

Chapter 2

Listening to Voices: Patient Experience and the Meanings of Mental Illness

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Abbreviation

DSM Diagnostic and Statistical Manual of Mental Disorders

One of the most important missions and mandates of sociology has been to “give voice” to those who have been forgotten, made socially invisible, or otherwise marginalized. Sociologists have always been ideologically prone to “take the side of the underdog” (Becker, 1967). As well, Peter Berger (1963) has remarked that an “unrespectability” motif characterizes much sociological work since the stories and experiences of those who are dispossessed and disenfranchised are as conceptually important as the accounts of those inhabiting society’s mainstream sectors. Indeed, early American sociology, beginning with the “Chicago School” (see Fine, 1995), was devoted to documenting a wide array of relatively invisible urban worlds including those of hoboes (Anderson, 1923), professional thieves (Sutherland, 1937), gang members (Thrasher, 1927), immigrants (Thomas & Znaniecki, 1918), and slum dwellers (Zorbaugh, 1929).

Similarly, anthropology teaches us that the meanings persons give to their lives arise from their immediate social contexts. Of particular interest for this review are those anthropological efforts demonstrating that the meanings attached to mental illnesses, and the culturally expected responses to them, vary dramatically from society to society (Kleinman, 1980, 1988a; Kleinman & Good, 1985). This work effectively shows that such presumably common-sense notions as deviance, mental disorder, mental illness, and insanity are largely social constructions (Berger & Luckmann, 1967).

The sociological analogue to an anthropological perspective is found in those theoretical approaches to social life that focus on basic questions of meaning making: “How do human beings impose order, coherence, and intelligibility onto their lives? How do we go about the business—the eminently social business—of making sense of our life situations? How do people understand complicated life circumstances and how are their behaviors, emotions, and attitudes linked to such interpretive processes? How are our interpretations of objects, events, and situations connected to our social locations?” While such fundamental questions are properly linked to phenomenological (Schutz, 1962), postmodern

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(Collins, 1990; Smith, 1987) and feminist (Devault, 1999; Reinharz, 1992) theories and methods, they are at the very core of “symbolic interaction theory” (see Prus, 1996; Stone & Farberman, 1970).

Although early “pragmatists” such as George Herbert Mead (1934) and Charles Horton Cooley (1964) provided the conceptual infrastructure for a distinctive sociological social psychology, the sociologist Herbert Blumer articulated the essential assumptions of symbolic interaction theory. In his book entitled *Symbolic Interaction: Perspective and Method* (Blumer 1969), Blumer suggests that this distinctive theory rests on three principles: (1) No objects, events, or situations carry intrinsic meanings; (2) Meaning creation is a collaborative venture, the product of interaction in particular settings; and (3) Meanings are constantly in a state of transformation. Blumer then outlines the research requirements presumed by these premises when he says that “...Since action is forged by the actor out of what he perceives, interprets, and judges, one would have to...perceive objects as the actor perceives them, ascertain the meaning of objects, events, and situations in terms of the meaning they have for the actor.... In short, one would have to take the role of the actor and see the world from his standpoint” (Blumer, 1969, p. 68). Methodologically, this means observing, whenever possible, the lived worlds of those we study and listening attentively to their stories.

Despite the seemingly obvious assertion that studying the construction of meanings is absolutely central to understanding human experience (and, in turn, our emotions, attitudes, and behaviors), such an approach is too often slighted, especially among those who imagine themselves to be following the precepts of “science.” The idea that social life is an evolving human construction appears inhospitable to the goal of documenting firm and unchanging empirical “realities.” Collecting and recounting narratives may be seen as an interesting exercise that yields a measure of insight. However, for those committed to a positivistic vision of science, a primary goal of research is to gather statistical data from large samples of individuals in order to establish fundamental causal connections among variables. While the tendency to slight the narratives of individuals is clear in the study of all aspects of social life, such an omission is perhaps most awkwardly and inappropriately evident in the efforts to learn about the experience of mental illness.

While we maintain that all social experiences require interpretation and meaning making, some life circumstances are profoundly and deeply problematic. These situations demand especially arduous interpretive efforts by those trying to make them coherent and sensible. Certainly serious illnesses of all kinds—perhaps mental illnesses in particular—are among life’s most perplexing situations. Yet, medicine, committed to seeing illness only in biological terms, largely neglects patient accounts. The psychiatrist and anthropologist Arthur Kleinman has written extensively about the importance, yet relative neglect, of patients’ stories. In his book entitled *The Illness Narratives* (Kleinman 1988b), Kleinman eloquently argues the importance of privileging the lived expertise of patients. He remarks (1988b, p. xiii) that

Nothing so concentrates experience and clarifies the central conditions of living as serious illness.... Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms [and] interpret complaints in the particular context of our life situation....

At the same time, the sociologist Arthur Frank (1995, p. 25) observes that

The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message.... These voices bespeak conditions...that most of us would rather forget our vulnerability to. Listening is hard, but it is also a fundamentally moral act.... [I]n listening for the other, we listen for ourselves. The moment of witness to the story crystallizes a mutuality of need, when each is *for* the other (italics in the original).

The difficulty of listening is compounded in the case of the mentally ill since stories told in the middle of an illness episode are often chaotic and seemingly indecipherable. Moreover, stereotypes about the mentally ill and the stigma attached to their conditions lead persons, doctors certainly included, to believe that patients are simply incapable of providing meaningful versions of their experiences (Hornstein, 2009).

One shortcoming of many mental illness studies is that we tend to hear the voices of experts (physicians, psychologists, nurses, social workers, academics) while the voices of those with mental illness are all too often excluded. Drowned out in the process is what it actually feels like to have a mental illness. Hearing one's "official" diagnosis for the first time, learning to cope with illness, disclosing to significant others or colleagues, taking psychiatric medications, and assessing psychiatric experts are major hurdles in the lives of persons with mental illness, and yet we do not hear enough about the ways in which they make meaning around these challenges. While we certainly need statistical analyses describing epidemiological patterns, causal models, and correlations, such studies need to be complemented by those conveying the extraordinarily difficult experience of living with a mental illness. Studies of feeling disorders that do not attend to the feelings involved are, at the least, incomplete.

We must note that the earlier writings of Michel Foucault (1973), Erving Goffman (1961), Thomas Scheff (1966), Thomas Szasz (1961), and Ronald Laing (1967), among others, provided the basis for a robust antipsychiatry movement during the 1960s and 1970s. Their writings collectively questioned the very existence of mental illness and, thus, the "medical model" as the only approach to helping persons with "problems in living." This writing remains vibrantly influential for those who would accord as much value to the experiential expertise of patients as to the professional expertise of mental health practitioners. Indeed, there has been something of a renaissance in qualitative research since the early 1980s and a corresponding uptick in the number of studies focused on mental patient narratives (see, e.g., Estroff, Lachicotte, Illingworth, & Johnston, 1991; Karp, 1996, 2006; Schreiber, 2001; Smardon, 2008; Weinberg, 2005). Still, such studies represent a relatively small fraction of inquiries into mental illness.

Perhaps the most conceptually revealing studies of being mentally ill are those in which researchers enter directly into the lived worlds of those persons. Such studies attend to the voices of afflicted persons while documenting first-hand the ways they daily negotiate their illnesses within particular cultural contexts. One such work, properly considered a classic, is Sue Estroff's (1981) *Making it Crazy: An Ethnography of Psychiatric Clients in an American Community*. Estroff, trained as an anthropologist, wanted to learn how chronically ill patients released from psychiatric hospitals during the period of "deinstitutionalization" adapted in a community residential treatment program.

As suggested by the book's title, her close observations revealed that many patient adaptations in the face of institutional rules and restrictions (e.g., the obligation to take powerful medications, the need to rely financially on government programs, placement in "protected" workshops) had the unintended consequence of affirming their identities as "crazy." More recently, the sociologist Darrin Weinberg (2005) used similar methods to study two ideologically different treatment programs for addiction and insanity. Both Estroff's and Weinberg's studies demonstrate that conceiving of insanity as either human constructions or independent illness realities is a false dichotomy. Rather, these qualitative studies based on "thick description" (Geertz, 1973) illustrate that mental illness is both an independent reality and a social product.

This introduction is meant to suggest that a static picture of "having" mental illness does violence to the complexity of an ongoing, emergent experience. We need to be committed to methodological and theoretical approaches that satisfactorily convey the moving, processual, and context-bound nature of any illness experience. Research committed to systematically gathering, carefully organizing, and then re-telling stories is the approach best suited to capturing the diverse and nuanced processes associated with mental illness. Thus, our argument for the necessity of giving voice to the mentally ill is premised on the idea that such illnesses emerge over time and take on multiple shades of meaning depending upon the particular social circumstances of individuals.

The Triumph of Biological Psychiatry and the Denial of Patient Expertise

While there have been relatively recent efforts to foster the development of “narrative based medicine” (see Roberts, 2000), such efforts appear to have had little effect in the field of psychiatry. Indeed, the persistent movement of psychiatry since the early 1980s has disproportionately emphasized symptoms over stories. If we believe that a renewed emphasis on narrative would promote more effective healing by legitimating the expertise of the mentally ill, we must first understand the historical processes that have undermined patients’ voices. There is wide agreement among observers of psychiatry’s evolution (e.g., Caplan, 1995; Healy, 1997, 2002; Horwitz & Wakefield, 2007; Luhrmann, 2000; Valenstein, 1998) that concerns about the scientific status of psychiatric medicine has relentlessly propelled the field toward biologically reductionist explanations of emotional problems.

Beginning with the “birth of the asylum” in the seventeenth century, “insane” persons were thought to be like brutish animals that needed to be tamed and controlled. Things improved somewhat in the early 1800s once doctors became the sole arbiters of the treatment of the mentally ill. Still, the mentally ill were subject to dreadfully inhumane “cures” based on alleged scientific advancement (Whitaker, 2002). The early twentieth century saw the emergence of psychotherapy and the consequent “triumph of the therapeutic state” (Rieff, 1966). Of course, Sigmund Freud’s psychoanalytic theory became the basis for psychodynamic approaches in psychiatry. Paradoxically, the treatment of mental disorders until the early 1980s was based on carefully parsing patients’ histories and personal accounts. A major turning point in the history of psychiatry was the discovery of major tranquilizers during the 1950s. By the early 1980s, the paradigm in psychiatry had shifted from “disorders of the mind” to “diseases of the brain” (Luhrmann, 2000).

When one looks at the numbers, the implications of this extraordinary paradigm shift become readily apparent. In the four editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM), psychiatric experts have “discovered” an astonishing number of new brain diseases (see Kirk & Kutchins, 1992). While the classification system of the first two versions of the manual closely followed the logic of psychoanalytic thinking popular at the time, the 1980s saw a radical disappearance of such language. *Diseases of the brain* abruptly replaced intrapsychic conflicts. The numbers tell a dramatic story. In 1953, the DSM named 60 psychiatric disorders. In 1969, the number of diagnostic categories had doubled to 120. In 1987, over 200 diagnostic categories were listed. The current DSM describes over 350 diagnoses. The newest version of the DSM to be published in 2013 promises yet again an increase in the number of diagnostic categories.

We are hard-pressed to see a nearly fivefold increase in the number of psychiatric abnormalities since 1953 as simply the product of dispassionate scientific inquiry. The transition from disorder to disease and the proliferation of such diseases is equally likely a function of cultural, economic, and political processes. In fact, the sharpest critics (Breggin, 1991; Glenmullen, 2005; Healy, 2002) of psychiatry’s current stance maintain that, except for a few major psychotic illnesses, there is no evidence that the hundreds of conditions listed as brain diseases in the DSM warrant that designation. Diagnostic disagreements (Brown, 1987) and the extremely tenuous connections among symptoms, diagnoses, treatments, and therapeutic outcomes significantly undermine the validity of the disease model in psychiatry. Thomas Szasz (2001, p. 25) puts it this way:

Asserting that a particular person’s problem is a disease because the patient or others *believe* it is a disease, or because it looks like a disease, or because doctors *diagnose* it as a disease, and treat it with drugs as if it *were* a disease, or because it *entitles the subject to be qualified as disabled*, or because it *presents an economic burden to the subject’s family or society* – all that is irrelevant to the scientific concept of disease (Italics in the original).

According to Horwitz and Wakefield (2007), the enthusiastic embrace of biological explanations was a response to the chaotic condition of psychiatry at the time. Prior to 1980, critics doggedly

attacked psychiatry as a “pseudoscience,” perhaps due to the widespread disagreements between different theoretical perspectives and the confusion arising out of radically conflicting research studies. The profession became eager in this environment to institute a “theory neutral” set of diagnostic criteria for disorders such as depression and thus establish itself as a scientific enterprise. Doing so would both ensure greater consensus among practitioners and enable more consistent epidemiological research on mental disorders. Psychiatrists wanted to convince themselves and others that troubled individuals need their chemical interventions just as badly as someone with diabetes needs insulin. Such a bid for medical legitimacy bears a synergistic relationship with the interests of pharmaceutical companies that make billions of dollars selling psychotropic medications (Angell, 2005). In something of an unholy alliance, the American Psychiatric Association “creates” diseases that, in turn, provide pharmaceutical companies the opportunity to invent new and profitable drugs. Finally, prompted by direct-to-consumer advertising, increasing numbers of patients seek the help of psychiatrists, thus securing the field’s professional status.

The claim has been repeatedly made that difficulties such as clinical depression are the result of deficits of certain neurotransmitters in the brain. For example, drugs like Prozac, Zoloft, and Celexa are thought to ameliorate depression by increasing levels of serotonin in the brain. Despite such repeated claims about serotonin deficiencies, this hypothesis has never been verified. Indeed, there is mounting evidence (Kirsch, 2010) that the latest “wonder” drugs are only marginally more effectiveness than placebos. Despite a range of conceptual and scientific misgivings, contemporary psychiatry remains firmly committed to a “medical model” of psychiatric diseases. The result of such a biologically deterministic model of human pain has been the nearly total muting of patients’ perspectives, accounts, and interpretations of their suffering.

The consequences of psychiatry’s full embrace of biological explanations for mental illness cannot be understated. The virtually hegemonic power of psychiatry to define the line between the normal pains of living and pathological disease has greatly expanded the number of people deemed sick and in need of treatment (Horwitz & Wakefield, 2007). We might now legitimately ask the moral and political question, “Who owns and controls human feelings, thoughts, and behaviors?” In addition, the pervasiveness of psychiatry’s biological narrative about the causes of human suffering has greatly deflected attention away from the structural sources of human distress. We now rarely ask whether so-called mental illnesses might often be a normal response to pathological social structures. Biologically deterministic explanations of suffering also create a sense of helplessness among patients who see themselves, after all, as victims of broken brains. In the words of the medical historian David Healy (2002, p. 355), there has been an evolutionary movement “from a theocracy through democracy to a sanitocracy.” Consequently, we now consider how listening to patients’ voices has potentially critical implications for their medical and political liberation.

The Politics of Listening

Those who study mental illness can draw many important insights from other theoretical perspectives for understanding marginalization, especially postmodern feminist theory, critical race theory, and critical disability theory. Each of these theoretical paradigms developed as a critical response to early ideas spawned by the political movements that fought, respectively, for women’s rights, civil rights, and the rights of persons with disabilities. Each has critical insights about the experience of marginalization that can be applied to the study of mental illness (or following Michel Foucault, “madness studies”).

Critical race theorists Lani Guinier and Gerald Torres (2002) expand on the idea of “the miner’s canary.” They argue, in a book of the same title, that like the canary whose distress call alerts miners to impending danger, frustrations expressed by subjugated racial minorities are indicators that something

is wrong with the functioning of American democracy. Therefore, it is crucial that “we,” whether members of racial minorities or the majority, listen to the canary’s distress call. To do so is relevant not only for the potential amelioration of the plight of the canary but for all of society:

Those who are racially marginalized are like the miner’s canary: their distress is the first sign of danger that threatens us all. It is easy enough to think that when we sacrifice this canary, the only harm is to communities of color. Yet others ignore problems that converge around racial minorities at their own peril, for these problems are symptoms warning us that we are all at risk.... The metaphor of the miner’s canary captures the association between those who are left out and social justice deficiencies in the larger community.... One might say that the canary is diagnostic, signaling the need for more systemic critique.... These pathologies are not located in the canary. Indeed, we reject the incrementalist approach that locates complex social and political problems in the individual. Such an approach would solve the problems of the mines by outfitting the canary with a tiny gas mask to withstand the toxic atmosphere (Guinier & Torres, 2002, pp. 11–12).

Similarly, we maintain that the voices of the mentally ill are equivalent to the miner’s canary. Their stories are alerting us to the fact that something is wrong with psychiatry’s overreliance on a biological model of suffering. As such, it behooves us to listen well to their voices as indicators of both the suffering of individuals and of a social structure that amplifies and sometimes even produces such suffering. In other words, it is not enough to listen with the aim of reducing individual pain. We must also listen if we hope to improve the system’s ability to respond to human suffering more generally. Psychiatry’s systemic, if unwitting, preference for attending to biological, biochemical, medical, or even genetic factors over subjective experience has harmful ramifications, given that meaning making is at the heart of subjective experience.

Sociologists of mental illness concerned with the subjective experiences of the mentally ill can glean significant lessons from the collective social critique of people who have been marginalized on the basis of gender, race and ethnicity, and disability. After all, diverse experiences of marginalization generate critical insights that would be familiar to anyone marginalized because of mental illness. Central to our discussion here is each group’s common emphasis on the political significance of storytelling. In each case, the narratives of the oppressed, subjugated, marginalized, or otherwise voiceless have spawned social movements devoted to the fight for the rights of women, people of color, and persons with disabilities. Storytelling has been foundational to the development of the “class consciousness” that gave rise to each of these movements.

The feminist insight that the “personal is political” meant that groups of women sharing life stories are not merely commiserating. Conversation is a form of “consciousness-raising” and, thus, itself constitutes political action. Over time, individual stories of struggle collectively formed a larger structural narrative of the struggle of women as a class. It was not long, of course, before women of color challenged this master narrative, for it spoke only to the experiences of privileged white women and resulted in the further marginalization of nonwhite or even less privileged white women. Standpoint theory (Collins, 1990; Haraway, 1988; Harding, 1991; Hartsock, 1983; Smith, 1987) was one strand of feminist thought that incorporated multiple groups and, thus, bears particular relevance for those interested in the sociology of mental illness.

Early on, those theorists identified with standpoint theory (Harding, 1991; Smith, 1987) argued that knowledge retrieved through scientific methodology and abstract, rational thought is not the only valid form of knowledge. Equally valid is the knowledge derived from one’s subjective experience of the world, which itself is determined by where one stands in relation to those in power. Each “standpoint” or perspective necessarily comes from a particular social position that both enables and limits one’s vision on the world. Donna Haraway’s (1988) notion of “situated knowledges” extended this assertion by positing that knowledge is always *embodied* (generated from and enabled by our specifically situated selves) and *partial* (incapable of grasping the totality of reality). For Haraway, to claim neutral and complete “objectivity”—a “vision from everywhere and nowhere” at once—is a kind of “god trick,” a pretense made possible by a privileged relationship to power that protects the interests of those whom such “objectivity” serves: typically, white Western males.

In a related vein, Patricia Hill Collins (1990) advocated that sociology should welcome “outsiders within” because of the distinctive standpoint they bring to existing sociological paradigms. Black women were, for Collins, a prime example of “outsiders within.” Unlike white women, they have been doubly marginalized by both their gender and their race and, therefore, embody an awareness of the interlocking nature of systems of oppression. White women did not then recognize that although they were oppressed in one dimension (gender), they were oppressors in another (race). In this way, the privilege of white women prevented them from fully appreciating the complexity of their own relationship to power. Black women, on the other hand, could “produce distinctive oppositional knowledges that embrace multiplicity yet remain cognizant of power” (Collins, 1998, p. 8). Collins’ notion of the interlocking nature of various systems of oppression (what she has called the “matrix of domination”) recognizes that all systems of oppression, whether based on race, class, gender, sexuality, religion, age, disability, or mental health status, work in conjunction with and depend on one another, ultimately forming a single system of domination and power. Being oppressed along multiple dimensions cannot be understood using a simple additive model.

Feminist theorists such as Haraway and Collins have articulated a truth with enduring relevance for those who wish to understand the subjective experiences of the mentally ill. Namely, when persons do not live up to unspoken cultural norms, they can view their subjective experiences as a situated knowledge that provides a window on self-interested systems of power and privilege. Audre Lorde (1980, p. 203) spoke of this perception of always standing beyond the normal:

Somewhere on the edge of all our consciousness there is what I call the mythical norm, which each of us knows within our hearts is “not me.” In this society, that norm is usually defined as white, thin, male, young, heterosexual, Christian, and financially secure. It is within this norm that the trappings of power reside. Those of us who stand outside that power, for any reason, often identify one way in which we are different, and we assume that to be the primary reason for all oppression, forgetting other distortions around difference some of which we ourselves may be practicing.... There is a pretense to a homogeneity of experience...that does not in fact exist.

Lorde argues that individuals need to embrace their differences and outsider status to realize the inherent creativity and critical insight they make possible. For the mentally ill, mental health is another dimension along which one can stand outside the mythical norm, and yet it is this very status as an outsider that gives the mentally ill a valuable perspective on the otherwise invisible norms propelling their marginalization.

Those who study mental illness can equally draw lessons from critical race theory (Bell, 1992; Crenshaw, 1995; Delgado, 1996; Gotanda, 1995; Harris, 1995; Lawrence, 1993; Matsuda, Lawrence, Delgado, & Crenshaw, 1993; Williams, 1991), offering powerful insights based on experiences of racial marginalization. Critical race theorists, like feminist theorists, emphasize the subversive power of stories due to the inherent connection between the personal and political, underscoring the fact that the dominant cultural narratives are invariably the narratives of those in power. The seeming normativity of these narratives only works to mask their hegemonic nature. Thus, a central method of political resistance and consciousness-raising in critical race theory is the act of “counter-storytelling.”

Critical race theorists use counter-storytelling as a tool for challenging and disrupting racial dominance. Such stories both create meaning and also debunk myths that work to sustain the dominance of the white race (e.g., see Patricia Williams, 1991). According to Solórzano and Yosso (2002, p. 26), counter-storytelling is a “method of telling the stories of those people whose experiences are not often told.” The dominant stories being countered serve to maintain the privilege of whites, men, the middle and upper classes, heterosexuals, and we would add, those free of mental illness. By defining these locations in the social structure as normative, dominant narratives implicitly label all who fall outside the norm as deviant, flawed, wrong, inferior, or sick. As critical race theorists often point out, however, dominant narratives do not only maintain the privilege of those in power but also, function to discredit and silence the voices of those who are subjugated, dominated, or oppressed. In a similar fashion, we argue that the voices of the mentally ill are discredited and silenced by dominant cultural narratives that presume mental health as the unspoken norm, defining all other mental states as deviant, deficient, and even dangerous.

The field of disability studies provides yet another theoretical perspective that offers critical insights on the experience of being mentally ill. In fact, some disability scholars have argued that mental illness should be included under the broader umbrella of disability studies. Like feminist theory and critical race theory, critical disability theory views the act of storytelling as a fundamentally political act. “Shame and fear are personal burdens, but if these tales are told, we can demonstrate how the personal is indeed the political” (Linton, 1998, p. 167). As long as disabilities are treated as pathologies, deficits, individual afflictions, and personal tragedies, the social, cultural, economic, and political factors sustaining such harmful definitions will remain invisible and unchallenged.

Many in the field have argued that disability is the “effect of an environment hostile to some bodies and not to others, requiring advances in social justice rather than medicine” (Siebers, 2001, p. 173). Indeed, the systemic marginalization of persons with disabilities closely parallels and works in conjunction with other forms of oppression based on human differences. Feminist disability theorist Rosemarie Garland-Thomson (2006, p. 260) analyzes which bodies in particular pose the greatest threat to society and concludes that most despised of all are those bodily forms and functions that “call into question our cultural fantasy of the body as a neutral, compliant instrument of some transcendent will.” Those deemed mentally ill are often guilty of the same crime: their mental status belies the illusory nature of this transcendent will.

Just as feminist, critical race, and disability theorists encourage women, people of color, and persons with disabilities to lift the veil of shame, to speak out, and to share their stories, we suggest that the distressing stories of persons with mental illness are a powerful signal that the mine is in danger. To be sure, a growing “psychiatric survivor movement” has been fueled by the creation of self-help forums for telling consciousness raising stories that challenge dominant psychiatric discourses (Cresswell, 2005; Hornstein, 2009). Sociologists of mental illness need to listen well to these distress calls not merely for the sake of the mentally ill but for the sake of us all. As such, in the following section, we will consider a few selected memoirs of those struggling with mental illness as representative of such distress calls. Memoirists tell us what it is like to try carving out viable identities in the shadow of the lingering societal stigma of mental illness.

In Their Own Words

Memoirs are a useful starting point for sociologists interested in the subjective experiences of the mentally ill. By definition, memoirists talk about living with mental illness in their own words. While memoirs are clearly windows only onto the lives of individual writers and are not intended to speak for an entire group, they offer sociologists clues about patterns of experience that merit broader, more systematic sociological inquiry. Consider, for example, how four widely known memoirs can sensitize us to important interconnections among mental illness, stigma, and self.

In Kate Millet’s (1990) *The Loony-Bin Trip*, a memoir that critically examines her experience of being institutionalized for bipolar disorder, she poignantly describes the marginalizing effects of institutionalization and the ways in which societal stigma, despite one’s strenuous efforts at resistance, can be internalized and damage one’s identity.

Outside, you will have a record, be a declared lunatic. Inside, this hardly bothers you.... Once outside... it begins to wear you down—snarling quarrels with your little circle of intimates about whether or not you were crazy.... A total stranger can destroy you by asking how you are—she heard you’d had a breakdown—and then it is all there about your ears again.... [Y]ou are branded. It is in you, implacably growing like a cancer, the more sure and strong because the few persons you try to describe it to fail completely to understand or even to be interested beyond their shock and disapproval at your attitude toward a place of healing. Their embarrassment becomes your shame. And your deliverance from the hell you lived through so heroically is not cause for rejoicing and congratulations but a stigma you will carry all your life. (p. 94–95).

Here, Millet speaks of stigma as a kind of “branding” that the mentally ill can never wash away, echoing Goffman’s (1963, p. 3) notion of stigma as that which is “deeply discrediting” and which reduces the person “from a whole and usual person to a tainted, discounted one.” Millet’s stigma, although arguably invisible, is nevertheless ever-present among her “circle of intimates,” given their knowledge of her history and even among those “strangers” who have “heard” about that history. Perhaps more importantly, as Millet points out, “it is in you, implacably growing like a cancer.” Even Kate Millet, as radically resistant to societal norms as she is, has internalized the stigma.

Once she has internalized the stigma and incorporated it into her identity, the mentally ill individual may feel the compulsion to try to capitalize on the relative invisibility of mental illness. In other words, she may attempt to “pass” as “normal” among others. Yet, this deception can cause tremendous distress. Further still, if she is not convinced by her own performance, she may loathe both the self trying to pass and the “mad” self she wishes to deny. Marya Hornbacher (2008, p. 162) writes of this dilemma in her book, *Madness: A Bipolar Life*:

Sometimes, I get the uneasy feeling that I’m fooling everyone. In the middle of a gathering of friends, at a party, at a show, on a walk... I’ll remember the past. It leaves me a little shaken, bewildered by how I’ve gotten from there to here. I feel it in the pit of my stomach, the shame of it, the feeling that I am getting away with something, living a life I don’t deserve. It’s someone else’s life. I’ve snuck in and am squatting in it. I’m wearing someone else’s wedding ring, occupying someone else’s house, and everyone loves the woman I’m pretending to be, not me. Who would love me? I hate the person I was. She disgusts me, her and her mess and her madness, her garish excess, her disorderly excuse for a life. She was a monster. She was sick. Suddenly I feel her in me, like bile in my throat. I can’t let her out. The spell will break, and she will take over again. I want to forget her. I want her dead.

This deep sense of shame effectively splits Hornbacher in two: the Marya “pretending” and the “sick” Marya whose “madness” she is hiding. As a result, she is haunted by a palpable sense that she is dissociated from reality. This unreality in turn inevitably drives a wedge between Hornbacher and those around her, further amplifying the socially isolating effects of mental illness. In another passage, Hornbacher suggests that as much as one may try to pass, the illness will often “out itself” anyway. The stigma will become known:

I am gripped with terror. I cannot go. I cannot go to this party. They will see me and laugh at me. My lipstick is crooked. My dress is not right. I am not well, and they will know it. They will see it (pp. 111–112).

In this passage, Hornbacher is literally crouched in a closet. The allusion is clear: she wants to hide her marginalized status as mentally ill for fear of the social stigma but is terrorized by the thought that she will fail to remain invisible. Again, the dialectic between self and society creates, in effect, two individuals: the ill person and the person observing or judging the ill person. This second witness takes on the perspective of others, or in Mead’s terms, “the generalized other,” society itself.

William Styron (1990) writes of this duality of self in his memoir on chronic depression, *Darkness Visible: A Memoir of Madness*.

A phenomenon that a number of people have noted while in deep depression is the sense of being accompanied by a second self—a wraithlike observer who, not sharing the dementia of his double, is able to watch with dispassionate curiosity as his companion struggles against the oncoming disaster, or decides to embrace it. There is a theatrical quality about all this, and during the next several days, as I went about stolidly preparing for extinction, I couldn’t shake off a sense of melodrama—a melodrama in which I, the victim-to-be of self-murder, was both the solitary actor and lone member of the audience (pp. 64–65).

It may have been Styron’s “second self” that, in the end, prevented his suicide. Suddenly flooded with memories of joy and life, he said, “All of this was more than I could ever abandon.... I could [not] inflict [suicide] on those memories, and those, so close to me, with whom those memories are bound” (p. 67). Taking the perspective of the other, arguably the job of that second self, ultimately preserved his first self.

Finally, in *Undercurrents: A Life Beneath the Surface*, a memoir that documents her experience with severe depression, Martha Manning (1994) also writes about two selves. In her case, however, Manning is struggling to reconcile her past, pre-illness self with her future, post-illness self.

One year ago today I ... was released from the hospital. I have struggled greatly over this year with the shame of the depression, the hospital, the ECT. I've seen them as concrete signs of giving up, falling apart, getting an "F" in life. Being hospitalized on a psychiatric unit was... like crossing over into a different state. I've lost citizenship in the old place, but I haven't totally settled into the new one either

My criterion for healing has been to be able to pick up right where I left off, like midpage in a novel.... I'm still not back to that page. Kay and Lew [daughter and husband] try to tell me, in their own gentle ways, to stop waiting. I think they're trying to tell me that I'm never going to get back to that page. That I'm in an entirely new book now, most of it unwritten. (p. 185–186).

There is in Manning's words a sense that she is in limbo—she is no longer who she was, but not yet sure of whom she will become. This liminality is uncomfortable. Distress at being “betwixt and between” two places may, however, be the catalyst that fosters one's transition to a new identity.

In this section, we offered a glimpse into the subjective experiences of the mentally ill—in their own words—to examine in particular how stigma has affected their sense of identity. Although small in number, our examples illustrate that memoirs embody a rich source of data on the subjective experiences of people with mental illness. They offer a valuable way for us to listen directly to the voices of suffering individuals. However, the memoir is by definition written from the perspective of a single person. Therefore, memoirs are methodologically problematic from a scientific perspective since they cannot represent more than one voice at a time. Sociologists, in contrast, provide the methodological rigor lacking in memoirs by systematically collecting data from strategically chosen populations. They are thereby able to discern broader patterns that may not be evident in single cases. In the following section, we show how sociological research conceptually extends the individual stories told in memoirs. In particular, we illustrate how qualitative research on mental illness attends to multiple experiences in order to uncover regularities in the ways that illness careers and identities emerge over time.

Unwelcome Careers

Social scientists systematically attending to the subjective experiences of mental illness have documented stories about hospitalization (Goffman, 1961), homelessness (Snow & Anderson, 1993), the stigma attached to mental illness (Dinos, Stevens, Serfaty, Weich, & King, 2004; Goffman, 1963; Moses, 2010; Wahl, 1999; Wright, Wright, Perry, & Foote-Ardah, 2007), the use of psychotropic medications (Smardon, 2008), life in half-way houses (Winerip, 1994), the impact of gender on personal experience (Jack, 1991; Schreiber, 1996, 2001), managing illness disclosure in work settings (Owens, 2009), and the meanings of recovery (Borg & Davidson, 2008; Howard, 2006). These seemingly diverse studies inevitably speak, directly or implicitly, to the changing identities of those pronounced mentally ill. In this section, therefore, we want to provide a more in-depth treatment of the way that illness and identity intersect. To do this, we have chosen to offer a brief overview of David Karp's qualitative research accomplished over more than two decades. Since Karp, one of the authors of this review, elects to tell parts of his own personal and research story—a story of how depression identities predictably emerge and evolve as part of a generic “mental illness career”—he should now speak directly to the reader.

Diagnosed with depression in my early 30s, I have been grappling for more than 30 years with the meanings and consequences of emotional illness. Since I am an ardent believer in C. Wright Mills' (1959) injunction that social scientists should “translate private troubles into public issues,” I began to explore the possibility of writing a book on depression in the late 1980s. As indicated earlier in this

review, I quickly learned that nearly all of the existing studies were survey research efforts linking the prevalence of depression to an enormous array of variables. In this respect, the starting point for my first book on depression, *Speaking of Sadness*, was to provide a forum for the unheard voices of the depressed. I also had the hope that by listening to others' narratives I might gain greater insight into my own life difficulties.

More and more, sociologists are utilizing their own life experiences to reflect on larger social processes. An entire field of sociological practice, "auto ethnography," maintains there is value in scholars sharing their own sociologically informed autobiographical narratives to contribute critical insights to the discipline (see, e.g., Bochner & Ellis, 2002). Consistent with postmodern sensibilities, I decided to tell parts of my own story at the beginning of *Speaking of Sadness*. It seemed to me that this was the most truthful way to approach the research. "When we discuss others," after all, "we are always talking about ourselves" (Krieger, 1991, p. 4). To give the readers an honest sense of any preconceptions that may have influenced my interpretations of the interviews at the core of the book, it was only fair that I describe my own experiences. *Speaking of Sadness*, published in 1996, begins this way:

In greater or lesser degree I have grappled with depression for almost 20 years. I suppose that even as a child my experience of life was as much characterized by anxiety as by joy and pleasure. As I look back on it, there were lots of tip-offs that things weren't right. I find it difficult to remember much of my early years, but throughout high school and college I felt uncertain of myself, feared that I could not accomplish what was expected of me, and had plenty of sleepless nights.... During all those years, though, I had no real baseline for evaluating the "normalcy" of my feelings.... Even though I was muddling along emotionally, probably like having a constant low-grade fever, I was achieving well enough in school to presume that underneath it all I was okay. It wasn't until my early thirties that I was forced to conclude that something was "really wrong" with me.

People who have lived with depression can often vividly remember the situations that caused them to have a new consciousness as a troubled person. One such occasion for me was a 1974 professional meeting of sociologists in Montreal.... During the week in Montreal I got virtually no sleep. It's true I was staying in a strange city and in a borrowed apartment. But I had done a fair amount of travelling and never had sleeping difficulties quite as bad. Then, I thought, "Maybe I'm physically ill. It must be the flu." But again, it was unlike any flu I'd ever had. I wasn't just tired and achy. Each sleepless night my head was filled with disturbing ruminations and during the day I felt a sense of intolerable grief as though someone close to me had died. I was agitated and sensed a melancholy qualitatively different from anything in the past.... It truly was a miserable week and the start of what I now know was an extended episode of depression. It was also the beginning of a long pilgrimage to figure out what was wrong with me, what to name it, what to do about it, and how to live with it. It has been a bewildering, frustrating, often deeply painful journey. (pp. 3-4)

The ongoing reflection on my own illness path reminded me how confusing and opaque my depression journey had been to that point. It took years before I could/would attach the word depression to my feelings. People do not typically wake up one morning and tell themselves, "I'm a person suffering from a disease called depression. Therefore, I better get myself to a psycho-pharmacologist who will give me an antidepressant to correct a serotonin imbalance in my brain." As eventually confirmed by my interviews, depression often remains for many years a pain without a name.

By the end of the study, I heard dozens of comments like these: "During my sophomore year in high school, when I'd wake up depressed and drag myself to school.... I didn't know what it was. I just knew that I had an awful time getting out of bed and...a hard time, you know, getting myself to school.... I kind of just had the feeling that something wasn't right." Another person said, "...I really can't pinpoint the moment [when I was aware that I was depressed].... It was just something that I felt I was living with or had to live through...." The more I thought about the social dimensions of mental illness and heard comments like these, the more persuaded I became that, apart from my personal stake in the matter, the subject would allow me to illuminate an important question, namely, "How does an illness identity come into being and then evolve?"

To be sure, every chapter in *Speaking of Sadness* deals with the dialectic of self and society, thereby demonstrating that a full understanding of depression depends as much on cultural chemistry as it does on brain chemistry. A paradox of depression is that sufferers yearn for social connection even as they withdraw from others. Depression is an illness of isolation. Feeling the urge to be alone when

interaction becomes increasingly arduous, individuals retreat from social life. Such a choice provides short-term gains, but ultimately withdrawal only deepens the anguish of depression. Here again there was impressive regularity in the stories I heard. A female graduate student explained the dynamic: “It’s a real catch-22 because you feel bad and you feel that if you see your friends you’re going to make them feel bad too.... So then you just want to stay by yourself, but if you stay by yourself it just gets worse and worse and worse.” “Thus, when the pain of human association leads to withdrawal and isolation, the self loses its social foundation, begins to wither, and in that process to social world comes to appear even more alien. It is in depression’s vicious feedback loop—the downward spiral of hopelessness, withdrawal, the erosion of self, the still more powerful feelings of hopelessness, the even greater impulse to withdraw, and so on—that we witness, in its most negative form, the dialectic of self and society” (pp. 27–28).

Seeing a pattern in the early interviews for the book, I began to focus on the idea that my respondents were following a distinctive illness “career.” My emphasis on the career concept was clearly influenced by sociologists like Everett Hughes (1958) and Howard Becker (1963) who applied the notion of career to such diverse groups as medical students and marijuana smokers, respectively. We most commonly associate “career” with professionals such as doctors, lawyers, and teachers, but a sociological perspective sees prisoners, lovers, criminals, and patients following career paths as well. I argued that one’s “depression career” triggers new identities similar to the new identities spawned by each stage of more “conventional” career paths. As such, I saw my analysis as operating at the intersection of illness careers and identities. Comments of the following sort bolstered this choice:

You know, I was a mental patient. That was my identity.... Depression is very private. Then all of a sudden it becomes public and I was a mental patient.... It’s no longer just my own pain. I am a mental patient. I am a depressive. *I am a depressive* (said slowly and with intensity). This is my identity. I can’t separate myself from that. When people know me they’ll have to know about my psychiatric history, because that’s who I am.

I was further persuaded by additional data collection that depressed people typically move through a predictable sequence of “identity turning points” (Strauss, 1992). Consequently, in Chap. 3 of the book, called *Illness and Identity*, I focused on how my respondents viewed their problems over time. My central argument was that the individuals describe first a *period of inchoate feelings*—they do not have the vocabulary to call what they are experiencing “depression.” Next they begrudgingly conclude that *something is really wrong with me*. Eventually, a *crisis* catapults the person into the universe of therapeutic experts. Finally, almost all interviewees had to *come to grips with their new illness identity*. Nearly always, this last stage depended on the acceptance of a biomedical explanation of their suffering. In sum, individuals progress along a career path with predictable junctures, each of which requires dramatic reformulations of both self and illness.

Attention to the processes through which persons finally say about themselves, “I suffer from an illness called depression” or, even more powerfully, “I am a depressive” describes the most fundamental features of an evolving mental illness identity. In a later chapter, I again rely on patients’ stories to explore a parallel aspect of mental illness careers. Despite substantial variability in the stories I heard, there is a predictable pattern to the way that most of my respondents cope with and adapt to a newly acquired mental illness status. In a chapter called “Coping and Adapting,” my attention turns to *action*, to what people *do* about the pain that they eventually label as clinical depression.

In the initial stages of depression, individuals often take part in behaviors (drinking, exercising, partying) that will distract them from their suffering. But soon it becomes impossible to claim one’s pain as normal. Having acknowledged this, they then try to “fix” the problem. Their new interpretations of the origins of their sadness may trigger a variety of life changes. Over time, they seek out therapeutic experts hoping for some resolution to their problem. When healers often fail to resolve the depression, individuals frequently conclude that they may struggle with depression indefinitely. Consequently, their focus typically shifts from trying to eliminate depression to learning to live with it. In the end, many individuals reject the medical language of cure for the more spiritual language of

transformation. Perhaps it is not surprising that as patients come to rely on their own experiential expertise, while losing faith in a purely medical model of mental illness, disenchantment often drives their evaluations of doctors.

After completing hundreds of interviews and spending years listening to people in support groups (Karp, 1992) discussing the contingencies surrounding their mental illnesses, I know that relationships with mental health practitioners trigger diverse and powerful emotions—hope, admiration, confusion, anger, love, hate, and despair, among others. Ill persons recount an array of treatment histories. Sometimes their stories are hard to follow simply because of the sheer number of therapists they have encountered. Others view themselves as psychiatric survivors who have escaped what they believe to be life-threatening medical treatments. Yet, other accounts of therapeutic relationships are effectively “love stories.” Consider a small sampling of the range of feelings I have heard expressed toward mental health practitioners.

This guy was just a supercilious, superior, arrogant prick.... I had the feeling that he was just looking down on me as a semi-vegetable, and did me absolutely no good at all. He was a resident, and what does he know? That was the feeling I had.... He was a tall, red headed guy with a mustache and this arrogant manner, because he was this great resident from Cornell, you know, and [he thought] I didn't know shit. And he didn't either. And I was really angry at this guy, because he wasn't helpful.... So I was for a while having to put up with that. [male administrator, aged 54]

I had to see someone to get medication. So to me, whenever I had to go see him I would basically say to myself, “Okay, I have to go see him, but it's just because I need medicine, for no other reason.” ... I didn't like his style. I just felt that he was kind of arrogant. His claim to fame was that he worked with a lot of teenagers going through different things and so he really understood. But he didn't understand me. He didn't at all, and he thought he did. And that's one of my biggest pet peeves, when people think they know me, and think they know what's going on, and they just don't [female college sophomore, age 19].

The chafing between psychiatrists and patients is most exacerbated by the latter's often-voiced frustration that doctors seem uninterested in their stories. Based on our discussion throughout this review, it is hardly surprising that the people with whom I have spoken over the years evaluate most highly those doctors who seem to really care about *them*.

[I loved] her gentle mannerism, her voice.... When I started seeing her she would call me at home to see how I was doing. And whenever I called her – no matter where she was – I got a phone call back within ten minutes. I thought she really cared about me and wanted to see me get better. And she made me feel that taking the medications [she prescribed] was the right thing to do (female administrator, age 50).

As suggested by the words cited just above, taking medications is clearly another fundamental feature of illness careers. Quite some time ago, Peter Conrad (1985) explained how doctors' conventional explanations of patients' noncompliance with medication regimens wholly neglected the meanings attached to medication. Medical explanations largely assumed that noncompliance was simply the result of poor communication between doctors and patients. Here again, medicine demonstrated a curious conceptual myopia by slighting the identity consequences of taking pills. After listening to just a few stories, combined with my own experience, it was evident that the decision to take psychotropic medications, and to stick with them, raises fundamental questions of personal authenticity. While a single chapter in *Speaking of Sadness* described the identity consequences of pill-taking, the matter seemed so profoundly important that I devoted another book exclusively to that subject.

Is It Me or My Meds? (Karp, 2006) begins with a simple observation. It is that the decision to take any medication has an impact on the way we see ourselves. Whether taking an aspirin, a vitamin pill, or an antidepressant, there are implications for our sense of self. Indeed, the decision to take psychotropic medications requires especially complex interpretive work. Unlike other medications, psychiatric pills have *as their very purpose* the transformation of people's moods, emotions, feelings, and cognitions. Consequently, these medications raise distinctive questions about our consciousness, questions about the very nature of our humanness. In fact, shortly after Prozac hit the market in 1986,

Peter Kramer (1993) described miraculous stories of personal transformation. In his passionately enthusiastic descriptions of Prozac's power, he predicted that an emerging "cosmetic pharmacology" would eventually allow us to choose our personalities, rather like choosing clothing from a department store rack.

While some interviews conducted for *Is It Me or My Meds?* reveal a nearly religious-like devotion to drugs that have "saved my life," the pill stories I heard were primarily about identity confusions. Over and over, respondents agreed that the decision to take psychiatric medications was scary, in part because it meant crossing an identity boundary from being merely troubled to being psychiatric patients. Many expressed sentiments similar to the woman who told me. "I have a hard time taking medication.... So, I kind of swallowed...my will and that's when I took Prozac." Despite such initial misgivings the narratives around medication reveal yet additional career regularities. Collectively, the accounts collected suggest a process through which taking pills becomes a ritualized and a potentially life-long involvement. Ill people begin their medication careers hesitantly, driven by a sense of *desperation*. The decision to take a pill is typically followed by a lengthy period of *experimentation* during which sufferers hope to find the medication that is right for them. Once fully embedded in the culture of psychiatry, newly minted patients express *commitment* to biological explanations of their trouble. The decisive moment comes with a resigned *acceptance*. For example, "I've accepted now that this is the way I am. This [using medications] is what I'll need to do *for the rest of my life*" (authors' emphasis).

Psychiatric practitioners need to understand that individuals who start a course of psychotherapeutic medication undergo fundamental changes not only in their biochemistry but also in their very identities. While they may eventually "capitulate" to drug treatments, they feel nagged by persistent identity questions. Chief among these are: (1) What does it mean to cross certain identity boundaries? (2) What does it mean to feel like myself? (3) Is my true self being revealed or obscured by the medications I take? To be sure, among the provocative questions raised by many of my respondents is: "How can psychiatric medications relieve a persons' symptoms but make them feel worse about themselves?" As a single example among many, consider the plight of a young man who could not decide his feelings for a woman he was dating.

It [drug taking] really impacts my identity, because I feel like I'm still developing who I am, and I haven't figured out my basic personality. I haven't figured out what I want in life, in a partner, in what kind of girl I'm looking for. And sometimes I feel like the depression and the medication and feeling better confuses that.... I mean, I've been trying to date a few girls recently. And I also think part of the medication's impact on me is that I don't know how I'm feeling. I always second-guess how I'm feeling emotionally about another person. It's a flat line. I don't have real joy. But when I feel sad and I feel like I should be depressed about something, I'm not. When I feel like I'm trying to figure out if I really like somebody, if I maybe love them, I can't figure that out, because I don't have those feelings.... When you're on medication that's part of the second guessing. So you don't know if that's you or if that's the drug.

These last few pages indicate the extensive "interpretive work" required of anyone eventually receiving a mental illness diagnosis. However, there is nothing sacred about the conceptual frameworks used to make sense of the many stories I have heard. I can well imagine that other writers hearing the same stories could notice quite different elements of the illness experience. Thus, my aim as a qualitative researcher is not to lay claim to invariant "social forms" (Wolff, 1950). Rather, the best test of a study's validity is that readers dealing with mental illness will strongly identify with the accounts of others and be provided new perspectives for understanding their own circumstances. Such new perspectives have the liberating potential to change selves and situations. For the same reasons, healers must learn to respect and to rely upon patient accounts. As ethnomethodologists (Garfinkel, 1967) have long demonstrated, we all necessarily create theories to explain our own experiences. Mental health practitioners who find no value in these theories diminish both the humanity of their patients and their own capacity as healers.

An Unfinished Agenda

Our discussion throughout this essay, but most especially our review of critical feminist, race, and disability theories, takes us beyond the core idea that the meanings of all experiences are contextual. We need to address the additional complexity that persons do not act in single contexts. Rather, our perceptions, reflections, and actions are constituted by multiple, intersecting social positions. We are not, for example, just men or women. We are, in addition, men and women of different races, social classes, ethnicities, and ages. Consequently, each of the studies cited throughout these pages, although demonstrating regularities in the experiences of mental illness, necessarily misses some of the diversity in the ways that persons define and deal with their suffering. Human distress encompasses an enormous array of hues, intensities, and responses depending upon the intersections of our multiple social locations.

Honest social science must create a balance between discovering general social patterns while documenting the many departures from those regularities. Consequently, we need more research that attends to the matter of “intersectionality.” We recommend that future qualitative research disaggregate disease, in effect. That is, research should resolutely focus on the ways that different subgroups (e.g., gender, class, race, ethnic, age) and different intersections of these groups differently make sense of all aspects of mental distress. Such an agenda might seem unfriendly to the positivist urge to describe “realities” that transcend historical, cultural, group, and individual variations. There is some legitimacy to that claim. However, there is a softer interpretation of our recommendation. We think that the most refined understanding of mental illness is contingent on simultaneously discovering patterns while being appropriately respectful of diversity. We believe that such an approach, rooted in personal accounts, gets us closer to the “truth” about the experience of illness, albeit a far messier truth than social “scientists” and healers normally wish to discover.

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