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Stigma Despite Recovery

Strategies for Living in the Aftermath of Psychosis

In this article, we identify an array of creative strategies used by persons diagnosed with schizophrenia-related illness to deflect and resist social stigma, and address the lived experience of deploying these strategies in the intersubjective context of everyday life. The data are derived from anthropological interviews and ethnographic observations of ninety persons who received treatment at community mental health facilities in an urban North American locale. Nearly all were keenly aware of stigma that permeated their lives. Their predicament is contradictory: on the one hand, they have recovered relative to previous states of psychosis; on the other hand, their subjectivity is saturated by intense awareness of social stigma that seems intractable in relation to temporal or functional criteria. Ironically, these lives can be characterized as fraught with stigma despite recovery. The strategies generated to resist the impact of stigma highlight the fact that persons with these illnesses are often not only exceedingly socially aware but also strategically skilled in response to social assaults on their personhood and survival. We examine these strategies in terms of (1) the social characteristics of each afflicted person, (2) the situational characteristics of managing stigma, (3) the cultural context of recovery, and (4) the illness-specific characteristics of schizophrenia.

Keywords: [stigma, culture, mental illness, psychosis, schizophrenia and schizoaffective disorder, antipsychotic medication, recovery, lived experience, intersubjectivity]

In this article, we examine the strategies adopted by persons with schizophrenia and schizoaffective disorder to struggle against rejection, discrediting, and distancing. In our view, such forms of “othering” constitute the social phenomenon of stigma. This problem of stigma is of particular interest with respect specifically to psychotic illness at this historical moment because a new generation of drugs that significantly reduces symptom levels and florid manifestations of psychosis has created a population of patients who are far more socially engaged than in previous decades. Paradoxically, their improved condition does not free them from confronting the

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stigma of severe mental illness; rather it, places them in a situation of having to deal with it on an everyday basis. Our work focuses on persons living this paradox of what we call “stigma despite recovery.” We aim to avoid two key problems in current literature in the medical social sciences on stigma: (1) overemphasis on individual attributes evident in social psychological research conducted with scalar instruments, and (2) absence of research on the lived experience of persons who struggle daily with stigma (Link and Phelan 2001).

Stigma and Intersubjectivity

We understand stigma to be intersubjective, that is, produced and experienced in the interactive spaces between individuals in culturally defined social worlds (Das 2001). The stigmatized are objectified as “others” and are impelled toward a subjectivity defined by “undesired differentness” that can result in a “spoiled identity” (Goffman 1963). Within the intersubjective milieu, stigmatizing others may be “a highly pragmatic, even tactical response to perceived threats, real dangers, and fear of the unknown. This is what makes stigma so dangerous, durable, and difficult to curb” (Yang et al. 2007:1528). The experience of being stigmatized can be a struggle against dehumanization in which the desire to “pass” as normal “dominates their lives and becomes the quintessential problem among these individuals” (Edgerton 1993:131). Our intersubjective approach foregrounds a twofold emphasis on experience and meaning. First, attention to experience emphasizes “the active engagement of subjects in processes of cultural construction” (Jenkins and Barrett 2004:9). Second, we employ a meaning-centered approach (Good 1994; Good and Good 1981; Good 1995), as a way to access and interpret the understanding of psychiatric stigma from the perspective of persons recovering from severe mental illness.

We intend this work to contribute to an ongoing anthropological literature on stigma that originated in the 1980s in part as a reaction to sociological studies of deviance focused on institutional forces and middle-class expectations regarding normative patterns of behavior. This literature promised to shed light on variation of stigma across cultures and across types of illness or disability, thereby transcending the “ideal type” mode of analysis exemplified by Goffman’s (1963) understanding of stigma as spoiled identity and Parsons’s (1951) articulation of illness as a deviant state manifest in the “sick role” (Ablon 1981). This anthropological literature has examined a range of issues, including mental retardation (Edgerton 1993), HIV/AIDS (Castro and Farmer 2005; Cullinane 2007; Lang 1991; Niang et al. 2003; Stanley 1999), lack of limbs (Frank 1986), leprosy (Barrett 2005), genetic disorders (Ablon 1999), dwarfism (Ablon 1984, 1988), epilepsy (Ablon 2002), infertility and pregnancy loss (Inhorn 2004; Layne 2006; Miall 1994), unintended pregnancy (Ellison 2003), sexuality (Lancaster 1988; Rebhun 2004), multiple chemical sensitivities (Lipson 2004), chronic pain (Jackson 2005), and tuberculosis (Karim et al. 2007).

Psychiatric Stigma

Particularly germane to our concerns are anthropological examinations of psychiatric stigma (Coker 2005; Bergstresser 2006; Estroff et al. 2004; Fabrega 1990,

1991a, 1991b; Hutchinson and Bhugra 2000; Kleinman 1988a, 1988b; Littlewood et al. 2007; Townsend 1979; Waxler 1977; Weiss et al. 2001). Stigma associated with psychiatric conditions appears to be a cross-cultural universal (Link et al. 2004; Pickenhagen and Sartorius 2002). In the anthropological literature, the cross-cultural validity of the concept of psychiatric stigma is supported by findings of stigma attached to mental illness in China (Kleinman 1988b; Lin and Lin 1982), Egypt (Coker 2005), and Italy (Bergstresser 2006).

Yet stigma must be understood in relation to particular local worlds insofar as, “Across cultures, the meanings, practices, and outcomes of stigma differ, even where we find stigmatization to be a powerful and often preferred response to illness, disability, and difference” (Yang et al. 2007:1528). Likewise, Coker (2005) observes the risk for committing a “category fallacy” (following Kleinman [1988b]) if the concept of stigma is applied uncritically cross-culturally. For example, in China, family ties are most “at stake” and thus most threatened by mental illness. In their comparative study of stigma in China, Lee and colleagues (2005) found that significantly more patients with schizophrenia (> 40%) experienced stigma from family, partners, friends, and colleagues than did their counterparts with diabetes (average 15%). In U.S. contexts, values of individualism, self-reliance, autonomy, and choice may be threatened by psychotic symptoms as well as by limits to education and employment faced by those with mental illness, and how mental, emotional, and behavioral distress is interpreted appears to mediate stigma. As Jenkins (1988a, 1988b) found among Mexican American families, conceptualizing problems as *nervios*, as opposed to schizophrenia, appears to mitigate the stigma associated with a mental illness, reinforcing interpersonal relations characterized by *dignidad* and *respeto* and facilitating family equanimity (Jenkins 1991a).

Although Fabrega (1991b) highlights the degree of variability regarding conceptions of, and responses to, mental illness cross-culturally, he concludes that “The potential for condemnation and frank stigmatization of psychiatric illness seems to be present in most if not all of the [non-Western] societies studied” (548). In particular, Fabrega (1991b) notes that stigma attaches to conditions that are viewed as chronic and unremitting, and that are understood to be manifestations of social, spiritual, or moral transgressions. In contrast to the emphasis on social relations that shapes stigma processes in China and elsewhere (see also Kleinman 1988b), scholars have observed an individualistic orientation as central to configurations of stigma in northern nation-states. Fabrega’s historical trajectory of psychiatric stigma in Europe and North America (1990, 1991a) identifies the ascendancy (esp. in the late 18th and early 19th centuries) of the primacy of the individual as a response to industrialization and urbanization. Consequently, those viewed as “dependent,” to include the mentally ill, poor, and criminal, became configured as a “social problem” and subject to state intervention and sequestration, thus reinforcing historical associations between madness and other forms of social marginality. Coker (2005) notes that mental illness poses a threat to Northern European Protestant formulations that emphasize the self as individualistic, rational, and constant. Hutchinson and Bhugra (2000) add that the longstanding “preoccupation of health as a moral imperative” in the West informs understandings of stigma and may account, in part, for the inability of medical models of psychiatric illness to ameliorate stigma.

Taken together, this body of scholarship underscores the social and cultural mediation of psychiatric stigma. Although an exhaustive review of this literature is beyond the scope of this article, we wish to draw attention to the circumstance that the anthropological study of stigma reflects broader shifts in culture theory toward lived experience, individual agency, and intersubjectivity (Jenkins and Barrett 2004:7–8; Kleinman 1988b). These shifts impel consideration of moral dimensions of human experience, to include violence, social suffering, and social abandonment (Biehl 2005; Jenkins 1991b, 1998; Kleinman et al. 1997) as well as resourcefulness, resilience, and sheer endurance of individuals whose lives are lived in the shadow of pain, fear, and uncertainty (cf. Biehl et al. 2007).

Ethnographic Setting

Our data are drawn from the NIMH-funded anthropological study “Schizophrenia and the Experience of the Culture of Recovery through Atypical Antipsychotics” (SEACORA), which examined the subjective experience of worsening or improvement among persons ($N = 90$) with schizophrenia-related disorders taking “second-generation” or “atypical” antipsychotic medications. In a metropolitan area in the industrial Great Lakes region of the United States, we obtained the complete rosters of two community mental health outpatient facilities that served Euro-American and African American ethnic groups. The first clinic is affiliated with an academic research community in which clozapine, one of the earliest of the so-called atypical antipsychotic medications, was initially introduced in the United States. Those attending the clinic, developed specifically to deliver clozapine treatment, often spent significant amounts of time on site, ranging from daily visits to twice per month. During these visits patients typically engaged in a variety of informal social activities. The second clinic had a relatively less developed research focus, and patients came briefly for biweekly or monthly medication checks. Although there may be a more keen and explicitly elaborated psychiatric ideology regarding the efficacy of medication to treat disorders of the brain in the clozapine clinic (which ultimately came also to prescribe other atypicals over the course of a ten-year period), the focus on the centrality of medication to treatment was common in both settings as indeed is widely the case throughout the country.

People lived within the metropolitan region and typically relied on public transportation to attend clinic meetings (individual, group), visit friends or family, or travel to work or volunteer activities or religious practices. Grocery or drugstore shopping was generally within walking distance from residences. Local fast-food restaurants nearby the clinic were frequented as hang-out sites, and shared public transportation routes were by far the most commonly shared medium for sociality in the form of gossip and conviviality.

Methods

Research Participant Selection

Participants, the majority of whom had been designated as “treatment refractory” (nonresponsive) in relation to older antipsychotic drugs, were taking atypical

antipsychotic medications (also termed “second generation” antipsychotics); however, six persons in the study were prescribed atypical antipsychotic drugs as their first psychopharmacological treatment. Research selection criteria included: (1) diagnosis of schizophrenia or schizoaffective disorder assessed through the currently standardized research protocol of the Structured Clinical Interview for *DSM-IV* (SCID; First et al. 2002);¹ (2) ages 18–55; (3) at least two years since first psychotic symptoms; (4) at least six months of treatment with an atypical antipsychotic; (5) clinical stability sufficient to provide informed consent and participate in interviews. Persons with current substance abuse problems or organic impairments were excluded from the study.

We assessed research eligibility by reviewing potential participants with treating psychiatrists and therapeutic managers, resulting in a complete list of all patients who met research diagnostic criteria. From this list, 167 eligible participants were then randomly selected. Of those selected, 90 (54%) were included in the final sample, with 46.7 percent of these subjects refusing research participation. The overall high rate of refusal is not unusual (Covell et al. 2003) for a U.S. community outpatient sample such as this, with males (55.9%) significantly more likely than females (29.3%) to refuse participation (Fisher’s Exact, $p < .001$). Reasons for nonparticipation included general lack of interest in research (stating simply they “didn’t want to”) or a reluctance to provide time for interviews (because of work scheduling or preferences to spend time otherwise). Given this, it is likely that those who did participate in the study differed insofar as they stated that they were interested in research, sometimes noting that they had an interest in cooperating with anything that might benefit others (or themselves) in the future. In addition, they may have been somewhat less disturbed symptomatically, making participation more manageable from their point of view.

Procedures

We studied the subjective experience of schizophrenia using ethnographic interviewing, naturalistic observation, and standardized questionnaires. The qualitative interview was developed for the study on the basis of prior studies completed to obtain narrative data using a semistructured, open-ended anthropological interview, the “Subjective Experience of Medication Interview” (SEMI). The SEMI inquires into the experience of medication and treatment, living situation, everyday activities, illness management, social relations, gender identity, stigma, and expectations concerning recovery and quality of life. The duration of these interviews was generally 1.5–2 hours over 1–3 interview sessions. All SEMI interviews were transcribed verbatim from audiotape and entered into a qualitative software program, Atlas.ti (Scientific Software 1997), to code and analyze qualitative data systematically (Good 1994; Luborsky 1993).

We considered participants to have been aware of stigma if at least one of the following conditions were met: (1) If the subject indicated that people react negatively in response to the question: How do others respond to your illness? (2) If the subject articulated stigma in relation to the illness; (3) if the subject articulated that he or she does not tell others that he or she has a mental illness or that he or she takes medication. Cases in which the participant indicated no attempt to

conceal illness or medication from others or in which the subject did not elaborate on stigma were coded negatively. Coding a “no” response cannot be considered an indication that the subject did not perceive or experience stigma but rather that the response reflects an absence of a report of stigma in the interview transcript. Reports of perceived stigma were secondarily coded for patterns in the contexts in which subjects experience stigma. A grounded-theory approach (Strauss and Corbin 1990) yielded statements that articulated the experience of stigma in relation to these contexts, such as self-presentation, gender, work, social relations, medications, and popular cultural perceptions.

Results

We have summarized sociodemographic and clinical characteristics of SECORAA participants more fully elsewhere. In brief, males constituted 54.4 percent ($N = 49$) and females 45.5 percent ($N = 41$) of the sample. Euro-Americans accounted for 77.8 percent ($N = 70$) and African Americans for 22.2 percent ($N = 20$). Mean age was 40.7 (SD 7.9), with the mean years of education being 13.0 (SD 1.9). Marital status was 84.4 percent ($N = 76$) single, 5.6 percent ($N = 5$) married or living with a partner, and 10 percent ($N = 9$) divorced, widowed, or separated. Those living alone accounted for 25.6 percent ($N = 23$), those living with a roommate or in a group home for 22.2 percent ($N = 20$), those with a relative or parent 42.2 percent ($N = 38$), and those with a partner or spouse 10 percent ($N = 9$). Fully 60 percent ($N = 54$) were unemployed, 22.2 percent ($N = 20$) were working half time or less, and 17.8 percent ($N = 16$) were working from half to full time.

Diagnostically, 81.1 percent ($N = 73$) of the participants had schizophrenia and 18.9 percent ($N = 17$) had schizoaffective disorder. The mean age at onset was 20.6 (SD 7.3), the mean years duration of illness was 20.1 (SD 8.4), and the mean number of hospital admissions was 7.0 (SD 7.0). Types of atypical antipsychotic medications taken were clozapine (56.7%), risperidone (17.8%), olanzapine (16.7%), or other (8.9%) investigational medications. Finally, measures of severity of symptoms (ranging from 1 to 7, absent to severe, respectively) on the Brief Psychiatric Rating Scale (BPRS) revealed remarkably low levels of symptomatology overall for a sample such as this (Burger et al. 1997). Factor scores for the BPRS range from a low of 1.23 for features such as psychomotor agitation to a high of 2.09 for anxiety or depression. There were no significant differences in socioeconomic status by ethnicity.

Most significant for the purpose of the present discussion, nearly all persons (96%) in the study reported perception of stigma across a variety of social settings they encounter on a daily basis. The existential predicament can be summarized as follows: the “good” news is that I have recovered relative to my previous state of suffering; the “bad” news is that despite this recovery I must daily contend with the onslaught of pervasive social stigma that nonetheless adheres to my personhood independent of my clinical status. The first step of our analysis is to illustrate each of the strategies, and the second step is to present the experience of four persons in greater depth.

Table 1. Strategies for Self-Protection and Resistance to Stigma

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- Concealing diagnosis or medications
 - Avoiding others
 - Attempts to “pass” for normal
 - De-emphasizing illness
 - Relativizing the illness
 - Educating others about mental illness
 - Socializing with others with mental illness or those who sympathize
 - Confrontation and opposition
 - Humor and joking
 - Reproduction of stigma
-

Strategies against Psychiatric Stigma

The variety of creative strategies that persons devise to deal with this formidable problem is listed in Table 1. Note that our emphasis is not simply on identifying these strategies, many of which are already known and reported in the literature (Ablon 1981; Edgerton 1993; Goffman 1963). Our further contribution is in presenting the lived experience of people insofar as how they use the strategies in an intersubjective milieu, the circumstances under which they are called into play, and their emotional and self-consequences.

Secrecy, silence, or concealing the diagnosis or medications are essential strategies for many, although it is also the case that patients clearly distinguish contexts in which they feel free and safe to openly acknowledge and discuss their condition. Although concealing information might in one ethnopsychological logic appear a matter of poor self-esteem or disempowerment, such actions may also be construed as self-protective strategies in a context where explanations and attempts to educate others about the problem not only may fail but also backfire insofar as people may be granted less social status for having divulged such information. With respect to medications, one female participant described the carefully executed strategy she employs:

There’s some things I do. Like with these, I wore these clothes yesterday to work too, and what I do is I wear my brassiere under my sweater. And what I do is I take a plastic bag and there I put my day’s worth of medicine pills. And I pin it to my bra. And I just go into the bathroom and shut the door and take it out and then go and take it in the fountain.

Decisions to conceal one’s diagnosis in the workplace are common, based in large part on fear of possibly or reasonably certain negative consequences of not doing so. One woman narrated her experience of having mustered the courage to divulge her condition to an employer following an interview encounter that she felt had gone quite well. Subsequently, she remains troubled by her decision to be forthright and fears that such action may well have cost her the job she was seeking:

I think it is (difficult) because in terms of getting jobs, I’ve applied at several places and I kind of hesitate telling them that I have an illness and not even

wanting to because I feel like I'm going to get turned down. I've had a number of interviews that went fairly well and, I remember this one time I was really confident about this interview. Afterwards I felt great, I presented myself well and I said all the right things and so I decided to call this person and say "um, you know, look, I have a mental illness." And he was pretty receptive to it. He said, well, "thank you for sharing that with me," and I never heard from him again about the job, so it's kind of up in the air. And, I don't know, maybe I shouldn't have told him. It's always going to be something that's unresolved.

People in the study struggled on a daily basis to engage and to disengage social situations that they felt were likely to be colored by prejudice or hostility directed toward them on the basis of being "different" by virtue of a mental condition. Managing numerous such encounters on a weekly if not daily basis, they reported that sometimes they would simply avoid others in an effort to recuperate for a time. There were also numerous narrative comments about the deep desire to return to normalcy or to pass publicly for "normal," not unlike strategies identified by Edgerton (1993) in his classic study of the lives of mentally retarded persons. One Euro-American man described his efforts as follows:

I try not to complain about my problems too much, or, I try to control my thinking and my emotions and my problems, by acting and behaving and thinking as normally as possible, in normal society as most people do, normal.

Another common strategy was to de-emphasize the mental illness by asserting that their lives are about more than just illness conditions. Also, comparative strategies to "relativize" the illness were not uncommon, such as the analogy of schizophrenia to diabetes (commonly put forth by many family and consumer advocacy groups) as legitimate, biologically based diseases that should entail neither shame nor blame. From a Euro-American woman:

I used to be really ashamed of being schizophrenic. I guess that's why I couldn't come to terms with having a problem. My mom always said some people are sick on the inside and some people are sick on the outside. Everybody has a problem. No one's perfect. I said, "of course, mother. I'm perfect." She goes, "Seriously, people are sick on the outside and on the inside. People have, like on the outside, you might have no legs. Physical or mental—it's the same. They're just different kinds of illnesses."

Yet others in the study were quick to note that, relative to "other" mental patients, they were not nearly as disturbed and were more functional and normal in appearance. They also downplayed any current (or recurrent) difficulties by invoking past states of suffering that, by comparison, were significantly more pronounced. Invoking the temporal, socially comparative, and physical criteria of conditions was intended to neutralize the otherwise harsh or dismissive judgments of them as naturally inferior.

Some people adopted the strategy of attempting to educate people about their condition or the need to take medication. Regarding themselves as experts, they felt they were in the position to help others understand what they often knew to exist within the realms of the frightening or strange. Often, however, such strategies were not met with success. Many persons in the study narrated interactions with others who challenged their social or clinical status in a manner that evoked confrontation and argument. For instance, a Euro-American male said:

I'll tell people I'm taking an antipsychotic, and they're like "You don't need to take that." They just give you that look, that shocked look, and *then* that jump a couple steps back. And I say, "I know I have to take it, because I've been without it before." . . . And they start arguing with me, and I just leave and look back, because I know better.

Yet another tactic to minimize social stigma is to socialize with others who may likewise suffer from similar conditions. In such cases, experiencing sympathy or even relief was not only socially appealing but also a salubrious form of interaction. However, as noted above, this strategy is not without problems. First is the problem of the reproduction of stigma among the ranks of the mentally ill themselves, who may insist, for example, that they would rather not befriend or date someone with a mental illness. However, there may be a measure of comfort in being with others among whom there is no need to explain or justify their extraordinary experiences. In addition, several instances of staunch resistance to stigma were prominent through rejection of negative responses as applied to the self, through various means that range from confrontation to humor as narrated by two Euro-American women:

People are the same, basically. People feel the same basically. People are scared of basically the same things. Schizophrenic people are not different than regular people. I'm not any different than you are. Except I might have different views on certain things, or maybe even the same views. Schizophrenia is not—is not what's in your head. Well, it is, but it's not—it's [voice trails off] . . . I don't know. I mean . . . a person thinks basically the same things and the same feelings than a regular person except you just hear bad things. I mean, my life is fine right now. I don't need anybody telling me that this is not healthy for you. That that is not healthy for me. My life is fine. I *like* my life. [adamant tone].

A 32-year-old Euro-American woman who describes getting the "short shrift" from her psychiatrist, impersonating him as follows, illustrates the strategy of humor:

[Imitating doctor's voice] "I'm sorry, I'm too busy. I'm very busy today—I have an emergency scheduled. I can't talk to you. Otherwise everything all right? Yes? Good. I'll see you in a few months. Bye."

Offering a superb counterexample to popular (and sadly, occasionally professional) perceptions that individuals with schizophrenia lack the capacity for

emotionality and humor, she employs humor strategically to express her frustration in a way that is socially acceptable. Her impersonation succeeds—it's hard not to laugh (ruefully) at the idea of a “scheduled emergency.” And from a typically gregarious woman who was ever present at the university clinic, we also saw the strategy of humor: “Hey: when you talk to God it's called prayer, but when he talks back it's schizophrenia!”

The final strategy is perhaps the most complex and highlights the difficulty of managing stigma. Our data confirm that stigma is not only directed at the afflicted from the “external” social world. Many SEACORA participants stigmatized others with mental illness ($N = 35$ or 40.7%) by making negative comments, and a substantial proportion even stigmatized themselves ($N = 18$ or 20.9%) with pejorative labels or negative self-perception. More women (31.7%) than men (10.2%) applied stigma to themselves (Fisher's Exact test, $p < .02$), as did individuals with schizoaffective disorder (41.2%) compared with schizophrenia (15.1%; Fisher's Exact test, $p < .04$).

When individuals apply stigma to others with mental illness this frequently involves a comparison between their subjective perceptions of their own appearance and behavior, on the one hand, and the behavior and appearances of others with mental illness, on the other hand. For example, a 28-year-old Euro-American woman describes her own “look” versus the “look” of the mentally ill:

I think I'm really lucky, because I went to some (social) function, and my mom was sitting at a different table, and this is like a prom kind of thing, like a dance. And I came over to say something to my mom, and I walked away, and someone said to my mom, “Is that your daughter?” And she said, yeah, and she said, “Oh, is she one of the therapists here?” and she said, “No, she's a patient.” And, people have said that I act better than people that have never been on medication, and never been sick. But I think a lot of people in my situation; they will sit there with their mouth open and their tongue hanging out, and all that stuff. And I'm glad I don't do that. I mean, I used to, obviously when I was in the hospital, but, I mean, I think I'm pretty normal.

In this way, the comparison offered serves as a marker of her own recovery relative to other people with mental illness she encounters on a daily basis. A 48-year-old Euro-American male notes:

I'm very reluctant to get involved with a bipolar since I had that bipolar girlfriend. They can bring a lot of trouble . . . I guess I'm more comfortable around normal people than other mentally ill people, except for ones that I've known awhile and I feel comfortable with. But in general, I think I'm just as bigoted as anybody else about mentally ill people. [chuckles].

These individuals make a clear distinction between themselves and others with similar illnesses and resist a singular categorization of the mentally ill by calling attention to the diversity of experiences or expressions of their disorder. Stigma in relation to recovery takes on a slightly different cast in these examples. Differentiating

themselves from the category of “the mentally ill” involves a reproduction of stigma, as these individuals define themselves in positive terms constructed in opposition to negative perceptions and stereotypes of others with mental illness. The management of stigma, for some, appears paradoxically to involve “othering” those perceived to be more impaired than oneself. A second form of stigma reproduction involves the application of stigma to the self. This involves the internalization of negative attitudes and perceptions associated with mental illness. A 39-year-old Euro-American comments she is “not as smart as most people” and “not normal.” Viewing herself as less intelligent than others and “not normal,” her sense of herself is dramatically shaped by the internalization of the stigma associated with mental illness.

Portraits of Stigma Despite Recovery

Having sketched the broad contours of how participants struggled to resist and subvert the destructive daily onslaught of stigma, we now turn to in-depth portraits of four individuals to illumine how stigma takes shape in the context of daily life for particular persons, at particular times, in particular places.

(1) Christy is a 26-year-old Euro-American woman who lives with her parents, three dogs, three cats, and two fish tanks in the same house she grew up in since she was five years of age. According to clinical and research diagnostic criteria, Christy has schizophrenia, an illness that first appeared when she was 18. Although she has received psychiatric care ever since the onset of her illness, she has managed to avoid hospitalization because she has had intensive care by family and friends who watch over her during illness episodes. She regularly takes atypical antipsychotic medication, insisting that it “keeps me from being crazy” and that it is “amazing” compared to the older antipsychotic she had been taking. However, she says, “[The medicine] made me gain a lot of weight, but, be crazy or fat. I choose *fat*.” Christy is forced to “choose” between two highly stigmatizing conditions, making stigma sadly and maddeningly inexorable. For the last five years, she has worked full time as a cashier and pet groomer at Pet Company, a large full-service pet store with numerous locations across the United States. In addition, she volunteers at a veterinary office on her day off.

At the time we met Christy, her life was remarkable for its utter ordinariness, even conventionality. Because she no longer suffered acute bouts of psychosis on a regular basis, and because she was content and even pleased with her life situation, the sheer awe of the extraordinary and terrible experiences she has known seemed all but vanquished, downgraded to brief and occasional “attacks.” Now, the wonder of her life was the quality of everyday routines involving family, work, socializing, and travel that animated the “rhythm of her life.”² Her family is close knit, with daily contact not only with her parents and older brother (married) but also aunts, uncles, and cousins, who live one block away and work within a radius of one or two miles. The rest of her social life centers on church activity, including a bible study group three times a week. Christy is not currently dating anyone, although she says she’d like to meet someone and one day hopes to get married, although that’s not a top priority right now.

Much of the time she is free from fears or voices. However, about twice a month—usually when she is stressed, overtired, getting sick, or has premenstrual

distress—she will have an “attack” of voices telling her to kill herself. She describes being depressed during the attacks, but not otherwise. These attacks may occur at work. When this happens Christy tries very hard to look normal (she thinks she succeeds—no one has said anything) and keeps her mind on the job at hand. She feels relieved when she can go home and be with her family, who help her to remember that the voices aren’t real and aren’t telling the truth. Overall, she considers that she has a very good life filled with a variety of satisfactions.

Even so, Christy struggles not only with occasional symptom “attacks” but much more so with the sting of stigma in everyday social interactions with persons outside her circle of kin and friends. Thus, her life embodies the paradox of being the social target of “stigma *despite* improvement.” She describes an acquaintance’s reaction to her as follows: “There’s this one person. I think she’s scared of me. But I don’t care. She’s not really a good friend. I just think she knows, through her aunt and uncle.” This exchange reflects not only the acquaintance’s stigmatizing reaction of fear, but also calls attention to rumor as socially harmful, as well as Christy’s attempt to manage this experience of stigma by categorizing the acquaintance as “not really a good friend.” Christy draws a distinction repeatedly in her narrative between “good friends” and strangers or acquaintances outside her circle of friends and family. She says, “I know my real friends won’t laugh at me.” Similarly, she speculates that

Say you were going to get married to the person, you would have to tell them that you’re schizophrenic, and maybe that would make the person go away. But if they truly loved you, they wouldn’t [go away]. But I believe if you tell somebody—or people know about me—my friends they never treat me differently or anything. But I’m sure word gets around. [laughs] But everybody has their own illnesses and they forget about it, ‘cause they’re so worried about themselves.

As such, although Christy expects rejection or teasing by those outside of her circle of family and friends, she is confident in her perception that her friends and family act as an effective buffer for stigma. In relaying a story about two friends of hers, Tony and Paul, she averred:

Paul knows I’m sick and Tony did but he forgot. He was saying, “Boy, you have a schizo cat,” and Paul kind of nudged him, but I didn’t care. I mean they are supportive. If I need help or anything, but I think they know that I’m doing well.

Yet another social distinction drawn by Christy relates to disclosure of her illness. Specifically, although Christy is open about her illness with family and friends she says that

I don’t tell people really at work. That’s the only place I really don’t discuss it . . . Word gets around . . . and I just don’t want that . . . I don’t want people to look at me differently.

Likewise, she expects that “. . . if some people knew at work, they would just laugh and laugh.” Recall that Christy has been employed with Pet Company for five years. This translates to five years of vigilant concealment of her illness on a daily basis, occasionally even during periods of symptomatic “attacks.” She feels acutely the social consequences that would ensue should her coworkers find out about her illness. Reflecting on public attitudes toward mental illness Christy observes that:

I think, um, people understand diabetes. They understand cancer. But when people hear the word mental illness, they get—not all people, but a lot of people just don’t understand . . . if someone hears oh, you’ve got a mental illness, it’s not the same as you have cancer and you’re getting treatment. It’s “*you’re seeing a psychiatrist.*”

This statement is an interesting counterpoint to the tendency of many participants to relate mental illnesses to chronic illnesses such as diabetes. Christy’s response highlights her perception, experience, and expectation of stigma as she draws attention to a strict distinction between stigmatizing impairments of mind compared to what she imagines as lesser stigmatized diseases of the body.

Thus the sanguine development in Christy’s life is that although she has had acute episodes of frightening illness experience, she has not only survived but also arguably thrived by virtue of personal effort and dedication to her work (care of animals) and social attachments to kin, friends, and religious affiliates. That her life experience counts for little when the specter of mental illness is raised in social arenas beyond her circle of family and friends is a daily social reality that haunts her. Unlike the psychotic experiences that have come and gone, the social imprisonment by virtue of being a suspect person is inescapable. To guard against this, she has developed strategies for concealing her diagnosis and psychiatric treatment, avoiding those she considers unsympathetic, trying to appear “normal” when having an intermittent “attack,” deemphasizing and relativizing the illness, socializing with those sympathetic to her, and invoking humor (see Table 1).

(2) Alicia is a 33-year-old African American woman of medium height who is overweight. Although reserved in manner initially, she is quite articulate. Currently single, she would like to marry eventually but has not yet “connected with someone in that way.” She is currently unemployed and shares an apartment with her brother, and her sister lives in the same apartment building. Her research diagnosis is schizoaffective disorder. Onset of illness occurred at age 28; she has been ill for 5 years and hospitalized once. She has been taking risperidone for three years. She emphatically affirms the necessity of medication, recognizing the interrelation of medications and self-motivation necessary for improvement while expressing considerable ambivalence regarding such a need and struggling with the strict discipline required to take medication regularly. Alicia fears that her illness is “getting worse” and that she hasn’t been doing as well as she should have been doing. She thinks this is because she doesn’t get to her treatment appointments as regularly as she’d like, and to account for that Alicia blames herself for “not being responsible, being lazy.” At the same time, she says it’s been a learning process for her in which what she initially thought that she needed to do, “to get my life together, get out,

get a job, get strong, get tough, with myself,” changed over time with her realization that such qualities were not enough and that she really did need medication.

Even though her sister “keeps to herself,” Alicia nonetheless considers her sister to be her closest confidant. Within her own apartment, she describes her living situation as a bit tense. The place is not as tidy or clean as she would like, and her brother works an early shift and gets angry when she’s watching TV late at night. She has little contact with her parents, which has to do with religious conflict, but sees religious affiliates and friends regularly. She confided that she worried for some time that having a mental illness meant that she was a bad Christian, but that people at church had finally convinced her that mental illness has nothing to do with religious faith. Most recently, her sister passed on her concern that Alicia was not doing well to church members. This prompted a “shepherding call” to her home by two church elders to see how congregants are doing spiritually. Alicia feels very guilty about not doing well (lethargy, suicidal thoughts) and worries that she is not worthy as a person with mental illness. The guilt Alicia feels over suicidal thoughts is perhaps most intense and can be triggered by feeling bad because people do something such as look at her in a certain way or do not say “hello.” Those particular social reactions she feels as a draw to end her life, to give up in shame and sorrow. It is her spiritual strength that has made her feel that she “can’t let this stop me.”

Alicia is convinced that her religious association provides her with a good way to be active, and she describes prayer meetings and ministry activities as “very therapeutic for me.” She is very devout and spends her time trying to “find out more about God.” Getting married is a goal for her some time in the future. She says that her religious practice is more a priority than dating for her. She worried before that being married and having children would tend to distract her from religious matters. She notes that in fact love is difficult for her because she has had a difficult time loving herself even though she affirms her strong love for her family.

Alicia’s attitude toward mental illness illustrates our observation that the mentally ill can reproduce stigma among themselves. Some popular negative perceptions of schizophrenia appear to hold salience for her. For instance, she says:

When I think of paranoid, I think of someone who always thinks that there’s something out to get them. Schizophrenic, I think about hearing voices. Sometimes it make me, I think about the disease and I, picture a person who’s very, um, unstable and, violent, and, that’s what I think of.

She adds a gendered component in her endorsement of violence associated with mental illness in maintaining that:

From what um, this is from me, what I’ve seen. Men tend to be more violent than women. I could be wrong. Um, but the experiences that I’ve seen from being in the hospital and, um, being around me, um, they tend to be a little more violent.

Although not stated explicitly, Alicia’s perception that men tend to be violent may be understood to influence her social and dating preferences:

I would rather get to know a person who does not have a mental illness. Well um, not to be prejudiced or anything, I mean, nobody's perfect but, um, I may have a mental illness but he might have a personality problem.

Alicia's hesitancy to date or to socialize with another person with mental illness, understood in concert with her previous endorsements of the mentally ill as unstable or violent, reflects a reproduction of perceptions that mentally ill individuals are less suitable or desirable as partners (e.g., on the basis of their unpredictability).

With regard to her physical appearance, Alicia is greatly bothered by the weight gain that she has experienced as a result of her atypical antipsychotic medications. Although she cites a series of troubling side effects—irregular menstrual periods, shaking, hair loss—it is the weight gain that bothers her the most. When asked by the interviewer why the weight is particularly troublesome Alicia says simply, “Well because, um, I'm just fat. The way I look, the way I look.” The weight gain has affected her self-image, altering the way that she would prefer to present herself. However, her diagnosis and the need to take medications have not resulted in a shift in her perception of herself. She says, “I look older. And I look worn out . . . I don't think I look like an alien and everyone else looks like humans or anything like that, no! (laughs).” In this way, although she is altered by the medications, Alicia does not perceive herself as looking different or in some way “mentally ill” as a result of either the illness or medications.

(3) Steven is a 42-year-old Euro-American man, currently living alone in his own condominium. He is diagnosed with schizophrenia. Onset of his illness occurred at age 19; he has been ill for 23 years and hospitalized 19 times. Steven is currently treated with clozapine and has been taking atypical antipsychotics for 13 years. In relation to his illness, Steven reports that he is “getting better.” He describes his life at present as quite good yet still feels unsatisfied overall. Steven works full time in a manual labor—cleaning job.

Steven's family is instrumental in mediating his illness experiences and perception of stigma. He now has fairly frequent contact with his parents but is not dependent on them—“They've got their own life. I've got my own life, too.” Steven is saddened by the lack of contact that he has with his two brothers and one sister. He describes not being allowed to attend his brother's wedding in England years ago because he was in “bad shape.” He contrasts this time with a recent family reunion when

We were sitting around the table and we were talking a little bit about my illness and . . . somebody said, “Well, you've come a long way.” And my dad said, “You'd better believe it.” My dad is the one that struggled with it so much. He had no understanding of it. They didn't read anything up on it. But now I think I've really proved to them, you know, when I took two jobs—that's when they really started to do a lot for me.

This aspect of Steven's experience suggests a “pull yourself up by your bootstraps” model of recovery, embedding ethnopsychological assumptions regarding work as preventive/curative and, by extension, reinforcing normative masculine roles and expectations. From Steven's point of view, his siblings deny or ignore his illness:

My brothers and sisters don't stay in touch. They don't write. They don't call. They don't visit. I have been in the hospital 19 times, and not once did they come to visit me. And it really blows a lot of people away when I tell them about that. That my family really doesn't care. They expect me to function as though I don't have schizophrenia . . . They never want to talk about it. They never want to discuss it. They never bring it up. It's like they want me to be normal, even though I have this illness.

This statement reveals cultural assumptions about traditional masculinity as well as about "aberrant" behavior. As such, Steven's illness threatens not only his status as "masculine" but also his class standing. It is the latter vulnerability that poses the greatest "threat of contagion" to the rest of his family, facilitating the erasure or delegitimation of Steven's experience described above. Similar cultural orientations are embedded in his parents' desire for him to be independent:

I think what [my parents are] trying to do is get me ready for when they pass. Pass away. So that I would be stable on my own two feet, so that when they're not there for me anymore, I can still get along. . . . They've got their own life. I've got my own life, too. There comes a time when you leave the nest and develop a life of your own. And there's just a lot of mentally ill people that I know of that are still at home.

In this statement, Steven situates himself in relation to "normality" and to others with mental illness, clearly revealing his sense of being "more recovered" than individuals who don't live independently.

Steven has an elaborate illness and recovery narrative, the trajectory of which is best characterized by the title of his memoir, *The Road from Hell*. This narrative is structured temporally—before-and-after—reflecting his sense of having moved beyond the "hell" of his illness. His present "recovered" status is no less remarkable than his low point of petty theft and homelessness. Steven was among the first people in the country to receive clozapine therapy and, as a result, has had his experience reported in the local and national media. On his business card Steven has given himself the title "Clozapine Role Model." In this way, Steven has assumed a new identity as a "model patient." As a "model patient" Steven resents being associated with other, lower functioning individuals with mental illness. Describing one particular psychosocial rehabilitation program he notes:

And they bring them together and expect you to be friends. Just because of your illness. But there's much more to friendship than just sharing an illness. I totally disagree with what they do, with bringing people together. It's very frustrating to me. 'Cause these people are all functioning on different levels. I'm on a pretty high level. A lot of these people are pretty low functioning. And they put me in there and expect me to gel with these people. I just can't do it. It just doesn't work. So I avoid them as much as I can. I play tennis with them on Sundays. That's not that bad, but other than that, I kind of keep my distance.

In this way, Steven's subjective perception of his recovery involves a reproduction of stigma such that he describes his own improvement relative to those less well functioning.

Medication and employment are the primary tools Steven uses to manage his illness.

Well, the primary thing is I take my medication . . . I try to keep myself busy, you know, so I don't have a lot of time to sit around and think about it . . . I just—I work two jobs. So, I just take my medication and work. That's how I handle my illness.

Medications and employment may also represent strategies employed for the management of stigma insofar as they facilitate a sense of "normality" for him. Prior to his current medications, "I wasn't able to control [the illness]—even if I wanted to I couldn't."

In spite of his substantial improvement—from being homeless to working two jobs and not being hospitalized for 14 years—Steven is nevertheless touched by stigma. In addition to his family's denial of his illness and lack of contact with his siblings, Steven describes being "rejected a lot." He speculates that he would not experience as much rejection if he were not mentally ill. He describes rejection in general terms, saying, "They just don't like me, you know. They don't want to get to know me, or they don't want to know me. I really don't know why. I don't know." Steven describes his difficulty with establishing friendships of "any quality or depth," having learned "that not everybody is compassionate or sorry for a person that has schizophrenia." Likewise, he has learned that not everyone cares about him, stating

I thought everybody cared. That really woke me up when I learned that. I learned that at work. There's some guys down there that don't, you know, they don't care. And that just makes it seem like that makes the long road [of recovery] ever colder. But that's a fact. That's a fact.

Most strikingly, despite Steven's improvement he worries that others can tell that he has schizophrenia. His viewpoint contrasts with ethnographic observations that Steven does not have the "look" of mental illness, describing him as "athletic," "clean cut," and "well groomed." Yet Steven is nevertheless sensitive to being perceived as different, stating

I might be by myself, like at the counter at the drugstore where I'd be paying for something, and somebody might make a stigmatized smart remark that where I know I'm not being paranoid that—they picked up on me. They were sensitive to something about me that caused them to make a remark like that.

Steven tries hard to "pass" for normal, "want[ing] to come off as though I don't have [schizophrenia]."

(4) Bill is a 35-year-old African American man who lives with a roommate whom he describes as his best friend. He is diagnosed with schizoaffective disorder. Onset of his illness is said to have occurred at age four; he has been ill for 31 years and hospitalized three times. His current atypical antipsychotic is olanzapine and he has been taking atypicals for two years. With respect to his illness, Bill reports that he is getting better. He describes his life now as good, yet he reports being mostly dissatisfied with his life overall.

Bill is not currently employed and has never been married. He estimates that he spends about 80 percent of his time alone, but he has regular contact with his family and a close relationship with his mother. Religion and church activities are particularly important for him; he attends church weekly and church-related functions frequently. Bill desires more social contact, noting that he would like to see more of his friends, “but they have lives” and he doesn’t want to depend too much on others. He is similarly reticent about romantic relationships in that although he is attracted to women he doesn’t want a relationship at this time because if it doesn’t work out he will take it “too hard.”

Bill’s desire to keep to himself may be interpreted as a particular strategy to avoid or manage experiences of stigma. He describes a past experience of rejection by saying, “I had a friend from high school and when I was hospitalized he stopped being my friend, so that’s my experience.” Similarly, he expects that people would have a “negative reaction” if they found out about his illness. For this reason, Bill selectively discloses his illness “to people I think I can trust” and states that “I usually just don’t say anything.”

Bill notes his family’s “prejudices about mental illness,” describing his perception of the dual nature of mental illness as both a basis for judgment by his family members and as a ready-made excuse for his behavior. For example:

I don’t have to always be the way they want me to be. I’m not that way. Sometimes they make allowances. Other times, they make judgments about me based on my illness. If I have an opinion that’s different, that they think is strange, they think it’s because of my illness.

Similarly, Bill describes himself as “lucky” insofar as

people don’t expect as much of me as they would someone normal, and I don’t have to um—be a certain way, ’cause of the illness I can be how I feel and have less pressure than a normal person would. I just attribute it to the illness.

Although on one hand “making allowances” might seem to be a sympathetic response on the part of his family and others, however, it could also reflect the pathologization of otherwise normal behavior, thoughts, and emotions. In addition, although Bill notes the benefits of “less pressure” as a result of his illness, his response nevertheless reflects, and perhaps reinforces, his perception of himself as “not normal,” setting up a strict opposition between those with and without mental illness.

Popular perceptions, as well as gender and ethnicity, also mediate Bill's illness experiences and perceptions of stigma. In describing others' expectations of him he states, "I think there's a tendency, everyone assumes, you know, the mentally ill, that I'm a danger to society. I'm more a danger to myself than anyone else."

Here Bill subverts the dominant popular "logic" that renders the mentally ill as especially prone to violence, instability, and unpredictability directed (randomly) toward society. Instead, he correctly notes that individuals with schizophrenia are much more likely to inflict physical violence or harm on themselves rather than on others. With respect to the role of ethnicity in shaping the stigma associated with mental illness Bill opines that:

I don't think [African Americans are] as open minded about it. I think they are a little more prejudiced about mental illness than other people might be . . . Because of their culture . . . Blacks aren't very sympathetic unless something is wrong with them that's wrong with you. Then they can understand . . . I think a lot of blacks think there is something wrong with me, like, you know, there's something bad about it.

Accordingly, empathy is understood to be the basis for compassion. Moreover, Bill articulates his impression that African Americans, on the whole, tend to attribute mental illness to a moral failing or character flaw. Adding still greater complexity to the social and cultural mediation of stigma are Bill's narrative statements regarding gender. In general, Bill speculates that mental illness is easier for women

Because I think men are supposed to stand on their own two feet and be strong and rely on themselves. They aren't supposed to be soft. With this illness [you can't help these things] so they think you're weak or something . . . [African Americans] have images, you know, man is supposed to be macho, women are supposed to be tough.

Stigma in each of these passages stems from a perceived incapacity or reduced capacity for individuals with mental illness to live according to normative gender roles, such that schizophrenia presents a blow to one's masculinity or femininity.

Discussion

In sum, both from the standpoint of the repertoire of strategies and from the standpoint of the individual cases we have examined, there are three overarching findings. First, there is a repertoire of specific strategies that persons deploy across a range of social contexts. Some are already documented in the literature, others have come into clearer focus in our data—notably those involving forms of resistance including concealment, confrontation, humor, or attempting to educate others. Second, examination of the strategies highlights a social resourcefulness not generally attributed to the "mentally ill." This resourcefulness is part of highly engaged struggle not only with personal illness experience but also with disparaging and discriminatory social responses. Third, we note the harsh irony of facing pernicious and multiplex forms of "stigma despite recovery." For these persons, there is an acute

awareness of life chances limited not only (or even primarily) by psychiatric symptoms, but also by the anticipation of rejection, attempts to steel oneself against hurt, the unpredictability of one's medicated body.

The strategies we have identified are vital for understanding problems of social engagement in that nearly all SEACORA participants acknowledged awareness of stigma as permeating nearly every domain of daily life. Although some might argue that this is only to be expected, we consider the magnitude of the perceived stigma to be striking. Our findings thus hold implications for the "work of recovery" (Davidson 2003) with respect to self-esteem and the negotiation of status loss, in addition to illness management and efforts to construct a satisfying and meaningful life. Previous scholarship calls attention to paradox, contradiction, and irreconcilable "catch 22" dilemmas as frequent defining features of the lived experience of recovery from severe mental illness (Jenkins and Carpenter-Song 2005). Life with mental illness, for many, includes the constraints of poverty, limited educational and job opportunities, social rejection, and discrimination. Particularly troubling is the pervasive awareness of stigma despite the overall low symptomatology and subjective sense of improvement among participants. The sequelae of mental illness, therefore, are crucial determinants of stigma over and beyond that produced by psychopathology itself.

Calling to mind H. S. Sullivan's (1962) maxim that those with schizophrenia are "much more simply human than otherwise," we note that social fears and anxieties are shared, at one time or another, by all of us. The struggle is perhaps only more vigorous for those in a situation of mental illness. This consideration reverses the tendency to deny subjectivity to the afflicted with the otherizing assumption that "nobody's home." It impels research toward more explicit attention to fundamental human processes and capacities for subjectivity in the context of schizophrenic illness and recovery, and it opens the door to recognizing that in certain respects schizophrenia can serve as a paradigm case for the study of fundamental human processes of everyday life beyond the boundaries of affliction (Jenkins 2004).

In this light, we understand stigma as an intersubjective social and cultural process of the production and reproduction of responses to schizophrenia and schizoaffective illnesses, particularly with respect to the multiple creative strategies that individuals craft to dampen and to counter the damaging and otherwise paralyzing effects of social stigma. To specify the experiential salience of strategies deployed by participants to manage stigma in such a way as to be of use for comparison with people afflicted with schizophrenia in other settings, it is critical to place our findings against the background of four sets of issues that define the intersubjective setting of their everyday lives: (1) the social characteristics of each afflicted person, (2) the situational characteristics of managing stigma, (3) the cultural context of recovery, and (4) the illness-specific characteristics of schizophrenia.

(1) Against the demographic background of our 90 participants as described above, we can most clearly represent the range of social characteristics among SEACORA participants with reference to the four case studies we have presented: a Euro-American woman (Christy), an African American woman (Alicia), a Euro-American man (Steven), and an African American man (Bill). Bill is most explicit that managing stigma is more difficult for men than women and for blacks than whites; Alicia's apprehension about becoming romantically involved with a man

appears to compound stereotypical concerns about the potential violence of the mentally ill and of African American men. Bill articulates that his illness allows him to function with decreased expectations, and both he and Alicia are unemployed; Steven articulates the need for employment as a hedge against stigma, and both he and Christy are employed. Gender differences are not pronounced, although men tend to experience challenges to their masculinity relatively more in relation to work and women to experience challenges to femininity relatively more with respect to weight gain; both men and women tend in principle to express a desire for intimate relationship, but few are currently so involved. With respect to social class, of these four persons three are of working-class background and only Steven can be described as upper middle class. This is reflected in his relative emphasis on employment and autonomy, his relative distance from parents and siblings, and his lack of religious involvement. By contrast, Christy has the most tightly knit supportive network of extended family and church connections, and it is to these social characteristics that we attribute her unique circumstance of never having been hospitalized for her illness. Alicia is more demonstratively religious and overtly devout but experiences guilt over her illness and requires spiritual reassurance from church leaders, although the numerous religious activities that Christy quietly takes for granted form part of the supported fabric of her daily life.

(2) In a forthcoming publication we will systematically examine a range of social settings (work, family, dating, leisure activities, church) and identity domains (gender identity, self-presentation, medication, popular culture perceptions, social class, ethnicity) in which SEACORA participants encounter stigma. With reference to the material we have presented here, however, by situational characteristics we refer to three critical distinctions that bear on the deployment of strategies for managing stigma when it is encountered. First is whether one is dealing with the direct expression of stigma in the form of stigmatizing words or actions, or whether one is attempting to avoid being subjected to such stigmatizing behavior. Second is whether the stigma to be managed is directed at one's overtly symptomatic behavior or at the mere fact that the person is known to have schizophrenia. Third is whether one is dealing with explicitly stigmatizing behavior or with suspected (covert) stigmatizing behavior on the part of others. In each of these instances, the second alternative is arguably the most anxiety provoking and difficult to manage because of its ambiguity and the necessity of discerning not only how to respond, but if indeed there is anything to which one should respond, and whether in any specific situation one is being perceived as "weird," "off," "different," or "crazy." In this connection, for example, SEACORA participants uniformly expressed sensitivity to whether in social situations they were exhibiting "the look"—that is, the look of someone who has schizophrenia as perceptible to others. This concern with "the look" is perhaps the key distinguishing feature of this group of relatively high-functioning patients with relatively well-controlled symptoms.

(3) Participants in the SEACORA study inhabit a cultural milieu in which their problem is explicitly identified as a particular kind of illness (not just generically mad or psychotic, although they often refer to their problem as "mental illness" rather than specifically as "schizophrenia"), and in which people with chronic illness have certain kinds of entitlements (disability rights) and even advocacy organizations (e.g., the National Alliance for the Mentally Ill). There are ideas about its origin

(genetic or psychogenic), about how to treat it (psychopharmacology or psychotherapy), and its expected course (deterioration or amelioration). The social environment is one in which options range from homelessness to security in an extended family, independent living or hospitalization, religious involvement as supportive milieu or religious delusions as socially isolating symptoms, interaction in clinic settings and therapy groups with others identified as having similar problems, and continued exposure to others' expectations of and their own desires for economically productive employment (Alverson et al. 2007) and intimate personal relationships. Certain living situations, including group homes and living with relatives, may threaten a cultural value of individual autonomy. Receiving government benefits such as Social Security income may create disincentives to paid employment (esp. insofar as people fear losing access to healthcare) and threaten values of self-reliance.

They are in a treatment environment in which their symptoms are relatively controlled such that they can compare their own florid episodes with their steady state and the everyday threats and risks to losing control and being hospitalized. They not only experience stigma but work with it as an emic concept, and in varying degrees can assess both their own expectations of themselves and how they appear to others. This comparison of their own states, awareness of stigma in the environment, and ability to see themselves as others might see them are components of a culturally constituted reflective self. This reflective self is not one to react to the objective encounter with stigma in cultural terms of karmic inferiority or kin-based shame, but primarily in North American ethnopsychological terms of self-esteem. It is also related to a cultural context in which self and personhood are closely associated with an intact mind as much as an intact body, such that somewhat who is "not all there" mentally is not a fully integral or legitimate person (Jenkins 2004). Moreover, to the extent the mind and self are identified with personhood in American culture, the more the mentally deficient will be singled out for stigma and experience diminished self-esteem and social status (Shuttleworth and Kasnitz 2004:147). In the case of schizophrenia construed as a weakness of will in contrast to organic impairment or retardation, such stigmatization is arguably less likely to be tempered by pity and compassion, as is the case, for example, among Mexican Americans (Jenkins 1988a).

(4) In comparison with those afflicted with other physical and even some mental illnesses, schizophrenia may be distinctively stigmatizing in light of typical onset occurring in early adulthood that "greatly compromises one's ability to meet developmental demands essential to achieving self-reliance, such as completing school, finding employment, and living independently" (Yang et al. 2007:1530). In the case of schizophrenia, the cultural environment directs attention not toward disability but toward behavior, not toward deformity but toward peculiarity. The potential stigma of being "different" or not "normal" does not carry the same connotation as it might for an amputee, a diabetic, or even a depressed patient. It is in principle contestable, as in the case when people with schizophrenia object to an interpretation that a particular behavior is because of their illness when they "considered it to be a normal response to a given situation (e.g., being criticized or trying something new)" (Davidson 2003:127). These are people whose symptoms are largely held in check by medication but who both accept the premise (and have occasional experience that confirms the premise) that the underlying illness remains and can be

exacerbated by factors such as stress, events, or not taking medication. The challenge of everyday life, whether or not it is explicitly formulated as such, is how to be and act, how to present oneself, how to inhabit a world that sometimes feels strange just as it sometimes sees one as strange. In the process they must contend with widely disseminated cultural stereotypes such as that “schizophrenics can be unpredictably violent.” They are not so much dehumanized as either not taken seriously or regarded as a threat, and as either being invisible or too visible.

Our purpose in this article has not been to propose a general theory of stigma but to examine the concrete lived experience of persons afflicted with schizophrenia and schizoaffective disorder as they struggle with stigma in a specific time and place. Thus we make no claim that our results are generalizable in the strict sense, but only that we have presented them in such a way as to facilitate comparison with the experience of afflicted persons in other cultural settings and perhaps with other illnesses. Our data are unique in the literature on psychiatric stigma in that they are derived from a meaning-centered cultural approach based on ethnographic interviews and observation focused on how lived experience is shaped by stigma, and in that they are based on data from a large community sample of persons with schizophrenia. We note that this sample consists of treated individuals whose symptoms at the time of participation in the study were relatively well controlled, who were relatively high functioning, and whose living situations were stable, and therefore cannot be considered representative of those who are untreated, highly symptomatic, have low functional status, or are living either homelessly or in institutions. A considerable advantage is that the more reflective and articulate among participants were able to verbalize comparison of their worst illness episodes and their most symptom-free periods. In addition, because we worked with this group relatively early in the period of transition from conventional to atypical antipsychotic medication, they were able to compare their experience with both types of medication, and we were able to document the experience of an early group of patients taking a class of medication that has since become the treatment standard.

Conclusion

Transnational research on schizophrenia suggests that the meaning of symptoms varies significantly between cultural groups (Jenkins 1988a, 1988b; Jenkins and Karno 1992; Kleinman 1988b; World Health Organization [WHO] 2001). Research has also documented variations in the threshold for psychiatric stigma between developed and developing countries, linking better long-term outcome for schizophrenia in developing countries to differential social responses to mental illness, and suggesting that stigma may be mitigated in developing countries other than those of the European Union and the United States by (1) greater social inclusion, (2) communal solidarity around the affliction, and a (3) higher threshold for labeling madness (Rosen 2003). Moreover, given the long-standing finding originating with the WHO International Pilot Study of Schizophrenia (IPSS; WHO 1973, 1979) that schizophrenia has worse outcomes in the Northern hemisphere and more affluent countries, we can hypothesize that stigma encountered in the North might be more pernicious for clinical and social outcomes. Although this could be a valuable hypothesis, we must also recognize the dismal reality of social stigma across all cultural

settings to guard against romanticized notions such as that in developing nations stigma is absent or that the mentally ill are valorized. Thus, although the findings of the present study must be understood as particular to an urban U.S. group of relatively high functioning persons who regularly receive outpatient psychiatric treatment, we nonetheless expect a commonly shared experience of stigma attached to serious persistent mental conditions worldwide along with culturally specific nuances of meaning (Hopper 2004; Jenkins and Carpenter-Song 2005; WHO 2001).

The broader implication of our analysis of stigma in the SEACORA study is that it points to the need to identify and describe strategies employed by mentally ill persons in contexts in which they are aware of stigma and that may either be shared cross-culturally or, conversely, found to be distinctively different. In-depth anthropological investigations involving a sufficiently large sample size such as the present study are required in future for further empirical comparison. We may speculate, however, that given the widely documented existence of stigma in relation to mental illness worldwide (Kleinman 1988b; WHO 2001), future research will find a broad concordance of an awareness of stigma as a matter of everyday lived experience across a range of settings. Even so, we would likewise expect that the cultural meaning of the specific domains of stigma experience are likely to vary (e.g., surrounding diagnosis, medications, distancing of social relations) in several respects yet be similar in others (e.g., dating prospects, popular perceptions of fear).

The predicament of the persons we have described is contradictory: on the one hand, they have recovered relative to previous states of psychosis; on the other hand, their subjectivity is saturated by intense awareness of social stigma that is intractable in relation to performative or temporal criteria. That stigma attached to schizophrenia-related illnesses persists in the wake of substantial improvement or recovery is indicative of just how hostile social response to those perceived as mentally ill remains even in the face of objectively low levels of symptomatology, relatively high levels of social and work functioning, and a substantial subjective sense of personal improvement. Ironically, these lives can be characterized as fraught with stigma despite recovery. Even so, a multitude of strategies were generated to resist the impact of stigma. These strategies highlight the fact that persons with mental illness can be not only exceedingly socially aware but also strategically skilled in response to social assaults on their personhood and survival. In this respect their existential focus, as well as our interpretive focus, shifts away from the exclusivity of victimization and toward the subjectively perceived possibilities for agency.

Notes

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1. This study identified psychiatric diagnoses through use of the SCID instrument, in standard use to ensure comparability of research reliable diagnostic criteria (as opposed to clinical diagnoses that can be more variable) administered by an SCID-trained psychiatrist. Persons were included in the study if they met criteria for schizophrenia or

schizoaffective disorders, also commonly included in schizophrenia-related psychiatric studies. Schizoaffective illness may incorporate a more mixed diagnostic picture to also include depressive or manic features.

2. For a discussion of subjectivity and the felt flow of experience as the “rhythm of life,” see Jenkins (1997).

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