

**THE SUBJECTIVE EXPERIENCE OF THE PSYCHOTHERAPIST IN
PRIVATE PRACTICE WITH A CHRONIC, INVISIBLE ILLNESS**

**A dissertation submitted to
The Sanville Institute
in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in Clinical Social Work**

By

CHERYL JERN

June 23, 2007

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PRIVATE PRACTICE WITH A CHRONIC, INVISIBLE ILLNESS

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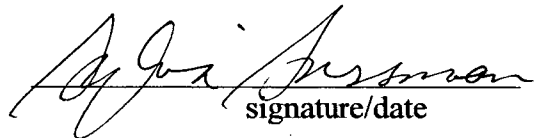
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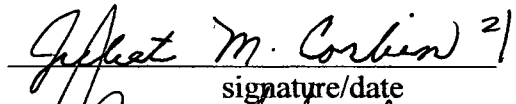
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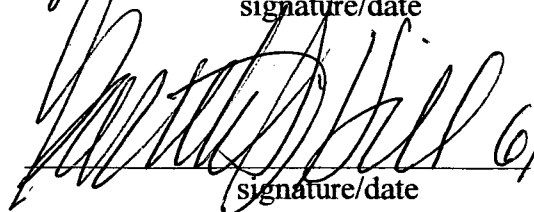
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Dear Mr. Hoagland:

This letter will confirm our recent email regarding the inclusion of your poem in my dissertation.

I am completing a doctoral dissertation at The Sanville Institute entitled "The Subjective Experience of a Psychotherapist in Private Practice With a Chronic, Unseen Illness." I would like your permission to reprint in my dissertation the following poem: "Emigration," as it appears on page 60, in *Sweet Ruin*, published by The University of Wisconsin Press, 1992. The poem will appear in the foreword of the dissertation.

The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you. Your signing of this letter will also confirm that you and The Board of Regents of the University of Wisconsin System own the copyright to the above-described material.

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Sincerely,

Cheryl Jern, LCSW, MFT

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ABSTRACT

THE SUBJECTIVE EXPERIENCE OF THE PSYCHOTHERAPIST WITH CHRONIC, INVISIBLE PHYSICAL ILLNESS

By

CHERYL JERN

This grounded theory research examined the subjective experience of the psychotherapist who is both maintaining a private practice and coping with a chronic invisible physical illness. Specifically, this study looked at how the therapist managed the illness while seeing clients, how the illness influenced the therapist's professional sense of competence, and the special problems that arose in the clinical work as a result.

Open-ended, semi-structured interviews were conducted with ten participants, all of whom were purposely selected to represent a broad spectrum of illnesses and conditions. Illnesses represented in this research are the following: Lyme disease, chronic fatigue syndrome, atrial fibulation, ulcerative colitis, sarcoidosis, rheumatoid arthritis, thyroiditis, epilepsy, chronic migraines, osteoporosis, asthma, and primary lower extremity lymphedema. The participants were chosen to reflect as varied a collection of health conditions as possible. Data from the interviews was analyzed using the constant comparative method as developed by Glaser and Strauss (1967).

Illustrating Kleinman's (1988) concept of the contextual nature of the illness experience, the psychotherapists in this study all struggle hard to straddle the two worlds of chronic illness and psychotherapy. They must alter their

behavior and devise strategies, including pushing themselves hard, in order to manage the demands of the work. They are motivated by an over arching, all-consuming commitment to the client and a desire to be judged, both by others and themselves, as competent in their jobs. This is challenging for them because intrusive symptoms influence their sense of competence. Chronically ill therapists must also grapple with whether or not to disclose their illness and how others will view them as a result.

The existing literature on the subject concentrates primarily on acute illness rather than chronic illness. What little relevant literature does exist focuses more on the “technical” issues as they arise in treatment. This study adds to the existing body of literature by examining the therapist’s personal illness experience in the context of the work.

**This dissertation is dedicated to the ten psychotherapists who willingly and
openly shared their illness stories with me.**

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In July, 2006, my husband, Ken Miller, was diagnosed with acute leukemia. I was in the midst of writing my final dissertation chapter. Coping with my husband's illness and completing my dissertation – simultaneously – presented an almost unbelievable challenge – one that I could not have done alone. The expression “it takes a village” has an intimate meaning for me, and I would like to acknowledge “my village” – those people without whose help I would not have been able to complete this project.

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A special thanks to my family. First, my husband, who never once lost sight of how important this was for me, even in his darkest hour. When I had decided that I could not do leukemia and a dissertation, he insisted that I continue.

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FOREWARD

Emigration
(Hoagland, 1992, p. 69)

Try being sick for a year,
then having that year turn into two,
until the memory of your health is like an island
going out of sight behind you

and you sail on in twilight,
with the sound of waves.
It's not a dream. You pass
through rooms and clinics

until the very sky seems pharmaceutical,
and the faces of the doctors are your stars
whose smile or frown
means to hurry and get well

or die.
And because illness feels like punishment,
an enormous effort to be good
comes out of you –
like the good behavior of a child

desperate to appease
the invisible parents of this world.
And when that fails.
there is an orb of anger

rising like the sun above
the mind afraid of death,
and then a lake of grief, staining everything below,
and then a holding action of neurotic vigilance

and then a recitation of the history
of second chances.
And the illusions keep on coming,
and fading out, and coming on again.

while your skin turns yellow from the medicine,
your ankles swell like dough above your shoes,
and you stop wanting to make love
because there is no love in you,

only a desire to be done.
But you're not done.
Your bags are packed
and you are traveling.

CHAPTER 1: INTRODUCTION

This exploratory research studied the impact of a chronic, invisible physical illness on the psychotherapist in private practice. My focus was on the psychotherapist's subjective experience of living with a chronic illness and the special problems that may arise in the clinical work when the illness is unseen. I examined the effect of the illness on the therapist's professional identity, how the illness influences the work and how the psychotherapist straddles the two worlds of illness and work.

Statement of the Problem and Background

Illness is ubiquitous. Over 90 million Americans have chronic illnesses (Center for Disease Control, 2004, p. 1). Because of improvements in medical procedures, treatments, and medication, illnesses that previously were fatal have moved into the chronic category, according to Sidall (1997), making "chronic illness a fairly new phenomenon" (p.5). Individuals with health problems are living longer than in previous years when these same illnesses might have caused death (Durban, Lazar & Ofer, 1993). As the population of the country gets older, there is a greater and greater chance of developing a life-altering chronic illness, making chronic illness the norm, especially for older individuals. Kleinman (1988) sums it up, "The chronically ill, if not you or I, are our parents, grandparents, children, siblings, aunts and uncles, friends, neighbors, co-workers, or clients" (p. 47). We can assume, therefore, that, just as chronic illness is increasing in the general population, it is also increasing among psychotherapists.

When we become ill, we usually have faith that our bodies will recover and that the illness is simply temporary. We are confident that our bodies, with or without medical intervention, will heal and that life will go back to normal. Chronic illness, however, is different. What is unique about chronic illness is that the person does not get well. Shuman (1996) states "Chronic illness is one in which a person's symptoms continue over a long term to impair his or her ability to continue with significant activities and normal routines. Medical treatment is frequently of limited effectiveness" (p. 6). By its very definition, there is no "back to normal." There is a new "normal," one filled with loss, fear, denial, grief, and an altered view of the future (Charmaz, 1991, 2000; Kleinman, 1988; Shuman, 1996). Chronic illness dramatically changes the sick person's sense of self (Charmaz, 1991, 2000; Corbin, 2003; Kleinman, 1988; Shuman, 1996), emotional life and management of daily activities (Charmaz, 1983, 1991, 2000; Shuman, 1996; Duff, 1993).

When the sick person is a psychotherapist, a whole new set of challenges emerges. We are groomed for a particular kind of awareness in which we must focus on and be attuned to the "other." We must "hold" the narratives of our clients - listening to and carrying the pain of their life stories. But what happens when this concentration is broken - and broken by our own bodies? How does the therapist "hold" when the vessel (the body) is impaired?

My interest in this topic arose out of my own personal experience with a chronic, unseen illness. In my early thirties, I began having strange and frightening neurological symptoms, which included headaches, perceptual changes, difficulty concentrating, and abnormal sensations on my head and face. It took years to reach

the diagnosis of migraines, migraine equivalents, and complex non-convulsive epilepsy, and I have yet to find a treatment that reliably manages my symptoms. For the last 30 years, I have struggled to understand this illness and its effect on my sense of self and on my career as a psychotherapist. It has been out of my own personal story that I have become interested in how other therapists struggle with chronic illness in their lives, and especially in their work.

It is generally agreed that for therapy to take place, there must be a consistency regarding time, place, and the reliable therapist who is ever-present and listening. A chronic illness can potentially be a threat to this system. How do therapists manage their illnesses and how do they think about their work in terms of the illness? What is the experience like for the therapist who is not feeling “whole” in her impaired body, what Silver (1982) refers to as the “colander or saturated sponge rather than a container” (p. 314)?

To prepare for this research, I conducted an informal interview with S, my friend and colleague, who has Graves Disease. Treatment for this disease required the “killing” of her thyroid and thyroid replacement medication to replicate the missing hormone. Thyroid replacement is a complicated process, taking weeks, sometimes months to get the right dosage – only to have everything change as the body changes. When I asked if I could interview her for my research, her response was “I don’t have a chronic illness.” Days later she called me back and said that yes, indeed, she did have a chronic illness. Her initial reaction to my request for an interview stimulated a series of discussions between the two of us, in which we explored all the ways our respective chronic illnesses have influenced who we are as

therapists, giving rise to many questions about how our chronically ill peers do their jobs and think about their work.

Chronic illness frequently brings with it fatigue, physical pain, and other unpredictable symptoms. S talks about her occasional overwhelming fatigue. I sometimes have intense pain. Normally the body is the ground and the mind is the figure, but with a chronic illness, there is the risk that the reverse will happen. The compromised body can pull the therapist back, away from the client. Often these symptoms become so loud that it is difficult to pay attention to what's happening outside of the body. Durban, Lazar and Ofer (1993) refer to this phenomenon as "the cracked container": the body, which normally would be outside of one's awareness, "an unobtrusive partner" (p. 708), becomes a distraction and in some cases, tests the limits of the therapist's endurance and capabilities. It takes a Herculean effort to maintain one's attention on the client.

This struggle between dealing with the illness and being present with the client always holds the risk that the therapist will feel that she is not doing an adequate job. Maybe the therapist's ability to concentrate is impaired. Does it generate feelings of incompetence, as Wong (1990) and others (Halpert, 1982; Schwartz, 1987), have suggested? Does the therapist feel guilty about moments of being preoccupied with symptoms? S admits to feeling inadequate because her illness interferes with her ability to carry a full caseload. When she is going through a particularly intrusive illness episode, S worries that she is not being a "good enough" therapist because she might be tired or in pain.

This issue brings up further questions. Is the chronically ill therapist capable of doing an adequate job? What if, in our efforts to compensate, we are going overboard in an attempt to make up for our real or imagined deficits? In order to compensate for her recurring symptoms, S takes frequent rest periods in the small apartment adjacent to her office. I cope with some symptoms by taking notes during sessions. I also do 45-minute sessions rather than 50-minute sessions in order to have more “down time.” But is this “compensation” enough or is it even necessary in the first place?

S and I have had frequent conversations about our fear that, if people knew that we had health problems, they would stop referring clients to us. Both S and I are even uneasy about having our names in this dissertation for the same reason – that referrals will stop. Many mental health writers talk about this same worry (Counselman & Alonso, 1993; Lasky, 1990; Morrison, 1997). We both notice that we tend to isolate ourselves professionally, for fear that the truth will come out. We feel that we have to keep our health a secret, which can cause a profound sense of isolation from our peers.

But is money the only concern we have about keeping it secret? The bottom line is that there is a stigma associated with illness (Charmaz, 1991; Scrambler, 1984). There is a prevailing belief in our culture that illness is a failing - almost a moral failing of the individual. There’s a popular belief that if people get sick, it is because they have done something wrong: they ate the wrong diet, they didn’t exercise enough, and in some way or another, they failed to live a healthy life. If sick people had just taken better care of themselves, this would not be happening to them.

Sollad (2002), himself, a psychotherapist, writes, “Some of my friends and acquaintances indicated that they thought my illness was a result of a personal failing of some sort. . . . They said that if I changed my thoughts and emotions, my kidneys would improve” (p. 1400). Illness brings judgment, and with this judgment comes shame.

What makes this particularly difficult for therapists is that we are caught between two extremes. On the one hand there is the overly idealized view of the therapist. Because of our acute understanding of the human psyche, we should somehow be above the problems of life. The implication is that we should have omnipotence over our bodies. On the other hand, there is the “wounded healer” concept, written about by Kidel (1988) and Guggenbuhl-Craig and Micklem (1988). In the “wounded healer” literature, a wound or psychological injury or trauma is regarded as an asset to the psychotherapist, intensifying his or her capacity to empathize with the suffering of clients. A therapist with a chronic illness can be caught in the middle – am I a better therapist because of this illness or am I a failure as a human being?

The other aspect of my research topic is the question of an unseen illness. When a psychotherapist has a visible health problem, the illness is always there; it is a known quantity. It is part of the base line contract between client and therapist. If a client cannot tolerate the seen illness, the client will not stay in treatment with that therapist. Those who can tolerate it will continue to work with the therapist, and the illness will simply be there, influencing and not influencing, depending on the client.

It becomes woven into the fabric of the transference and countertransference from the very beginning of treatment.

With an unseen illness, the impact on the treatment is more mysterious. The therapist's ill health is an unknown, unspoken part of the intersubjective field. Its influence is harder to discern, making it more difficult to evaluate its effect on the treatment. It is or can be the psychotherapist's secret, a secret that has the potential of influencing the psychotherapist's life, from her financial success to the length of her professional career, to her sense of professional identity, to the actual treatment with a patient.

An unseen illness brings up the subject of disclosure, which is the single most common topic in the mental health literature about the physically sick therapist (Abend, 1990; Cristy, 2001; Dewald, 1990; Elliott, 1996; Feildsteel, 1989; Friedman, 1991; Goldberg, 1984; Halpert, 1982; Hannett, 1949; Morrison, 1997; Philip, 1993; Schwartz, 1987; Silver, 1982; Weinberg, 1988; and others). Should the illness be disclosed or not? With a visible illness, the body and the situation do the disclosing. My husband's therapist is in the advanced stages of M.S., confined to a wheel chair with limited ability to move his body. The illness has been a part of my husband's treatment from the very beginning, being grist for the mill and a part of the transference, countertransference field. But with an invisible illness, disclosure takes on a new light. There is no pressing need for self-disclosure because there is nothing to see.

In this research, a different perspective of disclosure has unfolded. For example, does the chronic illness "leak" into the therapy hour? Aron (1991) writes

“Self-revelation is not a choice for the analyst; it is an inevitable and continuous aspect of the analytic process” (p. 47). He goes on to elaborate the need in the patient to know the analyst’s subjective world. If this is the case, does the patient “know” about the psychotherapist’s illness, either unconsciously or perhaps, by picking up on subtle cues from the psychotherapist? Can a psychotherapist discern such influences? Neither S nor I have reputations as “specialists” in chronic illness nor is it common knowledge that we’re sick. Yet we have what appears to be a large number of physically ill clients. Recent neuropsychological research (Schore, 1994, 2001, 2003) focuses on right brain to right brain, unconscious communication. What if the “knowing” about us – the knowledge that we are clinicians with chronic illnesses - is communicated unconsciously to our clients? Do clients bring up material that alludes to the therapist’s illness? And how do chronically ill therapists think about these questions?

In spite of how common chronic illness is, the subject of illness in the therapist has been significantly under represented in the literature (Abend, 1990; Dewald, 1990; Friedman, 1991; Goldberg, 1984; Halpert, 1982; Hannett, 1949; Lasky, 1990; Lindner, 1984; Schwartz, 1987; van Dam, 1987; and others). It is speculated that this paucity of articles stems from the painfulness of the subject (Lindner, 1984; Lasky, 1990). No one wants to relive and reveal the despair or fear associated with a chronic illness. Lasky, in discussing “catastrophic illness,” suggests that the therapist may “have been too traumatized by the event and its aftermath to be able to write about it” (p. 456). Lindner thinks it is related to a fear of death (p. 25). Schwartz (1987) speculates that it is enough just dealing with the chronic illness,

leaving little energy left over for writing about it. Even the more contemporary writers have not addressed the issue of chronic illness. Herbert S. Strean's article in *Psychoanalytic Inquiry* (2002) is the one notable article about illness written from an intersubjective perspective.

It is interesting that, for the last 17 years of his life, Freud had a horrific chronic health problem, that of oral cancer. In spite of his many painful and frequently disfiguring surgeries, he continued working. Yet, he never wrote professionally about his experience. Halpert (1982), offering his explanation for the paucity of literature on the sick therapist, speculates that there is "some degree of identification with Freud" (p. 374) in all therapists; and just as Freud seemed to ignore discussing his illness especially with patients, the rest of the profession has followed suit.

Thinking about the chronically ill therapist and the bearing on treatment is a timely topic when seen in the context of recent changes in the psychotherapy field. During the past two decades, there has been a broadening of our understanding of countertransference and the client/therapist relationship (Strean, 2002). I have been particularly influenced by Lewis Aron's article, "The Patient's Experience of the Analyst's Subjectivity" (1991), in which he discusses the "ongoing mutual influence in which both patient and analyst systematically affect, and are affected by, each other" (p. 33). With the introduction of intersubjective and relational theories and changes in the way we view countertransference, the therapist's subjectivity, whatever it happens to be, is now being studied and talked about more openly (Strenger, 2002). "In the last decade or so . . . it has become possible, indeed *en*

vogue, to speak in a subjective voice” (Strenger, 2002, p. 535). Fifty years ago, it was not permissible to talk about the experience of the chronically ill therapist. Currently, the therapist’s subjectivity is grist for the mill, rather than, as Freud suggested, something to be analyzed away.

In this research, I examined such concerns and more, as they arise, in hope of shedding some light on a complex problem affecting many in our profession.

The Research Question

Given the difficulties that come with illness, what is the psychotherapist’s subjective experience of coping with a chronic unseen illness while working as a therapist in private practice, and how does she think about any impact the illness may or may not have on psychotherapeutic treatment?

The following sub-questions were addressed:

1. How do therapists cope with a chronic illness; in other words, how do therapists manage, on a daily basis, the difficulties that come with having a chronic illness, while maintaining a private practice?
2. How do psychotherapists experience the chronic illness, i.e. how does it feel in their bodies, in their psyches, and how does it influence their thinking about themselves as therapists?
3. How does the chronically ill therapists think about the illness’s affect on the treatment?

This qualitative study focused on the subjective experience of the therapist, using a Grounded Theory approach (Glaser & Strauss, 1967). The data are the content of in-depth interviews with ten psychotherapists in private practice, who

identified themselves as living with a chronic, unseen illness. The psychotherapists were asked to reflect upon and talk about their subjective experiences of having a chronic, unseen illness and their thoughts about its impact on their work. The “constant comparative method” of qualitative data analysis as described by Strauss and Corbin (1990) was used to analyze the data from the study.

I limited my research to those chronic illnesses that were currently not life threatening, yet had a regular impact on the participants’ lives, and illnesses that the participants defined as “chronic.” I did not look at the many examples of non-physical chronic illnesses, such as developmental or cognitive disorders and mental disorders. The research looked primarily at psychodynamically-oriented psychotherapists in private practice.

Definitions

In this research, I defined “psychotherapist” as an individual licensed in the state of California to perform psychotherapy. This includes social workers, marriage and family therapists, psychologists, and psychiatrists. I used Shuman’s (1996) definition of “chronic illness”:

A chronic illness is one in which a person’s symptoms continue over a long term to impair his or her ability to continue with significant activities and normal routines. Medical treatment is frequently of limited effectiveness and contributes at times to both the physical and psychological distress of individuals and their families. Chronic illness typically impacts a person’s sense of his or her body, orientation toward time and space, ability to predict

and control life course and events, self-esteem, and feelings of personal motivation and mastery. (p. 6)

By “invisible” or “unseen,” I meant illnesses in which there is no visible evidence of the illness to the observer.

Significance of the Study

There has been little written about the chronically ill psychotherapist. The few articles in the mental health literature focus primarily on therapists’ sudden, acute illnesses and/or life-threatening illnesses. Unseen illnesses are almost never mentioned in the literature and no research has been done on my topic - psychotherapists with chronic, invisible illnesses. It was the intent of this researcher to fill a void and contribute to our understanding of a subject that affects many in our profession. Helping to establish a body of knowledge that addresses this topic could provide psychotherapists with a framework to better understand and cope with their illness experience. In addition, this research has the potential of encouraging a more open discussion about a phenomenon that, because of the stigma of chronic illness, is not talked about, contributing to the psychotherapist’s sense of isolation and shame.

CHAPTER 2: REVIEW OF THE LITERATURE

“The undercurrent of chronic illness is like the volcano: it does not go away. It menaces. It erupts” (Arthur Kleinman, 1988, p. 44).

This study examined the impact of a chronic unseen illness on the psychotherapist in private practice. This review first covered literature on the experience of chronic illness in general – the ways in which a sick person experiences a chronic illness, including stigma, shame and an altered sense of self. I then looked, specifically, at the mental health literature on psychotherapists with health problems, the bulk of which focuses on therapists with acute, life threatening illnesses and primarily visible illnesses. Finally, I reviewed psychological theory that pertains to this study.

The Impact of Chronic Illness

An abundance of literature on the psychology of chronic illness exists in the fields of sociology and medical anthropology, which reveals how the experience of chronic illness impacts a person’s sense of self, personal identity, personal growth and coping styles. Chronic illness is more than just the diagnosed disease. It is a deeply felt experience that alters everything from how the person spends his/her day to making plans for the future.

I will start with the works of Dr. Arthur Kleinman (1980, 1988), psychiatrist and medical anthropologist, and Dr. Kathy Charmaz (1983, 1991, 1995, 1999, 2000, 2002), sociologist. Because both scholars have contributed greatly to chronic illness theory and have relevance to my research question, I will review each individually.

Much of the research on chronic illness that I am reviewing, including Charmaz's work, has been influenced by Kleinman's seminal work in medical anthropology.

The Contribution of Dr. Arthur Kleinman

Dr. Kleinman, a psychiatrist and medical anthropologist at Harvard, has extensively studied illness and chronic illness by interviewing sick people, their families and their physicians. He has conducted comparative studies of sick people in China and the United States, looking at how these two cultures think about and subjectively experience chronic illness. His work has had far-reaching impact on how we consider and treat chronic conditions. He defines chronic illness as "a disorder which cannot be cured (i.e., made to disappear completely), goes on for years, requires ongoing self care and professional care and is recognized as 'chronic' by patients and care givers" (personal communication, December 19, 2005).

Kleinman (1988) makes an important distinction between illness and disease. He describes illness as a subjective experience: "Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (p. 3). Illness is keeping an eye on body sensations, describing symptoms to friends, initiating or terminating treatment, modifying agendas, worrying about money, and a shrinking self-esteem. Illness problems are those problems that the disease, with its symptoms and disabilities, creates in the life of the sick person.

Disease, on the other hand, is the actual medical diagnosis; it is a "recasting of illness in terms of theories of disorder" (1988, p. 5). Disease is the domain of the doctors and health care providers, i.e.:

The healer – whether a neurosurgeon or a family doctor, a chiropractor or the latest breed of psychotherapist – interprets the health problem within a particular nomenclature and taxonomy, a disease nosology, that creates a new diagnostic entity, an ‘it’ – the disease. (p. 5)

For example, a patient may have back pain that interferes with his ability to earn a living. The “disease” is a herniated disc of the spine, but the “illness” is, among other things, the fear of financial ruin, life style changes, and marital strain.

In order to understand how the sick person “wears” a chronic illness, one must go inside the experience and look at the broader context – societal, psychological, financial, cultural. According to Kleinman (1988), the illness experience is culturally influenced and cannot be understood without examining the greater culture in which the sick person lives. Where does the patient reside? What’s his/her socio-economic background? What’s his/her educational background? All of these questions and more are the backdrop for a sick person’s “illness experience.”

Kleinman (1988) urges health care practitioners, in order to adequately treat a patient’s symptoms, to examine and understand the culture in which the person lives. For example, in Chinese culture, because mental illness profoundly stigmatizes the sick person as well as the family, psychological symptoms are frequently hidden under various euphemisms, such as “neurasthenia,” implying an organic cause rather than a mental cause. From Kleinman’s perspective, symptoms are “a tight integration between physiological, psychological, and social meanings” (p. 14).

It is Kleinman’s contention that something important is lost with the disease model; “In the practitioner’s act of recasting illness as disease, something essential to

the experience of chronic illness is lost; it is not legitimated as a subject for clinical concern, nor does it receive an intervention” (1988, p. 6). In the disease model, the very soul of the chronic illness is missing. Focusing on the biomedical limits the practitioner’s ability to truly grasp what the patient’s illness is all about:

In the biomedical model the disease is an occluded coronary artery; in the biopsychosocial model it is a dynamic dialectic between cardiovascular processes (hypertension or coronary artery insufficiency), psychological states (panic or demoralization), and environmental situations (a midlife crisis, a failing marriage, the death of a parent from the same disorder). (p. 6)

Kleinman’s body of work, rich in conceptualization and in empirical evidence, informed my approach to this research by focusing on the subjective experience of therapists’ invisible chronic illness in the cultural context of their work.

The Contributions of Dr. Kathy Charmaz

Dr. Kathy Charmaz, professor of sociology at Sonoma State University and an international expert on chronic illness, has studied in depth the ways in which a sick person copes with and modifies her life around a chronic health problem. She has devoted herself to the understanding of chronic illness, writing extensively about the impact of chronic illness on the individual’s sense of self, about the illness identity and the illness experience. Dr. Charmaz’s in-depth interviews with 100 chronically ill individuals, some over a 5-11 year period, have been reported on in her many books and articles (1983, 1991, 1995, 1999, 2000, 2002). She has been particularly interested in how sick people make meaning out of their illnesses, and how chronic illness influences the sick person’s perception of time and sense of self.

The Experience of Chronic Illness – The Effect on the Self

Chronically ill individuals, according to Charmaz (1991), experience illness in three ways: “interruption,” “intrusion,” and “immersion.” These three categories are not necessarily successive, although they can be. Some people experience their illness “in a straight line” (p. 9), while others may go in and out of acute episodes. In my research, I am focused primarily on what Charmaz calls “intrusion.” I will review all three to give the reader a more comprehensive understanding of what Charmaz is suggesting.

1. “Interruption”: When an illness is interruption, the person assumes that the illness is only temporary, of a short duration, with a predictable outcome of recovery. Sick people who are viewing their illness as an “interruption” assume that they will get well and that the illness is simply a temporary crisis. Their concentration is on recovery, “retrieving a past self” (Charmaz, 1991, p. 14). There is no need to change one’s perception of oneself because the expectation is one of full recovery, with a certainty of life returning to the way things were.

One significant feature of “illness as an interruption” is the sick person’s altered sense of time. The past, present and future shift as the individual grapples with the crisis of the illness. Past takes on a new meaning – it’s a place where one longs to return. Future is uncertain. Present can consist of waiting – waiting for symptoms to go away, waiting for symptoms to return or waiting for the doctor.

2. “Intrusion”: With “intrusion,” the sick person is aware that the illness is no longer temporary and is aware of the subsequent losses associated with it. The individual now knows she has a chronic illness and that it demands attention and

accommodation. Consequently, the sick person's sense of self begins to change. "A fundamental form of . . . suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without simultaneous development of equally valued new ones" (Charmaz, 1983, p. 168). The self is weakened by "loss of production, financial crises, family strain, stigma, and a restricted existence. . . . Hence, suffering such losses results in a diminished self" (p. 169).

The sick person experiences the illness as permanent and must begin to accept the symptoms. Charmaz (1991) lists four approaches to acceptance: ignoring the illness, struggling against the illness, reconciling oneself to the illness, and accepting the illness. Acceptance ebbs and flows depending on the course of the illness. Of relevance to this research, Charmaz points out how easy it is to ignore an invisible condition because of the absence of obvious, noticeable symptoms, thus, delaying acceptance of the illness.

Individuals rate a day as good or bad, depending on the intrusiveness of the symptoms. A good day means minimal intrusiveness of illness, maximal control over mind, body, and actions, and greater choice of activities. During a good day, symptoms and illness routine are concentrated on minimally, if at all, or they are handled smoothly and efficiently. Illness remains in the background. Spatial and temporal horizons expand and may even become expansive during a good day. When illness abates, people have more good days, "Like ex-convicts just released from jail, they may wish to make up all at once for lost time" (Charmaz, 1991, p. 50).

Individuals in the "intrusion" category frequently are able to continue working, especially on "good days" when symptoms are less intrusive. In my

research, because I interviewed working psychotherapists, all of my participants fell into this category.

During the stage of “intrusion,” the illness begins to impact the individual’s sense of selfhood. The sick person begins to ask, “Who am I now that I have a chronic illness?” “Am I no longer a healthy person?” “Am I now a sick person?” There is a sense of apprehension, “Intrusive illness threatens control over self and situation, and results in uncertainty” (Charmaz, 1991, p. 43). Except on “good day,” sick people no longer feel like themselves. “Definitions of a good day derive from a sense of being in character, being the self one recognizes and acknowledges. On a good day, ill people have more opportunity to be the selves they wish to be” (p. 51).

The extent to which sick people experience their symptoms is directly related to the extent of obligations and responsibilities that they have, such as professional, financial, and familial. For example, those who must work experience their symptoms as much more intrusive than those who have minimal financial obligations. Charmaz found that many sick persons push themselves out of necessity. They set timed goals for themselves, what Charmaz calls “shorter timeframes” (1991, p. 62); for example, “I’ll push myself to work until my dissertation is done.” These “shorter timeframes” allow the sick person to cope with the “longer timeframes” that are more challenging. This issue is certainly germane to sick psychotherapists in private practice who are primarily responsible for their own financial circumstances, who do not have paid sick leave and who have no other source of income.

Charmaz refers to a “dialectical self” (1991, p. 70) which she defines as the contrast between the physically sick self and a “monitoring self,” the self that is

always aware of the illness, the symptoms, the possibility of a recurrence of symptoms, and the possibility of the new, more debilitating symptoms developing. The “dialectical self” is always on guard, hyper-vigilant, always on the look out for illness problems. The “dialectical self” is never able to relax and “ . . . is one of ill people’s multiple selves that emerges in the face of uncertainty” (1991, p. 71).

3. “Immersion”: An immersed illness is a way of life. A sick person in immersion is not able to work; consequently, I did not interview individuals who were immersed in their illness. However, it is important to be aware of what this stage entails, because the “dialectical self” lives in fear that immersion will occur. The individual must, as Charmaz (1991) puts it, “reconstruct” (p. 76) her life to accommodate the all-consuming illness. The management of the illness becomes all the person can do. An individual at this stage is physically, socially and financially dependent on others. The sick person’s entire self-concept must change to one of dependency, even victimization. The illness is always present, never fading into the background. It is easy to see why the “dialectical self” would fear immersion.

Disclosure

Charmaz is especially interested in the subject of disclosure, a topic that is also of concern to the physically ill therapist. Just as Kleinman’s (1988) volcano quote suggests, the chronically ill person has little control over the illness. It seems to have a mind of its own, erupting randomly and unpredictably. Sick people cannot control their illness, but they can, however, control when or how or how much to disclose.

Charmaz (1991) found that many sick people, in their efforts to hang on to their “past self,” will present a false front to the public, a theme echoed by Shuman (1996) when talking about his own personal experience with multiple sclerosis. Charmaz calls this phenomena, “passing,” i.e., concealing the illness from family, friends, and co-workers; first, to protect against possible discrimination, and second, to prevent the reverse from happening, i.e., special privileges stemming from pity.

The problem with “passing” is that it takes an enormous amount of energy and thought. Sick people might pretend to be well, acting in ways that will make themselves even sicker. Charmaz (1991) points out, “paradoxically, however, the very reasons for keeping illness contained – to pursue a career, to keep a job, to develop a relationship - can foster the conditions in which intrusiveness of illness escalates” (1991, p. 69).

Disclosure of a chronic illness is fraught with danger. The sick person can be rejected and/or stigmatized by friends and colleagues (I will discuss stigma later in this review). The reactions of others can potentially run the gamut from disbelief (particularly common with an invisible illness where there is no physical evidence of the illness) to pity, criticism, and exaggerated solicitousness (bordering on infantilization), to rejection. There’s the risk of probing questions (“Is it fatal?”), unsolicited treatment suggestions (“Have you tried acupuncture, massage, etc.?”) and other intrusions on the sick person’s autonomy, making it difficult to be known for anything other than the illness. It can strain relationships and alter the sick person’s sense of independence.

In her research, Charmaz (1991) found that, in order to maintain control, sick persons disclose in two ways: protective disclosing and spontaneous disclosing.

Protective disclosing is designed to control how, what, when, and who people tell about their illness. . . . Spontaneous disclosing includes full expression of raw feelings, open exposure of self, and minimal or no control over how, when, where, what, and whom to tell. (p. 119)

When an illness is invisible, disclosing is a little more complicated. People with invisible illnesses tend to do “strategic announcing.” According to Charmaz, the individual, in an effort to have control over the disclosure and to protect the self at the same time, will organize every aspect of the disclosure – the timing of when or what and how much to disclose and importantly, the frequency of the disclosures. Because of the lack of physical evidence, “invisible illnesses can necessitate repeated strategic announcing to inform, enlighten, remind and instruct others” (1991, p. 122).

The Impact of Chronic Illness – Other Writers

Besides Charmaz and Kleinman, there are several others who have contributed to our understanding of the impact of a chronic illness: Bury (1982), Corbin (2003), Radley (1999), Yoshida (1993) and Scrambler (1984). Because each writer has made his/her own unique contribution to our understanding of chronic illness, I am reviewing each writer separately. Except for Scrambler, whom I will review below in the section on stigma, these writers will be reviewed here.

As Kleinman (1988) has stated, chronic illness is more than just the physical and psychological sensation of pain, distress, fatigue, and other symptoms. Chronic illness becomes a way of life for the sick person. As the illness takes over, the sick

person's former sense of self gradually, and sometimes rapidly, erodes away, leaving the sick person with a feeling of "Who am I?" Chronic illness changes the entire course of the sick person's life and alters all the benchmarks by which the individual achieves validation. The damaged self-concept can give way to loss of self-esteem and self-respect.

Chronic Illness as a Disruptive Event – Bury

Michael Bury (1982), a sociologist, describes chronic illness as a "disruptive event." Based on semi-structured interviews with 30 rheumatoid arthritis patients, Bury concluded that "illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted" (p.169). Chronic illness is not just a small blip in the structure of the individual's life; it is a major event, dramatically changing the remaining course of the sick person's life, a theme reiterated by Charmaz (1983) and Kleinman (1988). "The experiences and meanings upon which these ill persons had built former positive self-images are no longer available to them" (Bury, 1982, p. 168).

Bury (1982), whose findings are congruent with the work of Kleinman and Charmaz, categorizes three phases of disruption. In the initial phase there is recognition that the ordinary predictable chronology of one's life has forever been changed. There is a mixture of shock, anxiety, disbelief, and fear. The expected trajectory of the person's life has become one of abnormality and damage.

Next, the sick person searches for an explanation and a sense of meaning about the chronic illness. Bury states, referring to his research on rheumatoid

arthritis patients, “The experience of the patients in this study underlined the uneasy balance which is struck between seeing the condition as an outside force and yet feeling its invasion of all aspects of life” (1982, p. 173). The sick person begins asking “Why me?” and “Why now?”

In the third phase, that of “mobilization of resources,” the sick person develops strategies for coping with the illness. Becoming aware of one’s limitations and recognizing the need for help are in the forefront. In spite of the disruption of chronic illness, there is an attempt to normalize one’s life.

The Horror of Chronic Illness – Radley

Alan Radley (1999), a medical sociologist, writes about the “horror” of living with a life-threatening illness. He takes an existential perspective, of being forced to come face to face with the overwhelming loss of one’s previous identity. Analyzing the narratives of persons with life-threatening or terminal illnesses, Radley concludes that illness is a disruption to a “person’s dreams, wishes and fancies” (p. 781). The illness, what Radley calls “the alienation of the mundane” (p.782), wipes out the stuff of ordinary life. He sees, however, the possibility of the illness experience being a transmutational one in which the sick person can create beauty out of the horror.

Assuming the Chronic Illness Identity – Corbin

A major theme in the chronic illness literature is loss of self and the subsequent reconstruction of a new self. Juliet Corbin (2003) focuses on the process by which a person comes to identify himself as having a chronic illness. Based on findings from her qualitative research on chronic illness, Corbin states that we define

ourselves by what the body can do. The body sends us messages in the form of sensations, the sensations have meaning based on previous experience with the outside world, what Corbin calls “the language of the body” (p. 258). Out of this predictability comes a trust in what to expect from the world. The body and the self are one unit, communicating back and forth.

With a chronic illness, the sick person is robbed of this sense of trust. Sensations take on new meaning. For example, before the chronic illness, certain abdominal sensations were the body’s way of signaling hunger. After the onset of the chronic illness, these same sensations might signal a frightening precursor to a relapse. The body isn’t reliable and familiar in the way it was before the illness. It can change, pending on the illness – it may develop an odor, be weak, have disfigurements, and imperfections. The “re-imaging” of the body requires the sick person to reconstruct the self into an illness identity, one that fits the changed body.

Similar to Charmaz’s (1991) theories on illness and time, Corbin (2003) talks about how the sick person’s sense of time is altered. Time becomes the illness, i.e. time is structured exclusively around symptoms, energy levels, health regimens, rather than around the wants and desires of the sick person. Future fears loom large, “During illness, time is often perceived as closing in – one might not be certain how much biographical time is left and what the time that remains will be like” (p. 259).

Identity Reconstruction – Yoshida

The development of a new self is the focal point of Karen Yoshida’s research. Yoshida (1993), a researcher from University of Toronto, conducted in-depth interviews with 35 adults paraplegics (a condition that she viewed as a chronic

illness) focusing on how these individuals reconstructed their lives post-injury. She conceptualizes the reconstruction of a post-injury self as a “pendulum.” Identity reconstruction swings back and forth between the nondisabled self and the disabled self, rather than proceeding in a linear fashion, and is a long-term process. Yoshida suggests five identity views – “the former self” (i.e. the pre-injury self) (what Charmaz [1991] calls “the past self”) on one end of the continuum, and “the disabled identity as the total self” (being totally identified with the disability) on the other.

In the center is “the middle self.” The individual is able to hold a dual identity view, acting upon aspects of both their nondisabled selves and their disabled selves. They accept the disability and, according to Yoshida, have a “wider social concern for other persons with disabilities and other segments of society” (1993) p. 230). In between is “the supernormal identity,” in which the individual “engages in activities that require a level of functioning more demanding than those who are able bodied” (p. 226), and the “disabled identity as part of the total self,” in which the disability is one aspect of the identity but does not encompass the total self. Yoshida stresses that these are not stages; that identity reconstruction is a pendulum, swinging back and forth, over time, between these identity views. Integration into the new self is a process of “reclaiming lost aspects of the nondisabled self and an initial process of inclusion of the disabled self” (p. 232).

Chronic Illness and Shame/ Stigma

Stigma comes from the Greek word meaning a “mark” or “puncture” and the Latin word meaning “a mark made on (the) skin by burning with a hot iron” (Harper, 2001). The word’s origins are derived from the practice of marking a slave, criminal,

traitor, or other undesirable person for easy identification. To stigmatize comes from an attitude that a person or a group of persons are not acceptable or are falling short of a societal standard and, consequently, are disreputable and undesirable. Shame is stigma's cousin – a feeling of guilt or disgrace in the stigmatized person. It is an internal feeling state that comes either from something external, for example, stigmatization, or it can develop out of an inner feeling of badness.

Shame and stigma are an integral part of the illness experience (Charmaz, 1991, 2000; Scrambler, 1984; Kleinman, 1988). There is a stigma attached to chronic disease, especially disfiguring and disabling diseases, evoking in the sick person a deep sense of shame and, as Kleinman (1988) puts it, “a spoiled identity” (p. 160), a phrase originally coined by sociologist Erving Goffman (1963) in his seminal work on stigma.

Erving Goffman – Notes on the Management of Spoiled Identity

Erving Goffman, a leading voice of the Interactionist approach to sociology, has influenced the research and thinking about stigma and chronic illness. In his analysis of the phenomenon of stigma, *Stigma – Notes on the Management of Spoiled Identity* (1963), Goffman addresses the nature of social deviance as a socially constructed identity. In other words, stigma, a “deeply discrediting attribute” (p. 3), grows out of a variety of societal rules and expectations.

A society, through social interaction, establishes “norms” that are especially accepted ways of being. Those individuals who meet these “norms,” Goffman refers to as “normals.” Those who do not meet the expected “norms” are “stigmatized” for their deviance.

Goffman classifies three types of stigma: “Abominations of the body,” such as physical deformities; “blemishes of individual character,” such as mental disorders, chemical dependency, criminality and poverty; and the “tribal,” referring to race, religion and nationality. He elaborates,

In all of these various instances of stigma . . . the same sociological features are found: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. (1963, p. 5)

Goffman makes an important distinction between “discreditable” and “discredited” stigma. He describes the individual with an obvious, unconcealable and sometimes intrusive stigma as “discredited” and, relevant to this research, the individual with a secret, invisible stigma he describes as “discreditable.” While the “discredited” must focus on tension management, controlling the awkwardness and/or hostility that is encountered when interacting with “normals,” the “discreditable” makes every effort to “pass” as a member of the unstigmatized majority.

Goffman goes on to observe that the “discreditable” lives with the heightened sense of vulnerability that comes with the risk of exposure. He/she is also caught in a divided affinity – passing as “normal” and yet, identifying with others who carry the same stigma. In relationships with intimates, the “discreditable” exists in a tension arc between telling friends/family and risking the potential consequences of their reactions, versus not telling but feeling guilty for not doing so. In either case, the

stigma “casts a shadow” (p. 74), extracting a high psychological price from its victim – self-hatred, suspiciousness, depression, anxiety, defensiveness and sorrow.

How does the psychotherapist with invisible illness confront this dilemma? Does the chronically ill therapist become Goffman’s “discreditable,” or, is he/she somehow exempt from this experience? This research has explored Goffman’s (1963) distinctions and how they are experienced, if at all, by the chronically ill therapist.

Shame and Illness

It is only human to try to prevent suffering. If the source of the suffering is illness, we want to know what causes the illness, in an effort to protect ourselves from falling prey to the disease. We want to know what we can do to steer clear of this cruel misfortune of nature. How often do we find ourselves saying, “If he had just exercised more” or “He shouldn’t smoke” in response to the news of a friend’s sudden illness? We need to identify a cause so we can avoid it. A good example is our concern – perhaps obsession – with cholesterol. If we keep our cholesterol count low, by diet, exercise, or medication, we assume we will never have a heart attack.

But in our attempt to protect ourselves from illness, we judge the very person who is the victim – the sick person himself. We imply that the sick person did something wrong or in some way was inferior, thus causing the illness. The sick person smoked cigarettes, the sick person ate too much fat, the sick person watched too much T.V., and the sick person did not know how to handle stress. Kat Duff (1993), in writing about her own experience with Chronic Fatigue/ Immune

Dysfunction Syndrome (CFIDS), states, “Patients are often viewed as morally deficient or psychologically damaged” (p. 30).

The sources of stigmatization according to Guggenbuhl-Craig (1988), a Jungian analyst, seem to be woven into the very tapestry of humankind. He reviews the historical moralistic view in which illness was considered evil and a punishment for bad deeds:

Ethnographers tell us that in archaic society illness was considered to be the result of bewitchment by either an evil power or an evil person. In many parts of Europe, witches were until recently suspect of causing disease. Jews were supposed to have poisoned the water and caused the plague in the Middle Ages. Or could it be that God himself punished and still punishes sinners with disease as He punished mankind with floods, fire and earthquakes? (p. 142)

One of the most powerful stories of illness-as-punishment is the Biblical story of Job, who was struck with a series of afflictions, including a skin disease resembling boils. Job was an exemplary, moral man. Why could all of these bad things have happened to him? Yet, needing an explanation for these horrific events, Job’s friends insisted that he had sinned and that his sicknesses were a punishment from God.

Mark Kidel is a writer and a filmmaker who, out of his own experience with chronic illness, organized two conferences at Dartington Hall in Devon, England, on “The Meaning of Illness,” between 1985 and 1986. The conferences brought together a wide range of helping professionals, medical consultants, psychotherapists, social workers, general practitioners, and alternative health care providers. It was out of

those conferences that Kidel compiled a series of essays into a book, *The Meaning of Illness* (1988).

In the book's introduction, Kidel asserts that the body has been equated with man's baser nature – the “flesh,” man's animal nature. “The body, according to this particular understanding, belongs to a lower order of things; it is in some essential way inferior to mind or spirit” (p. 7). The body is viewed as dirty, possessed by evil. In the Christian tradition, the body is the source of temptation and Kidel states; “There is still . . . an association between ‘health’ and ‘virtue’ on the one hand, ‘illness’ and ‘sin’ on the other” (p. 7).

Kidel, however, notes a paradox regarding the body: along side this devaluation of the body is a “fanatical cult” (p. 8) of making the body perfect, via exercise, fitness, diet, and plastic surgery. He believes that rather than uniting the body and spirit, this obsession, instead, furthers the detachment from the body: “This cult represents an obsession with the body as object; a distancing from, rather than an opening to, the essential vulnerability of which the body speaks in its ‘symptoms’” (pp .8-9).

Guggenbuhl-Craig postulates that the current trend to find symbolic meaning in physical symptoms is a continuation of the “illness as punishment” mode of thought. He points out:

When we look at the explanations given by psychosomatic medical doctors today, we make a strange discovery; every disease seems to be a kind of punishment for a particular sin in the sense of the sick person having an unbalanced psychological development. We seldom hear that someone falls

ill because he is psychologically well balanced, because he is able to express feelings in a fruitful way or because he is a loving and caring person. (1988, p.143)

Kat Duff (1993) writes about the experience of dealing with other people's perceptions and reactions to her chronic illness:

I dread having to tell people I am sick, or still sick, because many respond with theories about what I did to make myself sick or suggestions of what I could do to get well – both of which just makes me feel worse for being sick. (p. 39)

Both Kidel and Guggenbuhl-Craig believe that our “illness as punishment” attitude stems from a narcissistic belief that we can master nature. Rather than tolerate a sense of vulnerability, we search for answers to illness in a desperate drive to make it go away. Duff puts it this way:

When symptoms persist and illness becomes chronic, we often find fault with the victim, we call it a lack of will power, a desire for attention, an unwillingness to work or change, rather than question the hidden assumption that it is within our power as human beings to overcome sickness and, in fact it is our job to do so. (1993, p. 41)

In reality, there may be no “cause” of illness. It is a “tragedy . . . a dreadful happening without meaning or purpose” (Guggenbuhl-Craig, 1988, p. 145).

According to Micklem (1988), efforts to distance from the body distract from the real issue, which is that illness happens, without meaning or explanation:

In other words the meaning of illness – if it may be stated in terms of seeming contradiction – is not to search for meaning and turn disaster into good effect – but to withstand and to grapple with the meaninglessness of the tragedy.

(p. 150)

This means facing suffering and the fear of death head on without being burdened by guilt or shame.

Stigma and the Altered Sense of Self

Stigma and shame can seriously impact the sick person's sense of self and self-esteem. Sick people are viewed as "less than" by a society that values and idealizes health. Over time, this belief erodes away the sick person's self-esteem and confidence. The sick person is at risk of identifying himself completely with the stigmatizing viewpoint. The stigmatizing belief becomes the reality and the sick person's sense of self plummets.

Drawing on Goffman's (1963) work on stigma, sociologist Graham Scrambler (1984) interviewed 94 people with epilepsy to determine the impact of stigma in their lives. According to Scrambler, stigma evolves from behavior that is perceived to be "infringements against norms" (p. 204) and "a threat to the social order" (p. 205). The stigmatized person violates these norms and becomes forever locked in an image of imperfection.

Scrambler (1984) differentiates between two types of stigma: ascribed and achieved. Ascribed stigma refers to the stigmatized individual who has infringed on the norm in a manner that is entirely outside of his control (for example, the epileptic seizure). Achieved stigma refers to the individual who has earned a deviant status by

behaving in a way that goes against the norms of society (for example, the criminal). Scrambler makes a further distinction between “enacted stigma,” which is the actual episode of discrimination (an epileptic is shunned because of a seizure) and “felt stigma,” which is the internalized shame associated with the imperfection (how the epileptic feels about himself as the result of having the seizure).

Both Scrambler (1984) and Charmaz (2000) found that, of the two types of stigma, “felt stigma” is the most damaging to the self. Relevant to the present research, keeping the imperfection secret does not protect against “felt stigma.” Scrambler points out that epileptics who have been able to keep their disease a secret still feel shame due to “felt stigma”:

People felt ashamed fundamentally because they saw “being epileptic” as amounting to an infringement against norms relating to “identity or being” . . . the shame experienced by those with epilepsy may be said, as may felt stigma generally, to be based on a deep sense of ontological inferiority. (p. 215)

When an illness is visible, obviously, there is a greater possibility of stigma because the “infringements against norms” are apparent to the viewer. With an unseen illness, stigma and shame take on a new meaning; the sick person is able to hide the illness, thereby avoiding actual incidents of stigmatization. However, as Scrambler found, avoidance of “enacted stigma” does not eliminate “felt stigma” and its accompanying shame. The fear of “enacted stigma” was “the source of more personal anguish and unhappiness than was enacted stigma [itself]” (1984, p. 217). Scrambler found that epileptics, in order to avoid “enacted stigma” would go out of their way to keep their illness a secret, frequently to their own detriment.

Reminiscent of Charmaz's (1991) "passing," Scrambler states, "Most of them had paid a psychological price for their silence. Most obviously, they had had to learn to live with the stresses of guarding against the daily risk of exposure through stigmata or stigma cues" (p. 217).

Scrambler (1984), borrowing from Goffman (1963), describes the individual with a known and/or visible illness as "discredited" and the individual with a secret, invisible illness as "discreditable." The "discredited" strives to manage other's impressions of him. The "discreditable," on the other hand, makes every effort to control what information people have about him. Much the same as Charmaz's (1991) "dialectical self," the "discreditable" is hyper vigilant and careful, trying to manage how much and what others can know about him.

Charmaz's (2000) research suggests some additional ways in which stigma is different with an invisible illness:

People with invisible disabilities are judged by conventional standards and blamed accordingly when they transgress them. Thus, they suffer public accusations of usurping the rights of the handicapped (such as when they occupy handicapped subway seats or parking spaces), imputations that their poor performance reflects a sick mind, not an impaired body, and private doubts as to what is real. (p. 285)

Charmaz indicates that individuals who are able to hide their illness and thus avoid "enacted" stigmatization are also able to hang on to their previous sense of self for a longer period of time. The risk, however, is that the sick person, who is essentially living a lie ("I am sick even though I've fooled you into thinking that I'm well"), will

experience a greater sense of isolation. They long for and need empathy and acknowledgement, but cannot get it because of the invisibility.

The subjects of shame and stigma are curiously absent from the mental health literature. Elliott (1996) mentions shame in the context of how important it is for the sick person to work through the pain associated with the illness, so the material will not become ignored, “leaving numb spots secured in place by shame” (p. 22). Counselman and Alonso (1993) talk about it in terms of dealing with colleague reactions (a matter that I will discuss in more detail later in this review) – being viewed as a “pariah in the eyes of colleagues” (p. 595).

There’s a prevailing belief in our culture that illness is a failing – almost a moral failing of the individual. Illness brings judgment and with this judgment comes shame. As this research shows, therapists are not exempt from this judgment; consequently, shame and stigma can be important concerns. Sollad (2002), himself a psychotherapist, writes, “Some of my friends and acquaintances indicated that they thought my illness was a result of a personal failing of some sort. . . . They said that if I changed my thoughts and emotions, my kidneys would improve” (p. 1400).

Chronic Illness in the Psychotherapist

The subject of sickness in the therapist has been significantly under represented in the literature (Abend, 1990; Dewald, 1990; Friedman, 1991; Goldberg, 1984; Halpert, 1982; Lasky, 1990; Lindner, 1984; Schwartz, 1987; van Dam, 1987; and others). Up until the mid-1990s, there were only a handful of articles written about the sick therapist. It is speculated that this paucity of articles stems from the painfulness of the subject (Lindner, 1984; Lasky, 1990). No one wants to relive and

reveal the despair or fear associated with a chronic illness. Lasky, in discussing “catastrophic illness,” suggests that the therapist may “have been too traumatized by the event and its aftermath to be able to write about it” (p. 456). Lindner (1984) thinks it’s related to a fear of death. Schwartz (1987) speculates that it’s hard enough just dealing with the illness, let alone having the energy to write about it.

There is little formal research on the topic. Hott (2001), in her dissertation at the Union Institute, studied the coping styles of women psychotherapists with breast cancer. She interviewed 19 women. She concluded that female therapists with breast cancer fell primarily into three categories: Planful Problem Solving (determined and clear efforts to affect the situation), Positive Appraisal (making positive meaning out of the experience) and Seeking Social Support (efforts to obtain information and to gain social support). A subtext to Hott’s research was self-disclosure. For many of her participants, the breast cancer was an invisible illness. Hott found that participants handled self-disclosure in a variety of ways, depending on the client, where the client was in his/her therapy, and professional concerns (fear of referral loss, for example).

Counselman and Alonso (1993) did an informal study, asking 22 psychotherapist friends to complete a short anonymous questionnaire about their experiences with illness; 9 people responded. Counselman and Alonso do not go into the details of the “study,” except to say: “The results indicated that decisions about giving information were not difficult. However, the countertransference reactions of anxiety, denial, sadness, and avoidance (of patient anger) were often troublesome” (p. 602).

Grunebaum (1993), in preparing for the writing of a book chapter on ill and injured therapists, informally interviewed 12 therapist colleagues who had dealt with illness (some acute, some chronic) or injury in their personal lives, emphasizing questions about what “they had told their patients, why they decided to follow a particular course of action, and what the outcome was” (p. 22). Without getting specific, he reviews some countertransference issues that will be mentioned later in this review and he strongly advocates that therapists tell their patients of the illness or injury.

Even the more contemporary writers have not addressed the issue of chronic illness. Herbert S. Strean’s article in *Psychoanalytic Inquiry* (2002) is the one, notable article about illness written from an intersubjective, relational perspective, in which he discusses countertransference and transference reactions following his heart attack.

Most of the relevant mental health literature, which is limited to personal observation and informal discussions with colleagues rather than empirical research, focuses on varying aspects of sudden, acute and frequently life-threatening illnesses, usually not chronic and not invisible. For instance, Chernin (1976) talks about his bout with pneumonia, resulting in a month’s leave from work. Dahlberg (1977, 1980) writes about his stroke and its effect on his practice. Lindner (1984), Strean (2002) and van Dam (1985) describe their experiences with sudden, acute heart disease. Schwartz (1987) and Silver (1982, 1990) write about having surgery and Goldberg (1984), Halpert (1982), Friedman (1991), Morrison (1990, 1997), and Sollad (2002) all write about having life-threatening illnesses and the impact on their practices.

Others describe their experience with progressive illnesses, which eventually become obvious to their patients, for example, multiple sclerosis (Elliott, 1996, LeMaistre, 1985, Shuman, 1996) and Parkinson's disease (Christy, 2001). Pollak (2000) describes her patients' reactions to her going into a diabetic coma in the therapy hour, and Weinberg (1988) writes about changes in her appearance caused by medication taken for treatment of a long-standing chronic illness.

My interest, the therapist's chronic, invisible, physical illness is almost never mentioned in the mental health literature. Philip (1993) has a fatal blood cancer that she calls an invisible illness, but the focus of her article is on the termination of her therapy practice rather than the day-to-day living with an illness. Lasky (1990) alludes to an invisible illness when discussing the therapist's neutrality. Though the topic of this research is rarely mentioned in the mental health literature, I believe it is possible to extrapolate from the available literature factors and themes that are also present for the chronically ill therapist.

In this section, under the sub-headings of financial worries, getting support, gaining from the experience, countertransference reactions, and psychotherapist's subjectivity, I will review what little has been written about emotional reactions. I will also address the "technical matters" discussed in this review, under the sub-heading of disclosure.

Financial Worries

A topic that looms large for therapists in private practice is the issue of financial security. Not having the benefit of sick leave, the burden of financial well-being rests entirely on the psychotherapist's ability to work. Sick therapists worry that other

professionals will stop referring clients to them. I think we all have some reservations about referring, particularly long-term and more regressed clients, to our physically ill colleagues, unless we are confident that their illness has not and will not interfere with their abilities. So, sick therapists' fears about a diminishing caseload are not unfounded.

Lasky (1990) worried about whether or not people would continue referring to him, a topic mentioned by others (Kreichman, 1984; Morrison, 1997; Halpert, 1982).

Lasky (1990) writes:

Upon resuming work I called many of my friends and colleagues to tell them, straightforwardly, that I had a number of hours open that I needed to fill, and although they all indicated a hope to be able to send me some new patients, no one was doing so. Not completely taken by surprise, I did become progressively more concerned when I realized that, as time went by, it was not just a matter of time but of choice. People who readily referred to me in the past were now sending me no one. Of course I was distressed, because my friends knew that I had lost considerable income while sick and was continuing, at that time, to lose even more income because of the reduction in the size of my practice, but they still were not sending me referrals. I confided my concern to a particularly close friend who candidly said: "Everyone's waiting to see whether you're really going to live or not." (p. 457)

Lasky goes on to say that the sick therapist longs to regress, to curl up in bed with out responsibilities, a desire that is thwarted by the necessity of making a living.

Unfortunately, the financial worries come at a time when the therapist most needs to be free of money and professional concerns. In order to cope with the illness, the therapist needs less stress rather than more. Counselman and Alonso (1993), basing their opinions on their informal survey of nine clinicians, point out that a declining practice “may further cloud the ill therapist’s clinical decisions about such matters as accepting new patients and managing terminations, or *may push a recovering therapist to return to practice prematurely*” [italics added] (p.595), a topic echoed by Grunebaum (1993).

Another ramification for the therapist, one that is closely associated with financial worries, is how knowledge of the illness may affect the attitudes of colleagues. Kreichman (1984) said his colleagues saw him as somewhat compromised by the illness. Durban, Lazar and Ofer (1993), co-authors of an article on illness and the therapist, suggest that the competence of a sick therapist will be questioned. Durban et al., point out:

This ideal conception assumes the power of spirit and mind over the body.

Knowledge is what bestows the ability to heal. Thus, a therapist whose body is “wounded” will be seen, both consciously and unconsciously, as deficient in his healing capacities. (p. 706)

This view of the therapist can potentially exacerbate a feeling that the sick therapist already has - that of incompetence (Wong, 1990).

Kreichman (1984) noticed that many of his peers avoided him, possibly as a way of not having to face their own feelings of vulnerability. Counselman and Alonso (1993) echo this theme, “The therapist may feel that he or she is now a pariah

in the eyes of colleagues who (the therapist suspects) would rather not have their own denial and omnipotent fantasies challenged” (p. 595). Morrison (1997), who died of breast cancer shortly after writing her journal article, mentions the difficulty in managing the rumors and misconceptions about her health, which impacted people’s confidence in her abilities.

Dahlberg (1980), who suffered a minor stroke, Christy (2001), who has multiple sclerosis, and Silver (1990), who has cancer, tell a different story. They each reported seeing more and more physically ill patients, both from self-referral and referred by colleagues. Dahlberg, who went on to write a book about his experience (*Stroke*, with J. Jaffe, 1977), writes:

A few patients came to me because I had been ill. They thought I must have special knowledge of what serious illness is like; they were seriously ill and felt I would not enter into a conspiracy of silence with them. These were very rewarding patients. (p. 373)

Silver (1982) writes, “patients are seeking me out for analytic treatment *because they have heard that I had come through a harrowing experience of illness*” (p. 169).

Getting Support

Unlike clinicians practicing in an agency setting, psychotherapists in private practice, working by themselves in relative isolation, have very little collegial support. But when ill, the need for the support of others becomes more important. A few authors address this topic. Durban, Lazar and Ofer (1993) recommend that sick therapists join “a group of therapists who are in a similar plight” (p. 710).

Counselman and Alonso (1993) suggest that sick therapists need to have their own opportunity to process the experience, either through their own personal therapy, trusted friends or colleagues, a theme reiterated by Philip (1993).

Surprisingly, few authors (Philip, 1993; Counselman & Alonso, 1993) mentioned the importance of getting consultation when dealing with the treatment issues associated with therapist's chronic illness. Silver (1982) notes that, at the time of her illness, it never occurred to her to get consultation, but in retrospect, she strongly recommends it. Grunebaum (1993) urges consultation "from a trusted colleague" (p. 34) to overcome the potential problem of having to make clinical decisions at a time when the therapist might be the least capable, "less able to make these judgments wisely" (p. 34).

Gaining From the Experience

A number of therapists felt that the illness struggles actually helped their skills as therapists. Elliott (1996) states: "I believe that the constant reminder of my illness kept me flexible and open to her [speaking about a client] pain and humiliation" (p. 28). She goes on to say:

The gift and burden of my illness have forced a deeper immersion into the experience of my patients. It has left me with an expanded field of resonance to the painful affects of my patients and has imposed a self-awareness that helps me name and define these affects in both our lives. (p. 32)

She also feels that her absorption in her body keeps her more focused, as will be discussed in greater detail under the sub-heading, "Self-Absorption."

Friedman (1991) felt that her bout with cancer actually improved her abilities as a therapist: “I think I did some of my best therapeutic work that year; in the face of death, life takes on a special urgency and I was less likely to let things slip by” (p. 409). Durban, Lazar and Ofer (1993) claim that once sick therapists have worked through their feelings about the illness, “‘the cracked therapeutic container’ may serve as a facilitator of better understanding and enhance empathy” (p. 712). Morrison (1990), writing poignantly about her cancer experience, agrees:

Emotionally, I have gone through a number of stages: the predictable feelings of shock, sadness, anger, depression, worry. But there has also been another side: an energizing, a greater attunement to my patients, a sense of myself as courageous and as physically and emotionally strong; an experiencing of this siege as providing a strangely useful opportunity. (p. 228)

I find it interesting that only two writers (Grunebaum, 1993; Sollad, 2002) commented on the courage of the sick therapist. Sollad mentions courage as something gained from his life-threatening illness (end stage renal disease). Grunebaum reports being moved by the stories of “adversity and courage” (p. 22) of the therapists that he interviewed. Neither writer elaborates further on what they mean by courage or how they think about it in terms of chronic illness.

Countertransference Reactions

The therapeutic relationship is a unique relationship, mutually created and based on interpersonal trust. Unlike a schoolteacher or a physician, the therapist is not interchangeable with another human being. When the therapist is sick, a substitute cannot easily be called in. A therapist can provide temporary coverage in

the event of a planned absence, but it is nothing more than that -“temporary coverage” – since nothing can substitute for the relationship that is developing between the therapist and client. Aptly put by Counselman and Alonso (1993), the therapeutic relationship is based on “interpersonal trust and any deviation in the therapeutic relationship can undermine this foundation temporarily or permanently” (p. 59). A chronic illness, because of its effect on the therapist, has the ability to “undermine this foundation.”

Therapists are organized around being useful, giving, nurturing, supportive and, above all, having the capacity to put aside their own needs. But with a chronic illness, it is now the therapist who is in need of the nurturance and support, what Dewald (1990) calls “the reversal of roles” (p.78). Numerous mental health writers have explored the various countertransference difficulties that can arise in the sick therapist, and I will review them below.

Loss of Omnipotence – The Defense of Denial

Chernin (1976) knows first hand about denial. It wasn't until one of his clients expressed worry about his chronic cough that Chernin decided to seek medical attention for what turned out to be pneumonia. Using, what he labels “the use of omnipotence as a defense,” Chernin deluded himself into thinking that “illness affects patients, not therapists” (p. 1328). In a similar vein, Kreichman (1984) reveals his denial about an eye disorder: “As a physician, I would be magically protected from the diseases and disabilities I could treat in others” (p. 383).

Arlow (1990) writes poignantly about how, as he was having a heart attack, he assumed a quasi-analytic attitude, as the participant-observer, looking at his

symptoms from a distance as a way of denying the horror of what was happening to him. Others (Christy, 2001; Counselman & Alonso, 1993; Dewald, 1990; Kreichman, 1984; Lindner, 1984; Philip, 1993; Schwartz, 1987), also mention denial as the therapist's first reaction to illness. As Philip (1993) puts it, ". . . I did not even imagine that this could happen to me" (p. 13).

The literature leaves open some questions about denial and the chronically ill therapist. Almost all of the writers mention denial, yet none speculate whether or not psychotherapists are more vulnerable to denial than the general population of chronically ill people. Clearly, therapists' denial tends to be reinforced by patients' fantasies about our omnipotence. Strean (2002), Schwartz (1987), as well as Counselman and Alonso (1993), all talk about how patients think their therapists are immune to illness. Therapists come to believe this myth, too. Schwartz describes it as "a reluctance to fully accept . . . one's demise" (p. 667). Dewald (1990) writes "I would guess that many analysts harbor a fantasy that their own personal analysis has 'immunized' them against some of the diseases that afflict others" (p. 88).

Christy (2001) is the only writer to talk about denial from another perspective – what she refers to as "adaptive denial." This form of denial – "healthy denial" – allowed Christy to go on with her life, continuing to work in spite of her multiple sclerosis diagnosis. She would "push aside" feelings and thoughts about being sick, yet was still conscious of having a chronic health problem, essentially "forgetting" rather than "denying" the existence of M.S. Friedman (1991), who had a similar experience when recovering from a sudden, life-threatening illness, labels this same dynamic, "compartmentalization."

Putting aside her illness and continuing to work was a source of gratification for Christy, a theme echoed by Friedman (1991), Grunebaum (1993), Lindner (1984), Weinberg (1988) and Wong (1990). Silver (1982) calls returning to work “an occupational therapy assignment” (p. 314). Work helped these sick therapists maintain a sense of wholeness.

However, although it is not discussed in detail in the literature, one can assume that denying or minimizing one’s limitations can complicate the return to work. Durban, Lazar and Ofer (1993) talk about therapists returning to work too soon, over-functioning in order to compensate for the illness. Consequently, the return to work always brings with it the risk of relapse.

The Vulnerable Emotion – Depression

Little is written from a subjective perspective on the expected depression that comes with illness. Surprisingly, Chernin (1976), Elliott (1996) and Morrison (1990) are the only authors to mention depression by name and just briefly at that. Elliott writes, “After seeing myself fragment with fear, rage, denial, shame and depression while I groped for some sense of meaning, I began to recompensate” (p. 24).

A few others allude to depression or at least to situations that could cause depression. Lasky (1990) refers to the “traumas of the illness” (p. 471). Morrison (1997) mentions “the change and loss in one’s own identity, professional and otherwise. From strong and healthy to vulnerable and ill; from caregiver to caregetter” (p. 238). Silver (1982) alludes to depression when she talks about feeling alone. Dahlberg (1980) talks about depression in his sick patients, but does not

mention his own possible depression following a stroke. Silver (1982) mentions being afraid as she struggled with the effects of cancer.

Durban, Lazar and Ofer (1993), Israeli psychoanalysts, write, "The physical lability [referring to the ups and downs of symptoms] is accompanied by an affective lability and difficulties in maintaining the continuity and coherence of the self" (p. 708), but they do not say what these "affective labilities" are. They make reference to feelings of "persecution, shame, despair, envy of healthy patients, loneliness, helplessness, anger and guilt" (p. 709), as affective states experienced by the sick therapist during an intensification of symptoms, but the authors do not elaborate any further.

Self-Absorption

Many writers (Wong, 1990; Lasky, 1990; Dewald, 1990) refer to the "narcissistic needs," i.e., self-absorption brought on by the illness of the physically ill therapist. Freud (1914) in his essay "On Narcissism" describes this self-absorption as follows:

It is universally known, and we take it as a matter of course, that a person who is tormented by organic pain and discomfort gives up his interest in the things of the external world, in so far as they do not concern his suffering. Closer observation teaches us that he also withdraws libidinal interest from his love-objects: so long as he suffers, he ceases to love . . . the sick man withdraws his libidinal cathexes back upon his own ego, and sends them out again when he recovers. "Concentrated is his soul," says Wilhelm Busch of the poet suffering from toothache, "in his molar's narrow hole." Here libido and ego-

interest share the same fate and are once more indistinguishable from each other. The familiar egoism of the sick person covers both. We find it natural because we are certain that in the same situation we should behave in just the same way. The way in which a lover's feelings, however strong, are banished by bodily ailments, and suddenly replaced by complete indifference, is a theme which has been exploited by comic writers to an appropriate extent. (pp. 82-83)

Schwartz (1987), in talking about his emergency surgery for a chest tumor, puts it succinctly when he states that his "attention was exclusively focused on my body and my future" (p. 672). Many writers (Abend, 1990; Halpert, 1982; Lasky, 1990) go so far as to question whether or not the sick, and possibly self-absorbed therapist, should even be working.

Elliott (1996) writes about self-absorption from a different perspective. Because of the unpredictability of the physical symptoms of Parkinson's disease and also because she must monitor medication levels, Elliott reports being attuned to her body almost constantly. "There is a corner of my mind always attending to the state of my mind, muscles, and degrees of rigidity or dyskinesia" (p. 29). Elliott mentions a phenomenon, not mentioned by other writers, in which her body attunement gives her "visceral responses to my patients' productions" (p. 29). In other words, rather than detracting from her ability to be present with clients, she has found that the pressure of her bodily sensations actually force her to be more focused and attuned to patients.

Guilt, Envy, Shame

A number of other countertransference feelings are referred to in the literature and warrant mentioning in this review. A few (Kreichman, 1984; Pizer, 1997; Silver, 1982; Wong, 1990) mention feeling guilty for abandoning patients. In writing about her experience recovering from a life-threatening illness, Silver (1982) states, "If the ideal therapist serves as a secure container for the projected affects of the patient, I guiltily thought of myself as more a colander or saturated sponge than a container" (p. 314).

Christy (2001) envied her healthy patients, a topic echoed by Halpert (1982), Dewald, (1990), and Abend, (1990). Shuman (1996) carries envy further, suggesting that ill therapists may resent their patients for "being taken care of" (p. 161). He also wonders about other possibilities, such as "compensating for their illness by demanding that patients be 'tough' or, conversely, encouraging the patient's expressions of helplessness to satisfy their own dependency needs" (p. 160).

It would seem that shame would be a common subjective experience for the sick psychotherapist, yet only a few writers (Elliott, 1996; Counselman & Alonso, 1993) mention it. As previously discussed, therapists are idealized by patients and by the collective in general. As healers, we are not supposed to falter in any way. As recipients of our clients' dependence, we are expected to stay strong and healthy. Ironically, in the patient, weakness is something to be understood and explored, but in the therapist, it is usually hidden. I suspect this explains the reason for the infrequent mention of shame – it must be hidden.

In her 1996 article, "Through a glass darkly: Chronic illness in the therapist," Elliott writes:

The hope in writing this article is to break the remainder of a silence that exists in the professional community about impaired therapists. The admonition "physician heal thyself" has dominated the tone of the healing professions and has created an atmosphere in which personal pain must be held private. It has been agreed that the treatment should focus on the patient, not the therapist. However, secret pain ignored or denied can interfere in the mourning process of the victim or become split off, *leaving numb spots secured in place by shame* [italics added]. (pp. 21-22)

The Psychotherapist's Subjectivity

As we have learned from the chronic illness literature, a chronic illness is more than just the diagnosed disease. It is the lived experience of the sick person, involving every aspect of the sick person's life. Although we might wish otherwise, psychotherapists are no different from any one else with a chronic illness. The sick therapist must grapple with all of the emotional states, inconveniences, limitations, fears and pressures that come with having a chronic illness.

The mental health literature fails to adequately discuss the subjective experience of the therapist, focusing, instead, on the patient's experience - for example, how the patient feels about the therapist's absences or changes in the therapist's appearance brought on by the illness. What is not stressed is the personal experience of the chronically ill psychotherapist: how the therapist feels, psychologically, about the experience - i.e., what is it like for the psychotherapist to

live with a chronic illness, what Shuman (1996) calls “the felt truth of the patient’s experience” (p. 8). Strean (2002) puts it this way: “Missing from the analytic literature are clinical illustrations of how an analyst’s mourning a loss, suffering a financial hardship, a dispute with a mate or colleagues has influenced his or her therapeutic technique” (p. 570). Instead, this literature emphasizes treatment issues, the effect on the patient and the patient’s reactions to the psychotherapist’s illness, all of which are beyond the purview of this research.

While these mental health authors mention a number of psychological issues that are relevant to illness – for example, loss, denial, fear, worry – the emphasis is less on the therapist’s subjectivity and more on what Durban, Lazar and Ofer (1993) call “technical matters,” primarily, the patient’s reactions to the therapist’s illness and how, technically, to deal with these reactions in the course of the treatment. Friedman (1991) speculates that this preoccupation with the patients’ reactions, although understandable since it is the therapist’s job, is “more than likely a projection of the therapist’s understandable anxiety in coping with trauma of the illness and the challenge and threat to his or her professional self” (p. 418).

Two notable exceptions to this “de-emphasizing” of the therapist’s personal reaction are Ann-Louise Schlesinger Silver’s (1982) article in which she reveals, in stark boldness, her vulnerable feelings of rage, envy, guilt, and fear that emerged in her resuming work after cancer surgery. Claudia M. Elliott (1996) writes from a very personal perspective about her struggles with Parkinson’s disease, freely revealing her sense of vulnerability and powerlessness that began following childbirth when she was 35 years old. In failing to look at the sick therapist’s vulnerability, Elliott

believes that the professional community is reinforcing the “secret pain” (p. 22) of shame and isolation that comes with being sick. Although both writers do refer to issues with clients, their focus is on themselves, how they felt about being sick, how they coped, and how it impacted who they are.

Disclosure – Whether to Disclose and If So, What and How Much?

One “technical matter” that has been discussed in detail is self-disclosure. Should the psychotherapist disclose the illness or keep it a secret? There is no consensus in the mental health literature on the chronically ill therapist. The older, more classical therapists (Abend, 1990; Arlow, 1990; Dewald, 1990; Schwartz, 1987) caution against therapists’ self-disclosure. Schwartz wonders if self-disclosure is not really “masochistic exhibitionism,” a theme echoed by Lasky (1990). Abend and Lasky go so far as to say that the sick therapist’s judgment is impaired and, therefore, can not be trusted to competently assess disclosure issues accurately. The more contemporary therapists (Christy, 2001; Pizer, 1997; Streaan, 2002), on the other hand, argue that whether or not to disclose the illness must be decided on an individual basis.

In the past twenty years, the subject of self-disclosure by therapists has become a hot topic in psychoanalytic literature. This interest in disclosure is the natural consequence of a paradigm shift in psychoanalytic psychology – the development of the two-person psychology, growing out of the intersubjective and relational approaches. In the two-person psychology, therapist anonymity is held to be a myth; the therapist reveals himself or herself, both verbally and non-verbally, by what is said or not said, how the office is decorated, how the therapist behaves, and so

on. It is generally now believed that self-disclosure is inevitable, what Renik (1995) refers to as only a “pretense of anonymity” (p. 476). All of our behaviors are forms of communication – what we say, what we don’t say, what we do, what we don’t do. In other words, we cannot not communicate to our clients.

The debate about self-disclosure goes way back. In his 1912 paper on technique, Freud writes, “The doctor should be opaque to his patients and, like a mirror, show them nothing but what is shown to him” (pp. 117-118). In contrast, Freud’s colleague, Ferenczi (1919) was practicing mutual analysis with his patients. Balint and Balint (1939) argued that clients know about us just from the way we decorate our offices. Winnicott (1949/1992) was one of the first analysts to suggest the sharing of negative countertransference feelings, in “Hate in the Countertransference.”

Whether or not to disclose continues to be a controversial topic. One of the more radical writers on the subject is Owen Renik (1995, 1999), who advocated greater openness on the part of the therapist. In his article, “Playing One’s Cards Face Up in the Analysis: An Approach to the Problem of Self-Disclosure” (1999), he argues that anonymity for the analyst is impossible. He states that we need to “take the analyst off a pedestal and permit the patient to claim greater authority, thus expanding the patient’s functioning in the treatment situation” (p. 523), and he goes on to argue that honest self-exposure by the therapist can actually enhance the clinical treatment.

Theodore Jacobs (1999) takes a more cautionary position, advocating for careful self-disclosure, a theme echoed by most of the “sick-therapist” mental health

writers (Christy, 2001; Elliott, 1996; Pollak, 2000; Philip, 1993; Strean, 2002). He points out that rigid non-disclosure does not always serve patients' best interests; for example, clients with secretive, non-responsive parents can potentially feel angry or shut out by a therapist's non-disclosure. On the other hand, certain disclosures can "limit or inhibit aspects of the patient's imagination and the free flow of fantasy" (p. 164).

Barbara Pizer (1997), an analyst who had breast cancer, identifies three types of self-disclosure, "inescapable," "inadvertent," and "deliberate." Inescapable self-disclosure occurs when there is an important life event (for example, pregnancy, illness, death of a loved one) that, in the therapist's view, will affect the treatment. In this case, the therapist, using his or her clinical judgment about what will further the therapy, has time to deliberate on what and how much to say. She emphasizes "threat of disruption" to the treatment is the key; non-disclosure could lead to the "dread of a subsequent eruption in the analytic interaction" (p. 453). Pizer, like Morrison (1997), chose to disclose to her patients what she considered to be "inescapable" (breast cancer) because of its affect on her and the treatment.

"Inadvertant" disclosure is inevitable and involves such things as the way we dress, how we decorate our office, how/what we say to our clients. Strean (2002) and Jacobs (1999) voice the same sentiment inevitable disclosures occur outside of the therapist's awareness, such as slips of the tongue, errors, and omissions.

"Deliberate self-disclosure" includes answering clients' direct questions as well as any disclosures that enhance and advance the treatment. According to Pizer, "there are moments in the clinical process in which the patient indicates a need or a

ripeness to receive, for personal use, some elements from the analyst's subjectivity" (1997, p. 466). For Pizer, the key is assessing what will advance the progress of the client's therapy and, at the same time, reveal the "otherness" of the therapist.

Self-disclosure is an important topic to consider for psychotherapists who have a visible illness or disability, what Kreichman (1984) calls "visual evidence of therapist's illness" (p. 379). However, in this research, I am looking specifically at invisible illnesses, in which, I believe, the issue of self-disclosure takes on a different perspective. I do not disclose my health concerns to clients, nor is it general knowledge in the professional community that I have chronic health problems. Yet, a large proportion of my practice consists of clients with chronic health problems. I have always been curious about this phenomenon. Is illness, some how, revealed to clients and referral sources, perhaps through subtle changes in the behavior of the sick therapist? Although answering that question is beyond the purview of this study, in studying chronically ill therapists, this research has attempted to broaden our understanding of how sick therapists think about the flow of information from client to therapist and vice versa. Friedman (1991), in writing about her experience with cancer, wonders if we can keep any kind of secret, especially an illness, "such a palpable reality in the therapist's life" (p. 407), from our clients.

The Influence of Intersubjectivity and Relational Theories

Although this research is not theory-driven, there are two psychological theories that provide a back drop for thinking about the chronically ill therapist – Intersubjectivity and Relational Theories. Both theories are an outgrowth of the paradigm shift from the classical, one-person psychology to the more relational, two-

person psychology. In the classical Freudian, one-person model, “we are portrayed as a conglomeration of asocial, physical tensions represented in the mind by urgent sexual and aggressive wishes pushing for expression” (Mitchell, 1988, p. 2). In the two-person model, we are shaped by our relationships with others rather than by the clash between our drives and external reality. The mind is dyadic and interactive, seeking engagement with others. In treatment, the two-person therapist focuses on the relationship rather than viewing the client as a separate entity. Transference, for example, is seen as codetermined by both early life experiences and the current experience with the therapist. Winnicott (1960) said there was no such thing as an infant without a mother. From the two-person perspective, there is no patient without a therapist.

Thus, the question arises, is the therapist’s invisible illness somehow conveyed to the client? In my case, I do not consciously disclose my illness; it is not a “visible entity.” Yet, I have a disproportionately large number of chronically ill people on my caseload. How is it that they come to find me, when this is not a specialty area that I advertise?

This research has concentrated on how the therapist thinks about these questions through the lens of illness. Intersubjectivity and relational theories provide a theoretical context in which to reflect on the illness’s influence on the treatment. In the following section, I review these theories, concentrating on those aspects that pertain to my dissertation topic.

Intersubjectivity

The theory of intersubjectivity proposed by Stolorow, Brandchaft, and Atwood (1987) begins with the premise that subjectivity is continually and mutually being shaped within the context of a larger relational system. For example, psychological development must be seen in the framework of the child-caregiver dyad. Recurring patterns of this dyad establish in the child what Stolorow, Brandchaft, and Atwood call “organizing principles” that “form the basic building blocks of personality development and constitute the quintessential focus of psychoanalytic investigation and interpretation” (p. 183).

In psychotherapy, there are two subjectivities in the therapy hour – that of the client and that of the therapist – a blending, so to speak, of the two subjectivities constantly and mutually influencing each other, what Aron (1996) and others call “reciprocal mutual influence.” Therapeutic treatment is not solely about the intrapsychic experience of the client, but instead, the “interface of reciprocally interacting worlds of experience” (Stolorow & Atwood, 1996, p.182) of client and therapist.

The client and the therapist co-create the intersubjective field. Through a mutual feedback cycle, the client and the therapist are each trying to organize their experience of the other. Reality is not absolute: “what the analyst ‘knows’ in the psychoanalytic situation is no more ‘real’ than what the patient ‘knows’” (Stolorow, Brandchaft, & Atwood, 1987, p. 8). In other words, the client’s view of the therapist is just as real and present as the therapist’s view of him or herself.

From the viewpoint of this research, the client may not have concrete information about the therapist's illness, but from an intersubjective perspective, at some level, may have the "sense" of it, gleaned from the intersubjective field. Similar to Winnicott's inseparable mother-infant dyad (1960/1965), client and therapist form a dyadic unit—"an indissoluble psychological system" (Atwood and Stolorow, 1984, p. 64). Quoting Stolorow: "Clinical phenomena . . . cannot be understood apart from the intersubjective contexts in which they take form. Patient and analyst together form an indissoluble psychological system, and it is this system which constitutes the empirical domain of psychoanalytic inquiry" (p. 64). It is not one mind operating in isolation. Instead, it is two subjectivities forming a larger context "created by the mutual interplay between the subjective worlds of patient and analyst, or of child and caregiver . . ." (Stolorow & Atwood, 1996, p. 182). Following this line of thinking, the therapist's chronic illness lives in the intersubjective field and can influence the therapy.

Relational Theory

Relational theory is based on "the shift from the classical idea that it is the patient's mind that is being studied (where mind is thought to exist independently and autonomously within the boundaries of the individual) to the relational notion that mind is inherently dyadic, social, interactional, and interpersonal" (Aron, 1996, p. x). Its basic premise emphasizes that we are social beings; seeking contact and maintaining relationship with others are "the basic stuff of mental life" (Mitchell, 1988, p. 2).

In treatment, the focus is not on the individual as a separate entity, but on the relational matrix, in which the therapeutic relationship is almost like a dance between the therapist and client. Lewis Aron (1991) writes:

The relational approach that I am advocating views the patient-analyst relationship as continually established and reestablished through ongoing mutual influence in which both patient and analyst systematically affect, and are affected by, each other. A communication process is established between patient and analyst in which influence flows in both directions. (p. 33)

Mitchell (2000) equates this process to that of a Mobius strip, in which internal and external are “perpetually regenerating and transforming themselves and each other” (p. 57).

What is crucial to my research is the relationalists’ belief that clients want to know their therapists. All children study their parents, carefully learning about the inner workings of these most important people in their lives, in hopes of satisfying the longing for connection. Children speculate and develop theories about how their parents feel about them. The relationalists contend that, as children want to know their parent’s inner world, clients want to know their therapist’s subjectivity: “I believe that patients, even very disturbed, withdrawn, or narcissistic patients, are always accommodating to the interpersonal reality of the analyst’s character and of the analytic relationship. Patients tune in, consciously and unconsciously, to the analyst’s attitudes and feelings . . . ” (Aron, 1991, p. 36).

Aron goes on to say:

Patients probe, more or less subtly, in an attempt to penetrate the analyst's professional calm and reserve. They do this probing not only because they want to turn the tables on their analyst defensively or angrily but also, like all people, because they want to and need to connect with others, and they want to connect with others where they live emotionally, where they are authentic and fully present, and so they search for information about the other's inner world. (p. 37)

The client searches for clues about the therapist's inner life – even a therapist who might be fatigued, in pain, or having disturbing symptoms. The client studies, probes, speculates or fantasizes about the therapist's inner (and outer) world.

Intersubjective and relational theories give rise to the question, "Is the therapist's unseen illness in the intersubjective field?" This research, which is informed by intersubjective and relational theories, looked at how the chronically ill therapist thinks about and understands this question, broadening our understanding of the interconnection between a therapist's illness and therapeutic treatment.

CHAPTER 3: METHODS AND PROCEDURES

The purpose of this research was to learn more about the subjective experience of the psychotherapist who has a chronic, unseen illness. How does the therapist cope with the chronic illness? How does the therapist manage, on a daily basis, the difficulties that come with having a chronic illness, while maintaining a private practice? Importantly, how does the therapist think about the illness's impact on the work with clients?

Methodological Approach and Design

This research is qualitative and based on Grounded Theory (Glaser & Strauss, 1967; Strauss and Corbin, 1998). Qualitative research relies on interpretive rather than on statistical procedures; data collection is designed to preserve context, and, therefore, pre-established categories, which reduce the data prior to interpretive analysis, are avoided. The research process is designed such that explanatory concepts emerge from the data. Thus theoretical concepts are “grounded” in the data. Describing their approach, Strauss and Corbin say it is designed “for the purpose of discovering concepts and relationships in raw data and then organizing these into a theoretical explanatory scheme” (p. 11). This approach is particularly conducive for exploring a person’s subjective life – “lived experiences, behaviors, emotions and feelings” (p.11) – and is especially appropriate for studying chronic illness (Charmaz, 1999).

In the more traditional, quantitative research, the researcher sets out to prove or disprove a hypothesis and approaches the participants with a pre-set, structured set of questions, asked in an identical sequence and manner. Mishler (1986) criticizes

this method as suppressing the discourse rather than encouraging spontaneity. He recommends an interview style that generates a more organic process, where the interviewer and interviewee co-create the context in which the data emerge, with the researcher being very much an instrument in the data collection process. This interview method fits well into the Grounded Theory approach.

Following Mishler (1986), I used an open-ended, semi-structured interview guide in order to allow each participant to tell his/her own story as it unfolds. Using the “constant comparative” method of data analysis (Strauss and Corbin, 1998), each participant’s responses were individually analyzed and interpreted for contextual meaning and compared with the responses of the other participants. The analytic process began as the first interview was completed; thus, data collection and analysis proceed concurrently. This allows the researcher the option of revising interview topics as deemed appropriate by the material.

In qualitative research, the researcher is the instrument. According to Strauss and Corbin, one reason for choosing this method is the preference, experience, and temperament of the researcher. This approach fits who I am as a psychotherapist and a researcher. They list six characteristics of a “grounded theorist”:

1. The ability to sit back and critically analyze situations
2. The ability to recognize the tendency toward bias
3. The ability to think abstractly
4. The ability to be flexible and open to helpful criticism
5. Sensitivity to the words and actions of respondents
6. A sense of absorption and devotion to the work process. (1998, p. 7)

These characteristics are compatible with a psychotherapist's necessary skills. For my part, this approach felt very familiar to what I do professionally, making it an easy model for me to emulate in this research.

Validity and Reliability

Qualitative research, in contrast to quantitative research, requires different standards by which validity and reliability are judged. Reliability relates to the accuracy of the measuring instrument or procedure; validity is whether or not the study measures what the researcher intended. In more traditional quantitative research, validity and reliability are judged by "significance, theory-observation compatibility, generalizability, consistency, reproducibility, precision, and verification" (Strauss & Corbin, 1998, p. 266), the assumption being that traditional statistical and analytic methods will reveal one valid truth. These methods, however, fail to adequately judge the validity and reliability of qualitative research.

In this research, the analysis of the data was interpretative, with the researcher as the primary instrument of validity and reliability. Patton (1990) argues that validity and reliability depend on the skill, sensitivity, and integrity of the researcher. "Validity in qualitative methods . . . hinges to a great extent on the skill, competence, and rigor" of the researcher (p. 14). Following this same argument, Mishler (1986) contends that the validity of a qualitative study is in direct relationship to the care and quality of the research process. Patton (1990) points out that through the process of open-ended interviewing, the researcher takes in "the world as seen by the respondents . . . enabl[ing] the researcher to understand and capture the points of view

of other people without predetermining those points of view through prior selection of questionnaire categories” (p. 24).

Participants

Nature of the Sample

One of the ways in which quantitative research differs from qualitative research is the sampling method. In qualitative research, there is an in depth focus on a small sample that is “selected *purposefully*” (Patton, 1990, p. 169). Participants are picked who have the greatest capacity of adding to our knowledge of the subject under investigation. Patton advocates maximizing the sample variation in order to achieve “the central themes or principal outcomes that cut across a great deal of participant or program variation” (p. 172), by selecting a sample of “great diversity” (p. 172).

In order to add the most to this research topic, I interviewed participants who have lived the experience being investigated. Since this study focused on the experience of psychotherapists who have chronic, unseen illnesses, data was obtained from open-ended, semi-structured interviews with 10 chronically ill psychotherapists. Sample size was large enough to maximize the variation in the phenomena that I studied (Strauss & Corbin, 1998) yet small enough to provide “information-rich data” (Patton, 1990, p. 181). I continued interviewing until saturation (Strauss & Corbin, p. 214)—i.e. no new material emerges—was reached.

Criteria for Selection

My participants were psychodynamically-oriented psychotherapists in private practice who identified themselves as having a chronic unseen physical illness. One of the most important variables for selection was the therapist's own sense of the intrusiveness of the illness. There are many chronic illnesses that cause no daily inconveniences. Since my interest was how therapists cope with illness, I chose those therapists who reported troublesome and intrusive symptoms. My participants all felt that their chronic illness was intrusive enough to be a major issue in their lives.

I interviewed only those in whom the illness was unseen. There were no obvious, outward signs of the illness, allowing it to remain invisible to most observers. The study did not include participants whose illness was currently life threatening, nor did I look at the many examples of non-physical chronic illnesses, such as developmental or cognitive disorders and mental disorders.

In order to have the widest variation possible, I did not control for gender, age, or other demographic variables. To maximize variation I recruited from all those professionals who are licensed in California to practice psychotherapy – social workers, psychiatrists, psychologists, and marriage and family therapists. Although my interest was in psychodynamically-oriented therapists, in order to widen the pool of available participants, I broadened my sample to include other theoretical orientations.

Recruitment

In order to recruit participants, I sent a letter (see Appendix A) describing the research to colleagues and selected health care practitioners, asking for their

recommendations. In addition, I advertised (see Appendix B) in the newsletters of the California Society for Clinical Social Work and the Sonoma and Marin County California Association of Marriage and Family Therapists, briefly describing the research and asking interested therapists to contact me by phone. I asked potential participants to contact me by phone or email.

To those potential participants whose names I received, I sent a letter (see Appendix C) describing the research and its methodology. I included a brief screening questionnaire (see Appendix D) and a consent form (see Appendix E) for potential participants to review. I then telephoned those participants that I had selected for inclusion, setting up a time and place for the interview.

Data Collection: The Interview

Data for the study was collected through open-ended, semi-structured interviews. Reminiscent of Winnicott's "mother/infant dyad" (1960), this type of interviewing involves two people, neither of whom exists without the other: the interviewer and the interviewee. Together, as Mishler (1986) explains, they form a mutually constructed discourse. This form of interviewing lends itself well to a study about personal subjectivity, as it allows for "musing" about the research topic in considerable detail.

Procedure

Depending on the health of the participants, I conducted 60 to 90 minute interviews in the setting of their choice; each interview was audio taped and then transcribed. Before beginning the tape-recorded interview, I reviewed the purpose of

the study and issues of confidentiality and had the participants sign the Informed Consent Form (see Appendix E), a copy of which they received prior to the interview. I loosely used the Interview Guide (see Appendix F) to guide me during the interviews, covering important key and probe questions. However, I did not rigidly follow this guide, using it only as a reminder of possible topics, thus, allowing the participants to speak more spontaneously. Using the “constant comparative” approach of Glaser and Strauss (1967), as data began to emerge from the interviews, I added or subtracted interview topics accordingly, with the Interview Guide as a framework for further discussion and elaboration.

Topics of the Interview Guide

After reviewing of the purpose of the research and the confidentiality issues, each participant signed a copy of the Informed Consent Form (see Appendix D). I began the interviews, almost as I would as a therapist, asking participants to share thoughts they had about the research topic. Following the lead of the participants, I raised questions as they came up in the interview rather than asking them in a pre-conceived order. I was more interested in letting the material flow spontaneously rather than in directing it in any way.

I considered the following four categories of topics: (a) the illness narrative, (b) the impact of the illness on work, (c) the unique issues of the unseen illness, and (d) coping with a chronic, unseen illness.

The Illness Narrative

The purpose of this topic was to elicit the true raw, emotional data of the illness story. In regards to understanding the chronically ill, both Kleinman (1988) and Charmaz (1991, 1999) argue the importance of the illness narrative – the individual’s personal story about their illness experience. Kleinman writes:

Patients order their experience of illness – what it means to them and to significant others – as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. Over the long course of chronic disorder, these model texts shape and even create experience. The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering. *To fully appreciate the sick person’s and the family’s experience, the clinician must first piece together the illness narrative as it emerges from the patient’s and the family’s complaints and explanatory models; then he or she must interpret it in light of the different modes of illness meaning – symptom symbols, culturally salient illnesses, personal and social contexts* [italics added]. (p. 49)

In order to fully understand the illness experience, the researcher must hear the individual’s story. Charmaz (1999), who advocates the use of grounded theory research when studying the chronically ill, writes, “subjective tales have meaning.

They place the experiencing person in the center of the story and, thus, provide a perspective on events” (p. 371).

I began my interviews by asking the participants to tell me their illness narrative. I wanted to hear the various factors that made up their illness story. When did they get sick? What illness do they have? How long have they been ill? What has it been like for them as therapists?

The Impact of the Illness on Work

I specifically explored questions about the illness’s impact on the participants’ work. It was important to learn how my participants thought about and managed their private practices in relation to their illnesses. Were there any particular worries and/or accommodations that the participants experienced at work? I also wanted to explore the impact of their illness on their sense of confidence as a therapist. Had the illness shaken the participants’ sense of self as a confident professional?

The Unique Issues of the Unseen Illness

Since one of the focuses of this research was the “unseen” variable, I incorporated probe questions designed to encourage the participants to explore their thinking about the invisibility of their illness. I wanted my participants to speculate about what they thought clients knew or did not know about the illness, including the subject of disclosure.

Coping with a Chronic, Unseen Illness

It was important for me to learn how my participants coped with the ups and downs of chronic illness. I was especially interested in the internal adjustments that

the chronically ill therapist made in order to adequately perform the requirements of the job. I included probe questions highlighting the various difficulties that chronically ill therapists might encounter and that were designed to gain more information about how therapists maneuver through these difficulties.

Data Analysis

I analyzed material from the interviews using Strauss and Corbin's (1998) "constant comparative method." This method is useful in that it is a systematic method for generating hypotheses from the themes and patterns that emerge organically as participants talk about their experience with the topic. Polkinghorne (1986) proposes that the "constant comparative method" is best suited for research that is looking at subjective experiences.

Procedure for Data Analysis

In order to immerse myself in my participants' experience, I began my data analysis by taking notes of my feelings and thoughts following each interview. I listened to the audiotapes of each interview, paying close attention to both common and unique themes as they arose. Each interview was transcribed for additional review. As more interviews were conducted and the tapes reviewed, new themes emerged, requiring collecting more data until saturation was reached.

Strauss and Corbin (1998) suggest that data analysis is a fluid process in which the researcher goes over the data, line-by-line, culling out the various themes and meanings: "to uncover, name, and develop concepts, we must open up the text and expose the thoughts, ideas, and meanings contained therein" (p. 102). Using

the “open coding” method, each thought, idea and meaning is broken down and compared for similarities and differences.

Once the data is dissected, it is “put back together in new ways” (p. 96) using the “axial coding method,” in order to look for more precise connections between categories. The final stage in the coding process is “selective coding”: “the process of selecting a core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development” (p. 116). The core category identified by the researcher is the primary phenomenon which best describes the data. In this research, I examined each transcript, identifying concepts and their relation to one another in order to develop a schema of categories, their properties, and dimensions (subcategories).

Presentation of Findings

In qualitative research, findings are presented in a narrative overview and then by presentation of the thematic categories within a format that suggests their relationships to one another. Data from the interviews is used to exemplify the categories. In presenting the findings, I took precautions to protect the anonymity of my participants by only revealing enough information to address the common features and variations of the categories and subcategories that have emerged from the data.

The final chapter was devoted to a discussion of the data in terms of the research question. The conceptual schema or classification system was used as the basis for an explanatory hypothesis or model that encompassed my interpretation of the findings. The hypotheses generated by the data were discussed in relation to

existent theory and to the literature on the subject. Variations and deviant cases were discussed. Limitations of the study were also addressed.

CHAPTER 4: FINDINGS

This exploratory research examined the subjective experience of ten psychotherapists who are both maintaining a private practice and coping with chronic invisible physical illness. This study looked at how the therapists managed the illness while seeing clients, how the illness influenced the therapists' professional sense of competence, and the special problems that arose in the clinical work as a result. Prior to describing the thematic material of this research, I will give a short description of the participants and an overview of the findings.

Description of the Participants

Ten psychotherapists, all in private practice, were interviewed for this research. Eight of the participants practice in a traditional private practice; two participants are a part of a group practice in which each clinician practices autonomously. Their ages range from twenty-nine to sixty-five, with an average age of fifty and a half. Nine are female, one is male. Six are married and six have children. One has never been married. Nine participants are Caucasian; one is Indian, in this country for eight years.

All live and practice in the greater Bay Area. Three are PhD psychologists, four are licensed clinical social workers, and three are marriage, family therapists. All ten described their theoretical orientation as psychodynamic, one of my stated prerequisites for this research. Many of the participants also listed other approaches, in addition to psychodynamic, such as cognitive behavioral, spiritual, attachment and trauma orientation, EMDR, Gestalt, object relations, humanistic, relational,

psychoanalytic, and family systems. Their years in clinical practice post licensure range from five to thirty two, the average length in practice is nineteen years.

All of the participants work a minimum of twenty-client hours per week, averaging twenty-seven to twenty-eight hours per week. Two participants have other jobs. One participant is also an artist, spending approximately twenty hours per week doing her art; another participant is a staff member at an analytic training program.

The illnesses represented in this study are: Lyme disease, chronic fatigue syndrome, atrial fibrillation, ulcerative colitis, sarcoidosis, rheumatoid arthritis, thyroiditis, epilepsy, chronic migraines, osteoporosis, asthma, and primary lower extremity lymphedema. Four participants have more than one illness and/or condition. Participants have been ill from between four years and forty years, with the average length of illness being a little over twenty years. At the time of this study, one was in an acute relapse, while the others were in varying stages of constant intrusive symptoms. Two were in partial remission.

The participants are described according to their group characteristics for the purpose of protecting their anonymity. I also refer to all the participants as female, using feminine pronouns, in the interest of ease and to maintain confidentiality.

One interview was not recorded because of an audio equipment failure, and as a result, I had only the summary notes that I wrote after the interview. I have included this participant in the demographic description here, and incorporated her contribution to the study in a general way, even though I am unable to use verbatim passages.

Overview

The extent of the impact of the illnesses on their work was a complicated topic for the participants in this research, and it varied, depending on their symptoms. On my initial screening form, as well as during my phone screening, my participants answered that they had intrusive symptoms that interfered with their work. Yet, when discussing symptoms during the interview, many participants downplayed the work-related intrusiveness of their symptoms. On one hand, my participants must be managing their respective illnesses well enough, because they are all still working. On the other hand, they all reported symptoms that I would define as being very difficult to manage. One possible explanation, reported by a participant, for this discrepancy is that the work of psychotherapy is sedentary, not requiring much physical exertion, making it relatively easy for some therapists with chronic illness to function. Another participant proposed that by comparison to how the illness affected her personal life, the effect on her practice was less significant. Whatever the reason, one thing is clear: the felt-impingement on one's work is directly related to the intensity of the symptom and the therapist's ability to manage the symptom, with the overarching goal of maintaining focus on the client.

How the illness manifests itself will determine the extent of its impact on the therapist. For example, depending on how the symptom presents itself, the impingement on the participant can be very different, ranging from very difficult to mild. In terms of frequency, those participants with episodic symptoms live with the anxiety of wondering when the symptom, or symptoms, will return. This makes it hard for the participant to predict how she might feel during the course of a workday,

and whether or not she will actually be able to complete her workday. This is particularly challenging for a therapist because the work of psychotherapy requires being present with each client, in turn, all day.

For those participants with continuous symptoms, the sick feeling becomes part of the daily landscape of the person's life. It is "normal" to be sick. Being sick is the base line experience for that person, and the symptoms will always be intrusive to one degree or another. This is especially difficult for, but not limited to, those participants whose symptom is primarily fatigue, with its accompanying "brain fog." Feeling tired or in pain can interfere with the participants' ability to be "present" and focused. Subsequently, participants have to push themselves to great lengths to compensate for what they worry might be less than optimal performance, creating a tension between wanting to be a good therapist and taking care of themselves.

Managing the illness and the nuts and bolts of a psychotherapy practice is a major event for the participants in this study. Things that are taken for granted by a healthy therapist must be handled differently by the sick therapist. In order to manage symptoms, participants in this study have devised a variety of interesting methods for coping with the illness. Some will screen clients more carefully; some will schedule their workdays to accommodate illness. Others have developed methods of distracting themselves from their symptoms during sessions.

In addition, many participants report that they work in different ways when their symptoms are too intrusive, both in terms of how they listen in sessions and how they monitor their energy levels. When talking about this way of coping, they use

expressions like “listen differently,” “channeling,” “activating the intuitive,” and “energetic drain” to describe their behavioral changes during a session.

All of the efforts to manage their symptoms during sessions stem from a strong desire and commitment to do a good job with clients. Being competent and committed to clients are both highly valued by all the participants. The therapists in this study ignore very intrusive symptoms, and push themselves to do the best job possible, in spite of how they feel. The participants even put aside other important goals – such as professional development and professional advancement – using all of their available energy and resources for the work with clients.

There are important clinical concerns that relate to being sick. The question of whether or not to disclose the illness is a major theme for the participants in my study. How much does one reveal to clients about what is going on physically and mentally with the therapist? Or does the therapist keep the health concerns to herself? What about inadvertent disclosure, when the illness comes into the room “by accident”? What does the therapist do when symptoms are becoming obvious to the client? Everyone in my study struggled with concerns about how disclosure would affect and change the therapeutic relationship.

Disclosure of the illness to the professional community is another concern. My participants were mixed about telling colleagues about their illnesses. Revealing a chronic illness is complicated by apprehension about being seen as “impaired” or less than competent by peers. They feared the potential stigmatization that might arise if colleagues saw them as defective. Contrary to what’s written about in the chronic illness literature, participants in this study, in general, did not feel shame

about having a chronic illness. As a group, they did not buy the myth that we cause our own illnesses or that an illness is a form of psychological displacement; rather, the prevailing belief in my study is that illness is a part of life. However, in spite of this philosophical stance on illness, some of my participants reported significant fears about colleagues finding out about their sickness, yet denied that these concerns were connected to shame.

In my study, almost everyone struggled with issues of competency. The question that came up most frequently in the interviews was “Am I doing a good enough job even though I am sick?” The fear of not being “present,” which is imperative to the work, impacts the participants’ feelings about their own competency. Questioning competency was especially pronounced on days when symptoms were most intrusive. In addition, they felt that being sick changed the way in which they worked. For instance, one of my participants reported being more active in session than she would normally be if she were well; others reported being less active.

Because psychodynamic therapy revolves around the intimate relationship between therapist and client, illness forces the therapist to have alternative ways of being present. In an effort to be a good therapist, some reported trying harder to be in the relationship. Some reported pushing themselves; others were somehow able to sit back and “let another piece of them” take over.

The chronically ill therapist must pay attention to multiple menus: what the client is saying, not saying, what the client is feeling, not feeling, what the therapist is thinking and feeling. The participants in this research have had to add yet another

“menu,” that of the chronic illness. They must ask themselves, “How am I feeling?”, “Are my symptoms getting worse?”, “Does my client notice?”, and so on. The chronic illness “menu” adds a dimension by which therapists must think about the work and also, how they evaluate themselves.

I have organized the findings into five categories: (a) the impact of the illness on the work, (b) illness management in the context of the work, (c) wanting to do a good job while being sick, (d) disclosing (or not) the illness, and (e) the positive contributions of the illness to the work.

The Impact of the Illness on Their Work

How an illness impacts the work of psychotherapy is directly related to its symptoms. A symptom is described by the participants in terms of the properties of the symptom: its ambiguousness, its intrusiveness, how it affects the therapist’s focus, how it threatens to end a session, and the countertransference reactions that it elicits in the therapist.

The Symptoms

Symptoms come in all shapes and sizes, varying in intensity, duration, frequency, and intrusiveness. Some symptoms are episodic (atrial fibrillation [A-Fib], migraine, thyroiditis/Hashimoto, rheumatoid arthritis flare-ups, ulcerative colitis flares, epilepsy), and are characterized by unpredictability. As the participant with A-Fib says, the symptom “comes out of the blue.”

While interviewing this same participant, my telephone rang. The participant used the phone ring to explain the unpredictability of having atrial fibrillation.

(The phone rings) Interviewer: Oh, ignore it. You know what, no, I'm not going to take it.

Participant: See, that's a good thing, that's like having A-Fib. In a way. You know, it's like, ok there it is.

Interviewer: Annoying.

Participant: Annoying and you imagine all kinds of things about the impact of it, and it's so insistent, but you make a choice to, you . . . [ignore it].

Other symptoms are constant (CFIDS, Lymes, lymphedema, effects of sarcoid medication) and become, as one participant with CFIDS states, "like white noise." She goes on to say, "It becomes so much who you are, and you learn to manage so much and navigate within it that you don't even notice its parameters for the most, most of the time."

Many symptoms start out as episodic, but over time, get progressively more pervasive (ulcerative colitis, rheumatoid arthritis pain, side effects from sarcoid medication, thyroiditis, lymphedema), altering the way the therapist copes.

Ambiguity About the Intrusiveness of Symptoms

Even though all participants reported intrusive symptoms on my screening form and during the initial phone call, the interviews revealed some ambivalence about the actual intrusiveness of the illness symptoms. In terms of their professional life, some participants downplay the intrusiveness of their symptoms. These tend to be participants who do not have any cognitive symptoms. In general, participants with physical pain appear to have developed methods for keeping the pain at bay, which I will discuss in detail in the section on illness management and, thus, are more

inclined to disregard their symptoms as intrusive. Those participants with CFIDS, ulcerative colitis, Lyme's, thyroid dysfunction – in other words, illnesses that come with fatigue and cognitive problems – generally, were much more inclined to experience their symptoms as intrusive.

The sedentary nature of psychotherapy makes it easier to downplay symptoms, since physical exertion is rarely a part of the job. One participant who has a lot of physical pain pointed out that as long as she can sit, she can do her job:

What don't I have! . . . Yeah, my mind is absolutely fine. If you can tune out the body. Yes, I can be very comfortable . . . Uh, and if I – for instance, my head is okay. The only thing I really require is that my, uh, like I can sit and listen and pay attention. For instance, my mind is okay. I can't see why – I shouldn't do that.

Another participant, with a serious illness and very uncomfortable symptoms (shortness of breath and pain), said that her symptoms were not very intrusive on her work. At the end of the interview, I expressed my confusion about how her serious symptoms could not be anything but intrusive. The following day, she telephoned me with the following:

Thinking more about, at end, why many of us, including myself, seem to down play any sense of impact of the disability on one while you're in the office and I think it's the comparative. I'm not sure I said that, between the rest of my life which is so impacted and a career that is primarily my emotions and my intellect and not my body. So, it does impact me a lot in working with little kids, because it's hard getting up and down off the floor, um but I've

made adaptation and the kids seem to manage with that. But I'm seeing more adults and less children, and it impacts my stamina, but compared to the rest of my life, that's kind of minor.

By comparison with how intrusive and debilitating her symptoms are in the rest of her life, the impact on her work, from her perspective, is not that significant.

Yes, Symptoms Are Intrusive

As the data in this research shows, symptoms can become very intrusive, directly impacting the psychotherapist's ability to concentrate. Although episodic and constant, symptoms have some different characteristics; for the participants in this study, it almost doesn't matter whether a symptom is constant or occasional – all types of symptoms are intrusive to one degree or another, and there is a direct relationship between how the symptom manifests itself and its intrusiveness in the participants' work lives.

The two most common symptoms, which can be both episodic and constant, mentioned by my participants, are bone-weary fatigue and constant pain. A participant with CFIDS describes her “fluish” feeling, which she experiences every day, becoming the background in which she works:

And exhausted – you know, just that feeling when you have the flu, that you just can't – you just feel like you're whipping yourself to keep going. Um, lots of breaking out into sweats. You know, kept checking, never had a fever, but just constantly feeling like I was sick and hot and feverish and, um. Lot of aching. Mostly at that point in muscles; now it's more in joints. Um. A lot of, sort of weird head stuff. You know, a lot of spaciness and visually, I can

go into, you know, like, if you look above a candle where it's shimmery, I get a lot of that, visually. Um. Sometimes, um, disequilibrium kind of feeling when I'm walking . . . *just feeling, like fluish all the time* [italics mine] . . . and that's uh how I work.

When talking about its intrusiveness, the participant with A-fib admits that she cannot ignore her symptoms in a session. Sometimes the symptoms are just too intense:

It has some affect because your heart doesn't pump as efficiently, so you'll notice, for instance, if you're having a bout of it – particularly if the rate is fast. As well, you really can't exert yourself or you'll get really light headed, umm (pause) so, the – what I experience is, well, it's very, you know, it's very something, you know, you don't *not* [italics added] notice. . . . Well the nature of it is so terrifying. . . . It's so, so . . . melodramatically there. So I don't think, for me, I don't feel much of a tension around efforts to deny *because you can't.*" [italics mine]

One of the most bothersome features for the participants in this study is the way in which a symptom's intrusiveness can vary in intensity from day to day, or even from hour to hour, making it difficult for those individuals to judge how they will feel from minute to minute, leaving them with much anticipatory anxiety. For example, the participant with rheumatoid arthritis can wake up with such pain that she can't get dressed, but as the day progresses, the pain will subside. A participant with CFIDS described it eloquently, comparing herself to a car with a broken gas gage:

Everyday there is some fatigue I'm experiencing that I'm having to manage. And, the other symptom that I have as sort of secondary is anxiety . . . related to the fact that I may not feel well or kind of, can feel a headache coming on while I'm with a person, or there's anxiety related to when I have a full day, how's my energy gonna last me today. Is it gonna last until the end, or is it gonna crash at 6 o'clock and I've still got 2 more people. So, that's a symptom that's a little bit particular to me because I tend to have anxiety issues. But it's really exacerbated by driving a car with a gas tank with a gage that's broken – I never know when the gas is gonna run out and where I'm gonna be when it runs out. Am I gonna be far from home? Am I gonna be around the corner from a gas station? I never know where I'm gonna be when that energy's gonna quit. And I can sometimes anticipate it, and sometimes I can't because there are days I wake up feeling really good, and by 1 o'clock, I've got a raging migraine or I just feel like I can't do anything else; I've got to go to sleep. And, I couldn't anticipate that. 'Cause I was feeling fine in the morning. So it is, I mean, that gas analogy.

Trying to Stay Focused

Intrusive symptoms, which can not be ignored, make it difficult for the therapist to be attentive and present in a session. With intrusive symptoms, it is almost a competition – between the symptom and the client – over who will get the therapist's attention. The participants in this study talk about the pull between staying focused on their clients while trying to keep symptoms at bay.

In the following quote, the participant with A-Fib demonstrates how her focus is affected by her disturbing attack:

Now when I'm having an episode, if it's a difficult episode . . . I don't react much. . . . You know, I mean I think I, you know for one thing, it's a struggle in terms of focus and attention if you're having a, what we call a bad attack, which means it's a particularly unpleasant one, fast and hard beats, it's a – your focus is definitely affected. And so you might be looking as though you're paying attention and, you know, and I am to some extent but it would be like maybe, if you're in an hour and have any kind of physical discomfort that is significant, like say, maybe a bad headache, that's going to be a challenge.

The participant who suffers from migraines, like A-Fib, another episodic symptom, talks about how the headaches get in the way of her attention:

When I have a headache, I often will find myself . . . working really hard to stay focused and there. I'm clearly, you know, not a, um, you know, I'm not as fun and, you know, humorous and maybe not as, uh, engaging when I'm working with a headache.

Therapists with fatigue, “mental fatigue” and “brain fog,” all potentially constant symptoms, report difficulty in concentrating and difficulty remembering. A participant with CFIDS sums it up, “And the mental fatigue, I mean, as sort of a side note, that the mental fatigue is a really huge problem.” I will talk more about the impact of fatigue in the section titled “Wanting to Do a Good Job While Being Sick.”

When a Symptom Becomes Too Intrusive – Ending a Session

Occasionally, symptoms become so intrusive that the therapist can no longer manage them in the session. Although a rare event (spoken about by only four of the ten participants), some participants at times have to end sessions, and others expressed concern about whether or not they could complete sessions. One of my participants describes her experience with a debilitating migraine:

I had to get, I got, I, suddenly I started getting the whirlies. And I just went, “excuse me.” You know, I knew my eyes were crossing and I, and I literally got up and went into the bathroom and threw up. And at that point it was like, even though I felt somewhat better, I just had to tell her, “you know, I can’t, I can’t continue, I’m really ill.” I told her I had a really bad migraine. And I just absolutely, you know, and I said I’ll call her and make another appointment.

Another participant with a similar experience describes the session:

Oh yeah. I mean, they were only – I think there was only two times in all the years that, uh, that I’ve, that I’ve actually had to not – one time I saw a client and in the middle of it, I just, the headache got so bad that I just excused myself, went into another room and threw up and came back and told her (laughs) we had to stop the session ‘cause I was non-functional. And one other time I think that, that I ended up going to the hospital, that I ended up not being able to see clients.

The following participant illustrates the tension created by the worry about whether or not she will have to end the session prematurely:

Hmmhmm. Hmmhmm. Yeah. You know and the decision would have to be made if things got severe enough to terminate a session. Which is a hard thing to do. Umm, so that's always an issue. And that did happen to me one time. So I know that, that, and that leads to also some tension. You know, 'cause there's always this question, I hope it doesn't get that bad.

The implications of having trouble staying focused, impaired concentration, and ending a session, are numerous. There is a direct overlap between the intrusiveness of the symptom, the therapist's capacity for managing the symptom's intrusiveness, and how they feel about their ability to do their work. I will be discussing this relationship later in this chapter when I talk about how sick therapists feel about their competency.

Countertransference Reactions

Not surprisingly, several of the participants report that their illnesses activated countertransference reactions in them. A few participants mention feeling envious of their healthy clients. When asked about envy in her practice, one participant replies:

You know, one thing I find comes with clients, I don't know if other people have said this, is that I – I sometimes experience – well, two things I can experience . . . when clients talk about their lives, when things are going really well for them, I can feel envy sometimes. Like, uh, and that, that comes up. Definitely with certain clients, there's been envy there.

Three participants talk about a feeling of impatience with clients. The following quote expresses the participant's inner struggle to contain feelings activated by a client:

‘Cause I just realized an experience I had just recently, just very recently, where a particular person was really going on and on about, with tremendous kind of complaining about – uhh, see now this is my attitude that can be a problem – it was, an absurdly trivial thing and I was having A-Fib and I did, you know, I had these thoughts of, that, I don’t know what to think of them. I thought they were really getting in my way and that I was being, unable to be empathic but, I am not sure, I think it’s complicated. ‘Cause there was also an element of this person getting really locked into and using trivial things to kind of, I think, protect themselves. But at any rate I did have that very specific thought, I was like, you are complaining about that? (laughs)

Another participant describes the tension arc between being empathic versus being impatient with clients:

I mean, there are times when, I suppose the question is one of what’s the balance between the extent to which (inaudible) intensifies my empathy and increases my capacity to understand the position of the other, or to model the capacity to survive all this. Um, versus those moments when I find at times in my head – I had this deep desire to tell someone to grow up (laughs) and handle what sounds like an awful trivial problem. . . . There are times when patients talk about a minor medical problem, or they’re going to the dentist or they’re, um, having plastic surgery or something and they’re in really, in pain and scared of it all or there are times when they’re complaining about the most minor difficulties with a mate . . . [and] your head’s going, oh, grow up.

A few participants mentioned feeling guilty about not being “up to par.” The following is a quote in which the participant tells about having to terminate with a particularly troublesome client, who was literally making her sick, and her subsequent guilt:

It's a real dilemma. I also have one client who was, uh, attacking me viciously every session and, uh, as she would do. And I have flares correlated with seeing her. And I had the worst flare of my life the last time I saw her . . . she came in her usual vituperative rage – vicious attack. One of the things she said was “You look really sick. You're too sick to even be seeing me.” . . . So what happened actually– the next day, uh, she called to see how I was feeling and I called her up and said, “You know something. You're absolutely right. I am too sick to see you.” Because the way I felt the night before, uh, the flare I had after I saw her was the worst I've ever had in my life and I thought, I can't go on like this. . . . I keep in contact with her as a person. But she's not in therapy with me anymore. . . . Well, unfortunately, I wish I could have done it with her. And I feel very very sad and guilty . . . that I couldn't. But I realized that one night that I couldn't do that again because it was the worst night of my entire life.

Illness Management in the Context of Practice

The participants in this study, in order to continue their careers, have had to devise strategies in which they can work, manage their practices, and manage their illness symptoms. Managing an illness and a psychotherapy practice on a daily basis is a major challenge for all of my participants. By altering the boundaries of their

practice and controlling the impact of the symptoms during a session, they are able to continue doing their job.

Altering Parameters of Practice

Changing Their Schedule

All the participants state that they must limit the number of hours that they work. Yet, when I asked them, specifically, how many hours they worked per week, only one participant reported an actual reduction in client hours, from approximately twenty-eight to thirty client hours to approximately twenty to twenty-two client hours. In fact, most of the participants, in spite of their illnesses, carry full caseloads averaging twenty-eight clients per week. Those who keep smaller caseloads (twenty-plus hours) do not see this as bending to the illness, rather, just the average hours a therapist works.

One participant is able to work an unusually full schedule – a schedule practically unheard of for any therapist, healthy or not – in spite of having rheumatoid arthritis, osteoporosis, thyroiditis, and epilepsy. In addition, she keeps an active involvement in a training institute. She experiences the work as energizing rather than depleting:

Uh, at the moment, it's between forty and fifty. And that is cut back. It used to be sixty hours. Um, my brain actually gets energized from my work. As long as the people aren't attacking me, I get very energized by the work. I love doing it. Everyone knows I work seven days a week. I work three days here, three days there, and then Sundays I have the seminars.

Although four participants specifically stated that they have had to cut back on

professional activities (memberships in professional organizations, continuing education, teaching, supervising interns), another four reported the opposite. These four participants continue regular, active participation in professional activities such as consultation, public speaking, volunteer groups, and education.

Only three participants have modified their work schedule to accommodate the illness. These were typically only minor accommodations, not affecting the actual number of hours worked, e.g., getting off earlier in the evening and changing the number of days worked. The participant with lymphedema has a unique illness-related problem that does involve more effort at scheduling. Her symptoms (severe swelling of her legs, which causes intense pain) are exacerbated by heat. There are times during the day when the sun heats up her office. Consequently, the therapist must schedule clients around her office temperature, as the following quote illustrates:

And I don't, uh, try and schedule somebody in that hour of the week. It's Wednesdays at 11; I don't schedule somebody during that time. Um, I also have an office that has a, a, a square bay in the corner of the room and I get a lot of sun in the afternoon. . . . When it got too hot; when the sun [is] coming in, um, and then I would swell more. I had trouble concentrating through the pain.

Like all the participants in this research, this participant has a consciousness about her symptom issues that is never out of her awareness. She goes on to explain additional scheduling dilemmas caused by the intersection between her need to have the office cooled by an air conditioner and a client's need to hear:

And I had, like I had a client in that late afternoon when the sun pours in, who is hard of hearing. And, so she can't hear with the air conditioning on or even a little fan on. Anything that creates a white noise, then she can't hear me. So I moved her to a new time where it's warm enough from the chill from the night and not too hot yet for the afternoon. . . . And, so I can have all the sound [of the air conditioner] off.

Screening Clients

All the participants talked about the necessity of screening clients. They are cautious about taking on clients who might drain their energy. Even though my participants wanted to avoid clients who are draining, they each had different criteria for evaluating this group. In general, participants wanted to avoid seeing clients who were "worrisome," "more difficult," draining, and requiring more of a commitment on the part of the therapist.

One participant only wants to work with people who are seriously committed to the therapy process. She screens out clients partly on an intuitive basis and partly based on the client's ability to become "engaged" in the process:

I think I do more screening than I even realize because of that [her illness].

It's, it's, there's sort of an energetic and intuitive thing and when I'm not sure I want someone, I set up parameters for them that are really, you know. With a lot of clients that would come in, I wouldn't be, you know, these are boundaries and this is how I work and if, you know, if you're interested in work. With a lot of people I don't do that but if I am taking on someone I'm

not sure about, I make tight boundaries and that if they can choose whether or not they want to come into that.

She goes on to describe what kind of screening she does, specifically, for how “engaged” a client will be. In the case of the client that she mentions in the following quote, she protects herself from a certain kind of “unengagement” by setting up firm parameters for the client:

Yes, I would say that there is a little more screening but I’m not – it’s not a very systematic screening. It’s not necessarily someone who’s suicidal would get screened out. It’s not necessarily – I mean, I just took on somebody 6 months ago who, um, has been, has 6 months clean and sober and who is always on the brink. You know, not the kind that you’d normally think, well, if you’re going to screen someone out, maybe you’d screen this one out (laughs) but I took her, and. So there’s some quality and I think it’s around the engagingness in the therapy, the willingness to engage. I just turned somebody else down. I actually didn’t turn him down, but what I did is, um, he’s somebody who was pretty disabled, psychologically, mentally, and I could feel that what he really wanted was someone to complain to and be a victim with. And so, I told him I would take him on if he wanted, but the way that I worked, and I described some of the ways that I would work with him, and I didn’t give him a lot of wiggle room to say no to that. So there are some people I screen like that, you know . . .

Another participant was adamant about not wanting “worrisome” clients, specifically suicidal clients and rageful clients. When asked about her screening process, she replies:

People who worry me. Because I’m a worrier. People who are suicidal, I can no longer take on. I already have several who I can’t get rid of. Um. But, uh, I don’t want any more. And the ones that I have who are suicidal and also self destructive in other ways, I wish I didn’t have to deal with that. I love these people and I’m very happy to have them in my life. But I wish they didn’t have those particular issues because it worries me and when I get worried, it – I – has a direct effect on my body. I see it, I had it. I’ve had flares correlated with particular people.

Several participants stated that they must screen out low fee clients, feeling that their limited energy has to be used in the most efficient way possible. A participant with CFIDS explains her thinking about low fee clients:

You know, recently I feel like I’ve done that more. I mean, I don’t take on people who can’t pay anything. I have one of those in my practice who’s been with me for six years and probably will be for another ten, but (laughs). And I’ve lowered my fee to do a few Victim-Witness here and there, but I try not to do that so I at least feel like I can support going on vacations and, you know, things like that that are important to me. Um.

Even though participants try to screen clients, they all admit to the difficulty in doing so. For example, one participant tried to do an assessment but the client, because of her dissociative state, was not truthful about the extent of her pathology:

[When talking about asking the client if she was suicidal] And I realize with her that she's so dissociated, she couldn't talk. I try to screen, if I can tell right away of course I screen; I won't take the person. Um, but, uh, with somebody like her, she wasn't going to know. . . . You can't tell.

A number of participants reported feeling badly about not being able to work with "harder" clients. In a profession that, almost by definition, necessitates working with difficult people, this presents a pressure for the ill therapist – on one hand, a desire to help people, on the other hand, a desire to help themselves. I will discuss the tension between these two positions later in this chapter.

Controlling Impact of Symptoms in a Session

My participants have developed a variety of techniques for controlling symptoms in sessions. Some of the techniques involve their behavior in sessions, others involve how they think about their symptoms while in sessions.

Useful Strategies

Participants devised a number of useful strategies to control symptoms during sessions. One participant manages her cognitive dysfunction by taking notes:

Um, that's probably the biggest thing is taking notes. My cognitive dysfunction, um, really requires that I take notes, um. Sometimes I really can't remember from one week to the next what we talked about. As soon as they start talking or bringing up an issue, it comes right back. But my evocative memory, my ability to remember on my own, you know, when I sit down, I look at them, I can't bring it up. It's . . . the inability to name things,

... to remember words, remember names of people or things, um. And that's exactly what it is – it's a very specific memory deficit where I can't, I can't.

As soon as they say something, I remember the whole conversation.

One of the participants, in an effort to be more alert, splashes water on her face between sessions:

And so, during that session, you know, I'll try – you know, I'll splash some cold water on my face. That's a trick that I use. And I'll just go in there and just try my best to just, just stay on top of it.

Another participant hired a secretary to handle all of her billing. Still another participant uses the strategy of deep breathing, to re-energize herself in sessions. The participant with migraines puts her fingers on pressure points on her forehead, to distract from the pain, "You know, you have a headache and you just kind of press on it to just kind of – it sorta almost makes it localize so you can think better."

Avoiding Movement

Some symptoms, by virtue of the sedentary nature of our work, are more manageable in the session. In other words, "intrusiveness" must be evaluated through a variety of filters: how much exertion is required, how much concentration is required. The participant with A-Fib must restrict her physical exercise while having attacks, but because doing the work of psychotherapy is sedentary, and there is no physical exertion, her symptoms are less bothersome. "I do have to restrict my physical activity a bit, and when I am working as a therapist that's not a problem."

Several participants report being very careful about movement when in the

throes of a symptom flare-up. The participant with rheumatoid arthritis has pain upon movement, so she makes an effort to be very still during sessions to avoid attracting the client's attention to her pain, "But otherwise, no, the physical pain only comes from movement. And people who have seen me get up and move, that's when I've had a couple of people asking about it."

One therapist with CFIDS tries to keep her head still, "Sometimes, um, [I have a] disequilibrium kind of feeling when I'm walking. I have to be very careful in sessions not to turn my head too fast."

Distraction

Others talk about focusing extra hard on their clients as a way of distracting attention away from their symptoms. The participant with migraines explains her efforts at focusing on the client:

But a lot of what I do is I really work at just focusing out, um. And keeping my attention out on what they're saying rather than going, "Oh, I'm in pain," you know. So I'm, you know, a lot of times I can do that with my migraine in general, if I'm really engaged with something, I get some relief. And it's as soon as I stop being engaged that the thing just . . . whoosh, comes right back on and kind of recedes and comes back on.

The participant with lymphedema finds work, because of the intense focus that is required, to be one of the best things for her pain, "What happens is, in, in a way, working is one of the best activities that I can do for my particular disability because hyper focus is a fabulous strategy for pain management." She goes on to say:

If I'm at all distracted, like, I live right on . . . one of the street car lines, um.

Or, if there's any kind of road construction or, uh, my office is above a corner grocery store. So when the beer trucks or the Coca Cola trucks or, or dairy are unloading and they're moving their metal racks up and down. When I have distraction, then the pain bleeds through. And then concentration is much more difficult.

I asked her if she has any tricks to help her at those times, and she replies, with a laugh, "Um, I know when the dairy delivers!"

Taking a Sick Day

There's a definite tension when a symptom escalates in intensity. Sometimes the only way to manage a disturbing symptom is to take a sick day. Interestingly, in spite of how symptomatic they are, most participants say that they would never consider canceling a session. This attitude comes out of a strong commitment to keeping a reliable schedule for the client. Psychodynamic work depends on regular, frequent meetings, be it once or twice a week or even more. Intermittent sessions would simply be too disruptive to the therapeutic relationship. The therapist with rheumatoid arthritis sums it up:

Because I want the people to get the service that they need. Uh, and if I – for instance, my head is okay. The only thing I really require is that my, uh, like I can sit and listen and pay attention. For instance, my mind is okay. I can't see why I shouldn't do that. But if uh uh I'm not one of these people whose going to call in sick. It's not my style, and the people are coming for a reason.

Along those same lines, the participant with Lyme disease says:

Because, I, it's like I go into the session feeling like, oh god, I don't know how I'm going to do this, and these people are paying me a lot of money, and, you know, they've, you know, *they have to get their money's worth* [italics mine].

Looking at it from a different perspective, one of the CFIDS participants talks about the relativity of it all. She's sick every day, and if she cancelled when she was sick, she'd never be working. "Hmm, I don't know. I don't really give myself the option. I mean, I think if I were canceling every time I felt bad, I wouldn't have a practice."

Considering the impact of a cancellation on the client, i.e., putting the client's needs first is an important factor for the participants. Before taking a sick day, the following therapist first checks her schedule, assessing whether or not clients could tolerate the missed appointment:

Yeah. If I'm really, or especially if I didn't get sleep. If I look at my client list and I say there's nobody here who's gonna be so critical or this one and that one I could reschedule, I might take off a half day. Otherwise, no.

Letting Go

The participant with A-Fib has developed a mental attitude of "letting go" when a symptom arises. She can't control the symptom, but she can control her reaction to the symptom:

[When talking about an attack happening during a session] So I know that, that, and that leads to also some tension. You know, 'cause there's always this question, I hope it doesn't get that bad. Umm. But again I find that

letting myself get too wrapped up around that is just totally negative. It doesn't get me anywhere and then I am really distracted.

She goes on to say,

But it's way better, I mean it's way worse when you're tensing up. And so, you know. It's been interesting for me to have this demand, almost, that I really notice myself, and I don't know if I could [get] through therapy sessions if I couldn't do some sort of sensory awareness, you know, and try to let go and just be soft and, you know. Because it makes a huge difference in terms of my presence.

Changing the Way in Which They Work

The participants in the research, in order to cope with their symptoms, frequently must alter the actual way in which they perform their jobs.

Listening Different

Several participants report a phenomenon in which they listen differently on days when they are more symptomatic. These participants describe alternative ways of "being" in the session and it seems that these methods almost kick in automatically when the therapist is sick, without any negative detriment to the work. To the contrary, some participants actually feel particularly good about these sessions.

One participant speaks about a feeling that something else in her "takes over" when she is more symptomatic, and this allows her to continue with her work:

So, how I manage the symptoms while I'm with clients is. . . . And one thing that's actually pretty interesting is that I feel like I can actually use a different

part of myself when I'm in one of those places of either pain or fatigue. That I just feel like I just start channeling or something, like some kind of awareness or connection with the person that I'm not cognitively thinking about quite the same way as I normally would. My intellect's tired and taking a nap. The rest of me is there, and things are coming out of my mouth. And I usually feel pretty good about those sessions. . . . So that's what I rely on.

Another participant speaks about it a little differently. She talks about a kind of "letting go," almost as if she is *not* trying to make something happen. Her illness seems to thrust her into a different "mind state" or realm of consciousness:

So, I think that's probably what happens when one sense is going out and my ability to, you know, cognitively approach somebody isn't working quite as smoothly. I'm just present in another way. And I really do, I kind of surrender myself into being present and that feels, you know, I don't want it to sound airy-fairy, but I really do, I just kind of say, "I'm just going to be here" and allow this interaction to happen.

This same therapist goes on to describe the effect of this more intuitive way of working:

It kind of clears you to do something else. . . . Um, it's kind of like, you know, your hearing gets better if you're blind. You know, you just listen differently. Um, and I think that's true, too, uh . . . that does bring to mind, there have been times where I've been in group . . . and I've had a headache and we have one of the most astounding groups, you know. And afterwards I actually remember thinking to myself, "how did I do that, feeling that ill?" You know,

kind of being, and it's just like, because I'm not thinking and I'm working [on] a cleared intuitive basis, I'm not trying to figure stuff out, it's just I can't, so something else is working and it ends up being very powerful.

Another participant talks about a similar kind of experience in which she listens in a much "looser" way:

Well it doesn't let you be in your normal kind of zone and that can be a good thing. . . . Hmmhmm. Yeah, I mean, for instance, that is making me think that sometimes it can be to listen in a looser way to people . . . and I think when something's going on physically, that is easier to do and that's a good thing 'cause sometimes getting too focused on some logical thread or something, uhh, you know, can really be a bit diminishing.

In surrendering to the limitations of the moment, other "listening channels" seem to open up allowing the sick therapist to continue doing her job. The participant with sarcoid sums it up by saying, "I have a greater sense that, if one avenue isn't open for you, you just have to find others."

Monitoring Energy

Half of the participants report, in an effort to protect their own energy levels on days when they feel sick, that they hold back in sessions, not pushing for the more intense affect in clients. The following series of quotes illustrate how these participants pay attention to their energy levels:

Uh, I might be less inclined to go, to follow something real deeply into a place where I know I'm going to have to deal with or hold a lot of cathartic kind of

reaction and stuff, I just, and it's not a decision that I'm 100% conscious of but I'm aware that I'm not engaged as fully in, at a time like that.

One of the participants with CFIDS calls it "energetic drain":

Umm, and against energetic drain, which is one of the major issues with my practice because I will sometimes ward off people's . . . because I will sometimes ward off intense feelings in my patients, unconsciously, because I am too, I will feel too depleted. . . . That's the most negative thing, is that I think a lot of the times I'm titrating how much energy I will allow to be expended in a given time.

It's conceivable to think that this energy conservation might jeopardize the connection with the client, yet, none of the participants reported any adverse interference with the therapeutic relationship. In order to clarify the subject, I emailed one of the participants who talked more openly about this kind of energy monitoring. In her response, she suggests three ways in which "energetic monitoring" could potentially impact treatment and how it is hard to ultimately know. The first impact is that clients might hold back on expressing feeling:

Many patients are aware, often consciously, that I am protecting myself, and they hold back on the intensity of affective expression (and sometimes content) accordingly. It's one thing when we talk it over – as I do when the subject comes up. If that happens, I always say that I have one eye on this issue.

She goes on to talk about two other ways the treatment might be impacted:

Less overtly, I've had people stall out or end for one reason or another who I think have decided on one level or another that they are too much for me, but who don't say so. I feel a lot of regret about this but take comfort from the fact that they are probably acting in their own best interests and as such have my support. Lastly, there may be people where the honest exchange of limitations is just exactly the right thing for that particular person – helps them accept their own humanity as well as mine. In those cases, the limitations may actually help the process. . . . I am very sure it has an effect . . . *but just when and whether it's always deleterious, is an open question* [italics mine].

One other participant, who works primarily with trauma victims, mentions a possible – in this case, positive – impact of energetic monitoring on the client. She points out how important it is that the therapist has the energy needed for dealing with client's harder content:

There are times when, um, things are really hard where I'll not choose to go in the hardest direction, like going near trauma work. That's based more on my needs than the client, *although it's based indirectly on the client's needs, 'cause if I don't think I can handle it, I shouldn't be doing it, you know* [italics mine].

Wanting To Do a Good Job While Being Sick

The chronically ill therapists in this study face an on-going struggle, that of wanting to help clients without further jeopardizing their own health. The prime motivation for putting so much effort into managing and controlling symptoms is because the participants all want to be good at what they do. Wanting to do a good

job and to be thought of as competent, in spite of their health issues, is a major issue for all of my participants.

Self-Judgment

The participants in this study question their competency, especially on days when symptoms are more intrusive. Because they are living with chronic intrusive symptoms that impact how they work, several of them expressed concern about whether or not they were doing a good enough job.

When talking about the mental fog that comes with chronic fatigue, one participant worries, “There are days when I feel like I’m not doing my best.” Another shares this same concern, “I’m just not feeling well and I’m just, ok, I’m not at full strength.” Still another participant wonders:

Well, I, you know, I have mixed feelings about it. I mean, at times I think, you know, through some of these years when I’ve been just so incredibly sick, I shouldn’t [have worked] . . . I think I was certainly less productive - less competent as the therapist.

Participants vary in their self-criticism regarding their competency. One participant, in particular, was critical of herself for being “lazy.” The nature of her illness is one in which she is always fatigued, and drained of her energy. She says:

Um, and sometimes when I’m kind of only medium tired, I fall into a perhaps a worse mode, which is just kind of laziness. And I have had a couple of clients terminate, not over this, but I, I couldn’t help but wonder if perhaps they were terminating because of this.

She goes on to say:

And, you know, certainly during the periods when I was in very, very bad relapses, I had no idea how I did it. How my clients stayed with me. 'Cause, I can't imagine how I could be helpful to them! And yet, you know, nobody terminated. Nobody said, "God [her name], you look tired."

Another participant, along those same lines, hopes that her years of experience will compensate for any loss in competency:

There've been a couple of times when, you know, I felt like, should I be doing this, am I really here? Am I here enough? Um, you know, weighing the thing of, the difference between – uh, well, two things. Weighing the difference between, you know, calling a person at the last minute and canceling versus toughing it out and being there, and will I be good enough and after almost 30 years of being a therapist, sort of feeling like I can get through a session without, certainly without damage, but, um, uh, still add value.

One more participant expresses regret about not always being up to par. She talks about wanting to do a good job in a profession in which she has been trained, and the guilt and shame that arises out of feeling "not good enough":

I think that, um, you know, as a [psychotherapist] – as a professional – I think it's, you know, it's certainly, uh, narcissistically wounding to us, to the professional. To have a disability that prevents us from performing, you know, our job duties that we were trained for and that we love to do and so forth . . . and so, I think on those days when I'm feeling the worst, I, it, something just kicks in – some kind of guilt or, you know, um, some feeling that I, I am not good enough.

The data suggest that for some of the therapists in my study, the illness is the “default” position for evaluating their job. For several participants, illness becomes the convenient scapegoat for judging problems in one’s work. Rather than an unproductive therapy session being caused by something like a countertransference issue or a personal problem not related to illness, several participants are at risk of blaming everything on the illness.

One participant, being less harsh on herself, while acknowledging that she has her bad days, brings up this important point: she wonders how she compares to non-sick therapists, suggesting that her “bad days” might not be any different from any other therapist. She states, “There are days when I feel like I’m not doing my best. How that compares with other people, ‘cause I imagine all therapists have days and whether I have more or not. I wonder.”

One participant, whose illness causes debilitating fatigue, questions her own tendency to blame everything on illness. She poignantly muses about whether or not her lack of success might just be her, rather than the illness:

Um, it’s been hard to keep them separate, you know, my, my, my identity and sense of self separate from my self as somebody who can’t quite do all things I want to do. And that is still a really big challenge. Um, just the fact that I can’t, sort of, excel, uh, professionally, is like, well, that, is that just me or is that, is that how you deal with this illness. Maybe I’m just not someone who’s really that – got that much going. So it’s been hard to separate that out.

Another participant talks about her struggle to sort out feelings of wanting to be successful and how the illness easily becomes the most obvious thing that threatens the desired success:

. . . my parents . . . pushed, you know, being productive and successful. And so, you know, it's so much a part of me that it's important to be competent and successful, that anything that would make me not successful makes me feel inadequate. And so the illness, you know, if it wasn't the illness, it could be something else. You know, if I wasn't successful in some other area of my life, I might feel badly, *but the chronic illness is the – fits right in there* [italics mine]. It's something that makes me feel imperfect and, and it causes shame.

Pushing Oneself

When symptoms are present, in order to function as therapists, the participants just push themselves to work harder. It's the only way they can do their jobs. All the participants talked about "toughing it out" when symptoms persist.

One participant, with migraines, talks about choosing to endure a headache rather than taking medication that would make her sleepy, "I would, I would try to just tough it out and not use medication at all. . . . And so I just pushed myself."

Another participant chooses to take medication that allows her to "tough it out." "I will try and tough it out and take Naprosyn before I'll do any canceling. . . . Because I want the people to get the service that they need."

Along these same lines, another participant explains how her strong sense of responsibility to the client, motivates her to "push harder":

I'm going to do this, and these people are paying me a lot of money and, you know, they've, you know, they have to get their money's worth. And I have to be their [psychotherapist], you know, I've got to show up here. And so, during that session, you know, I'll try – and I'll just go in there and just try my best to just, just stay on top of it.

Another participant feels that it is guilt – guilt about not being good enough – that prompts her to work harder:

. . . I want to do good work and I want to help people get better and. And so, I think on those days when I'm feeling the worst, I, it, something just kicks in – some kind of guilt or, you know, um, some feeling that I, I am not good enough. Maybe a narcissistic kind of feeling that I am not good enough because I'm sick, and maybe there's shame or guilt. And, and so, to overcompensate for it, I push myself twice as hard.

The participant with lymphedema struggles with constant, excruciating pain. She must wear a full body compression suit to keep her body from swelling. As mentioned earlier in this chapter, the distraction that comes with focusing on a client helps her manage her pain. When the distraction is gone, she is flooded by pain. The following quote gives the reader an idea of the intensity of pain that she is pushing through during each and every one of her work days:

And I can hyper-focus in the middle of that activity [working as a psychotherapist]. . . . I have a very short commute. I'm just 5 minutes from my office. . . . Because what happens is, and, and. . . . What I found was that about a half hour after I'm done working, I get this absolute, flood gate of

pain . . . and it's not like my pain is worse than it was earlier, but the, the biofeedback system that I had to keep the, the pain at bay, is done. And I get this flood of pain that, that is really – that's my most excruciating time.

The Work Can Make You Sick

Pushing harder may very well be a good coping skill for the chronically ill therapist, but certainly it comes with some serious draw-backs. One participant talks about how pushing harder carries the risk of getting sicker:

It's taken me a lot of years to understand what it's really about. And what the significances are. And for so many people, when you're tired, you can push through. And sometimes I can, too. But it's always a chance. It's a chance that if I push through, that, then, for the next two days, I'll hardly be able to scrape myself around, you know.

The job itself is a double-edged sword – its sedentary nature allows the sick therapist to continue working, but on the other hand, the psychological intensity of the work can exacerbate symptoms. Similar to what participants have previously stated about “monitoring energy” and “screening clients,” one of the participants with CFIDS, when talking about a recent relapse, explains:

No, I mean and I did a lot of that stuff, and it contributed, actually, to my burn out. That's just, just overloading my system. . . . I mean, this is one thing I'll just say, which is I think really obvious, but my system gets so overloaded so easily. Stimulation wears me out; crisis wears me out; drama wears me out. Anything where I have to concentrate intensely for a long time wears me out, unfortunately.

Another example of this same concern, the therapist with rheumatoid arthritis, spoke of the risk in getting over-stimulated by her practice, which can lead to a flare-up:

I only get them [referring to flare-ups] when I don't sleep, which is, has been known to happen. That's why I stopped going to the osteopath, because his treatments started activating me too much, and I couldn't sleep. And also from jet lag. Um. Which is a major problem because traveling usually involves jet lag, and *if I'm too activated because of my practice and I can't sleep* [italics mine].

A variant on the theme of “work making one sick” is how work influences what medical treatment the participants choose. Four participants make medication decisions based on their work. All four participants avoid pain medication that could affect their cognitive functioning. Two participants make every effort to avoid steroids because of the visible side effects that could influence their work (for example, weight gain and manic speech that clients might notice). The participant with rheumatoid arthritis sums it up succinctly:

The problem is that all of these drugs are immunosuppressants. Especially the newest ones and . . . they have got a couple of them now that . . . everybody thinks [are] so wonderful . . . [but] how do you go out into the world? How do you have a psychotherapy practice for example? How do you go to a conference? The things that in my professional life are important to me. How do I have [name of her institute]? How do I have people come here [referring to her home office]? . . . I don't take those damned drugs , that's how I do it

(laughs). If I were taking immunosuppressants, I would be constantly worried. . . . And I don't want to be constantly fearful that I'm going to get sick. Somebody coughs in my office, I'm going to pick it up, and somebody comes in with the flu, and I have these people who have had colds for weeks now. And I can tolerate that now. I don't care. But, uh, if I'm on immunosuppressant drugs, you can't even see those people. What am I suppose to do then? Just tell them at the door, "You have to go. Call me on your cell phone."

Disclosure

Disclosure is one of the most controversial topics written about in the mental health literature. There is great debate about how much personal information therapists should reveal to clients. Disclosure is primarily a clinical issue, done in the interest of furthering the therapy. However, when symptoms become too intrusive, the therapist may be forced to disclose as a way of managing her illness. In my research, there is a wide range of opinions on this topic among participants. Some are very open about sharing details of their illness with clients, while others are very private.

The participants in this study all report thinking seriously about disclosure, trying to do what is in the best interest of the client and what will move the therapy forward. Regardless of their position on disclosure, all the participants consider such questions as: Will the disclosure help or hinder the therapy? Is it necessary that the client know? How will the client take the information?

Intentional Disclosure

Participants describe some situations in which they make a conscious decision to disclose information about their illness. But before doing so, they consider a variety of factors that influence this decision.

Is It Beneficial?

The primary concern for disclosure given by the participants in this study is how it will benefit the treatment. As one participant sums it up, “But. Well, for one thing when I am revealing something about myself, it really needs to seem useful.”

Another participant, who is more open about her illness, states:

... I think it's very important to come out, so to speak, about this kind of thing. ... I appreciate the need for protection where it's important [and] I haven't felt that everyone in the world needs to hear. Uh, to hear it. But also, I don't see any reason not to share it to people who – for whom it would be beneficial. That's part of why I wanted to be part of this study, because go ahead and write about it.

A therapist with CFIDS, on days in which she looks and acts particularly fatigued, questions whether or not a disclosure might actually be beneficial to her client. She worries that the client will think that her fatigue is really boredom:

Sometimes I think, yeah. I have lines under my eyes, and I think it looks – I think it really looks like I'm tired. Sometimes I yawn during sessions and that's – you know, I feel really awful about that 'cause the client potentially feels like, you know, they're boring you. Um, and, you know, sometimes I've pondered – here's a good thing for you to think about. I mean, sometimes

I've pondered, you know, would it be better to say to a client, "You know, look, I have an illness. It's nothing for you to be worried about. I'm going to be okay, but sometimes I'm tired, and if you see me yawn, please know that I'm not bored with you." You know? Would that be a therapeutic intervention, so that they wouldn't take it personally. So, maybe they're not saying anything, but are they wondering if they're boring? Are they wondering if I'm bored with them? And, um, and I never have taken that step to tell someone, "You know, I have this illness." But I've wondered, you know, what impact would that have? Is it better to not say anything and have them watch me yawn, or is it better to just be honest and say, you know, I have this illness and, you know, I'm gonna be tired at times. But I'm gonna do my best to be here for you, and . . . And that's, uh, something I've never worked out.

Like others in my study, she really has not made a definite decision on disclosure but is still wrestling with the issue.

The participant with rheumatoid arthritis has a unique attitude about the benefit of disclosure to the client. She grew up with a shame-based secret and sees disclosure as a way of helping clients overcome humiliation and embarrassment brought about by hiding truths about who they are:

Yeah, I don't like being hidden in a way that, uh, is related to shame. 'Cause that's what my family did with the whole Jewish thing. They were so ashamed of being Jews; you may have not heard about Jewish people like this, but I come from a . . . I'll, I'll, I'll, so many people that I've told this to, they

say, oh, aren't Jews proud of being Jews, and I said, not mine. They didn't want discrimination. . . . That's exactly the point, so that informs the whole way that I proceed with this. . . . I try to be careful about not informing people I see unless they specifically indicated the interest in knowing and, um, the fact that it would be beneficial for them.

She goes on to elaborate how the disclosure is also beneficial to her:

Uh, one of the reasons that I feel so strongly about being visible . . . is because I don't want to ever be in a position where people don't know who I really am. Um, that's a big, big deal for me. Um. It comes from, my family is Jewish, and I was told that I could pass for not Jewish, and I have many times in my life and [inaudible -- has something to do with people's anti-Semitic statements in her office] that I hide in my lifetime, not especially in my office, it's really amazing. Some day I'm going to write a dissertation on that one.

Only one participant mentions the difficulty of knowing, in advance, whether or not a disclosure is going to be beneficial to the treatment. She talks about this difficulty and shares her rationale:

So the way I try to put it, it has to be in the service of the therapy, and the only way I can know that is if I've spent an enormous amount of time processing and driving myself nuts with it. Or consulting with someone else!

Shared Experience

A couple of participants state that they disclose information about themselves when the client or someone in the client's life has the same illness. The participants see this as a way of furthering the therapy, connecting with the client, and minimizing

the client's shame. The following quotes illustrate the "shared experience" approach.

The participant with migraines states,

Right. If I'm, if I'm working with somebody who's telling me that they've got migraines, I say I suffer from them as well. I definitely talk about that. It seems like it's, uh, it's healthy and useful to do that.

One of the CFIDS participants gave this example of a shared-experience disclosure from her practice:

I've got, for example, right now a patient with Fibromyalgia who is almost, a, uh, a carbon copy of me in terms of how she deals in the world. She's had way too broad shoulders, she [has] worked compulsively, she's carried, you know, everybody around her, um, and she's gotten prone to raging and this kind of stuff, and her body broke down in her mid-50s with massive Fibromyalgia symptoms. And she's a mess. And she is so shame-prone because in her psyche, as is mine, um, and, um, any sign of visible weakness is a complete disaster. With her I've been very open about my own experience because it's become a way for her to talk to me honestly about how she feels and what's going on with her. Not out of mirroring but out of *shared experience* [italics mine], which has reduced the level of shame she feels . . .

This same participant sees disclosure as an antidote to the loneliness and isolation that comes with chronic illness. In the following quote, she talks about loneliness, although it is somewhat unclear whose loneliness is at issue – hers or the client's or both:

That's right. That's right. But in our culture the bridges that let that be a community are not very strong. So for me that's one of the major things that, that, I, it's gone on so long I'd really forgotten that, but I remember when I first got ill that that feeling of aloneness was one of the worst . . . and, and I think it's part of why I get self-disclosing with patients. When I feel like I want to crack that for them so that we can talk about the, that. Because many of my patients have things like Fibromyalgia or Chronic Fatigue so they also look okay and are far from okay, you know, and we talk about that. The hiddenness of the enormous loneliness that goes with that. Um, that's helpful. And healing.

Role-Modeling

Three participants talked about a certain type of disclosure, in which the therapist revealed some aspect of their own health as a way for modeling to the client. One CFIDS participant has an auto-immune reaction when she eats sugar; consequently, she avoids it. She sees a number of clients with eating disorders, and relates how, when they complain about not being able to eat sugar, she reveals some of her own experience, as a way of demonstrating that avoiding sugar is do-able:

Um, there are some clients who I've started – like with eating disorder clients – who say, you know, "I would die if I had to live without sugar; I don't know anybody who ever can live without sugar." There are times I've come out and said, "I don't eat sugar, and life is okay." Certain little things I'll disclose, you know, about diet or allergies or things I've experienced or know something about.

Another participant, because of epilepsy, does not drive. She reports a similar experience to the previous one. She had a client who also was unable to drive. The therapist spoke freely to the client how she got around without a car, as a way of both modeling coping behavior, and supporting the client.

One of the CFIDS participants broke her arm, and during her recovery, one of her clients revealed the benefits of watching her therapist cope with the injury. Although not an example of intentional disclosure, it does demonstrate the power of role-modeling in therapy:

And, the, the Fibromyalgia patient told me last week that she had been watching me from the day I broke my arm, which was visible on, and she said, "You don't know how much you taught me, but I watched you take care of yourself." She said, "And that probably taught me more than anything you and I have talked about, about what's possible." She says, "You don't have any idea how much that impacted me."

Weighing a Client's Ability to Tolerate.

Assessing a client's ability to tolerate and benefit from disclosure is a central issue for the participants. They think about whom they can tell, how they should tell, and when they should tell. The following two quotes illustrate the way in which the participants think about the disclosure in terms of the client's diagnosis, ego strength and maturity to handle the information:

And I won't necessarily – newer clients or clients who are more narcissistic or who are less developmentally, uh, astute, uh, engaged, what's the word I'm

looking for? Mature. Um, I'm not gonna probably bring up that I have a headache, and they're probably not gonna notice at least in that moment.

The participant with rheumatoid arthritis, who is very comfortable with disclosure, states, "I have done some very careful diagnostic thinking in each case to try to taper what needs to be said to each person."

This same participant, in thinking about which client can handle what kind of disclosure, thinks about it in terms of self-psychological theory:

Yeah, there's some people who in general don't want to know about me. That is, they seem to do better having my attention to who they are. You think about the Shane's theory about the interpersonal sharing dimension and the self-to-self transforming other dimension. If you're [in the] self-to-self transforming other, then you need to just simply be available to focus on them, who they are, what they're about, what their issues are. They don't want to know who you are. You have to have the kind of interpersonal sharing dimension of the transference in order for it to work. And I try and make an assessment as to whether people are there or not. Um, there are many people who change over time. I have somebody right now who is getting ready to terminate. It's not uncommon at that point that they want to know a little bit more.

Avoiding Care-Giving Behaviors in Clients

Several participants brought up the issue of activating care-giving behaviors in clients. The participant with migraines, who has a number of groups, discusses the possible risk that the group would take over more of the psychotherapist function in

the event that they knew she had a headache. "In other words, if they knew that I had a headache, it might be that they were, they would interact with each other more rather than having high expectations from me to be brilliant or something like that."

A poignant example of dealing with care-giving in a client is the experience of the participant with rheumatoid arthritis. She has a home office and on a few, rare occasions, her pain has been so intrusive, she has not be able to get dressed for her first client (who knows about the participant's disease), and has had to greet the client in her bathrobe. This participant feels very strongly about clients not taking care of her, and in this situation, to avoid that from occurring, she stresses to the client that she can do her job:

I try not to let anybody be put in situations where they have to take care of me. It's all they want to talk to me about. . . . It's not very often that I show up in a bathrobe. There have been times when I've looked really, really sick and times when I haven't been dressed. I was in a bathrobe. Now, I'll only do this [with] certain people whom I've known for many, many, many years. . . . So someone says "Are you okay?" I say "Yeah, fine actually, my head is just – I'm doing fine – uh – I can concentrate." And then they would just get into their session. . . . Because I don't want them to have the time taking care of me. I have a very strong ethic about that. A very strong ethic about that. I don't want anybody thinking that they have to, um, spend their time taking care of me. And I mean, there are days when I haven't been able to get dressed yet. It hasn't looked too good.

Invisible vs. Visible

When considering disclosure, the participants take into account the invisible/visible aspect of their illnesses. With a visible illness, the responsibility for disclosing is somewhat shared between the client and the therapist, in that the client might bring up the issue first, and then a discussion about the meaning of the question could ensue in the therapy. But with an invisible illness, the burden of disclosure is primarily on the therapist and can potentially have clinical implications for the therapy.

One of the participants with migraines elaborates on the tension around carrying the secret of the invisible illness and the question about whether or not to disclose:

The, the aspect of a headache, for instance, or an invisible issue is, it kind of puts on you, uh, the onus of declaring yourself or not. So then the question is, are you sitting in a room, covert? Are you sitting in the room with a secret? And is this a bad secret to keep or is this a secret that doesn't need to be shared. I mean, obviously if you're not disclosing your whole life story, you've got secrets. Which is normal. But it's something because it's pressing [referring to an intrusive symptom]. And is this a bad secret to keep, or is this a secret that doesn't need to be shared. You know, if I'm sitting there and my child has just been killed . . . you know and I'm trying to do therapy, I can compartmentalize that probably only so well, but what's not going to be available in the room, probably, is my ability to empathize much. It's gonna impact my empathy. If I'm in pain, psychic pain, I'm not gonna go there with

somebody in the room. Um. And I'm just gonna, it's just gonna be shut off and how good of a therapist am I in that moment? Well, maybe good enough, but not a good therapist, you know. Um, so I think that issue of, of that, that an individual therapist is going to be dealing with is gonna be really looking at whether being secretive about what's going on or not is serving the therapy, or not.

The participant with A-Fib is grateful that her illness is invisible, partly because it suits her temperament – she is a private person – and also because it gives her the control regarding disclosure:

Well. For me, I'm certainly grateful that it is invisible. I mean, umm . . . so then I can have it be a part of all, all, it just joins the rest of the me that is in there that's private, you know, that works for me. And it could be different, you know, I imagine other people could have a really different feeling about that. I could imagine, you know, all kinds of experiences around that, umm, maybe that could be more difficult. But, it happens to suit me to have it this way. Umm . . . (pause) For one thing because then I have, you know, some choice, it's part of my private life that I, you know, I think that for me that would be difficult. I mean I could see reverse concerns and difficulties but certainly, you know, having something where you have no choice seems harder. [Referring to a visible sign caused by her medication] . . . I find that much more disturbing if I can't, because I feel like it's out of control and then I'm exposed in a way and whether I want to talk about it or not, there it is.

The participant with lymphedema brings up an interesting point about visible versus invisible. With a visible illness, it is right out there, in the transference and countertransference arena and is, therefore, something to be discussed and processed.

This is not the case with an invisible illness:

And, the more invisible it is, the less process it gets to be. So, um, there are, there's less of an opportunity for us to work some of the, our counter-transference stuff out. [It] doesn't necessarily play out in the transference. . . .

The more hidden the disability is, the less that gets to be part of the dialogue in the room. And so the countertransference and whatever's happening in the transference gets really, um, isolated from each other. And . . . it's more to hold than, than usual. For, compared to other people.

This same participant brings up a subject not mentioned by other participants: that therapists might have feelings about their clients' inability to empathize with their illness, visible or invisible:

The other thing that is the, the um . . . I think this is maybe more, more true of, of, more visible disability, is when the clients can't empathize at all and the narcissistic injury to us as, as their care takers. To where . . . the clients who – both when, when, um, I was doing the, the bandaging and also after the hospital when, when, it was like – oh god, that was a real inconvenient time for you to be gone; I'm glad you're back, and, and no other mention.

Unintentional Disclosure

What about disclosures that happen inadvertently, in which the therapist does not purposefully reveal personal information to the client? What about times when a

client suspects that something is going on with the therapist, sometimes guessing correctly, sometimes having fantasies that are incorrect?

How the Therapists Think About It

There is controversy among the participants as to whether or not they believe that clients notice any thing that might reveal the therapist's illness. Some feel that clients don't notice, others believe that they do. One participant, who tends to be less in favor of disclosure, sums up a view shared by other participants: that clients are too self-absorbed to notice changes in the therapist:

Well, it reminds me, yeah, of another issue, which is that, you know, I have this big, beautiful, kind of abstract art painting on the wall, you know. Right when they walk in, it's just this huge print. And no one has ever said anything about it. And I once talked to a supervisor about that, and they said, you know, that when clients are coming in, they're in their head; they're in their emotions. And they're not looking at your clothes. You could wear the same clothes every week and they'll never notice [laughs a little]. Your office you could change, like something major in your office and they won't notice, because they're – so I think of it along those line. That, that they're so focused on their issue that they're not looking at whether I look tired or what I'm wearing or, um.

Another therapist states, along these same lines:

Um, I'm not gonna probably bring up that I have a headache, and they're probably not gonna notice at least in that moment. I laugh sometimes because my house is filled with art, and sometimes clients will come in here, and I can

almost judge when they start feeling better 'cause they suddenly look around and go, "Wow! Is that new?" You know [laughs].

The participant with chronic pain feels that she can keep her condition a secret as long as she remains seated in the session. When she moves, it becomes visible: "And people who have seen me get up and move, that's when I've had a couple of people asking about it."

The participant with A-Fib, although she has never had a client directly ask her if she's in an episode, does wonder whether or not the client is picking up on it by noticing subtle changes in her behavior.

Now when I'm having an episode, if it's a difficult episode, then I do assume that, I mean I am pretty, I don't react much, I don't think there are any obvious indicators but I think that, I believe, I guess, that on some subtle level that it's probably perceived.

A number of participants, especially those who believe that more attuned clients might notice shifts in them, mention the importance of listening to symbolic references in the client's material that might relate to the therapist's illness. One of the participants with CFIDS talks about listening carefully to client associations and metaphors that could, potentially, be connected to her illness:

Yeah, and for me the process of sorting that out has mostly been through listening to their associations and their metaphors. And that very often, I'm sure I miss it part of the time, but very often, I'll pick it up through their talking about something that seems wildly different.

Avoiding Inadvertent Disclosure

Six participants discuss their efforts to avoid accidental disclosure. The therapists may not be able to control the symptom's frequency, intensity, or intrusiveness, but they hope to control how obvious the symptom becomes to clients.

One participant, with CFIDS, not wanting clients to notice her fatigue, makes an effort to stifle her yawns. She states: "I feel like yawning all the time. I, for the most part, I don't, but sometimes I do. My therapist yawns and I see him." She then goes on, mentioning her own mixed feelings, as a client, when her therapist yawns, an experience that has no doubt heightened her sensitivity about yawns and her own clients.

This same therapist, because of various treatments, has lost a lot of weight. In an effort to avoid clients asking about it, she wears long-sleeved tops:

I think my weight is a bit of a clue for some people . . . I mean, I'm even a little shy about rolling up my sleeves, you know. My, my, when I do lose weight, you know, and I go through whatever cleansing diets I'm doing or whatever, I lose it in the extremities and um, look very thin and I'm very, I'm self conscious about that.

Another participant covers her hands with make-up to hide spots caused by medication, not wanting clients to notice.

The only side effects I have with the medication are the, the blood thinner which, you know, makes one . . . more prone to bruising. . . . That can come up on occasion in that I, I can get marks on my skin from the medication, whether it's bruises or little red spots, and, umm, sometimes, you know, I've

taken to using a little touch up make-up if I need to because otherwise people will, you know, notice and then it becomes a focus of "Well, gee, what happened to your hand?"

Validating Client's Perceptions

When a symptom does become obvious, what does the therapist do about it? The general consensus among the research participants is that it is important to validate and clarify the client's fantasies and perceptions about the therapist's health, especially to avoid unrealistic fantasies on the part of the clients. With an invisible illness, there is always the possibility that the client is picking up on something, real or imagined. At that point, self-disclosure, even for those who are less willing to disclose, becomes more of a necessity to the treatment.

One participant talks about clarifying and validating the perceptions of a client who has a dissociative disorder:

Um, I think that, uh, the invisible illness, many of my patients were prone to, um, notice and then reinterpret [it] as a problem of their own. That, you know, that, that, that they assumed that, um, they were either imagining me tired or causing my tiredness, or, um, or were too much for me emotionally, which is a major deal. . . . There was one woman who was a multiple personality that I was treating who would notice infinitely small alterations in my physical state and react by shooting different alters out to me, you know, depending on what she thought she saw, because she was, she was both noticing very accurately and misinterpreting wildly the data that she was getting. Um, so with her . . . from the minute I figured out what was going on

... we were labeling and naming my, my states even when she knew them before I did, which she frequently did. She'd say, "Are you feeling okay?" And I would laugh and say, "I think so. (Laughs) You know, what do you notice different, because a lot of the times you notice it before I do." So, again, you know, the deal was to use it without artifice.

As mentioned earlier in this chapter, this same participant is the one who looks for clues in the client's content, listening to any symbolic meaning that might indicate that the client is noticing things about her health. Also, because of the way she works, she encourages people to comment on their thoughts and feelings about her:

And, um, because of the way I work with people, they feel free to comment on it and do, and when it's appropriate, I'll confirm that the perception of me is accurate. And I say whatever I feel that needs to be said to a given person.

Another participant, who is less inclined to reveal her illness to clients, relates a story in which the client asked about her deep breaths. The participant believed that it was important to give the client some context for the behavior:

But um. I, I don't yawn but I find myself wanting to take a lot of deep breaths to kind of like re-oxygenate myself, and, and I've had clients who have gone, "Are you bored?" I have one client who's very tuned into that, and she's like, you know, you must be thinking I'm, you must be really frustrated with me. You know, I've had to explain to her, I'm not frustrated with you; I'm just trying to get some air.

The participant with A-Fib, who is more on the "no disclosure" end of the

continuum, admits to self-disclosure when she is pretty convinced that a client is already picking up on it:

The couple of people who know . . . either they or someone they were close to developed [laughs] atrial fib and I noticed that my responses and my engagement – I became aware that it was not my usual baseline. It was obvious that I had some unusual knowledge [laughs], you know, and so I decided for these people to actually just mention – for a variety of considerations, *but coming out of that since that it was on some level they were picking up on something being out of the usual range* [italics mine], I thought, just in terms of my activation maybe around it or something, so I mentioned that I had it.

The participant with sarcoid cites an incident from her practice that demonstrates the importance of validating a client's perceptions. The therapist's truthful self-disclosure was a turning point in the therapy:

Um, well, one patient, I think ultimately I did tell her. One patient basically, when I was so ill three months ago, had been a long-term patient of mine. Someone with a lot of sensitivity, um. . . . And she kept commenting on my cough. And it was true that my doctors thought I just had a, a little bit of a bad bronchial thing, and they had me on antibiotics, and I'd stay out for a few days and then come back, and I'd still be coughing. So I answered, just, I'm, you know, why don't we talk about what's going on with you and, yeah, it's just a cough and why is that concerning you and so forth. And we weren't getting anywhere. And after about 3 months, when it had been diagnosed as

to what it was, my lung functionings were in the 30s; I was quite ill; there was again talk about whether I might die. I mean, this time it was really serious. And I had taken a few days off, and then they put me on a high dose of Prednisone and I was fine. . . . She noticed the impact on my face, put it together with the coughing, noticed some other – I don't remember – I think it was, it was the puffiness of the cheeks, the way and the sound of my cough, and said, um, "You have a lung disease, and you're on Prednisone. That's what I'm imagining." And I laughed. And I said, ok, what's it like to be that empathic and in tune? And it was a, like a turning point for her to really have it be about that because that was, it was sort of a cornerstone piece of information in the therapeutic work. Obviously by the way I asked – and she said, "So I'm right." And I said, "Yes, now let's go back to what it's like to be that in tune." She, at times, came back to it and said – um, her mother was dying of emphysema and so, um, she, uh, needed reassurance that I wasn't dying. And I, I told her my illness.

One participant tells an interesting story of her own experience in analysis, being on the receiving end of fantasies. For months, she was having dreams and intuitions that her analyst was sick, but he said nothing. Eventually, the analyst had to take time off from work because of cancer. This participant wishes that her analyst had been more forthright with her, leaving her with unresolved feelings about the experience. She had felt "crazy" for all those months until the reality confirmed her intuition:

So for me it's sort of like, um, you know, I remember clearly, for example, when I was in analysis, my analyst did have the blank screen, you know, totally tight, contained routine going, and, um, one of the things I thought about in my, you know, as subsequent to my work, was that he – I began having ideas and references in my dreams and associations to him being sick and dying, and I became very uneasy. And, um, six months later he took a leave because he had cancer, and he was having surgery, and he was out for quite a long time. He never told me why he was gone. He didn't tell me anything; I heard it from other people. But I knew 6 months before the surgery, maybe before he knew there was something wrong, because of the way he sat in the chair.

Necessary Disclosure

When the therapist is no longer able to hide an illness or if the illness requires the therapist to take time off from work, some form of disclosure becomes necessary. One of the participants who, philosophically, is less inclined to disclose, sums it up when she says: "Now, again, if there were something real obvious I would be much more inclined, personally, my own inclination would be to say something." Along these same lines, another participant states: "Um. Because I . . . felt something was going on that just was too obvious it seemed to me to, that I felt, that I wanted to just to label it."

Several participants mention the importance of disclosing information when an illness interferes with their ability to work regular hours:

Again, if there's some kind of problem that you're having that may influence your ability to be available in the future, like something's going on with you, like you just got diagnosed with cancer. You're not talking about it, but you know that in a short period of time there's a good chance you're going to be in treatment. And you're really concerned about it, and you're, uh, and you may not be able to work. Then you're up against the issue of when to disclose and whether to make it part of what you're dealing with and not.

Sometimes a therapist must reveal much more than she would ordinarily reveal. The participant with ulcerative colitis reports that during a recent, severe flare-up, she had to take a three-month leave from work. Generally comfortable with self-disclosure, this extended leave required giving much more detail than she normally would, in order to provide an adequate explanation for her leave, and to reassure her clients that she would be returning.

Minimizing the Self-Disclosure

When disclosure becomes necessary (for example, the intrusiveness becomes obvious or the therapist has to take time off from work due to illness), some therapists minimize the illness by only giving a general statement, by lying and downplaying or letting the client think something else that is more benign.

One participant who needed to take a month's leave, due to illness, gave her clients a vague, general statement about her leave, rather than a more specific statement:

That's a really tough one. I don't disclose to clients, for the most part. Um, I took off a month . . . and actually went on disability for a month, state

disability. . . . but, um, I told people, well, I'm gonna be off for the month . . . and people, some people didn't question it at all 'cause it was in the summer. And some people said, "What's, what?" You know, and I said, uh, personal issues and if they pushed it, well, some medical issues. That's as far as I've gone. That's really as far as I've gone.

The participant with migraines, when she must disclose a headache or when a client notices it, minimizes the headache, " . . . and so when I would be sitting there and I'd have [a migraine] . . . somebody would say, "do you have a headache?" *And I'd say, "yeah, it's not bad, though [italics mine]."*

Another participant lies to clients who ask about her health: "But this is amazing, in eighteen years, I mean, like, once or twice or three times someone has said to me, 'Oh, do you have a cold? You look a little tired today.' And I'll say, 'Oh yeah, I have a cold.'"

One of the participants with CFIDS tells clients that she has seasonal allergies, rather than chronic fatigue. "I have told people in the past, 'cause I do have allergies, too, you know. I mean, I'm having allergies right now. So I think I've tried to keep it sort of more benign in terms of my explanation, to not – not severe sounding."

Lying to clients is a way of protecting them from possibly extreme and unrealistic fantasies about the therapist. When telling a client that she must cancel a session, this participant tends to lie to keep the client from getting afraid:

You kind of have a sense of who could handle what. Um, I know that a couple of my clients would be really scared if I told them I had a chronic

condition, and so I tend to more just say my daughter's ill or, um, I've had something come up, or, you know.

Disclosure to Colleagues – The Secret Shame?

Disclosing an illness to clients raises one set of issues, while disclosure to colleagues involves very different concerns. Since many referrals come from people in the professional community, a therapist's reputation is crucial to success. Someone who discloses a chronic illness runs the risk of being seen by her colleagues as impaired and not up to the therapeutic task.

There is a range of opinions and experiences expressed by the participants regarding "coming out" as a sick therapist. All have told their story to at least one peer, usually a trusted colleague with whom they share a close friendship, as well as a professional relationship. Some participants have serious concerns about how the professional community might view them, should the illness become known. For others, it is almost a non-issue.

Not Wanting To Be Viewed as Impaired

Over half of the participants express concerns that, if their professional community knew of their illness, they might be viewed as impaired or incompetent. The following quote illustrates this concern: "[talking about her illness] [it] invites a lot of questions and doubts. Something that I might, maybe I would be concerned about with colleagues. It's . . . like . . . are you really here? How present are you? Are you distracted by your [illness]?"

Another participant says something similar:

[When asked about disclosing to her colleagues] Hmmhmm . . . Well, like the whole thing we started with. . . . It, what it has to do with is, you know, what will they think about me if they knew that I said that I couldn't remember things or they knew that I said I'm tired. Would they think I'm not a good therapist for being – that's, that's the whole, that comes back to the whole shame thing.

I recently gave a talk about this research to a group of therapists working in a clinic setting. Several therapists in the audience said they would have difficulty referring clients to a chronically ill therapist, the concern being that the therapist's ability would be impaired by the illness. I mentioned this information during my interviews, and all the participants to whom I told this story responded with anger. The following quote typifies my participants' reactions:

Interviewer: I did give a talk about, uh, my research, at an agency in Marin. And a couple of people did say that they would not refer to therapists with chronic health problems. They said they would have to really make sure that the person had worked it through. I thought that was interesting.

Participant: [interrupting me] Worked it through? (Laughs).

Interviewer: Yeah, we don't always – yeah, first of all, worked it through.

Participant: Work it through! [said sarcastically] And, you know, we refer to all kinds of people who have had traumas in their lives and alcoholics, and why do we have to work it through!

Real Stigma

Participants have encountered concrete incidents of judgment and stigma that have influenced how they think about disclosing to other therapists. One participant reports an experience in which a colleague conveyed a negative view of her and her health problems:

And I remember one person who was an intern saying to me, you know, "Do you think the psychological plays into the physical?" And I said, of course and she said, "Well, I guess you feel like you're the exception." Or something really obnoxious, and I was so shocked because I think her way of looking at it was, um, if I just went into therapy and worked out my issues, then I'd be healthy, and that's not the way I see them playing into each other, you know.

Another participant with CFIDS gives an example of actual stigmatization she experienced in graduate school:

All my grad student friends knew. And it was humiliating 'cause this one idiot guy who said, "Oh, I heard that chronic fatigue syndrome is just depression." And he yelled this out in the hallway in front of, like, the entire school. And ever since then, it was like, you know, you jerks. You know, there had been a lot of articles too, in the early 90s, saying that chronic fatigue syndrome was caused by, you know, depression, and it needed cognitive behavioral therapy. I want to shoot these people . . . and ever since, I don't think I've told anyone.

Selective Disclosure

All the participants talk about what Charmaz (1991) calls, “selective disclosure,” telling just certain people whom they trust and whom they feel will not have prejudicial judgments against them. One participant relates a story that illustrates the “selective” way in which she discloses:

Um, yes. You know it's like clients; I'm careful who I tell. And, um, whether it affects people, I'm not sure. I mean, I do get referrals (laughs). So, um, you know. But I tend to tell people who I'm closer to – who, you know, know what it is I can give clients, you know. I mean, I think I wouldn't be comfortable just putting it out there to anybody. Um, I have felt from various people sometimes comments about, um, people who are sick all the time or, you know, I hear comments – a client of mine said the other day something about, “Oh, she has really negative, dark energy,” referring to somebody else, and I said, “Well, what does that mean?” And she said, “Oh, she's always sick and has headaches.” You know, so she wouldn't be one that I would disclose (laughs), obviously.

One participant chose to tell the members of her group practice about her health problems but waited until they knew her and were familiar with her work:

I mean, perhaps partly the stigma, but I think it's also just the, the idea of kind of being seen as less competent. You know, seen as less functional, you know and, you know, this place [referring to the group practice in which she participates] completely relies, for me, on, um, colleague referrals. I mean, some people call from the Yellow Pages, or mostly, where I get my referrals is

from the other people here. And it's sort of this idea that if they think of me as sort of foggy, tired and out of it that they won't refer me people. And so, I think there was a way I kind of wanted to prove myself before I disclosed that, and then people knew me as a clinician before they knew . . . I mean, it's been hard. It took me a while to sort of come out here.

Shared Experience

The participants in this study, as they do with their clients who have similar symptoms, are more inclined to disclose their illness to other sick therapists. One participant describes her own evolution regarding telling colleagues, first, out of a longing for sympathy, and finally, as a way of sharing a common experience. She says:

I mean, what happened, and I don't know how to talk about this because I think it was a gradual process. Hard to remember, uh, you know, twenty years ago because there's been so many shifts in how I think about myself. Um, I think at some point, at the beginning I told [colleagues] because I had the fantasy that it would get me sympathy and care. Then I had to go through the mourning of that fantasy and taking the, the responsibility myself. After that, it didn't seem very important to tell people. And it still isn't, but once in a while, if a colleague is also ill, too, then we can share, you know, some of our feelings and experiences about it, but it's in that way.

Upon hearing that a member of her consultation group has a chronic health problem, this participant took the opportunity to disclose her illness, an experience that proved quite positive:

One of the women in that group . . . was having a health problem. Um, and then when she . . . disclosed that she had . . . this health problem. And it, almost as soon as she talked about, you know, in front of everyone, that she had just come back 'cause she had . . . something. Um, that I just came, just came out and it was like I had been waiting for all these years! I just came out and said, "Well, you know, I have Lyme disease" . . . and I just threw it all out there. So I think it was because someone else in the room, who was a therapist, was saying she had an illness. And I think that's the only reason it came out.

Shame

Since shame, and its accompanying stigma, is written about as one of the major issues affecting sick people, I expected to see this same theme reflected in my data. In fact, I speculated that the participants would have a harder struggle with shame since there is so much idealization of therapists, i.e., we are somehow "above" or not touched by life's problems. It is, indeed, very surprising to find out that this is not the case in my study. Two participants adamantly state that they feel no shame at all about having a chronic health condition. Five say they have no shame and yet are cautious about disclosing their illness. Some of these participants seem to talk "around" the subject, for example, speaking at length about being very private about their illness, including keeping it secret from clients and colleagues.

Three participants, two of whom say they feel no shame, were very concerned about the confidentiality of this research, wanting a review and reassurance from me regarding my notes and tapes and how they would be written about in the dissertation.

In order to respect the privacy of these participants, I have purposely not revealed information that might inadvertently divulge their identities.

Interestingly, the participant with ulcerative colitis, who is from another country, was completely surprised by my question, not even knowing what I was talking about. I had to explain to her how shame and stigma are talked about in the chronic illness literature and my own curiosity about how therapists deal with this. She states that, in her culture, sickness as well as health is just an accepted part of life. It is not thought of as a personal failing or something that would activate shame in the sick person. Illness just “is.” It is something that is accepted, coped with and grieved over, but not something to feel ashamed about.

Psychological Vs. Physical

The data indicate concern about being seen, especially by colleagues, as someone whose illness is “psychological” rather than “physical.” This is especially true for, but not limited to, those four participants who have illnesses that are harder to diagnose. These four participants all mention concern that others, particularly other therapists, might think their illnesses are psychological rather than “real.”

One participant with CFIDS states:

Um, it's just misunderstood a lot and, and kind of judged like you could just think it away, kind of. So anyway, um, oh, I definitely feel the stigma part of it. Absolutely. Um, I think because it's the kind of illness where it's so misunderstood, too, in people. And, ah, especially therapists, maybe, but maybe a lot of people have a lot of ideas – well, maybe you caused your own illness and you're not working hard enough on yourself. Are you really just

depressed? Um, what is this a sign of that you're not dealing with? Unlike some other illnesses, you know, it just seems to lend itself more to that kind of questioning.

Another participant expresses a similar worry about people thinking her illness is psychosomatic, "That's perhaps why I don't talk to so many people about it because I feel like people would tend to, to think, oh, it's psychosomatic. Oh, you know, you have some issue or you're depressed or you're whatever."

One participant, whose illness does not have a clearly defined diagnosis, speaks about the complicated reaction in her family:

So, that's – even in my family where both of my parents are psychologists, my brother and sister are psychologists, my, um, my other brother . . . his wife is a social worker. My brother, who's a psychologist, his wife is a psychologist. My sister's a psychologist; her husband is a . . . counselor. So . . . you know, eight people are all therapists. . . . And even in my family, I sometimes feel – and they're totally understanding and open and accepting, and even in my family, I feel, sometimes, that maybe they're wondering like, why hasn't [she] gotten better? And, you know, why has this gone on so long? And, you know, what, what is it? You know, is it depression? Or, is it some therapy issue [she] needs to go work out? So, that's always there.

Another participant, with A-Fib, who answered "no" when I asked about shame, admits that she would not like it if others were viewing her as having a psychological illness, "Maybe because I think it's, umm, I suppose one thing that

most therapists, but, you know, I would be uneasy about would be people I respect imagining things [about my illness].”

Another participant, during the interview, told me that she is taking Sinaquin, a tricyclic anti-depressant, but went on to emphasize that this is for sleep, not depression. It was as if she was concerned that I, too, would jump to conclusion that her illness was psychological rather than physical.

Coming from a different, rather refreshing perspective, the participant with migraines, who also denies any direct feelings of shame, admits that she might be somatisizing her illness, but sees this as almost irrelevant – that she is only human, doing the best that she can and sees no need to blame herself for it:

Yeah. I might be somatisizing it. But I just, you know, ok, I think it's probably true. And I'm doing my level best at handling it, and I'm still doing it, and I don't see any reason to be mad at me on top of it about it. You know, it's like, that's not gonna help. And being ashamed about it, I guess, you know, if you preach, if you take the position that you're not human (laughs) as a therapist, you're more inclined to maybe feel that way, that you should have it all handled.

She goes on, elaborating on the theme of her humanness and vulnerability, which, although she doesn't state it directly, implies a climate in which shame does not grow:

[Speaking about the omnipotent therapist] Because I don't come from that position as a therapist. I really don't, you know, a great deal of mine is, you know, um, I feel, what's the name of that, Colombo? You know, I'm sort of

the therapist in the overcoat kind of diddling around and, you know, maybe I really know what I'm doing, sorta, kinda thing, what do you think? You know, letting other people be smart and figure it out and that kind of thing. I don't feel like I have to know it all. I try to live in the question a lot more with people . . . and come from . . . my own human frailty or, you know, disclosing stuff, uh, about, you know, I'm like that too.

Explanation for Lack of Shame.

So why don't more participants admit to feelings of shame? Is it that they simply do not feel any shame? Is it just a different perspective or could it be denial? I asked the two participants who did admit to shame about their opinions on the lack of shame. Here is one participant's response:

Well, um, just back to the shame thing for a minute, um. Well, I've found that actually just, just the topic of shame is shameful for a lot of people. For a lot of clients, I mean, even just using the word "shame" sometimes can sort of make clients extremely uncomfortable. Um, so it's – I don't think it's a word that's really, you know, embraced in a, in a neutral way in this culture. It's sort of like there's a lot of shame about shame.

The other therapist gives her opinion:

I think so. I think, I think, well, I think shame is, is something that, um, is not well understood, even by psychoanalytic clinicians. You know, guilt is, you know, is more of the, and fear, are more – fear of rejection, fear of abandonment, guilt – these are more prevailing emotions, but shame, I think, only in the last five or ten years, you know, how people started to talk about it

and understand it, and so, I think, um, yeah. And maybe it's just closer, closer to their, you know . . . they need to deny it because it's closer to home.

One of the participants, who asserts that she has no shame about having a chronic illness, brings up another aspect of the shame-stigma-impaired continuum. For her, having a chronic illness isn't about being impaired and, thus, being thought less of. Instead, it's about frailty, which she views as a humbling experience:

[Responding to my question about shame] . . . to whatever extent what you described has truth for me, certainly having something like this is a nice counterpoint. Again, I think the idea of feeling a certain frailty is a good thing. Not so much identifying as an ill person, which is a different experience but this sense of the kind of frailty and imperfection that's so present. I, I think it's a good thing because it's humbling and it's, you know. So again it acts in this, I think . . . hmmhmm. If one is, as a therapist, harboring any notions of an idealized self, this is a nice side (laughs).

The participant with sarcoid has a different way of defining stigma. She sees it, instead, as prejudice. She draws a distinction between prejudice, stigma and the "truth":

There's an enormous difference in my – stigma is a sense of prejudice against. Um, and maybe I'm also bringing that I ethnically come from a group with it . . . I'm Jewish, so I've thought a lot about being black or Jewish . . . what it means to be stigmatized . . . thought less of because of the name with that information. Um, which is kind of a prejudice. That's stigma to me. Um . . . the ego needs to be seen as whole, the reality is it's a little different. I'm

aware that I'm in some trouble. I'm aware that my hip hurts right now. I'm aware that, um, my breathing is slow when I walk up, you know, is problematic when I walk up the stairs and I'm hiding it. Because I don't want to be seen as, uh, less functionally capable, which in reality, I am just a little bit less functionally capable. So that's not about stigma (laughs); it's about how much do I let them know the truth. And I think there's a little difference there.

Stigmatization by Health Care Providers

Although beyond the purview of this research, it is interesting that all the participants experienced stigma in their relationships with their health care providers. It is important to this research in that this experience influences how the therapists work with their chronically ill clients. All of the participants, as health care providers themselves, talk about having a heightened sensitivity to the issues faced by their ill clients.

One of the participants with CFIDS, who experienced repeated episodes of stigmatization by her doctors, is very careful not to minimize the health concerns of her clients:

I do not doubt people's psychological or physical symptoms at all. I don't need to go there. I don't, um, I know the pain involved in being minimized, and, especially by professionals, and so I'm very careful not to do that, and I usually, if I find a tendency in myself to want to minimize [the client's symptoms], I will put it immediately back on myself.

I will discuss in greater detail this aspect of the illness's impact on their work in

the following section.

The Positive Impact of the Illness on Their Work

All ten participants report being changed profoundly by their chronic illness and that these changes directly impact their work in positive ways. As one participant puts it: “Like most trials and tribulations, it’s taught me a lot. You know, I feel I’ve learned a lot from it and, um, feel like I can really draw on it [in my work].”

Participants describe some “practical” ways that the illness has changed their work, such as having an increased interest in and awareness of illness in clients. In addition, several people are developing new career interests as a result of being sick. Even more importantly, the illness has brought on some profound changes in the therapists’ basic core and has influenced their philosophy of life. Like any other major life crisis, the illness has changed the therapists in personal ways that inevitably have influenced how they work with clients.

Shift in Awareness

Several participants believe that they are much more attuned to illness in their clients, routinely asking questions about their clients’ health, asking more detailed questions when a client does report a sickness, and making an effort to educate themselves about a client’s illness.

The participant with rheumatoid arthritis talks about her heightened awareness of client illness, a theme shared by most of the participants in this study:

Um, I, I think what it is, is everybody out there has them [health problems] and some people talk about them and some people don't. Uh, for a while, a long time ago, I kept thinking why is it that I have every neurological disease and kept attracting all these people with neurological problems? I kept getting people with brain tumors. . . . I had a whole slew of brain tumors way back in the '80s. Um, no, I think what it is is the world is filled with people with a chronic condition . . . and no one talks about them. And I think if you're open to it and you hear it, then you're more likely to ask more about it. . . . I could see where somebody could go to a therapist and happen to mention that I have whatever this is and the therapist could just not pay attention. . . . See, that's the kind of thing where I – if I hadn't known it, I wouldn't have picked up on it.

The participant with migraines takes a more pro-active approach with clients who have health problems, doing a “body-assessment” of clients:

I ask questions pretty quickly with people around things like, uh, um, you know, how's their sleep? You know, I do tend to look at all the aspects, um, with people, that check out what's their stress level early on and at regular intervals. I ask people when they're having migraines, or something like that, where are they in their cycle. You know, those kinds of things. 'Cause I've learned to look for things. It's educated me. . . . So that's the kind of stuff that I look for. You know, I also am more aware of people clenching their jaws and holding, so when I look at people, I'm looking at physically, what might

they be doing in their bodies that may be also adding to the way they stress or illustrating their stressors.

One participant with CFIDS, who specializes in trauma victims, describes how her illness has given her an increased awareness of energy in her own body, which, in turn, positively affects her skill in working with Dissociative Disorders:

‘Cause this is something I wanted to say. I think, because of my illness, I am much more in touch with subtle energy. . . . But, um, I feel like I’m very in touch with my body and my energy and, um, in a way that I can’t quite describe, that’s very helpful with clients. I can read my own energy better. I can read their energy better, especially [dissociative disorders].

Career Development

Two participants are using their illnesses as a springboard into specializing in chronic illness. One participant, as a result of what she’s learned from her own chronic health problems, has decided to market herself to cardiac patients:

Because I think a new area for me is to not only work with, um, chronic illness but to work with cardiac patients because cardiac patients are – many of them are type-A personality. I feel, I feel particularly qualified to work with executives who are type-A personalities, and I’m thinking about, you know, marketing myself to corporations, or to executives, or to cardiologists. Um, to seek those kinds of people because I think I have – I think I really, you know, I really understand, you know, what it’s like to feel a need to prove oneself and to just go overboard doing it. And whether the consequences for people are physical or emotional, for me they were mostly physical

consequences, for other people, they have panic attacks, or they drink. Um. I feel like I understand people like that and could really be helpful to them.

The other participant, drawing on her own experience of living with a chronic illness for 30 years, teaches various stress management techniques to clients:

And, I think that, uh, you know, some of the things that it's taught me is about stress . . . I have put into place so many ways to help me manage stress, for the most part, that I've really – and, and, so, I have a lot of organizational skills, and time-management skills, and I studied those things and I teach those things. So I have a lot of cognitive-behavioral approaches to work with people. I've learned things about putting, you know, um, obsessive thoughts on back burners and how to help people do that. Um, you know, I, I work with meditation techniques and relaxation techniques and breathing techniques with people. . . . So a lot of the things that I have sought to help myself with migraines along the way have also filtered into my practice as things to help people with anxiety or depression, stress, um, tensions, uh, um, obsessive thinking.

A Different View of Human Suffering

The participants were asked whether or not the chronic illness had provided anything positive in their work as therapists. None of the participants likes having a chronic illness, but they all report being enriched by their illness in a variety of ways. From a philosophical appreciation of “acceptance” to a belief in the importance of faith, the participants have been deeply changed by their illness and they pass these changes on to their clients.

One participant explains to a client the importance of faith, something that she can do from a place of personal experience:

Kind of being able to trust in the unknown, uh, being present, um . . . just saying something to a client today, oh, about she couldn't conceive of how she could possibly change these things because she was just going to lose something. And I was saying, you know, when you lose something, you never really know what's on the other side that you're going to gain. Um, all you can see is the loss. And there are things on the other side, you just can't know what they are, but then the loss of things means the gaining of something else, um. . . . I could say that from experience . . .

Another participant talks along these same lines:

It's really, uh, spurred me to work these elements that I've described to you [acceptance and faith], and I'm sure that's had an affect on my work and that, plus this kind of heightened sensitivity to, umm, you know, just the inherent struggle, the struggle that is inherent in life. So, certainly a kind of Buddhist framework is, is extremely helpful [to my work]. . . . And, umm, having that in mind is really helpful to me in my life and in my work. Probably more so than it would have been if I didn't have something like this [referring to her chronic illness] . . .

The following quote represents the thinking of many of the participants – the acceptance that their illness is chronic and has no cure – and has changed their view of clients' issues. Sometimes there is “no cure,” and this applies to clients, too:

And I also got the idea that you don't get over things. That you learn to work with them, but that you don't, you know, that very often if you have an illness of any kind, uh, that it's not something that you, that they give you a pill and you get over and go on with your life. That it's something you have to learn how to accept and take into you and work with. And God knows that's true with things like depression, you know, or um, or um, post traumatic states, or um, even personality disorders, I think that, uh, people have to learn to walk into and accept what they are and begin to work with it. And my earlier fantasies of cure were, um, were punctured in many ways to the good. Because I think, I think it's made me more accepting of myself, more accepting of the world around me, and more accepting of my patients.

This notion of "no cure" is highly significant for this participant and has markedly influenced her work. In many schools of psychology, as well as in the greater culture, there is a belief, valid or not, that psychotherapy can "cure." This participant now understands on a deep level that "cure" isn't always possible and has replaced it with "acceptance." She goes on about how her thinking has changed over the years:

And, the issue of working with the hand you're dealt rather than with some notion of overcoming it and then moving on. Uh, it took me a decade or two after I began that journey of my own [referring to her health problems] to get this, but it didn't occur to me until 15 years later, when I entered into an agreement with my patients to cure them, what I was actually agreeing to do was murder them. Because it was a consensus between us that the existing

self was a flawed, defective, horrible thing that had to be changed into something else in order to have a happy life, and that's not true and it's a, it's a real attack on the experience that make each of us what we are.

Several participants mention learning patience from their health struggles.

One participant elaborates this theme:

[In talking about how her illness has taught her patience] That's definitely true, and I have a few clients, including the one that is my pro bono, who, I don't believe she would have made it in therapy with very many therapists. I'm not saying there aren't some others who can't do this, but she has required so much patience. It took a year for me just to get her to come in. She'd either no-show, cancel or come in 35 minutes late. Not many therapists would hang out with that, you know. . . . So I do have a lot of patience for that . . . [that comes from the illness].

One participant believes that her own personal grieving over her lost years has enhanced her capacity to empathize with clients who are grieving. The following quote shows both her acceptance of "no cure" and her understanding of grieving what is lost:

A couple of years ago I went through a really deep grieving process where I started to get that even if I ever did get well from chronic fatigue, I'm now into menopause and aging and I'm never going to have that healthy twenty to forty. Those years are gone. I'll never have that. And I really grieved that and, um, it helped me to understand something about [clients] who have really felt, you know, maybe in their forties, are really looking, you know, are really

healing from trauma, but then there's that grief about, you know, for forty years, I have suffered . . . whatever the grieving is but just all those lost years that you realize. And that's a different thing for me because I think until then I really held out that, you know, I really am gonna get better, and I really am, you know. Um, and I wouldn't say I've given up completely but there is a – but I'm much more in terms of managing it than I do, rather than I'm gonna get well.

A number of participants spoke about how the illness has given them a greater sense of the fragility of life. Although she does not explain how it has influenced her work, the following participant talks about her understanding of life's frailty and her belief that it has impacted her work:

Maybe, umm, maybe in making it a lot harder to be in denial about this kind of frailty and the frailty for me is about, just the general frailty of life . . . I think I, I think I'm much more open to, and just, it's closer to my awareness now all the time in a certain subtle way. Not that, well, just that subtle way of, you know, gee, you just never know. Um. And so it has definitely affected my work I think in ways that have been really helpful – really good.

Two participants feel that they have become better people as a result of their illnesses. The following is a quote by one of the participants who feels personally changed in a positive way by her illness:

[In talking about her struggles, coping with her illness] . . . when I stepped back from that false self, in essence, I changed a lot of things, including I left the public persona behind and became a much more private person, which is

what rescued me and [made me] a kinder person. But I stopped being judgmental. What I came out of it with, it's very positive . . . um, and endures to this day is I have a belief that I am a person who can accept and cope.

One participant sums up her experience of having an illness as follows: "It teaches you to be more human . . . 'cause that's really all we have, I think, as humans. We're all mortal, we're all gonna die. You know, we all get sicker as we get older . . . [and] there is no such thing as cure."

CHAPTER 5: DISCUSSION

This research explored the subjective experience of the psychotherapist with a chronic unseen illness. Several research questions were proposed: What is the psychotherapist's subjective experience of dealing with a chronic, unseen illness while conducting a private practice? Does the sick therapist think the illness impacts her work, and if yes, how? How does the therapist manage, on a daily basis, the difficulties that come with having a chronic illness, while maintaining a private practice? Does the chronic illness influence the therapist's professional identity, and if so, in what way?

The research grew out of my own experience of coping with an unseen, chronic illness. I was curious about whether or not other therapists experienced the same kind of problems and issues that I have experienced, such as symptom management, coping with the illness in psychotherapy sessions, shame, fear of exposure to other professionals, inadvertent disclosure, and other issues that impact our work. I was interested in how therapists manage living in these two worlds – that of chronic illness and that of the work of psychotherapy. I had no preconceived notions. I just wanted to explore the phenomenon and see what emerged from the interviews.

As I began, I was surprised that the subject of chronic illness in the therapist is, for some reason, underrepresented in the professional literature. Given the prevalence of chronic illness, it is interesting that I found less than 30 references about illness in the therapist, and as presented in Chapter 2, most of this literature is about acute illness, such as heart attack or stroke. Even Freud, who lived seventeen

years with a horrific chronic health problem, never wrote professionally about his experience. It seems that illness in the therapist was and still is a taboo subject. I am hoping that this research may help to “break the silence” and shine some light on the experience of the chronically ill therapist.

Is there something about the profession of psychotherapy that contributes to this silence? The findings of my research suggest that the context of psychotherapy has a strong influence on the illness experience, thus, paralleling the medical anthropology literature on illness and the works of Dr. Arthur Kleinman (1980, 1988). So, how does the context of psychotherapy color the experience of chronic illness and how does a chronic illness impact the therapeutic work?

In this chapter, I will begin by presenting my interpretation of the data in two sections. The first places the therapists’ illness experience in the context of the two worlds in which the chronically ill therapist lives – the culture of chronic illness and the culture of psychotherapy. In the second section, I will discuss the importance of the illness narrative for the chronically ill therapist. Then, my findings will be examined in terms of the literature. The chapter will end with a discussion of the limitations of the study and suggestions for further research.

The Two Cultures – Chronic Illness and Psychotherapy

In order to understand the experience of the chronically ill therapist one must first understand the culture in which the therapist works. I will begin my discussion by explaining the demands of psychotherapy and by outlining the illness’s impact on two key aspects of the work – consistency and focus – and how they are influenced by a chronic illness. Next I will talk about what I think motivates the chronically ill

therapist and what adaptive measures the therapist will go through in order to do her job. I will then look at the therapist's sense of her own competence. This section will end with two important topics that are relevant to the chronically ill therapist who has an unseen illness: shame and disclosure.

The Demands of Psychotherapy

The profession of psychotherapy is a unique one. It requires a specific set of conditions and skills, involving an enormous amount of concentration, thoughtfulness, and reflective ability. The therapist must be "present," that is, the therapist must pay very close attention to what is going on in the room. The therapist must be sensitive to the subtle nuances occurring during the therapy hour. This means listening to what is being said and what is not being said. It means paying attention to one's internal state – emotions, thoughts and sensations. It also means paying attention to external states – any nonverbal movements in the client, as well as the therapist – and thinking about these states on a number of levels. In my mind, it is akin to having a number of computer menus open at any moment in time, with one being in the forefront, while the others are waiting in the background. The therapist must be alert and acutely aware in a way much different from non-therapists, paying attention to the constantly shifting internal and external states of both members of the dyad.

There is a depth of intimacy in the therapeutic relationship that is unknown in most other fields or professions. In psychodynamic psychotherapy, the relationship is a very important factor. What transpires in the "relational space" between the therapist and the client provides the environment in which growth and healing can

take place. To maintain this intimacy requires great concentration and focus of energy as well as a regularity and consistency in face-to-face meetings. The therapist must “be there” each week, with intense concentration and attention. An unseen chronic illness presents a host of problems that challenge these requirements, potentially interfering with the therapist’s ability to stay fully present in the relationship.

The Impact of the Illness

All therapists must maintain attention, reliability and focus, but how is this different for the chronically ill therapist? Do sick therapists have a harder time meeting these demands? Or is their experience the same as that of any other therapists? I have chosen two aspects of being a psychotherapist that are potentially impacted by the therapist’s invisible chronic illness: consistency and focus. Although there are other characteristics that constitute the work of a psychotherapist, these are two categories that are most likely to be impacted by a chronic illness.

Consistency

Consistency, reliability, and regularity of sessions are important tenets of psychotherapy. How can a client develop trust without knowing that the psychotherapist will be there, as promised, on a regular schedule? Knowing that the appointment will be at the same time each week gives the client something important to count on.

One would think that a sick therapist would have difficulty keeping regular appointments. The psychotherapists in my study all experience intrusive symptoms,

both episodic and constant, which hold the potential of interfering with their ability to show up. Yet, surprisingly, my participants rarely, if ever, cancel sessions due to illness. In fact, as a group, they are extraordinarily reliable in their attendance. Those few participants who do cancel pay scrupulous attention to the needs of their clients. They report evaluating the impact of missing a session and only cancel when they feel the client can manage the disruption. My guess is, when a “well therapist” gets sick, she takes a sick day. For the chronically ill therapist, taking a sick day is almost unheard of.

Why does the chronically ill therapist rarely cancel a session? A couple of possibilities emerge from the data. For my participants, not feeling well is the norm, not the exception. As one participant mentioned, if she cancelled every time she felt sick, she would be canceling all the time. What is more, with a chronic illness, there is always the possibility of symptoms becoming worse. The chronically ill therapist must be careful when canceling, always being prepared for the possible development of even more intrusive and serious symptoms, at which time cancellation is a necessity.

Money is another motivation for coming to work when sick. Being self-employed does not leave much financial wiggle room for taking days off or reducing one's caseload when one does not feel well. Although I did not ask my participants specifically about finances, I am aware that many of them are self-supporting. Even those participants who have other sources of income feel some financial pressure to work regularly. Many feel the need to work more hours to pay for their multitude of

medical treatments. So it is realistic to assume that chronically ill therapists must inevitably consider how a sick day will affect their income.

There is another possible explanation for this “devotion to duty.” It might be a form of denial. Having one hundred percent attendance reinforces the belief, real or fantasized, that the therapist really is not that sick. It goes something like this: “If I can go to work each day, with little impact from my illness, then maybe I’m not that sick after all.” Going to work each day helps preserve the therapist’s image of someone who is healthy rather than sick. This topic is a theme that I will elaborate on throughout this chapter.

The data, however, suggest something in addition to money – chronically ill therapists are driven by a strong commitment to the client and a strong desire to be viewed as competent by themselves and by their professional community. I will discuss these two topics in much greater detail later in this chapter.

Focus

The subject of focus and paying attention is a complicated one. Focus is the therapist’s ability to pay attention, closely, on a number of levels, to what the client is presenting. It involves a deep concentration that enhances the therapist’s ability to attune to the client. One would think, with symptoms such as those experienced by my participants, that chronic illness could impair the therapist’s focus. When the participant with migraines is in the middle of a throbbing headache with accompanying nausea, can she really pay attention to what the client is saying? Can the participants with CFIDS be present for their clients when in the throes of fatigue?

It almost seems like a competition – will the symptom or the client get the therapist's attention?

The mental health literature (Dewald, 1990; Lasky, 1990; Wong, 1990; and others) cautions that the sick therapist, because of “self-absorption” and “narcissistic needs” might be unable to pay attention and attune to clients. In fact, like the mental health writers, all of my participants worry that their availability to clients may be impaired, even when they have no logical evidence that they are less “focused” than any other therapist (see section regarding perception of competence). There is nothing to indicate that they are “unfocused” therapists. Is it possible that, because of a fear that they are not performing up to par, as a group, they overcompensate for their perceived lack of focus by trying harder when the illness and symptoms are active? Certainly, the data seem to indicate this. Almost all of the participants talk about pushing themselves. It's possible that even though on occasion their focus might be impaired, they manage to carry it off by trying harder. What the data indicate is rather than being self-absorbed in their symptoms and unable to focus, the therapists in this study are able to step outside of their own physical experience to be available to the client. In an effort to compensate for their supposed lack of focus they simply “try harder.”

Perhaps trying harder serves two functions. Trying harder can be a way for the chronically ill therapist to manage her illness. Like anything that requires intense concentration, one tends to “forget” or leave other problems in the background (see reference to Christy's “adaptive denial” later in this chapter). Several participants reported that focused attunement, that is, concentrating really hard on being present

and being sensitive to the client, is “time off” from their own preoccupation with illness. More likely, trying harder serves two purposes: enhancing the therapist’s ability to work, and helping the therapist to forget her symptoms.

Managing the Illness – Extraordinary Adaptation

Sick therapists do not want their illness to interfere with their clients’ treatment. All aspects of the work – things that are taken for granted by a healthy therapist, such as hours worked, type of clients, continuing education, fees – take on special significance when someone is also managing a chronic illness. In order to keep symptoms from interfering, chronically ill therapists become quite creative. They devise numerous methods and behaviors to manage their symptoms so they can continue working. They figure out ways in which they can have an illness with intrusive symptoms, yet sit in a chair and remain attentive and focused on the relationship.

Such measures as rearranging the work day and screening out more energy-draining clients are common. From deep breathing to splashing water on one’s face to taking notes to what my participants call “energetic monitoring,” chronically ill therapists find various ways to continue doing their job. One dramatic example of “extraordinary adaptation” is demonstrated by the participant with lymphedema. She must wear a full body compression suit to keep down the constant swelling in her body. She must also avoid heat. In order to continue working and not reveal anything obvious that would distract the client, the participant covers up the suit with loose clothing and keeps an air-conditioner going at all times.

So, how does the sick therapist keep symptoms at bay? For me, one of the most interesting adaptations used by my participants is distraction or “healthy denial.” By focusing really hard on the client, the participants can ignore their symptoms. Christy (2001) talks about “adaptive denial” which allowed her to work in spite of her multiple sclerosis diagnosis. She would, as the participants in this study also do, “push aside” feelings and thoughts about being sick, while remaining conscious of having a chronic health problem, essentially “forgetting” rather than “denying” the existence of M.S. The participants in my study, mostly through perseverance and distraction, forget their illness and continue doing their jobs.

In a personal communication from Dr. Juliet Corbin (personal communication, November 7, 2005), she shared her experience of working with Dr. Anselm Strauss, who was quite sick in his later life. She stated that he continued working and having a life, because “you can’t just let the illness take over. Sometimes it has to move over for the person to go on with life. The illness has to accommodate to the person.” This philosophy is common for all the participants in my study. They want to work, they enjoy their work, and in spite of their health problems, they are determined to have a career.

This constant effort raises some interesting concerns. Does pushing oneself compromise the therapist’s health? It just seems like good medicine to take care of oneself when one is sick. It seems that over functioning or minimizing an illness leaves open the possibility of jeopardizing one’s health and causing further complications. Is pushing oneself healthy for the therapist? Does it lead to further

health problems down the road? And, as speculated earlier in this chapter, is pushing oneself an over-compensation for feeling less than adequate?

Charmaz (2000) brings up an interesting point. Individuals with invisible illness, as are the participants in this research, can more easily hang on to the fantasy that they are not really that sick, what Charmaz (1991) calls “passing.” What we do not know is whether or not continuing to work actually enhances health in that it allows the person to have a strong sense of self, a personal sense of meaning, an absence of financial worry, and a feeling of worth in the community, or does continuing to work delay the person’s acceptance that they are really sick, thus contributing to a lack of self care that can potentially make the person sicker? The answers to these questions are not a part of this research, but the data indicate a delicate balance for the chronically ill therapist, wanting to work because of personal satisfaction and figuring out how to do it without getting sicker.

What Motivates the Chronically Ill Therapist

Why does the therapist push herself? Why does she come to work each day, struggle to stay focused, and develop ingenious ways of adapting to symptom-intrusiveness? My research illustrates two main factors that motivate chronically ill therapists to push themselves and strive to do a good job: a strong commitment to the client and a desire to be seen, both by self and others, as a competent professional.

Strong Commitment to the Client

The central theme of my findings is the psychotherapist’s overarching, all-consuming commitment to the client. Putting the client first is a deeply held tradition that permeates the work of psychotherapy. The first sentence in the Social Work

Code of Ethics (National Association of Social Workers, 1999) is “Responsibility to Clients – The primary responsibility of the clinical social worker is to the individual client . . .” In her paper on *The Ethical Attitude in Psychotherapy*, Dr. Claire Allphin (2002), in paraphrasing Jungian analyst Hester Solomon, states that “The ethical attitude implies behavior toward the other that is along the lines of altruism, that is, concern for the other that is not contingent on reciprocity, but rather is selfless behavior toward the other” (p. 1). She draws the parallel between parent and child and therapist and client: “The caregiver’s ethical treatment of the child includes meeting the child’s narcissistic needs” (p. 1). She goes on to warn therapists that “We are also mentors to our patients and need to act wisely” (p. 1). My research shows that even when faced with difficult and challenging physical symptoms, the chronically ill therapist does act “wisely,” motivated by a deep and abiding sense of responsibility to the clients.

My participants are not preoccupied by “self-absorption” or “narcissistic needs” brought on by the illness; this research shows just the opposite. Rather than being self-absorbed in their symptoms and unable to focus, the therapists in this study seem to step outside of their own physical experience to be available to the client. They are able to manage symptoms, even when the symptoms are very intrusive, to do their jobs and to do their jobs competently, driven by a desire to do what is right for the client. Everything pertaining to their work – including how they run their practices, how they “are” in sessions, how they think about clinical issues, whether or not they take a “sick day,” what medical treatment they chose – is evaluated and thought about in terms of the impact on the client.

This commitment to the client brings up the same question I had regarding focusing and “trying harder”: is this intense concern about the client also the therapist’s diversion from her preoccupation with her illness? It seems to me that this commitment, like strong focus, serves two purposes. Therapists do have a strong commitment to their clients, and it helps therapists detach from their preoccupation with their symptoms. It is as if the commitment is the frosting on the cake. It helps the client, and it helps the therapist.

Commitment to the Professional Self

Chronically ill therapists are motivated by a desire to be seen as and to see themselves as competent. Although assessing the illness’s impact on my participants’ self-esteem is not a part of my research, the data do reveal the impact of the illness on their “professional self-esteem.” In fact, my participants’ desire to be viewed as competent professionals is interwoven throughout this entire research. The participants in my study want to be recognized as competent, intact, unimpaired professionals. To a person, all of my participants are willing to work through a lot of pain and suffering in order to maintain this sense of professional identity. Preserving their reputations in the community, as well as their own feelings about their competence, is paramount. As the reader will see in the following section, protecting their status in the community may actually be a stronger driving force than money. Put simply, working regularly is, as Silver (1982) suggests, akin to “occupational therapy”; it makes sick therapists feel whole in spite of having an “un-whole” body.

The therapists in my study have a determination to be good therapists. The struggle between self doubt, worry about competence and the desire to be good

therapists requires that the participants push aside their symptoms – almost like stepping outside of themselves – so they can do their jobs as well as possible. It is conceivable that this push to be competent, in which the chronically ill therapist actually tries harder, ultimately enables the sick therapist to be a competent therapist. In other words, the trying harder overcomes any possible impairment or compromise in the treatment.

Professional Identity – Perception of Competence

This research does not attempt to judge the quality of the therapist's work. Doing so would require interviewing the clients, as well as observing the therapists in action, and, even then, the determination would be somewhat subjective. Judging one's effectiveness as a therapist is problematic for all therapists, because the experience of competency is so subjective. This is true for sick therapists as well as those who are healthy. There is nothing concrete, like a successful surgery or a newly constructed building, to point to that demonstrates good work. Therefore, judging one's work is a vague and hard to define process for therapists. For the sick therapist, this evaluation of self competence is even more complicated. No matter how well one copes, there is always the sense that symptoms are a burden, pulling the attention of the therapist away from her work.

Chronically ill therapists struggle with feelings about competency especially during illness flare-ups. Their professional self-confidence is influenced by the pull between the symptom on one hand and the client's need on the other. As evidenced by the study, the therapists are very concerned about the negative impact of their

illness on the work. They frequently worry that illness is somehow rendering them incompetent.

In my opinion, the participants in my study are all excellent therapists. During the interviews, I got to know them and couldn't help thinking about how they are as therapists. The way in which they talk about their work indicates a high level of competency. They are all experienced and have good reputations in their communities. They are respected by their peers. They all have full, thriving practices. They don't have a history of having clients abruptly quit therapy without an explanation. Several of them are considered to be top therapists in the field. Some are consultants to other therapists and also teach classes. They all have full practices. They are thoughtful when evaluating what they are doing with clients, thinking about things on a variety of levels. They are all warm, sensitive, and caring and are able to emotionally connect.

There is nothing in the data to indicate any serious negative impact on the therapy from the therapist's illness. Even when I asked them directly what the negative impact might be, they gave vague answers such as "not as focused," but could not give any concrete description of how "not as focused" would harm the treatment. Based on what the participants report, there are no obvious harmful consequences from the therapist's chronic illness. In fact, there was a glaring inconsistency in the data. On one hand, even though the participants questioned their competency during symptom flare-ups, many felt that they had their best sessions when they were forced to "let go" and "listen differently"; as one participant puts it, "If one avenue isn't open for you, you just have to find others." So, they question

competency while, at the same time, noticing that other ways of listening and working seem to kick in when they are at their sickest.

One can speculate that the illness has no more or no less impact than any other major event in the life of the therapist. In fact, there are many events in the life of the therapist, such as acute illness and sudden accident or death that could have a much greater impact than that of a chronic illness. My data show nothing to indicate that illness has impaired their ability to work.

Yet, even when there is some problem in the therapy, it is common for my participants to first assume that it is related to their illnesses rather than considering other possibilities like countertransference issues or other therapeutic disruptions. The illness has become a default position for evaluating their work. Being such a powerful presence in the therapist, illness becomes the convenient scapegoat for judging problems in one's work. For example, countertransference issues that could be stalling the therapy might be hard to notice when illness and resulting symptoms loom so large. Indeed, intrusive pain and suffering could influence one's capability, but it is not the only factor affecting one's work. Rather than a "bad" therapy session being caused by something like a countertransference issue or a personal problem not related to illness, chronically ill therapists are at risk of blaming everything on the illness.

There is a strange dynamic going on here. From my observations and from objective criteria, such as full caseloads, respect from others, etc., these therapists seem more than competent. Nevertheless, they all question their competence. They all, some less than others, mention varying degrees of concern about their ability to

stay focused, pay attention, or be present when symptomatic. Even those participants who have very little self-doubt, when in the throes of a flare-up, wonder whether or not they are being a “good enough” therapist. The conclusion that I am drawing is that chronic illness does not affect competence, but it does affect the therapist’s confidence.

Shame – A Taboo Subject

When thinking about doing this research, one aspect that particularly interested me was shame. According to the chronic illness experts (Charmaz, 1983, 1991, 1995, 1999, 2000, 2002; Kleinman, 1980, 1988; Scrambler, 1984; and others), shame and stigma are an integral part of the illness experience. I suspected, since therapists are frequently idealized, that is, they are often seen as almost omnipotent both by clients and the collective, that my participants would be carrying some shame about being in some way impaired. Therapists are expected to be strong and healthy, not weak and frail. I also wondered about what Guggenbuhl-Craig (1988) calls the “illness as punishment” mentality, in which the sick person, because of an “unbalanced psychological development” (p. 143), is somehow or another somaticizing a psychological issue. Since therapists are supposed to be so psychologically evolved, we should be immune to any possible psychosomatic illness. In falling short of this idealized image, I suspected that sick therapists would feel some embarrassment and shame about being chronically ill.

The data in this research, however, at least on the surface, seem to contradict this notion. I anticipated shame to be a prime concern for my participants, however, when asked directly “Do you have any shame about having a chronic illness,” most of

my participants said “No.” They do not feel shame about having a chronic illness. Yet, in spite of their strongly held conviction, many of them behave in ways that suggest the contrary.

Several of the participants go to great lengths to hide their illnesses from others. Some participants literally cover up any outward signs of ill health with clothing or make-up. Some were concerned about inclusion in this research, questioning me at length about confidentiality, requesting that I disguise their identities to avoid any possible recognition. Only two participants talked openly about feelings of embarrassment and shame, and they were the exceptions in my study. In general, my participants deny feeling shame about being chronically ill; yet they make every effort to hide their illness.

If they do not feel ashamed of being sick, as the chronic illness literature puts forth, then why are they so concerned about keeping the illness a secret? What does this discrepancy mean? I can only speculate. Shame is a difficult and complicated process. As one of my participants stated, “Well, I’ve found that actually just, just the topic of shame is shameful.”

One explanation is that my participants, in spite of their illnesses, are fully engaged in life. They may have a shaky confidence, but they are competent working professionals. Perhaps shame just does not come into it for them, because they are not functioning as less than others. The shame aspect may be neutralized by maintaining a professional life and an image of competence. In other words, working is an antidote to shame.

Perhaps shame is something that must be dealt with on a case-by-case basis and is not easily cast in generalizations. Some people tend to feel more shame, while others do not. It is also possible, since my participants are therapists, and all have had their own individual therapy, that, as a group, they have “worked through” shame, or at least have a level of insight about their own tendency to feel or not feel shame. Although there may be some truth to these explanations, such hypotheses disregard the chronic illness literature, in which there is a convincing argument that shame is a part of the chronic illness experience, and ignore the efforts my participants go to in order to hide their illness.

Denial of shame can be a central coping strategy for the chronically ill therapist. For the participants in my study, being in a state of shame while trying to work, trying to be self-supporting, trying to be available to clients, may just be too much to handle. It is like Christy’s (2001) “adaptive denial.” There is simply no point in living in a constant state of shame. In order to work, the sick therapist needs all her energy and being absorbed in shame is just too energy-draining.

I believe that shame is present with my participants but in a unique form. My participants do not personally feel ashamed about being sick, but they are aware of the general negative judgment about ill health. Shame is present, but it is articulated indirectly through fear of what people will think, of client’s reactions, and a fear of disapproval. They have a fear of being shamed by the rest of the world.

The psychotherapist in private practice is in a financially vulnerable position, relying on her reputation among colleagues and the community for referrals. The danger that comes with having a secret that could potentially affect referrals and

reputation is of concern to any therapist. Chronically ill therapists may not personally carry judgments about being sick but they have an understanding that others might. Their very reputations and livelihood are at stake. Therapists depend on their colleagues for referrals. If they are viewed, in their professional community, as less than capable by virtue of an illness, they run the risk of losing their referral sources.

I was invited to speak about my research topic at Community Institute for Psychotherapy (CIP) in Marin. Several people in the audience expressed concerns about making referrals to a “sick therapist,” wanting some guarantee that the therapist had “worked through” her illness issues. By “working through,” what the audience meant was that the sick therapist did not have any unresolved emotional problems related to being sick that might interfere with her work. No one wants to refer to a therapist who is in any kind of compromised situation that might negatively impact the therapy. Judging from the audience at CIP, many in our community automatically think that chronically ill therapists are in a “compromised situation,” so absorbed in their illnesses that they are too distracted to adequately do their job, even though the data in this research suggest otherwise.

When thinking about this topic, I asked a colleague who has a chronic illness how he thought about shame. Like the participants in my study, he said he felt no shame about having a chronic health problem. But when I asked him if he minded colleagues knowing, he emphatically did not want colleagues to know about his health problems. His concern being that his referral sources would be like the audience at the CIP lecture, overly concerned about his competence and, thus, not wanting to make referrals. Like it or not, there are concerns in the community about

sick therapists. So the participants in my study have good reason for keeping their illness a secret, and it goes beyond simple shame: it is based on preserving their reputations in the community.

I have been discussing shame as it relates to one's status in the community. But what about one's internal experience of shame? This more internally-directed shame dove-tails with the chronically ill therapist's sense of professional competence. Many of my participants talked about feeling guilty because of a perceived feeling that they were, on their sickest days, letting their clients down by not performing up to a certain standard. Other participants expressed guilt at refusing to work with "harder" clients, experiencing a tension between a desire to help people, on the one hand, and, on the other hand, a desire to help themselves.

Disclosure – Revealing the Secret

Whether or not to disclose their illness is a complicated issue for the participants in my study. On the surface, it appears that they view illness-disclosure like any other disclosure – thinking about it in terms of how it will benefit or affect the client's treatment. Some participants are more conservative and cautious about disclosing, and others are much more open. These dissimilarities are a product of differences in theoretical stance, experience, and personal style.

But when the self-disclosure is so personal in nature as it is with an illness, the consequences become more complex. The chronically ill therapist, before disclosing her illness, must consider a number of concerns. Dr. Whitney van Nouhuys, in her dissertation on *The Use of Transferences From Everyday Life in Psychoanalytic Psychotherapy: Exploring The Concept of The Extra-Therapeutic Transference*

(2005), talks about how therapists, in order to understand the client's deeper meaning, listen on several levels at once. This multi-level approach certainly applies when the therapist is considering disclosing to a client something as personal as an illness.

Many questions arise: How will the client respond to this information? Will the client worry or become afraid for the therapist? Will the disclosure activate caregiving behaviors in the client, or will it force the client to withdraw? Will the client, in an attempt to protect the therapist, withhold more intense feelings in the therapy?

Disclosing illness material might raise the specter of fear about the therapist's general competence and ability to continue working. What about clients who are themselves ill, how will they respond? How will clients handle their own illness concerns in light of the therapist's illness? The chronically ill therapist is aware of these questions and must take them into consideration before revealing the illness.

What about inadvertent disclosure? No matter how hard the therapist tries to keep the illness a secret, there is always the possibility of accidental disclosure. For many of the participants, their illness did eventually become visible, because of the intrusiveness of a previously hidden symptom. What surprises me is the lengths to which some sick therapists will go to in order to avoid inadvertent disclosure. The drive to appear whole and normal is very powerful. As was revealed in the Findings chapter, chronically ill therapists use various methods to disguise the symptoms, such as staying totally still in their chairs when they are sick, and putting on cover-up make-up, not betraying their true condition. It is clear that my participants prefer being the ones in control of the disclosure, rather than accidentally revealing the illness.

One aspect of this topic that especially interests me is whether or not the illness is in some way or another communicated unconsciously or non-verbally to clients and referral sources. Personally, I do not disclose my health problems to clients, nor is it general knowledge in the professional community that I have chronic health issues. Yet, for some reason, a large proportion of my practice consists of clients with chronic illness. Is illness, somehow, revealed to clients and referral sources, perhaps through subtle changes in the behavior of the sick therapist?

Friedman (1991), in writing about her experience with cancer, wonders if we can keep any kind of secret, especially an illness, “such a palpable reality in the therapist’s life” (p. 407), from our clients. Contrary to my own experience, when I asked my participants about this topic, none felt that they had that many sick clients, and most of my participants felt that clients don’t notice anything different about them. A few more relationally-oriented therapists speculated that their more attuned clients might know.

On this topic, I disagree with my participants and agree with Renik (1995) who feels that we can only have a “pretense of anonymity” (p. 476) with our clients. Certainly, many clients are too self-absorbed to notice anything different about their therapists. Yet, I think it is safe to say that many clients sense subtle changes in their therapists – particularly those with whom the therapist has a longer, more intimate relationship and those who, in general, are more attuned, and also, those clients who might have a special sensitivity around abandonment threats. The client may choose not to say anything about what they notice, yet they might privately speculate or fanaticize about the changes. The more attuned therapists might notice or hear

something that clues them into these speculations or fantasies. I think more experienced therapists might be more attuned to these subtle cues regarding whether or not the client is picking up on the illness. It's a complicated topic and not entirely fleshed out in my research. What I can confidently say is the chronically ill therapists in my research thought seriously about any disclosure of their illness, inadvertent or deliberate, considering, always, the impact on the client.

There is another aspect of the self-disclosure discussion. Several of my participants talk about not disclosing as a way of protecting the client from undo worry. Clients might get anxious if they knew of their therapists' health conditions. However, there's another way of thinking about this protection. One wonders if the therapists are also protecting themselves. In minimizing or avoiding a disclosure, not only is the client spared from what might be an anxiety-producing truth, but also the therapist is protected from having to feel the discomfort of watching the client's reaction and of having to admit out loud that she has an illness, and all the feelings that can come with it. It is a two-way street.

The Illness Narrative – Breaking the Isolation

In her dissertation on schizophrenia, Dr. Priscilla Fleischer (2004), borrowing from Kleinman, discusses the healing power of the illness narrative for the participants in her study. I do not know whether or not the telling of their stories was healing for my participants, but I do know the telling of their stories was important to them.

At the beginning of my interviews, I invited each participant to tell me her illness story, expecting that this would take a minute or two, consisting of a few facts

and comments. In reality, the “Illness Story” became the bulk of the interviews. All ten participants eagerly told their stories, in minute detail, starting in almost all cases with the onset of the illness. Efforts on my part to shorten the story and to move on to my probe questions were futile. These therapists were determined to tell their stories in detail, and I had no choice but to stop interfering and to listen.

One of my participants was actually having an intrusive symptom during the interview – that of atrial fibrillation. There was no outward indication that she was having an episode. She looked and acted completely normal until she blurted out, “Umm, I think I have it right now actually.” She continued with the interview as if nothing was going on.

All the participants looked healthy. In fact, many looked quite strong, healthy, and robust. The contrast between how they looked and the contents of their stories was shocking. One participant sums it up: “You know, ironically, um, during the time in the, that I was most acutely ill with the chronic fatigue, I looked blooming. I looked immensely, powerfully well.” It is a reminder of how deceiving an invisible illness can be. The only participant whose appearance revealed any possible physical frailty was a participant who had recently been on a special treatment diet. She looked unusually thin but did not look ill.

Each participant told about the onset of their disease, remembering in great detail when, where, and how the symptoms began. They could describe in detail the first symptoms, how it felt, what it was like, as well as the progression of the symptoms. They chronicled their medical treatment history from onset to present. Many had what I would call a “snapshot in time” – a memory that demonstrated the

texture, mood, and sensations of their illness – illustrating the power of the illness's entrance into their lives. One participant poignantly remembers that the symptom started on her birthday. Another recalls what was happening the week-end she got sick. It was not uncommon for participants to remember the exact date that they got sick.

Even though all the participants have family and close friends with whom they share about their illness, all the participants seemed particularly eager and pleased to be able to tell their story to me. Nine participants enthusiastically thanked me for giving them the opportunity to tell their stories. Three called me after the interview to thank me again and to talk about the impact of the interview on them. They described a sense of relief at being able to tell a story that so defined how they think about themselves. Two participants revealed that they had never before told anyone their complete story, not even their health care providers. One told me later that telling her story reminded her about how hard it is to struggle with a chronic illness, and she resumed her own therapy.

What is the significance of this eagerness to talk? It could mean, as Dr. Juliet Corbin suggests (personal communication, November 7, 2005) that participants in any study are eager to talk because they get to talk about themselves and something that is of interest to them. What's different, I suspect, between therapists and any other research participants is that therapists, by virtue of working in isolation, are more likely to crave the opportunity to share their own personal experience. Chronic illness is notoriously isolating. But so is the practice of psychotherapy, even for the healthy therapist. We work in our offices, behind closed doors, rarely speaking to

anyone throughout the day except our clients. For the chronically ill therapist, there is the added reluctance to discuss health with colleagues for fear of judgment that might lead to a lack of referrals. The isolation of chronic illness, in general, and the isolation of private practice, combine to form what one participant called “the hiddenness of the enormous loneliness.”

My participants have invisible illnesses. Charmaz (2000) reminds us that individuals with invisible illnesses experience an even greater sense of isolation, longing for and needing empathic acknowledgement, yet not getting it because of the invisibility of the illness. The very fact that my participants all have unseen illnesses contributes to the general secrecy about their conditions. The participants can easily hide their true condition or problem and, because of its invisibility, make isolation even worse. As Charmaz (2000) suggests, with invisible illness, the sick person pays a high price. They are essentially living a lie (“I am sick even though I’ve fooled you into thinking that I’m well”) and the price is a greater sense of isolation. Since several participants mentioned isolation, I believe that my research lends credence to the argument that the chronically ill therapist who does not feel comfortable revealing the illness to others, suffers, not only from the illness, but also from isolation and loneliness. It is my belief that my participants, who are isolated in their illnesses, were eager to talk because they have so few safe opportunities in which to tell their illness stories.

Discussion of the Findings With Respect to the Literature

In order to better understand the illness experience, I began my literature review by looking closely at the chronic illness literature, which is primarily in the

field of sociology and medical anthropology. Bury (1982); Charmaz (1983, 1991, 1995, 1999, 2000, 2003); Corbin (2003); Kleinman (1980; 1988); Radley (1999); and Yoshida (1993) all shed light on the illness experience; how the illness that never goes away influences and shapes the sick person. Scrambler and Goffman make major contributions to the subject of shame and stigma in the illness context. All of these writers have contributed to my understanding of the illness experience; in particular, the works of Kleinman (1980, 1988); Charmaz (1983, 1991, 1995, 1999, 2000, 2003); and Goffman (1963) are especially relevant. I will review the salient points of this literature and then compare and contrast them to my findings. I will also compare and contrast my findings to the mental health literature on the chronically ill therapist.

The Illness Context

The writings of Dr. Arthur Kleinman (1980, 1988) provide the conceptual foundation for the chronic illness literature, as well as this research. According to Kleinman, a chronic illness is more than just the disease name. It permeates the person's entire life – including her career. Kleinman believes that chronic illness is culturally influenced and cannot be fully understood without first examining the culture in which the sick person lives. In this research, following Kleinman's theoretical perspective based on empirical research, I have attempted to understand the experience of chronically ill therapists as they straddle the two contextual worlds of psychotherapy and chronic illness. For the therapists in this study, understanding their illness experience can best be achieved by looking at it through the lens of their

work. My participants must negotiate their illness symptoms, not in a vacuum, but, as Kleinman would hypothesize, surrounded by the demands of their work.

The Chronic Illness Literature and the Effect on Sense of Self

The works of Charmaz (1993, 1991, 1995, 1999, 2000, 2002), Corbin (2003), Bury (1982), Radley (1999), and Yohsida (1993) have influenced how I proceeded with this research. All speculate about the chronic illness's eroding impact on the sick person's personal sense of worth – in other words, the ways in which the illness alters how the person thinks about herself. A chronic illness can eat away at the sick person's morale, self-esteem and sense of self. Although looking at the illness's impact on the therapist's personal sense of self was beyond the purview of this research, I did examine how the illness influenced my participants' professional identities, and my findings replicate what the above authors state. To put it briefly, ill therapists, because of the intrusive nature of their illness, have difficulty maintaining a belief in their own competence.

Sickness Identity

Charmaz (1991) lists three illness categories – interruption, intrusion, immersion. I limited my research to those therapists who fit her “intrusion” category. Individuals in the “intrusion” category frequently are able to continue working, especially on “good days” when symptoms are less intrusive. Just as Charmaz outlines, my participants are aware that their illness is not temporary, that it requires almost daily attention, and that it needs much accommodation. During the stage of “intrusion,” on what Charmaz calls “bad days,” the illness begins to impact the

individual's sense of selfhood. The sick person begins to ask, "Who am I now that I have a chronic illness?" "Am I no longer a healthy person?" "Am I now a sick person?" There is a sense of apprehension. Charmaz (1991) describes the connection between a "good day" and the sense of self as follows: "Definitions of a good day derive from a sense of being in character, being the self one recognizes and acknowledges. On a good day, ill people have more opportunity to be the selves they wish to be" (p. 51).

Charmaz theorizes that, on "bad days," the "self" is no longer one that the individual recognizes. In other words, they don't feel like themselves. They don't know who the new self is or what the new self is capable of doing. This corresponds to what my participants report about their perceived sense of competency on days when they are the sickest. They begin to mistrust their abilities and to lose faith in their professional confidence. For chronically ill therapists, there is a palpable tension between "good days," when symptoms are absent or minimal, and "bad days," in which they question whether or not they are doing a good enough job.

Shame and the Chronically Ill Therapist

Shame, in terms of illness, is written about at length in the sociology and medical anthropology fields, but is rarely addressed in the psychology literature on illness. Goffman (1963) calls shame "a spoiled identity," the internal feeling state that comes either from something external, for example, stigmatization, or it can develop out of an inner feeling of badness. Scrambler (1984) makes a distinction between "enacted stigma," actual episodes of stigmatization, and "felt stigma," internalized shame.

In my study, participants have what I call an “occupational shame.” They are concerned about their reputations in the community (where “enacted stigma” may occur). They possess a fear that colleagues might see them as less than capable, ultimately, ceasing to refer to them. The participants have not necessarily internalized a feeling of “badness,” as is the case with “felt stigma.” Rather, they carry more of a worry about their own competence and abilities as professionals. In other words, they do not feel inferior about being sick, per se. Instead, they carry two factors that are cause for concern: how they feel about any possible negative effect on their professional abilities and how they will be perceived by their peers.

It is hard maintaining a strong professional identity while being chronically ill. Both Scrambler (1984) and Goffman (1963) talk about the impact of illness stigma on self-esteem. Sick people are viewed as “less than” by a society that idealizes good health. Over time, this process can challenge someone’s self-esteem including one’s professional self-esteem. Although personally denying feelings of shame, the chronically ill therapists in my research struggle with feelings of self-doubt and incompetence, thus, illustrating the impact of illness on their professional self-esteem.

Mental Health Literature and the Chronically Ill Therapist

What is missing from the mental health literature is a real understanding about the therapist’s personal illness experience – how the therapist feels, psychologically, about the experience; i.e., what is it like for the psychotherapist to live with a chronic illness, what Shuman (1996) calls “the felt truth of the patient’s experience” (p. 8). Strean (2002) puts it this way, “Missing from the analytic literature are clinical illustrations of how an analyst’s mourning a loss, suffering a financial hardship, a

dispute with a mate or colleagues has influenced his or her therapeutic technique” (p. 570).

What the mental health literature emphasizes are treatment issues, the effect on the patient and the patient’s reactions to the psychotherapist’s illness, rather than looking at the therapist’s experience. While these mental health authors mention a number of psychological issues that are relevant to illness – for example, loss, denial, fear, worry – the emphasis is less on the therapist’s subjectivity and more on what Durban, Lazar and Ofer (1993) call “technical matters”: the patient’s reactions to the therapist’s illness and how, technically, to deal with these reactions in the course of the treatment.

Unlike my participants, who talk openly about their experience, there is little mention in the literature of the effect on professional confidence or how sick therapists feel about themselves as professionals. The main themes of this research – that sick therapists are motivated by the dual commitment to clients and to self – are absent in the literature.

The mental health literature under represents concern about the sick therapist’s reputation. Grunebaum (1993) and Counselman and Alonso (1993) touch on the worry about loss of referrals. Kreichman (1984) and Morrison (1997) allude to it. Two issues of greatest importance for the participants in my study are how they are viewed in the community and their own personal view of their professional competence. Neither topic is elaborated on in the mental health literature. Although Wong (1990) mentions feeling incompetent, the distinction between the sick therapist’s perceived competence versus professional confidence is not mentioned.

The Self-Absorbed Sick Therapist – “On Narcissism”

Many mental health writers (Abend, 1990; Dewald, 1990; Halpert, 1982; Lasky, 1990; Schwartz, 1987; Wong, 1990; and others) suggest that sick therapists are too self-absorbed, going so far as to question whether or not they should even be working. Freud, in his essay “On Narcissism” (1914), underlines this theme, stating that the sick person “gives up his interest in the things of the external world, in so far as they do not concern his suffering” (p. 82). (It is interesting that Freud continued working during the 17 years in which he suffered from disfiguring oral cancer.) Rather than giving “interest in the things of the external world,” my findings show the exact opposite for the participants in this study, who are driven by a strong sense of commitment to the client and step outside of their symptoms in order to continue doing their job.

Gaining From the Experience

Elliott (1996), Durban, Lazar and Ofer (1993), Friedman (1991) and Morrison (1990) all write about how their illness struggles actually helped their skills as therapists. Elliott states, “I believe that the constant reminder of my illness kept me flexible and open to her [*speaking about a client*] pain and humiliation” (p. 28). Morrison and Durban, Lazar and Ofer stress their increased attunement and empathy.

My participants echo this theme, with many of them being profoundly changed by the illness experience. They report heightened attunement and empathy, an increased ability to accept adversity and the ability to accept what is. They also reported sensitivity to illness problems in their clients.

Above all, the chronically ill therapist understands the notion of “no cure,” a notion not mentioned in the mental health literature. One participant stated it as follows: “It teaches you to be more human . . . ‘cause that’s really all we have, I think, as humans. We’re all mortal, we’re all gonna die. You know, we all get sicker as we get older . . . [and] there is no such thing as cure.”

Courage

Although I have not mentioned it by name previously in this research, without a doubt, my participants have courage. Hearing the participants’ stories, I was deeply impressed by their remarkable strength and resiliency. My participants continued working in spite of some seriously intrusive and debilitating symptoms. Focusing on therapists’ courage is almost never mentioned in the mental health literature. Only two writers (Grunebaum, 1993 and Sollad, 2002) commented on the bravery and downright guts of the sick therapist. Sollad mentions courage as something he gained from his life-threatening illness (end stage renal disease). Grunebaum reports being moved by the stories of “adversity and courage” (p. 22) of the therapists that he interviewed. Neither writer elaborates further on what they mean by courage or how they think about it in terms of chronic illness. As my findings bear out, the participants in this study showed incredible courage in straddling the two worlds of chronic illness and psychotherapy, being driven by a strong dedication to their work.

Disclosure and the Literature

There were no major note-worthy differences between my findings and those of the sociology, medical anthropology, and mental health literature on illness and

disclosure. Certainly, Charmaz's (1991) "protective and spontaneous" disclosure and "strategic announcing" are all aspects of my participants' thinking about self-disclosure. Barbara Pizer's (1997) three types of self-disclosure, "inescapable" "inadvertent," and "deliberate," are also evident with my participants. Participants whose illnesses sometimes became visible had to deal with inescapable and deliberate disclosure, having to decide when and how much to tell clients. The mental health literature (Christy, 2001; Elliott, 1996; Jacobs, 1999; Pollak, 2000; Philip, 1993; Streat, 2002) advocates a careful, cautionary position in which the therapist uses her clinical judgment when thinking about self-disclosure. This is also evident with my participants.

Limitations of Study

There are several limitations to this research. I limited my study to those chronic illnesses that are not life-threatening. Without a doubt, a life-threatening or terminal illness represents a different set of concerns for the therapist. I also did not include illnesses where there is already a major stigma, such as HIV and mental illness. I did not look at visible illness, because I believe those illnesses also portray a different assortment of themes for the therapist. For example, disclosure is a different issue when the visible illness is right out there as part of the baseline contract between client and therapist. I limited my population group to those therapists who fit in Charmaz's (1991) "intrusion" category, rather than those who are no longer able to work. Lastly, my study is limited to the therapist's perspective rather than that of clients.

Explanations or hypotheses that are generated by this study must be accepted or rejected on the basis of conjecture and subjective interpretation of the data. These explanations may not be generalized as representative of all therapists with chronic invisible illness.

Directions for Future Research

This is an exploratory study of the chronically ill therapist. It brings up many other questions for further study. One major limitation of this study is the absence of clients' perspective on the therapist's illness and the actual impact, if any, on therapy sessions. What about the whole question of whether or not clients "know" about their therapists' invisible illness? How do clients feel and think about their therapists' illness? And importantly, do clients feel that there is some negative impact on their treatment caused by the therapists' illness?

Although I'm not sure how research could be accomplished, given the constraints of confidentiality requirements, I am curious about client's thoughts on this subject. Do any of the fears and concerns about clients' reactions to therapists' illness actually exist? Do clients feel protective? Do they hold back? Do they experience their sick therapist as less focused, less present? This would make an interesting topic for study.

Another question that arises from this research is what really is the attitude in the psychotherapy community about illness in the therapist? I think it would be interesting to do a survey addressing therapists' thoughts about their sick colleagues, something I wish I had done as part of this research.

APPENDIX A: RECRUITMENT LETTER

Dear Colleague:

I am currently involved in the dissertation phase of the doctoral program at The Sanville Institute, Berkeley, CA. I want to interview psychotherapists in private practice who have a chronic, unseen physical illness and I am writing to you as a part of my recruitment effort, asking if you know anyone who fits these criteria and who would be interested in participating.

My study will examine the subjective experience of therapists with chronic, invisible health problems. Specifically, I will be looking at how the therapist copes with having a chronic illness, how the therapist thinks about the illness in terms of his/her work and how the illness has impacted his/her professional life. I am particularly interested in how the therapist thinks about the invisibility of the illness in terms of his/her work as a psychotherapist. There has been very little empirical research about illness in the therapist. In the professional journals, several authors have written about illness in the therapist, but these articles are limited to acute, life-threatening illnesses, rather than chronic illness. Almost nothing has been written about illnesses that are invisible.

I will be conducting one, possibly two, tape-recorded 60-90 minute interviews with participants. The place and time will be arranged for the convenience of the participant.

If you know someone who meets these criteria and who is available and willing to participate in this research project, I can be contacted by phone (707-762-9398) or by email (irisjune1@aol.com; please put "Research" in the subject box). I will then contact the person about potential participation in this research.

Please feel free to call me at the above telephone number if you have any questions. Thank you in advance for your cooperation and participation.

Sincerely,

Cheryl Jern, LCSW, MFT
Doctoral Candidate, The Sanville Institute

APPENDIX B: RECRUITMENT AD

Cheryl Jern, LCSW, MFT
7 Fourth Street, Suite 13
Petaluma, CA 94952
(707) 762-9398

Ads to be submitted to professional newsletters:

1. SEEKING PARTICIPANTS FOR RESEARCH STUDY. I am seeking psychotherapists in private practice who have a chronic unseen physical illness. The research study will involve a 60-90 minute interview. If you are interested, or would like more information, please contact me: Cheryl Jern, LCSW, MFT, doctoral candidate at The Sanville Institute. (707) 762-9398, or irisjune1@aol.com (please put "Research" in the Subject Box).

2. SEEKING RESEARCH SUBJECTS: therapists in private practice who have a chronic unseen physical illness.
1 hour interview, Cheryl Jern (707) 762-9398.

APPENDIX C: ACCEPTANCE LETTER

Dear:

Thank you for your interest in participating in my doctoral research.

My study will examine the subjective experience of therapists with chronic, invisible physical illness. Specifically, I will be looking at how the therapist copes with having a chronic illness, how the therapist thinks about the illness in terms of his/her work and how the illness has impacted his/her professional life. I am particularly interested in how the therapist thinks about the invisibility of the illness in terms of his/her work as a psychotherapist. There has been very little empirical research about illness in the therapist. In the professional journals, several authors have written about illness in the therapist, but these articles are limited to acute, life-threatening illnesses, rather than chronic illness. Almost nothing has been written about illnesses that are invisible.

Illness is ubiquitous. Over 90 million Americans have chronic illnesses and, as the population ages, these numbers are increasing. We can assume, therefore, that, just as chronic illness is increasing in the general population, it is also increasing among psychotherapists. When the sick person is a psychotherapist, a whole set of unique challenges emerge. This research will examine these issues from the perspective of the therapist.

I will conduct one, possibly two, 60-90 minute audiotaped interviews. The time, location and length of the interview will be at your convenience. Interviews will be transcribed and coded to determine the central themes of this topic. All interviews will be confidential.

Please take a few minutes to review the enclosed Informed Consent Form (to be signed at the time of the interview) and to fill out the brief screening questionnaire? You may return them both to me in the enclosed pre-addressed stamped envelope. Upon receipt of your materials, if you meet the criteria for this research project, I will call you to set up an appointment.

Thank you for your participation.

Sincerely,

Cheryl Jern, LCSW, MFT
Doctorial Candidate, The Sanville Institute

APPENDIX D: SCREENING FORM

If you are interested and would be willing to participate in this research project, please complete this questionnaire and return it to me in the enclosed pre-addressed, stamped envelope.

NAME: _____ AGE: _____

ADDRESS: _____

TELEPHONE:(Days) _____ (Evening) _____

EMAIL: _____

DEGREE: _____ LICENSURE: _____

ARE YOU IN PRIVATE
PRACTICE?: _____

WHERE DO YOU
PRACTICE?: _____

THEORETICAL
ORIENTATION: _____

WHAT IS YOUR CHRONIC, PHYSICAL
ILLNESS?: _____

IS YOUR ILLNESS INVISIBLE TO MOST
PEOPLE?: _____

HOW LONG HAVE YOU BEEN
SICK?: _____

HOW DOES YOUR ILLNESS AFFECT YOUR DAILY
FUNCTIONING?: _____

DO YOU THINK YOUR CHRONIC ILLNESS INFLUENCES YOUR
WORK?: _____

IF SO, BRIEFLY STATE
HOW?: _____

ARE THERE ANY OTHER VARIABLES THAT MIGHT INFLUENCE YOUR
PARTICIPATION IN THIS RESEARCH PROJECT (i.e. serious psychological
disorder, family problems, drug/alcohol abuse, etc.)?: _____

Thank you so much for your cooperation.

APPENDIX E: INFORMED CONSENT FORM

Cheryl Jern, LCSW, MFT
 # 7 Fourth Street, Suite 13
 Petaluma, CA 94952
 (707) 762-9398

THE SANVILLE INSTITUTE

INFORMED CONSENT

I _____ hereby
 willingly consent to participate in An Exploratory Study of the Subjective Experience
 of the Psychotherapist with a Chronic, Unseen Illness, a research project to be
 conducted by Cheryl Jern, LCSW, MFT, under the direction of Sylvia Sussman,
 Ph.D., Principal Investigator and research faculty member, and Judith Schore, Ph.D.,
 faculty member and Dean of Students at The Sanville Institute.

I understand the procedure to be as follows:

- 1) One, possibly two, 60-90 minute audiotaped interview(s) will occur in a private, confidential setting to be arranged between myself and the researcher. I will be talking about my thoughts and feelings as a psychotherapist with a chronic, invisible illness. I am aware that some of these audiotapes will be sent to an outside transcribing service, and that the researcher will make every effort to avoid saying my name or other identifying information on the audiotape. I am aware that the audiotape will have an identifying number rather than my name.
- 2) I am aware that talking about my illness may cause some emotional discomfort. Should this happen during the interview, I understand that I may terminate the interview at my discretion. Should I experience discomfort after the interview I understand that I may contact the researcher who will make provisions for me to receive professional help for a reasonable and limited time.
- 3) I understand that I may withdraw from this study at any time. I also understand that this study may be published and that my anonymity will be protected unless I give written consent to such disclosure. Otherwise, no names or individual identifying information will be used in any oral or written materials. The audiotape will be erased at the completion of data analysis.
- 4) I understand that I have the option to receive feedback from the results of the study. Please send me a summary of the results at the address below.
 Yes _____ No _____

Signature: _____

Date: _____

Address: _____

Witness: _____

If you wish to receive a copy of the results of this study, please provide your name and address:

Name _____

Address _____

APPENDIX F: INTERVIEW GUIDE

INTERVIEW GUIDE

“First, I would like to thank you for participating in my research. The interview, which I will audiotape, will last approximately 60-90 minutes. If you want, we can take a break at any time, and if need be, we can schedule a second appointment to complete the interview. During this time, I will invite you to tell me the story of your illness and to talk about how your illness has impacted who you are as a psychotherapist. As you have no doubt experienced, being a psychotherapist with a chronic health problem presents a number of unique challenges and problems, and I hope, during this interview, you will feel free to talk openly about your experience.”

Illness Narrative

Probe Questions:

- 1) Could you talk about how it was for you when you first got sick?
- 2) What is your diagnosis?
- 3) What was your experience with the health care system?
- 4) Could you talk about your medical treatment?
- 5) How did the illness initially impact your life?
- 6) How has it been for your family?
- 7) How has your life changed since you've been sick?
- 8) How has the illness changed your sense of your self?
- 9) What's the hardest part about being sick?
- 10) How do you feel about having a chronic illness?

11) What about shame, depression, denial and envy?

Coping With a Chronic Unseen Illness

- 1) Talk about the ways in which you've had to accommodate for the illness.
 - a. Medical treatment
 - b. Rest and diet
 - c. Limitations
- 2) What sorts of difficulties do you encounter in your daily life that are caused by your illness?

Impact on Your Work

- 1) In what ways has your illness impacted your work?
- 2) Do you think your illness has changed the way you work?
- 3) Are you able to work on days when your symptoms are more present?
- 4) How do you cope with the intrusiveness of your symptoms?
- 5) Do your colleagues know about your illness?
- 6) Has the illness affected your sense of competency?

Unique Issues of the Unseen Illness

- 1) What are your thoughts about the invisibility of your illness in regard to your work?
- 2) Do you tell clients and/or colleagues about your illness? If not, why, and if so, why?

Conclusion

- 1) Finally, are there any areas of this subject that I have not covered

that you think are important and that you would like to add?

- 2) Do you have any final thoughts on the question or anything to say about the experience of the interview?

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