventures into the world of chronic mentally ill persons in an attempt to enlist their experience of *diagnosis* so that "we" in professional practice might be made wiser to it.

There is a personal awareness that early in my own professional practice I may not have attended to the phenomenon of *diagnosis* as a relevant one. Indeed, at that stage I would likely not have questioned the medical (psychiatric) diagnosis. Nor would I have recognized that it may be consequential to persons' sense of being, possibly even affect the course of their illness and healing. Indeed, in clinical scenarios it is unlikely I would have used the term "person" to refer to the ill individual. I would likely have used "patient," not considering that this in itself is a labeling. To me "patienthood" was simply confirmed by the diagnosis. Even those for whom a diagnosis was not yet established would commonly be diagnosed, "NYD" (not yet diagnosed). A diagnosis for non-diagnosis!

Contrary to earlier stages of my professional life at some point I began to wonder about how diagnostic labels might be impacting on the bearers of those labels and further, how those labels may be modifying the way I related to "patients." Too, I began to question a connection between the diagnostic label and "healing." Perhaps it was my years in "Psychiatric Emergency Services" which really brought this to the fore. With the "prime directive" of this service to establish an initial provisional diagnosis, I began to see more clearly the psychiatric diagnosis as a distinct phenomenon of consequence. The psychiatric diagnosis served "*disposition*" in health care well, but was there a subtle, unrecognized cost? One clinical situation vividly stands out. It concerned a young woman in her late twenties who arrived at emergency with her husband at some point after midnight. She was visibly disorganized, irrational in her speech, and not making much sense to the emergency night staff. Her husband related they had recently been married and he had not before seen his wife in such disarray. In her purse was found Lithium.

On discovering the Lithium the emergency staff may have concluded the woman to be having an acute psychiatric disturbance. Their action was to contain the situation while awaiting the morning arrival of the psychiatric assessment team. Something was indeed irregular about this lady's presentation, which very suddenly took a turn for the worse. Something cerebral, it seems, culminated in this young woman's death One can't help but wonder whether an assumption of "Manic Depression" had not compromised this lady's care. Had the Lithium not entered this scene would a different course of activities been decided? The questions have all these years stayed with me.

As the power of the psychiatric diagnosis was, for me, crystallizing, I began to see its influence on me later, in my role with nursing students. In an instructional capacity I always held to an abiding belief in "the relational process." Basically, though, nurse education was driven by curricula tailored to medical models of care. Patients were "schizophrenic," or "manic depressive," or "neurotic," and so on. Labels, which carried with them prescribed motifs of nursing care, dictated particular interventions. "Presencing" with patients had certainly not yet entered health care vocabulary. Is it any wonder the prime intent of students on "clinical days" was to access patients' charts. Of course, their need was to know "their" patient's diagnosis in order to establish care. The diagnosis seemed of absolute importance. I began to insist students have an introductory meeting with their assigned patient before accessing the charts. Students were required to reflectively write about this initial encounter. The exercise was intended to bring to light the importance of becoming acquainted with the person behind that medical label, a difficult message in health care systems so committed, as they are, to categorizing illness. Medical "languaging," and instituting "care" plans are designed to parallel *the* diagnosis. Without the diagnosis the blueprint by which health care is to act seems missing.

Increasingly, I came to feel distressed about the trend I was witnessing in mental health care, what I viewed as preoccupation with diagnosing as a "convenience" to health care professionals in their aims of "treatment." I questioned a perceived omission in treatment programs that manage illness to the exclusion of dealing with what being diagnosed might mean to the lives of persons receiving that pronouncement. It seemed, as one participant notes in this study, a lopsided-sided economy in health services that was self-serving. In my assertions about this I was aware of possibly earning a label of arrogance; standing in opposition to a "biomedical model." However, *that* interpretation would certainly be remote from the intents with which I approached this study. As I undertook this study, I became increasingly committed to the sincerity of its aims. I was convinced I was not at odds with the mandates or operations of other professional groups. There is no question I recognize "Medicine" operates primarily from a principle emphasis in cure that dictates a function to diagnose. However, I could see other professional groups also taking up this emphasis on diagnosing. My concern was how persons in treatment might navigate this "diagnosis maze." How did diagnosis impinge on the patient? This study I saw could serve to highlight *diagnosis* as something significant, and perhaps exceedingly consequential to CARE and HEALING. That was its essential purpose.

Limits to the target population were designed to capture the stories of those I determined would be reasonably able to express their lived-experience. The study, then, was directed to those with a severe and enduring mental illness (a chronic illness), who I thought would have achieved a semblance of life stability in managing their illness. This perhaps introduces an "elite bias" in that only those who had most successfully managed their illness may have stepped forward.

In contemplating this study, I had originally envisioned the need for about five to six "good" stories, thinking I would be hard pressed to find volunteer participants to meet this quota (see added procedural details of the study delineated in appendix A). Upon advertising through local organizations such as the Canadian Mental Health Association

(CMHA) and the Mental Health Consumers Network I was somewhat stunned with the forthcoming response. I then realized I could have obtained more than enough participation through word of mouth alone. Decision was made to cap participation for this study at fourteen. Some explanation for this unexpected response rate was offered by one participant to do with "consumers coming of age." They want to get their story out! With the new generation of medications involved in current treatment protocols, illness symptoms are better controlled, to the extent that "survivors" of serious mental illness are now better able to reflect on their experiences and articulate them in intelligible ways.

And so, interest in the study was coming from numerous places. I was facing the need to accommodate long distance telephone participation throughout Canada. I was required to travel to parts of Alberta and meet with participants in their home if that was their wish, or at their office locations, or at the local "A&W" if that was specified. My car in "a" parking lot was the desired location for two persons, and one other participant chose a church office as location for his discussion with me. Remarkably few meetings took place in formal office locations, and more remarkable yet was that every appointment time was honored and not one of the respondents retracted their wish to be involved.

It was an incredible experience to just sit and attend to peoples' stories. For some, the telling reawakened deep pain, and I was drawn into that grief. All of the participants had a significant story of *diagnosis* to tell, a story that seemingly could not just be told without also recounting the circumstances deemed to have induced it. For me as "interviewer" it meant listening to much sadness, hearing great suffering in those stories which sometimes involved childhood abuses. At times it was exceedingly hard to sit and hear it all, and the desire to remove myself from it was hard to control. Indeed, appointment times were intentionally spaced to afford respite from it.

In the end massive amounts of interview materials were amassed, that included drawings with participant interpretations of experiencing diagnosis. My quandary ahead was how to reduce and transform all these materials into a meaningful textual presentation. Was I to select only some of what I deemed the most meaningful of the stories, and incorporate only those into the phenomenology? Indeed, that would be a credible way to proceed. But then, how and on what basis would I justify representing some of the stories and not others? Could I say, "Well, of the four persons diagnosed with "dissociative disorder," I will pick this one because I like it best. And of these three with diagnosis of bipolar disorder, or schizophrenia, I will only represent this one and that one, because to me they speak the strongest. While this course is acceptable in phenomenology (Van Manen, 1990) my restlessness was that in so doing I was posed with having to choose some over others, and speaking for a select few of those who had contributed time and effort to be "heard." How could I say some stories were important and others were not?

Ultimately, I elected to represent all fourteen of the stories. This results in a rather massive product, but in choosing to take into account *more* rather than *less*, I had the self-assurance of a phenomenology that would "speak" the stories of those who had involved themselves.

Opting for "inclusiveness" did mean facing the awesome challenge of reducing all of what was being said in those thick interview files. At first, the computer program NUDIST was thought a good recourse, a way of condensing it all into categories.

Extensive effort was required to cull each transcription and fit every statement into one of eighteen emerging categories, such as, "the cauldron of events preceding *diagnosis,*" "trigger events to acute illness," and "the moment of hearing the diagnosis." Other categories spoke to "the power of the diagnosis (to explain, inform, direct)," "the losses," "diagnostic 'ID'," "coping," and so on. But as I stood back and looked over the entirety of this effort, I came to a sense of something critical missing. There seemed a sterility to the categories. Commentary on potent experience now seemed stripped of texture. What seemed thinned away was that which really spoke to depth of the experience in "soulful" ways. It was like having simply taken everything apart and in so doing loosing the heart of the stories. What remained was "pieces." This realization prompted a decision to go back and adhere to the wise counsel of committee members: "You have to write the stories."

From each transcription fourteen stories were constructed, each of which was deemed to meaningfully capture the essence of "that" person's experience of being diagnosed. From there the search took direction and this phenomenological text began to take shape. A confidence in the writing, itself, being "the research" began to build. Eventually, incidental themes became recognizable, as did the more distinguished and essential themes. Incidental themes, it was decided, would form a backdrop (chapter 3) to the more definitive themes that would direct the four major chapters of the thesis. These are, diagnosis as the experience of: "A Knowledge that Knows"; "Making the Invisible Visible"; "The Destructive Gift of Difference"; and "Making Knowledge Knowledgeable." As these themes are examined in more depth, relevant literature and personal anecdotes are brought to bear. From it all resulted a satisfying sense of a text that "shows" *diagnosis*.

This study has been an incredible journey to diagnosis, one that spans a lengthy "decision trail." Recorded in some fashion or another is collection of boxes filled with mounds of files and memos, personal writings, scraps of paper and notes scribbled from the middle-of-the-night musings. All that thought is hoarded in some corner or other, I suppose to serve if need be, as the audit trail of this study. But the work would not have reached completion without bringing it to action; to the arena of practice. I had long wrestled with the question of, "so what?" Will this study really be of any use other than to be a pleasant, albeit lengthy, "Read?" But, is it useful "knowledge?" Reflecting on this again and again the key word "discernment" came to the fore. Discernment became critical to describing how this knowledge might be used at the practical level, in the particular circumstance; to whomever as care giver would recognize the impact of "diagnosis" and assist in the healing of a "knowledge" that needs be brought to "knowledge-ability."

I've learned much in the doing of this study, much about myself, and much about valuing the tension between art and science in this kind of research. Fortunately, I knew enough from wise counsel at the outset, not to let it get "cold." I think had I put it aside – it would have lost energy, as would I. So never did I leave it for too long. I would push myself to stay with it. At points along the way, however, when I had almost lost complete vigor for it, I did come to realize that "it" retained compelling force over me and *it* would not let go. I am thankful that it was so.

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DEDICATION

to my husband, Marvin,
a mainstay of support,
and to our children,
Christopher and Danielle,
my principal source of *life* learning.

Table of Contents

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

CHAPTER FIVE

CHAPTER SIX

CHAPTER SEVEN

CHAPTER EIGHT

LIST OF FIGURES

CHAPTER ONE

Setting A Foundation Through Scenes Of Medical Diagnosis

Introducing the Topic

To come to a grasp of what it means to be diagnosed with a chronic mental illness, I could begin by trying to recall from my own experience what it was like to self-diagnose a bodily disturbance. That is, I might first try to remember a time when my body created a concern that induced a question about my state of "health." Perhaps it was that nagging cough that lasted just a little too long, a familiar ache in the joints of "my" writing hand which now seems also to be located in my back, a mild dizziness that keeps returning and momentarily distorts my vision. In each instance, my attention is drawn to a particular body part. Something is altered from its usual way of being. I find myself asking: "what is wrong with me?" The fact that I am questioning this at all means that my normal activities, my focus of thought has been redirected. I am alerted to something that is not as it was before, something that should not be. And, I want to put it right. I want it to be like it was before. But, to put it right means I must first figure out what is wrong. So, I become hypervigilant, watching to add up all the things that are out of sorts. In this way I can proceed to determine a solution. There are many possible things I could attempt to correct my problems but of course, not just anything will actually resolve it. Indeed, I may have even tried several things that have not succeeded in relieving my situation. Failed remedies! These, too, I add to the pool of information from which to reason what *it* is.

My personal horizon contracts more and more closely around "*me*" and my body and to that which might reveal the nature of my situation. In my effort to interpret what is happening I may ultimately reach a moment of realization: "ah that's what it is!" I determine the pieces fit together precisely in *this* way.

A Change in Life's Rhythm

To show self-diagnosis in a poignant way, Van den Berg (1966) re-fashions the story of *The Bottle Imp*. This story is of a man who, through the magic contained in a bottle, is advanced to a life of great wealth and good fortune:

> He buys himself a wonderful house on one of the sunny islands of the Pacific. He has it furnished to his taste, sparing neither money nor trouble. And he marries a beautiful and charming girl who fits exactly into these surroundings. When he wakes up in the morning he sings as he gets out of bed, and singing, he washes his healthy body. On a certain morning his wife hears the singing suddenly stop. Surprised by the silence she goes to investigate. She discovers her husband in a state of silent consternation. As an explanation he points at a small insignificant pale spot on his body. He has leprosy. At the discovery of this seemingly insignificant change, his whole existence is ruined. It is no longer of any interest

> to him that he is a rich man, the owner of one of the most wonderful houses in the world. No longer has he an eye for the beauty of his island; this beauty has disappeared; at the most it is an accentuation of his despair. If he thought of the happiness of his marriage just a moment ago, now his wife belongs to the caste of the healthy, inaccessible to him from now on.

In this story Van den Berg helps us to see self-diagnosis as a moment of realization, a point in time when a particular awareness takes hold. "*The singing suddenly stops,* " signaling that point of impact. This story of diagnosis is made all the more meaningful because it sets a portrait of details. It creates an image preceding *that* point in time of *diagnosis*. Our understanding of "diagnosis" is shaped because we now see a picture of this man in his ideal world; a world in rhythm; a world in harmony but now, a world that is brought to a sudden halt. From that moment on the scenes of an altered life begin to take shape.

The description of self-diagnosis provides a way of gaining a glimpse of the effects of medical diagnosis. However, the question may be raised: "what does this have to do with nursing?" Why should medical diagnosis be a subject of concern to nursing?

The task of nursing rests in its supportive activities, which means that nurses must understand how people actually experience their diagnoses to provide them that supportive care. The relevance of the study centers on the motif of "nursing care," an issue revisited at points throughout this dissertation. In the following section close focus is directed to how a person might be affected by diagnosis of a serious and enduring or "chronic" medical condition. In chapters that follow meanings of diagnosis in situations of severe and persistent mental illness are explored.

Scenes Of Medical Diagnosis

Thanksgiving is generally a time of gratitude for the abundance of life. As Bolen (1985) tells us, for William it marked a time of dread:

> . . . an instant of horror over one small purplish spot that he noted on the calf of his leg. An alarm triggered which could not be vanquished. Suddenly, what he had been feeling in the past few months was spilling forward and making horrible sense. The night sweats! The fevers that would come and go leaving him drenched and flaccid! The weight loss, and the utter and unshakeable fatigue! William could no longer push it all aside. Biopsy results soon confirmed the diagnosis he feared. Now, face to face with the physician, he was actually being told he had contracted Acquired Immune Deficiency Syndrome — AIDS! What William heard, though, was his own script. His mind had tuned out the doctor's words and was instead attending to the ring of "death sentence" he heard. "You are going to die!" Nothing else registered. There was a swiftness to the message, an *alert* that the disease would progress very quickly, that he would soon succumb and, in fact, that he would be lucky to live even another six months. In William's mind, all possible hope for life was extinguished. He made out his will. He made a hurried

> last visit to his family in Costa Rica. And then, he plunged into the frightening and irreversible thoughts of his own death. It would be some time before William could reckon with his greatest challenge in managing the disease.

One might think it ironic that a physician, customarily considered an agent for life, should be perceived as a messenger of death. But to William this was the case. This was his experience of being diagnosed. The diagnosis constituted pronouncement of a "death sentence," an unshakable reality that bred a despair which to William was as perilous as the disease. The approaching doom immobilized him and presented a mental barrier that paralyzed the life out of him. What would it take to steady his course?

William's story is one example of how a medical diagnosis might be experienced. But, *diagnosis* may not be a one-and-for-all same experience. In William's experience there is a sense of seriousness surrounding the event of being diagnosed. Being diagnosed is not an inconsequential happening. William is impacted in such a way that all else is occluded. He hears only a death sentence and is gripped with horror and despair. But does dire news of one's health necessarily provoke such an intense response? Consider Susanna's story related by Tamaro (1997). An event in Susanna's adolescence sets the stage for her particular diagnosis several years later. At age fifteen, Susanna thought she was in love. She recalls:

> It happened six months after we first met. I was expecting my period but it didn't come. I waited another month before telling him. . . . I was sure that he would lift me up in his arms with a hug. Instead as soon as I'd said . . . child - he stopped dead in his tracks. He looked at me without a word, then he scratched his chin. He said, "Really?". . . . He didn't show up for the next few days . . . [he disappeared] . . . everything fell to pieces around me. (pp. 108-110)

Against all protest, Susanna was made to leave school and to give up the child for adoption. In this, she would bend to the will of her parents: "I was a minor and thanks to the law they were to decide for me. There was nothing else to be said. One day, when I grew up [they said], I would understand" (Tamaro, 1997, p. 113).

But Susanna never did really understand and, she was never able to reconcile the loss of her child. Whisked away from her at birth all she caught of her infant child was a glimpse of red hair. She clung to the memory of it and throughout life, would not, could not let it go. Susanna would forever feel that she had been "forced to live a life that was a fake" (Tamaro, 1997, p. 113):

> . . . from the day you were born that's just how I've felt, as if I had nothing inside any more. On the outside I was the same polite, attractive girl as ever, but on the inside my guts, with all their power of feeling, had dissolved. . . . All these years my body has been nothing but an empty skin, a paper bag . . . (pp. 116-117)

The emptiness, though, was only partial truth, for each year that followed Susanna would experience a "phantom pregnancy":

> In exactly the same month as I conceived you, my stomach would slowly start to swell up. . . . I would start getting sick, my energy would flag. After nine months, a searing pain. . . . Then everything would return to normal. (p. 117)

Year after year, for twenty-five years the same pattern would repeat. But one year, there was a change in the sequence. The swelling occurred as in each of the past years, but then the swelling did not subside. Unbearable pain inside her eventually forced Susanna to the doctor. A week later the doctor conveyed the news: "I'm sorry," he said, "but inside you have a tumor almost the size of a baby" (Tamaro, 1997, p. 119):

> All those months it had never even crossed my mind that it might be that. Yet when the doctor told me I wasn't surprised. For more than twenty years I'd wanted something to grow inside my stomach and in the end my wish had been granted. With one small difference! Instead of nourishing a life inside me, I was harboring death. . . . Even the doctor was surprised. The news put me into a kind of euphoria. (p.119)

In this situation we have a fuller description of the circumstances leading to Susanna's eventual diagnosis. We see the elements of her lifetime brought to that moment of diagnosis. Like William she receives a diagnosis which is imminently threatening to her life. But, there is a stark contrast between William and Susanna's response to being diagnosed. William is devastated at his news. Susanna, on the other hand, is euphoric. Even though both hear the gravity in the health message each has a distinct and near opposite reaction. The diagnosis conveys to both a noxious disease. While William interprets his diagnosis as an announcement of death and despairs, Susanna, also hearing in her diagnosis a forecast of death, experiences release. Contained in her experience is a sense of liberation, perhaps, of deliverance.

The complexities leading into each diagnosis now pulls them in distinct directions. One could surmise that William will now face struggle. He braces to challenge the grim message of his diagnosis, to discover how to "beat" it. He must confront himself and the disease and in a sense try to overcome both. Susanna on the other hand, absorbs the news of her diagnosis quite differently. To her it seems rather simple and straightforward. There is nothing to fight or to resolve. The news was not at all expected, but now that it is here, well, so be it. One senses she is almost entranced by it. It is, perhaps, mildly unsettling but one sees a note of victory to Susanna's experience. The tumor almost likens to a crowning achievement. She need not struggle or try and defeat it. The "crazed cell baby" that has grown inside her may - in an entirely different sense, have even brought about renewed vitality.

In the foregoing situations, one can't help but question whether it is simply the diagnosis that provoked such diversity of response. Why would the grave message carried by each diagnosis not have stimulated a similar response for both William and Susanna? What would we say gave the diagnostic event its particular impact? It seems from these situations we must abandon the handy assumption that, if the diagnosis announces a rather benign condition then the moment of realization will have little impact, and vice versa. Susanna's story shows that it could also happen that a dire diagnosis might be reacted to as though it were inconsequential news. Her story makes that point. Not necessarily, then, does it follow that the more serious a condition the more devastating will be the news of its diagnosis.

Susanna's story may be unusual but it is nonetheless a possible experience of diagnosis. And, one must question whether it is so atypical. Are there chronic health conditions, perhaps, so distressing that even a formidable diagnosis is responded to with an attitude of detachment? Can the diagnosis be seen as comforting or experienced even as relief?

Barbara (Drossman, 1998) visits the emergency room complaining of severe and unremitting abdominal pain:

> Despite negative diagnostic evaluations in the past, within the last number of months the pain has led to three surgeries. Her appendix and gall bladder have been removed and recently she has also had a hysterectomy. Still she experiences continued pain. She seems to live from one pain medication to the next. The narcotics provide some relief but not complete control of pain and Barbara believes they are making her forgetful. She feels helpless and tearfully pleads with the doctor to make a diagnosis.

Barbara's story shows a situation of nondiagnosis. While William appears to act as though he would evade diagnosis by discounting his symptoms, Barbara has made repeated effort to seek diagnosis, to find an explanation for her distressing symptoms. She looks desperately to be rescued by *diagnosis*. She needs to be informed by it. Perhaps she sees a diagnosis as unfolding a way of putting her life back together; establishing an order to her now disordered life.

So, now we have seen three distinct scenes of diagnosis. William, who is struck with dread and terror on hearing his diagnosis, Susanna who shapes her diagnosis as a lifetime objective, and Barbara whose diagnosis is undetermined and therefore denied to her.

A Different Kind of Power

In each of the above scenes, we note a different response to being diagnosed, a reaction to the diagnosis as containing a different kind of power. Since William sees his diagnosis as a *sentence*, we could term the power in his diagnosis as *conviction*. To Susanna the power in her diagnosis could be thought of as *attainment*. And, to Barbara the diagnosis harbors the power of *healing*. The perceived differences to each story almost intone elusiveness to the experience of diagnosis. One cannot clearly point to the limits of the experience. Is the experience essentially tied to the diagnosis itself? Is it in the nature of the health disorder or, have we yet to look in an ill-conceived direction? Anecdotes already cited have shown that some people just sort of come apart when they are told their diagnosis while others simply resign themselves to it. Still other stories may show some sinking to despair while others wildly spend their money having a gala time and living "on the edge." And, others may subsume themselves in an interior life. What accounts for the potency in the experience of being diagnosed?

An Unexpected Happening

Since there would seem a complexity to the experience of being diagnosed which is not entirely explained by the intensity of the health incident one might look to other particularities in order to gain understanding of the experience. For example, predictability! While in good health we tend to take for granted that we will always have good health. There is a pattern of healthy functioning that goes unquestioned. But, in life it can also be said that health is an unpredictable asset. Even those of us considered as strong and in "great shape," specimens of good health so to speak, are not immune to sudden alterations of that health. And, the experience of diagnosis can as easily come out of harsh happenings as out of lingering changes in health. It can quite suddenly be there before us.

Reeve (1998) in an autobiographical account relates the events culminating in his diagnosis which resulted from an instant of misfortune. During an equestrian event, he and his horse Buck were headed over a jump. Without warning or hesitation Buck just suddenly put his head down and "put on the brakes," hurling Christopher through the air over his head.

> When I went over I took the bridle, the bit, the reins, everything off Buck's face. I landed right on my head because my hands were entangled in the bridle and I couldn't get an arm free to break my fall. . . . I came straight down . . . head first, landing on the top rail of the jump. (pp. 19-21)

Christopher sustained what is sometimes referred to as a hangman's injury. It's what happens in a hanging when the trapdoor opens and the noose snaps tight, hyper extending the neck. Five days following the accident it was as though Christopher had been hung, cut down and wakened to find himself in a hospital intensive care unit. The "head" of neuro-surgery approached him and in detail told him the extent of his injury. His first and second vertebrae were broken and he had a "complete spinal cord injury." He was "frozen" from the neck down and would never again be able to even breathe without a ventilator.

In human medicine, diagnosis never happens devoid of a context. Always there is a person, a life, a personal landscape. Christopher was forty-two years of age, an up-and-coming celebrity in the film industry, happily married and the father of three young children. To him, life had been bountiful and his future was full of possibilities. He was a fiercely independent person and had stepped around prior obstacles. What could possibly have prepared him for such an unexpected twist of fate, such a fateful pronouncement:

> . . . at first I thought this was just another temporary problem. . . . Always in the past I had recovered quickly from physical setbacks. . . . I'd be up and around before long. It was only after the doctors left that I really began to absorb what

> they had told me: This is a spinal cord injury, a paralyzing injury. I had the horrible realization. . . . I understood how serious it was. This was not a C5-C6, which means you're in a wheelchair but you can use your arms and breathe on your own. C1-C2 is about as bad as it gets. Why not die and save everyone a lot of trouble? (pp. 31-32)

Christopher would lie there and stare at his future in disbelief. Only sleep would offer a reprieve where he could be whole again: riding, acting, making love to his wife. Then he would awaken and the reality would be there. He was no longer able to do any of those things. In the upper-right-hand corner of his room he would see a monitor with his vital signs traveling across it — his heart rate, blood pressure, oxygen levels. Little purple beeps bouncing across a screen. The diagnosis C1-C2 told him it was final and irreversible. He would always be tied to all of this. Desperately he would think, "I can't get free." The diagnosis says it's final and irreversible:

> I'm grounded. I won't be able to fly, won't be able to sail, won't be able to ride, won't be able to ski, won't be able to make love to Dana, won't be able to throw a ball to Will. . . . I'm just taking up space. . . . I'm in a straitjacket, my whole body is in a straitjacket, I can't move anything. I can't contort my shoulders. . . . I'm trapped, I'm in prison. I've got a life sentence here. I'm stuck, I'm never going to get out of this. . . . I'm pathetic . . . somebody, please, let me out. Just let me out. (pp. 47-49)

The anguished plea does not penetrate the unalterable state of things. The "diagnosis," declares it final: "complete spinal cord injury." Short of a scientific breakthrough, the diagnosis reflects permanence to the paralysis. It is immutable, sealed and permanent. The message is not just a set of words about a medical condition. It goes beyond biology. It signifies much more. What accompanies the diagnosis is a multitude of messages about one's being. The words of diagnosis brought Christopher face to face with his life situation. He now begins to realize in bits and pieces that this is really real. This isn't a trick. There is nothing he can do to change the diagnosis anymore than he can go back and reverse the moment in time that brought him to this point. In this he is helpless. He is helpless in what the diagnosis pronounces to him. There was no "Houdini's key" to get him out of it. Despairing thoughts consume him:

> I've ruined my life, and you only get one. You can't say, "I've spoiled this one, so can I have another one, please?" There's no counter you can go up to and say, "I dropped my ice cream cone; could I please have another one." . . . I've ruined not only my own life but everybody else's . . . [my wife's, my children's] . . . this is going to be a huge burden on everybody. It's not my injury, it's our injury. Our entire family is hurt. We've all been destroyed by this stupid thing that happened. Over a nothing jump. For some reason, I didn't get my hands down and break my fall. I'm an idiot. I've spoiled everything. Why can't there be an appeal? Why isn't there a higher authority you can go to and say, "Wait a minute, you didn't

> mean for this to happen to me. This kind of thing doesn't happen to me." (pp. 43-44)

Floating in confusion and anger Christopher wants to shout out: "You've named the wrong person here." He cannot accept his fate, the permanence of his diagnosis, the devastation of its message. But, the statement has been made. Nothing is going to revoke it. No one is going to suddenly come in and say: "Sorry, wrong person; they meant somebody down the hall. It's not you, you're free to go."

One might think that maybe Christopher's reaction was so intense because his predicament was so extreme? After all, in his case it is not just the diagnosis that is devastating. Christopher *is* paralyzed. Who could easily accept, with equanimity, such drastic news? How does one come to reinstate a life that is now framed by the diagnosis: *complete C1-C2 spinal cord injury*? At the human level, what does such a diagnosis spell beyond severe spinal damage with no hope for repair? At least two things led to Christopher's affirmation for life. If being active and being alive equated to the same thing, as it did to Christopher, then he was faced with the task of redefining *active* so that it could fit with his changed life? For a time he found sustaining force in an image from a postcard picture of a Mayan temple in Mexico, the Pyramid of Quetzalcoatl.

> There were hundreds of steps leading up to the top. And above the temple were blue sky and clouds. I taped this postcard to the bottom of the monitor, where it was always in view. I let it become a metaphor for the future. Even as I watched all those sobering numbers on the screen, I began to imagine myself climbing those steps, one at a time, until finally I would reach the top and go into the sky. (p. 53)

The narration would seem to tell us that Christopher has found a way for his spirit to survive by opening himself to *meaning* through an imaginary world. That world of beauty and freedom is not bounded but paradoxically it is riveted. It is not pinned on a stick-board, or to the wall, or to the ceiling for visual access. Ironically it is *taped* to the monitor of his reality. There it contrasts to another world, the real world of his existence. That is the way it is for Christopher, living in two worlds, the real and the imagined.

When I first picked up Reeve's book, "Still Me" I recall thinking it seemed an odd title. The book jacket portrayed a man in a wheelchair, a motionless figure against a natural hillside. The lush green landscape provided a vital backdrop to the man in that chair, seeming to magnify a sense of stillness about him. My attention was pulled to him. I could almost imagine peacefulness surrounding the chair. I wondered about the inert body that sat there. Something suggested the muscles of that body would forever be still. I took the book title to suggest: "I am still." Weeks later, having finished the last chapter, I sat reflectively, fingering the book as I sometimes do after a good read. The title *Still Me* struck a new chord. My eyes now took-in Christopher, the man in the chair. I realized with a little amazement that I saw what I had not taken note of before in the picture. The chair was positioned with Christopher facing the landscape before him. I saw only his back but what I now saw of him was more complete than what I had seen before. He was *still Christopher*. Odd I hadn't taken note of that before!

The Shadow of Knowing

Christopher's experience of diagnosis is embroiled in the drastic predicament within which he finds himself. The diagnosis derives from a sudden incident. It is not at all anticipated, the prospect totally unplanned for. There is no sequence of happenings; no space of time in which to accustom to aversive possibilities. Just a sudden shift of reality! Diagnosis can happen this way. It can be of knowledge of the "right now," but also, as with Christopher, it is knowledge layered with a complexity that confounds one's sensibilities. Christopher is paralyzed!

However, it could also happen that a diagnosis is insidious, even anticipated and in some sense known, though perhaps not fully known, in advance of it's happening. Many of us could, no doubt, recount situations where minor symptoms accumulated subtly over time, becoming a prelude to diagnosis. One would live in a shadow of slow unfolding events that might alter the astonishment over the eventual diagnosis. Laura's (pseudonym) experience of diagnosis provides a case in point.

The Shadow of not Knowing

Laura (personal communication, July, 1999) started noting "health" deterioration beginning at about age sixteen. It would be three and one-half years later before she was diagnosed. Laura had characteristically been a lively, bouncy teenager and had never before experienced serious illness. So, for her, illness fell outside the scope of possibilities. Laura's earliest symptoms included things like a gradual loss of interest, lack of motivation, inability to concentrate, loss of energy, and a general sense of listlessness. Everything seemed like a chore and life had lost its luster.

This state of things continued, becoming more intense as time went on but so gradually that Laura could easily find ways to reason it all away. It was just puberty; she wasn't eating properly; university life was exceptionally demanding; the move away from home was overly taxing. Always things could be justified. On occasion when she did consult a doctor, by her perception, he would trivialize it and attribute it to such things as, "oh, just stress"; "you're anemic"; "it sounds like flu." On her way she would be sent with a new bag-full of iron and vitamin pills. Feeling more and more sick Laura remembers:

> It got so I just couldn't stay awake for anything. I was falling asleep all the time. Like, I thought everything was extremely boring. Then I'd think, "what's wrong with me? I must be mental." I'd be sitting there in lecture and -- out like a light! And I would try everything. And then I started missing lot's of classes because I just couldn't get up and go. And I started having lots of symptoms. But I thought it was the flu and then I actually did go to see student health services. And I just

> could not get anybody's attention. It was like, "oh well, maybe you have mono; maybe you have the flu."
>
> I kept struggling, just kept plodding along, but it was awful. I couldn't see a way out of it. I thought, "oh my God — just give me my life back." Unbelievable! I never thought about suicide but, like obsessively, I really wished for some escape. I managed to pass my courses. I don't know how. I wasn't even there! (personal communication, July, 1999)

In Laura's situation there is an experience of health deterioration over an extended period of time. No one is alarmed about it because the complaints appear vague and relatively minor. Because no one in Laura's life seemed concerned, Laura expects she should be unconcerned as well. This leads her to find all manner of justification for what she feels and essentially to whitewash the symptoms away. But, Laura too lives in a shadow of sorts. The shadow of not knowing leads her to wonder whether the symptoms are "real" or fabrications of her own thought. Increasingly her self-judgement is eroded. She worries about her state of mind in all this.

Someone's finally going to take care of me.

Being away for a number of months and then returning home for Christmas Laura's mother sees a noticeable change in her and insists she see their family doctor. The chest x-ray indicates a huge mass in Laura's lungs. Now, a sense of urgency grips everyone. The doctor arranges a fast admission to hospital. To Laura, a "mass" doesn't sound good but:

> . . . at first it was a relief — a real serious relief. I was just so sick that I thought, "oh good. Someone's finally going to take care of me." . . . But then, after about two weeks of mad testing in the hospital — if you can believe this — I had just had this biopsy done and I was sitting in a wheelchair, in the hallway waiting for another test. The surgeon comes up to me and says, "the results aren't all in yet but I can tell that you do have cancer." I don't know if he said Hodgkin's Disease — but definitely cancer. He wanted to tell me, but then he just left me. And, I was by myself, sitting there in the hallway. I was just so stunned. Somehow I had never really entertained that possibility at all. . . . And then the orderly took me back to my room and I was all by myself for hours. And I remember wanting so much for my mom and dad to come. I just wanted to tell somebody else. (personal communication, July, 1999)

The changes in Laura's health were so subtle that only in hindsight did they take on importance. Nonetheless, a serious disease process was in the works, slowly sapping her vitality. When the diagnosis is finally made it becomes all too clear. Now she wonders: "How could anybody have looked at me and not seen that I was dying? Even my one eyelid was drooping from the nodes in my neck that were pressing on something." The realization of her diagnosis leaves Laura feeling pretty numb:

> I didn't know if it was curable. I didn't know anything. . . . Mostly, I felt totally at the mercy of medicine. I wasn't really afraid though. It's funny cause I know, throughout the whole thing I don't remember having real fear of dying. Like I don't think I ever thought, "ok, it's over!" — well, maybe for brief moments. You sorta think, "well 'geese', I'm still a virgin" or, "I need to go to Hawaii" — you know? Like, "I can't die now" (laughter)! (personal communication, July, 1999)

With diagnosis the shadow is now lifted but, in fact, it appears in wake of a new shadow. In numerous ways Laura's youth influences her response to diagnosis. But, to her way of thinking, there are all those things that she hasn't done yet, all the dreams of a future that now become threatened.

Laura's scenario offers perhaps yet another dynamic to the possible ways that diagnosis may be experienced. Because Laura is an adolescent she brings the developmental aspects to the picture, which initially even complicates recognition of her complaints as legitimate. At her age, she is thought to be just having a difficult adjustment to puberty, or only to be having adolescent stress. In one sense when the diagnosis finally is told to her it comes as an immense relief. It sets her thinking straight again:

> I remember during that time thinking, "this is serious." I mean, I didn't want to have cancer but it was a serious enough disease to explain this complete, abysmal period. If they had told me something less big than cancer, maybe that wouldn't have been enough to go, "well, there! I can wipe out all that." — Like, I really felt it enabled me to wipe out that period easily — to sort of leave it behind. Cause I had really mentally beat myself up for a long time . . . and all of a sudden it wasn't my fault. (personal communication, July, 1999)

A reason to check-out.

The diagnosis is the statement that means Laura is required to stop all her regular activities. Everything unrelated to her treatment and the care of *self* is put on hold. The diagnosis provides her that basis, a reason for those decisions. In fact, she is lifted from those decisions by the diagnosis. The diagnosis decides for her, even before she herself can decide about which activities of life to interrupt. The definitive reason is there in the diagnosis.

> I had to drop out of school and not make plans for the future. I had to just stop, and just be subjected to this treatment. Holiday isn't the way to describe chemotherapy — but I remember I had wished desperately to check out for a while. Like my dream world was, "oh to have just six months where I wouldn't have to be responsible for anything." I wanted a time when I could just "be." And in a way, that's what I got. Because I wasn't always really sick when I was having treatment but I was still in this limbo world where I didn't have to take on any of life. And I relished it. (personal communication, July, 1999)

Initially Laura takes delight in the forced time of retreat from life. The diagnosis creates a respite for her, a space in which she can retreat. What lingers in her thoughts though, is the entire coincidence about how it all came about, the coincidences that brought it all together. Momentarily thoughts come to mind on: "How much of that did I wish upon myself? In a round about way I did get what I wanted, didn't I?" Laura thinks more seriously about how much the physical and the mental are intertwined and she is really careful, now, when thinking about what she desperately wants. She feels there may be a price to wishful thinking. Now, she seriously questions: "what's the cost?"

A break in time.

It took a year and a half of treatment for Laura to be deemed clinically cured. For the most part the disease that had for so long been a part of her life was gone, but the diagnosis continues to follow her around twenty years later, affecting her life in innumerable ways. For example, on more than one occasion Laura has been called-on to explain the question of her university grades which appear on her transcripts for that time period. "Why is there this weird break-period in my education and why did I have these 5s and 4s in my grade point average (GPA)?" It's something that can't be erased from university transcripts. Then, there's the issue of life insurance. No easy checklist, but instead, a whole thorough re-exploration of things is required, the kind that also comes into play with each job application. Each time, a rationale for decisions is based around *that* diagnosis. "It's never just: 'Fine, you have the job, or the insurance, or the visa, or whatever'." There is always this break in time that has as header: "Cancer!"

The *break* time is not only in the sense of respite. It is also in the sense of a fracture that won't heal. Much of life is now off rhythm. The diagnosis has influenced many of life's decisions; reshaped the entire landscape of life.

> I never felt like I was in synch with my time. I think it really affected how I made decisions, forever after. Like, people get to age 30 and they think, "where should I be?" I sort of felt outside of all that, released from that ages-stages thing, that — by such and such a time I should be somewhere in my career, or have so many kids. I felt exempt from it all. (personal communication, July, 1999)

Laura is released from many expectations that at once afford freedom, but, at the same time place her apart from others. Sometimes there is a longing to just be the same, to put everything back like it was before, to be like everybody else; a part of the others. Now, there are things that come up, things that twenty years later still call the diagnosis back into the present. The diagnosis is old news but it keeps going on and on, entering into one decision after another. It's, "no, I cannot be a blood donor," and "no, I must exempt myself from this *questionnaire*" and, "no, I don't qualify for this special medical coverage, or that insurance plan, or that job opportunity." Every time a form needs to be filled out it's another reminder: "No. That's not me!" The diagnosis declares Laura an insurance risk. She becomes "risky," perhaps in a sense even to herself. The diagnosis is there to modify her choices, alter her options, and certify: "I am sifted out of the common stream."

To be recognized as damaged.

Sometimes, because of the diagnosis, Laura is treated as being very odd. People act like she is something special, but not special in a way that feels good. Special like a "misfit," like someone who has survived something that has changed her in a major way. She is made to feel she isn't exactly like everybody else. She detects that sometimes even her friends, by association to her, are also treated as special, but in a different sense. "Like, isn't he something special! What a guy to take out that woman whose damaged, or more fragile. Or, 'Who knows what's wrong with her?'"

Women of Laura's age are very often having babies and generally there can be lots of chatter going on about mothering. Laura is "tactfully" left outside those conversations. People know that radiation therapy has left her sterile. They are careful to limit what they think will be upsetting for her. But Laura picks up the glances and nods they exchange. She reads their subtle messages: "Not now! We'll talk about that later."

Each new romantic involvement raises, anew, the childbearing issue. Each time Laura must decide on the appropriate way to go about sharing this information. When is the right time to tell somebody: "By the way, I can't have children." Infertile couples generally discover this kind of thing after marriage. Laura knows in advance. Each time there is a new involvement she must decide again. To talk about it resurfaces the issue of "that" diagnosis. To let herself be known she must let the diagnosis become known, and that says more than simply "a name." Beyond that the diagnosis recognizes that she *had* the cancer. She must make known what she generally keeps hidden, that which will disclose her differences from others.

> I think you always see yourself as slightly damaged. Like there's something very wrong with you and I did go through a phase when I found out I was sterile when I thought, "well, that's probably a good thing. Because, I obviously carry genes that are damaged." And so if you think of natural selection, I would have been selected out of the gene pool. And that's probably a good thing. Like there's a part of you that sort of accepts that. (personal communication, July, 1999)

Laura accepts that she is not ordinary. She even reasons that her sterility may be a good thing "for the human race." Because of it she will not procreate and carry on this bad gene pool. But at the base of such rational thinking there is wistful-ness about being normal, perhaps written in an element of doubt about *that* diagnosis. After all, look at her now, twenty years later healthy and strong. Maybe it really wasn't even cancer! But, even though she thinks of herself as now totally healthy and strong, still, Laura perceives that "Society definitely looks at you as damaged goods. Like, you'll never be a totally healthy person! Which really isn't fair, but it is there all the time. . . . I'm always the one that had the big 'C'." Twenty some years later, Laura continues to regularly find herself "put back there," reminded that she belongs in that category of damaged goods, "... wishing I could just be normal."

Now it's all possible.

A medical diagnosis prompts one to think about *health* in a serious way. Perhaps illness has never been a part of one's reality. People don't usually, for no reason, indulge in thoughts about serious ill health. They may hear of another's health misfortunes but seldom do they consider: "this could happen to me." A diagnosis of serious medical condition announces something of one's own vulnerability to all illnesses:

> There were times when I was physically ill and would be consciously sitting there — and I just couldn't compute. I just couldn't make connections between things. It was like I had fuzz in my head. And so from that time I know that it's more than just having a body with red blood cells zipping around, and also having a separate working mind. Serious illness affects you totally. It affects the total you. When I was really sick, I didn't have the same mental capabilities that I did when I was well. And it was a real shock to me when somebody gave me a "needle-point" and I could not do it. Like, I'm really good at sewing, but there was nothing I could do — I just couldn't count. It's like there was some missing connection. My brain was not working. And try as I might, I couldn't look at this chart and count the squares and make that stitch. (personal communication, July, 1999)

Here there is the experience of a physical-mental connection to illness. Laura has come to understand a unity of body-mind. She speaks, not of the body as located *here* and the mind *over there*, with somewhere in the middle a point zero where they come together. Laura cannot speak of the functioning of one separate from the functioning of the other. Her words express more of a symbiosis, an inter-connection of one with the other so that they are experienced as one and the same. Here, at the experiential level the notion of a mind-body dichotomy is countered.

And yet, modern medical science speaks as though there were such a thing as a sole body, one that could operate itself distinct and independent of a functioning mind. Could evidence of such a mindless body really exist? Perhaps, however, the near reverse of "bodiless mind" can be read into the story of Jean-Dominique Bauby, editor-in-chief of the French publication, "Elle" (Bauby, 1998).

When You Have Bodiless Mind

A vibrant man and successful socialite, Jean-Dominique Bauby in his early forties suffered a massive stroke. Suddenly, he was paralyzed from head-to-toe, able to move only his left eyelid. To add insult to injury, even his right eyelid was sutured shut in order to protect it from the effects of an absent blink reflex. Bauby's diagnosis of "locked-in syndrome," characterizes him as an utterly disabled body but, with a mind still intact.

Quite literally Bauby is imprisoned inside his body, entirely unable to speak or move. But Bauby finds voice in his speechlessness. In the manner of "Morse code" he speaks with his left eyelid. Opening and shutting, repeatedly, over and over, again and again, letter by letter Bauby dictates, "The Diving-Bell & The Butterfly", a book to share with us his experience of that time. He tells us what it is like to be trapped in "your" body, when you still have your mind.

When Bauby first "surfaced" from his days in deep coma he did not appreciate the full extent of his situation. He knew only that he was incapable of even twitching, unable to brush away that fly that buzzed about his face, and absolutely silenced. He was enclosed inside a human cocoon but no one had yet given him an accurate picture of his situation. In his book Beauby writes: "I clung to the certainty, based on bits and pieces I had overheard, that I would very quickly recover movement and speech" (Bauby, 1998, p. 15). For Bauby it comes down to the ritual of the wheelchair. It was that which connected him to the reality of his situation:

> Two attendants seized me by the shoulders and feet, lifted me off the bed and dumped me unceremoniously into the wheelchair. I had graduated from being a patient whose prognosis was uncertain to an official quadriplegic. . . . I was devastated by this brutal downgrading of my future hopes. In one flash I saw the frightening truth. It was as blinding as an atomic explosion and keener than a guillotine blade. (pp. 16-17)

There is horror in that moment of realization, a cruel awakening to the fact of being forevermore encased in something of a huge "invisible diving bell." Bauby uses this metaphor intentionally to help us fathom his experience of being trapped. Like the entombed divers of old, restricted to the bubble of oxygen within the bell, Bauby is captured within the confines of his own inert body. Henceforth, life must be embraced from within this rigid space, or so it seems.

Now, what seems truly astonishing is not that Bauby lives the remainder of his life as though from a cocoon, peeking out at the world from one eye. It is that he "sees" from a different source. It is that he is able to still participate in an active world. He may be bedridden but he is nevertheless a *butterfly* and: "There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court. You can visit the woman you love, slide down beside her and stroke her still-sleeping face. You can build castles in Spain, steal the Golden Fleece, discover Atlantis, realize your childhood dreams and adult ambitions" (Bauby, 1998, p. 13). Thus, Bauby shows us that with bodiless mind, and perhaps even because of this, he experiences the world in rich and exclusive ways.

Bauby's story allows us to know him in a special way. He has survived the devastation of a broken body and carries on to fully use what is left to him. He finds a *life,* and then he finds a way to let us know that *that* life is worthwhile. Through his "bedridden travel notes" we come to experience the things of his world. Bauby shares with us his treasury of what it is to be free— to be a butterfly! Is it not remarkable that with but one eye Bauby could see so much? But, of course the question endures: is it from the eye or the mind that Bauby sees? And, what is it that he sees?

Losing Mental Function

Bauby is in an extraordinary position. His is a total loss of voluntary body functioning but his mind is intact. Even though his human life depends entirely on technical support he is resilient in finding a way to touch our lives through his book. We can identify, in a sense, with his circumstance and relate to his experience through a common interpretation of what we see as real. Despite unique differences we are placed in a worldly existence with a shared reality and so are not all that dissimilar one from the other. He can still reach us with words, and so we can be touched by what he has to tell us. In that way he can still align with us, be one of us in a relational sense. His life is different but the things of his world are much the same. And so Bauby is delivered from his "confinement?" Through his book he enriches our sense of being and of what it means to be human. He opens his "restricted" world to us and somehow paradoxically portrays an existence of unrestrained possibility.

Bauby leads me to think about the range of human afflictions, and wonder which one of them it would be okay to have. I review a whole selection of diseases and disorders. Of course, there is a difference to hearing a diagnosis and actually having "the" illness. There is a trace of uncertainty to hearing it that vanishes if one is faced with existing symptoms. So, before long I might even note a tone of bargaining to my thoughts, like — "ok, I could handle this as long as I don't get that! I could bear diabetes before accepting cancer. Or, I could manage cancer as long as I don't get the kind where they have to take off an arm or a leg." And, so it goes! I might continue through a number of disorders deciding which one's are in a "no, not that!" category and which one's are definitely a "oh no! Please, not that!" category.

But what if I was told a psychiatric diagnosis? Say I am told I have "Obsessive Compulsive Disorder" or I have a "Schizophreniform Disorder." I sometimes wonder whether that would be better or worse or perhaps no different than hearing a diagnosis of "Multiple Sclerosis?" But, somehow I become more thoughtful if I include **mental illnesses within the** scope of my illness possibilities. While losing a limb might be a huge fear I know that losing my mind would be a different kind of fear. To myself, I admit that I could handle losing body parts before I could accept losing any **mental function.**

A Different Complexity

Each of the stories presented to this point describes an individual encountering a personal medical health crisis. Each presents a different modality of diagnosis in which we see, for example, "diagnosis with no symptoms," "diagnosis with annoying symptoms," "diagnosis with alarming symptoms," "diagnosis with devastating symptoms." As each individual comes to their diagnosis there is a time of realization when awareness of what the diagnosis declares is apparent. Distinct though they are, the stories have much in common. The persons spoken of, for example, each have a physical ailment. The disorder is tangible in that the affected parts of the body can be pointed to in x-rays, blood tests, brain scans, chemistry strips, etceteras; all converge to confirm its actual existence. There it is! Thus the diagnosis is supported by physical evidence and so, the experience of its naming is of what is known in "proven fact." Would the experience be at all similar if the health crisis were a mental (psychiatric) one, where there is little if any "hard evidence?"

Then too, the diagnosis in each aforementioned case has said something about the seriousness of the disruption in the bodily process. The person's fate is unpleasantly affected not only by the limitations brought from the disorder but because the diagnosis has confirmed a knowledge that what has gone wrong is not simply going to go away. In fact, perhaps it is the chronicity of it that is the most significant "piece" in the experience of the diagnosis. Knowledge contained in the diagnosis dictates a need for ongoing management of disabilities. Indeed, in a sense it is this knowledge which must now enter in and give new shape to one's worldview. Life is different now because new knowledge about oneself is there. Some life goals might have to be adjusted or altogether abandoned. One may not be able to fantasize as freely about future possibilities as was possible yesterday before diagnosis. And, as the pain, grief, and loss fluctuate in intensity from day to day perhaps, the "prediagnosis self" becomes less and less recognizable. The individual must struggle to rebalance, to take stock of altered functions, to regroup. This is the only way to move forward and to move forward includes the challenge of finding a level of wellness within the illness and within the knowledge of the illness brought by diagnosis.

To find a measure of stability and gain a sense of emotional wholeness in the face of such uncertainty, one would suppose, is no small task even for the soundest of personalities. How do those with serious mental illness proceed in dealing with knowledge of an illness that, at least from the "outside" (to the observer not in the experience), is vague and abstract? From the "inside," that is to the sufferer, there is perhaps little real question of real pain and distress? How do they contain the natural fear and anger induced by an uncertain course in illness? Their repertoire for dealing with crisis may have been in question before the illness and be even more severely affected as a consequence of the illness. How does the individual, then, gain a sense of perspective on being *named* mentally ill? If self esteem is fragile to begin with and there are few personal resources to draw on, can we assume that the experience of being diagnosed mentally ill is at all similar to the experience of being diagnosed physically ill – or, is there actual difference?

Some would say that the only "truly handicapped of the world are those who suffer from emotional limitations that make it impossible to use the capacities and controls they possess" (LeMaistre, 1995, p. 18). With mental illnesses, at least from the "outsiders" point of view, innermost feelings are assaulted, judgement often affected, perceptions distorted in alarming ways. Indeed, the person may appear "muted" or "high wired" and out of control. On the one hand, the physical world may or may not even be acknowledged as having relevance. On the other hand there may be a brittle sensitivity to external stimuli which, in some cases, cannot be distinguished from stimuli coming from within. Where is one to gain a sense of direction, and why should direction be taken from a medical science lacking in physical evidence? If diagnosis can be thought of as a statement of "the damages," a sort of declaration about the nature of one's impairment, would that statement be viewed differently if it declares a physical impairment from when it declares mental impairment? From one point of view it could be said "to be diagnosed is to be diagnosed." But, between "diagnoses of kind" (mental and physical) one could query sameness and differences to human experiences of these. Upcoming chapters are dedicated to exploring these questions. We now move to Chapter two whereby the experience of being diagnosed with enduring mental illness is approached from the perspective of existing literature, and "hermeneutic phenomenology" the methodology used to guide the study, is introduced.

CHAPTER TWO

Ways Of Coming To Know *Diagnosis:* Literature And Methodology

Explored in this thesis is the phenomenon of experiencing this kind of "awesome" knowledge, that is, "medical diagnosis" in relation to one's self, specifically one's own mental functioning. Recognizing there are many different kinds of medical diagnoses, up-front is singled out psychiatric diagnosis as the particular form of medical diagnosis in question. Certainly, all health care disciplines employ diagnostic methods in their practices that, in some way resemble and in other ways different from each other. Their distinctions, however, become more apparent when considered against the background of the respective knowledge forms that inform their practices. This thesis commits to the question of "psychiatric medical diagnosis" as it pertains to nursing care practices. It wants to know: What is the experience of being medically diagnosed with a severe and enduring mental illness? How might response to *this* diagnosis translate at the individual and personal level, *to the patient?* Speculation could be made as to how that experience affects patients' potential for healing, possibly impacts their lifelong management of the illness, and, though some inference to that can be made (as it is throughout this study) ultimately, those questions are left to another study. The primary intent in this study is to give proper vent to persons' early experience of "psychiatric diagnosis," that the phenomenon might more fully "show itself in itself."

If we are to come to see the "phenomenon" of *diagnosis* then it must be pointed out in a perspicuous way; with an expressiveness that helps to reveal its nature. To approach such manifestation, in this chapter a foundation is set through the formal venues of literature and methodology. Some personal background introduces the discussion and cursory scan is made of "diagnosis" in its every-day view. The phenomenon, as addressed by the question of this study, is then approached through existing literature and the methodology underlying the study. The study is thus grounded in current perspectives and delineated by hermeneutic phenomenology, the approach underlying the "search." The chapter is so structured that the reader might more easily engage in the process of revealing the essential nature of *diagnosis* and exposing its hidden-ness.

Some Backgrounder in Coming to the Study

My own interest, embarking on this study, is professionally motivated. It is from my encounters with clinical situations of clients experiencing psychiatric diagnosis (herein referred to as "diagnosis") that I have come to identify a lapse of discussion on the subject, a near absence of materials that would inform practitioners regarding these difficult clinical circumstances. Beyond some few "survivor" (term preferred by persons managing mental illness) accounts recently appearing in scholarly journals there is scarcity of any publication that would give credence to the experience of diagnosis as being a legitimate one, let alone a significant one. Less, yet, is available that would inform care providers of diagnosis as potentially a powerful determinant to the course of healing and ongoing illness management.

Perhaps there is enduring belief amongst practitioners in mental health arenas that care related to diagnosis is captured under the umbrella of "anxiety-related needs." Such belief would pre script that "diagnosis care" be addressed generally, along with the host of other anxiety-related concerns. Too, patients' subjective response to their diagnosis may be thought somewhat generic to all illnesses/disorders and so thought appropriately dealt with in common ways. Limited documentation, however, suggests it dubious that individuals' specific responses to diagnosis are, in fact, dealt with at all, possibly simply overlooked, thought inconsequential within the range of "more pressing" health-care demands. And yet, in psychiatry much that is relative to what is termed "treatment success," "compliance," "stable management," and so on, would seem to hinge on personal resolution at the outset, originating from the point of diagnosis. One cannot presume such constructive resolution to merely happen! It would seem mental health care providers have responsibility to assist in nurturing patients' recovery to a state of healthy functioning thereby facilitating their transition to a realistic sense of wellbeing.

Since one cannot be expert in all fields, and one cannot assume diagnosis to be common to all kinds of medical health experiences, I have elected to focus on the "specialty" of my interest in Nursing, that is, "psychiatric nursing." In psychiatric health care, it might be thought that nurse practitioners have been guided on the issues of diagnosis relative to the paradigms of psychology and medical models of practice. However, little is in evidence across disciplines that would formally recognize the impact of diagnosis at the individual level. This suggests "diagnosis" as a subjective experience is an unattended area. The outstanding question remains: "What might be done to humanize the force of diagnosis, aside from cure and irrespective of discipline or domain of practice?" What, for example, might be introduced into care planning, educational curricula, research designs or, in other places where diagnosis might be of notable concern to practitioners?

Perhaps the topic of diagnosis must first be seen to surface in various professional sources if it is to be seriously recognized and effectively dealt with in practice settings. Currently, diagnosis may occasionally be alluded to in team conferencing, but rarely is it scrutinized for its subjective propensities. Instead, a diagnosis tends to be viewed as a necessary attachment that directs treatment. It is hoped the outcomes of this study will show its relevance beyond this. Nurses, occupational therapists, recreational therapists, social care workers, and "community care liaison workers" may have interest in the results, but the study is driven from its relevance to Nursing. It is from this perspective and from a focus in psychiatric-mental health nursing that I approach the study. Indeed, this focus may be reason for what I identify as one of my greatest challenges of this phenomenology, that is, to realize and resist inclination to "psychologize." It was a constant struggle to keep open to the phenomenon and keep it free of psychological interpretation. Phenomenological interpretation required a shift of thinking on my part that I may not have been totally successful with at all times. That said, maintaining a phenomenological mode was my primary intent and one that proved most advantageous.

Entering-in to Diagnosis from Common Understandings

With little effort we might come, first, to recognize *diagnosis* through its many instances in daily life, aside from its varied forms of usage in the domains of health care. Roget's International Thesaurus (1977) associates the term "diagnosis" with the general activities of scrutiny, examination and analysis which, then, would reasonably apply to any number of situations where examining and determining the state of function is the aim. We note *judgement* and a kind of *knowledge* as key to diagnosis. Indeed, Wain (1958) describes diagnosis quite literally as a *knowing* through "a judging or a deciding", presumed to entail aspects of *identification* and *determination*. An everyday example of diagnosis might well play out at one's local service station, particularly if one's own motor vehicle is slated for "overhaul, or tune-up" pending "inspection" as to its operative status. Too, one may find oneself choosing between food items at the market place, say between butter or margarine, by carefully comparing the ingredients cited on their respective labels, leading to a determination of choice. And so, we note *diagnosis* in common usage is not so dissimilar, in principle, to its use in the domains of medical activity. Use in medical domains, however, does imbue diagnosis with a certain kind of awe, perhaps stemming from the "scientific ness" we *there* attribute to it. Van Manen (1996) enlightens us to origins of *diagnosis* that may further account for the awe based in its medical usage:

> Literally dia-gnostic means "to know thoroughly" in the sense of seeing through the body. The term gnostic derives from the Greek gnostikos, meaning "one who knows". The notion is related to "mind, judgement; maxim and opinion". In the second century, Gnosticism emerged as the sectarian belief that reason was the proper device to teach and practice religion. In its extreme forms Gnosticism involved the mystical revelation of supernatural knowledge for an elite of knowers and saviours. In our age, at the more secular level, the gnostic attitude in medicine and the health sciences also proceeds on the principle that the process of healing is approached and defined in terms of rationalistic factors. It is not surprising, therefore, that we find the term "gnostic" in the most commonly used medical terminology of "diagnostic" and "prognostic". Indeed, to the lay person gnostic knowledge may still command an element of awe and blind faith. (p. 15)

Keeping in mind the "awe" inherent to this knowledge, attention is now directed to reflections on *diagnosis*, or facets thereof, presenting from the literature. Some salient thoughts from the literature are enhanced through the anecdotal accounts of participants.

Turning to the Experience of Diagnosis through the Archway of Literature

Literature sources can provide vital contribution in hermeneutic phenomenology, to delineate the nature of the study itself as well as to the creation of "rich" text. Although *search* through the literature is carried on and evidenced throughout the chapters of this study, a literature review at the outset can help to more clearly identify the nature of the phenomenon of interest and alert the researcher to the breadth of the surrounding issues. Exploration of current knowledge may lead to secondary questions that bear on the primary interest. For example, underlying the question of *diagnosis* might be query of what exactly it is that a person has once they have received a diagnosis? Is "having" a diagnosis the same as "being" diagnosed? How might these differ? Then, one might begin to wonder about the nature of the social statement made by a diagnosis, start to consider possible predictive propensities of certain diagnoses, and so on. Beyond *diagnosis* as name-identity for disease or disorder are there other dimensions to *diagnosis* (the experience of it)? We proceed, here, to narratives of *diagnosis* as a subjective experience and then take to literature that speaks to the terms that describe aspects of the phenomenon of *diagnosis* in "chronic mental illness" (CMI).

Referencing anecdotal accounts.

A backdrop of insight by which to glimpse meanings of the experience of being psychiatrically diagnosed is more often than not obtained through anecdotal documentation. Bjorklund's (1996) published personal account, for example, gives voice to his experience of being given a psychiatric diagnosis as akin to being handed an "alter identity," one which superseded his own. He describes the label of diagnosis as taking on a life of its own. The diagnosis becomes like one's "epiphany," he says, transforming *the person* into an illness and shaping "present and future life expectations" (p. 1329). By his expression, to be diagnosed with a severe and persistent mental illness was to experience a type of *sentencing* to a destiny outside his choosing. Others, like Kathleen (Gallo, 1994) express a deep feeling of "outcast":

> At the age of 40 years, I heard myself being referred to as a "chronically mentally ill" individual, that is, "just another CMI". This was news to me, and the impact of its implications had an almost totally catastrophic effect upon me! . . . I was in hiding from everyone. I perceived myself, quite accurately, unfortunately, as having a serious mental illness and therefore as having been relegated to what I called "the social garbage heap." (p. 407)

Fourteen participants constituted the core population of this research (henceforth in this document referred to by first name "pseudonym." In reconciling their diagnoses, some of the participants in this study were noted to set a backgrounder outside themselves by which they could see a more favorable standard. For example, some participants were deliberate in mentioning known personalities, such as Ted Turner, Picasso, Leonardo Da Vinci, who they believed had the same diagnosis as they did.

Example of such "identification" is seen in Steven's statement (henceforth in this document only the voice of study participants in block quotes, will be printed in italics):

> *And what about Jim Carey, Robin Williams and Rose Anne Barr? You think they're completely level? There's a reason why they're able to function at such a high level you know.*

It was easily recognized that such as these personalities created an esteemed, even enviable, context for Steven. Since his own diagnosis Steven has tapped into his talent for stand-up comedy. One could interpret his identification with famed comedians as valuable in serving to place Steven in a favorable light to himself. So positioned, he is able to recognize his own possibilities, open himself up to relish in self worth, and, pursue being appreciated and respected in his own right.

By contrast, more often than not, participants saw themselves in an unwelcome light against a sensationalized negative standard, one that inhibited a sense of valued self and impeded a personal development. One detects this in Teresa's comments:

> *When I tell people what my diagnosis is, immediately they think of books they've read; especially-made-for-TV movies that they've seen. And that's what they think my life is. That's what they think I am. They don't understand that my illness is not all that I experienced, or was, or am. That's not ME! Even if the story is a true story, it's still not me. Even if the diagnosis is the same, that was a different person with different symptoms, and different doctors and different treatment and different life experiences. They lived in a different time frame and Schizophrenia diagnosed 40 years ago is not going to be the same as it is today.*

To Teresa the experience of *diagnosis* was one that denied her individual identity. She gropes for recognition of her personal self, midst what she perceives to be the congealed attitudes of others, mired in myth and history and stereotypical thinking. She tells us of her struggle to shed a "persona of *diagnosis*," so that *she* might be seen. As well, she brings to light a realization that the experience of *diagnosis* is, in many ways, peculiar to the time period in which it occurs. The experience of *diagnosis* does not occur in a vacuum. It exists against a receding history, in a current time era, against the emergence of new scientific knowledge and new treatments and, so on. In one sense that's what makes this whole subject of diagnosis rather vacuous; a matter of *words* given particular potency?

Touching on the nature of *diagnosis* in terms of its terms.

Pepper and Riglewicz (1988) ask, "What's in a diagnosis?" To broach understanding of what it means to experience diagnosis of a chronic mental illness at least three aspects of the question loom. To begin with, there is the issue of **medical diagnosis**, as itself an experience. Then, one must consider the potential experience that resides in **psychiatric diagnosis**, a distinct form of medical diagnosis. Third, there is the experience of not just any psychiatric diagnosis but, specifically, one tied to a mental illness identified as **chronic**. Indeed "chronicity" may be what weighs the *experience* in a decided way. In this section, then, each of these three terms, and what is imputed to them from literary sources deemed relevant to the study, is reviewed.

Literature on "What's in a Medical Diagnosis?"

As touched on at the outset of this chapter, generally a medical diagnosis conveys some information about one's state of health functioning. It is, however, often the case that medical language is incomprehensible to nonmedical persons. A diagnosis such as "scleroderma," for example, to nonmedical persons would most often need explanation. But, with or without clarification it would not be unusual for people to experience a degree of dread on receipt of it as *their* diagnosis. Cousins (1981) points out that just the sounds of diagnosis, sounds emitted in the air, can vibrate in catastrophic ways depending on who is doing the transmitting and what is being associated with that transmission. What one *thinks* is at issue! And, what one thinks can stimulate or suppress the human immune system, the adrenal glands and the autonomic nervous system (Cousins, 1981; Siegel, 1986; Weil, 1995). The "up" side of this is that, what one thinks can set into motion human capacities for healing and health maintenance (Weil, 1995).

Of his own experience with the dismal diagnosis of tuberculosis Cousins (1981) made note of two distinct attitudes displayed by copatients: "those who were confident they would beat back the disease and be able to resume normal lives, and those who resigned themselves to a prolonged and even fatal illness." Cousins maintained he learned, then, about the integrative role of mind-body in surmounting disease.

Siegel (1986) contemplated diagnosis through the experience of patients diagnosed with cancer. In commentaries on "spontaneous remission" of cancer, Siegel borrowed the term "self-induced healing" from Solzhenitsyn's "Cancer Ward," attributing cancer remissions in large part to the awakening of a personal "life wish." The "life wish attitude" is said to be born of the belief that recovery is attainable in spite of what may seem like dire odds conveyed by the words of diagnosis. According to Siegel (1986) healing is achievable by transcending the diagnostic "Cancer Victim label" (p. 24). Weil (1995) contends that such a healing response is a researchable phenomenon, though to date literature is restricted almost entirely to cases of *cancer* remission and evidence remains anecdotal in nature.

The notion of a power contained in the messages of medical diagnoses that may implicate in health and healing is not common to the literature. A connection however, might implicate from the works of Canon (1935) and Selye (1946). Their central theses posed stress as the source of all diseases. Hinkle (1987) furthers this thinking stating, "the relation of an organism to its environment is in large measure a communicative interaction. Its response to a threat to its integrity is based upon the evaluation of the information received" (p. 566). He thereby accents the importance of social and interpersonal responses. This does not negate the experience of *diagnosis* as a unique and individual one but does take into account the extent to which messages of diagnosis generate from the interpersonal environment.

It may also be possible to attach significance of mind/body connection in the experience of *diagnosis* to placebo effects (Addington, 1995; Pearce, 1995). The fact that patients can derive healing because of beliefs about medicinal properties of drugs, whether or not in reality the drugs actually contain any such properties, speaks to a powerful mind/body cogency. Hypnotic suggestion is reported to be, yet, more favourable than placebo treatment by Spanos, Williams and Gwynn (1990). Results from their study would suggest that "subjects' subjective sense of cognitive involvement in and control over treatment" (Spanos et al. 1990, p. 113) may be a factor in healing. In relating this to the experience of *diagnosis* one is left to question whether the "messages" of diagnosis (generated internally or externally) – the kerygma – contain placebo or hypnotic potentialities. Of course this could cut both ways. A central message of doom heard by a patient to an actual benign diagnosis may have devastating effects. One is led to the bottom line of "effect" in the experience of *diagnosis*, an effect that may be quite removed from the illness with which it is associated. To what extent, one could ask, might such effect factor in the interest of "health?"

Does the person informed of a diagnosis of "cancer," "AIDS," or "schizophrenia" receive a mental suggestion that can act as "friend" or "foe" to health? Experientially something psycho-physiological reportedly does seem to happen when one is confronted by one's diagnosis. Cousins (1997) reports direct worsening of illness (as in disease symptoms) in cancer patients relative to their hearing the diagnosis. Contentions such as these remain unsubstantiated by formal study; however, the effect of patients' attitudes to their diagnosis is documented. Some reports surface wherein patients who demonstrate a defiant attitude to a presumed bleak diagnosis were noted to fair better in terms of disease remission and recurrence-free survival. Greer, Morris and Pettingale (1979), for example, report on a ten-year survival rate of 75 % among cancer patients who reacted to their diagnosis with a "fighting spirit," compared with a 22% survival rate among those who responded with "stoic acceptance," or feelings of helplessness or hopelessness." This would seem to support Mishel's (1988) advocating of "affect-control" strategies in situations of uncertainty and, Miller (1989) who determined that hope was the fortifying mechanism in reinforcing physiological and emotional defences in critical illness. Hall (1989), too, notes similar findings from her qualitative study of patients with cancer and HIV. Those who challenged the medical predictions of a terminal diagnosis were better able to see hope for a normal future, maintain a positive outlook, and discover their potential for an increased quality of life. Hall (1989) states "medical labelling has a powerful and pervasive effect on our views of reality" (p. 180). She is convinced that through diagnosis physicians and nurses can create self-fulfilling prophecies that carry the potential to destroy hope and cause "early death for many . . ." (p. 183).

Instances such as these suggest a possibility that the power of medical diagnosis in human health may be enormous. But, research that may enlighten health care to the actual significance of psychiatric diagnosis and how it plays in the health of persons with chronic mental illnesses has not been presented in the literature. This void expresses a great need for a focussed study which may assist nurses to understand their role in mobilising what may be innate power to move "illness" in the direction of healing and health maintenance.

Literature on the nature of psychiatric diagnosis.

In forgotten obscurity a small, undistinguished gravestone of reddish sandstone bears only a name: "Dr. William Chester Minor." Buried beside a slum in the state of Connecticut, Dr Minor had, during his time in "a mental asylum," become the greatest contributor to the Oxford English Dictionary (OED). More than half his eighty-five years of life had been spent in legally mandated asylums, his illness identified by the vague word *monomania*. Shortly before his death the term monomania was replaced with the new phrase, *dementia praecox*, by literal definition meaning, "early-flowering failure of mental powers . . . to distinguish a condition in which a person begins to lose touch with reality" (as Minor had done early on in his teen years). In this sense the illness *dementia praecox* was markedly different from "*senile dementia* a term once used to describe the decrepitude that specifically accompanies old age . . . " (Winchester, 1998.p. 209). It is almost fitting that the man, Minor, so dedicated to accuracy in the scores of thousands of *terms* he submitted to the OED, had been spared the daunting word *schizophrenia*, which as psychiatric terminology has evolved, would no doubt have been his diagnosis in modern psychiatry.

Diagnosing in the medical specialty of *psychiatry* professes sound practice grounded in the principles of "science," the hallmark of all medicine. Currently, *psychiatric diagnosis* is based primarily on the categorical terms as detailed in the Diagnostic and Statistical Manual of Mental Disorders (DSM). DSM-IV-R represents the current state of knowledge with respect to diagnosing mental disorders. Specific diagnostic criteria are listed in the DSM manual with official numeric codes and terms for all recognised mental disorders, along with a comprehensive description of each (Fortinash & Holoday-Worret, 1999). Relative to the "symptoms" manifested by a given patient a clinical judgement is made on any of five DSM axes. Diagnoses may, then, be applied at any given time to describe a particular patient's "mental health" profile.

Successive revisions of the DSM instrument are testimony to its evolutionary nature. Some disputation has surrounded each stage of its use. Walker (1996) refers to use of DSM in medical psychiatry as "an epidemic of nondiagnosis" (p. 4) charging that "psychiatry has replaced the science of diagnosis with the pseudoscience of labelling" (p. 5). In Walker's opinion, much psychiatric symptomatology caused by biological distortions of brain function is lost in the DSM labelling; not properly explored and therefore left improperly treated. Too, the DSM as an instrument of diagnosis has been questioned by Nikelly, 1992; Rosenhan, 1992; Townshend, 1980 who query its reliability. In its defence, however, are those who suggest, "although detailed diagnostic categories [are] often unreliable, the broad categories (psychosis, neurosis, organic disorder, and personality disorder) [are] fairly reliably diagnosed" (Gove, 1982, p. 80). Gove further states that multiple revisions to the current DSM have resulted in, "psychiatric diagnosis now appearing to have a satisfactory level of reliability" (p. 80). Irrespective of contentions, use of the DSM manual has become standard medical practice in contemporary psychiatry. DSM is heavily relied on in coming to determinations of mental disturbances.

Psychiatric diagnosis is said by Brown (1995) to act as a specialised "voice of medicine" (p. 39). It is thereby recognized as a determinant force within the interdisciplinary mental health care arena. Hall (1996) points out that psychiatric diagnosis in many ways rules the underlying beliefs and practices of all health care constituents in psychiatry, including nursing. She directs attention to the power of the psychiatric diagnosis; a power she maintains can devastate the identity of the individual designated as chronic mentally ill, and impose lifelong limitations through prophetic labelling. Yet, no formal study is found to support or refute assertions as these. Is there a power in the diagnosis that positively or negatively influences healing?

Brown's (1995) documented account of the social construction of medical diagnosis, by extrapolation, represents psychiatric diagnosis as a function, "integral to the practice of medicine" (p. 38). Psychiatric diagnosis provides the biomedical framework by which health professionals are said to gain insight into the psychophysiology and psycho-dynamics of the mentally ill. As has already been stated, psychiatric diagnosis most often dictates appropriate treatment and, to a great extent, signals the prognosis of the psychiatric illness. By this description psychiatric diagnosis carries heavy significance within the larger social structure. The psychiatric diagnostic voice is instrumental in establishing institutional and health care policy. Decisions of diagnosis legitimate illness for access to health care benefits. The word of diagnosis is respected in situations of litigation, and, "diagnosis" brings a "world view" to psychiatric disease conditions (Brown, 1995). These many powerful functions of psychiatric diagnosis attest to its inherent *might* and may come to bear on diagnosis, in a phenomenal sense, to individuals in times of their illness.

In spite of those who question the use of "DSM" in psychiatric diagnosis as credible (Iqbal, Schwartz, Cecil, Imran and Canal, 1993; Limandri, 1989, and Warner, Taylor, Powers, & Hyman, 1989), still, psychiatric (DSM) diagnosis bears formidable authority. We see its most potent function in its power to mandate treatment by imposing "involuntary status" on patients deemed dangerous to themselves and/or to others. While some defend this propensity of psychiatric judgement and involuntary treatment (Gove, 1982) others speak to the searing *stigma* induced by such enactment (Krauss, 1989). The exploratory study of Joseph-Kinzelman, Taylor, Rubin, Ossa, and Risner (1994) identified the extreme powerlessness bestowed on those having been subjected to mandatory treatment, an experience that resulted in long-term reactive "anger . . . fear . . . [and] sadness . . ." (p. 29).

Powerlessness experienced by persons with various chronic illnesses is common in the literature (Conrad, 1985; Corbin & Strauss, 1988; Craig & Edwards, 1983; Thorne, 1993). Indeed, some speculate that the behaviour of self-regulating medication may be the way of chronically ill persons reclaiming personal power (Muliak, 1992; Thorne, 1990). Dzurec (1990) points out that persons who operate from an external locus of control (such as those with schizophrenia) may feel particularly powerless and literally seek ways of maintaining power and control. Supporting this notion would be Baker's (1993) assertions that persons with chronic mental illnesses may actually ignore symptoms that signal their need for "restorative" attention because they fear return to the "patient role," which would denigrate their sense of personal power.

Conversion of powerlessness to hopelessness may have some bearing on high suicide rates (Beck, Kovacs & Wessman, 1975; Byrne, Woodside, Landeen, Kirkpatrick, Bernardo & Pawlick 1994) characteristic of this population (Prasad & Kumar, 1988; Salama, 1988). Research focussed on the perspective of those living CMI is needed to gain greater clarity surrounding their experience of power/powerlessness. In this vulnerable population such insight may stave off hopelessness and translate ultimately into saving lives. Deegan (1993) who writes of her own experience with CMI suggests that without a sense of empowerment, that is, "the ability to find your own voice" (p. 10), reintegrating and sustaining healthier modes of functioning are not possible. One way of persons with schizophrenia asserting personal power, pointed to by Davidhizar (1985), was the ability to choose to participate in research and provide credible and reliable information. Evidence of choice in consents to research by CMI persons (Davidhizar & Wehlage, 1984) respects and legitimates their rights and personal power. These authors endorse the credibility of mentally ill persons as research participants who, in their study, were able to demonstrate factual understanding, appreciate the nature of a situation, and rationally manipulate information.

Discovering meaning in the experience of one's illness is a central notion expressed by Craig et al. (1983), and personal meaning is believed to be fundamental to "actualizing" one's being. Finding "meaning in illness" would seem to encompass "meaning in *diagnosis*," generally fundamental to the experience of illness. But that which might give rise to meaning and, further, how meaning might be construed within the context of *diagnosis* is a topic remiss in the literature. Research that would disclose the elements of the diagnostic event, that might expound, for example, who and how the message of diagnosis is delivered is not to be found. Knowledge of this nature may be extremely useful to nurses in their relationships with patients.

Literature on *diagnosis* in chronic mental illness.

CMI as a categorical term is not a clear-cut determination. At issue is how to adequately describe "chronic mental illness" in a way that encompasses the nature of several varied illnesses. How are these disparate presentations and their respective sequel of symptoms to be captured in one definition? At question, too, is "who comprises the population of the chronic mentally ill?" Critics allege that use of the term "chronic" is itself disparaging, forecasting hopeless and lifelong deterioration (Bachrach, 1988, p. 386). Indeed, most portrayals of CMI are of lasting functional impairment resulting from psychiatric disease (Chafetz, Risch, Furlong, & Underwood, 1992). Goldman, Gattozzi, and Taube (1981) have sought to standardize thinking by offering a description of CMI that has gained general acceptance in the psychiatric community:

> The chronically mentally ill population encompasses persons who suffer certain mental or emotional disorders (organic brain syndrome, schizophrenia, recurrent depressive and manic depressive disorders, and paranoid and other psychoses, plus other disorders that may become chronic) that erode or prevent the development of their functional capacities in relation to three or more primary

> aspects of daily life -- personal hygiene and self-care, self-direction, interpersonal relationships, social transactions, learning, and recreation -- and that erode or prevent the development of their economic self-sufficiency. (p. 23)

The terms "diagnosis," "duration," and "disability" are essential elements of current descriptions (Bachrach, 1988). However, the nature of the interactivity between and amongst each of these facets continues to pose issue.

It has been said, "we do not like to speak of our diagnosis because it puts us in our place" (E. Scarfe, personal communication, 1997). This speaks to a *dis ease* in the, "place of diagnosis." In this study, the place of diagnosis is a place marked by issues peculiar to chronic mentally ill persons. Charmaz (1983) may refer to such a place as one of "discredited self" (p. 188). Some first-person accounts would attest to such a description. Keil's (1992) account speaks to a profound sense of loss at hearing his diagnosis, tantamount to hearing his own death sentence.

> Distorted and confused as my thoughts and feelings were when first diagnosed, the word "schizophrenia" was momentous enough to account for the cataclysmic tremors I experienced inside. It rang in my ears, a death toll for the life I had once known. I sensed that then, but certainly could not have communicated it to any one. The thoughts that emerged from my mouth were fragments, isolated snatches of what was going on in my mind. (p. 5)

Charmaz (1983) and Deegan (1993) make strong statements about the loss of "self" associated with a diagnosis of chronic illness, a loss which can dispossess the individual of resistance to the disease. However, excepting individual testimony, the subject of grief as a specific response to being diagnosed CMI is not attended to in the literature:

> I've had to mourn for the dreams I had that I wasn't able to realize and [for] the expectations . . . the gains, wiped out by bad days and weeks and recurrent hospitalization (Anonymous, 1989, p. 639).

Diagnosis with CMI may also be described as a place of uncertainty, a place where illness is of unknown cause and has a disquieting, unpredictable course. To be diagnosed with a CMI is to be in a place fraught with possibility of relapse (Chafetz et al., 1992). Self-protective and "avoidant" lifestyles are sometimes ways of managing such uncertainty however such lifestyle stance is counterproductive to acceptance needs, as identified by Vellenga and Christenson (1994). How, then, is self-restoration accomplished by those who live the uncertainty proclaimed by such diagnoses? How might care-providers assist in the experience of being diagnosed so that it eventuates in meaningful life-directions? The phenomenology of Vellenga and Christenson (1994) explored severely mentally ill clients' perceptions of their illness on their lives. Aside from turmoil in apprehending the diagnosis and coping with the deep losses evoked by it, *the place of diagnosis* from Vellenga and Christenson (1994) displays as one foreshadowed by lifelong stigma. George's (1992) exploratory research with chronic mentally ill persons reveals very early experiences of felt stigma. Reportedly, "stigmatization began upon entering the doors of the hospital" (George, 1992, p. 40). Such perception extends to an unwelcome fate conveyed through the diagnosis:

> Once our personal identities are transformed into a psychiatric label, we are objects that are never allowed to be people again. (Stocks, 1995, p. 1014)

Stigma is rather well represented in the literature. It is defined as "the process wherein one condition or aspect of an individual is atributionally linked to some pervasive dimension of the target person's identity" (Jones, Farina, Hastorf, et al. as cited in Mansouri & Dowell, 1989, p. 70). Several writers have discussed stigma in association with mental illness (Chafetz et al., 1992; Fabrega, 1990; Kearns & Taylor, 1989; Krauss, 1989; Miller & Miller, 1991). Immense feelings of self and social stigmatization surface in George's (1992) study, feelings of being branded, of forevermore being in bondage by "the label." The *place of diagnosis*, then, might be depicted as a place where thereafter "... every emotion [will be] observed as a measure of the label" (George, 1992, p. 10).

Rosenhan's ethnography, likewise, attests to an unremitting "stickiness" (1992, p. 209) of the CMI label. Only Teasdale (1987) determined a single positive outcome of stigma. Fear of being labelled insane was by Teasdale said to account for treatment compliance. Many writers conversely, impute defaming societal attitudes to CMI diagnostic labels which may prophesy illness relapses, treatment failures, and lifetime impairments (Krauss & Slavinsky, 1982; Gallop, 1988; Gallop, Lancee, & Garfinkel, 1989).

Other complexities that may be associated with the experience of being diagnosed chronic mentally ill are voiced by Bachrach, 1992; Boyd et al. 1992; Gournay, 1996; Vellenga and Christenson, 1994. The literature is replete in expressing need for specialized care required by the chronic mentally ill geriatric population, and of the young chronic adult client, as an emerging prototype (Brunger, 1986; Bachrach, 1982; Sheets, Prevost & Reihman, 1982; Gallop & Wynn, 1986). Substantial literature appears on a current state of inadequate community supports for both these populations, indicating a need for comprehensive health care systems to redirect orientations from "the acute" to "maintenance care" needs posed by chronic illnesses (Bachrach, 1992; Beebe, 1990; Chafetz et al., 1992; Kearns & Taylor 1989). Yet, little appears of the internal world of the ill persons involved or of what they may express their needs to be.

To date there is little that truly helps nurses understand their patients' responses to being diagnosed CMI, or that would provide them guidance in easing their patients' dis ease related to this. Muller and Poggenpoel's (1996) qualitative study attests to the need for subjective knowledge as essential if nurses are to help patients to process feelings and progress toward health. Their study indicates that nursing care of these patients is disturbingly stereotypical and that nurses are remiss in establishing the type of relationships that would negotiate entry to their patients' inner worlds.

Rarely, in the literature, are both the aspects of "diagnosis" and "chronic mental illness" treated together. Two studies did offer some enlightenment to both these aspects in combination. Karp's (1992) ethnographic study reports patients' receipt of a diagnosis meant that finally the process of interpreting meaning to the CMI could begin. However, there was also a sense of foreboding at feeling somehow devalued with now having such an illness label. A study by Warner et al. (1989) also revealed conflicted experiences by persons diagnosed with CMI. When compared, diagnostic "label acceptors" manifested lower self-esteem and self mastery but had better overall relative functioning than did "label rejectors." In this study patients' functioning was assessed by professionals but lacked the patient's point of view.

Sullivan, Marder, Liberman, Donahoe, and Mintz (1990), using quantitative instrumentation, directed their study of functioning to the social activities of patients diagnosed with schizophrenia. In this study, patients' subjective experience was left unexplored. One might speculate on a good deal to be learned from tapping into the patient's perspective on *functioning*. Hamera, Pallikkathayil, Bauer, and Burton (1994) in a qualitative study did elicit descriptions of *wellness* from individuals diagnosed with schizophrenia. Here, findings reflected individualized descriptions of wellness. Some perceived wellness as the absence of illness symptoms while others described wellness as being able to be involved in particular activities, such as socializing with others.

How does *diagnosis* of CMI, of itself, influence self esteem? What care measures would bolster patients' self esteem under these circumstances? In what ways are self-esteem and self-mastery related and, what would promote the enhancement of both these characteristics? Might active self-monitoring, be an important way of exerting control over psychotic symptoms (Gardner & Thompson, 1994)? In nurse/patient partnershiped care (Hall, 1996) which illness "benchmarks" should serve as times of decision? Is there valuable knowledge yet to be had about "diagnosis-secrets?" Hall, Stevens and Meleis (1994) allude to an interface between *secrecy* and *power*, known facets of a "marginalization" that peripheralizes the disadvantaged and keeps them segregated and oppressed. Is a central *dis ease* of *diagnosis* (CMI), then, tied to an uncertainty of, "who knows what about me?"

Having reviewed, to some extent, the breadth of the topic of *diagnosis* as presenting in the literature, a base is established on which to proceed in approaching the study per se. It may be worthwhile, however, to first stress that the purpose of this study is not to arrive at formulated theory, though it could be immediately added that themes arrived at through this study may present such potential if that is the aim of future study. Remarks in this regard are left to this study's concluding chapter. Suffice it to say at this point that with the "experience of diagnosis" in chronic mental illness underrepresented in the literature, this study is held as a plausible entry to comprehension of the experience. *The question* begged a methodology that would render enlightenment to lived-experience (in this case of *diagnosis*); insights which may yield benefit to practitioners of varied health disciplines in various "practice" arenas. Hermeneutic phenomenology was identified and adopted as the most appropriate approach to satisfy this intent.

Embarking on *Diagnosis* through the Archway of Methodology.

Events transpiring during the phenomenological movement in the latter half of the 19th century account, in great part, for an impetus in philosophical thought which underpin the Human Science of Hermeneutic phenomenology. Two German philosophers, Edmund Husserl (1859 - 1938) and Martin Heidegger (1889 - 1938) emerge as key players in its development. Husserl is central for his "ideal of rigorous science," expressed in the hope that the philosophy of the time would re-connect the natural sciences with the "real" concerns of humanity (Cohen, 1994). Heidegger departs from Husserlian thought, shifting from an epistemological focus to an ontological stance and gives primary attention to the nature of "Being." Heideggerian philosophy becomes a major influence in what is to become hermeneutic phenomenology.

Central in Heidegger's thinking is the interpretive feature of hermeneutics, known in biblical times as a theory and practice of interpreting the meanings and messages of sacred texts. In Greek mythology, hermeneutics derives from the Greek god Hermes who had the grave task of clearly conveying messages from the Gods to ordinary mortals. Emphasized in this mythology is need to avert "misunderstandings," a task equal to none less than a God. Perhaps Heidegger viewed understanding of human existence equally onerous. Albeit difficult, Heidegger did believe in the possibility of such understanding and considered it to reside in the power of interpretation (Steeves & Kahn, 1995). Through interpretation hidden meanings could surface and the phenomena of "Being" could be unveiled. In this sense Being refers to a fact of existence or "presence in the world," as distinguished from "being" which connotes the "things of the world" (Cohen, 1994).

And so is recognized Heideggerian philosophy underpinning hermeneutic phenomenology, a human science approach to, "exploring the humanness of a being in the world" (Bergum, 1989, p. 43). In this study, how diagnosis is experienced is believed best accessed through use of this qualitative research approach. This approach accommodates a phenomenology of existential understanding as well as hermeneutics, the interpretive aspect of understanding. According to Van Manen (1990) both phenomenology and hermeneutics are essential facets of inquiry in that "there are no such things as uninterpreted phenomena" (p. 180). Van Manen reminds us, as well, that all knowing happens through human consciousness therefore anything that is consciously perceived is viable for phenomenological study.

A local newspaper provides us sample (Bronskill, 2001) of a perceived phenomenon:

> A *Top News* story carried the title, "**Mystery swirls around ice rings: Rarely documented frozen phenomenon baffles Canadian Crop Circle Research Network.**" Under the title is pictured a woman pointing from a water shoreline to a large circular imprint. The caption underneath read, "A woman in the Eastern Ontario town of Delta awoke Dec.2, 2000, to find an ice ring almost five metres in diameter on the pond behind the family barn." (p. A3)

To my thinking, mysterious ice rings is a gripping phenomenon, something self-evident yet not readily explainable. A perfectly round offshore ice formation! How would one go about exploring *that* phenomenon? But is *diagnosis* any less a formidable phenomenon? Offhand it may not be so sensational as ice rings but perhaps that is the point. Isn't it that "taken-for-granted ness" which shrouds *diagnosis* in its own kind of mysteriousness? Hasn't it lost its self-evident nature because of its everydayness, so to speak! We could say we've de-sensitized to *diagnosis* because of our stance in a "scientized" world! *Diagnosis* has hazed-over in accepted ness. Perhaps its place in medicine gives it, so much the more, an unquestioned absolute "given ness." It just is! *That,* we could say, has led to a neglect of the *experience of diagnosis*; left *it* unattended. In the subjective realm *diagnosis* remains a bit of an enigma. It begs an exploration, a phenomenology that would intentionally search persons' "lived-experience" of it; of *diagnosis*!

In phenomenology, those who have lived an experience are regarded as the resident experts on it. They are the source of understanding the phenomenon. Thus, the researcher must listen to their story with focused attentiveness, contemplate the intricate details of their particular experience (in this case, of *diagnosis*) so that the essential meanings of the experience are able to reveal. What was tired and swept away in an aura of ordinariness is revitalized through that description. And so, not unlike the phenomenon of frozen ice rings, in this study the phenomenon of *diagnosis* presses for comprehension. We peer at *its* mystery, regard it "from the shoreline," a rarely documented and somewhat baffling phenomenon. Hermeneutic phenomenology is the means selected to unravel its mystery.

Between "Being" and "being".

The foundational theme of hermeneutic phenomenology might be captured in the single word "being." In this word being, depending on its capitalization or not, two separate notions can be advanced. *Being* (capitalized) seems the more fundamentally incomprehensible and, indeed, one wonders if this accounts for Heidegger's ready use of metaphor in discoursing about *Being*. He parallels *Being* to a clearing in a forest into which things, or beings, enter. Another analogy he uses to further our comprehension of Being is that of *Light*. Discounting the measurable characteristics of light, such as particle elements or color, Heidegger puts before us light as solely a sensate experience. Thus, paradoxically he brings us to see light, which is in itself never seen. The point is made that like light, the existence of Being is known principally through its effect of illuminating the things of the world (Steeves & Kahn, 1995). In other words, the proof lies before us as the evidence of things or beings of the world.

Notions as *Being* and *being* can be enigmatic and, as I sit here before my computer I begin to resign myself to simply a cursory grasp of it. Perhaps *Being*, like "God" is forever destined to remain ineffable. Nevertheless, as I grapple with the notions my mind comes to settle on Kevin's story of *diagnosis*. Perhaps it is the rawness of his pain which brings it to the fore in my thinking. Or maybe what connects Kevin with my musings on *being* is the anguished message I hear expressed from the core of his being: "*I didn't ask to be this way. I didn't ask to be at all.*"

I hear this same note in many of the stories of *diagnosis* but Kevin's story seems distinguished by the pain in his expression. Kevin seems not only to question his existence in this world. He grants that he does exist, as a *something* opposed to a *nothing*. He is an entity in this world, albeit an un-consulted presence here. In his stream of tears this sense of entrapment is conveyed. His voice chokes and falters with a sense of futility. "Why," he seems to ask? "Why have I had to live my life imprinted by this label? Where is the justice in it?" "Why have I been twice punished (with the sickness and with the label of sickness)?"

I sit across from Kevin with similar questions about him. There seem no ready answers for Kevin and I abandon any temptation to fashion one for him. In my heart I know I have none that would satisfy. I also sense that Kevin may not be seeking a direct answer. In fact, the questions may not be asked with expectation that answer exists. But in the asking is note of "*hope* in despair," a hope for something, for some enlightenment about it all, for some understanding. Maybe Kevin's hope is that added clarity will come to him, possibly through his participation in this study; that his *experience* will not have been for naught, that it will in the end stand for something; something worthwhile to give to others. In some way this may diminish his suffering, give transformation to it.

And so, I stay present with Kevin hearing in *his* questions the echoes of that fundamental question: "What is the nature of human beings?" This is Heidegger's philosophy, that which recognizes the primacy of human beings as the basic unit of existence. The philosophy is actualized in hermeneutic phenomenology, an approach to comprehending human existence. Ascribing to this mode of inquiry means one accepts that access to the world is attained through human consciousness. One commits to a belief that all that presents itself to human consciousness is rife for study. Therefore, it is fitting I stay with Kevin. He is an "expert" source on the experience of *diagnosis*. I look to him, directly, in searching out the meanings embedded in that experience. Through this inquiry I anticipate a revealing of what is only answerable through him.

But, to research in this way requires a patient disposition, a distinct way of attending to one's self as researcher and, of being present to those others participating in the search. One cannot regulate the emergence of insight. Rather one must in some sense "sit" with the disclosures, allow a precognition about them to eventuate. If an attitude of expectant openness prevails then a "fore knowledge" about the experience can emerge. McMorrow (1997) likens the process to an archaeological dig of one's own consciousness. As the dust of inattentiveness, boredom, prejudice, and convention are carefully brushed away the skeletal outline, the form, or what Van Manen (1984, p. 64) terms the "meaning structure" of the experience under investigation, slowly begins to appear.

File bc39.

I wait and witness Kevin's immense struggle to overcome whatever resists his getting his story out. Kevin struggles to push forth the words. They seem to grab in his throat and lock him in silence. I sit, quietly, waiting for him to pull together, waiting for him to form a thought, to shape a word. He seems locked in a "warp." Great tears roll down and drip from his chin. Now and then he sends a desperate, fleeting glance that would say, "I want to tell you, but the words are stuck." Slowly, deliberately, his lips tighten and press a shape as though to force muteness to surrender. Still, it defies him. All that escapes are spasms as he gulps for air and looks despairingly at me. I ask, "Can I get you a glass of water?" For him, that breaks the swollen silence:

> *Some of them have a heart of wood. "Oh a schizo! A schizo! Ha, ha, ha, ha" [imitating the mocking the laughter of others]. What hope is there for me when they keep referring to, "Kevin . . . File bc39, schizo" — "Oh! A schizophrenic!"*
>
> *I tried a lot to help myself. But you know, I'll tell you something. When you're labeled schizophrenic [choking tears] it's very lonely inside. The label causes that. Because people don't trust you! They say, "well you know he's not normal. Abnormal!" So because of that, people shun you.*
>
> *I was falsely accused one time and had to go to court. The judge asked where I was working. My lawyer says, "Oh! He's not working. He's on welfare. He's schizophrenic!" After that the judge just stopped talking to me. He didn't seem to think I knew what I was talking about or what I was even saying. In the end the judge said I was innocent but the other people kept saying, "Well a schizo! What do you expect? Abnormal! Violent! Sooner or later they're going to be violent you know. They're crazy people. They're not all there. You gotta watch those kind of people!"*

I try and make some soothing comments to Kevin and consider bringing the discussion to an end. But Kevin is on a roll. There's no stopping his story now. "File bc39" lumbers on like a 737 airliner down the runway. He's engulfed in recall and a painful past that bubbles forward.

We can see (as in Kevin's recall) that phenomenological reflection is always retrospective. It is always reflection on things past, things that have been lived, things of personal history. As such, apprehension of lived-meaning is in some sense a near impossible endeavor. This is so in as much as lived-meaning, "the way that a person experiences and understands his or her world as real and meaningful" (Van Manen, 1990, p. 183) is described and communicated through recollections. One must assume some alteration of the actualities of that experience. That is, recollections of past experience are, after all, filtered through one's present reality, a reality evolved in the passage of time between the occurrence of the event and the telling of it. To some extent the sheer act of recall results in some alteration of the actual happening. But at this moment in time a vivid "see ring" hurt is rekindled in Kevin. Immersed in this way he recounts:

> *What hurts is, I didn't do it! The judge said I didn't do it . . . but they said --- "an f'n schizo! What do you expect? You can expect anything from an f'n schizo." [Crying, long pause] I heard so many heartbreaking remarks [choking through sobs] that I had to pull out of the area.*

I sit silently, wondering if I should try and divert Kevin's attention, maybe take him to a lighter place. As I deliberate with myself about this, Kevin blurts out:

> *I think I could have had a job or went to university or went into the seminary. **That** screwed me up completely.*

I presume "*that*" refers to the Schizophrenia, or perhaps the symptoms, or the illness, or maybe the fact that he is *File bc39*.

One sees in these ambiguities that the "receiver" must be accounted for in the interpretations, that is, the researcher interprets the story through a reality separate from the "teller's." How then, one wonders, is even approximate apprehension of the actual happening possible? Ricoeur (1973) assists us in this, explaining that understanding is served by a "primordial capacity to place oneself into the psychical life of others" (p. 117). Ricoeur speaks of the passage from understanding to interpretation as possible because of an inherited "universal history," a history of social and cultural worlds which is successively passed on from generation to generation and which then becomes the hermeneutic field. "Hermeneutics is the merging of the individual with the knowledge of universal history; it is the universalization of the individual" (Ricoeur, 1973, p.119). Steeves and Kahn (1995) extend thinking on this, intoning "there is no such thing as raw data" (p. 186); perhaps recognizing the limitations of interpretive text to an "approximative reality." As I mull these thoughts my attention is grabbed by Kevin's comments:

> *I'm very old today. . . . I used to go to church every day, to pray it would go away. But, how are you going to fight it? You know, I've been fighting since I'm 5 years old. I'm very old today. Very old! [Tears]*

I take in Kevin's countenance. I know I am looking at someone in mid fifty's. But, I presume Kevin is not talking about his chronological age. I see sheer exhaustion in his face, and recognize that Kevin speaks through lifelines etched by suffering:

> *If people don't want to treat their kids right, they shouldn't have any. That's the way I see it. They should lead a celibate life. At least they're not destroying a human heart, a human person.*

Kevin is referring to having been "farmed out" during his infancy by his mother. His sorrow culminates in formulation of a critical question:

> *Did she have to give me away? She was ill though -- at the time she gave me away. But she could've handled it differently. She wasn't a stupid person. I think she knew better. She had no use for me. She cast me around like a worn out shoe.*
>
> *I was seven months* when *she gave me up to a family who wanted a son. They had daughters, teenage daughters, but no son. And they said they would take care of me. And she gave me up to them. They took me in. And they didn't want to*

> *give me back after. But what my mother did; [first] she tried in a friendly way to settle with this couple to pay them for the room and board or services. They would not accept it. They loved me like one of their own. So, when I was five years old my mother hired someone to kidnap me back. And when I was kidnapped – my life -- that's when I started to see horrible faces and hear horrible voices. I was very happy before. Why didn't she leave me there?*
>
> *It went to court and it was dismissed. And you know I recall one event at that trial. I was about 5½. . . . The judge says, "which mother do you like best? This one here, – or that one" [pointing to one mother, then the other]? And since they had taken me when I was seven months, I didn't know any better. I said, "that one" [the adoptive mother]. And my [birth] mother never forgave me for saying that.*
>
> *I would hear a whisper. I don't remember exactly what it used to say. It's too long ago. I'd hear a loud, loud whisper in my ear. "Your mother doesn't like you. Your mother doesn't like you." I used to hear a very loud whisper in my head. And I knew it wasn't right. I knew there was something wrong. But I was so petrified I wouldn't tell nobody!*

Kevin's story absorbs me in an "intersubjective" space. Intersubjectivity, in hermeneutic phenomenology, might be thought of as a bridging between "approximative realities." In intersubjectivity is the belief that reality is created across the spaces between individuals because of the "existence of others who share a common world" (Cohen, 1987, p. 31). In intersubjectivity is granted, "in the human order . . . man knows man; no matter how foreign the other may be to us, he is not alien in the sense of the unknowable" (Ricoeur, 1973). Though each individual is author of a unique and distinct reality, knowledge of the other is accessible through dialogue, through empathic understanding, and because intentionality connects meaning to an object. Thus, what is implicit becomes capable of being identified and made explicit, not in the sense of particular meaning being generalizeable to all, but that there is mutually "recognizable" meaning in an experience (Van Manen, 1990).

Breaking glass.

There's no rushing Kevin's story. He labors through it, visibly toiling over some details, stumbling at some points into long pauses as he relives passage through to age nineteen. This is the time of early detection of "disease." In the pauses, I come to ask Kevin if he knew during the intervening years whether something was wrong? Did he recognize that his thoughts were not normal? Without hesitation he declares:

> *I thought I was haunted by demons. And I thought "how come I'm hearing voices? It must be demons."*

Later we talk about the first time he heard his diagnosis:

> *He told me, "It's the brain chemistry." I didn't know what he was talking about. He said, "You have schizophrenia." I says, "What's that? What's schizophrenia?" And he said that the trauma that I had made it flare up. Well I thought I'd been injured a lot. I'd been hurt a lot. And giving me a label like that – that was so off color -- I couldn't take it. It seemed to me, you know, after all what happened to me it sounded like he was adding insult to injury.*

Clearly, Kevin feels impacted at hearing his diagnosis. First are the unfortunate childhood events. Then, "demons" lock him in years of terrified secrecy, and now there is *diagnosis*. Kevin muddles to find words to express how he felt at learning the diagnosis. Eventually he blurts out:

> *If you're told you're "schizophrenic" it's like breaking a glass. It shatters. It damages. It hurts.*

For Kevin, there is no relief in knowing the name of that illness. His statement speaks to a personal fragility. In his pain I "hear" breaking glass; shattered at hearing the word of *diagnosis*. It is here that Kevin would seem to say he feels doubly victimized. Now there is not only the illness. There is the label of diagnosis.

Significance in story.

Kevin's story has been cited in this chapter as a way of discourse about the methodology underlying this study. Vestiges of his story will also be picked up in forthcoming chapters, as will certain concepts of methodology be revisited in new light. It was deemed expedient at this stage, however, to exemplify through Kevin's accounting the approach used in this study and to thereby highlight the significance in use of story. "It is the storied nature of our existence that sets up the possibility for one of us to dwell within the lived experience of another" (Baker & Diekelmann, 1994, p. 67). Narratives and story are heavily relied on as a primary means, in this study, of coming to know about the *diagnosis*. A harvest of personal accounts of persons' experience with *diagnosis* CMI was obtained as the primary "data" collection. In the telling of their story, diagnosis was chronicled from persons' inner reality with the experience, in ways that made sense to them. In hermeneutic phenomenology narrative is vital to understanding experience.

The knowing that evolves through hermeneutic phenomenology might be thought a kind of primal knowing embossed in the contours of a written text. "What we must do is discover what lies at the ontological core of our being, so that in the words, or maybe better, in spite of the words, we find 'memories' which paradoxically we never thought or felt before" (Van Manen, 1984, 39). Hermeneutics necessitates a careful attention to language so that a textual expression of the experience becomes almost a poetizing exercise. The task of *text* is accomplished through a process of writing and rewriting so that *that* which unfolds is of a quality which awakens in the reader of it recognition of the significance to his or her own experience.

In bringing this chapter to a close, a note is made to stress from the outset that hermeneutic phenomenology is an *approach* to study. It is not a method per se. Varied means may be implemented in search for the essential nature of a phenomenon. In this chapter, Kevin's story lends flavor in keeping to the style adopted throughout this study. Beyond this, are the elements particular to this study, the task of "locating participants," "collecting the stories," "conversing with participants," and thematically analyzing the stories," each of which is elaborated in "Appendix A." The reader is, so, more explicitly put in touch with those elements relative to *this* study's search for *diagnosis* CMI.

Outlining the Heart of this Study

It is anticipated that enlightenment gained from this study may in some ways relieve the "predicament" of persons with chronic mental illnesses. Jim, in this study, alludes to mental images that set the stage for his predicament: "I think that even within consumer survivors (group) different diagnoses conjure up different images in peoples minds." Jim carries on to elaborate a circumstance set by *diagnosis* that places him in "contradistinction" to the rest of society. Perhaps Jim's expressions speak to the "existential predicament" cited by Rawnsley (1991, p. 210) a state intentionally explored within the aims of this study.

The investment of this study is, then, to clarify the experience of *diagnosis*, recognizing the gap of understanding that currently exists. Chapter one has opened the question through experiences of medical diagnoses. The intent of this chapter is to bridge our thinking, through the archways of literature and methodology, to the particular form of medical diagnosis that is psychiatric diagnosis. Having thus positioned the question in context, attention is now directed to the unfolding of upcoming chapters. Chapter three details a "tapestry of story" specific to psychiatric diagnosis. Each story in this chapter illustrates a different modality to the experience and renders a distinct but perhaps "incidental" theme (Van Manen, 1990) of diagnosis. Chapters four through seven each add another story that attends to what is termed a more essential theme to *diagnosis*, that is a theme that fundamentally typifies the experience. In these four chapters what constitutes "*diagnosis*" is able to be taken to increasing depth, a deepness that speaks "*diagnosis*" as: "The Experience of A Knowing That Knows," "The Experience of Making Visible the Invisible," The Experience of the (Destructive) Gift of Difference," "The Experience of Making the Knowledge Knowledgeable." Extended insights culminate in the summations of chapter eight, a chapter invested in praxis. Thus, the value of *this* knowledge to the real world of health care is speculated on.

Before turning to the heart of this study: "What is it to be diagnosed with a serious and enduring mental illness?" a final note bears mention. That is, hermeneutic phenomenology as an approach to inquiry makes no pretense of attempting to speak for *all*, nor is it this study's expressed aim. Neither does hermeneutic phenomenology presume to effect generalizeable theory as the outcome of study. Hermeneutic phenomenology, as in this study, addresses the unique and the particular. It studies the subjective experience of individuals, attempting to arrive at a deeper understanding through lived-experience. It does this knowing that any human experience is not exhaustible. A phenomenological text is never the final and definitive statement about any subject. At most, it is but one expression, one interpretation of a reality which, if done well, succeeds in becoming an "icon" to the real thing; a thoughtful and evocative representation of a particular experience. It always concedes another description and interpretation may be fuller, richer and eclipse prior representations in meaning and depth. In that way, the subject can never be sealed (Smith, 1991). In a sense, the phenomenon forever beckons new sightings of itself, challenging onlookers to the task of further exploring its complexities, retelling yet another version of *that something* about it that defies closure. There is always more to be known (Bergum, 1991), perhaps that which alludes to the ineffability of life.

CHAPTER THREE

Psychiatric Diagnosis: A Tapestry Of Story

To attempt to capture the lived quality of any experience is, perhaps at the outset, a daunting task. Undoubtedly, to try and surface what is entailed in an experience as sensitive and complex as "living psychiatric diagnosis" is all the more awesome. The challenge is taken up in this chapter by broaching the experience through several first-hand accounts. Participants, here, offer their stories of diagnosis portraying incidental themes to the experience of diagnosis. Each story is unique in circumstance and intensity and introduces us to particular aspects of the experience that takes us closer to understandings of what it is to be diagnosed. Thus, in this chapter a tapestry of rich detail unfolds, rendered by persons who have "walked the walk" of diagnosis. The reader is hereby invited into the potency in the stories, that in sum highlighting the elusiveness that is the nature of the phenomenon. We turn now to a tableau of experiences with diagnosis of chronic mental illness (CMI) that we might initiate our quest of its essential nature.

Cathy's story: To be re-named.

Cathy had frequently struggled with feelings of depression in her life but she never knew why. The sixties had led her to a chaotic teenage life-style that included heavy drug use. She tried to turn things around for herself by becoming involved in "the church" but by the time she was thirty the clues were numerous that all was not well. Past drug abuse seemed a logical explanation to Cathy who thought: "it's the price I pay for all those drugs I did. I fried too many brain cells." At age forty she heaved a sigh of relief and thought ". . . finally, if there was a mental illness it would have surfaced by now. I must be fine." But something was pressing its way to the surface and Cathy was soon to exhume a truth that would change her life.

Cathy had long suppressed the expressions of illness but an event involving her fourteen-year-old daughter, Janice, actually triggered its manifestation and the eventual diagnosis of "multiple personality disorder." Janice's grade-nine teacher had said, "if you forget your calculator tomorrow Janice, everybody in the class gets to smack you." When the teacher asked the next day: "Janice, do you have your calculator?" Janice immediately covered her face with her hands because the students "ganged" her. It happened so fast, the teacher had no control. Seeing her daughter's cuts and bruises is what "unglued" Cathy. A few sessions of supportive therapy settled Janice, but Cathy's sense of trauma over the event had roused the slumbering illness. Now, she was unable to sleep, was tearful much of the time, felt tremulous, and began having scenes of abuse play out in her mind in which she "knew" the little girl in the scenes was herself. ". . . I felt like I had lost control of my world. . . . I wanted to believe, at that point, that I was having false memories. . . ." For a time, Cathy tried to grope her own thinking; figure it out herself:

> *I thought, "maybe I'm demon possessed," because that gave me an explanation of what might be happening to me, because I had no concept for where all this stuff was coming from. I just knew that I was a mess. I kept using the phrase "I'm going over the edge. . . ." I was terrified actually, for some reason, of going into therapy or even of looking at the issues of childhood. I was, somehow, in fear of what I would discover.*

Eventually, Cathy could no longer function. Life was a constant fear and a constant replay of childhood scenes of abuse. To her four children, "the Mom that they knew was gone."

Therapy proceeded for a length of time marked by a tip toeing around a diagnosis. Cathy would attempt to minimize what had happened; somehow try to flatten the pain of the childhood she was recalling. "I just couldn't get in touch with the emotions. Like, when I talked about it, it was like something that happened to somebody else." Each time the doctor would suggest "multiple personality disorder" Cathy would become panicked:

> *I would go . . . "We're not MPD." . . . And I was using "we" [all the personalities that make up who we all are as a group]. . . . I said, "we're not, we're not." And she'd go, "okay. We'll go in another direction." And she would try and do a little bit of work around all the trauma that was coming up for me a few sessions later she would go back to the, "if you were multiple, do you have any idea who would be there?" . . . And, we did that for about three months.*

Weeks later, Cathy was getting into some "really heavy duty flashbacks" and felt in awful bad shape. Still, the doctor had not really put a diagnosis to what was happening because, Cathy admits, "I wouldn't let her." Each time a diagnosis was even gently suggested Cathy would frantically push it away with assertions of, "that's not what we are." Something terrified her about the diagnosis that was taking shape:

> *I knew . . . that I did switch personalities, but I didn't want it to have a name. Because, I knew that the name, actually giving it a name, meant that (we) multiples were multiples because of severe childhood abuse. I knew that . . . giving it a name meant that in all probability the memories that I was having were not false memories. They really had happened and that I had been severely traumatized and I had a lot of stuff to work through. . . . And, it meant that all the stuff that I was going through in my life now had a reason . . . that I was so dysfunctional in so many ways because I had been severely abused. It wasn't something that a five-minute prayer was going to cure. I wanted something a five-minute prayer was going to cure.*

Cathy did not want to have to recognize that all that abuse is what her young life was made up of. *That* kind of a history meant "shame" and ugliness and sickness. But, the diagnostic indicators were in place and Cathy was worn out with the struggle of "wanting to know" and, "not wanting to know" the diagnosis. She wanted to be an ordinary person, to have had an ordinary upbringing. Yet, she knew something was seriously not right with her. The desire to be "whole" impelled her to know what "it" was; to hear the words she eventually heard:

> *". . . you know, you really are very, very dissociative!" And, I said . . . "could we get a second opinion?" And, she [the doctor] said "yes." And I said, "I would like a psychiatrist. One with lots of letters behind his name" because I want to be sure. . . . I thought, "if he says that I am then I need to accept that this is the diagnosis." So she got an appointment and came with me to see Dr. S. . . . we went in [to him] and said, "we want a confirmation of diagnosis." And then it was said. . . . "This girl definitely has been through ritual abuse, and she's incredibly multiple."*

The pronouncement is made. "This is the expert," thought Cathy. So, now:

> *I have to accept this stuff — that I'm not having, false memory syndrome, that I'm not demon-possessed, that this stuff really happened. And he said, ". . . in all probability yes! . . . I have many women from the same area as you, who have described very, very similar stuff." . . . Like, how do I argue with his diagnosis? He's got lots of letters behind his name. He's not going to misdiagnose somebody in all probability . . . he's met other multiples. . . . He's worked in the States, in a ritual trauma unit with ritual abuse survivors. And I go, "and he's saying it happened."*
>
> *So there was a lot of conflict and emotions — of belief . . . of, of not wanting to believe because it was — it made it so horrible. . . . Him really confirming that* ***that*** *was what we had been through and that's what we were. . . . There just wasn't the cohesiveness of life that there had been before that point.*

Cathy feels, "it fits!". . . It explains the amount of "horrendous emotional pain." But Cathy's world is forever changed from what it was a moment ago. She has bartered for *wholeness* but the cost is a sense of lost cohesion to life. The circle of support immediately vanished. Friends accused her of attention seeking. Cathy wondered why they wouldn't stop to think:

> *. . . who'd do this for attention? She's lost everything. She had a life, she had a home, she was suburbia. She had four children. She had a husband. She had an active "volunteer-life," a fulfilling and enriching life, and she lost it all. If she was doing that for attention, why wouldn't she have picked something that wouldn't have given so many losses?*
>
> *It was just all of a sudden: "She's got a mental illness!" All of a sudden it had a name. . . . They just wanted life to be comfortable and all of a sudden it wasn't comfortable for them so they disappeared on me.*

Of the changes brought on by the diagnosis the losses were most difficult to bear. Diagnosis had lanced a deep and throbbing wound for Cathy that others could not look at. Cathy says she herself could hardly handle it.

> *I wanted to say, "give me that DSM. I'll find another one; bipolar or something a lot better than that one. I want that one -- not this one." Because, who would want to be multiple? I didn't want to be. . . . I didn't decide "oh gee, when I grow up I think I want to be multiple. . . . I want to be mentally ill."*

What hurt the most was accepting the dreadful things diagnosis meant. To Cathy it meant she had been brutalized. The diagnosis acknowledged "the depth of depravation, that had been there." It named a lost childhood:

> *. . . the losses of knowing that . . . I really didn't have a childhood, that I wasn't nurtured, that I really wasn't loved and that everything that I had felt, was true . . . the emotions were true to the experiences.*

To be diagnosed is to have one's personal past emerge and be scrutinized. In this light, for Cathy, diagnosis was to realize a "lost" childhood and thereby to know a moment of truth that would alter her outlook and change her world.

Cathy interprets her own drawing (see figure Cathy) of how she visualizes herself before and after diagnosis:

> *The "me" before was a very contained circle. There was lots of shattering within, and there were a few parts of emotion let out. And there were a few children that "we" let out and a few adults that we let out; but there was very much fragmented control, and so there was so much inside, but very little ever got to come out because it was maintained through incredible effort . . . control. But, this kind of control cost very much. . . . And see, in the beginning . . . the black part of us and any part that held any kind of really horrible stuff -- we were so out of touch with that we didn't even know . . .*
>
> *Okay! So the second picture uhm, [after diagnosis] is kind of very free flowing abstract in which it represents where we feel we are now, in which everybody gets to kind of come out and freely express within the system whether they're, the black parts of us that hold incredibly evil things that have happened to us and that we have done, or whether it's sunshine or whether it's rage, or whether it's you know, any kind of emotion, they kind of get to freely come out and expose and just be there and we accept that they are all there, and that it's okay for them all to be there.*

In comparing Cathy's *before* and *after* anecdotes we note her expression of release as a consequence of diagnosis. *Diagnosis* itself is not imaged, perhaps really could not be imagined. But, the experience of it is storied through the before and after

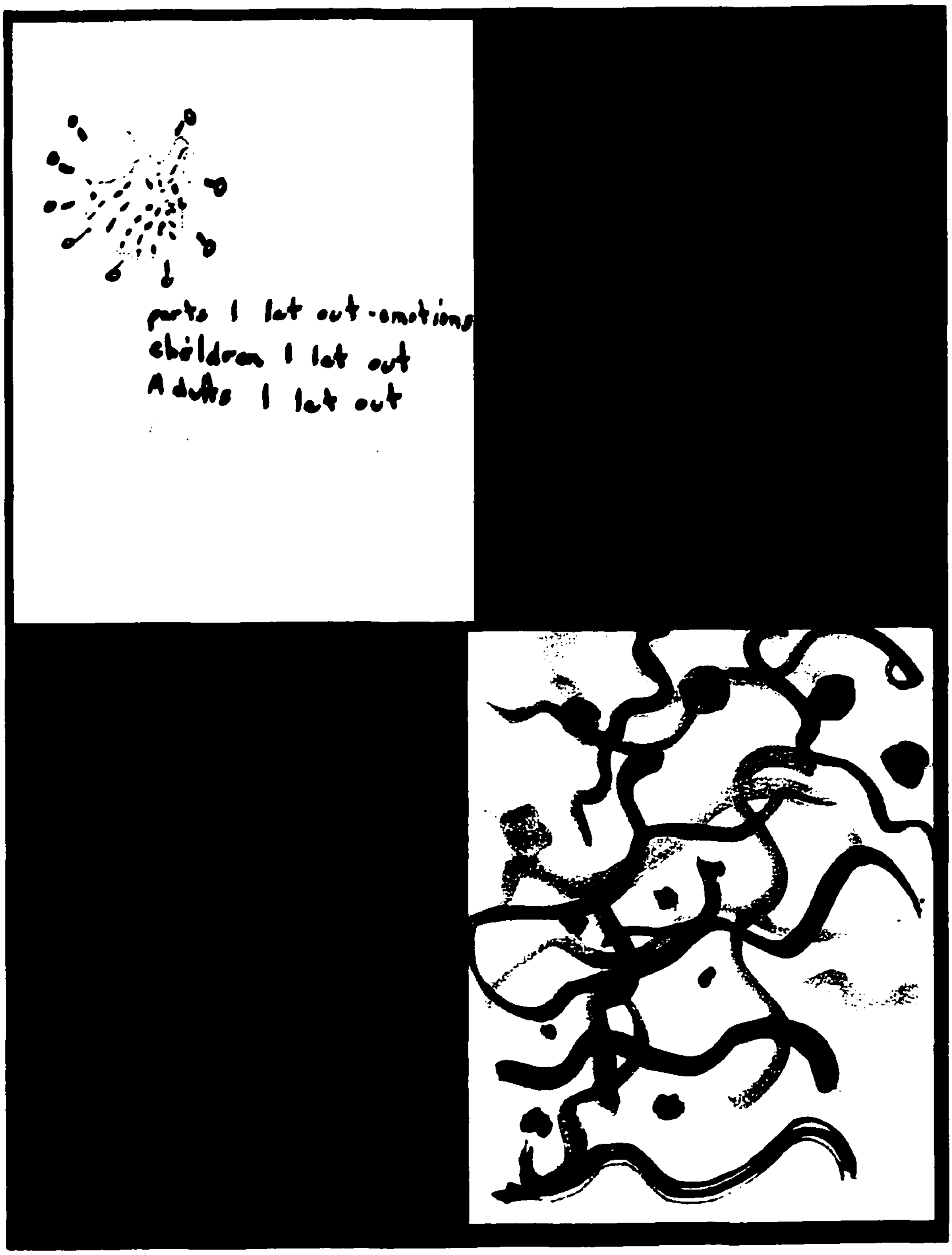


figure Cathy

drawings as a re-naming which happens between the time frames. It's as though Cathy tells us that what happened *there* [between] is the "real" accounting of *diagnosis.* For all that happened *there* the experience of being re-named seems the most poignant. Thematically we could say that **for Cathy, to be diagnosed is "to be re-named."**

Evelyn's story: To be re-integrated.

Evelyn had always felt she had a strong sense of herself. Then things started falling apart for her. It was like a vague and nebulous feeling that not only was something wrong but that her once unshakeable world was heaving. Then Evelyn began having "attacks"; periods of time when she would become unduly anxious and would feel she was about to die on the spot. As things spiraled downhill she began to think of things from her past which she had managed to bury for years. Once the memories started they seemed to flood her every waking moment. She had the sensation of "floundering in the middle of the ocean." Several short-term hospitalizations followed, with Evelyn being treated for an assortment of "mental" problems. She felt she was getting nowhere, simply treading water:

> *It was just a very dark feeling that I had all the time and . . . the uncertainty of what was going on in my life . . . because everything was so chaotic and I was questioning everything, and not knowing where I was going, or why I was going through the things I was going through.*

Then, after months without notable improvement, a new line of questioning took things to uncommon territory. At first the doctor's questions didn't seem so unusual. Then at other times she'd be asked things like:

> *Do you ever lose time? . . . She [the psychiatrist] would ask me if I am ever doing something and then all of a sudden it's two hours later, for example, and I'm doing something else. I thought, "doesn't that happen to everyone? I'd always thought it was normal, that it was how people experienced time — in a similar way to highway hypnosis . . . you realize that you're twenty miles further than you last realized and you don't really remember driving the last twenty miles but you did.*
>
> *She would ask if I ever found articles of clothing in my closet that I don't remember purchasing, or, misplace things that I was sure that I had put somewhere.*

The doctor was picking up on stuff that started to fit an uneasy pattern for Evelyn:

> *. . . definitely the hearing of voices; often finding pieces of paper around the house in different handwritings; losing time; finding clothes in my closet that aren't really my taste and I don't remember buying.*

What she had accepted as usual and normal in the past was surfacing as not normal for most people. Evelyn began to wonder what in the world was happening:

> *I just remember hearing, the words Multiple Personality Disorder and, and just freaking out. . . . She [the doctor] told me that I had Multiple Personality Disorder and I looked at her, and I said "you're crazy!" My second reaction almost immediately following was "you're telling me I'm crazy." I said, "well I've read Sybil and Three Faces of Eve . . . years ago and my life is nothing like that."*

The fear that welled up in her was enormous, "Oh god! Tell me this can't be true!" On the one hand it seemed impossible but then, in an absurd sort of way she thought, "Oh my God, this could be true!" She tried to push the words away; reason it out of her awareness. But the words wouldn't leave. It was such a difficult diagnosis to confront face-on. It left so much unknown. It simply dropped as a condition that wouldn't go away and would take a lot of hard work for a very long time, to treat. Even at that, the outlook would be so uncertain. What kind of a future would that bring? Evelyn wanted to cry out and say: "No, not that one! Please change it to anything else." But, Evelyn was becoming aware of a deep unalterable sense of loss, a feeling that "it" fit and with it her identity was being striped away from her. "Oh my God," she thought, "I have no idea who I am anymore!"

Evelyn knew she was the same person she'd always been: "It's just now I had a label attached to me," she states. And the label didn't make *her* any different than before, or did it? In fact, the naming did make things different to her partner and, it was frightening to everyone who had known her "before." Actually, even Evelyn sensed she was talking from both sides of her face on this. On the one hand she was professing no difference from before diagnosis but, on the other hand she spoke of her identity as a "primary loss." She was saying she was no different while at the same time she was openly despairing about having lost all sense of who she now was. This was the confusion entailed in the experience of diagnosis:

> *I'd always felt like I knew who I was and then all of a sudden I didn't. And it was very frightening to think that there were parts of me that I wasn't aware of, and that in some cases the parts held contradictory values to what I held, and, the realization that all of these parts put together is who I really am. It felt like my identity was taken away and, I didn't have a clue who I was – the Self I thought I was isn't!*

A fractured self! A blemished past! A present filled with fears of things she has still to discover about herself! A future where the only certainty lies in the uncertainties made manifest by *diagnosis*. In Evelyn's own words, to be diagnosed meant, "I couldn't take anything for granted anymore." The facade of her stable world crumpled.

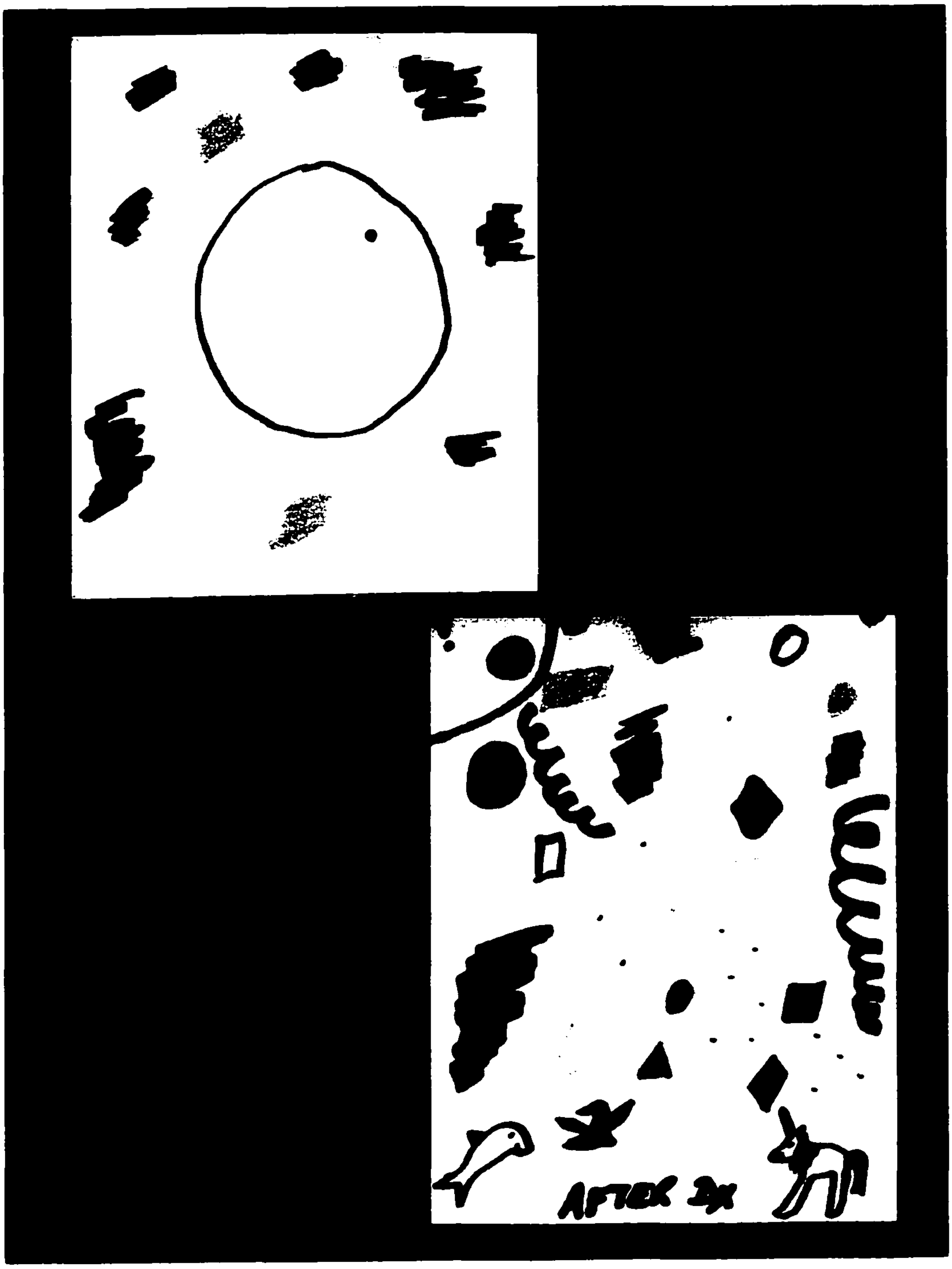


figure Evelyn

Now, months after first hearing *that* diagnosis Evelyn draws her own before and after representation of herself (see figure Evelyn) which she interprets in the following manner:

> *The circle in the centre is how I would have to perceive myself before my life started falling apart . . . the different colors would be different aspects of my life and experiences and they're somewhat orderly but also a little bit chaotic too . . .*
>
> *The black spot within the larger one is a kind of blemish on the soul. Ever since I could remember, I always felt that there was something about me. If I had to conceptualize the soul I would have thought of it as a white ball of energy. But I always felt that my soul had a black spot, a dark black hole in it.*
>
> *After diagnosis, this is me walled off from the rest in the upper left-hand corner. There is still the question of who I was or, who I am. With the increase of knowledge the barrier is there because I don't really have a good consciousness. . . . My consciousness is walled off, for the most part, from aspects of myself . . . in all different shapes, sizes, and colors. And spirals are more like a feeling . . . probably a fear of mine of just being caught up and not being able to get out again. The baby unicorn is like the kid in me . . . carries a lot of open optimism and has been waiting for the psychiatrist to remember her magic and bring "it" back to life. . . . For me the goal would be integration.*

Evelyn is noticeably thrown into inner chaos by *diagnosis*. From it, however, is promise that new shape will eventually emerge to define her. **For Evelyn, to be diagnosed is "to be re-integrated."**

Susan's story: To have a re-instated self.

Eleven years ago, before the depressions started, life had seemed pretty rosy. Susan had married her high school sweetheart. She had two children, a boy and a girl, and she was practicing in the profession she had excelled in as a student. There was only one downside to life. Susan felt she was wasted working at the twenty-two bed hospital in the small town where her husband had moved the family. That didn't fit Susan's picture of how she expected her life to be. So, when Susan started feeling down and started having trouble sleeping she simply attributed it to, "sitting in my little hometown thinking 'uh! I'm here for the rest of my life'." She didn't think her mood so unusual given her circumstance.

To manage her gloom Susan joined an exercise program. She changed her diet and tried a number of things including acupuncture. But, nothing lifted. Instead, things steadily got worse and it was now showing at work. Her concentration had become so affected she was unable to think clearly, let alone do medication calculations. She was "teary-eyed at the drop of a hat" and was becoming so emotionally erratic she felt, "I just couldn't count on myself anymore." Eventually, Susan admits to herself and to her Director of Nursing: "I cannot continue to work."

Treatment after treatment proved only marginally effective at leveling out Susan's moods. What eventually marked a change was a book a psychiatrist gave her to read. Then, like a flash she knew:

> *I walked into his office and said, "I have bipolar disorder, don't I!" I can remember it as clearly as if it was right now. I remember feeling shocked about it; turning numb. . . . [The doctor was] pretty good at playing down the seriousness of anything. Like, [implying] it's not a big deal. You know! But it was a big deal for me. . . . I was sort of in shock about this diagnosis and the thought of manic depression.*

Susan had participated in diagnosing herself yet, to have it confirmed by the doctor brings home a stunning realization: "oh my God, it's manic depression!"

> *. . . suddenly I was a permanent psychiatric case . . . medical professionals talked about people with a psychiatric diagnosis, and if I'm one of them now. . . . I'm one of the crazies, one of the loonies . . . one of those people, the rejects of society? The feared diagnosis . . . just said chronic things to me . . . it was like a knife was being thrust in my chest . . .*

It all made sense to her now. "The Lithium he had prescribed had worked. Within three days I was back like that— just back. Working, everything! I couldn't believe how well lithium worked for me." Susan wondered why hadn't she seen it sooner. But, this diagnosis meant that the illness was going to be persistent in her life and, that was the heaviest thing to accept about it. Susan "knew" she would have to work full-time at managing it if she were to keep "it" at bay:

> *. . . taking my medication, getting myself out of bed, going for a walk everyday, eating properly and – I'd just pray lots for it to lift.*
>
> *Suddenly I'm starting to hear about this illness in very scary ways. But I had some knowledge about myself now . . . and I'm like "okay, fine, I'll deal with this -- this beast. I want to stay healthy."*

And so, Susan faces the beast. Sometimes her choices feel predestined and she thinks, "I'm on some path in life that has not been determined by me." She wonders at these times if choice by default is choice at all. Susan thinks she has paid attention to the things the diagnosis tells her about herself. In that way *diagnosis* is seen to objectify the self. It gives her some answers about ways she has behaved. It says certain things about what she feels and how she thinks. The diagnosis also excludes what she doesn't have and, it tells her what she does have: "a cyclical brain disorder that for me responds pretty well to lithium."

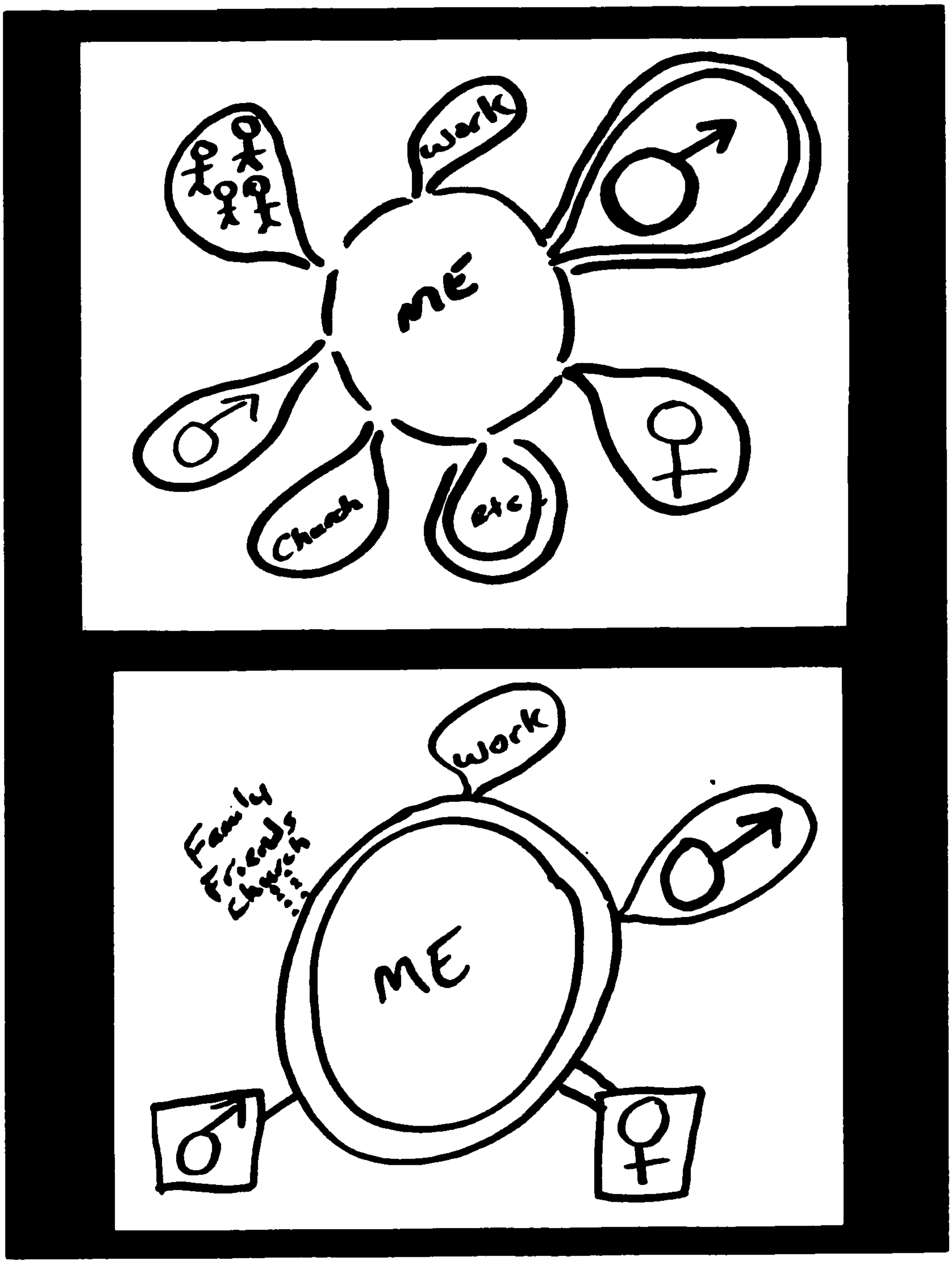


figure Susan

Susan had been treated for recurrent bouts of depression for eleven years before receiving the diagnosis of bipolar disorder. In hindsight, she notes the earlier diagnosis of *depression* had a different feel to it than *manic depression:* "It was nice not having that chronic mental illness label attached to me," she says. But, the correct diagnosis made more sense. It explained to her the periods between the depressions, when people would say "God you're hyper. . . . I wish I could have that energy!" She had never even questioned these periods as anything but normal. Now she knows they were not normal. For Susan, to be diagnosed meant facing the beast of an unremitting illness. In this, it also meant reckoning with the thought, "I'm one of them now!"

Of her drawings (see figure Susan) Susan says:

> *In the first picture I have me as blue. Blue is a kind of cold color. So, before diagnosis I'm drawn as a circle. I was a broken line circle. I was struggling to manage everything in my life. The double line, my husband, was the biggest focus. Then there was my daughter and my son, and then all of the other parts that had to be figured out; church, business, work, friends, family. . . . I felt fragmented that's why the break in the circle.*
>
> *Green has always been health for me. Me, after diagnosis, has become a more whole person, to the point where I do feel I've a couple of layers, and I think I need more yet, but I'm insulating me and prioritizing. I'm in control with all of this. I'm still struggling with recognizing I can't control everything in my life, but still knowing that my life is how I determine it to be. I'm the one in charge and I'm doing what I'm doing because I choose to do it, and I'm exercising the right to be my own person.*

By Susan's interpretation of the drawing, being diagnosed moved her from a state of feeling fragmented to a re-connection with herself as the one ultimately in charge. In that sense it moved her from one state to another. **For Susan, to be diagnosed was "to have a re-instated self."**

Gary's story: To gain self-knowledge.

Gary's years of weightlifting have given him a thick and solid look. At age twenty-nine, however, Gary looks weary beyond words. It is not the kind of "tired" that would be relieved with one or two night's restful sleep. It is the tired that yearns for a thousand "sleeps." But, in spite of the deep dark rings about his eyes Gary has a determined stride to his step. Today he is off to university where he works as a research assistant. He is going to the library to get some information for a report that needs doing. He is determined, seeing education as the key to "unlocking his future."

Gary remembers his life before diagnosis as an "unrestrained period in time" (see figure Gary). He was very active in athletics, pushing himself a lot to excel at sport. But, this was also a time when Gary and his buds were heavy into drinking and drugs. And as well, steroid use went along with his bodybuilding. It is ironic to Gary as he thinks of it now, that for all the attention he put on his body and all the emphasis he put on a muscular image, he really thinks he didn't respect his body. He "*ab* used" it. These were his teenage years and he was out to have a blast. Lots of girlfriends! Lots of parties! Lots of getting "high" on drugs! Living a high was the theme of those days. And then it all shifted. A change crept up on Gary making it hard for him to really know when it took place. But, at some point the high life just was all gone. Gary was sitting alone. He had lost interest in his friends and generally, he had lost interest in most of what was going on around him. Even his love for sport had faded. Before he knew it, "*it*" was upon him. Gary had gone from being "very aggressive to being very passive and withdrawn." In fact, he barely felt human anymore. He was simply going through the motions of day to day. Inside he "felt almost like a robot."

Early on, when things were going all wrong, there was mostly a black depression and the voices. Gary thought it was all brought on by the drugs he had used. Whatever had set "it" off, once started things quickly spun out of control. Now, there were huge fights with his parents until the disturbance was unmanageable. Gary's parents took him in to a doctor who immediately hospitalized Gary:

> *They gave me Rivotril, which I thought wasn't really for treating psychotic symptoms. I thought it was treating my epilepsy, which I had since I was about six years old. But there was no psychiatric diagnosis at this time. They did not want to diagnose it. The Dr. said it was nothing. He said it was just an "episode." I just wanted to get out of there, and get home, and get over the depression, and start to work things out again. I spent a lot of time thinking and figuring out where I wanted my life to go.*

Things did not get better and other "episodes" and hospitalizations followed. It was about a year and a half later when Gary first realized there was an actual psychiatric diagnosis:

> *The doctor was in a room with my mom and I heard him say something to her about "schizo-affective" something or other. I'd never heard of it. It was something I didn't recognize. I didn't know what it was.*

In time Gary has come to know his diagnosis as "schizophrenia" but he doesn't remember ever being told that by the doctor. He's uncertain but thinks he may have learned about it from his parents. He does know it took "quite a while" for him to realize what schizophrenia really was. He's unsure exactly when it was he started to make sense of it. At some point he knew that he "owned" it. The diagnosis was his! Perhaps he came to understand it from a course he took; began to recognize and accept that the label did describe some of what he was experiencing.

The first person Gary remembers telling was his weight-lifting partner. "I have schizophrenia," he said. Gary thinks things weren't the same after that. Soon after, the friendship seemed to drop away. Gary is thoughtful about this and wonders whether it is he or "them" that has changed. He knows that he is not as outgoing or as spontaneous as he used to be. Maybe he's not as much fun to be with? Maybe they're scared of him? Maybe they don't understand him now or, don't understand what it is that he has.

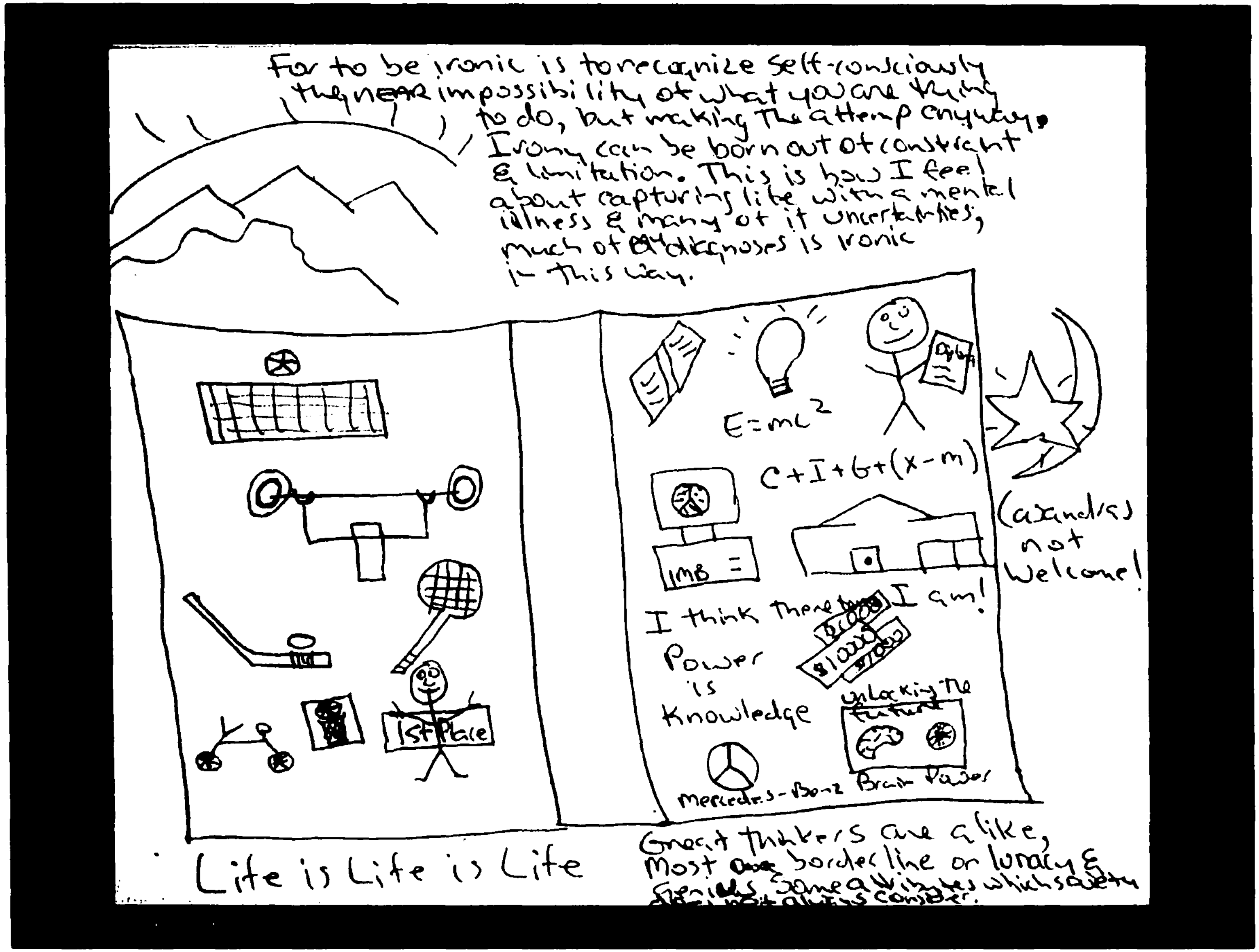
When Gary returned to university shortly after his hospitalization he decided to prepare a story on his own experience with schizophrenia. He read this to thirty or so of his classmates. Most of the students in the class had wanted to hear about the story. Gary thought they were quite accepting of it and of him. However, one young woman in the group made a remark loud enough to be overheard: "Oh, I better watch my neck now!" she said. That single, statement struck to the core. It continues over time to stay lodged:

> *It kind of was an offensive statement that brought to mind my own perceptions of what the mentally ill were about. Before I ever was ill I used to have these biases and thoughts about mass murderers and all of this. It really was quite ignorant when I think of it now.*

Gary thinks more seriously about this now. He knows what thoughts other people might have about him. He knows because he remembers his own thoughts from before. He thought those thoughts! His gaze drifts and eventually he blurts out: "I would like to shout out my diagnosis." Then he decides this wouldn't be a wise thing to do."

Gary never used to think about God at all until now. Now he wonders "if God has anything to do with this?" It's like the whole experience has awakened a sense of the spiritual in him. He can't really reason it but he believes that something powerful has moved him in "a totally different direction" from where he was headed. This is reflected in his drawing (see figure Gary). The left side of his drawing portrays a hockey net, barbells and symbols of his interest in basketball, tennis and cycling. In all his athletic interests Gary was driven to compete, and being in "first place" was the ultimate prize. He was a "jock" before. But now as reflected on the right side of his drawing, Gary is drawn to scholastics, illustrated in the symbols of science. He chooses to see himself as a "scholar" and draws himself with "diploma in hand." Much of his thinking is tied up in academics, as this is where "it's at." Possibly in the computer industry (represented as IBM) he sees his earning potential and "unlocking his future," acquiring a home, and maybe even owning a "Mercedes Benz." "I have a good chance of becoming educated now . . . " he says. "I couldn't have done it before." *Before* means before the illness was diagnosed. Gary sees the diagnosis as unraveling a mystery about what was happening to him. It also opened a door for him through which he could see a new path for himself.

In his quest to be educated, Gary's comment "power is knowledge," comes to mind. Why he phrased it that way is curious. Shouldn't it have been: "knowledge is power?" Of the many different kinds of power: money, leadership, political and so on, how is it Gary identified power as knowledge? Perhaps Gary just mistakenly said it that way? But then, maybe to Gary the only real power available to him is that which is imbedded in knowledge. Then it strikes me that *power* figures a strong theme in Gary's entire life. First, there is his passion to build body power through weight lifting. Then there is a shift to power of the "mind" through academia. Perhaps for Gary, diagnosis was



For to be ironic is to recognize self-consciously the NEAR impossibility of what you are trying to do, but making the attemp anyway. Irony can be born out of constraint & limitation. This is how I feel about capturing life with a mental illness & many of it uncertainties, much of my diagnoses is ironic in this way.

Great thinkers are alike, Most ~~are~~ borderline or lunacy & Genius. Some attributes which society [illegible] not always consider.

itself knowledge which enlightened him to a different version of the same "tune" of innate power. In any case, much has happened since life was a blast and he was diagnosed. His intensity *now*, shows. We see it in his drawing (see figure Gary) that is heralded: "For to be ironic is to recognize self-consciously the near impossibility of what you are trying to do, but making the attempt anyway." Without a doubt, to be diagnosed has created such a determination about Gary. "Cassandra(s) not welcome," he says, and strides on. For **to Gary, to be diagnosed was "gaining self-knowledge."**

Teresa's story: To be denied self-knowledge.

For as long as she can remember, Teresa has thought of herself as a bit of an enigma; somehow not quite whole. Curiously, this she thinks may account for her distaste of puzzles. To this day, puzzles of all kind key her into recall of when she was small:

> *We would be at my grandparents quite a bit and there were lots of puzzles there. I kind of wonder if the connection of my being around abusive people and then being told to go behave myself or go amuse myself with the puzzles has something to do with it.*

Picture puzzles, jigsaw puzzles, riddles and so on! Just to be around them actually makes Teresa nervous. Somewhat ironically, Teresa's drawing (see figure Teresa) depicts herself in parts; pieces of a larger whole. Yet, when it comes to puzzles Teresa says, "There's something about them I just don't like":

> *It's like, "you had the whole picture to begin with. Why would you cut it up? And you cut it up. Why do I want to put it back together? And even after I do, what do I have?"*

And so, puzzles have never made sense to Teresa. It's like somebody chopped the wholeness out of "it" and then expects someone else to make the picture complete again. Defiantly Teresa says, "I'm not going to try and put it back together?" Whatever the symbolism, puzzles touch Teresa in a particular way that connects her to the things of her early life. Perhaps puzzles confirm to Teresa a thought that she was always "the strange child." It's not that Teresa wasn't a bright child. It's just that "parts of her never seemed to fit together."

At school, Teresa never did align herself with the good students. The kids she "hung" with were the underdog kids, those who were in trouble a lot, kids that sat at the back of the room because "they" were too disruptive! By the time Teresa was seven years old she was making attempts on her own life; a prelude to a lifetime of feeling, "my life doesn't work." As the years moved along Teresa was unable to ever feel good about who she was or what she did. Jobs and relationships never held together for long. When life got too out of hand Teresa would escape to sleep. She would just up and tell people, "I have to go home right now. I need to sleep." And that seemed to work for a time, and when it didn't, she drank a lot. Even so, it was harder and harder to keep things in control:

> *Every time that my life got totally out of control I would change jobs, change environments, change friends. So I'd just go from one little tiny life that had lasted maybe five years, maybe five months, to another life with totally no connection. And then start over or start from that point! But I was always de-escalating, always getting a less responsible job, less money on the job -- to the point where at the last job that I had I couldn't even use my calculator. I was working in a fabric store and I'm supposed to be giving in-store seminars and I can't do it. I'm department head and I can't talk. It got to the point where I couldn't sell fabric because I couldn't figure out how much fabric the person needed. I couldn't do it on paper and I didn't know how to run my calculator most of the time because I was so stressed out.*

Year after year Teresa searched for some kind of help, one doctor then another doctor. One hospital, then, another. Nowhere could she find help that sustained her for long. Then, she got "known," and no one wanted to help. It's like they could see her coming and just wanted to look the other way. One doctor just went, "I can't deal with this. I'm going to have to send you to somebody else." Over and over Teresa felt abandoned to someone else:

> *I went to a therapist. . . . I was making a minimum wage and paying a hundred dollars an hour to this person. But I went in and I said to her I don't want to waste your time or mine and I need to tell you that this is what is happening. I hear voices and this is how it started and this is what they talked to me about. . . . Now I thought, "if she likes you and she keeps you and she knows what's wrong with you, good. If she doesn't at least you've only wasted a hundred dollars; an hour of your time, and an hour of her time."*

But "real" help never happened and again, Teresa was shuffled to someone else, then yet, another and on and on. From one referral to the next! At times she would just give up on herself all together and decide she was "too sick to be on the planet." Like the time she remembers walking straight to the medicine chest and just taking absolutely everything she could find there. But suicide attempts really accomplished little more than emergency treatment, then, she was out there to face it all over again. There didn't seem anyone out there who could see her distress:

> *I can remember begging them, -- like one of them, like hanging on to his lapels and crying and saying, "help me," you know, "just get me to see somebody. Just help me." And they would all pat me on the head and say, "you're just overwrought, you just need to sleep." — Yeah, I need to sleep and get myself back together! But by that time I'd figured out that sleeping and getting myself all together so that I could get through the next day wasn't doing it. It was still there!*

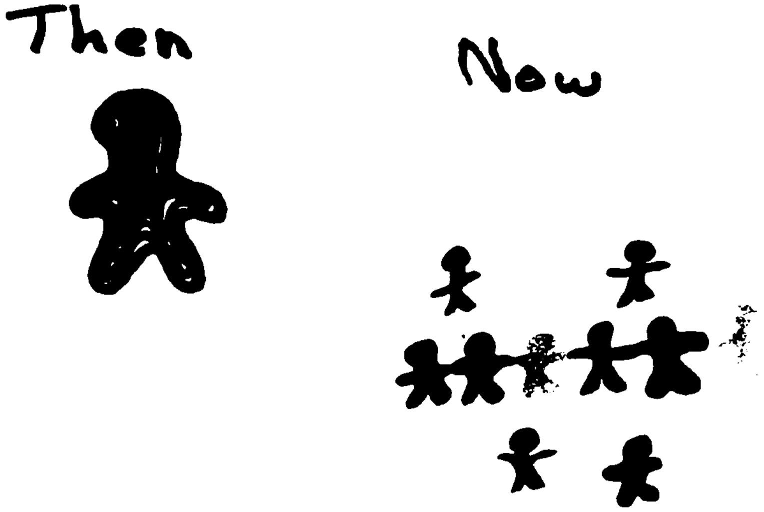


figure Teresa

> *You know the voices didn't go away because I slept. They didn't get less because I slept . . . it wasn't getting better.*

Teresa states, "I knew I couldn't do it anymore. . . . I had really given up." She found her way in to the hospital emergency one more time. It was the same routine but with one difference. This time "old charts" were carelessly left within her view there in the interview room. Teresa strained to see and her eyes settled on what was written there at the top:

> *The first thing on that first page of my file is MPD??? [Question mark! Question mark! Question mark!] I looked at that sheet and I went, "They knew! They knew that then! Twelve years!" Twelve years ago they knew what was wrong with me. And they didn't send me anywhere for "it." It's like, "You came into the hospital with a broken leg." And, they looked at it and go, "Hmm, we don't treat broken legs. We'll just like hang on for a while and put her back out on the street with her broken leg. But we're not going to tell her, her leg's broken because heaven forbid she should go somewhere else and get it set." And that's the way I felt.*

"They put me together enough that time so that I could go back out," she says, explaining this in her drawing (see figure Teresa). Teresa self interprets the "Then" left-hand image to simply be a mass of turbulent energy. It is drawn as a form with a black centre from which emanates heavy, dark green and red color. The colors "bleed" into one another and the energy, though held together in bodily form, is "diffuse" and "foreboding." Teresa says she was undifferentiated "then," living in turmoil and at the mercy of the unexplained forces she felt within. Since diagnosis and treatment, the "Now" side shows the emergence of a number of distinct personalities. Teresa talks about becoming acquainted with these distinctions of herself. She now feels a sense of permission to allow the personalities "to be." She can even value them because she has come to know them and accepts them as aspects of herself. Because of this it is not so frightening she says. She sees possibility of all the personalities living together. But, Teresa cannot ever see possibility of complete integration.

Teresa is 46 years of age. She wonders how the course of things might have been different had her diagnosis not been withheld from her. She thinks of the time, the pain, the *living* that has gone down, and she wonders: "Would any of it have been different?" Clearly, if one looks at the anecdote carefully, we see ". . . *MPD ???*" suggesting that what Teresa saw and took to mean definite concealed knowledge [a withheld diagnosis] was in fact written with decided apprehension. Why else the three question marks? Perhaps here we glimpse the notion of an *inside* versus *outside* theme. "Outside," that is from *health care*, is a knowing layered with marked uncertainty, from that point of view a very provisional diagnosis. From "inside," however, Teresa doesn't even recognize the tentativeness to it; totally passes over any doubt. To her, she was simply refused *diagnosis*. She thereby feels victimized through denial of appropriate treatment. In her story, we view the meaning of diagnosis from what has been denied. **By Teresa's**

perception, there is a withholding of diagnosis making her experience, one of a "denial of self-knowledge."

Julia's story: To know for certain.

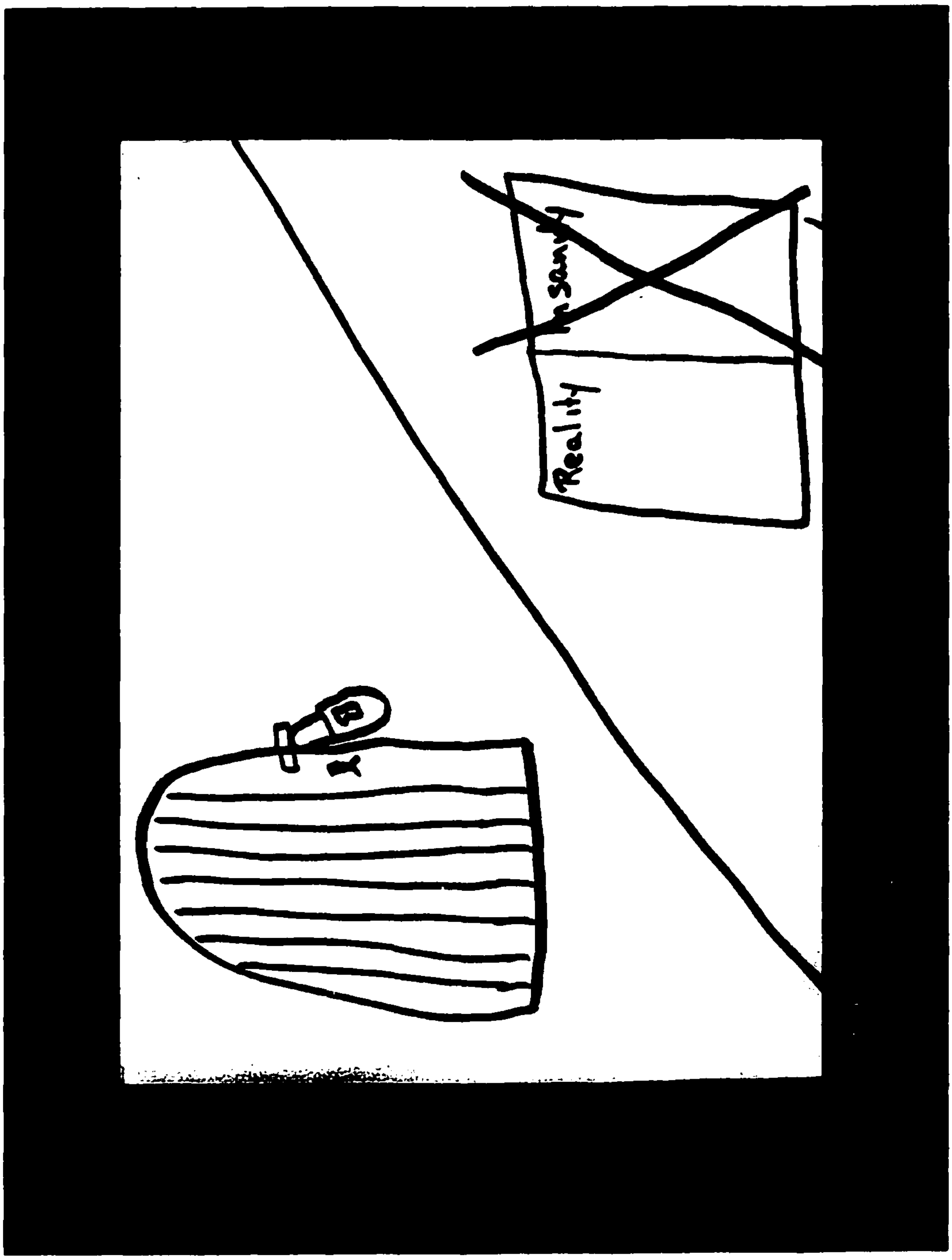
Julia, an articulate lady, moves quickly from one idea to another without pause, recounting those things that precipitated her illness and led to its diagnosis. Her symptoms were very subtle in nature and didn't overly interfere with her life until she reached her 30s. Then, all of a sudden she started to experience more anxiety, couldn't function effectively at work, and realized that it was getting harder and harder to function altogether. She began having sudden, unprovoked episodes of uncontrollable tears. Then, most frightening of all, she started hearing voices and thought, "I'm going crazy." One day, while driving to work, Julia deliberately let go the steering wheel allowing her car to careen wildly and end up in the ditch. From this she sustained head injuries which she believes became the turning point for her. "Head injury," she says, "made the disorder more evident and therefore diagnosable." Following the "motor vehicle accident" (MVA) Julia experienced unprecedented panic. She was no longer able to keep things at bay and in panic, she phoned her doctor.

> *I'm just bawling and saying, "could it be the medications?" . . . he stopped some of the meds. . . . "I think you're losing it" [he said]. . . . "Before all the flags come unfurled you better go to therapy." . . . We all went to therapy.*

"*We* all went to therapy" is a key statement in Julia's story. In the six months of therapy that followed she exposed a "system of alters"; three distinct personalities, each identified by her own name Julia, but each distinguished by a different number:

> *We were split and we talked about three separated selves. . . . Myself which is "nine". . . . We talked about "five". . . . We talked about "thirty" who was the nurse and who went to work. . . . She's very maternal. . . . So we always go by our numbers. . . . It's just convenient.*

This revelation of alter personalities resulted in an abrupt termination of Julia's therapy. The stunned therapist was evidently unprepared to deal with what he put down as Dissociative Disorder. Julia went back to work, discounting the symptoms she was having and struggling ever harder to hold herself together. She would have to ask people to repeat things two and three times because she was unable to take in the information. She was constantly misplacing things; keys, pencils, files! The other big concern was *losing time*. Julia could not account for her activities over time. It was like she would start at one point in time and end up at another point in time without knowing what had taken place in the intervening period. Then, she began to realize that time gaps characterized her entire life history. For example, she was stunned to realize a complete blank of recall for long age periods. "I'd lost virtually everything," she says. Julia was exceedingly distraught and needed to determine what was wrong with her.


Insanity
Reality
B

With home remedies, Julia attempted to heal herself. But she couldn't shut out this little voice that said, "we are real." She "knew" she couldn't do it any more. "I knew that I was in terrible trouble." Julia was horribly frightened. She had to find out if her "self-talk" was really different from "how other people think":

> *I went around for a long time asking people, what does it sound like when you think? And people would be stumped by that question. And the only person who's been able to answer that to my satisfaction is my therapist. . . . 'Cause he thinks in words and there is sound when he thinks. But there's only one voice. There's not several. Like it's his own voice. . . . Whereas in my situation one of us is verbally asking the questions and then there's this conversation . . . this noise you know [with several voices] . . . everybody [all the alters] has something they want to say and they can't all get out to say it.*

Through all the "self diagnosing" Julia decided that what was wrong with her had to be one of two things. In her words, either she was "multiple" or, she was "one very insane schizophrenic woman." She was desperate to get a diagnosis and know which of these it was. Over a number of years, Julia pursued *diagnosis*, being shuffled through different therapists and various modes of therapy. No one seemed prepared to make a diagnosis. Julia was insistent believing only with a diagnosis could she confirm her sanity. If she wasn't a "multiple" then, she reasoned, she must be insane; completely out of touch with reality. If she were multiple then she was experiencing symptoms as a result of actual childhood "happenings" and could say to herself, "this is something coming from the past." Julia dreaded "insanity," believing it meant "she would have no ability to work with the disorder, no ability to control it, no ability to do anything with it." At one point Julia laid twelve hundred dollars on the table in front of her therapist and said:

> *"Well, here's your fee. I've just put a twelve hundred dollar check in you hands." . . . I said, "I suppose now maybe you could give me a diagnosis? . . . He says to me, "I don't like labels." And I said, "well I'm a medical model person. You humor me." . . . I said, "We've gotta have a diagnosis because otherwise what's the point of my coming here. Like why am I coming to therapy if there's nothing wrong."* He says, "well," and he starts fingering the coffee table. "I think we're looking at Multiplicity."

The minute the diagnosis came down "it was a tremendous relief because it meant that I wasn't Schizophrenic," says Julia (see figure Julia). In one corner of her picture, Julia draws a prison door, to show her sense of captivity. In the opposite corner is what appears as a "page" on which is written "reality" and "insanity." Insanity has an "X" on it, crossing it out. This is what diagnosis has done for her, she says. It has certified that she is not insane. It makes her thoughts "real memories," places her in a shared reality with others. She's not insane! Now, finally Julia feels released. The padlocked door is unlocked and Julia emerges able to face herself. A diagnosis of schizophrenia would've meant she was in a "deluded reality." MPD, however, to her meant hers was a "common shared reality," and Julia took a measure of comfort from that; from knowing that her "perception of reality was the same as everybody else's." Now she could say that the way she perceived herself and her world was located in the generally shared reality common to others. But, hearing the diagnosis finally declared also stimulated an awareness of the awful "truth." Now it became clear the sordid memories she was having were, indeed, real memories. These were not just contrived imaginings. It was actual recall and "it had actually happened!" Now she had to struggle to get her mind around what the diagnosis actually confirmed:

> *. . . around the fact that our parents did this, that that was my life . . . having to realize that I never really had the kind of parents I thought I had . . . that this is the reality. It is a tremendously difficult thing. The diagnosis represents all of that ugliness . . . that that's what really happened . . . I mean, that that is reality for us.*

But still, for Julia, having the diagnosis is better than not. Julia wanted to know what this was. Was she severely depressed? Was she bipolar; schizophrenic? Just what was wrong? If someone could say, "this is what you have, then I could come to the treatment experience knowing what the disorder was, what the implications of the treatment were; what the medications were for, what the side effects might be." Julia could be a player in it all and she could make some of the choices. This is the important thing about the diagnosis she says. It speaks to the reality of who I am! It's hard to take that this will never go away. Julia can visualize, perhaps in time, transcending the disorder. That is, she might come to function healthily, in spite of it. But, transcending it is not erasing it. Both the diagnosis and the disorder, she believes, will be with her always. It is woven into the fabric of, "who I am as a being," she says.

Julia's is not a story of dreading psychiatric diagnosis. Indeed, it is a story of search and struggle to have herself legitimized through a diagnosis. The diagnosis confirms to her the reality of a childhood so silently and tragically abusive. "If I'm not believed," Julia states, "then I might as well just lay down in the street and allow anyone to do what they will to me. Because, it is obviously easier for everyone to just regard me as a flaky crazy than to believe that the despicable and heinous events of my childhood really occurred." In effect, Julia does not suffer the diagnosis. Rather, she uses it as instrumental to her sense of being. **To Julia, to be diagnosed is "to know for certain."**

Jean's story: To know unshakable permanence.

Jean grew up in a household where there was a lot of chronic pain. She had watched her mother struggle with different medical concerns, including breast cancer. Consequently she had seen "some pretty massive depression and anxiety behaviors." But, never did anyone go to the doctor to see about how they "felt." Jean says people just didn't do that in her family. They kept their mental distress in the dark because there was a common attitude then, that "only *those* vulnerable people have mental illnesses. If you were unwell in that way then would people even want to be around you? Maybe they'd think you would do something odd or unpredictable." If you had multiple sclerosis, then people would show you sympathy. But if you had schizophrenia people would back away and "make a wide circle around you." Mental illness put "you" in a subordinate position relative to others.

This attitude made it difficult for Jean when she started "crashing" shortly after the birth of her first child. She was crying all the time and it was as though she had a "gray cloud on her chest." This was so, so heavy and it just wouldn't lift. Her family doctor put it down to postpartum depression but, when Jean returned to work after the baby, things got even worse. She knew she felt out of control but she didn't really know what was wrong. It was that very first psychologist that nailed it. "Girl," he said, "you're manic depressive!" Jean immediately discounted the idea:

> *How could you know that? You've only spent the last half-hour talking to me. How can you make that kind of diagnosis? I've just been through a terrible pregnancy, a terrible childbirth experience, then, back to work really quickly; couldn't there be something going on physically? Don't we need to explore that? It was just too snap of a diagnosis. . . . Yes, I am depressed and yes, I need to be treated. But to be labeled! To have a label stuck on me at the age of twenty-six? I wasn't quite ready for that. Twenty-six is too young for hopelessness. And, I certainly wasn't raving mad like the people I had seen on "One Flew Over A Cuckoo's Nest." So this must have been the wrong diagnosis. No, I wasn't going there and never would.*

Off went Jean with her prescription believing her stress was work related. But, year after year the "ups" and the "downs" continued. The *ups* were feel-good times. But, the *downs* were another thing. They were times of "massive insecurity and self-doubt; hiding out in the bedroom and crying." They were times of desperately searching for some kind of balance:

> *I would read about such and such a food that might make me feel "up." . . . And so I would eat that food. And then I would read about an exercise that would make me feel up, and then I would exercise. . . . If I took a downward turn, if I was depressed, if things weren't going well, I would just sleep. . . . I would just go to bed and sleep for days. So I would do anything humanly possible to try to maintain myself without admitting that maybe there really was a problem.*

Jean had episode after episode of ups then hitting rock bottom; feeling fragmented with worry and fear (see figure Jean). She shows us this in the upper part of her drawing with "blue" and "worried" faces. The frightened "eyes" seem almost swept into a funnel of fear and uncertainty. It was now thirteen years and three babies later:

> *Much of the time I could not cope. . . . And it's a real tiring thing to feel that way all the time. . . . That doom kind of feeling . . . being so highly suicidal that I was*

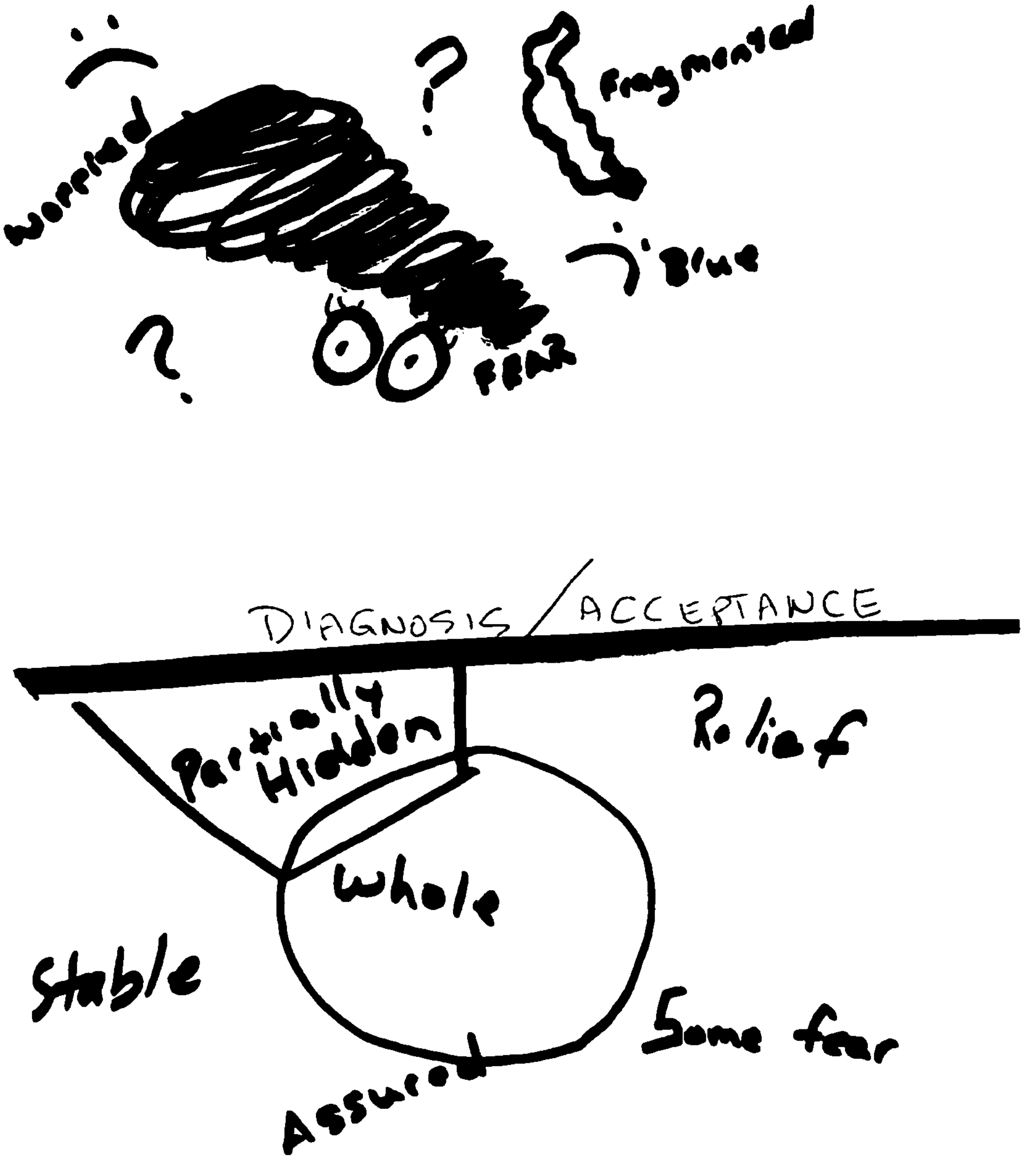

worried
?
Fragmented
Blue
?
FEAR
DIAGNOSIS/ACCEPTANCE
Partially Hidden
Relief
whole
Stable
Some fear
Assured

figure Jean

> *afraid to drive. I was terrified! I thought I'd kill myself driving; just drive into another car!*

Then, Jean crashed really big! Like on past occasions, she found herself at the doctors pleading for help:

> *We sat and talked about what the issues were and she said, "I can't make a diagnosis, but I'm willing to treat you without a diagnosis at this point in time because we need to do something fast. I wouldn't mind giving you this medication (Lithium). Let's see! We won't make a diagnosis. Let's just try it and see." -- Instantly I knew that it was the right drug.*

Jean stayed on the lithium for three months. She went from being wound-up tight and thinking she was going to die to feeling more solid again. She could have said, "no thank you" to the lithium," as in the past. But, maybe there was too much history that had gone down. For once Jean could "see":

> *It was almost like a moment of truth. It was the difference between waking up in the morning and being able to take a deep breath and actually feel the air coming in, as opposed to being restricted with that gray weight on my chest . . . for me the contrast here is dead or alive. It's just that clear.*

So when the doctor said, "yes, you are bipolar" it wasn't a terrific surprise. Jean "already knew." The Lithium had said it loud and clear. Hearing it come out in audible sound: "bipolar disorder!" "It was clinical! It was cold!" Had the doctor simply said, "breakdown number one. . ." it might've sounded different:

> *"Breakdown number one!" It's short-term. It's a virus. It's like the common cold. "Bipolar" is more like "HIV." It's there. It's in your face. It's big. It's not going to go away. It's not fatal, but it's not going to go away. But hearing, "you have bipolar disorder" come out in audible sound says something about who you are, because that's how it's said. "You have bipolar disorder" therefore, you are mentally ill. If somebody says, "you have cancer" then you are physically ill.*

Hearing the diagnosis said out loud told Jean something about herself. Letting her self hear "it" seals a moment of truth about herself. It brings an instant of awareness of "who you are." Perhaps it's the chronic piece of it that rubs the most; the piece that says this is going to need ongoing day to day treatment and management. Over the long-term this illness will require daily attention. And, there's the element of uncertainty in that. One doesn't know what the final outcome might be:

> *All kinds of different things have happened to people as a result of this illness and you wonder if that could be you. . . . We know that right now nine hundred milligrams of Lithium a day keeps me stable. We don't know if that will happen*

> *next month. . . . You know it's not going to get better because, you've gone through it enough.*

For Jean, to be diagnosed surfaced the greatest of fears: that of uncertainty. Some of this mixture of relief and uncertainty is portrayed in the bottom half of her drawing (figure Jean). Essentially, in the "after" part of the drawing, Jean points to a sense of "relief" and growing self-assuredness. There is, however, still a "partially hidden" aspect of herself depicted. But compared to the time of *before,* Jean now speaks of "growth" and "possibility." And, a feeling of "wholeness." That came following diagnosis. Still, though, there is some fear shown, perhaps of the future and "how will it all play out? Will I progressively deteriorate from this?" Jean saw the reality of all that. In a personal journal she even recorded her confusion and the great fear that she had. She bared her soul there in that book with detailed description. Then one day Jean thought there was some cleansing that needed to happen:

> *And so I thought that if I put it all on fire then I would cleanse it all from me. But it kind of goes with you, -- because it's got a label.*

For some diagnosis is a judgment, for others knowledge. For others (as with Jean) diagnosis is a label experienced as recognition of "trouble," an acknowledgement of things being wrong. **To be diagnosed, in Jean's case, was to experience the unshakeable permanence of her mental illness.**

Jeff's story: To have a battle-plan for living.

"You may find this hard to believe or even appalling," says Jeff, "but to this day no one in the medical profession has ever told me my diagnosis." Jeff has been treated for his illness more than five years now and this is his recollection of things. Not once, he says, has his diagnosis been discussed with him. Yet he does know what his diagnosis is and he knows much detail about it. How then did he come to learn about it? Jeff mulls about how his mother has been told, and likewise his spouse and even some of his friends have been told. And so he has come to learn about it through them, in kind of veiled ways. But in all these years the explanations about what "it" is has never come from a medical person: "They have never actually sat down and talked to me about my diagnosis."

It's not that Jeff was in any rush to find out what his diagnosis was. In fact he admits he never did push for the medical label, and conveniently everyone concerned always found a way to talk around it." They talked about it and around it and always managed to sidestep the actual words of diagnosis. In some sense everyone kept it the "best known secret." Then, one incident brought Jeff face to face with the medical name for what it was. Jeff had been out of work and had decided to stop payment on his student loans. The two hundred dollars a month toward the loans had become more than he could manage. To be excused from the loan he needed support from his doctor and so, he went about having the "medical forgiveness" forms filled in. As the doctor entered what he was required to put on the form, and handed it back to Jeff, there it was in black and white: "paranoid schizophrenia." Jeff looked and looked and then, he put his own signature in the space provided for him.

Jeff had known all along that he had an illness that required he take care of himself in special ways. He had come to accept that he needed to take the daily medication to avoid getting really very sick and ending up in hospital again. Looking back he could never have predicted it would come to this, but it had. At the beginning of it all, it just seemed like a huge amount of stress in his life that was getting out of hand. He had recently had two big losses in his life; his best friend to leukemia, and an "important relationship" had ended. Reeling from these loses he was then hit with another catastrophe; a "horrible" fight between himself and the partners of the business firm in which he worked. His desperation peaked.

Now, Jeff had experienced problems with depression before but nothing like this. This time he felt like he was being sucked into a vortex by a force that was more intense and beyond anything he had ever before known. As time went on Jeff became increasingly suspicious of others and their intentions toward him. He noticed he was becoming more forgetful and at times would actually forget the entire day. Then whole weeks of time would be gone. But mostly, it was the voices that haunted him. If only he could find a way to turn off the voices:

> *I thought I should be able to do that. I tried the "Walkman trip" with the earphones. You put the Walkman on and you turn it up really loud. . . . I sort of ended up singing along with the songs. It didn't work and as they got worse I would drink and I would pass out. And then there was just peace -- just peace and nothing. I was looking for nothing. I wasn't looking to feel better. I was looking to feel nothing.*

It had become unbearable to Jeff and he felt really lost and confused. Several times he thought of ending it all. At one of these times he remembers walking for miles in the rain, from his house to the Broad Street Bridge in Vancouver:

> *I just stood up by the bridge and just . . . tried to get up on the ledge there, and then just tried to get up from the lip to look over the edge. The "do it side" was very dominant. The "don't do it" things said, "imagine what this is going to do to your Mom and to your Dad; to your brother and to your friends." I just wasn't quite there yet. So even though I was completely and utterly miserable, I thought maybe I'd stick around for a little while and try to work out some of these things. So I walked to St. Paul's hospital which was a few blocks away.*

In the treatment that followed, Jeff brooded about the most awful thing for "it" to be. Schizophrenia! He had long lived with that very fear. In fact, his whole life had almost become shrouded in the gray gloom of that possibility. But now, as sick as he was, he just wasn't in a state of mind to really integrate what was being said about him or to absorb what condition was being implied and, at that point:

> *Quite frankly I didn't care about it. I didn't care, I just wanted it to go away . . . mainly the voices. . . . They're horrible; it's just abuse, horrible abuse, laughing and telling me I was worthless.*

When antipsychotic medications took the voices away Jeff had a strong indication that his worst fear might be true. But at this stage, he was sensing his own need to know what "it" was; to have the short word for it would mean he could say, "that's it." He could say, "this is the battleground!" But mental illness is not a "hard and fast" thing. There is always room to talk around it, to not "see," if that is one's aim. And that is the space where, for years, Jeff chose to stay. For years he managed to do this quite well. He took the medications and he took care of himself in the best way he knew how. And never out loud did he say the words of the diagnosis and never were they said to him. But there was no sidestepping it on "that form." As Jeff looked at it he saw it and it felt right: "hmm, that's it!" Jeff had been through so much by this time that the sting of that diagnosis had neutralized. It was no longer so dreaded. In fact he recalls thinking:

> *Thank God! Here it is. Now, it's out in the open. Maybe there won't be so much confusion over what to do with it or, "what on earth do we do with this guy." Now that they've finally decided on, on a battle plan, uh, we can advance towards the enemy instead of running the other way all the time.*

Now he could recognize and "advance on the enemy." Being diagnosed meant treatment that effectively managed the symptoms, and, that was a tremendous relief to Jeff. Earlier on, the only real concern had been his friends:

> *I didn't know what to tell them. . . . I had this idea that, "well there's a friendship down the tubes once they find this out. They'll be afraid that I'm going to run around with an axe coming for them; running amok." Often, you just assume that you've been put at the level of anti-person. It's not a very nice feeling to be looked at in that light.*

He remembers the first person he decided to tell:

> *I think it was my friend Allan. I'd known him for about ten years. I had just seen Dr. R. and he had said, "you might feel a bit weird for a while." So I told Allan that I might be weird for a while. Allan's greatest concern was to know how he could help me if I was acting strangely. He just let me know that I could call him anytime I felt like it. When I told him it was schizophrenia he said, "Oh well, carry on with style."*

That response from his friend meant a great deal to Jeff. It meant their friendship was genuine and would continue. After that Jeff just felt much more at ease telling other people who he knew were friends. He has come to believe that people who are real friends will show themselves for that.

Jeff has made space in his life for the diagnosis that identifies "only a part of who he is," the part he has to watch out for and take care of. The diagnosis serves Jeff in these ways but it also says to Jeff that he has lost some aspects of himself to the illness. He knows he is different now, in some ways, than he was before. For example, his level of expressiveness has changed. He feels he has "less" emotion than he used to. That is, he believes he once cared tremendously about things that he just can't get worked up about anymore. And then there is his level of trust. He sees that he has lost a lot of trust in himself. "I know that when I 'loose it,' I don't know I'm losing it. It all seems perfectly normal to me." So in that regard Jeff has to rely on the judgement of others. This is tremendously tough for him; to know what the diagnosis says; to know that he can't rely on his own judgement:

> *I have to listen to the judgement of others to know where I am at, what I'm doing, and that's a very difficult thing to do. It's very difficult to surrender that part of myself, of my self-probe, of my self-image especially when I've done so well for so long. . . . I just can't trust everything that goes on in my head. It's a very hard thing. I can trust myself not to steal money. I can trust myself to balance all my bank accounts every month. But I can't trust myself to not believe that the house wasn't broken into, or that if I happen to be wearing the same kind of jacket as someone else that there isn't a [creepy reason]. I can't necessarily distinguish between those things. So, it's a big thing to have to surrender to someone else's judgement.*

These are big aspects of himself that the diagnosis tells Jeff he has lost but, still, Jeff notes "the diagnosis is far from the most important thing in my life. I don't like being paranoid and I don't want people to see me as being that way." But it does seem "the" big thing about him that he feels preoccupies a lot of other people. In fact, according to Jeff other people may have more a problem with his diagnosis than he does:

> *To this day, people treat me as if I'm totally incapable of looking after myself. . . . "Did you eat today?" "What did you eat?" "How much did you spend on it?" -- Things like my taxes! They don't want me to fill out my own tax forms, which I can do better than they can. . . . "Should you really be driving a car? . . . People don't seem to realize that I'm able to do that. . . . I'm not an absolute idiot! But people sometimes insist on treating me that way.*

In spite of all this, Jeff maintains that being diagnosed has, in many ways, been self-affirming (see figure Jeff). He had long known there was something wrong. He draws a scarecrow to depict himself before diagnosis. Interpreting it, he talks of how he is forgotten in the field somewhere, in disarray, just stuck there on a pole. He is not going anywhere so over time dead leaves and snowdrifts have piled up around him. The scarecrow is blue:

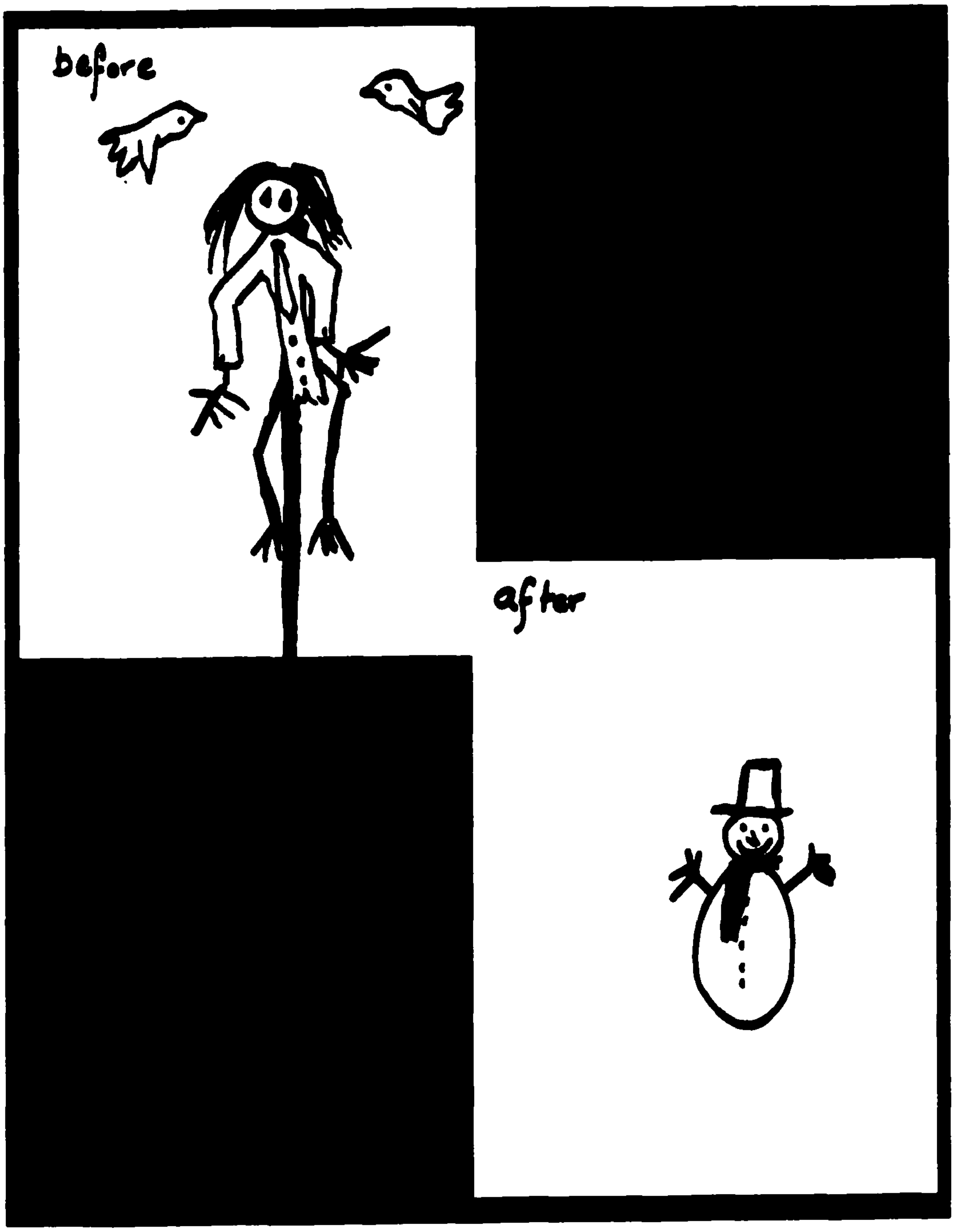


figure Jeff

> *. . . because the scarecrow is cold. I was very cold. Life was very cold. I didn't put a smile [on it] at all, because the smile would have been upside down. A pole is holding the scarecrow up. It's hung on the pole and it does not touch the ground. It's suspended here on a pole, blue and cold with a ratty jacket on and wearing a tie. I was always profoundly overdressed for the places I worked and, I was always in a suit. I'd always wear a suit even if I was doing messy stuff. So now I'm stuck there. I'm angry and hanging in my suit. I'm cold, and don't think I can find any words to describe my crappy mood. Even the birds are not paying any attention to me, because I can't reach them. They can come as close as they want. They just do their business.*
>
> *After diagnosis, the snowman has got a smile . . . and he's green, which is a very peaceful and calm color. He still has cold hands, but that's just physical. I always have cold hands and my feet are always cold. Nobody is making me wear a suit. I'm there in the snow, but it's not cold. Obviously somebody is melting up some snow to build me and fill me up. Maybe the scarf is a little warm too. But, I was built, or perhaps re-built, whereas the scarecrow one is built originally and I was just suspended there. In the snowman, "after diagnosis" someone cared enough to build me. Snowmen don't have legs. They don't need to run away. They just are. And the arms are kind of outstretched. They're happy arms.*

After much pain, the diagnosis made "it" clear! And Jeff identifies that as a feeling of relief. It brought a way of working at things and helped dispel, for Jeff, that he was so strange or different from the rest of the world. It was like: "Wow! Other people have this too." And so, Jeff was lifted away from a tremendously isolated feeling. Some of that heavy aloneness was gone. On most days he feels he functions exceptionally well. And, says Jeff, ". . . clouds pass!" **For Jeff, to be diagnosed was to have "the comfort of a battle-plan as a basis for living."**

Concluding Remarks.

In this chapter an array of experience has been presented as recounted by persons who have, at some point in their lives, encountered *diagnosis* of serious and enduring mental illness. With some basic interpretation, a central theme was distilled from each account, highlighting one particular distinction to that experience of *diagnosis*. Thus is brought into closer view the varied possibilities of *diagnosis* CMI. For some, like Cathy, to be diagnosed is ***to be re-named,*** while for Evelyn it is ***to be re-integrated.*** Thematically, Susan's experience is one of ***re instatement of self.*** Others, like Gary, recognize *diagnosis* as ***gaining self-knowledge*** or, contrary-wise, Teresa as ***denial of self-knowledge***. Julia's story theme is, ***to know for certain***, while ***unshakeable permanence*** seems the theme coursing Jean's diagnosis story. And for those like Jeff, diagnosis means ***comfort, a battle-plan for living***. And so in this chapter we glimpse several modalities to the experience of the particular form of diagnosis that is "psychiatric diagnosis."

Nevertheless, it could be said that *diagnosis* (the experience itself) still, by in large, remains in the shadows. Though we see, through the variety represented in this chapter, certain thematic "variations" still the themes might be thought incidental to *diagnosis*. Thus it remains somewhat elusive. Much stays hidden. For *diagnosis* to resonate, one must look for, yet, more essential themes, those that speak to the essence of the experience, those that perhaps lay well beneath the surface of things seen thus far. This chapter provides a backdrop and themes from it will be seen to resurface in different guises in forthcoming chapters. Each upcoming chapter is thematically entitled, the title not to be taken as an unyielding abstraction, but rather to serve as an invitation for the reader to enter into a vein of thought about an essential theme to "*lived diagnosis*." Four chapters thought most apt to dispose such thought relative to an essential theme of diagnosis, now follow. Thus, we are engaged with Matt, Cheryl, Steven and Jim. In each of their stories hidden meanings to the experience are searched out and we are taken to a level whereby more essential themes provide a distinct *structure* to "experiencing psychiatric diagnosis."

CHAPTER FOUR

Diagnosis As The Experience Of A Knowing That Knows

One of my earliest recollections on the notion of "conscience" revolves around truthfulness. Fibbing, as mom called it, was very serious business indeed! It seemed, to her, honesty was the cardinal of virtues. If ever I was in "question" mother would look deep into my eyes as though there were some obvious connection between my eyes and the truth that she could see there; a "real knowing."

Thoughts on "real knowing" set a mode of thinking whereby we now enter into Matt's world and his experience of *diagnosis*. Matt's story is selected for its apparent strong potential to explore what appears an essential theme of "knowingness" to *diagnosis*. By way of this exploration, what now follows, is structured in two parts. Part I contains details of Matt's life circumstance according to Matt; his issues and concerns, his perceptions of the world about him, and the events which ultimately culminate in his diagnosis. In Part II a more interpretive stance is taken, a reaching to possible meanings imbedded in the story. The reader is now invited to participate in apprehending varied dimensions entailed in Matt's experience.

Part I: "Like being on a Fast Runaway Train"

Matt felt under a lot of stress during the time he was at university in 1986. It started to disturb his sleep and he began having big problems studying. He had the feeling his life was taking off out of control. It was "like being on a fast runaway train" and he "knew" that something was going to break eventually. It reached a peak, one day, when he went to write an exam. He knew he couldn't perform. He simply sat there and at the end of the exam Matt handed in an empty paper. Returning to his condominium Matt started to pray. Here is where his grip on reality began noticeably to fray. Questions whirred in him about what was going on? Was he just losing it or, was he truly having a spiritual experience, "seeing where my soul was at":

> *What I saw in my mind's eye was a lake of fire. And I heard voices, both good and bad, sort of shouting at me. And I came to. I don't know how long that would have took place? It might have been a minute. Might have been 10 minutes. I don't know. And my heart was pounding and I couldn't breathe. And I figured "well, I'm possessed by the devil. I'm going insane! I'm having a heart attack!"*

That fast runaway train had crashed! Matt became steeped in a massive concern about the salvation of his soul. He felt very panicky about what was happening to him and tried desperately to pull himself together, but he couldn't. After several days of this, he got his stuff together and left, driving several hundred miles to be with his family. By then he had convinced himself that he was "a psychopath," a term that was truly terrifying to him. Finally, on home turf, he sought out a psychiatrist and was somewhat consoled when the psychiatrist looked at him, smiled and said, "no, no, no Matt, not a psychopath! You are sort of like a homing pigeon." To Matt, the metaphor meant that he had left the "nest" to study in another city, and now he had found his way back to the nest. Now he would be taken care of and now he could heal.

Wanting to see it normal.

Hospitalization was for Matt like living-out "a big nightmare that had come true." He speaks of a memory way back when he was taking a course in abnormal psychology. Vaguely he remembers a notion that his sickness might be there with him already. It was like a first inkling of the "bizarre" things that would haunt his future. Now, there was a sense of "self fulfilling prophecy" to that memory. The hard line in the sand of his reality had, indeed, actually shifted.

But, Matt was super sensitive to the whole thing of being "insane." And so everyone took great care to step around using any diagnosis with him. They would just say "depression" or whatever adjective they could find. In kind of frenzy Matt remembers saying to one nurse, "I'm insane. I'm insane." And, the nurse simply said, "no Matt, you're having a *very bizarre experience.* " Then there was another therapist who tried to explain to him what was happening by comparing him to a war veteran who was suffering from something like a "mortal wound." "You're sort of similar to a Vietnam war-veteran," he said. "You've sort of challenged your whole ideology in your mind, that you've been instilled with since childhood and you've lit a bomb. And it's exploded! You have to rebuild."

And, Matt did come to accept that maybe it was sort of like a landmine that had gone off. Perhaps it had been laid there long ago, waiting the right conditions. Eventually it would go off and rip through his entire being. Yes, maybe it was, after all, just a matter of coordinates in time! Everything converging to a footstep, to a moment when his step came down and touched off the blast!

But, before the end of his first hospitalization all the efforts to "normalize" the experience for Matt were undone by one nurse's callous remark:

> *When I first got sick I didn't want to talk about anything. I was petrified and didn't want to tell anybody about it. And in my first hospitalization I had a very bad experience with a nurse. I was walking down the hall and he was walking down the hall toward me. And we sort of made eye contact. And he just blurted out, "you're a psychopath just like your cousin Joe." Getting that sort of stigma from a person in the hospital was devastating.*

To Matt, this remark carried a dreadful message. It clearly said that he was "insane." It said that he was tied to his predicament through heredity. And somehow, to Matt it said that his "insanity" was the result of a flawed character, that heredity had dealt him a bad hand. Now surfaced a notion that he had a fundamental character defect that had been simmering beneath the surface all along. From then on, no matter what term was applied to what was happening to him, it would always say, "there's a flaw." When Matt got the message that he was mentally ill, that is basically what he heard. It came at him as "a flaw in his moral character" and it entirely affected the way he had previously known himself:

> *You feel something about who you are. . . . Your self esteem, your self image is blown apart. . . . Just the name of the illness attached to you, would give that message. . . . Originally it did. . . . My self image, my self esteem! — I was at ground zero.*

In Matt's instance as perhaps in many instances of mental illness, devastation of the "self" happens because diagnosis actualizes long-held subtle apprehensions of a basic defect of the self, to the self. Does diagnosis, then, alter one's relationship with *self* by saying one's fundamental being is faulty? In the altered interpretation of self through diagnosis, then, is there message of making real what is already fearfully held there in reality to be real?

Part II: Matt's Experience of Diagnosis In-depth

To achieve fuller understanding of Matt's experience, what now follows is in-depth focus on his story. Holding close to Matt's account of things, discussion is directed to themes in the following areas:

(a) ways Matt perceived the nature of the world about him,
(b) the past as it is brought to Matt's experience of diagnosis,
(c) understandings contained in Matt's activity of "going home,"
(d) experiences within the layers of *mystery* in diagnosis.

As this portion of the text unfolds we witness possible workings of Matt's inner life. Through this we are put in touch with effects *diagnosis* has on his perception of *self* and varied meanings diagnosis creates for Matt in his day-to-day world.

(a) Ways Matt perceived the nature of the world about him.

Early in conversation with Matt, he makes numerous references to the nature of today's society. He talks about things that are happening in the larger world, things that are almost beyond his belief. This makes it increasingly difficult for him to determine where the line is between what is real and what is unreal. He remarks: "What becomes fiction and what stays in reality gets very blurry." Matt picks up on a quote from a once popular rock song: "I can't tell the difference between ABC news and Hillstreet blues" (U-2). In this there is a likeness for Matt to today's world. For example, he perceives the media to really "jazz" the news up, to make it colorful, even way-out and sensational. "The Gulf war starts to resemble a Star wars movie sort of thing," he says.

With these remarks Matt tries to tell us something about what he observes in the world and how he experiences what he observes. Perhaps more to the point, Matt tries to set a context in which to express his own experience of becoming ill and of coming to be diagnosed. What does diagnosis mean when everything in the world seems strange and surreal? If a situation is described as surreal it means that it is experienced as very strange. The combination of the ideas, images, or objects in it would not normally be expected to be together (Collins Colbuild Dictionary, 1988, p. 1473). In Matt's words we see this surrealism as the texture of how he sees his world. Media *news* and theater *views* fuse together with little there to help him keep it all separate. Which is which?

When Matt began to question his grip on reality, he found it not at all easy to determine what was "real" and what was maybe just peculiar. According to Matt, ours is a postmodern world. And, unlike most of us, to Matt a postmodern reality is more than just a little confusing. The average person sees and indulges in the postmodern milieu of our time but can chose, at will for the most part, to return to the grounding of the "modern-world." For Matt, however, the postmodern elements of life introduce a complexity from which he cannot so easily extricate himself. How, he asks, was he to know for sure if the Federal Bureau of Investigation (FBI) or Central Intelligence agents (CIA) *were* actually after him? Was the Royal Canadian Mounted Police (RCMP) really out watching his every move? Matt knew that it was not like these kinds of things didn't happen in our world. And so he was left puzzling even about whether his prayer had brought him to a religious experience or to a "sci-fi" anomaly! Was any of it genuine or was he just "losing it?"

And that is the confusion for Matt in the context of our world, a world of "web-oriented logic" where all principles of reality are but approximations and all approximations can succumb to intuition. Van den Berg (1972) says, if we want to gain insight into another person we must do so by looking at the solid, real things of his world. So to gain knowledge of Matt and his experience of diagnosis we must "look at the world as he sees it in his direct, day-to-day observation. . . . The relationship between man and world is so close that it is erroneous to separate them. . . . If they are separated, the (person) ceases to be this particular (person) and his world ceases to be his world" (Van den Berg, 1972, p. 39).

In Matt's circumstance, he is at a loss to identify or describe the solid, tangible objects in his world. He cannot call into words many descriptions of the material things of his world that would give us insight into his nature or his disturbance. More often than not he resorts to introspective accounts of how the world appears to be. Van den Berg (1972) notes that this "on-second-thought" reflection considerably hampers knowledge of the person (p. 39). But in Matt's case, it is all he can manage and so we venture into his "on-second-thought" reflections of his world and how it was for him. We see his scramble to identify objects that might set a foundation to his experience. In introspection he portrays to us "his" world of few solid objects, little that would give him a sense of under-girding, a "center of gravity." His recall of "the exam" supplies us some notion about the extent to which he is in growing turmoil.

In relating his experience of life around "the exam" time, Matt describes himself as being on a fast runaway train. He uses a heavy, solid, metal object, a train, as metaphor, perhaps to describe the rate and the power of his thought. From his story, it is obvious that only his thoughts race out of control. In fact the rest of his activity is at a standstill. He sits for two hours physically stalled in front of his exam paper, in the end handing it in empty. But the train is an apt metaphor for what is taking place in him internally. The train lunges, as do his thoughts, on a wild ride. It is no longer him, he feels, directing his thoughts. His thoughts are being propelled by a force seemingly greater than he, a force outside himself. Nothing can stop the propulsion of the locomotive as it powers forward, careening wildly and taking Matt on a whirlwind of mental activity. To Matt, there is no stopping or even slowing down the heavy lumbering steel object, just as there is no stopping or controlling his thoughts that push on. They are in all directions at once, on a course of unknown volition.

Inevitably Matt is led to pray, a last bastion of hope for re-linking with a structured reality. But even in prayer he is left tremulous and uncertain. Matt has long strayed from his religious upbringing but now he has groped for any sort of lifeline, anything to help him reconnect and adhere about a center; gather himself together. He thinks he may be able to interpret his experiences within the Faith in which he has been raised. But his prayer mires him in further confusion and he is left with a sense of "indeterminacy." *Good* and *bad* pour in on him, leaving him unable to roll any of what is happening to him into any one thing. Now, even his "credo" has failed to clarify to him what is "real" about his current reality. "Am I blessed or possessed," he wonders? "Am I having heart attack?" Matt flounders and muddles: "From what reality does his experience derive?" Or, in actuality has he somehow just slipped all reality entirely?

And that, it appears, is Matt's problem. As has been noted, Matt is in the "New Age," in a milieu that has left him feeling groundless and "unreal." The postmodern person, generally, resolves the tension of being modern and living a groundless existence. But in this postmodern condition Matt flounders. He puzzles about: "What is real and what is bogus?" And, what (how much) of *what* is real, is real? In that sense we can see his tension is to the extreme, beyond the *simply postmodern*, so to speak. His is frenzy about reality:

> If we listen deeply, do we not hear Matt's anxieties echoed in his comments on ABC news resembling Hillstreet Blues? In some sense, is he not asking: "Where is the ground on which I can hinge my thoughts?" Is he not telling us that his thinking has lost grounding because to him the world has lost grounding? He would seem to say, "how can I answer to myself what is real and what is fake, what is actual or what is virtual?" To Matt the objects of his world have no ground. His world groans and moves underneath him, giving him no stable footing. What he sees happening all around him, to him, could as easily be simulated as true. When Matt speaks of the Gulf War televised with smart bombs and spectacular pilot runs, is he not in some sense saying that he is unwittingly drawn into a confusion of an unstable world-reality? The stable markers of reality for him are lost and a world remains where covert interests are what design the constructs of ordinary life.

We could see Matt in all this a casualty of postmodern facets of the world as he sees it. He finds himself slid into a borderland, fallen through a trap door into groundlessness, perhaps because he has fragile grounding in "modernism" to begin with. "We" (in general) all do! However, we stabilize with an intuitive sensing of what is real. We look at the "postmodern," take note of it and return to our grounding in modernism. Matt would seem to have difficulty with this back and forth transition. Even resort to his traditional orthodoxy does not serve to anchor him. Here too he is faced with indeterminacy. He looks for something to reinstate him in the world, direction of "the Master," a voice that would say: "*Do this,* and all will fall back into place; into a rightful orientation." But he flails in indeterminacy per Jencks (1987) that entails:

> . . . a lack of coherent agreement about the meaning of reality or the words used to make sense of reality. . . . There is a rejection of any foundation by which coherent agreements can be reached. The foundations of traditional authority [eg. Orthodoxy] and of scientific rationality are "de-constructed," and reduced to a wrecked rubble. [Parenthesis added]

Matt seems unable to selectively "see" postmodern elements in his world, discriminate between what is real and what is conjured, even appreciate it for a time, then, choose to reinstate himself in comfort standard zones of reality. He is in turmoil, deluged with questions about, "how much of any of this (his world) can really be real?" Now, if he were to pick up and read a science fiction novel he would know up-front whether it was real or not. He wouldn't even have to decide. It would just be there; labeled "fiction!" But here in his everyday activities, there are no labels for the world. He must decide for himself what *is* and what *is not*. He has to choose "what" and "to what extent" of that which he encounters is real. This is a world of "isms" but for Matt it has created a *world* of bedlam. How is it possible, he wonders, to distinguish whether he is in *fact* or in *fantasy*? He keeps re-deciding whether the objects of his world are authentic or artificial. Under this is the question: Is it he or the world before him that is adrift? How is he "to be" in this world; to decide on what "other" motives may be *there* to obscure his world? What path is there for him?

(b) The past as it is brought to Matt's experience of diagnosis.

To this point, we have followed Matt's experience of diagnosis from the vantage of his own personal historical account (given that his experience of diagnosis is to be taken as *in the present).* That is, the mode of arriving at Matt's experience has been from the perspective of his past; his history of events, his account of university life, his traditional orthodoxy, the objects of his world. These are what seem to bear on Matt's eventual experience of diagnosis. It is what he brings to his *present,* indeed, what creates his present. We have looked to his past recognizing that to understand something, (in this case Matt's experience of being diagnosed) one has to comprehend its particular origins. "Put another way: everything is the outcome of a development. To grasp the present, one must investigate the previous condition" (Van den Berg, 1972, p. 86).

Admittedly, the past is not the only course that might have been taken. It is conceivable that the *present* could have been equally understood from focus on the present. Then too, focus on Matt's future (as anticipated) might have given us insight to his "present" experience of diagnosis. After all, couldn't the future be what one looks at as making the present? Consider the example offered by Van den Berg (1972): When a person goes out, he goes out to do his shopping — a future. Further, consider a person driven from his house by fire. He is in a hurry to get outside. He is driven by his future. That is where he will be safe. Van den Berg (1972) continues in the same vein:

> Is there even a single act determined only by the past? The conditions of a decision are given by the past; the act itself originates from the future, from the expectance, the wish, the fear, the desire. . . . The past provides the conditions for what is going to happen in life, but the acts of life are rooted in the future. (p. 86)

And so, in this discourse it is recognized that we might have used another vantage to arrive at comprehension of Matt's experience in the present. However, the obvious is declared, that is, Matt's past as the context of his world has been chosen as venue to his experience of diagnosis. Perhaps this has been because it seemed easier to look there, at the past. Says Van den Berg (1972) the past is a fixed quantity, so to speak, not only because of incidents that have occurred but also because of the assumption made about *engrams* as fixed impressions in the brain:

> What is, *is* not fixed! What is, is being fixed, also as an impression on the brain. What comes, is not fixed at all, it is not there, at least not as an impression, not as an *engram.* How, then, can anything originate from it? Nothing only results in nothing. Where there is no memory, no impression on the brain, no *engram* no matter, there cannot be a beginning of something either, for there is nothing to start from. If the anatomy of the brain is to be our guide, we can see it no other way. (p. 87)

That we take Matt, from his past, within the context of his world and the objects of his world, in order to view his experience of diagnosis is neither exclusive nor is it novel. It is simply the way selected. His chronology and the objects of his world have been explored as the means of revealing Matt. Some would say there is no other way to truly know the person, in this case Matt. Could we have brought his experience of diagnosis to light by simply studying him, the subject, outside the world that gave shape to him? Van den Berg (1972) would say this is not possible, that there is no purely, inner subjective man:

> The strict separation of man and world is neither natural nor original. This separation originated from a philosophy. Descartes, with others . . . dug a gap between man and world. . . . Since then . . . the science of the subject (became) ultimately the science of an emptiness, of a nothingness. For the subject, the pure subject, the completely unsubstantial inner man, does not exist. . . . Purely subjective events never happen. . . . Thinking, one thinks something, a matter ultimately always located there, yonder, outside; an object, or something concerned with objects. Feeling, one feels sympathy toward matters or people,

> there; one feels absence, a lack of something, an absence of something there, outside one's own self. (p. 40)

And so we tend to Matt, the subject, in his past, in his object world, that we might see him. We look at Matt through the world as he knew and experienced it to be, in the final realizing that without a world there would be no Matt.

(c) Understandings contained in Matt's activity of "going home."

We might come to some understanding in Matt's human activity of "going home" by looking at how Heidegger, the German philosopher (1927) might approach the subject. No doubt Heidegger would broach the question: "what does it mean to go home?" by way of "Dasein," the term he used to refer to "human being." "Human beings, it will turn out, are special kinds of beings in that their way of being embodies an understanding of what it is to be" (Dreyfus, 1991, p. 14). In other words, the distinction of *Dasein* (one's way of being) is in that it is self-interpreting. This feature of self-interpretation is ultimately human being's existence. It is what makes human being a conscious subject, in other words a self. In this Heidegger has advanced the notion that "a human being always embodies an understanding of its being. . . . Dasein's unique characteristic" (Dreyfus, 1991, p. 16). How does this *understanding of being human,* which is primary to persons, happen? The answer distills to the supposition that it happens as a result of social practices. Implicit in Heidegger's view is that person, object, and society, fit together in constituted patterns of behavior that are "nonmental," that is, they are less taught than imitated. Dreyfus (1991) elaborates on "distance-standing practices" as illustration:

> We all have learned to stand the appropriate distance from strangers, intimates, and colleagues for a conversation. Each culture has a different "feel" for the appropriate distances. In North Africa people stand closer and have more body contact than in Scandinavia, for example. These practices are not taught by the parents. They do not know that there is any pattern to what they are doing, or even that they are doing anything. Rather, the children, always imitating the adults without even trying, simply pick up the pattern. There is no reason to think that there are any rules involved; rather, we have a skilled understanding of our culture. . . . Distance-standing practices are simply something that we do. Of course, learning to do it changes our brain, but there is no evidence and no argument that rules or principles or beliefs are involved. Moreover, this is not an isolated practice; how close one stands goes with an understanding of bodies, intimacy, sociality, and finally reflects an understanding of what it is to be a human being. (pp. 18-19)

This leads to — Dasein's ways of behaving then not as mere facts. Rather, ways of behaving contain an understanding, an understanding that can be studied as an interpretation (Dreyfus, 1991, p. 19). How then do we take this to draw out the implication in Matt's story? Precisely, we do this to look at Matt's choice to go home. What understanding is contained in this way of Matt's behaving?

To begin with, we have seen that Matt is in a dilemma. How can he sort out his dilemma from the perspective of his stance in the world, from a world where he can see nothing to tell him what in the world is real and what is not? What can he do? Where can he turn? We have to ask: "Is Matt's choice to go home an inconsequential choice?" If we take "home" in the vernacular as a place where "I" can relax with myself, in safety from the eyes of the world, then perhaps not. When I am at home I can drop my defenses and just be me. No roles, no enactment, nothing to measure up to except what I put in place. No one to judge me if I happen to drink milk straight from the milk carton or soup straight from the soup bowl. At home I can be completely at ease because I am in my own space. It is my sanctuary in a way, reflecting aspects of me. *There* are the pictures on the wall that I selected because they suited my taste. The hardwood floor is something I chose and even the bathroom towel that hangs on my shower, with its very large royal Egyptian king on it, is something of me. And so, home is my place to just be who I am. This is fitting preamble then, to bring this notion of "home" to the activity of "going home" and, more pointedly to Matt's activity of going home.

Going home can be, simply, a turning to one's place of origin, going back to the basic structures where one was first socialized, first experienced a sense of boundary and safety. But, it is opportune to ask: "Is this the way that Matt sees it?" We have glimpsed Matt away from home, caught in a world of perceived distortions, a world that in many ways alters his sense of time and space. We see illustration of this in the way Matt relates to us his experience of "the exam." During that period we perceive that he seems held in a type of time warp. We see that he sits out the entire two-hour exam divorced from the world so to speak, attending to nothing beyond his thoughts. Two hours evaporate. Except for his metaphor of the train we have no sense of what the "time-quality" for him is. Vacant time! Suspended time! Tumultuous time! Is it "frozen time, mundane time, timeless time" (Dick, in Hurst & Williams, 1985, p. 15)? The train metaphor would suggest blinding speed but even Matt doesn't know the character of his time. A clue presents about Matt's "prayer time," when he tells us: "I came to." He knows not whether one or several minutes have passed. Have his thoughts traveled light years at lightning speed or, for Matt has time stopped entirely? We know only that Matt is contained in a time of turmoil, a space where his spirit is in significant distress, and he tells us he came to a time of prayer.

Then, we recall the metaphor Matt uses, the *train*, a symbol of imposing power. Yet, as Matt tells his story, we see that he is not entirely at the mercy of his *time* or his *train*. He is able to choose to direct himself in a course of action. He packs his belongings and drives himself back to the "nest" several hundred miles away. He takes himself to his family home. When we look at the possibilities, we could speculate that Matt might have elected to go most anywhere. To a Church perhaps! To a friend's place! To the police! A bar! A hospital, and so on. But Matt makes a determined choice to go home. In his hour of extreme and dire confusion Matt manages to pack his bags and maintain his bearings sufficiently to navigate a path hundreds of miles away, to home. Why home, we ask? We might look for enlightenment by taking this again to Heidegger's *Dasein*.

If Dasein is what, in its social activity it interprets itself to be (Heidegger in Dreyfus, 1991, p. 23), then to understand Matt's experience of diagnosis it appears important to ask the question of why he goes home. Does Matt seek *home* solely as escape from the location of his terror? Or, does he go home to be in a location of refuge? Here, we might consider the difference between *running from* and *running to*? Then too, we could ask, is Matt really looking to take a stand on himself, to go to where he can face up to things and re-organize? Indeed, Heidegger would say these three possibilities capture Dasein's three essential modes of existing. If we take Matt as *fleeing from* then we regard him essentially seized in a sort of passive condition, simply evading his "unsettled ness" with unfocused anxiety. If we think of Matt's going home as *fleeing to* then we might assume he wishes to return to the child role, to be taken care of by home and family. This being the case, we would hold him as trying to reassemble himself in the social mode of an adolescent trying to answer the question: "Who am I?" The third condition of dasein described by Heidegger is that of owning up to oneself. As such, one takes a stand on one's own individuality, defines oneself through one's own uniqueness, and we could interpret Matt's activity of going home to be in that pursuit as well. That we, at this stage, establish answer to which of these three conditions Matt is in is perhaps less important than it is to ask the questions. The questions lead us to different perceptions of Matt:

> Dasein can "choose" itself and win itself [the third possibility above]; it can also lose itself and never win itself [the first possibility], or only "seem" to do so [the second possibility] (Dreyfus, 1991, p. 27).

And so we question, knowing it is all we can do to broach the possible inner feelings of another person: "Is Matt's going home *passive*, *fleeing to*, or *facing-up*?" What is it for Matt to "to go home?" We use the word home, in general, as connecting with notions of *residence*, *household*, *house*, *abode*, *shelter* and so on. But, is this Matt's story? Of all the possibilities, what drives Matt's activity to take himself home? Perhaps insight is garnered if we recognize that Matt has in a sense become *homeless*. He is buffeted by all manner of ambiguity in the world. He finds himself disconnected, living in a no-where zone, a nomad, and so he goes *there*, home, perhaps to find his base; to anchor himself.

Thus, we come to speculate that it is more than shelter that Matt seeks. It is more than familiar walls at a particular place on the map. We come, also, to a different notion of *home*. If we consider Matt's need to go "home" as need to be there, where family can care for him, where he can go "to lie, to settle down" (Klein, 1971, p. 350) then, that is one thing. But there is the other notion of home we have not yet considered, that obtained from etymology of the word home. Home derives from the German word *Hei-rat*, the second element meaning "advice, counsel" (Klein, 1971, p. 350). Applying this element to Matt's activity, we could conclude that more than anything, Matt looks for direction and counsel to find his internal *home*? This idea of *internal home* takes us to the notions of being at home with self. In this sense, one feels comfortable, relaxed, satisfied, and generally ok with one's self. So then, is Matt really going home to a place or, is his activity representative of his going to "*his* home," to be restful *there,* with himself?

Accordingly, in going home Matt would be returning to his roots, the origins of his being where he could hope to "touch down" and find his ground. Like a "homing pigeon" Matt journeys home. We surmise that he is not only going to a place. He is going to *the* place. Figuratively he is turning back to a convention wherefrom he may be able to re-organize and function. He is re-convening with the familiar (from family) with the traditions that offer hope of re-regulating his life. So *home* is getting back "inside the frame" so to speak, being in a solid world. In the *home* object, perhaps we can see what Matt sees, not simply retreat to haven, but is Matt not *homing,* as in "gnostic" quest?

(d) Experiences within the layers of mystery in diagnosis.

In Matt's experience, mystery in diagnosis surfaces in at least two ways. First there is mystery of diagnosis as "secret." That is, there is secret to the nature of the knowledge that is cloaked in the term of diagnosis. In Matt's case there is at once a recognizable push-pull to "the secret" contained in the diagnosis that we will henceforth explore in more depth. Then, there is another level of mystery in the diagnosis by virtue of the nomenclature itself. This, to Matt, is his experience as it relates to being confronted with the unrecognizable and formidable words of psychiatry. At this level Matt speaks to a differential power, a sense of being caught in a powerless position, which he terms a "lop-sided economy." Aspects relating to Matt's experience in each of these "knots of mystery" will now be examined.

1. The mystery of diagnosis as secrets of knowing.

It seems, at first, a conundrum to use of the word *mystery* to offset the word *secret* when both words seem so etymologically connected. "*Mystery*" according to Klein's (1971) etymological dictionary has the word secret imbedded in its very meaning. The word derives from early Greek, meaning "secret rite." Distinction in the word secret, however, is recognizable from its own etymology. "*Secret*" derives from the Latin secretus: "separated, set apart, hidden." Thus, the etymology of *secrecy* underscores the relational significance of human secrecy. Van Manen and Levering (1996) describe this relational aspect as the "commentaries about human relations as well as commentaries about the relation of the person to his or her inner self or inner life" (p. 7). In Matt's case, momentarily we will see some of the secretive nature of the long-held secrets he has. These have become the "monsters-in-the-closet" holding him apart from others, but mostly he is beset with secrets that scar his identity to who matters most, namely himself. As we journey with Matt, it will be difficult to ignore the paradox that begins to surface as we witness him *going home* to seek out that *(diagnosis)* which threatens to disclose the secret he works so hard to keep secret. Perhaps this is added mystery to the phenomenon of diagnosis.

i. Trembling at the secret held in the diagnosis.

No sooner is Matt at home base than he seeks out a doctor, not a general practitioner but purposefully he chooses a doctor who specializes in psychiatry. So, of his own volition he places himself in the realm of traditional medical science. It is here that he goes home to the known, conventional world of medicine and its psychiatric subset. It is here that Matt returns; looking to a known structure, that he might determine and receive pronouncement of what is real. From the formidable medical institution Matt hopes to have answered his fundamental question: "Is 'it' (henceforth Matt's *"ethereal"* experience) real, or, have I simply detached from all that *is* real in the world?" Matt, through his own testimony is as visibly terrified of what the answer might bring, perhaps as frightened of that answer as he is in need of it. Thought of it sets him trembling deep down inside himself. Slowly, his ethereal experience has begun assuming frightening shape as in the dream he once had. The elements of that "nightmare" now come back to him.

Likened to Dante's Inferno, the terrifying nightmare forecasts Matt's own eventual insanity. Like his cousin Joe he saw himself also becoming "insane." The inkling of his insanity had arisen from somewhere inside and had expressed itself in this horrifying dream. For ever-so long Matt locked that fear away. Never did he speak of the dream. Never did he want to even bring it to immediate thought. But somewhere it found its way to the surface and Matt trembles in its shadow. He tries to lock the dream inside himself, perhaps even from himself. But can he forever contain such fear? It threatens to spill, and at the thought of it, Matt trembles.

"What does one do when one trembles," asks Derrida (1995, p. 53)? Trembling, he says, is different from a quiver or a shiver. These too can manifest extreme fear, occurring as one anticipates awful happenings ahead. Derrida likens quivering to the agitation of water in its pre-boil stage. One observes increasing agitation below the surface which threatens to break through. Quivering, however, differs from trembling, which Derrida suggests follows what has already happened, as in the aftermath of an earthquake [*tremblement de terre*]. If we take what Derrida says about trembling to inform our understanding of Matt's experience, we see in Matt's case elements of both a *"pre-boil"* and *"earthquake"* nature.

More than one thing has happened to cause Matt to quake and tremble. He sees his cousin Joe with a long history of "insanity." He has had the nightmare predicting his own similar fate. And, he holds the message of his dream as a dreaded secret to himself about himself. Then, there is his more recent *ethereal experience*, one that he cannot or will not interpret. Better it too should be left secret, if that can be managed.

But Matt is now in anticipation of a diagnosis. He faces the prospect of something terribly wrong with him. Now we see him in *pre-boil* state. He shudders in anticipation of what is possibly ahead; held in the diagnosis. In this stage we realize Matt's dread about *insanity*. It is stark. To de-escalate his frenzy about it efforts are made by those around him to withhold the diagnosis from him, or at least dim its message. "They" keep it secret from him, trying to "normalize" his *ethereal* experience. *It* is referred to as "bizarre," framed as "mortal wound," fallout couched in "war veteran's" analogy. All is designed to keep cryptic the diagnosis. Only the whispers and glances serve as clues, heightening the *pre-boil* activity. The aim is to buffer Matt, but in the effort to keep all at the level of *the unusual,* the secrecy adds mystery to Matt's experience. Now, for Matt there is a sort of postmodern indeterminacy to all of this secretiveness as well. What *it* (i.e. the diagnosis) is becomes an illusive, now-you-see-it now-you-don't sort of thing. The analogy of a hologram seems to fit. Looking from different points of *view* one sees "some *thing*" differently. Shifting three-dimensional objects are produced through mysterious transformation of two-dimensional images (Fuchs, 1996, p. 34).

Matt's behavior would suggest that he wants to know but he doesn't want to know the opinion of medical psychiatry. We note that he deliberately "goes home" and places himself in the hands of psychiatry, that he might summon their verdict on himself. At the same time, his behavior postures him so as to impede that happening. As the stage of secrecy is enacted, we see that his dread intensifies. All those who circulate around Matt seem to know the "stuff" of the secret but all are engaged in maintaining it as secret; held in unspoken contract to hold the secret from Matt.

Perhaps the secrecy is even a veiled agreement between "them" and Matt. No one openly states the terms in this. Those are simply assumed, another layer of mystery to Matt's experience of *diagnosis*! All know of the secret. Not so subtle innuendo thickens the air with it. All know but only one faction is privy to its content. But, after all, perhaps even Matt knows though he, above all, invests in blocking it, maintaining the facade of not knowing. The harshness of the "play" is that "a secret always *makes* you tremble" (Derrida, 1995, p. 53). Whether one carries a secret about oneself or whether a secret about one's self is held by others, still, one must work to keep at bay a center that trembles. And that is the situation that Matt finds himself in. His life abounds with his own hidden secret fear about himself. And, he shudders at thought of the secret held in the diagnosis that is soon to come.

ii. Experiencing the force of raw secret.

The moment happens when, one nurse shouts the diagnosis at Matt:

> *. . . he just blurted out, "you're a psychopath just like your cousin Joe!"*

In actuality the nurse may have said "psychotic," or may not have even said those exact words at all. But that is not, here, at issue. What is of consequence to us is Matt's experience of that moment, a moment when he felt confronted by that nurse. And, the experience of that moment is carried in the choice of words Matt uses to tell us of it. No matter that *psychopath* carries a different meaning from *psychotic*. To Matt they are one in the same thing; psychopath, psychotic, psycho, insane! He may experience it all the same way, and now it is all in his face! "Pandora's box" has been thrown open and the secret is revealed. This is the event, the "*tremblement de terre*" which at once sets off with unfamiliar intensity a tremble rippling through every fiber of Matt's being. It cannot be undone. Like the tale of Pandora that teaches of the incredible power in secrets, "secrets, once revealed, may never be revoked" (Van Manen & Levering, 1996, p. 19).

Here, we are brought to the secret fear of *insanity* that has long consumed Matt's existence. It isn't just being told something. Insanity! Matt shudders at the thought of being insane. Insanity is a heavy word for him because he has already seen insanity in his cousin Joe. It has been part of his life's constellation. So its all that stuff that comes with it; that has gone before through his experience with his cousin Joe. Matt has lived *insanity* through Joe, much as Lamb (1998) shows Dominick lives it through his mentally ill brother, Thomas:

> When you're the sane brother of a schizophrenic . . . the tricky thing about saving yourself is the blood it leaves on your hands—the little inconvenience of the look-alike corpse at your feet. And if you're into both survival of the fittest and being your brother's keeper . . . then say so long to sleep and hello to the middle of the night . . . get used to the . . .view of the bedroom ceiling, or the indifference of random selection. Take it from a godless insomniac. Take it from the uncrazy [brother] — the guy who beat the biochemical rap. (p. 47)

Matt has long been unsettled about his bloodline to *insanity*. Is it genetically too close? How close is too close? Is there difference to the experience of diagnosis if one has lived in regular front row view of it? Would it not be easy to feel you too are cast in the same shadow? For Matt, it was somewhat like an unwanted dress rehearsal, surfacing images to layer his own eventuality. Through the story of Dominic and his brother Lamb (1998) helps us to see the foreboding power of "image":

> I know what I know about what happened in the library on October 12, 1990, from what Thomas told me and from the newspaper stories that ran alongside the news about operation Desert Shield. . . . Thomas . . . praying in silence, reciting over and over Saint Matthew's gospel, chapter 5, verses 29 and 30; "And if thy right eye offend thee, pluck it out and cast it from thee . . . and if thy right hand offend thee, cut it off and cast it from thee: For it is profitable for thee that one of thy members should perish and not that thy whole body should be cast into hell." Thomas removed from his sweatshirt jacket the ceremonial Gurkha knife our stepfather had brought back as a souvenir from World War II. Until the afternoon before, it had hung sheathed and forgotten on an upstairs bedroom wall at the house where my brother and I grew up. . . . The surgeon who later treated my brother was amazed at his determination; the severity of the pain, he said, should have aborted his mission midway. With his left hand, Thomas enacted each of the steps he'd rehearsed in his mind. . . . Blood banged inside my head. I loved my brother. I hated him. There was no solution to who he was . . . [*or to who I might come to be*] (bracket italics, my emphasis). (pp. 5-7)

This is "scenery" resembling the type that Matt carries with him because of his cousin Joe. Acknowledging the diagnosis enters the prospects of what might be in store for him; all that he has been witness to in his cousin. This is the frightful foreboding; usher to Matt's moment of diagnosis. Matt has a host of thoughts about what insanity means. Insanity has been object in Matt's world. *Insanity* drags its personal baggage about Joe, *and* its own long history of dreadful images, the kind that make Matt tremble (in the sense of Derrida, 1995).

Insanity! The word itself, can conjure up association with *sanitation*; intone being unclean. In fact however, the word *insanity* derives from the Latin word insanus, meaning, "mad, outrageous." If one is in-sane, then one is not (*in*), sound, whole, healthy (*sane*) (Klein, 1971). In the vernacular, one is "out of reality," "not like everybody else," "loco," "loony," "out to lunch," "crazy." To be in-sanus generally places one in the realm of mentally ill, but what does that mean and what does it call up for Matt?

Matt shudders! For him to be "mentally ill" places him in the category of "*the* mentally ill," those there, to be feared, ignored, banished, sheltered, laughed at, pitied, even, tortured. In preliterate times, primitive healers (be they of medicine, magic, or religious persuasion) acted to counter the supernatural force or spirits thought to be creating the disturbance of the individual "mind." Magic ritual, incantation, exorcism! All were justified means of repelling the *demons* thought to cause the madness.

It might be said that times have changed but, in some ways primitive logic endures as in the Middle Ages (400 AD) and into the Renaissance period (1300-1600). Then, there was an inordinate fear about madness. During this time the "mind" was feared and shrouded in mystery leading people to grasp at all manner of explanation for the troubled mind. At times, external forces such as the moon (from which derives lunacy – meaning a disorder caused by the lunar body) were blamed. At other times the mentally ill were declared witches or "heretics" and, witch-hunts were reasoned as the means of purging the earth of such undesirable influences. And so it goes through history; magic, mysticism, demonology; confinement, exclusion, outcast. These are the images of insanity portrayed by Wilson and Kneisl (1992) that Matt brings to his own circumstance; his tableau of *diagnosis*:

> . . . the violent insane shackled in prisons . . . others sent on symbolic voyages. . . . The "ships of fools" . . . boatloads of mad people sent out to sea to search for their reason. (p. 8)

With the exception of some regions in the Arab world, being mentally disturbed has never been a place of privilege. In contemporary time "madness" has been taken-in, to the sphere of medicine. The decade of the brain flourishes, but even so, there still persists the social contamination of past attitudes. That is Matt's take on it; what increases his cause for tremble.

To Matt, yes, insane does mean mentally ill but it means well beyond that. Matt fears the whole notion of *insanity* because, in a manner of speaking, if he is insane *it* (insane -*it*-y) says to him that he inherits into his being all of that historical archetype. It is not that he has done anything or that he has not done anything to cause it. It is for no other reason than *it* was born to him, planted there in him at conception, a tainted seedling part of him, uninvited; only there.

Then again, he thinks, perhaps it is in something he himself did or did not do that created the condition for it? Reared in an orthodoxy where body, mind and soul are distinct aspects of the being, Matt wonders whether he has conducted himself improperly, perhaps sinned in a way that has shaped the madness there, in his soul. Maybe in fact it is he who has cultivated a deep and basic moral flaw in his character. His sensibilities are haunted by thoughts as these and, Matt tries to mend the rupture in time created when the diagnosis was thrown in his face. But try as he might Matt cannot evade a glaring connection between what has been yelled in his face: "psychopath," and "the condition of his soul."

iii. After-shock: secret shudders.

We have seen that *psychiatric diagnosis* says terrifying things to Matt. Paradoxically, he has sought to maintain the secret of diagnosis from himself. Revealed, the diagnosis would say what he does not want to hear. Indeed, it would say: "You are mentally ill!" But it is those things beyond the "illness" that Matt shudders at the most. Matt equates "psychopath" with insanity and that is what the diagnosis pronounces to him as his fate. It says that he is *psychotic* and *that* to Matt leaves him with one terrifying thought about himself: "I am flawed!" Not, I have a flaw but I *am* flawed. And so Matt hides until he can hide from the diagnosis no longer. To not see it, not hear it, is to not allow it to take on reality, to not be what *it* (the diagnosis) says of "me." He puts his hands to his ears to shut the sound out, squeezes his eyes tight, but in the end Matt cannot keep the secret from exploding before him, breaking his psyche open.

Through the heaves and waves we come to find that, in time, the trembling spawned by the "news" of diagnosis dissipates. It long creates for Matt an unlivable relationship with self. But, knowledge brought by the diagnosis eventually takes root and Matt learns to live with himself in *diagnosis*. In coming "home," to his roots, to conventional medicine, to diagnosis, Matt eventually comes to a sense of himself. We take up his story to see that the diagnosis directs him to a sense of being grounded.

iv. Getting grounded: Dispelling the secret.

It takes time for Matt to come to understand a relationship between what his illness was, and the term "bipolar" that named that illness, though he is not certain whether he ever actually heard it explained in any way by his doctor. He believes he may have really only come to know the illness from a publication, *"Where's The Balance."* For sure that is how he came to really understand what his illness was about. He began to recognize the diagnosis as a fit for him and what he was going through. Acceptance, however, of what that diagnosis was telling him did not come easy. What Matt really came to was a *grounding* in the "flaw" he identified within himself. This he saw as a huge fear: "A lot of fear . . . fear of life!" Matt fought and fought what the diagnosis said about his fears and so, it took a very long time for him "to get grounded":

> *It was like an evolution of a self-acceptance . . . 'cause I would fight it. After I got stable on my medication for, say 6 or 7 mos., I would say, "ok! Fine! Now I can*

> *go out and try acupuncture or RIEKI, or herbal medication from China. I'll cure myself." I didn't want to be on medication for the rest of my life.*

But, these home remedies never worked. Inevitably Matt would start to believe that he was "a prophet or something, and that the end of the world was coming." The problem was that in that state of mind it was very hard for him to see reason since what he perceived, he believed to be real. So, Matt would crash again, and again. Only with time did he come to accept that *the name*, the diagnosis of that illness tells him the reality of his life and that it is a life with an illness that requires ongoing care and day to day attention. That is the reality. "That is what I have to accept for now," he says, "unless they can find a miracle cure." But for now, Matt is satisfied to realize the change of being that has come to him since the advent of *diagnosis*. He illustrates representation of this through *before-and-after* colored self-imaging (see figure Matt) to which he adds the following interpretation:

> *I really didn't have any sort of logic or reasons going through my mind as I did these. I just let them take shape. The yellow part outlined in red on top of my head in the first picture is supposed to be like my halo or the soul. The red means my soul is trapped. Like to me the color red is sort of like the flames of hell. So, it's like my soul is trapped by a red force! Ah, blue hair might mean like I'm melancholy.*

Matt's two pictures seem much the same at first glance, but as he explains some fine differences, essentially in the color of the hair and in the fine yellow border surrounding the red casing of the halo, the distinction between the two becomes significant:

> *I think green is a sign of hope. So in the picture of myself after diagnosis the hair is green and green is a sign of hope or beauty or rebuilding of my self-esteem. And the reason I put the slight yellow border outside of the red is that I don't think anybody can escape the phenomenon of evil while they're living in this world. But now the soul encases the evil rather than being trapped.*
> *I guess the color of the hair represents to me my brain. So my brain is not as melancholy after. Like I said before, green to me is sort of like the color of spring or hope.*
>
> *Getting diagnosed has resulted in something better than before? It's like I sorta had to go through this episode in my life to get self-actualized.*

In Matt's representations he shows us tangibly how he perceives himself to have been before diagnosis and, then, how the event of diagnosis marks movement to particular changes in his self-perception. Melancholy, and hopefulness, are two notable features in this change.

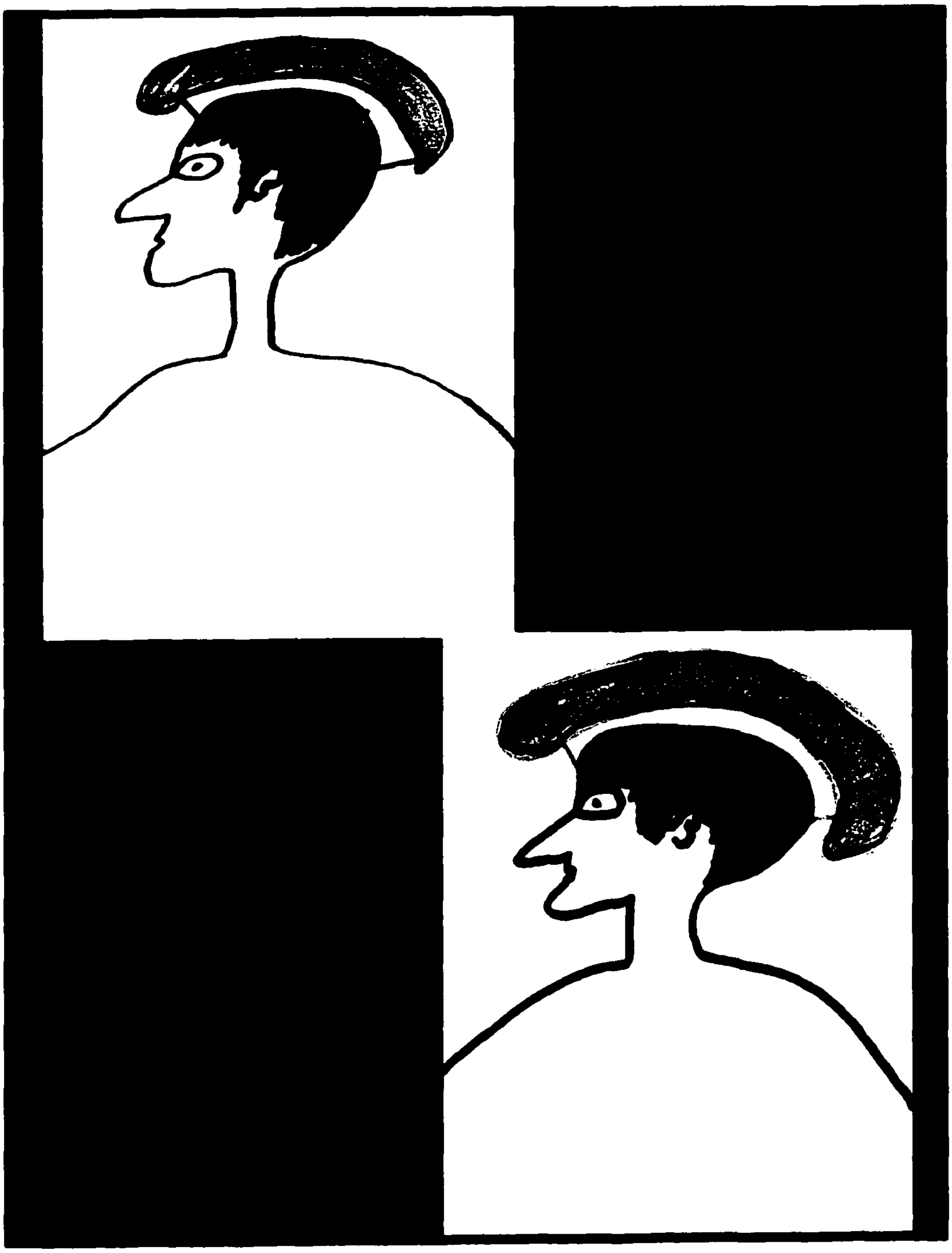


figure Matt

What also resonates in both drawings is how the *soul* permeates Matt's concept of being. Matt makes clear distinction of his body, mind and soul, much in keeping with views of Cartesian "dualism" (Searle, 1999) wherein:

> . . . each of us consists of two separate entities, a body on the one hand, and a mind or soul on the other, and that these are joined together during our lifetimes but are independent to the extent that our minds or souls can become detached from our bodies and continue to exist as conscious entities even after our bodies are totally annihilated. (p. 11)

It would appear, for Matt, that mind and matter are exclusive, that is, "if something is mental, it cannot be physical; if it is physical, it cannot be mental" (Searle, 1999, p. 50). It is unlikely Matt would conceive of consciousness, the essence of the mind, as caused by brain processes or, agree with Searle (1999) that consciousness is as much a biological phenomenon as any other. Matt holds these aspects of himself as separate and strives to assemble them into his reasoning of *self*. But, this does pose Matt with some serious problems. That is, how can Matt adhere his activities and his ways of behaving into a coherent consciousness for himself? How will he transform any number of single percepts into a unified experience? To illustrate the significance of this per Searle (1999), assume your consciousness at any given moment to be your present conscious field made up of various elements of perception:

> There is the perception of the dried leaves as they blow across the deck outside your window, the warmth of the sun on your body, the sound of wind gusts mingled with muffled sounds of traffic in the distance.

Now, how are all of these single elements brought together into a coherent experience? Merging the elements into an integrated dynamic experience is less of a problem if we think of it, as Searle (1999) points out, using the *field metaphor* in lieu of the *theater metaphor*. The theater metaphor would conceive of various characters or elements, appearing individually to consciousness as on a kind of stage. The problem here is: the experience is experienced by *me,* somewhat as a little viewer inside my head adding binding power to the elements while viewing the play. As viewer, I am separated from the event, an observer of a rather dissociated experience. However, by using the *field* metaphor (Searle, 1999) I would think of my consciousness like an open prairie:

> . . . change in my conscious states will be more like bumps and mounds appearing on the prairie. Shifts and changes in the structure of the field, I think, are the correct metaphors for understanding the flux of our conscious experiences. Now, if we think of consciousness in this way as a vast field, and think of the particular percepts, thoughts, experiences, and so on, as variations and modifications in the structure of the field, then we do not have quite the same binding problem that we had before. There isn't any question how consciousness is unified. It is unified from the start by definition. Nothing would be conscious if it were not part of a

> unified field of consciousness. So, there are not two questions— how does the brain cause consciousness, and how is it unified? — but, only one. An answer to the question, how the brain causes consciousness, is already an answer to the question, how it produces a unified consciousness. (p. 89)

Here, consciousness comes to us already unified by definition.

In Matt's scenario of consciousness, he first defines distinct aspects that comprise his sense of self (body, mind, soul). To these he assigns separate realms of activity and experience. He, then, appears to find some resolution to the net compartmentalization of his inner world by maintaining a sense of fluidity or communication between the separate aspects. They are not static but, instead, dynamic. This becomes evident in the *after* portrayal, in which Matt purposefully draws "*the thin yellow border outside of the red,*" reflecting a fluid nature to the soul. Perhaps here, again, is suggestion as to the nature of Matt's immense struggle. *Mind* as a biological phenomenon is quite outside his considerations thus he grapples for a sense of that unified self. Nor does Matt look to his *brain* for causal explanations of his being. He meaningfully finds a way, in his struggle, to integrate the varied dimensions he perceives himself to be, and, thereby attempts a sense of whole-ness. Is this, in the main, the nature of Matt's healing? It would appear, in this, that *diagnosis* provides Matt catalyst, serving to contain him while he re-instates for himself a live-able relationship with self.

2. Experiencing the mystery of diagnostic nomenclature.

We have already, in prior sections, seen that central to the mind is the attribute of consciousness. A second characteristic of the mind is described as intentionality, which ties us to what Searle (1999) deems our "external realism" (p. 39). In other words, I might talk on my cell-phone, take the transit to work, send a birthday card, book a flight to Toronto; all intentional sorts of actions. This is the capacity of my conscious mind to direct my activities to objects and states of the world outside myself. This is my individual intentionality from which I can reason the next step to a "collective intentionality." Thus, "I expect," "I judge," "I want" now changes to "we expect," "we judge," "we want," and so on. This preamble, then, takes us to the role of words and language in institutional reality. It is well to keep in mind that words are generally assigned a function that is particular to the society in which they exist. As example, money, ownership, marriage, and parenthood exist only in as much as they are believed by the people of a particular society to be real. Further, each of these may be constituted differently within given societies, carry different power and be part of conditions special to defining the beliefs and values of the culture in question. Attempt is made in language to capture all of this. It is in the function of words and language. Money is the word that stands for money, pencil for pencil, house for house. But paper is only money if it meets certain conditions and is assigned the function of being money and is agreed to as indeed being *money*. Otherwise, it is just paper. This is how the word *money* gets its power in language. Similarly, this is how "performative utterances" get their power in institutional reality.

But, as pointed out by Searle (1999), performative utterances seem a somewhat more puzzling part of language in that they tend to create a reality more than simply describe it. If I hand you a $10.00 dollar bill and say, "here's ten bucks!" I simply describe what it is that I am handing you. I give you in the words that I am using the function that is assigned to the words. That is different from when a minister says to a man and woman, "I now pronounce you husband and wife!" Here the minister has uttered a pronouncement. And that is what makes it so! The pronouncement makes "it" a marriage, a standing thing that did not exist the moment prior. Until the words were actually spoken, no marriage existed (at least, not in the institutional sense). Likewise, "You are hereby appointed *Chief Justice!*" "I quit!" "Your retirement starts tomorrow!" "You're fired!"; these all create *a something*. There is a kind of reality that wasn't before and now is. In the pronouncement is declaration that constitutes the something. But, consider the following. If a judge says, "This court finds you guilty!" is this what creates the guilt? Well, maybe yes and no! True, the accused is innocent until the verdict is pronounced. And so from that point of view, the declaration not only announces but also creates the guilt. But, what if the accused was actually innocent? The thing is, whether there is an actual guilt there or not, has there not in a way been created a kind of guilt? And this is the interesting thing about the power of pronouncements. "You're a loser!" ". . . a winner!" ". . . stupid!" ". . . brilliant!" ". . . pompous!" ". . . devious!" ". . . psycho!" At some level do they not (as with a statement of diagnosis) create what they announce?

i. Diagnosis means dealing with lop-sided economy.

> *When I tell somebody about my illness, say a girlfriend or somebody at the hockey group or whatever, I don't use the term bipolar. I don't really think that would help them to understand what is going on with me or much about my illness.*

Here we note Matt's preference of the original term *manic depression* to the more current usage of *bipolar*. He thinks manic depression better describes the illness, in a straightforward and simple way that others can understand. Matt thinks the term bipolar is far too "clinical." "Yes, it does mean there are two poles; *up* and *down*," he says, "but most people can't easily relate to that kind of clinical talk. It's like saying 'root canal' instead of, 'bad tooth'." So, Matt's thought is that the term, *manic depression,* is closer to the lay language that describes the "highs" and "lows" he experiences. And it is more easily understood like this. People find it easier to talk about it this way and can maybe see more easily, for example, "why I can't take them up on their offer of a drink of beer or wine or whatever." Bipolar is such "a mysterious word for people," he says, and ties this to what he sees as "a character flaw in the field of psychiatry." Matt seems to deepen our understanding of his experience of being diagnosed by noting the mystery in the words of diagnosis, mysterious words framed in pronouncements which Matt thinks induce a "lop-sided economy."

Systemically speaking, I suppose a lop-sided economy could be said to exist if the state of affairs within a system were tipped more heavily in one direction. Some elements in the system would be seen as serving more heavily on one side. In *diagnosis*, for example, the person stands in the gaze of the doctor who makes the pronouncement. At the same time, the doctor is beyond the gaze of the person. There is exposing of "the *other*" in a unidirectional way.

By Matt's account, we see his view of *diagnosis* as a kind of equation. In this he is suggesting the existence of elements beyond himself that factor into his experience of diagnosis. By looking at but one part of the equation we could not say we had much comprehension of his experience at all. And yet, that is what Matt experiences with diagnosis because, in some sense, the diagnosis precedes him, announces him and follows him. The *diagnosis* itself brings its own past to the center of Matt's experience. It creates the landscape, sets the horizons as to who he is and who he can be. At least this is how Matt speaks to the particular power of diagnosis that rests in the mysterious nature of the words used.

ii. The *power-ful* character of diagnosis.

In Matt's view, when powerful people use mysterious language that activity is motivated from a stance designed to maintain the interests of *power*. Imbued with its own power the "scientized" "languaging" of psychiatric diagnosis feeds on its own power and taunts the public into campaigns of further "mythologizing" those mysterious words. Not that long ago, says Matt, the "C" (cancer) word was example of this. It was a "mythologized" word, a "don't talk about it" word. In the field of psychiatry Matt feels there are many such words; upwards of 300 diagnostic DSM labels, all cloaked in the kind of aura that engender some people as "ok" and others as "not." Matt would suggest these are long shadows cast by an "institution's" use of words that exert their power by maintaining their mystery:

> *Um, they sort of like live in their own sort of world . . . there's power struggle . . . in that this other person can define who you are, can put you on medication if he deems it necessary, and he can invoke legal powers or rules to have you locked up.*

Here, Matt gives expression to the awesome power of psychiatric diagnosis. Like official imprimatur, the DSM diagnostic terms carry a unique kind of power, a power that goes well beyond simply declaring health status. Its power derives not only from its assigned function as, "message of health." It carries, also, whatever society happens to invest in it. This shapes the power in the pronouncement of *psychiatric diagnosis* much differently from the power of other medical diagnoses that might announce a biological disorder. Kutchins and Kirk (1997) assert that "the diagnosis of mental disorder is susceptible to external pressures and contemporary culture in a way that the diagnosis of, say, influenza, TB, or cancer is not" (p. 241). Would diagnosis of *bladder infection* call into question one's character? Kutchins and Kirk (1997) suggest big differences between these two forms of diagnoses stating:

> A bladder infection does not lead to involuntary commitment to a state hospital [though tuberculosis patients are quarantined], to removal from normal educational programs, to disqualification for public office, or to stigmatization or employment discrimination, and it does not affect your claim to custody of your children or grandchildren. In short, diagnoses for physical ailments rarely have the social consequences that diagnoses for mental illnesses do. This is because how you think, feel, and behave is what you believe constitutes your "real" self; it is your essence as a human being. To know another person means to be familiar with their thoughts, emotions, and patterns of relating to others, not with how well their heart, kidneys, or lungs function. (p. 263)

By nature, then, do there not seem to be big differences between these two forms of diagnoses? At core, one notes a number of issues that do have to do with the nature of diagnosis as a statement of medical science. But, perhaps even more so, the issues have to do with distrust of obscure definitions, and pejorative attitudes to *mental illness* and, more pointedly, *mental illnesses* that are of a chronic nature.

In chapter two of this thesis "we" came to know more closely the ordinary conception of *diagnosis* as it shows itself directly. Through the archway of literature and methodology we caught glimpses of diagnosis as a particular kind of knowledge giving rise to a particular kind of knowledge experience. If one considers *that* the case, then, it begs the question: "what particular knowledge of psychiatric diagnosis stimulates a particular kind of experience?" Clearly, in Matt's story we see a lot of his energy invested in evading the word of diagnosis? Diagnosis takes on an aura of mystery, because it is a kind of a word draped with *secret*, a word with clandestine and mysterious power. Yet, with all that, we see the net effect of diagnosis for Matt. It gives him *grounding*. It "pops him back in," so to speak, into a common reality, a reality in which he can cohere and, coherently relate to himself and again function.

That Matt *finds himself* in the diagnosis is a rather curious thing, particularly if one thinks of his diagnosis as a judgment of aberrant mental workings. After all, isn't *that* what psychiatric diagnosis is all about? If psychiatric diagnosis serves to distinguish "normal" from "demented" thought and Matt's mental workings are deemed irregular and abnormal, how then does a statement of his defective state of mind have the effect of realigning him internally with himself? This thought is made the more convoluted if we take it back to Matt's core questions about reality in a world he points to as postmodern. If we assume that psychiatric diagnosis says a whole lot about what is real in the world then we are left with the stickier question of what makes for psychiatric pathology in a postmodern reality?

In his everydayness, Matt relates to a world in flux. He cannot establish link with anything that might give him hold on his thinking. The artifacts and the operations of his world have failed to provide him a footing. The codes and norms that might have secured his thoughts in the past have given way to a world of reason-in-slumber. Diagnosis, however, professes a gnosis that knows. However dreaded, Matt appears to go home to seek diagnosis because it is a knowing that knows. *He* gives *it* that, and for that it does reign him back in. For Matt, the diagnosis does demonstrate that kind of power. It does put Matt's intricacies of thought back together; eventually soothes his fears. For the time being, at least, he can put aside his questions of unreal and artificial environments. Now he has something to hang on to, or perhaps more correctly, something hangs on to him. How is it that one word of *diagnosis*, can reinstate Matt's whole world, re-establish his standing in relation to himself, refashion his identity? And yet, in the end, does the question not loom, for Matt, about *psychiatric diagnosis* itself? Does it not also exist in the very postmodern reality that it judges?

In the aura of Matt's story of diagnosis comes to mind Philippe De Broca's screenplay, "King of Hearts." The play is essentially a portrayal of ambiguities about "madness" in the midst of wartime absurdities. In this satire, supposed lunatics present as the more rational of the population while the rest of the *war-world* appears quite "mad." De Broca depicts a French village, hastily abandoned in fear of the advancing German army. The town folks' absorption with their own quick retreat causes them to forget behind the inmates of the local mental asylum. Left to their own devices the inmates manage to find their way out of the asylum and come to inhabit the deserted village. They organize themselves in admirable ways and conduct themselves reasonably (with sound reason) and with thoughtfulness and consideration for one another. By contrast to the carnage and the "craziness" of war all around them, the asylum inmates themselves present as quite rational and well balanced. De Broca succeeds in instilling question into the whole notion of madness (and hence, what it is that diagnosis really establishes). The play would seem to say: "What is madness after all? Are the inmates in De Broca's play really so deranged? And, what of Matt! He hears wide difference between *bizarre* and *bipolar*. Is his *bizarre* experience, then, not *madness*? So, is diagnosis really a knowledge experience? Perhaps the whole experience of diagnosis does simply, in the end, come down to *a word;* a word experience. What if Matt's diagnosis had simply stood as: "bizarre incident?"

CHAPTER FIVE

Diagnosis As The Experience Of Making Visible The Invisible

The old grand piano had long sat in storage, a pariah with only resemblance to the grand-ness it might have once had. In fact it could've gone unnoticed entirely had there not been a subtle contradiction to it. It was the size, I think! For all its hugeness the great "thing" seemed to shrink from view, there, in the corner: like it was embarrassed with the black varnish coat that deadened it. In fact, it looked as though it had several times been dipped in a large vat of old molasses. One could barely visualize melodious sounds ever emanating from it. Yet, at the touch of a wafer-thin yellowed ivory, there it was! A rich and remarkable sound! Odd that tone should so inspire me. I don't even play much piano! Yet, every spare moment for weeks I was heavily engrossed in the task of revitalizing the thing. Section by section, layers of surface "tar" were melted away, wood grains massaged to the surface, natural color tones brought back to life. Finally, enticed from its hidden-ness, there it stood, the embossed engravings displayed as its most cherished feature. And those irreversible blemishes, well, they too became added adornment.

What is it that gives beings presence or, takes it away? Some may say charisma, but what is that? The anecdote, above, sets a tone for us to engage with Cheryl's story. Part I contains an encapsulated version of her experience of *diagnosis,* from her point of view. In it is described how Cheryl perceived her world, the events surrounding her wedding, her accounting of the disturbing things that happened to her preceding her first hospitalization and, her recollections of how it was to be diagnosed. In this first part, Cheryl's story is intentionally re-told. Focused interpretations of Cheryl's experience are reserved for Part II, where some integration of Irene's and Susan's story adds particular emphasis to interpretations in certain areas. Thus we are taken to deepened dimensions of Cheryl's experience of diagnosis as one of making visible the invisible.

Part I: "Slipping Behind a Curtain"

Cheryl's story of diagnosis begins with a belief of being stalked by gangs of thieves and, about wedding gifts that went missing on her. To this day she is quite certain that her landlady is suspect in all of this; somewhat responsible. But that's the dilemma for Cheryl! To this day she believes that at least some of those events preceding her diagnosis were "real." "Maybe some parts of it were real and other parts of it weren't," she says, and that's the on-going puzzle! How is she to discern which was which? What was real and what wasn't? For the time being she decides to just not think about it. She simply says, "that's in the past" and tries, willfully, to put it away.

Cheryl wasn't always so controlled in her thinking. She describes herself in her mid twenties as quite spontaneous, operating on a lot of whim, a joyful and carefree spirit. But, that was before "it" all began. *Before*, life was full of anticipation. She was getting married! She was exuberant and alive and her bubbly personality was endearing to all who encountered her. But planning a big wedding was not an easy ordeal and for Cheryl it exacted a cost. What should have been a time of jubilation became marred by feelings of desolation. By the wedding date, Cheryl felt incredibly alone. Those pre wedding days are now recalled as turbulent. She sighs, "I got through it . . . but I got sick."

No sooner was Cheryl home from her honeymoon than the signs of illness were heavy upon her. She didn't even want to eat, believing "the food was poisoned." At every turn she felt certain she was being followed! She thought "thieves were conspiring to steal things from her!" She was afraid to leave the house but, then, she was afraid to be in it too. She was unable to sleep and even refused to shower for fear someone sinister might enter the house during those times and do her harm. What was so distressing about it all was her feeling of being so discredited. No one would believe her complaints! Not her family! Not the police! Not the private detective she hired! Not the "psychic" she sought to help her find a way out of her dilemma! People just wouldn't believe the "reality" of what she was saying:

> *Oh, I told everyone and their dog. My friends stopped wanting to hear about it so I lost some friendships over it. . . . I was so upset that nobody would help me and, I'd lost credibility somehow, -- that people wouldn't believe me. . . . My husband didn't believe me. I didn't know that he was sitting outside in the bushes after work watching people come in and out of the house to see if there was anyone scruffy looking or . . . anyone who looked bad or whatever. He couldn't find anything!*

Cheryl's mother decided to intervene and give Cheryl a time-out from everything by taking her on a short holiday to Vancouver. But, this didn't relieve what was happening to Cheryl. In fact, by the time she returned home from Vancouver she had changed so much her husband Ken (pseudonym) became truly alarmed:

> *He said that there was nothing left of "me," no personality at all. . . . I was just really quiet, I wouldn't speak and ah . . . my hair was thinning, I was 110 pounds and I just looked a fright. . . . I thought there were microphones in the house. . . . I thought that the people that we got the house from were gang leaders. I thought the TV was talking to me. . . . There was none of my own personality left.*
> *The happy go lucky person he had known before -- just so full of hopes and dreams-- and high energy-- and assuming the best in people. . . . That's what really left. . . . Like, it was all behind a curtain or something. . . . I just was wasted away.*

A point in time when everything changed.

Cheryl refused to go to the hospital. She denied anything was wrong. In her mind she wasn't ill. If only she could get someone to believe the things she was telling them! Her plight was real and she wasn't sick! But, so little was left of the woman he had recently married that her husband pleaded and convinced her of the need for medical attention. He reasoned with Cheryl:

> *. . . if "it" is real then the medication won't work and we'll figure out who's bothering you. If "it" isn't real, well then, the medication will help you.*
> *So I thought, "well I'll show you it's real and I'll take the medication and it won't work." But, it did. It worked!*

It baffled Cheryl exactly why the medication was changing things or why she felt improved. After about six weeks in the hospital she asked the doctor, "What do I have? Am I sick? Why is it I seem to feel a little better? What's wrong with me?" It was then, alone with the doctor in a hospital interview room that Cheryl was told: "Well, you have schizophrenia." And that was all he said about it. Cheryl remembers feeling kind of "dumbfounded." "It was just a shock to have the diagnosis." Like a direct hit! It meant that "it" was all sickness after all. But, just what kind of sickness was it? Cheryl desperately wanted to hear the doctor say: "Look, it's OK! You can get better. And, you can participate in your life again." But she heard none of this. She saw no show of concern for her. She heard no information, no explanation. Just nothing beyond, "you have schizophrenia!" Those were the only words that lodged in her mind.

Cheryl sought to soften the impact of the diagnosis for herself by recalling a family friend who functioned rather well in spite of having schizophrenia. She thought about him a lot in those days after her own diagnosis, trying to convince herself that "*it*" wouldn't be all that bad? But then, in a way the diagnosis was that bad, a kind of "horrifying thought" and for ever so long after hearing it, "hope was taken away." What would become of her? What would this do to her new marriage? "How could 'he' love me now, with this?"

A short time after the diagnosis, Cheryl remembers Ken trying to console her. Distinctly, she recalls him saying, "we both have it." It was then that Cheryl realized that Ken knew it would affect his life too. That remark, that in one way felt so supportive, also left her feeling terribly "sad for him." Being diagnosed not only told her of the disorder that would alter her own future. In a very real way, it had "stolen" Ken's future too:

> *. . . there's a lot of things that we aren't able to do [even] financially because of my illness . . . I don't earn enough money. And so because of it we have a different life than we imagined . . . We were going to work really hard and I was going to get my degree in communications and we were going to ponder "The Seven Wonders Of The World." That's what our goal was. And like, I just don't make enough money to do that. We can't do that.*
>
> *There's a song on the radio that says, "I want to stand with you on a mountain, I want to bathe with you in the sea . . ." And I said to him: "Can we change it [our dream] to that? That's much more manageable." He didn't say yes or no.*

Diagnosis becomes the mechanism for a different meaning to life for Cheryl. It brings about a change to "everything" from the way Cheryl knew it just a short time ago, before diagnosis. In some ways it is like a viewfinder, each frame drawing in a new scene of a past and a future that is now transformed. With diagnosis the landscape changes and so too does one's entire world.

Part II: At Different Levels of Cheryl's Experience

In Cheryl's story are several themes that can be examined not the least of which is Cheryl's utter dismay at the realization of what diagnosis says. This section seeks greater understanding of her experience by first giving witness to Cheryl's crumbling reality and exploring that startling "verdict" of diagnosis. Attention is then directed to Cheryl's realization: "This is illness!" and her perceived changes of "her past" and "her future" with the knowing of diagnosis. Too, we see in this section diagnosis as a kind of knowing that impacts on the human sense of hope which is presented as consequential to one's sense of who one is and who one can be. We are shown this through Cheryl's story, a story made all the more manifest through Cheryl's perception of body and *body* experience. Thus, we are brought to yet a fuller grasp of what it is to be diagnosed.

Becoming invisible.

At the outset of Cheryl's story, we see her puzzlement concerning what of her experience of everyday life is real and what is not. She turns to those around her for validation. None supply it. Cheryl's accounting of things just doesn't "fit" with their view of things. Cheryl continues to look frantically from one source then to another and another and so on. No where does she find the affirmations she seeks. As she is repeatedly denied, a kind of insidious defeat seems to befall her. Her entire being appears to shrink until she looks to be vanishing, slipping farther and farther into "nothingness." This is reflected in her husband's remark, "there is nothing left of 'you' at all!" Bit by bit, as her reality evades her (in the sense of being deprived of others' validation) all seems to crumble around her. She is told: "No, there are no gangs." "No, nobody is stalking you." "No, there are no gifts stolen." Piece by piece her reality disappears and seems to take her with it: as her reality is denied (in a sense is taken from her) so too is she denied and seems to wither away.

One might wonder at the parallel occurrence of erosion between Cheryl's "reality" (as Cheryl can find no affirmation of it) and the fading away of Cheryl's being (as we see it wasting to "nothing"). To consider this, we could first note how Cheryl existed increasingly in a reality of her own construction. Yes, perhaps it was external expression of her inner turmoil. But that as it may be, it was no less vital to her. However, she must have complicity with others in this but is unable to succeed in convincing them of the validity of her "world." Her continued effort in this regard takes its toll on their patience. It makes it difficult for others to tolerate her. They see heavy contradictions between their world and Cheryl's. From their vantage they see nothing of the threats that Cheryl sees. It is all fallacy, they think; deluded thought! Still there is no question of it in Cheryl's mind, as in the analogy supplied by Van den Berg (1972):

> Let us assume that I am accompanying [a] patient on a walk. It is a clear day; the sun is shining; people are out in the street, which does not look at all unfriendly. We can see this from the patient's window. He confirms my observations, although he perceives danger. We go outside. There the change sets in. Just outside the door, the patient grabs my arm, his face gets a glassy expression and he looks about anxiously. When I ask what the trouble is, he replies that the street frightens him. It looks so strange. So wide, and yet so narrow. The houses lean over the street, he expects them to collapse. I talk to him quietly and tell him that there is nothing wrong with the street, that it even looks quite agreeable, but he shakes his head and is not convinced. No, the further we go—in spite of my quieting words, so much based on reality—the more anxious he becomes. He clutches my arm . . . sweat is on his forehead. He looks as if something serious is about to happen. He wants to return home, for God's sake! (p. 11)

Van Den Berg (1972) uses the above anecdote to point out that what is in the streets to the patient is without question, in the streets. This is because "we (all) see things with their context and in connection to ourselves" (p. 37). Therefore, we cannot say the patient's reality does not exist. In other words, Cheryl is right! Her reality does exist! Though we may take her perceptions to be a falsification of "reality" nevertheless, what she perceives cannot be denied. It is her reality! Gangs do stalk her! Thieves are lurking! Gifts are missing! It is all just as she describes. What Van Den Berg wishes to emphasize in all this is our effort to persuade Cheryl to the contrary would be to no avail. Arguing would accomplish nothing but to diminish her. Furthermore, Van Den Berg would add that to really know and understand Cheryl one is compelled to accept her reality. Of necessity one would have to become acquainted with it, get to know it well, because it is only there in her reality, precisely through the "objects" of her world, that we have access to Cheryl. The objects of that world are the means to Cheryl's existence. How else is she to reveal herself, if not through her world? But, no one confirms Cheryl in her reality. Therefore, she withers. Soon she cannot reveal herself even to herself, so, she "slips behind a curtain" she tells us, becoming obscured to all (including herself).

By Van Den Berg's (1972) assertions, no matter how incongruous it sounds we would have to maintain that there are indeed "thieves" stealing from Cheryl. This thievery is literal expression of her condition in which she is, in a sense, actually being robbed (we see her fading away). Van Den Berg would no doubt concede that Cheryl is ill, but, only in as much as her world is ill; "literally that her objects are ill. . . . When the psychiatric patient tells what his world looks like, he states, without detours and without mistakes, what he is like" (1972, p. 46). This is to say that to find the patient we must look to his or her world of existence. Added illustration of these same fundamental notions is obtained from Irene' story.

At the onset, Irene did not at all think of her experience as "psychosis." Indeed, she thought it was "the rapture" as she, at some point, had heard of. So, in the beginning it was all very spiritually profound, she says. "It was extraordinary light":

> *It was as though I would ask a question and an immediate answer would come to mind. I had never experienced a state like that before. . . . It's like it was a profound enlightening experience . . . until those elements of darkness just came over and transformed the experience . . . where I was very fearful.*

Throughout the intensity of it Irene felt emotionally "very far away" from others. She tolerated their presence but intentionally she sought to keep herself remote from them, to maintain a facade of relating to them while in fact limiting her "presence with them." This purposefully served to protect her for "the more important activities" of thought she was engaged in. It was like she was being pulled in another direction, pulled to do "a greater work." To her thinking *she* needed to go through this experience, convinced that none other could do it for her. And so, she was drawn ever deeper into her inner world in a way she could not resist:

> *Do you know when you go to a movie theater, and there are these spectacular recordings of events that are occurring. And, it's not only in front of you. It's kind of around you and the sound is profound. . . . That's the way the experience was like for me . . . [both] the light side and the dark side. . . . As compared to reality. . . . I knew reality was going on. Reality would be a 4" x 4" little box here, in black and white, in the midst of all this other panorama. . . . Reality would just be in this little corner. It's difficult to describe, but the magnitude of the other was so profound that the pull of the little black and white was an intrusion. It was like just an awareness as opposed to all the other that was going on in my mind.*

Capturing Irene's attention is "panoramic activity." She seems to struggle between that reality and the little black and white glimmer of the "other" common reality that beckons. But, she thinks, "How can I leave all of this spectacle for that black and white?" Sometimes things would be going on in that little black and white piece to summon her there, but she "would just laugh to herself and say, 'You think that, that's where I am? That's not where I am! I'm out in this other panorama'." Irene especially remembers this reaction when there would be specialists in to examine her. She recalls thinking to herself, **"Where are you looking? Don't you understand that you're trying to find me in that little 4 x 4 square and this (spectacular panorama) is where I am!"**

Irene appears to be absorbed in what Van Den Berg (1972) talks of as "a different existence." She speaks from experience, with a knowing-ness that she wasn't where others were looking for her. She knows they were trying to find her in the "little black and white square." However, she was located in a larger (to her more real) reality. Irene was driven to engage in *her* reality. It is through this reality that she reveals herself, for example, when she says she scarcely slept, because "if you've got this panorama going on you cannot sleep." Sleep agents are the only way to submit to sleep. But drugs of any kind stir an inner rebellion, she explains, because sleep and drugs intrude on that which has to be done. In Irene's case they interfere with what she describes as "not being in my body, and being in my body at the same time – or going back and forth, perhaps." She explains the not being in-the-body sensation as the lure of the panoramic happenings while being in the body is being in that little piece with others' reality. And, that's where "they" were focusing when Irene was not there.

Diagnosis as verdict.

In Cheryl's as in Irene's story, we are shown a "language of objects." Within their respective worlds they tell of the things that tell of them. These, the things of their reality, Van Den Berg (1972) would explain, are the real testaments to each of their existence. There is no need, he says, to judge or to take a position (take sides) with respect to the things of the patient's world. There is only one side. The patient's. Diagnosis, however, is not always experienced so laden-free of judgement. We see by all that has been said, that the tenor of diagnosis should be at least as much a statement on Cheryl's world as it is of Cheryl. And, too, Irene's diagnosis must be at least as much a statement on Irene's world as it is on Irene. In effect, Cheryl's world is ill and, likewise, Irene's world is ill, and so on. However, we note Cheryl and Irene to respond to something different imputed by the word of diagnosis. Both hear a pejorative emphasis to it. To both there is heavy judgement, a strong denunciation of their operative reality which, in effect, renders the diagnosis a kind of verdict on them. They experience diagnosis as de-legitimizing them and their world.

Being put in a box is the analogy that comes readily to mind when Irene talks about her experience of diagnosis. It is an experience not easily described in words but Irene is quite clear about a feeling she had, which in essence took the "I" out of Irene. In her view, the experience was one of feeling put in a box. Irene got the impression that that box they designated her was comfortable for "them." But it sure was not comfortable for her:

> *It didn't seem to give any answers other than that I was in a box that they named. . . . But they couldn't tell me how long I would be in the box. Whether I'd get out. Whether I'd be back in and out of the box. They couldn't tell me any of that. So the box just seemed like an empty shell as opposed to something that would help me better understand the experience or to find meaning in the experience.*

When she first heard the diagnosis Irene didn't even quite understand what it meant. Immediately, though, she was filled with uncertainty. It was the questions without answers that seemed to intensify her fears:

> *It created the sense that, would I even recognize it another time because I didn't this time. And it also just made me unsure of why it would've occurred in the first place. And nobody could help me with that. It was just that "it occurs [and re-occurs] sometimes, and sometimes it lasts a long time and sometimes it doesn't. And sometimes it can occur for the rest of your life." My I felt vulnerable!*
> *I remember the other thing I said, after I had been told about the diagnosis was, "I don't know what I'm talking about but today I feel like I'm a newborn baby. . . . I*

> *don't even understand what I'm talking about but it's as though I'm newly born." So I spent a lot of time searching for myself.*

We hear in Irene's words an experience of massive uncertainty with diagnosis. It answers no questions for her; simply "decides" and puts *her* "in a box" where medicine might allude to some clinical understanding about it. But, in fact, their *real* understanding was experienced by Irene as precious little, in as much as it seemed entirely devoid of "the person" living the experience. Here, we detect a note of derision on a diagnosis that annuls the person (in this case Irene) from the experience. We witness her "panoramic" reality extinguished by the verdict of diagnosis and so she vanishes (i.e. feels diminished and vulnerable, "like a newborn baby").

Cheryl, too, feels "concluded" by the verdict of diagnosis. She is powerless to dispute its word. That it might even be challenged doesn't really enter her thinking. But, accepting it tells her that all the "suspicious" things that were going on in her life were exclusive to "her reality." Her husband was right after all! Her mother is right. Her friends are right, as is everyone she had solicited for help. It's like their version of things aligned them against her. After all, if they were right, she was wrong! They're on one side and she alone on the other. There was subtle "condemnation" (Van Den Berg 1972, p. 47) to it that was hard to fathom and it leaves Cheryl "dumbfounded." Why is it, one might question, that the diagnosis that discredits her world of "danger," her world of perceived gangs and thieves and plots to poison her, wouldn't have brought her comfort; a sense of safety? Shouldn't Cheryl have felt enormous relief at such news? Instead, she feels alienated from them; like she was deficient, had a malfunction or something. She was the big mistake! She had somehow failed! It had all just been her; a "sickness" within her.

Realizing the illness.

There was something frightening to Cheryl, even terrifying, in knowing that her own thoughts could conjure up such enemies against herself. It was her own mind that had become the real enemy. To what extent could *that* enemy go? Cheryl labored over, "who would take control if she wasn't able to control her own mind?" She somehow felt incredibly vulnerable and alone, not knowing how to fortify herself against such an enemy of her own design! What measures could one take? How could she ever feel safety within herself again? More frightening, might those around her also be in jeopardy? Would they ever feel safe with her again? Thoughts such as these tormented her as fuller and fuller realization of what the diagnosis said took hold. Life had suddenly become horribly uncertain.

Reflecting on Cheryl's story, one might muse their own similar circumstance? If it were "me" would I lock myself "safely" in a room? What a dreadful thought that I could be harmful to myself or, possibly even to those I love! How would I get through each night after night, year after year, feeling my own behavior was now so unpredictable? What terrible things might I be capable of, if it were me that was sick? Could I ever again let down my guard? Sure, to some extent one can always exercise restraint, could they not? But, I know that I cannot completely harness my mind. I cannot thoroughly control my thoughts. And, I cannot ever totally get away from my mind either. But, in a manner of speaking it now seems entirely evident that my mind can get away from me, as it did with Cheryl.

My mind is, in essence, free to roam. On auto pilot what is its facility? Is a sick mind erratic and volatile or is it dormant and stagnant? What would it be like to hear a diagnosis of schizophrenia, and to realize that there was dis-juncture in the way my thoughts fell together, that my "head" was bizarre, actually "sick." A disordered mind! This is what the diagnosis says to Cheryl. In effect it points out that the terrifying things she thought were going on were actually unfounded happenings. It was not happening "out there." It was all happening "in here," "in my head!"

For Cheryl, that is the dismay that leaves her feeling "dumbfounded." It is the "horrifying thought." To be dumbfounded is to be dazed, bewildered dismayed, perplexed, staggered. If one is dumbfounded one is thoroughly stunned, in utter shock, in disbelief about something, speechless. Indeed, perhaps *speechless* is apt description for Cheryl's sense of pathos on being diagnosed. In the root words of dumbfounded we find, *being founded dumb*. In the vernacular, to be founded dumb is to be without speech. But, we know that experientially feeling *dumb founded* goes well beyond a state of being speechless. Yes, to be dumbfounded is to be mute in the sense that one might be lost for words. But, to be silent and not speak is but one facet of feeling dumb-founded. Let us look at this more carefully.

In historical time, to be mute was associated with being deaf. The term *deaf-mute* carried a derisive meaning, signifying (erroneously of course) that if one could not hear then one was naturally unable to learn, or at least the ability to learn was thought to be significantly compromised. The person's intellectual capacity was believed muted as was the auditory capacity. Unable to communicate organized thought through verbal language the individual was simply believed to be feeble minded. After all, without speech there was no evidence of words so, as the logic went, could words possibly exist? "I gotta use words when I talk to you" (T. S. Eliot in Searle, 1999, p. 40). To use words, in this sense, is to have organized thought and to have the ability to receive and convey organized thought. Ergo, the existence of a "mind" since without a mind one is thought unable to formulate words. Without words one is thought somewhat of a phantom, unable to make associations or to relate to the world in intelligible ways. One's mind is (albeit erroneously) thought vacant. Is not the mind integral to one's ability to interact with the world? In a sense, is it not with the mind that one really "sees" words and thus the world, or is it vis-a-vis?

Without words, one is thought to be incomplete, not whole. Even the famous scientific thinker, Stephen Hawkins, exemplifies the need to use words to articulate his thoughts. His computer-generated voice articulates his thoughts at the rate of 15 to 20 words per minute. Without his words would we see anything more than a degenerated body? Would we know any remarkable thought existed at all?

Helen Keller's famed teacher, Anne Sullivan, is known to have referred to the Helen of early childhood, as "phantom-Helen." In later years Helen's own writings allude to the significance of this term. In Herrmann (1998) she writes:

> Before my teacher came to me, I did not know that I am. I was a phantom living in a no-world, she later described this period in her life, which she referred to as "*before the dawn of the soul.*" I had neither will nor intellect. I was carried along to objects and acts by a certain blind natural impetus. . . . My inner life, then, was a blank without past, present, or future, without hope or anticipation, without wonder or joy or faith. (p. 46)

A vacant being to be sure, but by age seven Helen could comprehend some few isolated words. She communicated through pantomime gesture but, her soul was not "set free" (Herrmann, 1998, p. 45) until the incident at the well. Up to that time, Sullivan writes of Helen:

> . . . "mug" and "milk" had given Helen more trouble than all the rest. She confused the nouns with the verb "drink." She didn't know the word for "drink," but went through the pantomime of drinking whenever she (finger) spelled "mug" or "milk." This morning, while she was washing, she wanted to know the name for "water." When she wants to know the name for anything, she points to it and pats my hand. I spelled "w-a-t-e-r" and thought no more about it until after breakfast. Then it occurred to me that with the help of this new word I might succeed in straightening out the "mug-milk" difficulty. We went out to the pump-house, and I made Helen hold her mug under the spout while I pumped. As the cold water gushed forth, filling the mug, I spelled "w-a-t-e-r" in Helen's free hand. The word coming so close upon the sensation of cold water rushing over her hand seemed to startle her. She dropped the mug and stood as one transfixed. A new light came into her face. She spelled "water" several times. Then she dropped on the ground and asked for its name and pointed to the pump. . . . (p. 46)

This story shows the emergence of Helen to an increasingly "mind-ful" state. Within a few hours Helen added several words to her vocabulary. "Door," "open," "shut," "give," "go," "come," and so on. But, it would be wrong to conclude from this anecdote that before this point in time Helen had no mind, or that she did not use her brain in a way that gave some expression to herself. The point of the story, is that she had neither *eye* nor *ear* with which to see and formulate words. How could her brain make the connections, associate *the word* with *the thing*. Without words, how could she be connected to a world beyond herself. Thus, Sullivan's reference to Helen as "phantom!" Years later, Helen tells of "the well" incident (Hermann, 1998) as a quickening to life and the world about her.

> What happened at the *well house* was that the nothingness vanished, but Phantom was not yet in a real world. She associated words correctly with objects touched, such as "pump," "ground," "baby," "teacher," and she gave herself up to the joy of release from inability to express her physical wants. . . . But the first words which she understood were like the first effects of the warm beams that start the melting of winter snow, flake by flake, a patch here and there. After she had

> learned many nouns, there came the adjectives, and the melting was more rapid. Finally Teacher dropped in the verbs, one by one, sometimes in groups, but for Helen there was no connection between the words, no imagination or shape or composition. Only gradually did she begin to ask questions of the simplest kind. Earth, air, and water were quickened by Teacher's creative hand, and Phantom disappeared as life tumbled upon Helen full of meaning. . . . (p. 53)

To be sure, Helen's story shows us it is more than a set of eyes that is needed to "see well." The "mind" mediates the world and the being. It is the agent that interprets the world, accurately or otherwise. It gives one a point of view, represents the objects of one's world with words, and ordains words to have particular meaning. Can there be "sight" or "in-sight" otherwise? Do not words with meaning ultimately translate to a world with meaning and vice versa? And so, the dumbfounded-ness that Cheryl feels at hearing her diagnosis of schizophrenia speaks to the incredible dismay of an instantly collapsed world. *Her* point of view on the world is now substituted with an alien point of view, a diagnostic "take" on the world that leaves her bereft of utterance. Her world-of-meaning at that moment is entirely changed.

What is a world-of-meaning?

To reflect on a world-of-meaning, we might question what *a world with meaning* really means? It seems one would have to at the outset clarify the whole notion of our use of the word *world.* "Which world?" is the immediate question! My inside world or the world out there! The world as I see and experience it or the world as it is commonly seen and experienced by myself and by others? And, we might say, "whose world?" Mine, ours, yours or, someone else's! Are there worlds within worlds? How can we know about the world and how things really are in the world? As one gets into the question of "the world" we realize how very complex it could get? But here, philosophical debate about this or that world is not the immediate intent. What is intended is to find whatever means at hand to deepen our understanding of what *a world with meaning* would be to Cheryl in her experience of being diagnosed. To this end, we might venture into discussion of *a world with meaning* by simply saying that *a world,* of whatever description, is able to take shape in as much as *a mind* is able to turn to the objects of that world as a source for knowing it. Herein is presumption of a basic conscious awareness of *that world,* a consciousness that *is* because it is aware that *it is.* Alluded to in prior chapters, we again come to recognize this well-known theme to originate with Rene Descarte in the seventeenth century. It is a notion repeatedly given particular attention, more recently by Searle (1999) who states, "I cannot have the illusion of consciousness if I am not conscious. The 'illusion' of consciousness is identical with consciousness" (p. 56).

But, that Cheryl is consciously experiencing her world is not in particular question. What is horrifying to her and leaves her feeling dumbfounded is the *statement of diagnosis* that, in effect, tells her that "the world" she is consciously aware of is, in main, an illusory world. In the past, when her friends, her husband, and her mother had first implied this same thing to her, Cheryl could brush it off, and indeed she did.

However, this same message now has astounding significance to her. There is an unusual strength in *that* diagnostic statement. Essentially, it is that word of diagnosis, which puts Cheryl's entire world into question. Isn't it what clearly says there are no gangs, no plots, no "realness" to all of her thinking on that? These are all her own fabrications. The diagnosis delivers this in an absolute way and it is a message of enormous consequence to Cheryl. But how does the word of diagnosis come to have that kind of power to Cheryl? How is it able to extinguish worlds, at least, change everything about her world? Let us look again to our earlier statement: *a world with meaning* is able to take shape in as much as a mind (or one's thoughts) are able to turn to the objects of that world as a source for knowing it. Our statement, here, most certainly aims on *a world with meaning* as an intentional world, a world of significance because it is *my* world? It in fact, brings to the fore Heidegger's statement "the being with which this kind of being is concerned with is always my own" (Being and Time, p. 67 in Grossman, 1984, p. 158). Deliberately brought to light, then, is *intentionality*, an essential feature of *consciousness* and therefore of fundamental significance to a notion of *the mind.*

The concept of intentionality, introduced in a former chapter is now revisited here. We recall that *intentionality* means that one's mind, as a conscious mind, is almost always directed to something. Indeed, almost all of the mind's conscious representations are of things and objects in the world. If I want to drink tea, I drink a cup of tea. I want to play tennis and I play tennis. I'm tired so I lay on my bed to sleep. And, so on. My actions are all oriented to things I want out there, and result from a particular state of mind. By definition, "... mental states are directed at, or about or of, or refer to, or aim at, states of affairs in the world" (Searle, 1999, p. 64 - 65). This is "intentionality." Given this, could one then say that it is through intentionality that a conscious being creates one's own world; an internal world and perhaps one that is common to others as well? My own world is a thing of my own creation because it has its genesis in me. I live and roam in it but curiously, like some self-constituted, fully animated galaxy, it is a system that has come together and it lives in me. And so too, we might say the same of Cheryl. Cheryl created her own world, a singularly unique reality of her own, as we all do. The nature of Cheryl's reality would be in the meanings of her experiences as she uniquely interpreted them to be, relative to her own specific situation and her very own circumstances. And, if we each do create our own reality can any two realities be the same? In this sense, yes and no! There may be a common reality that we all do share in, however, the world fashioned *within* is identical to no two individuals. This must be so because "my own reality" (synonymous with world in this context) has collected and taken shape as from a magnetic source of individual meanings that are peculiar to me. Could even so-called twin experiences be truly identical?

Now, we could probably say that the sunset I see out there, or the mountains in the distance, or the 747 airplane in flight overhead, is also a sunset, a mountain and an airplane for others as they would also be for Cheryl. But we could not say that those objects are in fact seen and experienced in the same way for me as they are for Cheryl or, for any one else that might be perceiving them. And so in that sense, they are the existence of things and objects and events as they appear. It truly is my world; my reality. And it is your reality and, it truly is Cheryl's reality, too, because it is an experienced reality that is of consequence here. The truth of this reality cannot be disputed, perhaps, only the difference of it. And, therein is "the rub" in the experience of psychiatric diagnosis, in this case Cheryl's experience of diagnosis.

There is another thought that bears consideration to added comprehension of *intentionality* and ultimately in what meaning diagnosis might have to Cheryl. That is, "not all conscious states are intentional, and not all intentional states are conscious" (Searle, 1999, p. 65). Understanding the latter part of this statement might be easier than understanding the first part. I can simply think of myself asleep and unconscious, and still I know that I retain my hopes and beliefs and fears and desires. But, to grasp that not all conscious states are intentional is a little stickier though, no doubt, more to the point in our apprehension of Cheryl's experience of diagnosis. First, consider whether we do not all, at some time or other, have conscious feelings of anxiety, elation, fear, shame, love, hate, and so on, for which we do not readily know the reason? I may ask someone: "What are you so up tight about?" only to hear, "I don't know!" or, "Why do you hate that person?" and get the response, "I don't know. He's just a jerk!" And so it goes with intentionality. Many of the emotional states exist, as conscious states, without an actual object of intentionality being represented. With surface emotion, generally we get through the uncertainties of our feelings but sometimes the intensity of it all can run inexplicably deep. Addy's narration in "Angels Turn Their Backs," (Buffie, 1998) provides a case in point:

> Close your eyes. Now think about the one thing that really scares you — I mean *really* scares the hell out of you. A spider crawling up your leg? Standing on a high ledge that's slowly crumbling under your feet? Maybe it's the fear of finding yourself deep, deep under water, not knowing which way is up? Your lungs are bursting — you can't find the surface. Do you feel your heart pounding? Can't breathe? Is there a hard tightening in you chest?
>
> Multiply those feelings by ten thousand. That's a panic attack. It's white light in your eyes. It's a bomb going off in your chest. And it's not being able to tell a single soul what's happening to you. You don't even know why it's happening. It's as if you've lost the *real* you and you don't know how to find her. Now imagine having that feeling dozens of times a day. You're almost normal for a while and then, just when you're letting your guard down — beginning to relax — it shatters in your head.
>
> How small a space can you hide away in? How small? How secret? (p. 9)

This anecdote gives a sampling of a conscious state (i.e. panic) without an identifiable object. The panic is incredibly profound and we know that *fear* like love, and all those other emotional states we might experience cannot of themselves exist. All emotion exists in association with an object. But, that an object of those feelings must exist does not say that the object is known or can even come to be known. Perhaps this is essential to the message of psychiatric diagnosis. Psychiatric diagnosis points to the emotionality and, also points to that *something-object* which it readily admits it cannot readily identify. That is its limitation. Psychiatric diagnosis declares what it cannot see; *that cloaked something.*

If intentionality (Van Manen, 1990) is being connected to the contexts of life and being in affiliation through all of the possible human encounters and activities of life, then "diagnosis" would say that Addy, in the above clip, is "dis connected." Likewise, it points to similar dis connection in Cheryl's "world." Cheryl's conscious state is bereft of the object of *that* state. The diagnosis pronounces Cheryl's "world" invalid (against what standard is left open). Perhaps it is that which Cheryl takes to mean *a world of no meaning,* or, maybe more correctly stated, a world of "meaningless meaning" (since no meaning would indeed pose conundrum*)*. At that moment of diagnosis the only meaning left to Cheryl is *meaningless meaning.*

So, Cheryl is dumb-founded. And in that sense she is saying much more than that she is lost for words, as we might all be lost for words at some time or other. What Cheryl seems to be saying is that hearing the diagnosis has, like an ink blotter, absorbed all else! She is left without context, without "external" referents, in effect, without a "world." The diagnosis has sucked away all that had meaningful meaning. Everything is gone away and, in place, *diagnosis* has substituted itself. All that Cheryl has known evaporates at that moment. It's all "*not*" anymore, gone – meaningless. She feels vacated, so much so that for a time she loses all coherent thought. Utterance on the diagnosis or on anything else is not in that instant possible. She is mute, yes, but she is also founded-dumb in the sense that there is "nothing" she sees left accessible to her, nothing thought or to be thought; nothing to be but what the diagnosis says to be. Only the diagnosis *is* and at that moment it is "*everything.*"

At that moment it is every-thing.

How does one's entire world suddenly get absorbed into one word? A moment ago, before the diagnosis, Cheryl had a *self.* She could picture herself, as she so often did, in particular ways. Young! Attractive! Vibrant! In-love! She was surrounded with wedding gifts, and all those thank you notes she still owed to people. She could imagine setting up a new home, decorating it exactly in those ways she and Ken had often talked about. She could think about coming home from work, candle-lit suppers, walks in the park, visits with friends. She had rather modest tastes, she thought. Soon they would have the car paid off and, with any luck at all, by this time next year they would be in their very own new house. That's how it would be. She could see it all play out in her mind; her and Ken, finally married, making a life, making love, making babies, together making a home. But all those images have now crumbled away. With *the* word of diagnosis she slips into a no-where land. It is not the "schizophrenia" per se that has dislodged her, it is the knowledge given her about herself, the knowledge held in the word of the diagnosis that has done this. The disorder is one thing. But accommodating the knowing of the disorder (the diagnosis) is another. That is what seems to jar Cheryl's foundation. No more does she think herself as reliable, connected, intact. She sees herself differently now. The "suspicious" things that happened weren't even real. The diagnosis makes that clear.

But *it* had all seemed so real! No one could've reasoned otherwise with Cheryl. Now, hearing the diagnosis places a whole other judgement on it all; superimposes a "reality" on it that redefines her own. It is an altered reality she has difficulty getting her head around but a reality she feels unable to refute. It comes as an absolute pronouncement, one that declares some-thing for certain. And that is the only certainty left to Cheryl. The diagnosis brings-down all the rest, all her past thinking. It creates its own "some-thing" which, in her dumbfounded-ness, Cheryl can't instantly identify. She only senses it as "horrifying," a dreadful and shocking thing. At pronouncement of *diagnosis* she becomes nothing. *It* becomes everything. It has the power of history, the centuries of a respected, scientific tradition. On that basis Cheryl finds it near impossible to challenge. How does one challenge a knowing-ness that knows? That pronouncement means that everything she thought she knew she doesn't know. The diagnosis is irrefutable in what it now says. And that, to Cheryl, is the "horrifying thought": the schizophrenia is suddenly brought into being *to her*. It is undeniably there. Perhaps in actual fact it was there yesterday too, and the day before that, and all along. But until she heard it as the diagnosis, for her it did not really exist. Now, declared in audible sounds, the *something* that was *nothing* before is now *everything*. With announcement of the diagnosis, the schizophrenia is given an identity, given life in that for her it starts to take shape. It is real, because the diagnosis says it is! A moment ago *it* wasn't, even though all that bizarre and inexplicable stuff was happening then too. But, now *it is* schizophrenia! For Cheryl, "it" now has features, has a structure and takes on an energy of its own.

Two sides of the diagnosis.

From somewhere distant, high school banter seeps into Cheryl's recall:

> *"I'm Schizophrenic and so am I." I used to joke about it back then. That's when I didn't know what it was about. That's a terrible joke now that I'm on the other side of it. But uhm yeah when I was in high school we used to say that. You'd say both and so you'd be two people in one body. And that was kind of funny. Now I think, "oh my gosh!" Now that I know what it is, it's nothing to joke about. It's not very funny. It's not even accurate. You're not two people in one body. You're split from reality.*

The diagnosis enters in that awareness: "You're split from reality." How easy then, on the before-side of diagnosis, to joke and tease as long as it didn't truly apply to one's self. Joking about it then simply said that it was empty, without substance, unfounded and remote from "me." But it leaves one "dumbfounded" to hear it in one's own diagnosis. Now Cheryl is on the opposite end of things, the after-side of diagnosis. On this side, it is no joke. The diagnosis makes it a dead serious issue. The diagnosis doesn't fool around. Once said it cannot be washed away, cannot be unsaid. There is a kind of finality to it, an official dictum of sorts. To be diagnosed meant the schizophrenia descended upon Cheryl and in that instant she had *it*.

Once given, the diagnosis imparts to Cheryl a startling "visual" of herself that has a kind of blinding "certainty" to it. It is not given to her in the ways that other things have been given, in ways that can be refused. It is given to Cheryl by its mere utterance. The mere utterance is what places her on the after-side of diagnosis. She can't, now, effectively say, "excuse me. . . . I think this is all a mistake." She may try to say something of that nature, if she can find the words, but she stands somewhat powerless against a respected medical establishment. Has *the diagnosis* not earned a formidable power to legitimize (or not) all manner of one's fevers, hunches, fears, concerns, and so on; to say to Cheryl who she is, who she can, and cannot be? It has now ruled on her reality, de-legitimized the construction of her thought and, her "world." And, if in that moment "it (the diagnosis) is everything," then ipso facto it follows that everything else on the after-side of diagnosis (at least for a time) is nothing (in the sense of meaningless). On hearing the diagnosis this seems the way it is to Cheryl, and it rendered her abject and idling in a state of hopelessness.

"It took away my hope!"

We've come thus far in Cheryl's story to see what we take to be some about her experience of diagnosis and the meaning it may have to her. We see, for example, that it is the naming function of diagnosis that registers to Cheryl that her state of mind is a *disorder*. We note that the physician's act of conveying the diagnosis to Cheryl, in a peculiar sort of way is what calls the disorder into being for her. At the same time we are aware that *naming* a set of symptoms does not really actualize the disorder. We see that the naming in diagnosis bequeaths a kind of judgement that is different from what other acts of naming do. Other acts of naming may simply give title to something. But, diagnosing is different from when I might name my pet cat, for example. When I conjure up the name Misha for my cat, I may try to fit my wants and expectations of what a pet cat means to me, to what I see is *the* cat before me and what I think the name Misha conveys. I call the cat to me using the name Misha, and before long the cat may assume the identity of Misha as I assumed it to be. But it could happen that at some point I might think I made a mistake in the naming of the cat Misha. The nature of the cat seems better suited to "Tao" I now think, because as I come to know better the personality of the cat it seems more "Guru-like"; has somewhat of an oriental stature. And so the cat draws to itself a different name; its own name through its own special character. Maybe it is in this sense actualizing its name rather than the name giving shape to who it is to become.

And so, there is a whole curiosity to this notion of naming that is in some ways the same and in some ways different than the naming of diagnosis. There is a different thoughtfulness that is brought to bear. The turn of the millennium gives evidence of something new brought to naming, even heralding new-generation names for babies, such names as "Breathe," "Promise," "Matrix," "Ocean" and "Legend," as opposed to conventional names of earlier decades: "Sarah," "Bruce," "Emily," "Ryan" and "Christopher." And then we see yet a different dynamic in *pet nick-names*: "Bo-Bo," "Chi-Chi," "Pee-Wee" and, in *name-calling*, "Ditz," "Dimglo," and "Psycho." Now, the point in all of this is that in diagnosis a unique kind of thoughtfulness and reasoning is involved which distinguishes the naming of diagnosis from other kinds of naming and which, in Cheryl's case, bears negatively on her sense of hope.

Cheryl knows that the naming of diagnosis comes from a kind of authority that is ascribed to professional psychiatric medicine. That is why she goes to the hospital in the first place. She actually goes there with the attitude: "I'll show them!" She is going to elicit a judgement in her favor. She goes *there* believing the clinical judgement cast will validate her. It will "name"; give affirmation to her. But something unexpected happens, a twist that quite stuns Cheryl. The judgement in the diagnosis given her de-legitimizes! It names her experience *a dis-order.* It *classifies* her and so it is stunning because it is as though very suddenly the disorder is on her, there, in her face. A moment ago it wasn't there to her. Now a physician "names" it and because he is a physician and has named it, his powerful position influences her sense of hope. His authority makes the disorder happen, so to speak, because it sets *it* before her. The name he presents her in the diagnosis gives rise to this "thing" – this schizophrenia and immediately she falls into a kind of despair about it.

Yet, during those six weeks of waiting in hospital, of being watched and eyed, Cheryl had increasingly become aware that there was a *something.* She knew this because on the medication she had come to feel better. "Why is this," she asks? But then, last week, and until she actually heard the name in the diagnosis, she could still think it was just an odd "bleep" of happenings. She could even maintain the assumption that people were, indeed, harassing her. Or, perhaps she had just over-stressed herself, and all that! But now, the diagnosis seems to strangely mitigate all that. It seems to induce the experience of schizophrenia. She doesn't even really know what schizophrenia means. She asks, "what's that?" Yet, she knows enough to know in that moment *a horror.* "You have schizophrenia!" It's an alien kind of word -- a strange and icy word. It zeroes in on her like none other could, and she shudders because an authoritative voice now makes visible what, before, she did not see.

Now that Cheryl is confronted with a new realization about herself she is compelled to see herself and her world in entirely different ways; ways that she cannot bear to look at; ways that dissolve her hope. What is Cheryl really expressing in her remark: "It took away my hope?" What is that intangible something called hope, that Cheryl notes has been taken from her? When Cheryl says this, we hear it in a way that conveys she has lost something fundamental and crucial to her existence. In fact, it is as though of all the many things she sees lost to her life *hope* is the most precious of treasures that vanishes in the wake of *diagnosis.* The diagnosis has aimed and struck at her center; her hope. Cheryl's statement, "It took away my hope," carries a note of desolation, a listless resignation of spirit. In it we are brought to some awareness of what hope has supplied to her life. Perhaps it is in the vacancy of hope, that we see the dispiriting effects of the diagnosis. To Cheryl hope is now gone.

It would seem in her statement of lost hope Cheryl is letting us know that there is much to *hope* that needs understanding if we, in health care, are to limit the depletion of hope in our acts that surround psychiatric diagnosis. Yet, if one were to ask, "What is this necessary ingredient to life called *hope*?" we might be hard pressed for answer. Without answer, how could we help Cheryl refurbish her sense of diminished hope? Would we even deem it necessary to do so? What is it we would do?

The hope Cheryl talks of seems well beyond the level of wishing. We may all wish for things like a new car, a house and so on. While there may be an element of wishing in *hope* Cheryl rightfully gives us the sense that there is much more to hope than that. Indeed, Cheryl's statement suggests hope is that which has empowered her being; that innate something which was a must in sustaining her. Carpenito (1989) describes this kind of hope as that which "helps a person to feel whole" (p. 436). This is the level of hope Jevne (1991) suggests "helps to convey that the future will be somehow benevolent" (p. 151) and without which persons could well lose touch with their own "sense of aliveness" (p. 152). We might say, then, that loss of hope to one's life is as loss of expression to one's face. What remains, in both cases, is flat. In the extreme Shneidman (1986) speculates that hopelessness is the "active impotent ennui" that predisposes persons to willfully end their life. By this, hope is represented as life's vital force?

So, when Cheryl comments that hearing the diagnosis took away her hope we can surmise despair. Is she not talking of a state of mind in which she "sees limited or no alternatives, no available personal choices" to her (Frisch & Kelley, 1996)? And too, is she not talking about an inability to summon the energy to go forward with her life? She openly tells us she cannot even, now, organize her thinking: she feels "dumbfounded." She can see but limited future possibilities for herself. She feels a loss of self-definition, is unable to make plans for herself, unable to decide what she will or won't be, should or should not do. Hearing the diagnosis strips her and puts before her only a *dense grayness*. The color of life clouds over, occluding all visible hope. The diagnosis implies to her a serious illness and one that will always be there. It will hang there like a burden, always lurking, leaving her only a day-to-day existence shadowed with apprehension and uncertainty. Cheryl is menaced by such grim thoughts:

> Will this "craziness" ever completely be gone? How much of it will center in my life? Will I always need to live "low stress"? How little will it take to push me right over the edge? I'll never be able to go back to university like I planned. I might as well just fold up 'cause I can never face the world again. How can I go out there and work? I'd only ever get a second-rate job if I did. We'll never have enough money to buy that house, to travel, to realize our dreams. That was all possible before. Those dreams and plans with Ken will never be. I'll just be a burden to him now. Our freedom is stolen. I can't trust myself anymore. I won't be able to decide anything ever again? He will have to make all the decisions. Everything will have to be thought and re-thought and planned in light of "this." I'm flawed. I'm not normal. I don't think right. I can't just "DO IT." Three or four kids! No, there will be no babies now. I don't have what it takes? I'd probably pass it on to them too.

And so it goes with Cheryl's thinking. For ever-so long, she feels all her assumptions about the way life would've been are over-written by the knowledge of the diagnosis. She can assume nothing about anything any more. The diagnosis has taken all "taken-for-granted ness" away and dissolved her carefree lifestyle. Now, she is but a "glass ball," like Susan in the following anecdote, set in uncertain motion at the time of diagnosis.

"Feeling like a glass ball!"

There is an ongoing tension in life that didn't exist for Susan before the diagnosis. She sees each day as a battle. "I forever think, 'maybe I'm going to lose it again. . . . Maybe I'm going to get sick again'." Because the diagnosis identifies the disorder as *chronic* there is, always *in* the background, possibility of relapse. So Susan is never sure of herself; constantly wary of her life. Activities are staged as a kind of insurance, trying to ensure that "health" is retained:

> *I don't allow the opportunity for life to affect me because I just don't want it [the illness] to sneak up on me; you see the illness can sneak up on you sometimes, and you can be in the throes of it and lose insight . . . even when you are on medication. So I get frustrated because I would like the opportunity to not analyze everything about myself . . . that's what the diagnosis does? I'm always analyzing to make sure, "okay, this is okay today." I feel like I'm a glass ball. My concentration is affected. I can't remember things. And, I'm always double-checking and not wanting to let things get out of hand.* (Susan)

Like Susan, Cheryl too sees herself having to live in a state of constant hyper alertness about herself. She doesn't want to believe that she will be permanently afflicted with this but that is what the diagnosis says to her. She sees forever having to guard herself against undue stress because there is the huge fear of relapse. The diagnosis itself forecasts it, intones it like some sort of prophecy. What can she do, or say, or think that will in any way offset that possibility?

What the diagnosis says makes Cheryl, like Susan, feel liable in ways that would not otherwise have been. Her decisions become measured:

> *. . . well maybe you, your judgement was off when you made that decision; maybe it was your mental illness that caused you to do this or that. . . . And suddenly you can't get angry, or, "it is your illness flaring." And you can't be happy either - at least not too happy - or, that might be your illness too. People will watch you and wonder.* (Susan)

The glass ball precariously rolls along, of its own volition maneuvering a track that may or may not stay out of harms way. The tiniest pebble in its path can be shattering.

It is the information told her in the diagnosis that, to Cheryl, wipes out her notion of normal living; of an ordinary future. And so, in her mind's eye, hopelessness prevails and *living* life vanishes. And, isn't that the thing about "diagnosis?" In Cheryl's experience, the diagnosis determines her entire future a wash out. Her future looms up, right there in her present, at the time when she apprehends the diagnosis? Shouldn't one's future unfold in the future? Isn't that where the future belongs? But that sequence is altered for Cheryl. Diagnosis up-fronts her future and face to face with it she sees no benevolence there. Without hope she aspires to no future at all. But, "thankfully, hope is seemingly as much a condition of life as suffering" (Jevne, 1991, p. 146) and, in Cheryl's story, we are shown a rekindling of hope and a new vision of self and future. We know not from where it springs, but we do see it, hope anew that somehow enables her to walk the walk through her fears and to try, at least, to pull life back together again.

"Putting away a lot of my past."

For a long time Cheryl mourns the lost promise of the "life" she imagined would be hers. She grieves a lost sense of "normal," a honeymoon tainted with noxious memories, the joyfulness of young married life that "should've" been hers. Hers is a lost fortune, now, seized in a single word. What can she ever think of the wedding pictures there on the shelf, and the album of photos that will only reawaken memory of her "crazy" past. She recoils at the thought of her absurd behaviors back then. How would she ever get beyond it?

The weight of the diagnosis hung on Cheryl, pulled her down to where she felt she would forever be tainted. She was tarred and painted by what the diagnosis declared to her about herself? For a long time there was only despair about a life gone sour. But, the sum of Cheryl's story was far from concluded. Something began to change over time. Slowly she became aware of a stirring deep inside. Perhaps the tinniest wellspring of new hope was pressing for the surface, prompting Cheryl to reach out for life. And isn't that the marvel of hope; that it can find its kindling in despair?

Of the earliest signs of renewed hope was Cheryl's ability to lock-on and, "stare at the diagnosis." For some reason the fear of it was abating and she could just simply look at it, and see it as "dis order." She felt the better for this new "take" on the word disorder. Cheryl had always valued order in her life. She put a good deal of effort into keeping appointments, being on time and, in general keeping herself well organized. Maybe it was that *value* that was helping her now. If she could just see herself as having fallen-out-of-order then maybe she could come to see herself reestablishing a new order. It made her feel better to think about it this way. It made it all seem less "clinical." She felt more normal, reinstated into the arms of humanity. In this light, she didn't have to view her bizarre thoughts and behaviors as having been so absurd; they had simply slipped out of order. This new way of thinking didn't take the diagnosis away. Nothing could do that. It didn't make it less knowledge of CMI. But it did make it sound better, and feel better. It was more "ok" to think of herself as being *out-of-order* than to think of herself as "crazy." Yes, she was disturbed, but that was because she was lacking order. There was something transitional about this way of thinking. Somehow it placed it all more within her control and spawned new inklings of hope. Now she could dare to think of how she might help herself to new *order*.

What was a broken world to Cheryl could at least now be conceived of in ways that put it back together again. In the wake of rekindled hope Cheryl dawns on an instrumentality to the diagnosis. She begins to realize that the very thing that seemed to have shattered her world could possibly be what mends it. She fathoms that she can actually use the diagnosis to help create a new "normalcy" for herself. To do that she deems the diagnosis to be a sort of packaging thing. Metaphorically, why can't it be a sort of storage bin? So be it! And into storage she deposits all the painful memories, the peculiar thoughts, the absurd things she believed were happening.

Cheryl conceived she could just put it all away, and leave it in that container in the attic. She could do that, and it wouldn't mean she couldn't go back and take the things out again if she wished; look at them bit by bit from time to time. If she was the one to put those things away then she could also be the one to take them out when she chose. And, if they crept out uninvited she could will them back to storage. In fact, this was to happen more often than not but at least, now, Cheryl had a thoughtful means of dealing with her pain. The diagnosis had itself presented it to her.

So now, when Cheryl says, "that's in the past," she is saying that all the dark and bizarre happenings that culminated in the diagnosis are put away. It's part of her re establishing *the new order*. And, it is the diagnosis that provides her that mechanism, a way to block out what, at any moment, might be disturbing. To put "it" in its place means she is freed to attend to what needs attending. The diagnosis has become a means to her restructuring through knowing of it all as *disorder*. The diagnosis becomes the depository for all the things in her life back then that went wrong and got out of order. The diagnosis gives reason to what spun out of control. Cheryl can point to it. *That name,* "a box to put it all in the past." Lumping all that stuff together in the diagnosis modifies the pain and confusion. There is at least two years of her life that lie in that repository. Thus, the diagnosis has in some sense released her *to be*:

> *I don't remember half the time that I've got Schizophrenia . . . even though my life revolves around it. . . . I don't go around thinking "oh I've got Schizophrenia." I go around thinking what can I do about this situation. . . . I take it [life] on a situational basis. . . . Situation by situation.*

Making myself visible.

Cheryl knows she need not let go entirely of the things that are there in storage. They remain for her to take out and reexamine at will, to rethink and reinterpret and to bit by bit use the diagnosis itself to redraft the past, if need be in more palatable and self-forgiving ways. She can, to some extent, modulate the timing and the activity of all this so that in between she will be free to engage in the task of "*now,*" a task of making herself "visible" again. The now she creates has new horizons, indeed, a new reality through which she can again reveal herself. The diagnosis has drafted the challenge. Increasingly, Cheryl discovers ways to use it, to insist the diagnosis become a kind of ally to her in composing a new story for herself. It can be the way for her to see things differently for herself, a way for her to rewrite the awful things of the past. Now, when she thinks of the "craziness" in those days leading up to *diagnosis* she can say to herself: "It was illness. My *body* was ill. I was ill. My thinking got "dis ordered." It wasn't my fault." "I know I've lost friends over it," she says. But now, Cheryl can even rethink that to herself. She can say:

> It's them! *They* weren't able to take me with what the diagnosis says about me. But Ken (husband) and my mom and the people that really count are still with me. They didn't split. They could see the sickness as sickness even when I couldn't. And, they hung in with me. They could separate what the diagnosis names (illness) from *me* and who I was, and they're pulling for me. They really love me and that makes me think that I can love me too.

And so, Cheryl adds benevolence to her own story. She is restructuring herself in self-evident ways, ways that use the diagnosis as an instrument in her own behalf. That *she* is doing it at all is, to some extent, what inspires her. Perhaps, somewhat like striping layers of old varnish away to discover the hidden wood-grains beneath, so too Cheryl refashions a "new" emergence of "self." She accepts that the world has changed for her. Could it ever be the same? After diagnosis it's been a learning to live all over again, like being in "terra incognito" and coming to navigate it all through a whole different way of being. She might notice things she never before took note of, like the "Hat Lady" downtown, and the guy in his old ragged coat pushing a twisted Safeway cart piled high with "junk." Now she sees them as people — those who had to her been invisible before are now visible — like herself.

Because of diagnosis Cheryl has gained new comprehensibility about herself. She sees the "knots" of her illness at the surface, within her control. Now if she thinks people might be pointing or whispering about her, she can say to herself: "It's just those weird thoughts again. Cut it out!" and, she can just get on with it. She can filter her view of the situation through the diagnosis and carry on in designing *a visi*ble self.

A different way of knowing my body.

That Cheryl is accommodating to a change of world shows in her sense of a new relationship with her body. For her, the diagnosis has created a different kind of focus on her body. She perceives it differently and she attends to it in a different way than she did before the diagnosis. Cheryl has drawn two portraits to depict her experience of body before and after diagnosis. Her portrayal "before diagnosis" shows two images reflecting a changing sense of corporeality as the illness progresses (see figure Cheryl):

> *The first image is me before I knew I was sick. It's me before I was experiencing real problems. Happy go lucky! I always made sure I had make-up on and, my hair was long and I felt good. But I had, one time, met a girl that was in a gang and I thought, "don't let them get me." And then (shown in the second before image) when things started going downhill for me I thought the gang was after me. And so there are thieves that are terrifying me, and horror. It was horrible! There was a real horror about it. And the thing is that I couldn't escape it. That was the feeling; that I was trapped. That's when I got really thin and my hair was*

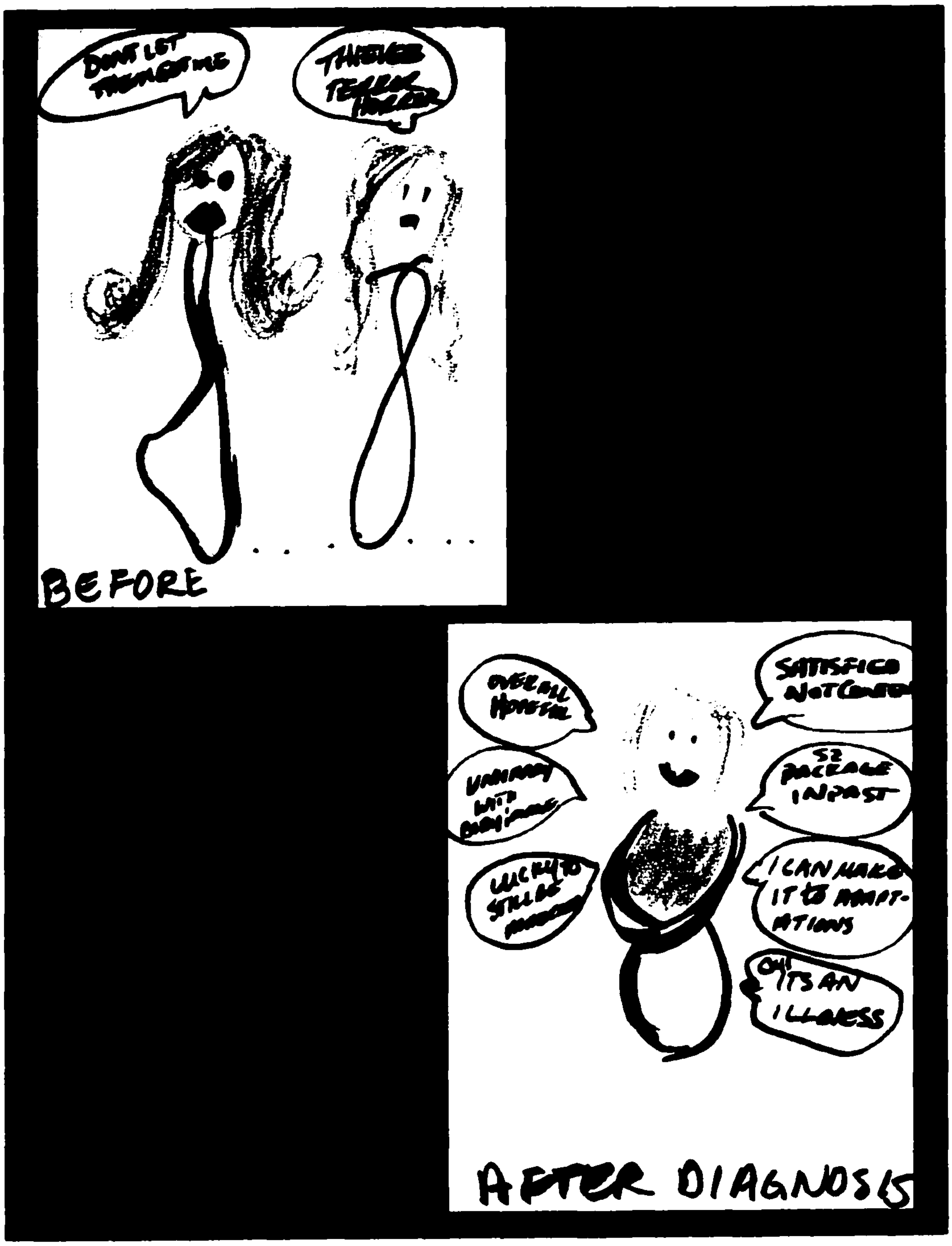


figure Cheryl

> *falling out and I was scared most of the time. And I thought the police were following me and, with that was the idea that the gang would overtake me. . . . So, the seed of that thinking was started well before the wedding.*

In the second picture Cheryl shows how she perceives her self after diagnosis:

> *I try to think of light! And that's the central yellow area. I'm a little rounder. And my hair is short and my arms are relaxed. They're just kind of waiting for my future to happen. That's the blue piece. Overall I'm hopeful. I'm not a size 8 anymore. Part of it is the medication. I'm lucky to still be married. I think, "Oh it's an illness just like any other illness." "I can make it with adaptations." And I have a "schizophrenia package" for the past. I'm satisfied though not content. I'm still searching for something, ultimately for a life free of Schizophrenia. I'm not waiting for a cure but I'm hoping there's one around the corner.*

As long as we are healthy, we have little reason to think about our body other than to tend to it in our daily ministrations. This is why Sartre speaks of the body as "passed-over-in-silence" (cited in Van Manen, 1994, p. 3). But, upon diagnosis, as in Cheryl's depictions, the relation with the body changes. Almost her entire story of diagnosis is woven about her body. We see the wasting, disappearing body "before" and, a center of brilliant yellow light in the after image. After diagnosis Cheryl shows her "*self*" lit-up as it were, visible and emanating from the inside out.

That her sense of "corporeality" becomes heightened is made evident through Cheryl's *before* and *after* imaging. But, we see also, that the diagnosis has given her an instinctive knowing that her body and her mind are one. It doesn't dawn on her to separate them. She just signifies the mind as present to her through her body and she scripts her story as emanating from her body. It is as though she can no more separate her mind from her body than her body from her *self* or, her self from her story. Hers is not a body from which a mind becomes lost. It is clearly, a "mind-body" loss. Could it ever be possible that one would lose one's mind?

To consider what it is to lose one's mind, one would have to first start with: What *is* the mind? The question is somehow baffling, though "we" may talk much in ways that would suggest we know just what we are talking about when talking about the mind. Consciousness, self-awareness, sentience! What comprises the mind? Behaviorists would say that thought and mental events are only epi-phenomena of particular patterns and neuronal activity. Idealists believe in "pure thought" without any associated physical world. Dualists believe in a mental and physical realm. They see an interaction of mind and body as mind/body. Solipsists believe that "only I and my experiences exist. We can know nothing with absolute certainty beyond our own mind" (web on altavista.digital.com under Descartes). Others believe in the faith of God and the strength of God to be the consciousness.

"Cogito ergo sum. I think, therefore I am." Descartes saw a mental and physical realm with no interaction between the mind and the body. He deemed God the keeper of the realms. It has become the common way for many of us to explain our world. But, the

"Decade of the Brain" has yielded increased knowledge of neuro-biology and neuro-physiology and the modes of message transmission in the brain. Still, "I" can only lamely theorize about the mind. I can say: "The mind or consciousness is evidenced though the body." I can say: "We act and behave as our mind allows, through previous knowledge and learning." Others, in more eloquent fashion, advance thoughts on the mind as follows:

> What is mind but motion in the intellectual sphere? (Oscar Wilde in Gilbert, 1891)
>
> We live in the mind, in ideas, in fragments. We no longer drink in the wild outer music of the streets—we remember only. (Miller, 1963, pg. 10)
>
> The human head is bigger than the globe. It conceives itself as containing more. It can think and rethink itself and ourselves from any desired point outside the gravitational pull of the earth. It starts by writing one thing and later reads itself as something else. The human head is monstrous. (Grass, 1967, pg. 51)

There would seem no question that we do physically exist, as our bodies present the vestiges of a physical existence. However, it is conceivable that I could construct this evidence to be only in my mind? But, then, that is the thing! In all of this I could not conceive of one without conceding the existence of other. And further, I must concede the unique nature of the mind that must use itself to conceive of itself. And so I return to that question which prompted this bit of thoughtfulness on *the mind* and ask: "Is it ever correct (in the literal sense at least) to say that I could lose my mind? In saying this do I say more than, "I have lost my brain's faculty of thinking and reasoning and applying knowledge so that I have become less mind-full?" Is that, then, what *diagnosis* presumes to judge?

I am my mind and I have a mind just as I am a body and I have a body and I question, "could I have one without the other?" But of course, Cheryl doesn't really fuss about all that. She is simply attuned to a fact that the diagnosis stands her in a different relationship with her body and, with her world. That is what she puts to picture, a picture in which she tells us she knows that if the mind "breaks down" so does her body. She shows this by drawing a less vivacious "body" as she becomes ill. She tells us: "I was really thin and my hair was falling out." Without question, she tells us that she uses her body to see her body, and with her body she "sees" her mind and vice versa. That is truly the marvel of the body. It is the very uniqueness of the body as a "thing" of the world that prompted Merleau Ponty (1962) to remark that of the things in the world one's body is a thing rather unlike any other thing in the world. It puts thought on other things of the world that might breakdown. Somehow "I" know they can be more easily restored than if the things of my body break down. And, perhaps it is precisely this, which makes this whole notion of *diagnosis* so consequential?

"Before I knew what my illness was it was impossible!"

Cheryl knows that the diagnosis did for a time take her hope but it also, in a different way, gave her hope. Before *it* life had become unlivable, a maelstrom of dread and confusion. There was no possibility for reasonable life. The diagnosis signaled a change of life for Cheryl, yes, but it was the *only* life possible to her. Diagnosis colored a different landscape whereby Cheryl could be visible. Making visible is making possible what was impossible, "making reasonable," "making undisturbed!" Day-to-day living can now be envisioned differently. As livable!

Cheryl doesn't assume a lot of things any more. She feels it is the diagnosis that has taken that freedom away. It tells her things about herself that made her carefree lifestyle a thing of the past. Now, everything is "either climbing a mountain or modifying the conditions in order to make them happen." She knows what the diagnosis tells her; that she must somehow adapt the "things" to her or, she must adapt to the things in order to manage them. Everything becomes a conscious and deliberate decision, made in light of what the diagnosis says. But still, Cheryl is grateful:

> *That whole message of, "I can make it" has come back. I really want to go back to my Studies. I didn't do well before when university was just tremendous pressure to succeed, for my family. I didn't do anything well at all. It [the stress] immobilized me. And so now it's different. When I go to classes now I don't feel that ominous force in my life. I really want to do something. Before I knew what my illness was it was impossible. In my thinking I'm a lot more appreciative of things now. I take joy in little things. And I try to appreciate what I do have rather than what I don't have. And I guess I'm still trying to strive for what I want.*

The dreams and plans imagined have needed revising. Going back to school means asking questions of herself, considering all things in light of the diagnosis. "I have to be careful of my stress level . . . so I probably can't take a full course load." It is the knowledge given by the diagnosis that has done this. As a couple Cheryl and her husband are both affected by the diagnosis. They sense a lost freedom to do the many of the things they had once fancied doing. Even thoughts of having children must to be carefully debated in the light of the diagnosis: "Do I have enough energy? Will the children be affected?" And so on! They cannot simply give in to the longings. In most things now, there are the "doubts" and "ifs." It's not a matter of wanting and, just "going for it." As long as there is the illness there's too much at stake and the diagnosis says the illness is enduring. Cheryl longs for a cure:

> *A cure would mean freedom. It would mean that I would be able to be more carefree. I would definitely have children. And it would clear up a lot of "ifs" in my life; ifs about being in school, and having a career that is low stress enough that I can handle it, but not so mundane that it's boring. If it's cured then everything opens up.*

Concluding Remarks

As one takes overview of Cheryl's story, the dominant theme that crystallizes is that of "visibility." At the outset we see a steady effacement of Cheryl. As her reality erodes, she quite literally seems to "waste" away. With her world denied, she seems to lose a context for being and becomes quite "invisible." Cheryl's initial response to *diagnosis* is to feel further deprived of all means by which to reveal herself. Diagnosis seems to render a "verdict," one that absolutely denies the "objects" of *her* reality. Cheryl is dumbfounded! She is now on the "after side" of diagnosis, and initially it truly is seen to devastate her. That given her by diagnosis (the knowledge) shatters her dreams of young married life as it "should've" been. Cheryl seems reduced to mere existence, left idling in a state of meaningless meaning, at least for a time. But, we see too, the same diagnosis, which steals her hope and holds her chronically captive, in the end, serves Cheryl. After a time she begins to emerge from the "box" where she felt placed by diagnosis. We see her create renewed visibility for herself, establish an order from the "dis-order" given identity by diagnosis. Now, Cheryl glows from within. She gives us visual of this in her "after" drawing, placing "light" in her "center." As in the movie "Shine," Cheryl too seems to now shine. Perhaps like David Helfgott, she takes stage; advances to that "grand piano" to give concert. At her own keyboard she now "plays" in ways that express her being.

CHAPTER SIX

Diagnosis As The Experience Of The (Destructive) Gift Of Difference

It could be said that the stories of mythology are stories riddled with paradox. We note such paradox, for example, in the well known Greek myth "King Midas." The gift of the "golden touch" is at the cost of all means to food and water (everything turns to gold). Then, in Norse myth we see Oden, bartered out of one of his eyes as cost for drink at the "well of wisdom." And, in Roman myth we see the beautiful princess Psyche, "gifted" with Cupid's love, but only on condition of his anonymity from her. Indeed, Psyche is left to wander desolately after she steals a forbidden look upon "his" face. In each example, there is notable effacement of "gift." There is some semblance of this same state of affairs in Steven's story, into which we now venture. The pattern set in the prior two chapters is maintained. Part I of the text is committed to Steven's accounting of *diagnosis*, what precipitated it and how it impacted on him in his world. In Part II we enter into deeper reflection on his story, to explore varied realms associated with his experience, and, impart interpretation to his story of what it is "to be diagnosed."

Part I: Leading to my Diagnosis

Essentially, Steven believes he is the same person now as he always was but, looking back, the diagnosis gives him a view of himself that is different from how he viewed himself before. In some ways it actually presents him with an understanding of things about himself that he'd been dealing with his whole life. He'd always known he was a little bit different but he never really knew why. Now, through the scope of diagnosis he "sees it." He understands the things that he did as having to do with his condition. "When you're manic you think faster," he says. "And when you think faster you process more. So, I was just always processing more information quicker." That rate of processing, though, influenced the things Steven chose to do and the way he did them. Now, because of the diagnosis, those somewhat outrageous things that he did back then make perfect sense. Even the whole recent business catastrophe makes perfect sense. With newfound wisdom Steven says, "I should've never started that business at that time; nobody should have." But, he did start it and the diagnosis makes it clearer to him the reason for some of the drive he felt to do it. And, amazingly he very nearly made it all work, perhaps, because of his "difference." Now, Steven knows and he values that "he is different" not in the sense that we are each different one from another. But now, through the diagnosis he *sees* that **he** was, and is different and he knows where to locate that difference that he sees about himself.

But, it wasn't like Steven was looking back at his life and going, "oh my God I wish I didn't have this." It was more like, "so what's the big deal here." The diagnosis simply supplied a reason to why he was always so full of energy, so full of creative ideas and, perhaps even "a little bit not quite grasping reality sometimes." And, Steven didn't regard these as negative things. In fact he appreciated all of that as good, maybe even wonderful things about himself. To him the diagnosis was saying he had "a near genius type of condition." To Steven, what he had was what made him special and he will always see it as a "gift":

> *I have the energy that most people can only dream of. I'm 99% of the time a very likeable, outgoing and very creative guy.*

Steven becomes energized just talking about his "gift." Whimsically, he glances up and says: "I don't know if you have ever been lucky enough to have mania?" Without waiting for a response he carries right on:

> *It's a wonderful, wonderful place. It's obviously not good for you as a person; I mean, especially in our society. In days gone by, we probably would have been fine. But, it's a feeling of absolute contentment. Incredible energy! I mean, you can do anything, anytime, anywhere. Peace of mind! Everything just seems to kind of be in its right space. And, maybe you have no money, no house, no job, no family, no friends, no food, -- and still you feel incredible. 'Cause, none of that matters. It's like the ultimate high.*

Steven wants to make clear that the diagnosis actually originates from himself. *He* gave first actuality to it. He emphasizes that the condition has not been induced by drug, or virus, or anything else. It comes from his being and therefore, in effect, so does the diagnosis. It doesn't come from the doctor. It is only, pronounced by the doctor. It comes from him, Steven. Time and events have led him to awareness of his diagnosis and perhaps the doctor has played a role in this, he admits. But, the doctor only articulated what was already there; gave a medical identity to what was already in place in his being. The bottom line for Steven is that the diagnosis, in fact, names a personal gift that he possesses. True, had the gift not, in some respects become an "impairment" the medical identity would not have been realized. But, the diagnosis attests to the gift, as well as to the impairment and to the point of impairment the gift, he insists, has always been beneficial to most aspects of his life.

"When things started happening that made it an impairment."

Many oil businesses of that time were in turmoil and Steven's was no exception. He frantically went into overdrive trying to save his business. So much of his life was tied up in that company. Now, he could see it going down. Desperately he wondered how he could spare his employees, how he could protect his family from what was about to happen. Then, major marital strife spilled into the mix and, Steven "just kind of lost contact with everything":

> *I guess if I looked at it, my mind just shut down. . . . It just refused to deal with reality. . . . Because I wouldn't quit my mind quit. . . . And it just literally went into la-la-land. I mean, I just lost all sense of reality. . . . Who I was? . . . I just started dreaming about what life would be like on Mars. . . . I mean, your mind*

> *just doesn't come down to earth because there's nothing here on earth that you can deal with.*

When Steven was admitted to hospital he recounts, "the doctor looked at me for eight seconds and said 'manic depressive'." The term meant nothing to Steven at the time. It was only after discharge, when he started reading about it, that he began to relate to it and particularly to the notion of mania:

> *I could really understand because of the way other people would talk about having their mania, and the creativity, and the excitement, and the feeling of euphoria, and the ideas in particular, and the energy.*

Now, Steven believes that if he went to some parts of Africa he might be considered a "Beddash or, 'one that communicates with God'." In ancient tribes he may even be regarded as a spiritual leader or, healer. "We've always had these people throughout history," he says. "They've just gone by different names." But, as Steven continues, his point is made abundantly clear: the name (or the title) carried is what makes all the difference. "If you're a Beddash," he says, "then you get the best pieces of meat and the choicest women. If you're a "nutcase" (declared by diagnosis) you get thrown into a psyche ward and locked away."

"It makes you feel sick."

While Steven terms his *condition* a gift, to him, the diagnosis represents *illness* (per sickness). To be diagnosed bespeaks illness where before he wasn't ill. "It's a very large step," he says, "to go from one day being gifted to the next day being mentally ill":

> *I don't think the doctor ever did explain the diagnosis to me. . . . He told me that I had the diagnosis and he told me I'd have to take these pills for the rest of my life. . . . It took me 15 years before I could even accept the treatment. . . . Before that, I would disagree completely with the treatment. . . . I didn't want to be "treated." I didn't think that my gift needed treatment. . . . What it needed was management. There's a whole difference! Because they can't cure me. . . . there's never been a cure. . . . All you do is you learn to live with it. . . . And you learn to manage it.*

Because the diagnosis represents an "illness" and because the illness cannot be "cured" Steven sees that he will "always have the diagnosis." Knowing this has changed the way he *is* to himself and, the way he feels about himself. In some sense it has changed his entire attitude to life because it entered the notion of sickness into his concept of self and to his life, that had not been there before. The diagnosis even provides him an excuse for things if he chooses to use it that way. If he chose not to do something, for example, not to get out of bed some morning, well, he could always just say to himself: "it's my illness." But, Steven knows if he didn't have the "diagnosed illness" then he would have to admit to himself: "I'm just lazy." The diagnosis is declaration of illness; a built-in excuse for whatever wants excusing. And so, in that sense the diagnosis counters wellness. It is a resistance to wellness, a resistance that Steven must continually reckon with if he is to ably function.

Steven believes the diagnosis has imposed on him other disabling effects. The bleakest of these are: "to never again be defined by *who* you are but instead by *what* you have, to never again be allowed to function as you functioned before the diagnosis, and, to have removed from you the opportunity to be treated like your former person." With a degree of rancor, Steven insists that the diagnosis does little to serve the individual. He adds, "the diagnosis does serve the doctor by instituting a health history." So, the next time Steven gets admitted to hospital the doctor can simply "pick up this form and go, 'oh, manic depressive. Ok, lithium, that'll work!' And, he knows how to treat me." And, maybe this does make it easier for the doctor to decide on treatment. But, he adds:

> *At no point in any of the stays that I've ever had, have they ever asked me how I got there. "Why are you here?" Because once I got given that diagnosis and that label all they do is treat that label. . . . They don't treat me. They don't find out why I got in there, or what happened, or what were the circumstances. They just know that I am "bipolar.". . . "Ah, --Lithium! You'll be fine."*

As Steven sees it, the diagnosis has done little to help him value his gift or, to manage his situation. It has merely designated him a "case" to be treated. One is struck by the paradox in Steven's story that bespeaks of a *diagnosis* that renders him different yet allocates him the same, at the same time.

Part II: Looking More Deeply into Steven's Story

In Steven's story is opportunity to come to yet a fuller understanding of the experience of diagnosis (CMI). The forthcoming discussion will be approached in the following manner. First, "diagnosis" will be viewed as enabling recognition of *difference*. Then, *diagnosis* as confirmation of "gift" will be considered. A third theme surfaces in *diagnosis* as assignment to status of *"chronic mentally ill."* The chapter closes with a segment on the experience of being "dis abled" by diagnosis. Discussion in each of these areas draws primarily on Steven's personal recollections. But, the voice of other participants is also entered, so that certain aspects of the experience might be accentuated.

Diagnosis as confirmation of Gift.

It is unusual to think that one would very often wish to stand out as, "different." After all, do we not spend much of our time and energy trying to shape ourselves in ways that conform to *the* norm? Each time I observe my young teenager glob on the hair gel, taking great pains to plaster down each and every hair on his head, I see his effort to fit with the image of how he sees *the* others: the image of what he at all cost wants to be. At this stage of his life he desires to be "one of them"; certainly not to have himself be viewed as *different*. Right now, one uncooperative strand of hair is the enemy that would stand against him and set him apart from "the" group.

But, to be set to the periphery does seem a concern for more that the teen age group. We see this played out in all age groups, enticed as "we" are in our commercialized world where, more often than not, our *wants* are seduced into the realm of what *we need*. Capitalism aims at the so called "needs" of the norm, with retailing, merchandising and marketing all operating on a premise of sameness. But, on second reflection, is the appeal really to "sameness?" Yes, our notions of wanting, to be "cool," to be "in-the-know," to be somebody, are teased as the standards of "the norm." But isn't it the same "standard-bearers" that also propagate the subtle dictums of social distinctiveness? It is as though they say: "It is ok (if not enviable) to be different but, *not too different*." Isn't that the dilemma we're left with: "*How different* makes for too much difference?" In Steven's story we see a sense of his being held in this kind of quandary?

Delving into this theme in Steven's experience of diagnosis serves to explore the notion of belonging. One might ask: "Is the experience of *belonging* ever solely uni-directional?" Doesn't the word *longing* itself imply an inherent pull to the two extremes of wanting human distinction while at the same time wanting sameness? In this regard, we are enlightened by Klein's (1971) etymology of the word *sameness*. We note derivative words such as *same-ly, same-li-ness* and *same-ness*, denoting *likeness, resemblance* and *similarity*. The German word zusammen, meaning "together," in the sense of "together with," seems to factor in that which introduces *belonging* to *sameness*. And, the Old Indian word samah, meaning "even, level, similar, equal, the same, identical" (p. 653) adds a competitive tone to *sameness*. Through this we can see in the word belonging a strong suggestion of connected-ness; perhaps at core a sense of being-with the rest of humanity.

"Be" and "longing"; two element words locked together as one "in" the same word; not in the manner of being one and the same thing, but in the manner of two disparities being held together within a single notion. Unto itself, *to be* is the singular notion of being complete as a unique entity, with and of oneself. But in actuality can this ever be so? Is one's sense of sufficiency ever complete in the absence of communal fusion? We see this undertone in Steven's story?

Through the notion of *be-longing* we can peer into varied conceptions of what it is *to be* in the first place and, in so doing we are brought ever closer to Steven's experience of diagnosis. It would be simple to say that *to be* is just to exist. But, to say that something exists does not say much about its real being. To say something about *that* is to say something of the nature of what it is for this or that to exist. It is not enough to ground a response in traditional causal explanations of what it is to exist. We could limit explanation to: a *being* is a collection of approximately 100,000 genes known to make up human DNA (Http://www.orn/.gov/TechResources/Human_Genome/about.html). Now, there might be some practical benefit to knowing about *being* in that way. Indeed, "Cellmark Diagnostics," a branch of Forensic Sciences, is premised on being able to identify one person unequivocally against all others. But, even if "I" could decode the different genomic recipes (the full complement of genetic material in a human cell) that account for the fundamental differences of the world's five and a half billion people would I really know the man next door. On what basis would I say he was different from the man that was Gandhi? Would I know one man's creativity, from another man's charm, from another's intelligence and so on to each man's authentic nature? Perhaps in a material sense I might be able to respond. But again, in this do I not fall short of knowing beyond the "what" of *being*?

Heidegger's way in *Being and Time* reaches for the centrality of human individuals through the study of *Dasein,* specifically, *Dasein's way of being.* Dasein, Heidegger's designated term for "being-there" is actually undercut by an even more basic interest in "the way of being," that is, the special kind of being that human being is (Dreyfus, 1991, p. 14).

And what has all this to do with our grasp of Steven's experience of *diagnosis*? Let us look back to our thoughts on *be-longing.* What if we question whether Steven has a particular longing? And what if we look to the nature of what Steven's particular longing might be? Do we come to full focus on his as an issue of connected-ness or, do we see predominantly his preoccupation with uniqueness? Let us examine more closely elements of Steven's experience which take us in both these directions.

That we are all different one from another is, in a shallow sense, easy to recognize. But to apprehend this in any kind of a soulful way is not so easy. Addressing a school forum Bishop Henry (1999) heightens appreciation of *individual uniqueness* by elaborating on the astounding odds that we exist at all:

> Think about it not only as the odds of *that* sperm and *that* egg from all sperms and eggs coming together. But, back things up a little from there. What are the odds that of all the people in the world your mother and dad knew, and all the moments that occurred in each of their lives, that they just happened to even meet? Then, think to their mother and dad, and that meeting. And think of their parents and that meeting, and so on, and so on. With that in mind, don't you think that the fact that you happened at all is quite incredible? And not only that; you weren't a copy of anything! You exist and you are an original. There is none other like you.

A touch of *infinity* overcomes me when I contemplate this anecdote. Circumstance! Chance encounters! I'm not quite able to track the coordinates in time, generation upon generation, thousands and billions of years to the beginning of time. I'm placed in exceeding reflectivity about this whole notion of how I came to be and my resultant uniqueness. At the same time there is a thorough connected-ness to it all. I am virtually touched in an intimate way by each generation, carrying an insignia of sorts, reformulated from one age to the next throughout time, eventually culminating in me. I come "to be" thoroughly pre-scripted by the ages. In an utterly singular way? Maybe! Somehow, in the final analysis I just can't take in my own awesome "originality" without also seeing the flip side, that is, realizing myself as a product of the *connected-ness* to all prior ages. So I come full circle knowing, once again, that I am the same but *different.*

In these reflective junctures it often seems easier for me to apprehend my own sameness with, than difference from, the rest of humanity. I am, after all, of the human species. It's when I dwell on what makes for my ultimate difference from *other* that I spin? In the most fundamental sense, I grind on what is the last word on my own different-ness? Basically, is this also Steven's question; made the more poignant by *diagnosis?*

The diagnosis does at one level explain a difference to him about himself that he had not seen before. But, while it locates something of his being that differs from the norm, doesn't it at the same time "group" him? Doesn't it categorize him; classify him? This thought bears further exploration.

We are stimulated in our reflections on the matter of ultimate difference by the selected writings of Jan Patocka (Derrida, 1995). In these, the issue is approached from the stance that one must "take into account the uniqueness and irreplaceable *singularity of the self* as the means by which . . . existence excludes every possible substitution . . . to have the experience of one's absolute singularity and apprehend one's own death. . . . Death is very much that which nobody else can undergo or confront in my place. My irreplaceability is therefore conferred, delivered, 'given' one can say, by death" (Derrida, 1995, p. 41). We see here, that which touches to the core of individual *life,* that which signals *death,* as the utmost point of no exchange between persons. Patocka brings the issue of individual difference down to eventual death! Only in dying, then, is one fundamentally differentiated from another. And only there is one distinct, in that one must do one's own dying. One cannot not respond to one's own death and none other can substitute theirs for someone else's. Of course, one may choose to sacrifice one's own life and die for another, to spare one's child, for example, but, as in Heidegger's *Being and Time*: "No one can take the Other's dying away from him" (Keiner kann dem Anderen sein Sterben abnehmen in Derrida, 1995, p. 42). Ultimately I must take on my own dying!

To "take on one's own dying" does seem the *hardest* of the distinctions between individuals, perhaps more stringent than what we are given in Steven's story. Nonetheless, taken to its extreme, for me to say I am different is to declare my own unique different-ness. To expound this is to specify that which characterizes my uniqueness, that which differentiates *me* from *other*. Different-ness in the sense of uniqueness seems of consequence to Steven and is largely what preoccupies him in the face of his diagnosis. It is a prime tension for him, voiced in his declaration of "gift." Isn't it there that he is saying the diagnosis has located his gift; that he tells us the diagnosis really says he has: "a near genius type of condition?" Do we not hear it, too, in his resistance to *diagnosis* which he treats with cavalier casualness; that it would pass-over *him?*

There is, however, a double-edge to all this for Steven. Yes, diagnosis *has* located for him the gift. Yes, it helps him recognize his "near genius." But the other side is that by virtue of its medical function, diagnosis has also categorized him. In that sense he experiences being homogenized. Diagnosis puts him in a place that makes him the same as all "those" others. It is a place where he is in no way remarkable, except that in it he stands together with those who are ill, those who might be feared or pitied. In that way, he is just like all those who are symptomatically *like* him. In that sense, *diagnosis,* doesn't differentiate. There, *diagnosis* effects a loss of distinction. *That* is the message we hear when Irene states: "When they name the mental illness it denies you a being."

Likewise, Susan declares it in *her* experience of diagnosis when she says: "It's becoming a statement."

But, Steven defies this aspect of diagnosis. He will not abandon the *person* that he is. The diagnosis would shroud his being, make him merely a collection of "those symptoms!" He shouts back: "No! There is more to me! The diagnosis itself attests to *more*. Look here! See! It points also to another side of me; to a wonderful *gift*? See it here! This is me too; this gifted, and talented, and energetic, and likeable person!" That is what the diagnosis also says, doesn't it? Steven struggles to hang on to how he must see diagnosis; in those ways. Onlookers might question whether it is only the diagnosis that has cast him or was it behaviors as well? But there is certainty in Steven's expression. To him, the diagnosis has done the major scripting. Surely, with the cost of such scripting there must be some dividend, he thinks. It cannot only be that diagnosis names a dreadful disorder. There has to be a claw-back. He hangs on to what it tells him about his significance; his enviable quality; that something that has been commonly over-looked; that confirmation of something that distinguishes him for who he is. That *gift*!

Seeing "it" as gift.

Steven resists the side of diagnosis that would tell him to lose himself and not see his gift. He sees *his gift* very clearly now because of diagnosis. The diagnosis, like a divine blessing, confirms it. In a sense it tells him that he is "blessed," that he has always had *the gift*. Now he can recognize it, choose to own it, celebrate it. Above all he fights to keep his *gift* from being disqualified, from disappearing. *Diagnosis* might also do that; declare it all sickness, treat his gift; dissolve his talent in a haze of medicines. So, in that sense, diagnosis is enemy. In him is evoked a "love-hate" dynamic that says: "Don't treat my gift. Don't "pathologize" it! Don't make *it crazy*!"

At the heart of every diagnosis are the multiple factors, the behaviors, thoughts and feelings that act as diagnostic criteria and enable the clinician to determine: "mental illness." Are the extremes in any of these areas, though, sufficient cause to deduce "disorder?" If it were as simple as that wouldn't all excessive displays be considered sickness? Wouldn't every skydiver, car racer, speed skater, mountain climber, tightrope walker, stunt artist, be mentally ill? Wouldn't Tom Thompson, Jim Carey, Ted Turner, Leonardo DaVinci, Wolfgang Amadeus Mozart, Edgar Allan Poe, Pablo Picasso, and many more also fall into that category? But wouldn't it be a travesty to label all these inordinate personalities disordered? And, wouldn't it be indiscriminate to judge all ubiquitous behaviors *illness*? Isn't it the essential task of the diagnostician to decide when, for example, insomnia, fears, anxiety, poor appetite, loss of concentration, disinterest, loss of energy, and so on, are the result of illness and when they are simply the result of the vicissitudes of life? To say otherwise would be to make us all crazy--"when we are just human" (Kutchins & Kirk, 1997, p. 252).

And this, it would appear, is a contentious area for Steven. To him, even at the time he was originally diagnosed, what wasn't taken into account was that he was reacting normally to an extreme situation in his life. His company was going under, taking with it his "life," his "reality" Steven was losing everything, all that he owned;

money, home, marriage, children, friends, status. It was all slipping away. Everything by which he was identified! Everything that marked him! That's what made him *him,* to him. But nobody asked him anything about any of that; nothing at all. They simply said, *bipolar illness*! "Eight seconds" later it had all been said. Since then it has always been that way. If he has a flare-up that requires treatment, nobody asks anything about him. Not, "What was going on?" "When did it start?" "What were the events in life at the time?" Just, "Bipolar! Ok! Lithium! You'll be fine." But diagnosis has put him in touch with something he hadn't stopped to consider before. Perhaps all along it was too close at hand to be recognized. Now, it is evident. Diagnosis has told him about himself; that he has a gift. And so now Steven has a better sense of who he is inside. Now, he is internally defined. The gift is the one thing he feels he must hang on to. He cannot give all of himself away to *diagnosis*. The gift is what he decides will give him definition. How can he let that dissolve into illness; have it treated away from him?

To what gift does Steven refer when he talks of that with which diagnosis put him in touch with? Does he mean to say something has descended upon him at the time he was told the diagnosis? Does he refer to something he has received, as with acquiring a present? What is the significance of the gift that makes it so treasured to Steven? We might explore this matter by first distinguishing the difference between a present and a gift. Langeveld tells the story of a little girl who gives her baby brother a tiny feather:

> The four-year old comes to her mother, who is busy with the newborn baby, and has a "treasure" in her hand. It is a tiny feather of a sparrow. This is for little brother, because he is still so small. . . . Now that is a true gift! (in Van Manen, 1990, p. 115)

The anecdote shows a gift from the heart, somewhat different from a present, which may be given from a sense of obligation, debt, or to nurture friendship. A gift is more than a thing from the store; "whoever gives a gift (and not just a mere present) gives himself or herself. He or she is the thing" (Van Manen, 1990, p. 115). If we apply this notion to Steven's account, do we not see something deeply powerful in his experience of diagnosis? It would seem diagnosis tells him of a gift that cannot be bought. The gift is invaluable, an intrinsically irreplaceable personal asset. It takes its shape in Steven's awareness through the experience of diagnosis. It is not the gift of friendship or love, fame, fortune, longevity, power (though all those things could touch on it) but, "the gift" is of an amazing psychic energy, something which swells from deep inside him to activate his thoughts and animate his being. That is the treasure.

And so, the gift Steven speaks of is not of the ultimate kind, that is, the "gift of death" alluded to by Derrida (1995) which fulfills our core responsibility to life. Steven's gift is part and parcel of who he is as a person, experiencing life. His gift is *"like the ultimate high"* to living. The diagnosis is what brought that to him in the sense that he was unaware of its existence before. It didn't accent his life in that he took no note of it. He took his gift for-granted, was even indifferent to it. Even as the diagnosis announced it to him he reacts with: "So what's the big deal here?" It (the diagnosis) is just naming something I've always had. But in time Steven comes to see: "it is a big deal," made the more so because the gift is set in contrast to the other unwanted things also intoned to him by the diagnosis. In that sense, like some cruel joke, doesn't the diagnosis pose the gift before him, then, snatch it away? It makes evident the gift but in an acrid way. At least, to Steven, that seems the intimate experience of it.

In the social sense, too, Steven feels denied in that his *gift* is made invisible to the eyes of others. What is actually *him* in the attributes of *the gift* he possesses (his actual identity) is removed by a society that imputes to him a *characterization of the diagnosis; a virtual identity*. As such he becomes a person "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p 2). In that sense, isn't Steven dispossessed by a diagnosis that cuts both ways? He must live as benefactor of a gift that is eternally kept hidden from view by a name which occludes it. But perhaps, after all, that is the true nature of "a gift that is not present" per Langeveld and Patocka in the following:

> For one might say that a gift that could be recognized as such in the light of day a gift destined for recognition, would immediately annul itself. The gift is the secret itself, if the secret *itself* can be told. Secrecy is the last word of the gift which is the last word of the secret. (Derrida, 1995, p. 31)

It may be this paradox, the realization of what is secret, that sets Steven in such conflict. He feels called to respond but to which acclamation of diagnosis? On the one hand diagnosis would render him entirely sick, prescribe and treat him. It must be so if the disorder is to be managed. On the other hand, there is the gift. How can compliance with treatment *not* affect expression of the gift? He feels faced with this impossible duality; torn between allegiance to adjoining aspects of himself. To honor the one aspect is to loose the other. To be responsive to diagnosis is to be response-less to his gift. To be interested in treatment is to be disinterested in his treasure; the seat of his being. Steven's logic, here, in some manner follows that cited in Derrida (1995): "Every other (one) is every (bit) other [tout autre est tout autre], every one else is completely or wholly other" (p. 68). Derrida furthers understanding of this with examples:

> By preferring my work, simply by giving it my time and attention, by preferring my activity as a citizen or as a professorial and professional philosopher, writing and speaking here in a public language, French in my case, I am perhaps fulfilling my duty. But I am sacrificing and betraying at every moment all my other obligations: my obligations to the other others whom I know or don't know, the billions of my fellows . . . my fellows who are dying of starvation or sickness (p. 69).

Steven waffles in this kind of dual allegiance. "If I am responsible to one thing must I forfeit all other things," he would ask? To which extent can I stay in treatment, take my medication, and also be responsive to my gift? But there is insufferable tension for him in this midline approach. Always he is brought back to: "Which is my first responsibility?" Repeatedly he defiantly abandons medications and chooses his gift. But in this is he not somewhat like the tragic hero, mourning his loss, sacrificing all for the sake of the gift? Again and again he falls back into acute illness. That is the quandary of life for Steven since diagnosis; the *unlikely* place he is left in.

One day gifted the next mentally Ill.

With diagnosis, Steven feels himself suddenly reassigned, as it were. It's as though he "wakes up," coming to find himself in entirely different circumstance; the unlikely place. Rhetorically Steven would say:

> It is "he," the physician who delivers me to this unlikely place of diagnosis. There is dis-symmetry of the gaze he casts upon me, a gaze of disproportion to what I can return to him. Behind his gaze seems a secret, a knowing that remains remote from me. Yet it commands me and speaks adieu to me without really knowing *who I am.*

Derrida (1995) supplies three meanings to the word *adieu*:

> 1. The salutation or benediction given (before all constative language "adieu" can just as well signify "hello," "I can see you," "I see that you are there," I speak to you before telling you anything else— and in certain circumstances in French it happens that one says *adieu* at the moment of meeting rather than separation);
> 2. The salutation or benediction given at the moment of separation, of departure, sometimes forever (this can never in fact be excluded), without any return on this earth, at the moment of death;
> 3. The *a-dieu*, for God or before God and before anything else or any relation to the other, in every other adieu. Every relation to the other would be, before and after anything else, an adieu. (p. 47)

How does this idea of adieu position in Steven's experience? If we take license with Derrida's interpretations, we can glimpse the "first adieu" in the physician's gaze that says to Steven, "I can see you," -- *really* see you to the core of you. The gaze penetrates like a "seeing machine" to eye into varied dimensions of the mind but in its survey, "I" am passed-over. Like the x-ray machine that permeates different densities of anatomy, the gaze determines a knowing that "I" can't reciprocate. Without effort or permission it concludes in an "eight-second diagnosis," pronounced to Steven at the moment of meeting rather than at parting. To Steven the discourse implies the *looker* not fully *looking*, a seeing that doesn't see; if *seeing* is to truly take-in the *other*.

Then, we see the "second adieu" in Steven's experience of diagnosis. The pronouncement, to Steven is not only signification of illness and disorder. There is a note of farewell to it in the way it is said. There is adieu to a life and being as it was; loss of what was familiar and valued, and now consignment to the "unlikely place." The *adieu*, is all the more pronounced because it is declared from a physician's privileged position, metaphorically from a "god-like" position (the third adieu). Is the diagnosis at all tentative, negotiable, provisional? Is there no redemption from this unlikely place of diagnosis?

What does it mean to speak of the unlikely place of diagnosis? Is an unlikely place un-like any other place? Irregular, inconceivable, unspeakable, unthinkable! An unlikely place seems more a feeling than a location. There is unpleasantness to it, a place of little vitality, a place one does not willingly go. If one had choice, would one be drawn to reside in an unlikely place? To Steven, diagnosis is an unlikely place, a place of unhappy significance. It is a place in his words that: "makes you feel sick." Van den Berg (1966) with words paints a picture to help us see what it means to be in a place of sickness, "*the sick bed.* " Here, the father of a family details it this way:

> After a restless and disturbed sleep, I wake up in the morning, not feeling too well . . . I have a headache; . . . notice an uncontrollable urge to vomit and I deem myself so incapable of facing the day that I . . . return to the bed. . . . I turn to the wall, nestle myself in my bed, which guarantees a comparative wellbeing by its warm invitation to passivity, and close my eyes. But I find that I cannot sleep.
>
> Then, slowly, but irrevocably, a change, characteristic of the sickbed, establishes itself. I hear the day begin. From downstairs the sounds of household activities penetrate into the bedroom. The children are called for breakfast. Loud hasty voices are evidence of the fact that their owners have to go to school in a few minutes. A handkerchief has to be found, and a book-bag. Quick young legs run up and down the stairs. How familiar, and at the same time how utterly strange things are; how near and yet how far away they are. What I am hearing is the beginning of my daily existence, with this difference though, that now I have no function in it. In a way I still belong completely to what happens downstairs; I take a share in the noises I hear, but at the same time everything passes me by, everything happens at a great distance. "Is Daddy ill?" a voice calls out; even at this early moment, it has ceased to consider that I can hear it. "Yes, Daddy is ill." A moment later the door opens and they come to say goodbye. . . . Everything about them indicates the normal healthy day, the day of work and play, of street and school. The day "outside". . . a meaning emphasizing my exclusion. . . .
>
> The world has shrunk to the size of my bedroom, or rather my bed. For even if I set foot on the floor it seems as if I am entering a *terra incognita*. Going to the bathroom is an unfriendly, slightly unreal, excursion. With the feeling of coming home I pull the blankets over me. The horizon is narrowed to the edge of my bed. . . .
>
> The horizon in time too is narrowed. The plans of yesterday lose their meaning and their importance; they have hardly any real value. They seem more complicated, more exhausting, more foolish and ambitious than I saw them the day before. All that awaits me becomes tasteless, or even distasteful. The past seems saturated with trivialities. It appears to me that I hardly ever tackled my real tasks. Future and past lose their outlines; I withdraw from both and I live in the confined present . . . which guards me against the things that were and those that will be. Under normal circumstances I live in the future, and in the past as far

> as the future draws upon it to prescribe my duties. Apart from a few special moments I never really live in the present, I never think of it.
>
> Normally I am not aware of my body; it performs its tasks like an instrument. Now that I am ill, I become acutely aware of a bodily existence, which makes itself felt in a general malaise. . . . The body which used to be a condition becomes the sole content of the moment. The present, while always serving the future, and therefore often being an effect of the past, becomes saturated with itself. As a patient I live with a useless body in a disconnected present. (pp. 23-28)

With this story, we are shown some of what it is to be sick. From his place of illness the father is in a sheltered but confined world. He hears from a distance the things he feels removed from and we get a feeling that he would wish to be connected to them but, wishes also to stay protected from involvement in these things. There is much that would call him to the things happening outside the house; his clothes hanging over the chair at the foot of his bed; his hat and his shoes. But these only remind him of his healthy self. These are the call of things that emphasize his confinement to a shrunken space, to a time constricted to the present moment of illness.

This story illustrates what it is like to *feel sick*, but Steven's sickness is of a particular nature. His diagnosis is of mental illness. Like the man in van den Berg's story, Steven has fallen but, in a different sense. He falls to *his* "sick bed" where he "no longer belong(s) to the life which nonetheless is still (his); his street, his road, lies outside the horizon of his existence" (Van den Berg, 1966, p. 35). His diagnosis tells him of a life as it was, and signifies a life as it now has become. Steven too paints a picture for us of his unlikely place of sickness. He presents a pictorial representation (see figure Steven) of himself before diagnosis. It is his depiction of self after diagnosis that gives us particular grasp of his conception of the unlikely place of diagnosis. Steven tells us:

> *The first drawing represents my home, family, hope. Kind of a feeling of belonging and well-being, feeling and being a part of the community. The sun to me is more like the hope. The family is the hope that there will be pleasant days ahead and warmth and sunshine and happiness. That's what I was before diagnosis. I was very happy. It was, "a family, a wife, a nice job, good business, beautiful house." I had every reason to believe that the sun would shine for many years to come.*
>
> The second drawing is a fairly bleak depiction of after diagnosis:
>
> *That's what it (the diagnosis) does. It takes away all the elements of the first picture. It takes away all the sense of belonging to the community, 'cause now, you're different. You're not a part of the community anymore. You're out there somewhere, marginalized. You're stigmatized.*

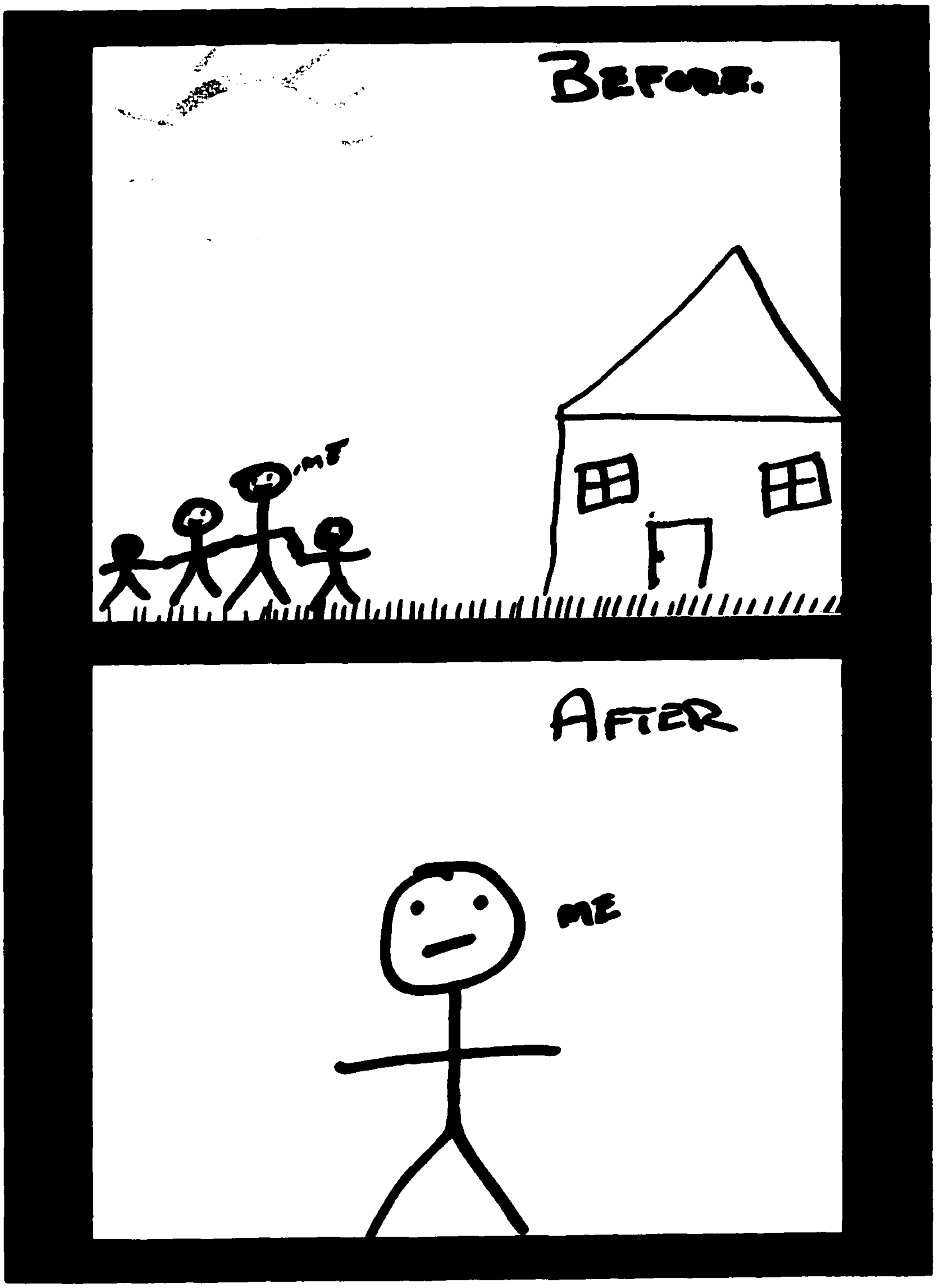


figure Steven

> *After the diagnosis, what I realized is that I could no longer count on the normal supports to be there, available to you as "just a person." All I could count on was me. Before, if I had a problem, if I was sick physically or if I had an accident or something bad happened to me, I could count on my family, friends, the support network to assist in catching me, or helping me, or seeing me through a bad time, and then helping me move on to the next period. I know now, after having too many experiences, that if I falter there is just "me." It's me! It's me alone. Last year because I had an episode and went into the hospital, when I got out I had no money, and I had no friends. And it was just "me."*

There seems a desolation of spirit to Steven's "after" representation. It speaks of a broken life, an experience of being abandoned. It is the diagnosis, that which named the disorder, that relegated him to this unlikely place of isolation. It matters not that treatment and management would contain the disruptive aspects of the disorder. The diagnosis foreshadows the "huggest most black beast of all?" that which casts Steven aside. That is a token of the diagnosis; that which is what is experienced as truly "dis-abling" to him. It is what has dissociated him from his former place in life. To Steven, that one word *bipolar* has done it. With that one word Steven went from "one day gifted to the next mentally ill." And that has made all the difference.

Labeled and disabled.

Once past the acute phase of the illness there is little observable about Steven's appearance that is different, however, much indeed has changed. In fact, at least from the perspective of others, nothing is the same. He feels a watchfulness from those whom he knows *know*. It is a furtive staring, one that keeps him distanced from them. He becomes aware of the other's knowing of him because he notes their glances; experiences their evasiveness. His inclination is more and more to keep "it" secret, to not let the diagnosis be known so that he can be "normal"; be treated ordinary. But it dawns on him that he is preceded by his diagnosis. In some unspoken way it stands out; "like a curse it stains (his) existence" (Hayne, in press).

Steven maintains, like most people with mental illness he functions very well but, he believes the diagnosis is what dis-ables him:

> *We're not disabled in any way, shape or form. But we, as a society, look upon it as either "they're psychotic killers or they're mentally deficient." . . . Once you get that diagnosis you're bunched in with the people on the street that are walking around, salivating and eyes glazing, and walking into door-ways.*

Because of the diagnosis Steven perceives that he is lumped together in people's thinking with all manner of the disabled in society. This to him is one of the most damaging of consequences to being diagnosed. *It is* what is dis-abling: "you're not abled, you're dis-abled." To be dis-abled is to be undone, disassembled in some way, even taken apart or rendered inert. If I disable my computer it means I neutralize something vital to its functioning. I de-operationalize it. The name "bipolar" is what Steven believes did it to him. It de-legitimized him. As a "bipolar" he feels bound, even somewhat shaped by the imaging of what "a bipolar" is. The name places a parameter, a limit on how he can be seen and who he is allowed to be. His "difference" (gift) is stifled and he is related to as being his label. Such, is typified in the following anecdote cited by a mental health worker to her colleague:

> Recently I received a call from an individual with bipolar illness who at a leisure facility had requested a reduced rate pass because of his disability. He saw exercise as a constructive component of his therapy. His conversation, at the front desk area, had supposedly taken place in private. Shortly thereafter, however, he was told that the facility staff had been immediately informed of his condition and that they had stood watching him from the viewing area as he swam in the facility pool — "as if they were expecting to see some freak in the pool." He felt violated and angry.

To Steven's thinking it is the label in the diagnosis that he feels constrained by. It limits the expression of his personality, establishes who he is allowed to be and who he cannot be. He must struggle ever harder to express who he is; to celebrate his "gift"; to be "himself." His true person is resisted, passed-over, not allowed to exist. He feels held-up for consideration, caused to feel oppressed, suppressed, irrelevant, overlooked, not there, de-legitimized. He has been dis-abled:

> *If I walk up to someone and say, "you know, I've just been diagnosed with diabetes." The first thing I'd get is sympathy, and then I'd get empathy, understanding, tolerance. . . . People would probably go out of their way to help. But if I got up and said: "I have a mental illness," it would just be this glazed-over look.*

In Medieval time, it is said that of the assorted implements in possession of the alchemists was often a glass mask. This was used as a protective device for the face of the alchemist who, in "scientific" zeal, may be compounding corrosive substances. It is not difficult to see the utility of the glass mask to the alchemist. The metaphor of the glass mask, here, in the context of diagnosis, has use for its symbolic significance. It can be said, for example, that the mentally ill are made in effect to don such a mask in being diagnosed. This is the *virtual identity* rendered by society to the mentally ill person. Now, the irony of this situation is that the mentally ill have no bodily disfigurements that announce their circumstance; only the statement of diagnosis. In that respect, their predicament is unlike "Desperate's" in Goffman (1963):

Dear Miss Lonelyheart—

I am sixteen years old now and I don't know what to do and would appreciate it if you could tell me what to do. When I was a little girl it was not so bad because I got used to the kids on the block making fun of me, but now I would like to have boy friends like the other girls and go out on Saturday nights, but no boy will take me because I was born without a nose— although I am a good dancer and I have a nice shape and my father buys me pretty clothes.

I sit and look at myself all day and cry. I have a big hole in the middle of my face that scares people even myself so I can't blame the boys for not wanting to take me out. My mother loves me, but she cries terrible when she looks at me. What did I do to deserve such a terrible bad fate? Even if I did do some bad things I didn't do any before I was a year old and I was born this way. I asked Papa and he says he doesn't know, but that maybe I did something in the other world before I was born or that maybe I was being punished for his sins. I don't believe that because he is a very nice man. Ought I to commit suicide?

Sincerely yours,
Desperate

With mental illness there is nothing so obvious as a hole in one's face, no outer accouterments to manifest the illness. There are no crutches or wheelchairs, no aides or appliances. But there is, perhaps, something no less desperate, something just as subversive to the self. There is the psychiatric diagnosis, the self-disclaimer, that "glass mask," so to speak, which presents no obvious impediment; no barrier to being seen. It is transparent but none the less a mask. And it is always held in first view. Perhaps that is the desperation in *diagnosis* that it forever ushers in the person. It is what is seen first. Does it not in that way present as the hole to one's being?

To further our analogy of the glass mask, we note its rigidity. As well, much of the time it creates light-glare while at odd times it shades and shadows one's countenance. It is for certain that its refractive property mediates a visual accuracy of one's facial expression as mirror to the soul. In this sense, does the glass mask not leave the person somewhat faceless, presenting but an attenuated view of the person? Doesn't the mask precede the person, blur and steal the individual person-hood? One might discern that the glass mask of psychiatric diagnosis does, in some sense, transpose the individual into a persona of this or that diagnosis. In all this, the feature of transparency is seemingly maintained presenting a curious contradiction. Unwittingly, is it not the very transparency of the mask that creates the illusion of a reciprocally unobstructed view while at the same time obstructing the view?

Through the glass mask a persona of the person's diagnosis (e.g. *bipolar*) presents as the real person. Like a drop of red ink in a glass of water the diagnosis colors the entire view of the person. Hugo (1965) likens the glass mask to "a crystal wall harder than brass, which separates all . . . from the truth" (p. 277). In place, the glass mask of diagnosis creates a solid obstacle to who one really is. And, its transparency is what serves to cloud the vision. That is, one believes it is the person who is in full view. But, what is really being seen? Is it person or persona? It is not difficult to see how the person may actually be hidden from view (possibly even to he/she who wears the mask) while the appearance of obvious visibility is maintained. Through the glass mask, one is looked at but will one ever be seen again:

> *I can remember a doctor going up to my girlfriend. . . . I'd been hospitalized. . . . She wanted to know a little bit about what this was; you know, "is he going to be like this for the rest of his life?". . . The doctor says to her, "this is just him." Well, I mean, it was the first time I'd been hospitalized in like four years. And, "this was me." You know, the other three years, 11 months and two weeks don't matter. That wasn't me. This is me. Sitting in a hospital. So, of course the girlfriend went "eeehhhh!" you know; just screamed and went running for the hills. 'Cause who wants to have to deal with this as a relationship.*

In my relational life, "I" don't wish to be typecast. I want to enter into relationship in full possibility. I want to be touched by another for who I am. I do not want to be "a condition." I do not want to be cast as a "case." I do not want to be assumed a "known" quantity.

The type of relationality "I" can have with others is inscribed by how I am characterized. The over-arching question of diagnosis in mental illness is: what kind of relationality will I be permitted? I wonder if I can separate who I am from my diagnosis? Now, Steven talks about the option of secretiveness in his relationships. He has on occasion, particularly with girlfriends, chosen the secret way. At other times he's been up-front about his diagnosis and "who he is." When he has used the up-front approach and shared information about his diagnosis right at the outset of the relationship, inevitably the relationship has ended in short order. On the other hand, in some relationships he has allowed the health issues to sit for awhile, until *things* got more stabilized. But, a secret like that cannot be contained for long. "At some point or other it's gonna come out, and then it's, 'you lied to me. How dare you'. . . and they're gone!" So neither way has worked well for Steven. In his estimation, the diagnosis has deterred people from wanting to be involved and "stick with him."

Perhaps it is the impulse of fear that triggers when the diagnosis becomes known to others, the internal whisper that says, "I'm not going to go anywhere near him, he's mentally ill." The diagnosis, he presumes sends up the flags; "gives a label to people around him." "Family! Friends! I lost them all, the minute I got diagnosed," says Steven:

> *My wife thought she married a gifted person. She didn't marry a mentally ill person. . . . So I went into the hospital, and I came out without them. . . . I lost my family. They just would have nothing to do with me. . . . Two weeks after the first time I got out of the hospital I went to a party. I probably had these people over to my house fifty to a hundred times before. We had always hosted parties. This time, he [the friend] was hosting the party. And I went over there and, I walk in. The*

> *whole place went quiet and my friend came up to me and just asked me if I would leave. They didn't feel comfortable having me. I was mentally ill!*

In the mind of others the diagnosis makes declaration of a "changed being" someone now different, in the pejorative. "My" gift is concealed, my being sealed. Diagnosis has done that. Perhaps in this aspect, the experience of psychiatric diagnosis is distinct from other medical diagnoses. Psychiatric diagnosis is felt as a blemish to the being. It takes away the gift that it makes evident; leaves only "illness." It cannot "believe" in the gift as gift – as making a person special. Its resolve is a basis in "science!" From that basis it destroys all belief that is not "scientific." But, a gift needs to be believed in by others to remain a gift. And, Steven's gift earns no public endorsement from diagnosis. Quite the contrary!

"Eight seconds" was the time it took for a diagnosis to be determined but in those few seconds, Steven believes he was "stigmatized" for the rest of his life. The diagnosis has been "the one thing that has followed me through it all," he says. At first it might have served to further some self-understanding. But, to Steven's thinking, that gain has been wiped out; offset through time by all the ill effects of stigma, by the fear it has induced in family and friends, by what it has caused in terms of lost job prospects, career opportunities and a sense of future:

> The Greeks, who were apparently strong on visual aids, originated the term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor— a blemished person, ritually polluted, to be avoided, especially in public places. Later, in Christian time, two layers of metaphor were added to the term: the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin; the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorder. Today the term is widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it. Furthermore, shifts have occurred in the kinds of disgrace that arouse concern. (Goffman, 1963, pp. 1-2)

Stigma is without hesitation "the huggest most black beast of all" (Susan). *Beast* is metaphor for the denigration of *illness*. In *beast* is expressed the magnitude of Susan's greatest fear, that of becoming acutely ill again. That fear is written in the diagnosis. The diagnosis is constant reminder of that possibility. "It's like always waiting for the other shoe to drop," she says. But, beyond that is yet a greater "beast." Larger and blackest of all is what stands as the disparaging aspect of *diagnosis* — stigma.

There are few diagnoses that pillage one's life like diagnoses of mental illness. "I don't believe that society . . . treats people with a physical illnesses in the same negative way as they treat people with a mental illness." When Susan refers to stigma as the "huggest" (biggest or greatest) most black beast of all she means to say there is something greater and more devastating than the illness, something more dreaded in the diagnosis than in the illness. The illness can be managed. A place in one's life can be made for the illness. But how does one accommodate the labeling of it? How does one preserve one's self from that which surrounds the illness and is publicly announced by the diagnosis? Stigma comes from outside the person and its aim is deadly:

> *Their sense of worth, their feeling of hope is taken from them because, there's always something [to] feel ashamed about.... If someone with diabetes forgot their insulin they could say, "oh my God, I have to run back. I forgot my insulin." But if I need to take my lithium I make sure I do it after the meal in the bathroom, instead of at the table, so no one sees and asks me what it is... cause I tried it a few times. I took [the lithium] out and took it in front of people and they'd go, "what is that?" and I'd go, "Lithium."... You can just see the wall go up between you and them. They won't even ask you to explain why you're on it. (Susan)*

The diagnosis is spoiler of the identity (Goffman, 1963). It lays the conditions to always question the intent in peoples' comments. Even things that may be quite ordinary become suspect. Like: "Are you okay?" A common show of concern can cause suspicious arousal to those *with diagnosis*. When Susan hears it she wonders if there is the underlying implication: "How fragile she is!" She wants to respond tersely: "Look, I'm fine" instead of saying, "thanks for asking." Outside of *diagnosis* one wouldn't grasp that, wouldn't even buy into that sort of thing. There just wouldn't be the same sensitivities. The diagnosis is what brings that to "you" sets one in the position where: "you're always trying to build yourself up," to justify your worth, to prove your ok. You feel disqualified by the questions you see in the eyes of others; assaulted by what the label of diagnosis has brought to you:

> *When you're labeled schizophrenic the label attacks your mentality. It goes to the core of a person. You **are** your mind and your heart. If I attack your finger or another part of your body, indirectly I'm attacking you but it's not as bad. Because it doesn't attack the spirit and the mentality of the person. It's not like saying, "you're an f'n schizo." It's not the same thing. That goes much, much deeper. Then the very being of the individual is attacked. That's like a knife for me. A knife to the heart* (Kevin).

Kevin ascribes a kind of deadliness to *diagnosis*, one that can strike and devastate his spirit. He knows about such attacks because he has lived through them. There is no buffer in time to what he has endured. The years have not built immunity; have not desensitized him to the harshness of the label. It is a label that targets his mentality; discredits his very core. There is no defense to it, but for one:

> *You know, if I keep my mouth shut and if I act and talk sensibly like everybody else, nobody suspects I have schizophrenia. Those who do— the worst enemies*

> *are those who know your label. . . . Those who know you're schizophrenic! Those who don't know your label, they treat you right.* (Kevin)

To be diagnosed is to be destroyed.

"If I wasn't diagnosed with the illness, I could be considered to be off the wall, or inventive or gifted" says Steven, "but the minute the diagnosis enters in, then, all the other positive traits that could be associated with the condition are removed and, 'you now have an illness'." The week before Steven was diagnosed he thought he had it all. Family, friends, business associates who respected him and thought him quite ingenious. After all, he'd started up a new business that had for a time looked to have brilliant possibilities. It was innovative, very technical and had required the kind of energy that he, Steven, had been able to give it. But now, it was all lost. The business had gone down and, he was just regarded as, "sick." The diagnosis declared that, to Steven and to those in his life who mattered most to him.

For Steven, the diagnosis has changed, forever, the way he feels about himself. It will never go away. In the eyes of others, also, he feels transformed into something alien. To them "I was now ill," he says. "I wasn't now a person who was just different, even gifted. I was a person who was mentally ill. . . . I would phone them and they would say, "sorry, I can't talk to you," and hang up." And so, while *diagnosis* has confirmed Steven's gift, to him, it has at the same time destroyed it. From his point of view, it has limited him to being mentally ill and so, destroyed "him."

CHAPTER SEVEN

Diagnosis As The Experience Of Making The Knowledge Knowledgeable

For Eva, the evening of "fun" bridge was anything but. Even the great crash course to "Better Bridge" did little to avert the caustic comments: "What do you mean 'Pass!' That was a *demand* bid!" "You can't bid 'no trump,' with a void in one suit." "A slam is only a slam if you bid it – you know!" Why didn't you use "Blackwood convention?" "Why didn't I?" she thought. "I'd reviewed it only the night before!" For those who have survived the novice stage as bridge players, something of these comments may ring familiar. What made one eventually able to "play well?" When did "normal bidding" really mean what it said? At what point did Blackwood convention become the strategic formula it was touted to be?" And, if "you're" a *real* bridge player you probably know that all the strategy in the world, of requesting specific information of your partner's card hand, goes out the window if you aren't able to read the subtleties of intended responses.

Most would agree, there is something more to success at "the game" (whichever game that is) than knowledge and information. Rules and protocol might even be quite mute, striped of context. And, one might say, "Isn't it more important to know how to apply information?" Further, could one be knowledgeable in isolation? A "master player" once said: "If you take everything from me, you will have nothing and I will have everything!" Only years later did I come to realize he wasn't only talking about "bridge."

With this template to our thinking, we now turn to Part I of Jim's story, in which he tells us of his experience with the particular kind of knowledge that is diagnosis. Part II, which follows, gives opportunity to explore the theme of "*knowledgeable knowledge*" within the experience of being diagnosed. Thus, yet, another theme of *diagnosis* is highlighted.

Part I: "When Everything Really Accelerated"

Jim was 33 years of age and worked as a junior welder in a steel mill. "It must be the shift work," he thought, "that was running him down?" He had felt tired, irritable, and often he would be overcome by a general sadness. There was nothing specific he could put it on. So, it had to be the shift work. A by-product of the unusual hours or, maybe it was burnout? Jim decided to do research on the issue. He read a whole lot and actually wrote a report on the subject of shift work and how it affected people. The study, though, did little to change things for him. In fact things seemed to steadily get worse, until about a year later:

> *I was driving home and about every fifteen minutes I had to stop to take two tranquilizers just to get me home. So I called my family doctor and I told him, "put me in the hospital until you find out what's wrong with me." . . . There's no way I was going to be at home with this happening cause I just couldn't sit still. I was pacing all over the place. My nerves were shot. So, I spent a week in the hospital and they did all the hospital tests.*

Jim thought whatever was going on had to be either a massive heart attack or a good imitation of one. The doctors wondered as well. They did a number of things to figure it out, like blood tests, scans, stress test and all that sort of thing, until heart attack was decidedly ruled out. Then at the end of the week the doctor came in and said to him, "Well, you have panic disorder." "It was a five minute visit at tops," says Jim. The doctor was in and out and Jim couldn't believe it:

> *He basically said just that. "You've got this thing called panic disorder and there's so many millions of people in the world that have it. Here's some pamphlets. Go home. Take these pills. And I'll see you in a month," kind of thing.*

Now "there's a zillion things" Jim wanted to know; needed to ask. But, he was stunned. Thoughts flooded his mind: "Shouldn't it have all taken longer than five minutes?" "Shouldn't there be more things to talk about than just, *you have this* and, *take that*?" "You'd think it would take longer to figure out what the whole problem was in the first place." How could it all be figured out that quick? As his mind flooded with these thoughts Jim puzzled about the doctor: "Either he's a really good doctor or he really doesn't care too much about his patients." But what conclusion could Jim really draw? He felt unable to determine anything from something that was dropped on him in five minutes.

"It just blew me away!"

Jim sat in the hospital room waiting to go home. He called his wife and said, "I can go home now. I have these pills and I can go home now." And Jim did go home. But the five-minute scene was something Jim just couldn't accept. It wasn't so much that he had *panic disorder*! It was the five-minute delivery of news that taunted him. It was the way he had heard that explanation. It sounded like such a trivial explanation. Jim was a "nuts and bolts" sort of guy. He needed the "guts" of things. But the way the diagnosis was dropped on him had left him quite bewildered. There was no information, no support. And, what really astonished Jim was that there was so little expression of interest or concern. Hearing the diagnosis in such an impersonal way, Jim felt he'd just been lumped together with a bunch of "those others." Scornfully he thought: "gee, I guess I'm just one of those people over there.... Guess that's just me there and I'm nuts!"

"You go in, you see him, you get drugged and you go home!" "Is that all there is?" It didn't make sense to Jim. He had counted on the diagnosis to explain everything to him but instead, it had ended up saying nothing. Without more, there was no knowledge in "panic disorder." Just, empty words:

> *They don't really mean anything to you when you're trying to figure, "well, does that mean I'm going to be ok? Am I going to have another one [attack]? Is this going to re-occur?" So they say, "take the drugs." And at first they [the drugs] knock you out and you want to sleep. But that isn't what I really wanted. What I really wanted to do is go back to work... to get a regular hold on life again. But it didn't work that way.*

Jim needed to know beneath the words. Couldn't *they* see this? You'd think, "they'd" know that, that they'd take into account his personality when they were telling him things. If they had done so, wouldn't they know that the more information he received the more he would be willing to accept the whole thing? Thoughts as these plagued Jim and each question seemed only to spawn another and another. Was it even the "right" diagnosis? All it seemed was:

> *. . . a short burst of conversation and then, that's it! "You've got this cause I told you you got it." And, "take these and you'll be better in the morning," kind of thing. But it doesn't work that way. Not for me!*

Jim felt a growing "fury" with that doctor. How could "he" make that kind of decision, come to that kind of a conclusion with so little to go on? What was he basing it on anyway? Jim was full of doubt, anger, confusion. He could think of only one way out of his distress and that was to seek another opinion. Yes, perhaps another hospital and another doctor would do it!

Basically, the second opinion confirmed the first, but it was an entirely different experience, really, a "more convincing" experience. People sat there! They talked and they explained to Jim what was happening. They told him about the diagnosis in a way that helped Jim to feel less ill at ease, more in touch with the knowledge of his disorder. Jim thought *this time* "was more rational," a more reasonable approach. He came away knowing and understanding. There were still some things about it that he didn't fully grasp right away, like the lifelong nature of the thing, but at least with the more personalized approach he could come away "knowing," and even with some level of acceptance. Perhaps he *could* come to live with it -- at least for a time, he thought.

Part II: Peering into Jim's experience of diagnosis

In Jim's story we are able to expand on our grasp of meanings in the experience of being psychiatrically diagnosed. Taking the lead directly from his account, the forthcoming discussion is formulated along the following themes: diagnosis as a relational experience, diagnosis as a different way of knowing the self, and diagnosis as call to healing.

A. *Diagnosis* as a relational experience.

a) The five minute thing that taunted.

Have you ever noticed how each generation brings into being its own language? It's like words come and they go. Certain words come into vogue, maybe simply come of age, only to be replaced by other "new age" words. I note a teen's greeting to his friend: "Hey dude!" The other responds: "Yo! Wazz up man?" Their brief exchange might go something like:

"Wanna hang later?"
"Can't. Grounded!"
"That blows. How come?"
"I blew an exam."
"That's lame."
"Yeah, it sucks!"
"See ya dude."
"Yeah! Rock on man."

We could ponder this kind of idle exchange, reflect on the slang utterances in young people's "rap" sessions. How would one be viewed if one were to use these same words at work some day, say, with a colleague? The words wouldn't seem to fit. They are particular to the context of this young age group. Like medical languaging, which is particular to the context of medicine, the words and expressions of adolescence have unique meanings to that generation. They have significance *there*. To the young generation, expressing oneself in the mode of the day can make one *cool* or expose one as a *"dork."*

Another peculiarity might be noticed in talk amongst the young set. Rarely is spoken the names of the persons engaged in conversation. Perhaps it wouldn't be "*cool*." It might sound "*dorky;* make one a *woose*." At this one might wonder: "What's a *woose*?" Again, this might be recognized as "talk of the day." Years ago, a *wimp* might've been a *woose*.

In this vein one might come to question what really gives voice to words at all, let alone to "new" words? Words like "online," "offline," "surfing," "hotmail," "e-mail," "p-mail," "snail-mail," "rebel cell," "hacker!" New words or, old words with new meanings! Like "windows!" Not long ago windows might've brought to mind a bucket of water and a squeegy. Now, it is a rectangular shape with information on a computer screen. Along with other idiomatic expressions of the day "windows" becomes incorporated into common, "current" everyday usage to constitute what might be known as "generational talk." Once one begins to pay attention to generational talk the nature of what comes may be rather intriguing. Before long one might hear: "He *schmoozes* with the right people" (i.e. he caters to those he knows will benefit him). "That guy is *high maintenance*" (i.e. demands a lot of energy and attention from others). "Don't have a *hissy fit*" (i.e. don't loose your composure). "I really hate when people *spam* you" (i.e. when people send you lots of junk e-mail). It soon becomes evident that not knowing the "new-age" talk would easily identify who was *in the know* and who was *out of the loop*. We may be struck by the significance of words and how a word may come to be other than itself even, come to be larger than itself. Does any of this bear on the experience of diagnosis? Perhaps all the more if we see something in the *phenomenon of diagnosis* of what gets imputed to words.

Gadamer (1982) states, "We seek the right word, i.e. the word that really belongs to the object so the object comes into language" (p. 377). In this he brings us to think about the words involved in the act of naming things. Gadamer would seem to say that in the naming of something, *that* something actually becomes what it is. It loses anonymity or at least becomes less of a mysterious complexity. In the determination of a clinical diagnosis one readily recognizes the utmost effort made to establish, in medical naming, the *correct* diagnosis. The diagnostic term aims to be an exact statement, one that indisputably defines the nature of whatever ails the human system at a given time. *Diagnosis* must be precise and generally there is fastidious effort that goes into establishing the term that will most accurately describe the health issue in question. What is required is an essential statement that is accurate, the word(s) that would say something credible if not "factual." "What is it that is wrong with me?" should be unequivocally answered. So, shouldn't answer to that question have come as a relief to Jim? To know what all that dreadful experience leading up to the diagnosis was about? But there is no relief in it for Jim. There is no consolation, no comfort in the "knowing," no lifting of the uncertainty, nothing that would allow him to accommodate thought of *this* disorder as it now dominates his being. Why was this so?

Jim tells us "it was the five minute thing" that taunted him. In this what is he saying? Didn't the diagnosis, "panic disorder" give him information about his chest pain? Didn't it tell him there was nothing biologically amiss with his heart? Didn't it explain his restlessness, his inability to sleep his difficulty in focusing, concentrating, and so on? One could think the words of diagnosis, in transmission to Jim, would have such explanatory power, carry a message of comfort. But instead, Jim felt "blown away." How do two words strike such a chord; result in one feeling estranged from oneself? Being caught in a wind gale, a squall, a blizzard, a hurricane, a tornado; these can devastate one's life; blow one away! One can be blasted into eternity by lighting or by some other explosive. But how can the sound of words "bring someone down?" Of course, one would readily say that words go well beyond the sounds they emit. The impact of words goes, also, into what is said by their usage? Indeed, experiencing the *word* of diagnosis may be less an experience of content than it is of context.

Panic disorder is "the word" given Jim by a particular person, *this* physician. This is a big part of the context. Then, the words are delivered in a specific *space*, pronounced with particular style, mingled amidst various other words that shade them in certain ways. They are heard in particular association and, against what one expected to hear, and so on. Of all that might've mixed in the event of diagnosis, Jim hits on a sense of *proportion*. To him, there is a disproportion between the time it takes to deliver those *words* and, the magnitude of them to him. It is "the five minute thing" that fractures; makes him feel "blown away." Words that might've been fortifying information to him about himself, instead cause him to feel unimportant, insignificant; de-valued.

For Jim, to be diagnosed created more of a dilemma than it had solved. He was confronted with feeling trivialized, easily *figured-out*; having a determination made of what he was all about. He felt shallow; the mystery of his uniqueness snuffed out and he felt put in a place where he may never again be allowed to be uniquely himself, since who he was had now been determined. Jim sensed he would forevermore be predetermined, confined to a definition as "one of them!" Further, because he heard the diagnosis conveyed in a brief and shallow way, it became all the more caustic. *That* translated it into something that was of little importance, without significance, even trite. In his thinking, maybe it conveyed that he too was *small* and insignificant and of little consequence. How could he hear the diagnosis as separate from him? "Wasn't it a pronouncement on himself?" A statement on, "who *he* was!" Certainly, the diagnosis was *that;* over there, where he could point to it; in those words. But wasn't it also him, here, in himself! And now his entire story threatens to sum up to two small words! The words would make him merely a static solution. He would now be answered, a problem solved; a puzzle simplified to an: "ah, that's it!" The paradox is that for all this Jim, to himself, felt "like a big question mark." He might've become an *end-point* in "their" eyes but to himself he was left in a no-man's-land, groping for who he was. The feeling rings of being shut off from future *happening* because "he" had now, already happened. It was as though he was now end stage. *Diagnosis* had created but a small slice of space and Jim felt jammed into it, compressed into a place where the diagnosis stood to become the ground of his entire being.

Jim had been eager to know, even urgent to know. But, what he got was unexpected consternation. Yes, he had wanted "it" to be *something*; to hear the "right" word! Yes, he had expected he would have to make room for it in his life, but he had expected it would be something of significance, something that would confirm the enormity of his pain and discomfort, something of magnitude, something that would *affirm him.* Five minutes worth made it common, simply a tease; a cold, a flue, a hangnail! This was like AIDS! Not, "*something* to *not* be overly bothered about," not a tiny virus! *It* felt huge to Jim, because *it* was he himself. And *he* was more than "five minutes" worth, wasn't he? Five minutes put into question his entire sense of self. He could feel himself unravel into "a big question mark?" On the one hand diagnosis had defined who he was but on the other hand he wondered, now, "Who am I?" Panic disorder! "What does that make me? A 'psych' case? A discard! Guess I'm one of them now; one of those — over there!" Shouldn't the knowledge have given him more?

b) A more convincing experience.

In Jim's case, it appears from his quest of a more convincing experience that he seeks something more meaningful to himself. What is it that would make "the word" of diagnosis the *right* word. To this point we have seen some of what gives impact to words that had previously been silent. A moment ago Jim had never heard the term *panic disorder*. Now he is brought to a realization of a certain power in those two words. Medically speaking he feels little wiser as to their meaning but experientially, even as he works to negate them, he realizes the impact of them in what he feels. He is left with a kind of numbness that courses his being on hearing them. It seems the power obtained in the words descends from the physician who has unlocked their silence. If his neighbor had told him those words or even his wife, would he have had the same reaction? But it is a physician who has declared them and it is by his authority that the two ordinary words seem to carry a particular power for Jim? This doctor, who simply rushed in and out, after five minutes and two words, would change his world! Who was "he" that he thought he could do that? A dark emotion is seen to kindle in Jim. Who was that person, the physician; man who would be "knower?" In "five" minutes, how could Jim trust the giver of the word; know the *knower;* trust his word; know whether the "oracle" might even be imposter. Maybe not imposter in the sense of pretending to be something one isn't, but maybe imposter in the sense of posing knowledge without thoughtfulness, with little notion of its impact? These were the misgivings that settled over Jim because of "the five minute thing."

In this initial experience of diagnosis there was nothing, for Jim, of *the oracle* as represented in the traditional sense of the word. An oracle can be taken to be a "divine pronouncement" (Klein, 1971, p. 517) but in ancient Greece an oracle was also a personification of the wisest of men, one who told people "the truth about a particular situation" to guide their future (Collins Colbuild dictionary, 1988). Make them truly knowledgeable one might say! *There* was a respected influence, a source of enlightenment, distinguished by caring and intelligence; someone who conveyed dignity and had a gift for the kind of "riddling formulas" which pointed to risks and offered warnings (Grant, 1962, p. 123).

One such oracle oft referenced in Greece was said to reside at Delphi. It was, thus, fitting that Delphi was to become the center of worship for the Greek God Apollo, the God of Light, whose stateliness and distinctive gifts matched and outclassed those of the oracle who had, there, preceded him. As God of Light, Apollo was revered as the essential symbol of inspiration, doing "for the soul what light does for the world: swift and powerful as the sun's rays, he was also the dazzlingly splendid young Lord of music and song . . . the giver of prophecy . . . the healer of bodies with medicine . . ." (Grant, 1962, pp. 121-122). Could one imagine the nature of Jim's appeal to such a being? Is Jim inspired with the 20th century oracle before him?

Because it is "He," the oracle of modern medicine who speaks, one might generally accept that what is being said is "truth," the kind of truth that assumes a "blind" trust. But, as we see in Jim's case, it is only truth if it can be apprehended as such. Only then does it become the kind of truth that can truly guide one's future. After all, isn't it that which distinguishes *truth* from mere words? For Jim, hearing the diagnosis amounts to but words, albeit words with designate power. But, he would ask, "shouldn't it have been much more?" We could imagine, in this question, Jim's appeal to Apollo, the God of Light. When Jim goes for a second opinion isn't it *a light for the soul* which he seeks? Isn't that which he searches for far beyond the words? Certainly, it would seem he goes for more than *the words* he already has. Could we even remotely imagine the God Apollo responding to Jim's plea for *more*, by offering him simply more words?

What Jim seems in search of is perhaps to challenge the words, and then at the very least, to make sense of the words he has been given, to see the meaning in the words; the meaning *for him*; even be directed by a kind of prophecy, as it were. What will be *his* "world" now, his future, his life with "Panic Disorder?" In what those words say, how will that impinge on him? Even if he could accept those words as the words that rightfully apply to him, surely they would not mean the same thing one-and-for-all so diagnosed? That would make them, all the more, merely words: a label on a row of cans, each the same as the one beside it?

So, what is it that would satiate Jim in a second consultation? What ingredient(s) would net him a more convincing experience? It could be that Jim wishes to see behind the words, wants to know not what they represent (green beans) but what they *mean* in their nakedness. But is this really knowable? Is *that something* Jim might look for behind the words really even there? Undressed of words, would *panic disorder* be anything at all? Is *panic disorder* knownable in this "level of raw existence" (Van Manen, unpublished paper)? This darkness behind the words is said to be that which the phenomenologist seeks to illuminate? In this thesis, for example, we search for the nakedness of what it is *to be diagnosed* but, for all this scripture, are we not limited to but a cursory glimpse of diagnosis, as it were, a glimpse reflected from the barrier of language? In the ordinary daylight can the cloak of the words ever be sufficiently lifted to reveal what it hides? Perhaps this is what Van Manen (unpublished paper) means by, "language kills whatever it touches. . . . The words constantly substitute themselves for the things they are meant to bring into presence."

But, in Jim's quest, is it such penetration of diagnosis that he seeks? Certainly, to pierce the darkness and have such primal gaze at *diagnosis* would bring Jim face to face with its allusiveness. But can Jim's need for a convincing experience be satisfied short of this kind of "Orpheus Gaze?"

From mythology, the Greek God Orpheus seeks to retrieve his beloved wife, Eurydice, back from the dead. Orpheus is permitted descent to the "underworld" to lead Eurydice out and back to life, on condition that he not look behind him. But, on retracing his steps towards the upper world, followed by Eurydice, Orpheus in lapse of his promise, glances back (perhaps to ensure she was really there). We read Virgil (cited in Grant, 1962):

> Pardonable, you'd say, but Death can never pardon.
> He halts. Eurydice, his own, is now on the lip of
> Daylight. Alas! He forgot. His purpose broke.
> He looked back.
> His labor was lost, the pact he had made with the merciless king
> Annulled. Three times did thunder peal over the pools of Avernus.
> "Who," she cried, "has doomed me to misery, who has doomed us? . . ."
> Thus she spoke: and at once from his sight, like a wisp of smoke
> Thinned into air, was gone.
> Wildly he grasped at shadows, wanting to say much more,
> But she did not see him; nor would the ferryman of the Inferno
> Let him again cross the fen that lay between them. (pp. 267-268)

In that moment, I suppose Orpheus would've seen; really seen the rawness of death, that which was there behind him. But, the verse tells us that in life, none can see past the veil. To see into pure death would mean Orpheus, too, must be given over to that realm. Applied to Jim's situation, perhaps it comes down to him too reckoning with "seeing beyond what can be known"; accepting that some things in life, are unknowable. In life, the sight of the living must settle for a vision of what can be seen. But, to appease Jim, what from "the realm of wild being," as Van Manen writes, can be wrestled of diagnosis? What, short of a total apprehension (were that possible) would make for "a convincing experience?"

c) A sample of knowledge made knowledgeable.

Anne phones to tell her friend of the ordeal she has recently been through at being diagnosed with breast cancer. “The doctor,” she says, “who informed me of the biopsy results was a young physician who was visibly distressed about having to tell me such information.” Perhaps the doctor was also aware that Anne, during her teens, had lost her mother to cancer. The current scene, then, brings news to Anne that is all the more ominous.

On hearing the news, Anne struggled hard to keep herself centered. There were particular questions she wanted to ask and she definitely needed to talk about “the cancer.” She had worked in oncology and she knew about different cancers. Now, she needed to understand about *her* cancer, know it at the cellular level in order to come to terms with it, grasp her circumstance, know what was before her and what she was about to face. And so, Anne asked, “what kind of cancer is it?” But, the Dr. acted rather vague and evasive and conveyed something like: “No! No! No! Talk isn’t important right now. There is no time to talk about it. What *is* important is to initiate treatment as quickly as possible and hopefully you will be a candidate for radiation and a lumpectomy.”

Anxiety in the doctor’s manner was florid and transmitted to Anne. What she heard was the urgency to move fast because, “this was an aggressive kind of fast-growing cancer.” The physician “gave no acknowledgment to the fact that ‘this body’ was connected to a soul, a psyche, a spirit.” The focus was on prompt and radical treatment; the need to set up a course of radiation and to “surgically remove all (between thirty to sixty) lymph nodes.” “Anything else,” said the doctor, “would be substandard.” On hearing this, Anne left feeling she had little hope for a future.

Something about it all nagged at Anne and she decided to change doctors. The second doctor was, in Anne’s words, “a wonderful man — a real special guy.” They talked at length about the cancer. He wanted to do an in-depth analysis so he decided to do another biopsy. He discussed the results of it in detail with Anne. The good news was, the results showed this was almost regarded as a benign cancer — “the least offensive of cancers.” It characteristically would slowly grow for years without creating problems. Options for treatment were discussed and Anne was fully involved in the choices. She states: “All kinds of hope was generated by this guy.” In the end, a small resection of the breast tumor was done and it was deemed unnecessary to remove any nodes.” Anne says, “there was a sense of completion; a sense of miracle when it was done.”

What stands out in this story are the two different approaches used to convey the diagnosis and, the effect each of these has on Anne. To use her own words: “it was the difference between *nothing* and *something* on the side of health and healing.” And that, to Anne, made immeasurable difference!

Anne’s story would accentuate Cousin’s (1997) belief that the “word” of diagnosis can act as the enemy of treatment. Anne’s story shifts our thinking closer to the spirit of Cousins’ thought, that is, from “what has been intoned about diagnosis as simply a word experience” to, “a relational experience.” Who is transmitting “the word of diagnosis” becomes significant to that transmission. Anne’s story, then, suggests that hearing one’s diagnosis is at least as much about persons as it is about knowledge. What helps one to be truly knowledgeable seems tied to knowing the “knower.” The real knowledge is what emerges from the human contact Anne has with the second physician. Now she knows that she is not alone in the event of *diagnosis*. Anne's story shows us that knowing the knower may, indeed, enter as the most critical element in what makes diagnosis truly diagnostic, that is, what make knowledge truly knowledge-able.

d) Elemental to shaping knowledge.

Several of the ancient myths are stories illustrating human relationship as the elemental catalyst for a kind of metamorphosis, supporting a notion that "our process of becoming is always in, with, and through others" (Bierlein, 1999, p. 40). The story of Pygmalion, a sculptor in Roman mythology, is a well-known example:

> Pygmalion hated women and resolved never to marry. He worked, however, for many months on a statue of a beautiful woman, and eventually fell madly in love with it. Disconsolate because the statue remained lifeless and could not respond to his caresses, Pygmalion prayed to Venus, goddess of love, to send him a maiden like his statue. Venus answered his prayer by endowing the statue with life. The maiden, who Pygmalion called Galatea, returned his love and bore him a son, Paphos, from who the city sacred to Venus received its name.
>
> "Pygmalion," Microsoft (R) Encarta(R) Online Encyclopedia 2000

What is immediately conveyed here concerns love's transforming power. The story is of metamorphosis on more than one count. Obviously it is the coming-to-life of the lifeless statue. The giving of the *name*, Galatea, acknowledges life brought into being. No longer is this now simply a cold, hard, ivory statue. The name announces there is present a living maiden. The statue has changed from a thing to a "real" person. *That*, we may say, is signified in the act of the sculptor naming *her*. But of course, it is his love, indeed his ability to love, which is awakened, and the more significant metamorphosis in the story. Surmounting his initial "hate" for woman the sculptor's love is what makes the whole thing possible. The genesis of life in the statue is, after all, a consequence of this awakening in the sculptor. In Ovid's "Metamorphoses," (Grant, 1962) we read:

> In sculpture exercis'd his happy skill;
> And carv'd in iv'ry such a maid, so fair,
> As Nature could not with his art compare,
> . . . Pleas'd with his idol, he commends, admires,
> Adores; and last, the thing ador'd, desires.
> . . . Art hid with art, so well perform'ed the cheat,
> It caught the carver . . .

This last line exclaims the awakening; a change that gripped the sculptor from within and re-directed the course of everything. Isn't it in that moment of being caught that the real "magic" happens? When the quickening of life is initiated inside the sculptor and hence extends to the statue? This marvelous occurrence seems less pronounced in George Bernard Shaw's rendition of "*Pygmalion*." Shaw's screenplay effectively portrays the dramatic transformation of Eliza Doolittle; a "homely," know-nothing pauper into a beautifully alluring, sophisticated lady. But in the end the viewer doesn't quite see the "gripping" effect on Professor Higgins. Higgins is not, like the sculptor, *caught*; a point announced by Eliza herself:

> . . . You see, (she says) really and truly, apart from the things anyone can (learn) (the dressing and the proper way of speaking, and so on), the difference between a lady and a flower girl is not how she behaves, but how she's treated. I shall always be a flower girl to Professor Higgins, because he always treats me as a flower girl, and always will; but I know I can be a lady to you, because you always treat me as a lady, and always will. (G. B. Shaw, *Pygmaliaon*)

Professor Higgins, unlike the sculptor in myth, doesn't to the same extent *get caught*. To him there is no quickening of life in his creation, Eliza, because there is no quickening of love in him. And so to Higgins, Eliza remains an object, a thing of his ambitions, a carving so to speak, without life or significance; she is remote from his soul and thus but a statue. How can he instill *that something* into his "creation" when it has not been sparked from within him? The irony about it is made the more potent in that the insight is uttered by "the simple" Eliza herself, perhaps to show "even a no-nothing pauper girl knows *that*!" Can we take this to what makes knowledge knowlegeable?

In the renditions of Pygmalion we are brought to a message of what Van Manen terms "heteronomy, the other side of autonomy: it means to be claimed or dependent on something that comes from the outside" (Olson, 1993, p. xvi). The heteronomy of responsibility might be said to be at the heart of the relationship between health care provider and health care recipient. Heteronomy recognizes that which Jim seems in search of, that which would offer him a more convincing experience and, that which would ultimately give shape to his healing. We can see that if "healing" is tied to our perception of things (as Cousins would have it) then *how* one is presented one's diagnosis would seem of utmost relevance. *How* the ministrations of health are perceived may, indeed, have ultimate significance. Experientially, isn't it the difference between being an object of care and, being a person invited into healing? In this, one could speculate on far reaching effects to *diagnosis* particularly if it is viewed as a kind of *calling*; a call to a new way of being; through a new knowledge! Isn't it this which is knowledge-ability? The knowledge imparted by diagnosis may be brutally frank, still, it is there before one and it must be reckoned with. What else but to proceed! In the words of Bierlein (1999) "the only way out is through" (p. 111).

To be called into being requires two parties, the caller and the one being called. Both would seem to share in the event of *the call*. But, it is interesting to ponder the extent to which the mode of reckoning with that call originates in the *mind* of the beholder. Who, of the players involved in the call, is the real harbinger of comfort or of distress? Will the outcome be statue or stamina? Will knowledge be truncated at knowledge, or will it ripen to knowledge-abibity? Perhaps it is much destined at outset by the health provider who, like Pygmalion, becomes "caught," as it were, "caught up" in the human-health encounter. How else is one to be response-able to the call diagnosis makes?

B. Diagnosis as a different way of knowing one's self.

a) Discovering one's ancestry.

Not long ago I received e-mail from a brother of mine. We had often had occasion to share confidences but on this one occasion, the news he related was quite startling. My brother had stumbled on information about our maternal surname:

> By the way, (he writes) you'll never guess what I ran into the other day. I was in a bookstore and here was a book by Lionel Kochan on Jewish History. It got me thinking about looking up the name Kochan to see what I could find. Well, lo and behold it's a Jewish name. In fact at the Holocaust museum that I went to visit today there are 134 Kochan's listed in the ghetto at Bedzin in Poland and two Kochan's who are listed as having died in Auschwitz — Herz Kochan and Mordka Kochan — one from Bedzin and the other from Lublin. There's another Kochan, Vladimir Petrovich from Odessa in the Ukraine, who died in the Ukraine. Interesting, eh! (Bro)

Some may have treated this as but a small bit of incidental news, however, on reading it I had the strangest experience. Here I was in latter midlife and it was like I had never really known who I was before. Something about the news felt right and yet it was so startling. It was more than just newfound info to me about a historical past. It's that I had never defined myself in my own thinking to account for this kind of history. It's like I had to take time to think about it, revisit it again and again, to make room for it in my thoughts about myself. Imagine! I was connected to all that awful tragic stuff! It became personal to me in a fundamental sort of way I wouldn't have imagined. I began to dwell on it, seek out literature, to look for more facts on which to fix my thoughts about it. To me it was more than just history or genealogy I'd happened on. "It was me!" By direct descent it was "who I was!" On the face of things, nothing had changed, but then, for me in another way nothing was quite the same either.

The story of ancestry here can help to distinguish between having knowledge and being knowledgeable. To pursue this vein of thought it might be worthwhile to consider the difference between what it is "to be" and, what it is "to have." To get the e-mail, I suppose, was for me *to have* the knowledge of my lineage. But the knowledge brought something that directly impinged on the center of, "who I am." I became subtly aware of its consequences for me. If we look to the experience of being diagnosed, couldn't we see something similar transpire? *To be* diagnosed is, also, to be aware of oneself as the subject of being so diagnosed. I not only *have* that knowledge; I experience and recognize myself as the subject of my experience of it (Omery et al., 1995, p. 143). I become aware (in this case) of "my" experience of being diagnosed as intentionally meaningful to me in a deep and intimate way. This may be all the more, given the diagnosis is of a psychiatric disorder as opposed to if I were told I had appendicitis. To be told one has appendicitis means one has an inflamed appendix. This is *to have* that something. It can be extricated so that one, then, would no longer have it. The impact must surely be different, though, if one is told one has a psychiatric disorder. That, can't be pointed to, can't be tangibly removed. In a sense, it may be broader in terms of its ramifications because it says something about one's entire person. So, now, Jim ruminates on how "that" diagnosis impinges on "him" as a being; on his person. Jim is integral to the experience of hearing that diagnosis because he is the subject of its happening somewhat in the fashion that I was integral to the news of my maternal lineage because it made me confront the core of being.

One would easily know that to be told one has a disorder is different than it is to be defined by one's disorder. Is it different to be told, "you have diabetes" than to be told "you are diabetic" or, to be told "you're a schizophrenic?" For Jim to hear his diagnostic declaration was to acquire a particular kind of knowledge about himself. But, his story tells us that upon receiving that knowledge he felt like he was being stripped of himself. He was not "abled" in the sense of being knowledge-abled. He was not equipped to become more fully who he was. Instead, he felt left "to be" something else (i.e. "I guess I'm one of them over there!). Like Bjorklund (1996) he related to the diagnosis (the knowledge) as a kind of "epiphany" that destined him "to be" his illness rather than be himself, with an illness. The diagnosis became a formula that re-cast his past, re-shaped his present, re-drafted his future; all with "illness." This goes well beyond simply *having* a disorder. Jim reacts as though the news were a *sentencing;* a displacing of his known self to a designated place of an unknown "other" self (i.e. "Who am I?"). In these, his words, we see something of his experience of diagnosis as involving the centre of his being, the centre of his experiencing self! "I" as ego! Is it so dissimilar to the sudden dawning of my genealogy, an experience that seemed to affect the very fiber of "who I was?"

These notions seem to fit well with Omery and Mack (1995) who tell us that ultimately all experience is always subjective; "there is always, in experience, an experiencing subject, an ego. . . . I am aware of acting" (p. 142). But, *to be* something seemingly exceeds *having* something in that I am brought to an awareness of myself to myself, in a way that makes me fundamentally different from what I knew of what I was before. By similar token we can say that to have knowledge is by no stretch the same thing as, to be knowledgeable.

b) Keeping my story intact.

If we focus, momentarily, on the aspect of diagnosis as an act of naming we might say that it (diagnosis) aims to sum a story. In a sense it is like one's own name which is essentially, culmination of one's story; the sum of "who one is" and has been? I suppose one's name could even be viewed as a kind of storytelling, a distilling of characteristic information such that the story of "*who* one is" becomes highlighted. The person's name, itself, simply titles the story? No doubt this accounts for why we see many biographies entitled with the name of the person written about. The name of course is not the full story; indeed doesn't even necessarily tell the factual or true story. But, the name does contain a story of the person of sorts, at least from some perspective. One could, as well, recognize in each diagnosis a kind of story. The story contained in a diagnosis could be thought to narrate a particular health scenario. At the very least, *diagnosis* can be imagined as a story of signs and symptoms, a summary of laboratory results, an array of findings from standardized tests that may profile a fit in the rubric of categorical names. But in and of itself, any medical diagnosis like any biography limited solely to its title would make for a sorry story indeed. Without details of the person accounted for in the text, title as story is simply an abridged view; a one-liner, one dimensional, if not a one-sided "snapshot" of a much larger story not there. In this same sense, diagnosis (as name for disease) in and of itself is hollow. Without "person" what does it say? Every diagnosis (medical) must be attached to a living, breathing person to bring it to life. Indeed, isn't it the person who must fill in the details, bring it to its fullness and most complete description?

Jim relates his experience of diagnosis as "title known in advance of *him*." Script, too, was largely pre determined, set out like some intricate crossword design, a puzzle waiting for the blanks to drop into place. But where, in all this, was space for *Jim*. Where did his side of things fit in it? Where was he in *his* story of diagnosis? For all intents and purposes it was like he didn't exist. His version of things wasn't indulged. Even as he tried to tell *his* story it appeared to have little significance; seemingly went unheard. And so, the diagnosis wasn't about him. It was about anyone. Everyone and no one! And maybe that's what we really hear in Jim's statement, "gee, I guess I'm just one of those people over there!"

That's the thing with names and titles! I sometimes find myself scanning the newspaper headlines, subtitles of articles; trying to sift the actual story from the one-liners I pick up on. There is tendency to assume I know the heart of the story from the name/title alone. But I do realize this is giving secondary credence to the body of the story, not unlike the assumption of knowing a person only by knowing their name. It's like grabbing a glimpse; having just the introduction and taking it as the whole story; like limiting the read to the jacket of a hardcover book. Getting to know someone is allowing them to know me, opening to the possibilities of being drawn in, touching the other in a way that they too might feel free to fill in their story. It is the telling and the hearing of our happenings; where we have been in life; plan to be, and much more. In effect, it's getting some eye-witness account of that which is wrapped up in the names we carry and become; even *all* that went into the entitlement of our having *that* name. In relationship something is said of what it is for each of us "*to be*" who we are.

It could be said, *diagnosis* is a scientific accounting of things, medicine's side of a story. But shouldn't diagnosis be much more than a bottom-line statement? Can it ever be set in place remote from a person, in the manner of: "Sold as is!" A de facto term of text, would diagnosis be diagnosis or simply word?

Signs and symptoms seem an abridged kind of diagnosis; amounts to little more than words. Signs and symptoms are what one has; not what one is. And, that's what seems to rankle Jim; erupts in his comment: "It blew *me* away." This is a remark on the five-minute diagnosis that would de-legitimize him entirely, negate him from his diagnosis: his story! Put another way, it would take his story away from him; "blow him away." But, in actuality, can this ever be so?

For a good long time Jim felt de-legitimized by what the term *panic disorder* said to him about himself. He tried to resist a feeling of being negated and neutralized. At work he wrestled with the attitudes of coworkers, picking up on their glances and whispers: "There's a problem with Jim." In Jim's eyes, the diagnosis had made a caricature of him, something foreign, certainly something other than how he had known himself before.

c) To be "public" knowledge.

Jim never did try to hide his diagnosis from others. He would just say, "this is what I've got; this thing called Panic Attacks." At first *panic* did seem easier to say than *depression* but now Jim will just say, "I have this problem with depression." Of course, it's not like Jim ever would've been able to hide it all to begin with. Twice, the panic attacks had struck so severe that everyone at work thought he was having a heart attack. "They" had rushed Jim into the hospital by ambulance. So everybody knew there was a problem with Jim. Jim always felt conspicuous about this. Instead of having the choice about who would know about him he didn't have that opportunity to decide with whom he would or wouldn't share his story. In his case there was no secret. It was right out there: "Everybody knows who you are!" Indeed, aside from the ambulances blazing through town, Jim thinks, "they can see it in my eyes when I'm not feeling good. Some days my eyes will tell the tale." For the longest time, Jim would wear sunglasses!

Jim believed people didn't understand how hard it was for him to come back to work and try to get back to a sense of normal. They couldn't see that the diagnosis made him a very, very scared individual "trying to get his life back together." He worried they might think:

> *. . . you're hoaxing, or you're not working or whatever, 'cause you're trying to get free money . . . or you're kind of slacking off?*

On occasion Jim would overhear someone make a callous comment like, "well he's crazy," or something of that sort, and that would make him feel even more vulnerable. And, there was something about that word *depression* that to him sounded fragile. In Jim's mind, it conveyed a message to his coworkers that he was "a fragile person," perhaps, that he was weak and had to be treated with kid gloves:

> *. . . You always see that theme . . . the person walking around with circles under their eyes and all these other things. And at that time that's what I would be thinking they would be thinking of me . . . that's what would come to mind.*

Jim had never before thought of himself as fragile by any stretch, but that was "their" knowledge. That was the knowledge of the "public eye" and through it Jim believed he would portray that way, contrary to how he'd always seen himself. His private view was of himself as hardy and "head strong," at least, before all this. Then, he was somewhat of a "perfectionist," but never had he conceived of himself as fragile. Until now he had thought there wasn't anything he couldn't overcome, that is, if he did everything just right. And so, even with this knowledge of the illness, he believed he could beat it. He would do it by sheer determination if nothing else. He refused to be saddled with it; would not be known by *diagnosis* forever! The way out, he thought, was to "loose the meds":

> *I thought, "ok! So yeah!" You know, "I can get rid of this." . . . It would be like, "you get sick and you get over it. You get on." But I've tried to go off the meds and it doesn't work. Now it's like, "no, it's going to be there forever." I'm on the drug and I will have to always take something. I've tried it without it and it doesn't work.*

C. Diagnosis as call to become knowledgeable

"I thought I could beat it," says Jim, but he had to travel inward and listen to what beckoned to discover what "beating it" really meant. In fact, Jim had to come to a realization that there are worse things than being thought fragile. He now thinks it is much worse to be "frozen" by the illness. To stay frozen would be to forever feel broken, to never again feel whole and complete. Jim journeyed a course that taught him something of his ability to heal.

a) A story of healing.

> In 1981 Peter Cropper, The British violinist, was invited to Finland to play a special concert. As a personal favor to Peter, the Royal Academy of Music lent him their priceless 285-year-old Stradivarius for use in the concert. This rare instrument takes its name from the Italian violinmaker, Antonio Stradivarius. It is made of 80 pieces of special wood and covered with 30 coats of special varnish. Its beautiful sound has never been duplicated.
>
> When Peter Cropper got to Finland, an incredible nightmare took place. Going on stage, Peter tripped and fell. The violin broke into several pieces. Peter flew back to London in a state of shock.
>
> A master craftsmen, named Charles Beare, agreed to try to repair the violin. He worked endless hours on it. Finally he got it back together again. Then came the dreaded moment of truth. What would the violin sound like? Beare handed the violin to Peter Cropper. Peter's heart was pounding inside him as he picked up the bow and began to play. Those present could hardly believe their ears. Not only was the violin's sound excellent, but it actually seemed better than before.
>
> In the months ahead Cropper took the violin on a worldwide tour. Night after night the violin everyone thought was ruined forever drew standing ovations from concert audiences.

A Stradivarius is a precious thing, to be sure, but it cannot compare with the human spirit. Perhaps if every person experiencing diagnosis were treated as if they were a precious "treatment" they would be crafted to wellness. For the human spirit to heal requires response to this kind of craftsmanship, one that takes knowledge to knowledge-ability; to inner cultivation of a restorative belief, perhaps even to knowing there is nothing in life so broken that it cannot heal:

> *You're diagnosed and you can say "ok, I've got this and I'll take this and I'm just going to be in my little corner." Or, you can say, "I'm diagnosed. I'm going to get over it. And I'm going to live with it. And I'm going to see what I can do. And if there is something I can do, I'm going to do it."*

Here resonates a will to self agency, a response from deep within to stay the course and simply carry on one day at a time, in opposition to all that might lure one to stay frozen. In this way one is opened to a healing that may take one to something even "better than before."

b) Re interpreting one's narrative.

Jim wonders what he would be like if "it" had never happened. If he had never been diagnosed with his mental disorder, would he be involved in the things he is now involved in? And, would he be as tolerant of people and of the differences in people, as he now is? You see, Jim believes he has "kind of changed as a person," as a result of it. *Before*, he would never have said: "Oh, I'll give you a hand with that!" or, "I'll volunteer to do that!" He would never have done that. But now, Jim is more willing to be involved in things he feels need to be done for people, and specifically for "those people." But perhaps, that is the greatest change. Jim no longer thinks of them as "*those people*." Since his own diagnosis with mental illness Jim's view has shifted. He now "knows" differently. He has, in a particular way, become knowledgeable. To him, it's not *them* and *us* anymore. It's just ***us***. "They're us," he says:

> *They're just people. Like um, before I was diagnosed I would say, "these people." But I think that now, it's not these people. It's just people. . . It's "us!"*

Responding to his *diagnosis* in this way has given Jim opportunity to fill in the question mark about himself, perhaps, to even embrace what he has, as prospect to increasingly see *who he is.* Sometimes he sort of feels that "it" was supposed to happen so that he could get in touch with himself. When he was first going through the worst of it, it didn't feel that way. In fact it almost felt like he didn't exist. He dwelt in helplessness and saw nothing he could do about it. Then Jim looked beyond his fear and he saw in the knowledge of diagnosis that there was much more to see. His knowledge became enabling in helping him interpret anew, "*his* story." And, in coming to value what diagnosis has brought to his story Jim seems comforted and able to embrace his place with others:

> Your story is your only possession no one can take from you. Your story is the source of your strength. Your story is your map - of where you have been - and where you are going. Telling your story is like making a pot out of a lump of clay - your story is a vessel to hold memory and to shape meaning. . . . What holds <u>you</u> together is your story — the common and simple, the complex and profound story that you have lived, and are living today (Scarfe, 1996, p. 6).

Jim is now able to talk about his diagnosis and in some sense has even come to embrace it as a *calling*, perhaps a calling to live life in more meaningful ways. The diagnosis, he notes, has given a context to his world and to "who" he is. It has in that way given shape to his story, a story yet in progress. In his day-to-day living Jim fashions his "story" with more care than he used to. Diagnosis has heightened his sensibilities about those things that most matter to him.

No longer does Jim edit painful parts from his story, parts that might speak to his diagnosis. Instead, he owns it unabridged. It is "his story," and ultimately in it is his source of strength.

CHAPTER EIGHT

"To Be Diagnosed": Shaping A Composite Portrait

How does one conclude a thesis like this? I propose to conclude this exploration on a personal note by reflecting on my own experience of an early diagnosis. Having now been long with the question of this research I come to realize that a strong impetus for my interest in this study may have generated from my own life-long lived-experience with a diagnosis. I have become aware that the question of diagnosis has in some sense "always" been there with me, but, rather silently so. The methodology lends an approach, opens a personal reflectivity. I'm put in touch with a diagnosis of my early childhood. "Poliomyelitis!" I'd not yet reached my second birthday.

Like a quiet shadow *that* diagnosis of "polio" has accompanied me. In subtle ways, (and not so subtle) I think it has been chronicled in my life. But largely, the reality of it had gone unnoted by me, considered almost incidental, like: "Oh yes, I have blue eyes instead of brown!" It was simply passed-over in my day-to-day living. Mostly I was just invested in the things of my daily life, hardly for a moment dwelling on "it." Now, attuning to my own reality I've become much more aware of a space within, one that made for the emergence of particular meanings woven around that early diagnosis of mine.

My space of reflectivity recognizes the visuals often associated with "polio." Flaccid muscles, traction, braces, casts, crutches, and so on. But mostly comes to mind President Roosevelt! Why do I always see him in my mind's eye, running "the" country from a wheelchair? Then, it dawns that *that* diagnosis of "poliomyelitis" locates me in "that" era; places me in a context of the medical and social happenings of the "day." It was the aftermath of Pearl Harbor and Hiroshima, of Normandy and "D-day." It was a time of "science and discovery," of penicillin, and insulin, of Sigmund Freud, and the first human kidney machine. It was a time of the iron lung and, of "polio." In my reflections I am situated in that time frame.

Then, I ponder the name of that illness and how it may account for certain perceptions I have of my body; the adequacy of its "parts," the parts of "me" for which I compensate. Sometimes the diagnosis gives me a source on which to fix frustration; anger for certain deficits, things I'm unable to accomplish or can't get to work. It thereby, in some ways affords me allowable margins I may not otherwise have. I think, now, *that* diagnosis may even have figured in my character development; for example, in how I perceive my overall capabilities, in how I think others might take measure of me. How very often I have heard the dubious commendation: "You certainly are a very determined person!" Somehow I wonder the connection between that character trait and that early diagnosis. Instinctively *my* "lived-experience" tells me there is one.

Now, these are not astounding realizations but they are relatively new in that I have only recently given pause to them. I come now, these many years later, to grasp through my early diagnosis, something different about myself; something I had not realized before, something tightly related to having had a disease way back then that carried with it a particular medical name. *Diagnosis*, created a personal milieu for my life. The word for that illness has never lost significance. Indeed, it even reemerges particularly relevant in "health care" today with the advent of "post polio" symptoms. I even toy with the possibility that it wasn't really polio that I had. But "what else?" How would that ever be checked out? How would I ever know for sure? And, more curious, why should I even care about that now? Does it really matter? Well – yes. I think it does because the information contained in the "name of *that* diagnosis" might explain some things to me; may possibly reveal details to me about myself. I think I would like to know all *that!* But, I resign myself to the "impossibility" of it.

And, all this reflectivity on *my* diagnosis at an age and stage of life when I had felt complacent in my own sense of knowing self! I would not have these particular thoughts had I not had that particular diagnosis. Paradoxically, I come to see two sides of that diagnosis. On the one hand it presents a touch of uncertain curiosity. On the other hand it affirms "who I am." And, certainly because of "it" I see that I am moved in my quest of this thesis question, and now turn to a summary of salient features that have shown in this study.

A Wide-angle View of This Study

Diagnosis as a "contextualizing" force.

In this study, diagnostic formulations presented as subtle"evolutions of influence over time." There was evident throughout, an interface of a particular "diagnostic nomen" with a particular personality. An individual was being shaped by the experience, constantly becoming other than, who he or she was a moment ago. Person-diagnosis in synchronous formation! One could not have separated one from the other.

Throughout this thesis certain themes of *diagnosis* resurfaced to manifest uniquely, relevant to whomever was in focus. Themes presenting in chapter three, for example, were seen to surface again, in latent fashion or otherwise, in subsequent chapters. Thus, we could see Matt's experience of diagnosis "***a knowing that knows***," actually, picking up on Julia's experience of a ***need to know for certain***. A *knowing that knows* is also, *there,* in Jean's story. We see it implicate in her struggle to accept her diagnosis; her effort to avert the *knowing* that tells her she has an ***unshakable and permanent mental illness.***

So incisive is the *knowing* of diagnosis that Cathy experiences it as ***being renamed***, a most fundamental kind of experience if we acknowledge the intimate nature of what it really is to be named. Then, in chapter five, Cheryl's experience of diagnosis highlights the theme of ***making visible the invisible***. Here we see etchings of what Teresa tells us she is denied. By Teresa's perception, she seeks but is denied diagnosis, thus, visibility. Related to the theme of visibility is Evelyn's story-theme in the guise of being ***re-integrated*** by diagnosis. Couldn't we say, in that sense, being re-integrated is re-establishing identity, gaining personal visibility?

Continuing our theme trek, we might take note that the ***unshakable permanence of mental illness*** again touches in Steven's story-theme of ***the destructive gift of difference***. Then, perhaps easiest of all is to see traces of all prior themes embraced in ***making the knowledge knowledgeable,*** dominant in Jim's story. Couldn't we say, after all, that it is *the knowledge* of diagnosis that becomes *knowledgeable knowledge* when it enables Cathy "to be whole again," when it helps Evelyn to feel increasing integration, gives Susan a sense of reinstated self, provides Julia certainty in knowing about herself? And, through Gary's theme of ***gaining self-knowledge*** we see perhaps most directly, *knowledgeable knowledge* in action. Because of diagnosis Gary is moved in "a totally different direction." "I have a good chance for what I couldn't have done before," he tells us. The knowledge of diagnosis informed Gary to what was happening to him and opened him to new possibilities for himself. Likewise, to Jeff diagnosis became enabling. It gave him "happy arms" through the ***comfort of a "battle-plan"*** by which to survive.

And so, we see the array of themes, small floodlights poised to highlight the experience of *diagnosis*. For no participant in this study was *diagnosis* inconsequential. Each took on an altered countenance to life because of it; each was shaped and reshaped through the crucible of his or her diagnosis. Too, at different points we note the diagnosis *giving* as well as *taking-on* distinction, somewhat like the child becoming what "his" name stands for, but, from the alternate view, the name also coming to mean something different from what it originally did. *That* holds with a diagnosis (name) that molds to the uniqueness characterizing the person with whom it interacts. We do see a kind of malleable quality to *diagnosis* as it shapes to the person while shaping that person. Perhaps it is this malleability that allows for the varied and sometimes even contradictory meanings that are seen to surface from it, even to the same person. Steven, for example, experienced diagnosis as limiting him to, "mentally ill person," in that sense destroying the "gift" it distinguished him as having. To Cheryl diagnosis extinguished her hope but also served as a benevolent depository for unsavory experiences. Matt saw in diagnosis his worst terror but at the same time it established for him a fundamental sense of grounding. And, Jim felt stripped of his identity by diagnosis, but he recognized it also empowered him to rise above and go beyond who he might have otherwise been.

So it was with all participants, each realizing specific though sometimes contrary meanings to his or her experience of *diagnosis*. None could look back without seeing *diagnosis* as an identifiable force that had accounted for changes of being and of character. *Diagnosis* had altered existence! Somewhat like the influences in the "Mending Wall" (Frost, 2000) that alter the earth's terrain, diagnosis was an insistent force, powering subtle transformations to one's being and way of being in the world:

> Something there is that doesn't love a wall,
> That sends the frozen-ground-swell under it,
> And spills the upper boulders in the sun,
> And makes gaps even two can pass abreast.

Winter frost, analogous to the determined forces within "the word" (i.e. diagnosis) heaves and presses against resistance (and counter resistance), setting context to which the being must respond. And so come forth the themes of response, themes addressed individually. It is not to say that they should be viewed as items separate one from the other, or that they couldn't with some effort be viewed conjointly. Indeed, we have seen weave and over-lap already. But for the most part each theme was left to create its own path in this study, as Heidegger would say, its own woodcut through the dense forest.

Each converges to that central area, illuminating a clearing in the forest that is the phenomenon of "what it is to be diagnosed with a severe and enduring mental illness?"

Discussing the essential and incidental themes that emerged from this study can be undertaken by converging them under a common heading of "broken ness." A discussion under this header can facilitate consideration of "care" implications in that the experience of diagnosis seems largely one of change that springs from "broken ness." If we carefully attend to the stories we note that *broken ness* permeating the stories. Steven's statement, "It makes you feel sick," in a sense captures *that* thread of brokenness. But we also hear it more patently typified by the many references to "glass," such as in Kevin's remark "It shattered me." Drawn into focus, then, we see *broken ness* layering its way through the participant's experiences. Broken ness of history, of relationship, of space, of future, of self-narrative, of spirit! Always a broken ness to heal.

Perhaps the notion of broken ness associated with the experience of diagnosis, is not surprising given the word "diagnosis" itself etymologically intones separation. Comprised of the two root elements "dia" and "gnosis," each is noted to carry distinct meanings. Already noted in a prior chapter, "gnostic" derives from the Greek gnostikos meaning "one who knows." Accordingly, that element gives literal meaning to *diagnosis*: "to know thoroughly." But, it is the element *dia* that, at this juncture, may be the more relevant to informing the current notions of broken ness. Klein's (1971) dictionary cites "dia" as a prefix, meaning "through; thoroughly, entirely, utterly." It derives from the word "twice," originally meaning "divided in the middle" (p. 209). In other words, what was once perceived as *one* is now seen as *two*. This note of divisiveness is seen in many words that contain the prefix dia, such as *dia*eresis (dissection . . .), *dia*gonal (transverse crosswise . . .), *dia*per (waistband . . .). A *dia*meter in geometry is a bisector or straight line that cuts through the middle of something. A *dia*critical remark is one that differentiates and, in human biology a *dia*phragm separates the abdominal cavity from the thoracic cavity. So, extending this to "diagnosis" it is not difficult to relate to the experience of it as a kind of knowledge that has the potential to create a sense of division; to result in a feeling of estrangement from a familiar self.

Forthcoming sections speak to the varied themes attended to throughout this study collectively, as they relate to this sense of broken ness, a broken ness viewed essentially as a disruption of relationship with one's perceived "self." "Broken ness through knowing," "broken ness through de-legitimization," and, "*diagnosis* mending broken ness" are notions brought to focus, each then considered within the context of a discerning practice. In such a way, "discernment" is characterized as the "practical wisdom" (Van Manen, 1990) derived from this study that is most consequential to practice.

Diagnosis inducing a broken ness.

To this point it has been noted that broken ness in the experience of diagnosis opens areas to significant need for healing. To stimulate a grasp of the nature of the healing required, we could take cue from Dawn Francis' (unpublished document, 1999) insights in terms of interrupted "embodiment." In recounting her experience of unexpected disruption to "body narrative" following her stroke Francis tells us:

> . . . time, by which I had regulated my former life, had ceased to be important. . . . I had entered the world of the powerless. . . . My world had become, in an instant, *that* inhabited by medical experts and professional carers, imbued with discourses of science treating the . . . pathology . . .

For the first time in Francis' adult life she was totally dependent on others. She makes particular mention of the dis-empowering effects of having herself carved up into different parts, as separate sites of diagnosis. Says Francis, "diagnosis of any illness that involves pain inscribes the body so that the mind-body can no longer be seen as separated" (p. 8). Holding to the spirit of that remark, we take its intent is to convey that diagnosis of *all* illnesses involve pain, though the nature of the pain may vary. The crucial point being made by Francis would seem to be that the inscription of pain, in whichever experience, is not autonomous of the self. The pain is not "buried somewhere in the brain . . . it has become self!" (p. 8). Further, says Francis, the world is related to and given meaning through the inscribed pain that has reconstituted the self.

The message of embodiment gained from Francis' story seems a powerful one perhaps more easily grasped in the context of biomedical disorders. Translation to the realm of diagnoses specific to psychiatric disorders is, however, more difficult, especially if these disorders are conceived (as they often are) as "problem(s) to be diagnosed" (Kleinman, Brodwin, Good, & Del Vecchio Good, 1994). In such instance, there is easy inclination to see "the holistic nature of the embodied experience fragmented into a series of dichotomies . . . physiological, psychological; body, soul; mind, body . . . dichotomies . . ." (p. 8). One might recognize proclivity to such inclination in mental-health care.

Like Dawn Francis who experiences disruption to "body narrative," we can see in the various experiences of "diagnosed mental illness" a disruption to "self narrative." We saw Jim, for example, frightened at the nature of the news brought to him by his diagnosis; a feeling of estrangement descended on him leaving him the question: "Who am I?" To be diagnosed meant he had to question the ways his body/mind had let him down. His sense of "self" betrayal left him floundering. How was he ever to trust his body, *himself*, again? But, herein may rest major distinction in how psychiatric diagnoses are personally experienced. Vivid in the stories is the notion that being diagnosed with mental illness is a significant characterlogical pronouncement; on "ME." Diagnosis of biologic disorders would not generally be related that way. Diagnoses of biologic disorders are thought by participants in this study to be more a pronouncement on the functioning of some aspect of "body." They made repeated reference to "the person with diabetes" or, "the person with a broken leg." These kind of diagnoses weren't thought of as judgements on the "holistic self." A psychiatric diagnosis on the other hand, was said to be like a dictum on the entire "being." The diagnosis was oft talked of, by those in this study, as a judgement on the "ME," perhaps because the brain is generally deemed the center for the expression of "who I am," as a being. The brain explains "you to you," so to speak, me to me. I suppose this can translate in poignant ways if one hears through diagnosis that one's brain is dysfunctional; in essence one's malfunctioning brain is causing one's senses to lie to them. One is thus being told they have no reliable way of knowing the "self." If "I" am being told *that* then I am being put on notice that all incoming perceptions to me are unreliable. With psychiatric diagnosis that is what can be heard; the message that one has no reliable way of *being* or of defining oneself, except possibly to rely on the word of an "other." I'm being put in a position of having to consult, even defer to someone else's definition of "who I am," so to speak; a determination of a "me," who in my opinion, may or may not even correspond to who or how I view myself to *actually be*!

Carried to the extreme, wouldn't *psychiatric diagnosis* suggest that "I" must submit, on the issue of "who am I" to the determination of someone else? To Jim, however, the diagnosis was experienced as saying he didn't know who he was and that *he didn't even know that he didn't know it!* Cheryl is so stunned at this same realization she becomes "dumbfounded." So it was with others as well, each having to accept that what was being perceived by "the" brain about "who they were," about the nature of their world and how they were experiencing it, was basically unreliable. In other words, the diagnosis would be telling "me" that my brain and my perceptions must be preempted in favor of external "more reliable" readings. One's locus of control is in that way displaced to outside one's self, at least that is so if one is to have the assurance of "a world as it really is." Does this not pose incredible loss of freedom announced by diagnosis, an unparalleled sense of broken self-sufficiency? Indeed, by Francis, "needing another person, when that threatens one's identity as self sufficient and autonomous can be experienced as a kind of violence against the self" (Frosh, 1995, p. 226 in Francis, unpublished paper).

Perhaps it goes further yet, because in the diagnosis "I" hear that my brain's unreliability is not so all the time. In other words, at some times my brain may function reliably and at other times, not. Conveyed is the expectation that I second guess myself; decide when and in what circumstances *my* brain-readings are reliable (and can be acted on) and, conversely, when and in what circumstances they are not. Essentially, what "I" am told is that my sensitive brain is functioning like "a misinformant," but not at all times. The uncertainty of it requires I relinquish internal control to an external locus of control (e.g. family, care team) that will monitor my choices and activities. Others, then, must be relied on to mediate "me." In the end, I am also expected to function independently and responsibly, an onerous task, given "I" am told to operate in all this with an unreliably functioning brain. Isn't it tantamount to being told to describe "light" while in the same voice being told "you're blind?" In that predicament "I" wonder: isn't that an unreasonable expectation? Or not! Perhaps the entire dilemma simply generates from "my" dysfunctional brain?

But to be diagnosed can be experienced as a sense of liberation too. It can present as comforting in that finally "I" have explanation for those puzzling and frightening things that have been happening. We've seen that in *diagnosis* too. And that's also what makes *diagnosis* in "mental illness" its own particularity. It seems a statement that can validate "me" and invalidate me, make me visible and invisible, and, even do both at the same time? It can credit yet discredit my experience of self; affirm yet undermine my entire experience of world, give me gift with one hand and take it with the other. "How" I might ask myself, "can I *be* in the world with such contrary baselines for being in it?" How does one's *self* serve *oneself* when one is told, through diagnosis, they are gripped and being misguided by a misinforming brain? Now, this sense of threatened personal legitimacy isn't noted with diagnoses of other body systems. *Legitimization* may, indeed, play in the experience of all diagnoses of sickness but the pervasive uncertainties created by psychiatric diagnosis seemingly fracture in ways that circulate about one's intimate sense of personal being. Need for *knowledgeable knowledge* to effect healing may, thus, be of a particular kind.

And so different facets of broken ness associated with the experience of diagnosis profile a derailment of self from the self one had before known. At this point one could elect to a conceptual mode of summary about the notion of broken ness, but, it seems in keeping with the tenor of this phenomenology more appropriate to gather voices of participants and allow broken ness to speak through them.

Broken ness through knowing.

Receiving the knowledge that a psychiatric diagnosis brings may well result in a knowing which can separate and divide "self" and "life." The following examples show marked confusion in knowing self:

i. "All of a sudden I felt like a big question mark!"
"I wondered: Who am I?" (Jim)
ii. "Life as I now knew it just had completely ended!" (Cathy)
iii. "Oh my God, I have no idea who I am anymore!"
"The self I thought I was isn't!" (Evelyn)

i. Early on with *diagnosis* we saw that Jim's sense of self and future was affronted in a way he had never expected. He felt in no way prepared to deal with a diagnosis that gave him news of which he was terrified. He had to figure out what he was going to do with all that, with what the knowledge said about him. He had always been the sort of guy that "smiled a lot." But he didn't smile very much anymore for a very long time. After hearing the diagnosis he "wasn't very happy." His world had quite suddenly shifted and he felt altogether different. He would long for how things used to be, telling us wistfully, "I just want to be me again! . . . I want the old guy back."

ii. With the diagnosis, and even because of it, for Cathy the truth of things eventually came to a psychiatric diagnosis that brought with it a whole process of coming to terms with the fact that there had been horrendous abuse in her childhood. It meant she would have to go back and relive it all; connect to all the emotion and trauma that was there and, accept the brutality *that* was really there. Cathy had wanted something a five-minute prayer could cure but she couldn't escape *a knowing that knows;* a diagnosis that said there wouldn't be an easy mend. The diagnosis said it would be more like opening up old wounds that had festered and scabbed over, and taking a look at what was to ooze out of them. That's what was written in the knowledge; what would be needed so that healing could happen from the inside out.

iii. Evelyn had always felt she had a strong sense of "who she was" but the diagnosis brings her to a sense of great confusion. All of a sudden she doesn't know who she is and she is very frightened by this. She feels like her identity is taken away and she has no notion of who she is anymore (becomes invisible). As her story progresses we eventually see diagnosis bringing her to integration.

Before diagnosis, there was a continuity of *knowing* for Jim, Cathy, and Evelyn, (albeit a turbulent knowing). We see the experience of *severance* introduced to them by diagnosis, *a knowing that knows*. Herein is a *knowing* that fractures, because it results in rupture of customary ways of knowing of "self" and world. *This* break is distinct from what may be happening to "the self" as a result of the illness. We note the fracture of diagnosis results from "pure knowing"; from hearing a medical term that is taken to be absolute and unquestionable knowledge. Dread of this *knowing* is most evident in Matt's experience (chapter four). Matt expresses "petrifying" fear. Diagnosis, to him, carries stronger impact than that of illness. Matt could cope with the illness as long as it was cloaked in the everyday term "bizarre experience." But the medical term: "Psychopath!" Psychotic!" "Bipolar!" That's what forecasted everlasting doom; would carry a *living* sentence. *Diagnosis* was the real dread. Matt's "self" may indeed be fissured from the effects of illness/disorder, but the fracture of "knowing self" seems to set off his deepest tremor.

Similarly, we see represented in the anecdotes issues beyond that of "illness." In each case, *self* may truly have been assaulted by the illness. What rings in the statements, though, is the fracture induced by *diagnosis*; specifically, the torn perception of known "self" and the rend in usual ways of knowing one's way of being in the world! Diagnosis is *the thing* that happens, the thing that intersects life! Isn't it *that* news that attests to the clear through slicing of one's regular *knowing ness*? Of all that is significant to the experience of being diagnosed it seems that *that* absolute knowing most disrupts the sensibilities. And, isn't it ironic that "*a knowing that knows*" can stand for such disturbance; can yield such a personal sense of "not knowing anything at all!" It might be likened to finding oneself, at least temporarily, in a pitch-black universe.

Broken ness through de-legitimization.

Alluding to "a dysfunctional brain" in an earlier section, brought to light some of what it may be to experience having a de-legitimized baseline for being. What is hidden from direct gaze may, indeed, be the greatest cause of de-legitimization in the experience of psychiatric diagnoses. Where little "hard evidence" exists all may feel hard-pressed to "legitimize" and tolerate manifestations of aberrant thought and conduct. "Will-power," "learning," "lack of character" may be faulted. In that light, prevailing attitudes and de-legitimizing beliefs flourish. And yet, how vital "legitimization" is to wellbeing! How critical to health and healing! In the ordinary sense, to legitimize something is to give it justification (Oxford Dictionary), to make it legitimate by making it logically acceptable: to make it allowable, to accept or approve it, all that in this study would "*make visible*." By the same token, wouldn't the converse hold? To de-legitimize something would be to make invisible, would invalidate by making illogical and therefore unacceptable. In this vein *legitimization* may be a distinct keynote in this study.

We saw in Steven's story: "Diagnosis as the experience of destructive gift of difference," a kind of broken ness where he at once felt extended a gift (legitimizing) that at the same time was de-legitimizing to him. In that sense, the gift, his essential uniqueness, was destroyed by diagnosis. Other participants experienced de-legitimization as "a slippage from visibility," a sense of no longer being at home with a self as a known self! What became problematic in this was not limited to estrangement from known beliefs about one's world. We see in the expressions that follow a feeling of being personally fragmented; even torn from a sense of person-hood:

i. "When they name the mental illness it denies you a being." (Irene)
ii. "It's becoming a statement." (Susan)
iii. "It's like breaking a glass!" (Kevin)

> i. Hearing the diagnosis stripped Irene of "being." She remembers feeling very vulnerable, of hearing the diagnosis and thinking, "today I feel like a newborn baby." . . . You know, a newborn child is very vulnerable. Everything is seen through new eyes. In the back of my mind I would say to myself, "I've got to watch what it is I do." Because I was afraid of anything that might precipitate it again. And I wanted to be safe. . . . It's as though the diagnosis is always over your shoulder. . . . It just makes me understand that the naming is a description by a person not involved in the experience. So that, it gives them confirmation about what's going on. But it doesn't allow them any understanding of what happened during that experience. . . . I don't think it gave me anything constructive.
>
> So when Irene says the name "denies you a being" isn't she saying the diagnosis denied her experience in the way that *she* experienced it? In that sense she too would experience invisibility; be bereft of "self!" She describes this as now being like a newborn baby, entirely vulnerable and having to re establish identity. The diagnosis says what the unfounded occurrence was. But the diagnosis is experienced as absence of explanation to her. It creates unparalleled insecurity. To Irene the real sting is in the much more that is left unsaid by diagnosis. Ironically, Irene sees that the seeing of diagnosis is in what it doesn't see. In this it is de-legitimizing. Its limitation creates this; by what remains undisclosed. Irene experiences it's restricted knowing as deceptive; creating illusion of a knowing while leaving things that would be important to her, hidden.
>
> ii. Susan was hospitalized in a small rural hospital close to her hometown. It was during her first hospitalization that she became aware of a shift of attitude by professionals with whom she had once worked. With diagnosis, she experienced herself as simply "a statement" in their eyes; a patient with a mental illness.

> *The girls [nurses she knew from her hometown] wouldn't talk to me when they brought me my [meal] tray. I remember thinking things like, you know, if I had a broken leg, people would walk in here and say: "gee Susan, you broke your leg! It's okay. . . . It will heal. You'll get better. Life will go on."*

But nothing of the sort happened. Instead Susan perceived an attitude of indifference, "a huge wall of silence" between her and those with who she had once felt closeness. She might have returned to her former job but for this. "I knew," she says, "I had nothing to be ashamed of. I hadn't asked for this illness." But, there was something about that mentality, that wall of silence that made her feel less than the person she had been; made her invisible. "Nobody asked about it so, I pretended it wasn't part of my life," she says.

iii. From early childhood Kevin thought he was haunted by demons. "I thought, "how come I'm hearing voices? It must be demons." Kevin talks about the terror of the demons throughout his childhood, then, finally his initial but unpleasant contacts with health care. At age nineteen he reaches the first point of hearing his diagnosis:

> *The doctor told me, "You have schizophrenia!" . . . I think I had the doctor write it down on a piece of paper-- SCHIZOPHRENIA. Then I went to the library. And I checked it out. And then I started to get more and more angry about it? I was angry at the label.*

Kevin hears a cruel culmination of his childhood misery, a childhood marred by abandonment and abuses, a life besieged by "demons" that haunted him. He flounders for words to express his feeling, at learning *that* diagnosis. Seizing a blue flow-pen from the table, Kevin scrawls a thick, heavy jagged blue line across a sheet of paper (see figure Kevin). "It's like this," he says, comparing it to a second softer flowing line. To hear that diagnosis, "it was like breaking a glass. It shattered me." Here Kevin's sense of *broken ness* comes through. Yes, the diagnosis does explain the terror and the horrible demons. Even so, to Kevin, the label rankles and deepens his sense of dejection. He feels devastated by a pejorative label. For Kevin, there's no comfort in knowing about his illness. In diagnosis there is only a crushing sense of de-legitimized being.

But, beyond de-legitimization we've also seen throughout this study stories of mended broken ness initiated by diagnosis. We turn now to those whose healing was instated by *diagnosis*, who, like Cheryl had lost "visibility" and then were "made visible."

figure Kevin

Diagnosis mending broken ness.

To some, for whom "life had become impossible," who had indeed lost sight and yearned to "touch the reality of their being," diagnosis was a life-giving source. In the voice of one participant, "It was like breathing and feeling the air come in." In this sense what had become invisible was made visible. "Diagnosis" was ***knowledge made knowledgeable***, truly liberating in that it represented a kind of knowing that slides in a new lens for understanding "self":

i. "Parts of my life never did fit together." "My life doesn't work!" (Teresa)
ii. "It goes to knowing what's wrong with you!" (Julia)
iii. "The contrast here is *DEAD* or *ALIVE*: It's just that clear!" (Jean)

i. Teresa knew for many years that something was amiss with her. Problems that started in childhood became unbearable by early adulthood when she began hearing voices. "I'd been in the park and I heard these voices," she says. "And I looked around and there was nobody there. And I was standing by a shed so I went around the shed about six times to make sure that I wasn't just overhearing somebody that was also walking around the shed. And finally I determined that I'm alone. . . . And so I'm telling him (the doctor) about this and he said, "you need to know that if you talk like that they'll lock you up." And so I shut up for another six years. I never said anything to anybody. . . . And the voices continued. I heard them all the time. It was like an ongoing dialogue in my head; constantly. . . . And I kept saying to therapist after therapist, "what do you think is wrong with me? . . . There has to be something somewhere that says what was wrong with me!" . . . And I mean I wanted to screech! Doctor after doctor and always I got nowhere; found out nothing."

Then, years after the turmoil all began Teresa is given a diagnosis of her disorder. Her relief is summed in the words, "Finally I knew!" With diagnosis withheld she had come into hospital with the attitude: "I'm going to find a little black hole somewhere and I'm going to crawl into it and I'm never going to see the light of day again. I had really given up!" But, with the diagnosis (thus appropriate treatment) Teresa finally felt "put together" enough to go back out and make a life. "I've never been admitted since," she says.

ii. The diagnosis had tremendous explanatory power for Julia. For starters, it said something about her state of sanity. Before she was diagnosed she thought she was either depressed and having false memory syndrome, or she was having post-traumatic symptoms consequent to childhood abuses or, she was psychotic and totally had lost her touch with reality. Having the name for what it was (the diagnosis) was immensely important to Julia. "Its that whole thing, if you can name it, you can claim it, you can

> tame it kind of thing. It goes to just knowing what's wrong with you. Like, when I had ovarian tumors I wanted to know their names. You know: Was it a functional cyst? Was it benign? What was it? The name could tell me those kinds of things, more of the details. . . . With *this* (psychiatric diagnosis) the biggest thing was that it was relevant to my perception of myself, my world, and my environment."
>
> For Julia, "to know" was legitimizing because it was consequential to her taking ownership for managing the disorder and moving on to a healthier functionality.
>
> iii. Jean's first, "oh my gosh! I'm in big trouble" seemed to happen after she had her first child. Her roller coaster life continued for the next thirteen years. There were the "ups" when she just had lots of energy and felt good. But then she would crash. Crashing meant crying all the time and feeling out of control. Life was about ups and then downs that came really fast and really hard; when hiding-out in the bedroom was all that could be managed. During these times she didn't want to see anyone. There was, "massive insecurity, massive self-doubt, crying. . . . I felt like I was going to die. I couldn't breath. . . . I thought my heart was going to start racing so fast it was going to stop."
>
> The pattern went on and on and nothing seemed to level Jean's moods. "Its a real tiring feeling to feel that way all the time," she says: "That doom kind of feeling! This cloud hung over me all the time. Sometimes it sat on my chest. It was really awful. It was always there. I was always really worried. I was always going through this, 'what's going on? Somebody help me. Can anybody tell me?' I felt really fragmented and I was just terrified." Apprehending and accepting the diagnosis was making a choice between life and death. That's what it came down to! Diagnosis, *a knowledge that knows*, intervened. Diagnosis, was knowledge that mended (made visible), knowledge that enabled! We see that joyfully expressed by Jeff in his "after diagnosis" illustration of *happy arms.* (see figure Jeff).

Recognizable in each of these exemplars is a sense of affirmation. Through confirmation of "non normal" happenings and legitimizing of "symptoms," providing a name confirmed the reality of sickness, and *that* could lead to treatment (Tishelman & Sachs, 1998). In each case the diagnosis introduced the person to an affirmation of self whereby life could move to new "centering." By having the disorder named, new order was made possible. From "non diagnosis" to diagnosis evolved knowledgeable knowledge, an opening for re-interpreting self and life and reorganizing one's world. The experience seems, in these cases, essentially one of "cohering"; anticipated rescue from inner battle; a way to mend; a way, again, to become whole.

Looking To The View Of Practice

In bringing the entirety of this study under review, what has become ever clear are the number of polarities that present in the range of experiences of *diagnosis*. We saw, for example, that some persons experienced the force of diagnosis as de-legitimizing while others experienced it as legitimizing, and still others as both legitimizing and de-legitimizing at different times and in different respects. Some were caused to be "invisible," others "visible," and so forth. Apparent in *diagnosis*, then, is this potential to stimulate a number of extremes or the gradations thereof tending to either extreme. The idea of paired opposites within the experience may, of itself, be an issue of significance. It may be exactly *that* which prompts for "change." In the context of the therapeutic relationship it should, therefore, not be under-regarded as a significant factor. One could assume, the nature of the responses within the dualities of experiencing *diagnosis* has to do with "dialectical tensions" (Altman, Vinsel, & Brown, 1981). This takes the experience of diagnosis well beyond simply comprehending a message contained in it. It recognizes the experience as one of struggle, within the pull of each polarity, with contradictions and adaptations required for self re-structure in light of this.

Aside from the dialectical tensions party to the experience are the influences of what is brought to that event of diagnosis by all parties concerned. From the stories one can identify great influence brought to bear from at least three sources: "Conveyer of diagnosis," "Recipient of diagnosis," and "Nature of the diagnosis." In the end, it may well be the "inter-actional" effects amongst all of these, more than any single influence, that impacts in the arena of health care practice.

With these prefacing comments we now come to the critical question of this concluding chapter: "Of what use to professional practice has it been to do this study?" What have we arrived at through it? Is it of any particular value? For all our delving of "the question," is there anything garnered that will take health care practices to another level and really make a difference to health care? Perhaps answer lies in *what,* of the study, will enter into humanizing the experience of *diagnosis* for persons' involved.

Humanizing the force of diagnosis.

In conversation, participants of this study gave entry to their "lifeworld"; allowed us glimpse of their lived-experience through personal descriptions of "being diagnosed." So we now ask, has anything really been gained beyond "*text*?" What could be done with just text? Is there anything at all of practical value to this phenomenology? Some might say nothing can really be done with phenomenological knowledge, let alone with the knowledge of this particular phenomenology. But, if we were able to ask Heidegger, what would he say? In all likelihood he would say the vital question is not: "Can we do something with this phenomenology? Rather, the real question we should wonder about is, 'Can phenomenology, if we concern ourselves deeply with it, *do* something with us'" (Van Manen, 1990)? And so we are prompted to look to this phenomenological study of "being diagnosed" and ask, "what can it do with us?" If *the experience* of being diagnosed rings of ***broken ness*** and, "the only way out is through" (Bierlein, 1999, p.

111), then, what might there be of use to us that would enable us to better assist that journey *through*?

If anything at all has been gained from this study, perhaps it is best reflected by the word "discernment." One could hope a more refined sense of *discernment* is what primarily obtains from this study. "Discernment is the ability to be able to judge which things of a particular kind are good and which are bad " (Colbuild, 1988, p. 398). It is associated with words such as "detect," "know," "see," "understand." Wouldn't discernment, then, be what helps us to a practical sensitivity with respect to persons facing, or in the prospect of facing *diagnosis?* Wouldn't *discernment* attune us to be helpful instruments of *mending*, better equip us in assisting with the healing of broken ness; make us a little wiser in our dealings with "such" situations –in other words, better enable us to humanize the force of that which is "the experience of diagnosis?"

One would assume care-providers with honed discernment would be attuned to the subtleties in situations in order to judge wisely in "care." So discernment is the hoped for outcome that is now brought to the spotlight; *that* something arrived at through this phenomenology. It behooves us to look more closely at "discernment," particularly as it relates to the *broken ness* that courses through the themes within this study: **broken ness through *knowing***; **broken ness through de-legitimization**; and, **diagnosis mending broken ness**. In addressing discernment as it relates to each of these modes of broken ness we will, in turn, be touching on all presenting study themes.

Discernment in "broken ness through *knowing*."

Incumbent on *discernment,* as a product of this study, is wakening to the strength of the *knowing* that is carried in diagnosis. Chapter four highlights "*diagnosis as the experience of a knowing that knows*" bringing to the fore the force of that knowing to Matt. We also find impact of that forceful knowledge of diagnosis vividly expressed by Kevin and Susan, who use identical words: "It was like a knife to the heart" to register the fierce effect it had on them. By these words diagnosis is said to pierce to the center of life and being. Jim, too, refers to a similar potency in diagnosis, attributing a loss of self to the "the knowing" that has utterly changed the perception of the Jim that was familiar to him. A discerning attitude would pick up on the depth of the loss expressed in his comment: "I want the old guy back." One detects, here, a longing for the familiar self that is gone; a wistful-ness for all that might have been possible had diagnosis not entered in. One senses a lost way of being; a need to grieve all that "was" and all that is now viewed as beyond reach. "Discernment" is able to support the grief work that needs happen in the aftermath of diagnosis, and nurture the impulse to new possibilities within "the knowledge" of existing realities.

There is need to grieve the varied losses associated with the severe force of the knowing that is diagnosis. Diagnosis brings to light Cathy's need to mourn a lost childhood; her need for support to confront the awfulness of childhood abuses. Evelyn, too, knows a kind of loss. The tact and sensitivity that reside in *discernment* may lend a disposition that guides Evelyn through fears and confusion introduced by *diagnosis*; a "knowing" that, to her, has "stolen" her sense of identity.

Shifts of insight made possible through this study open the potential to deal wisely yet realistically with those who, like Matt, are terrified beyond belief about what they have just learned through diagnosis. Discernment knows that in time and with support "all is not lost" and fear can be transcended. New trust can be nourished and, re-trust in the viability of "one's own knowing-ness" in the face of this "almighty knowing-ness" that is diagnosis. If I, as care-practitioner, am discerning I am able to identify the needs of those who feel fouled by "*the knowing.*" I am positioned to help them regain a sense of self-assuredness. I can point out that even with what might feel like a sense of "knowing nothing," still, much *is* known, indeed, only known by the individual. This might be what needs the most reinforcement, that it is "they" who are the real experts, in this. In this event of diagnosis, they are expert on their own experience. The expertise of practitioners is a different kind of expertness, but it is "they" who need to share the uniqueness of their experience with "us." The discerning practitioner would take that stance, perhaps in that way convey authentic respect of the individual, thereby re-instate control to "them" and give balance to oft perceived power differentials in "the therapeutic relationship." Perhaps a spirit of discernment knows that in the individual case nothing is presumed; that it is in the individual case that true understanding takes shape.

As care-providers, if we are discerning are we not responsive to those who like Matt are terror stricken at the prospect of *diagnosis?* Do we not see that theirs is a need to "see it normal?" The practically wise care provider would be cognizant of this, would be more apt to have good timing when broaching conversation about diagnosis, would be thoughtful in deciding the most fruitful times to hear and learn more about what is "my" diagnosis. The discerning practitioner is attuned to what will relax the frenzy in the individual circumstance, what are the best conditions for receptivity to information, and how to language it most usefully. This practitioner may open conversation in the following manner:

> "The name of what's happening to you, might be telling you frightening things right now." "Try not to panic about this." "It's not the same for everyone." "What you've heard, or seen, or read are the experiences of others. Tell me yours."
>
> "I know you might be having frightening thoughts because of hearing your diagnosis. It's not unusual to be afraid." "What do you think might be the course of things for you that could be similar to what you've heard about others? What might be different for you from what you've heard about others?"
>
> "I know you are having frightening things happening to you right now because of the illness, that makes knowing your diagnosis hard to handle. It won't always be this way." "People *will* know you when you're well. You are not just *sickness*."
>
> "There might be a lot of worrying going on inside you right now because of hearing your diagnosis. What would be the most useful thing for you right now?"
>
> "It's very tiring to hear about this, and have everything going on inside you. What would help you right now to feel a little more in control over it?"

Participants related the least helpful approach was to be told: "Go lay down." Or, to be dismissed with, "Things will be ok." Comments like these made them feel passed-over, evaded, "talked-down-to" and did nothing to acknowledge the depth of the turmoil in their experience of being diagnosed.

Discernment knows that the *best* time to broach issues is often that which is signaled by the individual in need. *These* timely moments, set by the one who knows more than anyone else what is the "perceived need," are not necessarily convenient times for the care-provider, but if passed by, they are simply gone. Appreciating the potential depth of fear (guilt, loss, and the like) the discerning care-provider watches, listens, is *there* to pick-up on subtleties, seize cues as receptive moments. This care provider negotiates the sensitivities in perceptive fashion, perhaps acts as buffer to the fear through sheer presence, all the while keeping in mind the sharpness of this *knowing that knows.*

Isn't it discernment in situations of diagnosis that can help the vulnerable in their state of vulnerability to grope for stable grounding, as with Matt; direct his thinking to "what is real," intuitively anticipate what might trigger his "trembling" or, blur his base of reality. "*Discernment*" senses the need to confirm *the* uncertain in the face of diagnosis. Indeed, confirmation as the "process through which individuals are recognized, acknowledged, and endorsed" (Laing, 1961, p. 83) would seem a vital antidote to "fracture." Confirming Matt might help guide his way back from "post modern" to "modern" connected-ness. Caring discernment may facilitate "meaning" to the entire experience, dispel fears, nurture *will* to cope with perceived losses and take on an uncertain future. Discernment is not there to judge, perhaps only to witness and support the individual's restructuring. Matt, for example, seemed eventually to view his crisis as somewhat a "rite of passage" to a new level of personal spirituality. How one makes sense differs, and may simply need non-interfering "care-giving" support. An enhanced spiritual life is not uncommonly the outcome of health crisis. In Matt's drawings we see him alluding to this as his mechanism for transcending the "misery" in the experience. Spiritual resourcefulness gave him an avenue to personal comprehension for what had happened to him and fortified his "healing" in the most holistic sense.

Discernment with commitment to involvement is recipe for healing *broken ness through knowing*. The patient's strengths and potentialities are elicited in ways that are self-caring ways. Damaged identity is re-structured with recognition that *this* (diagnosis) names *illness*, not *person*. There is no fundamental fault of "being," no "character flaw." There is no reason for guilt, blame, or shame. It is not a question of "moral character" if one keeps *pathology* separate from "the condition of the soul," and turns it into opportunity (for Matt, a spiritual opportunity). The discerning practitioner simply recognizes individual need to unravel the knots of mystery within the particular situation made evident by diagnosis. This practitioner does whatever is entailed in helping the individual feel comfortable and safe within his/her own interior.

Of no small import, discerning practitioners are more prone to recognize themselves as sources for dispelling the myths of medical nomenclature. All effort to do so is directed to re-instating balance to the relationship; level the "lop-sided economy" in mental health care. With discernment, the practitioner realizes the effects of nomenclature and limits the use of medical (psychiatric) "jargon" in conversation. Lapse of sensitivity to these effects is what some would think a "chloroform mentality," a clouding to the realities of the *person* in the health-care scenario. R. Jevne (personal communication, November, 1997) speaks of this as "psychiatric anesthesia":

> When you think about it, perhaps there is a parallel between *diagnosing* and *anaesthetizing*. In surgical situations, the body is anaesthetized to allow the surgeon to perform mutilating acts on what is "an insensate body." The body is neutralized, becomes "dehumanized," so to speak; merely a machine that requires fixing. This allows the surgical team to dissociate from the person-hood of the body being worked on. Invasive and assaulting acts can be performed on this body without the perpetrators experiencing the horror that would generally accompany such things. The chest cavity might be split open and the heart itself exchanged. The abdominal cavity can be entered to remove kidney, staple stomach, excise pieces of bowel. Chunks of cranial bone can be "flapped" to permit micro- surgery to *that* vessel, or to siphon off that tumor. Anesthesia allows the entire surgical team to get on with the task of mending the body. They do not have to be concerned with *the person*, at that moment. They are freed from identifying with an experiencing body because anesthesia has rendered the body a non-experiencing "thing." But, in the process isn't there more than what lies inert on the table that becomes anaesthetized?

One can visualize the surgical team, operative in this well orchestrated event? Finely rehearsed, almost reflexive! In a sense, isn't it something of a collective anesthesia in this scene; everyone unencumbered of *feeling;* anything that might impede the doing of "the job." Everyone gets on with it, attends to the "object" there; the person-less body. Perhaps it is not so difficult to construe the effects of psychiatric diagnoses as similar to anesthesia. One might even see it all extending from the professional sector to encompass the "popular sector" and in little time, even, the client/patient.

Like a dose of "psychiatric pentothal," "diagnosing" (as labeling) becomes administered at its time of pronouncement! Is it so far fetched? Imagine the intense effort of professionals directed at classifying psychiatric symptoms. And then a fit with some categorical term is found! What happens next? Does the care-provider ever really need enter that person's world again? Like the surgical team, can the psychiatric team simply spend time attending to symptoms; in a sense be spared to focus on "real" work; fix what's "wrong?" The care-provider need not really ever enter the patient's world of intense pain, need not engage in the things of "real" healing. Conserving self, the care-provider can say, "*now*, there is something left of me to go on to the next patient." The "label" is thus justified. The label has taken care of things, possibly even for the patient who too can now distance from self. But isn't person-hood thus sacrificed, entombed, as it were, in a category? Once boxed and packaged, all concerned may be effectively "anaesthetized." Metaphorically, the diagnosis (like psychiatric pentothal) will have surrendered the person?

But, the discerning practitioner, we will presume, has been touched by the insights of this study. This practitioner has "awakened" to the utter subjective potency wrapped in the words of a diagnosis: ***a knowledge that knows***. A knowledge of such extreme energy that dire consequences might be bestowed on the one who must bear it, consequences that can be attenuated by the practitioner who might discern what comforting is needed, and might be moved to act accordingly in humanizing the force of diagnosis.

Despite the suggested importance here inferred with "quality of the relationship," Barry (as cited in Muller, & Poggenpoel, 1984) notes that practitioners' interactions with patients "are often characterized by emotional disengagement and uncaring and aloof attitudes." One could surmise that in such cases practitioners' affective communication styles have succumbed to the effects of diagnostic labeling and that in these instances discernment has been "laid to rest."

Discernment in "broken ness through de-legitimization."

In this section, we purposefully pick up on the two dominant themes: *"diagnosis as the experience of making visible the invisible,"* and *"diagnosis as the experience of the destructive gift of difference."* In each of these we select de-legitimizing aspects to the experience of being diagnosed, distinct kinds of broken ness that, in this study, we've seen to dispose the individual(s) to notable need for legitimating kinds of healing. Cheryl, for example, tells us *diagnosis* was a "horrifying thought," one that left her "dumbfounded." Steven, too, describes *diagnosis* as effacement of his gift, a distilling and discarding of *him* to "mentally ill!" We note in the composite statements of others: "being denied a being," "becoming a statement," "like breaking a glass." Each statement speaks to this notion of feeling de-legitimized. In light of this, we seek insights from this phenomenology for an improved practice. How might we, in our day to day efforts, be advantaged from this study, in dealing with "broken ness through de-legitimization"? Will understandings (taken from herein) direct our healing practices to legitimizing outcomes?

Kevin's portrayal of "fracture" of itself holds potential to influence the seed of discernment. If one is so inclined, couldn't it be found *there* in Kevin's comparative drawings: "sharp, blue-felt amplifications" contrasted with "gentle, blue-felt rhythmic flow?" (see figure Kevin) A simple yet powerful statement showing that what was so shattering to Kevin, in his view, need not have been quite so! The harshness, he would seem to say, could've been softened. His whole sense of being would not have convulsed, might've stayed intact; would not have lost such cohesion (or, *visibility*) to the label. "Puddles of Water" (re-constructed from personal communication, Sargeant, March, 1999) is narrative that comes to mind to describe varied "care" approaches in this regard:

> Crispy autumn, as children, was always such a fun time for puddles! It was delightful to tromp along until a *shallow*, lightly frozen-over, puddle of water was found. You could peer right through the thin surface layer of ice to the water beneath. The delight was to tip toe along on the fragile ice without breaking the surface. Inevitably, ice fractures would begin to fan out until, SPLASH! All would give way and in "you" went.

Using the narrative as a metaphor for care approaches, we could say one interpretation might be very straightforward. It is referred to as a direct, "deal with it" approach. It sees the care provider forging ahead with a matter-a-fact stand to the person newly confronted with diagnosis. It would be somewhat like marching across the fragile ice surface without caution. The undiscerning practitioner in this scenario has a dispassionate attitude, is seemingly unaware of the vulnerability underfoot. The thought of breaking through the ice is of no consequence because there is no attunement to the notion of fragility or possible *broken ness* to begin with. Accepting reality and getting on with it is the sole objective. But this approach would seem to strip the *care* right out of *health-care*? It would, no doubt, shatter (from this view, "magnify invisibility"). More than once, health care providers are pointed to, in this study, as those who adopt such a stance. Their callous use of "terminology" is said to be dehumanizing. Kevin punctuates the whole notion with his comment: "those that don't know, they treat you right."

A "deal with it" approach would seem to have lost sight, from the start, of the "person." In this mode health-care is reduced to little beyond technical ministrations. The discerning care provider, on the other hand, is more concerned about *care that is caring* and, individuals who are persons? Ideally, *diagnosis* should generate from this kind of care? *Care* that really *cares* is able to discern persons' fears of invisibility and de-legitimization resultant from diagnosis. The discerning practitioner who cares in this fashion is wise to the potential of *diagnosis* to effect an experience of "destructive gift." Without this health-care has lost sight of what real care is really about, that is, to "relieve the other" (Van Manen, 1990):

> From the etymological point of view, and in its current usage, the term "care" possesses the dual meaning of worries, trouble, anxiety, lament on the one side, and charitableness, love, attentiveness, benefice on the other side. So in caring for another person I can relieve the other of "care" in the sense of trouble, worries, or anxiety. (p. 58)

Returning to our metaphor, "Puddles of Water," *care* in the sense of wanting to relieve the other of undue worry and anxiety in their experience of *diagnosis* considers an approach different from "deal with it." The aim of care in this second approach would be that of "nurture-strengthen." In this mode effort would be directed to raising the individual's level of coping by, in a sense, pouring layer upon layer of water on the ice surface thereby making it stronger. In this regard, activities of care might aim to prevent shattering, to preserve identity. It would discern "what" information is needed in the situation to preserve the individual, to limit the feeling of being "a statement," and to help the person retain or regain visibility. It would inspire hope by searching-out viable strategies for coping, such as that which Cheryl tells us of in making *diagnosis* truly functional to her as an "imaginary depository." Here can be placed all the unimaginable pain and the incomprehensible thoughts. The discerning practitioner is more caring in fashioning new coping skills with the person, in strengthening existing personal assets and enhancing "personal gift." Perhaps, "management" versus "treatment" is emphasized (as with Steven) so that individual resources are fortified and "gift of difference" highlighted. In keeping with our metaphor, the ice is made thicker and harder through management of "strengths." It becomes increasingly solid and so, can endure and withstand the stress and strain of "footsteps" just as the individual, by analogy too, is assisted to greater resilience.

These are two distinct modes of caring. It is not to say one is superior to the other or that both approaches could not be used in tandem, even with the same individual. It is to point out, however, that the discerning care-provider is better able to wisely walk softly, knowing the fragility of the situation. Sensitivities acquired from this phenomenology may instill a sense of discernment that assists the practitioner to operate from a baseline of "practical wisdom." Irene, through her story, tells of the vital need for *this,* if care-providers would truly help persons find *meaning* in their experience of being diagnosed. Through her lived-experience Irene drops a pearl of wisdom in this regard, reminding practitioners that *diagnosis* is a critical juncture, perhaps even the most critical of junctures in the mental health "illness-wellness" trajectory. It is not end-point, as it often becomes in health care. Of all else discernment counsels *diagnosis* as a "critical start point" that can direct the individual to positive or, negative possibilities. A sense of optimism that "new meanings" can be etched from *this* is the positive direction facilitated by the discerning spirit. This care provider is better equipped to know what is needed in each instance, to assist and support individuals to renewed "visibility," help them to fashion meaning in "this" (diagnosis) that restores and re-launches life.

That, it is suggested, is what it is to have in hand "this knowledge" which we designate "action sensitive knowledge" (Van Manen, 1990, p. 21). It could be said this study shows foremost "heartfelt discernment" turned into tactful action; knowledge in practice that is sensitive because it has "knowing of" and "knowing in" relative to the situation of *diagnosis*. In this, focus on "*diagnosis*" has been *awakened*; the issue of that "experience." It shows *that* experience to be *something*. We are roused from a mentality that would see only the utility of diagnosis in "treatment" and, loose the person. Through this knowledge we can instate personal legitimacy to persons through diagnosis – that is, make visible, and thus fulfill a commitment "to care."

One might add that a commitment "to care" is mindful of the fact that it is first and foremost the *person* whom we serve in health care, not the symptoms, not the disorder, not the diagnosis or the institutions of health service delivery. Unless we hold to this, we de-legitimize, that is, fail the *person*. Person-hood is legitimized when service providers mediate the problems of standardized care and stereotyped communication styles, and resist ". . . attitudes that assume a common unitary internal world for all people" that would effectively tar people with a common diagnostic brush (Pollock, 1988 cited in Muller & Poggenpoel, 1996, p. 147). Once tarred, the person becomes passed-over, lost to a circumstance where regaining person-hood may well come to a question of who will be given to ever enter that person's world again. Yet, the work of redefining "normal" that is the critical task of healing in psychiatry is work requiring the willingness to "enter-in." It cannot be well facilitated from the fringe of involvement.

The notion of redefining normal as the critical task of healing in psychiatry, takes cue from the work of Tishelman and Sach's (1998) who address "redefining normality" as integral to experiences of *diagnosis* in general. From their accounts, it would seem that healing relative to the experience of diagnosis is consequential to persons' knowing what to expect from themselves given their specific circumstance. In the end, "legitimization" appears to generate from constituted conceptions of normality, be it from the "popular sector," "the patient," or "the professional sector." In other words individuals, experiencing whichever symptoms, felt legitimized when their symptoms were given credence or, stated differently, when the symptoms were believed and known to have a basis for being. Success in management and treatment actually hinged on this sense of legitimization. A supporting study, in this, specific to the field of psychiatry, was not found, however, Young (1982) noted *legitimization* was vital to cancer patients, who adapted more readily to treatment demands and were better able to redefine their beliefs and behaviors within the context of their diagnosed illness. It seems reasonable to put forward that *legitimization* is no less crucial for persons experiencing mental disorders. One could venture that the work inherent to being so diagnosed is basically an interior journey, one not made easy by keeping "arms length" to patients through specialized medical jargon. Practitioners must have presence, be "in-relationship" to be of true influence to healing through "normalizing."

"Normalizing experiences" was key to re-structuring by the words of many participants in this study. Of ultimate challenge was coming to terms with a "name" which identified them the same as others in *dis ease.* They struggled to maintain their uniqueness, in a sense transcend the effect of being diagnosed. Transcending seemed accomplished best through others. It was in relationship that common ground for expression could be found. Relationship was forum for reflectivity, for exploring and for coming to viable coping with what diagnosis said and meant, for feeling supported and accepted by the *other* believed to "know" and understand their situation. Relationship is what showed, genuinely, the commonalities between *persons.* One practitioner (personal communication, Downes, 2000) described the essential value of commonalities in the following:

> To be told: "My son did not sleep last night!" holds very different meaning if said to me than, if it is shared between mom's who both have sons diagnosed with schizophrenia. *Their* commonalities, allow them to recognize what it means to have a son in the throes of "psychoses." They can appreciate, "*the boy*" was paranoid, and thus his illness rendered him unable to be consoled, or touched, or approached, or reasoned with. Logic would have no meaning, hold no truths for them with their sons in this situation. In their common experience of being "parent of a son with schizophrenia," they can understand together what it is to abandon the prospect of helping their son in "those" ways, and simply console one another. All of that looks a lot different to persons sharing the experience than it could possibly look to me.

In this anecdote, what is shared is shared from a common base of experiences between mother's with their sons, perhaps, a common base of heart-felt sorrow for one another. Likewise, for persons in relationship sharing experience of *diagnosis*! Informed by this phenomenology, what transpires in the truly therapeutic relationship may be of immense consequence to healing.

Discernment in "*diagnosis* mending broken ness."

"*Diagnosis as the experience of making knowledge knowledgeable*," the dominant theme emerging from Jim's story, is that which is brought into focus in this section. If to heal is to mend broken ness, then, the object for discussion now must relate specifically to what can assist in making *knowledge knowledgeable.*

To address this *focus* we might start again with the assertion that discernment is the attribute fundamental to care-providers in the mending of broken ness consequent to diagnosis. In-relationship, what might facilitate in making knowledge knowledgeable given the individual circumstance is brought to light? Throughout this thesis, recognition has been accorded to *healing* and, by implication, to how healing may be largely shaped in the discourses between the "knower" (the giver of diagnosis) and the one "known" (the ill person). In Jim's story, we saw the "five-minute diagnosis" as a disturbance of "relationship," one that resulted in *mute* knowledge. In some cases negative knowledge, in as much as diagnosis results in dire effects to the person's integrity, may be an outcome. One would presume such result to be in direct opposition to the actual aims of psychiatric care, that is, if the real work of psychiatry is to fortify "the person." This, suggest Muller and Poggenpoel (1996) is the real work of health care workers in psychiatry, the work contained in the interpersonal process, in the quality of the interactions with patients that either facilitate or stall patients' progressions toward "health." These authors emphasize that quality in the relationship is relative to "whether or not (practitioners) ignore or deny their patients' internal processes" (Muller & Poggenpoel, 1996, p. 143).

Participants in this study were unanimous in declaring the "experience of diagnosis" to significantly pervade their "internal processes." Discernment, then, would seem crucial to practitioners' interactions with persons confronting diagnosis. A well-tuned ability to discern what is needed in the given instant is what Benner (1984) might say distinguishes one as "expert" practitioner in psychiatry. Wouldn't discernment be the "know how" of clinical judgements, those based on the qualitative distinctions of a given situation? In this vein, Benner enjoins philosophers of science such as Kuhn (1970) and Polanyi (1958) who observe two different kinds of knowing: "knowing *that*" and "knowing *how.*" The point of relevance herein is that many (know-how) skills are acquired without knowing the causal relationships integral to them, that is, without "knowing that." Water skiing is a handy, illustrative example. The "know how" of the skier takes him or her quickly to the water's plane. It facilitates a graceful "back and forth cut across the water's wake." To the skilled skier this is automatic "know how" quite apart from knowing the size of the motor boat against the drag of the water relative to the speed of travel. These scientific formulations of "*knowing that*" might even elude the skier but, in the actual situation, it is the practical "*know how*" knowledge that keeps "him" in balance. He can simply "enjoy the ride" based on past successes and *know how* skill.

The kind of discernment nourished from understandings acquired through this study (when combined with experience) can contribute to "that" kind of expert *know-how* in psychiatric practice settings. The experienced practitioner, one would hope, is enabled by a refined sense of discernment to perceive the situation through prior knowledge and through former encounters with similar situations. This practitioner is less deliberate and analytic about situations, and possibly more accessible in rising to "the" occasion. The "know how" of this practitioner knows what is required, has integrative ability to reach "the person" in a purposeful way. This practitioner knows that it takes more than mere words to effect knowledgeable knowledge.

Establishing what specific knowledge needs to be made meaningful to the individual also requires much "knowing that" knowledge. Astute observations, deep listening, picking up on cues and processing almost at an instinctive level is all part of this. Expertise in reflexive questioning may be a particular advantage to intervening, in the event of diagnosis, by way of assisting persons' reflexivity in the experience and, encouraging externalization of feelings in nonthreatening ways. Questions can be softened in keeping to more natural conversation while at the same time effectively exploring. The following are such examples:

> "I am curious about how you understand the words of your diagnosis."
>
> "What are you doing to help yourself get through this time of transition in your life?"
>
> "I've seen others go through similar transition and it appears difficult at times. I was wondering what your experience of being diagnosed has been like for you so far?"

Wright and Leahey (2000) describe a means of proceeding through circular questions. One could hypothesize that *discernment* knows better how to proceed with such questioning, knows the line of questioning that will be most apt to stimulate insight and, so, directs conversation to that end.

But, the ability to discern is more than a script of asking questions. One would suppose the "know how" of the discerning practitioner would assist through functioning with a more refined grasp of the presenting situation; be more accurate with questions that zero in to touch on regions of concern to the individual. Perhaps the discerning practitioner gently explores areas of, cognitive, affective and behavioral functioning. In this way ideas, concepts, beliefs, values and feelings which might prompt behavior (possibly perpetuate negativity) can be tactfully broached within consideration of the individual's social and historical context. Conversations can be solution focused with ideas conceived and generated by both "client" and helper; thoughts evaluated, modified and/or discarded accordingly. In that way, the practitioner does not stand as the sole source of possibilities. Indeed, the discerning practitioner knows full well that ultimately, solutions rest with the individual involved. These ideas are primed to surface through the reciprocal interactions of the relationship. The practitioner conveys trust that ultimately strength and mastery resides in the individual.

And so, the discerning practitioner takes direction not necessarily from expert certainty within, but is guided by the individual involved, and by a heightened perceptual acuity. For example, a more refined judgement in this practitioner might demonstrate as an ability "to recognize" Cheryl's need to re-conceptualize the knowledge of "*disorder*" as "dis order" (falling out of order). In this way the knowledge becomes knowledgeable for Cheryl. It becomes palatable and useful in guiding her recovery and sustaining her future functioning. Is this not what *knowledgeable* knowledge is about? Now, Cheryl can re-focus her anxiety about "the disorder," use the anxious energy to reinstate order within the varied realms of her being. She can re-establish organized thought for herself around the diagnosis, re-set modes of her activity within prescribed limits. Cheryl resumes living and gets back to "normal" through a re-formed way of thinking about "dis order." Discernment has helped make this operational by nourishing Cheryl's will to self-healing, by helping (in this instance Cheryl) to modify her thinking in ways that are consoling to her, in ways that help her face-up to her diagnosis. The discerning practitioner has more accurately "known" what was needed for Cheryl to accomplish for herself what needs to be accomplished, so that she can move forward with her life. In discernment is the "know-how" needed to be navigator to Cheryl in her particular clinical circumstance. In relationship Cheryl and the practitioner have together sparked hope, by finding an acceptable interpretation to what the diagnosis might be saying.

Perhaps in the end it does all simply come down to "being there," but, the point is that to be instrumental in really helping *make knowledge knowledgeable*, it is not just any *being there* that is required. The discerning practitioner detects in what ways it will be most meaningful to be there; allows a personal self-involvement in *being there*. *That* is a distinct kind of *being there* because in it is an involvement that "sees" (in this instance of *diagnosis)* its role in identifying what is needed to help make knowledge knowledgeable. Foremost, this practitioner understands there is a role, here, where healing and recovery needs be promoted differently for Jeff than, say, Julia. Knowledge that is knowledgeable may for Steven be that which translates into ways for him to manage yet, preserve his "gift." For Teresa it may establish reasonable "fits" between parts of her that never did before fit so that she can feel "put together." For Jean, it might sustain her conviction of what she needs to maintain her life. And so it is for each; that knowledge is knowledgeable because it is of value in, *this*, "my" situation. Discernment recognizes the elemental facets of what it will take to raise knowledge to levels of knowledge-ability, and facilitates its happening.

One could say that discernment cannot be standardized because it features a kind of "discretionary judgement" (Benner, 1984, p. 177) which, of necessity, must respond to the unique characteristics of a particular situation. *Diagnosis* does not happen void of context. The discerning practitioner has an ability to recognize this; see *diagnosis* as potentially a central "dilemma" to *this* individual, within his or her existence. Discernment knows an ability to determine what, in that event of diagnosis is of significance to the person's "know how," and what of that knowledge needs be made knowledgeable. Discernment may be the outcome of a true awakening (promoted through such as this study), a waking-up to the event of diagnosis as one of incredible significance at the "person" level. In sum, discernment enables one to identify the threads (as individually evidenced) to healing and by helping make knowledge knowledgeable "transform the person's sense of possibility" (Benner, 1984, p. 210).

Advancing our future.

The difficulty of relating to the experience of being a patient, particularly if one has not oneself ever been in that position, is echoed in the question posed by Morse and Johnson (1991): "What is it like to be ill?" It could be said that few things are more definitive of *illness* than is *diagnosis*. With medical diagnosis, one truly realizes one's self as the "subject" of definitive knowledge that declares illness. D*iagnosis* is *that* kind of scientific knowledge. Yet *diagnosis* is a dimension of the illness experience that is left virtually silent in health care. Beyond its function in psychiatry of defining mental health status, diagnosis in this thesis has shown itself a "thing" that can utterly transform one's concept of life and being. It manifests as pivotal to persons' sense of future and well-being. Little is reflected in health care literature to support or refute this or, indeed, to substantiate *psychiatric diagnosis* as a phenomenon of consequence at all. One would conclude this registers lapse of disciplinary knowledge respective to those disciplines associated with psychiatry and mental health care.

Professional practitioners require access to experiential and disciplinary knowledge that can guide their "care" activities. Relevant knowledge must speak to both the "*knowing that*" and the "*knowing how*" dimensions of care. And so, here advocated is need to take up the banner of research in this topic area of *diagnosis*; to pursue both forms of knowledge. Interdisciplinary models of research may be ideal to explore multiple perspectives of *diagnosis* as a critical juncture in illness. Enlightenment to the dynamics within this *juncture* would contribute much to assisting practitioners in knowing how best to engage the person in a "partnership" of sustained health management. Goals of care to persons experiencing severe and enduring mental illness go well beyond acute-illness recovery. Eliciting patients' participation in programs of "health maintenance" may, over the long term, be found to originate in what is here referred to as the critical juncture of *diagnosis;* that point in time when "the news" of diagnosis is imparted and comprehended. One could speculate on the multi ramifications of this to health care resources in general.

There appears much potential for exploration within the realm of "paired opposites" appearing in this study. Paired opposites seem associated with certain prompting(s) for change. As seen in this study, persons' change was very often directed through their experience of opposite impulses. What accounts for this directional influence presents fertile ground for future study. Would we say, primary influences generate to direct change from within the individual or, from the disposition of the care-provider? Or perhaps, we would say that primary influence is essentially a product of curricular emphases to student practitioners? Is "influence" something that can be taught or is it predispositional to what persons bring to the "moment?" Are the relational elements of significance to such moments able to be isolated, described, taught and learned?

In spite of the ambiguities posed in all of this, there does seem sufficient support implied for the notion that quality in the "helping relationship" has bearing on persons' "meaning-making" relative to their experience of being diagnosed. Assorted examples of "first-person accounts" with the experience have been placed throughout this study. But little professional attention speaks to psychiatric diagnosis as a distinct experience, or to the dynamics of influence that might be imbedded in the experience. Perhaps it is that practical wisdom has essentially relied on intuitive instinct to navigate such cases, an instinct that has been honed and nourished through genuine encounters within domains of practice. Certainly, it would seem potentially advantageous to give well-placed voice to this topic in educational curricula. Simulated learning, through experiential scenarios, may be one way of fostering *discernment*, recognizing "it" as a practical asset in dealing with the complexities of the diagnostic experience. What "normalizing" means as a concept of care and its practical utility, may be of immense value to positive and enduring outcomes. Through this the practitioner aims at being increasingly instrumental in helping persons in their critical task of redefining normal for themselves. Planned integrative seminars with practitioners can be designed to raise awareness, in general, to the manifestations of "broken ness" through *knowing* and *de-legitimization*, and instill a concern for involvement in the activities of mending "the spirit." As a bottom lime, of major import is attunement to *diagnosis*, an experience of significance, a force within the illness encounter to be reckoned with.

Concluding in Continuance.

Through the preceding chapters, we have had privileged view into the lives of persons whose experience it has been to receive diagnosis of severe and enduring mental illness. A tapestry of incidental or provisional themes forms backdrop to four dominant themes deemed essential to demonstrating as mainstay to the experience in this study. These four essential themes are searched in depth, and identify as chapters entitled: **"Diagnosis as the Experience of a Knowing that Knows," "Diagnosis as the Experience of Making Visible the Invisible," "Diagnosis as the Experience of the (Destructive) Gift of Difference," "Diagnosis as the Experience of Making Knowledge Knowledgeable."**

Though this thesis makes concerted effort to accent meanings integral to "experiencing diagnosis CMI" there is no question that it is but one "take" on that lived-experience. This description provides small glimpse into that "lifeworld" experience. There are no illusions of its being the end-all and be-all, conclusive statement on it. Hopefully it is one account that succeeds in illuminating a phenomenon of life that had been, before, left in the dark. Indeed, "search" of this phenomenon has been very much an exercise of "writing in the dark" (van Manen, in press). Like Freud's analogy of the iceberg, the "tip" of the phenomenon was seen to surface only to again re-submerge several times. And so, in now bringing this text to a close, it is with recognition that enlightenment achieved may be to but the smallest portion of "the" experience that is visible. *This*, then, stands as invitation to whomever would take up the task of "continuance," perhaps engage in a follow-up "program of study" to explore related aspects glimpsed in this study. Thereby, the ever-greater piece of that iceberg which lies hidden beneath the water's surface might be increasingly brought to light.

It is perhaps appropriate this thesis ends in this way, on a note of *continuance*, since we saw in the experience of diagnosis itself a thread of continuance. To those receiving psychiatric diagnosis, what was seen to, at first, be life's most wrenching experience, did, never the less go beyond "the moment"; depart the devastation. What was "rupture," perhaps fracture to all that might've been imaginable to one's "story line," was ultimately borne out as a phase, a kind of transition in response to a call to be "knowledge able," a call for "restructuring." Therein is continuity of "becoming." As broken ness mended story line, too, mended. A reality unfolded that "none" can ever truly become severed from "one's own story." It may be that things like *diagnosis* can threaten one's vision of self, at least for a spell, but it is equally true that even *that* is merely planted in the continuity of one's "story." By the words herein, being diagnosed mentally ill *is* schism to one's "story," but it is after all but one frame within the overall continuance of that story. And, as put by Gary: "A life is a life is a life!"

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APPENDIX A

The Way Of Search For *Diagnosis*

Six research activities described by Van Manen (1990) provided a structure to delineate the particular perspective of this study:

1. turning to a phenomenon (in this study, *diagnosis*) which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented relation to the phenomenon;
6. balancing the research context by considering parts and whole. (p. 30-31)

From this, one realizes that hermeneutic phenomenology is not simply a reporting of experience. To aim for a "rich," textual account of the experience of *diagnosis* CMI this researcher turned to persons' "lived-experience," reflected on implicit meanings that characterized the stories of participants, and pondered the stories deeply so that meanings began to surface and supply understandings about the phenomenon. This was arduous activity in which participant and researcher collaboratively participated.

Collecting Data

Many sources of data collection are acknowledged in hermeneutic phenomenology, as was the case in this study. Each source contributing potential insight to understanding meaning in the experience of *diagnosis*. Any person diagnosed with a chronic mental illness and demonstrating understanding of their illness as *chronic* was considered a viable participant in this study. Sampling was regarded as purposive in that participants (data sources) fitting this stated description were deemed likely to supply valuable insight.

Locating Participants

Gaining knowledge about lived-experience must be undertaken in the natural settings of the "lifeworld." In this study, the assistance of the Canadian Mental Health Association, South Central Region, (CMHA) was sought to locate willing participants. Interview/conversations were conducted at what was believed an impartial location. Since the mandate of CMHA caters specifically to the chronic mentally ill, they willingly involved themselves in the task of locating participants. The "Consumers Network" became a second formal source of assistance. However, personal contacts and word of mouth yielded surprising interest and requests for involvement in the study. This did necessitate eventual capping to limit the number of participants which, in the end, stood at fourteen. As participants verbally committed to the study, a letter explaining the intent of the research was forwarded to them, and they were extended formal invitation to become involved in the study.

Conversing with Participants

My role as a nurse educator in psychiatric-mental health nursing has afforded me considerable opportunity to work with the vulnerable population of chronic mentally ill persons. This assisted me in the study. That said, I soon came to realize from well-articulated stories imparted to me that the study may have attracted response from the most lucid and literate of the population in question. This, then, acknowledges possible bias to the study, skewing input to those best accommodating their diagnosis and who manage it in the most favorable of ways. Taped conversations were carried out asking participants to attend to their experience of being diagnosed. Conversations were moved in a natural way, designed to relax and engage. In all cases, the quality of information forthcoming from each participant's first conversation was ample in meeting the needs of the study.

At the outset of each interview the intent of the study was reviewed and an informed consent was signed. Some sharing of information about my interest in the study and clarifying of expectations about participation in the study typically ensued. As rapport developed, "prompt questions" were used to invite disclosures about the experience in question, such as:

- Can you tell me some of what was going on in your life prior to your first hospitalization for this illness?
- When did the notion that you had this diagnosis first come to mind?
- Do you recall who told you your diagnosis? What do you recall of that event?
- Can you tell me what explanation was given to you?
- Do you remember any of the words that were used to explain the diagnosis to you?
- Who was there? Who said what?
- Did you expect to hear the diagnosis that you were told?
- What was it like to realize you had this diagnosis?
- How did you go about telling others of your diagnosis?
- What was it like to tell others about your diagnosis?

The conversational tapes (with permission) were, then, transcribed to create hard documents of personal accounts. During the interview session, drawings had been solicited and were subsequently self-interpreted by each participant. Drawings were thought useful because of their symbolism and became valuable in stimulating thoughtful recall of the experience. Drawings proved invaluable in this study, confirming a notion put forward by Siegel (1990) that "... the unconscious always knows more symbols and finds new ways of revealing something that consciousness has concealed" (p. 159). In this study, drawings "warmed" participants' re-entry to the experience and assisted a deepened disclosure about it.

It is worth mention that each participant elected to "set the stage" for his/her own experience of diagnosis by placing it in the context of their life prior to illness. Without exception, each story tended to accelerate in emotional pitch until personal turmoil was said to have led to hospitalization, diagnosis and treatment. It is acknowledged that this sequential recounting may be attributed to the line of questions by the researcher.

Thematic Analysis of the Stories

In hermeneutic phenomenology, data collection and data analysis proceed concurrently. Intense reflections on the data are hallmarks of the analysis (Baker, Wuest, & Stern, 1992). Sometimes analytical reflection takes place with participants, as in this study with participants' drawings, however, this is not the general expectation. In this study thematic analysis took into account transcripts, observations, drawings and collateral textual materials on the "body" deemed relevant. Autobiographical accounts and a variety of literary sources were accessed. Phenomenological texts were expeditiously used to enhance comprehension. Those authored by Van den Berg were found especially helpful in this regard and thus heavily relied on in this text. Central phrases or statements thought to be particularly relevant to core meanings of participants transcribed accounts were highlighted. These were given special significance in establishing incidental or provisional themes, and distinguishing these from the more dominant and essential themes of the experience.

Writing and *re-writing* was the fundamental exercise of the analytic process. Van Manen (1990) asserts that writing *is the research*, therefore, each written activity was approached as an exercise of search to more deeply understand *diagnosis*. Writing aimed for a continually finer expression of embedded meanings in the experience.

A collection of spontaneous commentaries, personal notes, memos, clippings and reflective journalling proved invaluable to the analysis. It developed into a depository of thought for impressions; observations and ideas, a means of clarifying personal values, attuning to new ideas and beliefs, and stimulating sensibility toward an evolving insight. Tracing of word and term etymologies, tracking of artistic, literary and film "relevancies" became worthwhile preoccupations throughout the study.

Approaching the close of the study it became apparent, that the "heart" of this search lay imbedded not so much in the before and after drawings as somewhere in-between the two. If that could be harvested, the questions aim would be accomplished.

Attending to Rigor

Sandelowski (1993) states, that in qualitative research "... rigor is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work" (p. 2). In this she does not minimize the need, in qualitative study, for standards of trustworthy research. Like all credible research, qualitative study must adhere to ideals of rigor but, and here is the point, not at the expense of its meaningful relevance. Hermeneutic phenomenology is termed a discovery-oriented approach to inquiry and gives greater emphasis to its own conventions of rigor. It may mistakenly appear "unprincipled" if it is rigidly evaluated using the same standards of rigor as are applied to other forms of inquiry (Van Manen, 1990). Some forms of phenomenological inquiry would sanction *bracketing*, a practice of setting aside one's own preconceptions in order to enhance rigor. This assumes the researcher can, or even should, hold separate from the research all personal experience which could potentially influence it, the value of which is, by some, thought dubious (Bergum, 1991; Smith, 1991; Van Manen, 1990). It is argued that all experience (perhaps most especially the researcher's) is relevant and, brought to bear on the research interest potentially effects a deeper interpretation of inherent meanings. What distinguishes a phenomenological text as reliable and valid is a strongly oriented text that epitomizes the experience (in this case, being diagnosed chronic mentally ill) in a way that evokes a recognition of it "as one we have had or could have had" (Van Manen, 1990, p. 27). If the phenomenological description is vivid enough to evoke such a response, then, it is considered valid and succeeds in accomplishing its aim.

Considering Ethics

Human participants are involved in this study, therefore, ethical clearance to conduct the study was sought and obtained from the Health Research Ethics Administration Board. A copy of the research proposal was shared with the Canadian Mental Health Association (CMHA) South Central District board of directors. My availability to CMHA was made known in order to supply additional information and respond to questions as warranted.

Chronic mentally ill persons, as a population, may feel especially vulnerable at the prospect of being "studied." Within the usual ethical aspects of: informed consent, confidentiality, anonymity, and evaluation of risks and benefits, the participants of this study require special consideration (i.e. ensuring opportunity for repeating questions, anticipating lag time between questions and answers and respecting pause times, repeating explanations and assurances, etc.).

Informed Consent.

Advance information was strategically made available in known treatment localities frequented by consumer populations. The term "consumer" was used, as the preferred term by persons with chronic mental illnesses, on information notices and in correspondence when referring to the population of study. By definition, consumer refers to "an individual who has experienced significant mental health problems and used the services of the Mental Health Care System" (Alberta Mental Health Care Consumers' Network, 1993).

As noted above, an information letter was given to all those who agreed to participate in the study and met the criteria for inclusion. A mutually agreed on date, time and location for meeting was decided. This establishing of an appointment was taken to constitute a verbal consent for enrolment in the study. At the first meeting, the information letter and the consent form was reviewed and questions responded to in an effort to ensure understanding of the study's intent. Options for future meetings were addressed. The written "informed consent" was, then, signed prior to further conversation.

The researcher stressed to all participants that at no time would their treatment be compromised as a consequence of the study. It was emphasised to them that their access to health care resources in no way depended on their involvement in the study and that they were free to withdraw from the study at any point in time. At the meeting's conclusion it was ensured that participants took with them their copy of both the signed consent form and the information letter.

Confidentiality and Anonymity.

Participants were explained in detail of strategies in place to protect their identity. That is, "raw data" is accessible only to the researcher and researcher's committee members, and to the transcriber used for tape transcriptions. Information known to these persons will be kept in confidence. Transcribed copies of interviews and corresponding tapes are identified with code numbers. Names of individuals, and identifying organizations were removed and codified in typed copies to protect the anonymity of participants. Audiotapes and all transcribed materials were kept by the researcher in a locked cabinet. Likewise, all consent forms were kept in a locked place and these will be destroyed on completion of the study. In written reports of the study, every effort was made to safeguard the identity of participants. This on occasion necessitated some alteration of quotations used. As well, some story quotes were minimally modified to "optimize readability" or, extracted and placed from one story to another as enhancement. In this, every effort was made to correctly identify the source of quotes and to hold to their intent.

During the course of the study, no information pertaining to unethical or unsafe practices by health care providers was made known. Tapes and transcribed materials will be kept for seven years after completing the study, at which time they will be destroyed. Transcribed interviews will be kept for an unspecified length of time.

Risks and Benefits.

No perceived risks to participants became evident during the course of this study, although it was recognised that conversing about the details of the diagnostic event held potential to precipitate personal stress to some participants and, possibly, even exacerbate their illness. In this event, the researcher was prepared to assisted the participant to connect with professional services, keeping in mind that at all times the welfare of the individuals involved in the study held the highest priority.

Although no tangible benefits were thought associated with this study, it was recognised that some incidental gain would be experienced by participants by virtue of their exploring their experience of diagnosis with the researcher. Beyond this, it was also recognised that some satisfaction may extend to them consequent to their knowing of their contribution to professional insights concerning *diagnosis* and, the possibly effects that *that* might have to improving "care."