Awareness of Stigma Among Persons With Schizophrenia

Marking the Contexts of Lived Experience

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Abstract: This article investigates the subjective experience of stigma attached to schizophrenia-related disorders. We examine data from anthropological interviews from a community sample of 90 out-patients residing in a metropolitan area of the United States. Patients were under treatment with atypical antipsychotic medication, and their symptoms were for the most part relatively well controlled. Overall, 96% of participants reported an awareness of stigma that permeated their daily life. Based on an understanding of stigma as a product of interpersonal, reciprocal social processes, we identify 6 types of social relations and 5 identity domains in which social stigma is routinely encountered by participants. We describe the experience of stigma in each of these 11 subcategories, and suggest that taken together they constitute a framework of social and personal factors involved in the struggle to recover from psychotic illness. Among types of social relations, anonymous social interactions most commonly generated an awareness of stigma. Among identity domains, being a person who regularly takes medication was most commonly associated with an awareness of stigma. The finding that multiple forms of stigma are encountered irrespective of substantial symptomatic, functional, and subjectively perceived improvement creates a complex situation of stigma despite recovery.

Key Words: Stigma, schizophrenia, subjective experience, antipsychotic medication, recovery, qualitative methods.

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Stigma is increasingly recognized as a global public health problem across a range of illness conditions (Green, 1995; Keusch et al., 2006; World Health Organization, 2001). The global impact of stigma on health care systems, economic productivity, and society at large is extensive and is “a very persistent predicament in the lives of persons affected by it” (Link and Phelan, 2001, p. 9). Stigma associated with mental illness appears to be a cross-cultural universal (Link et al., 2004; Pickenhagen and Sartorius, 2002; Yang et al., 2007). In spite of increased public knowledge about mental disorder, findings from attitudinal surveys suggest that psychiatric stigmatization is pervasive (Angermeyer and Dietrich, 2006; Bhugra, 1989; Rabkin, 1974) and has increased in the United States, particularly with respect to the perception that individuals with psychotic illnesses are violent and frightening (Link et al., 1999; Phelan et al., 2000). Corrigan et al. (2003) conducted a survey of 1824 persons with serious mental illness on perceptions of discrimination applied to mental illness compared with other social characteristics such as ethnicity, gender, or sexual orientation. Over half reported experience with discrimination and the most frequent source of this discrimination occurred in relation to mental disability. Such findings are particularly disturbing when coupled with the observation that surveys of explicit attitudes toward those with mental illness may underestimate the pervasiveness of stigma due to socially desirable response tendencies (Link and Cullen 1983).

THE PROCESS OF STIGMATIZATION

Much of the social psychological scholarship on stigma concerns specifying the mechanisms underlying stigmatization. Measures of implicit attitudes—so-called “unconscious” attitudes or biases—are a recent development intended to avoid the pitfalls of socially desirable responses. A study by Teachman et al. (2006), employing the Implicit Association Test demonstrated negative implicit attitudes toward mental illness, with 58% to 78% of participants associating the concepts “bad,” “blameworthy,” and “helpless” with mental illness. Explicit and implicit attitudinal measures are useful in documenting broad societal orientations toward persons with mental illness. Yet these studies do not examine the impact of stigmatizing attitudes on those with mental illness (Hinshaw and Stier, 2008; Link et al., 2004). Thornicroft et al. (2007) have recently noted that attitudinal and social distance research has “generally focused on hypothetical rather than real situations, neglecting emotions and the social context, thus producing very little guidance about interventions that could reduce social rejection” (p. 193). Moreover, research by Corrigan and Watson (2002) highlights that psychiatric stigma does not manifest solely in public attitudes. Corrigan and Watson (2002) have usefully distinguished public stigma, “the reaction that the general population has to people with mental illness,” from self-stigma, defined as “the prejudice which people with mental illness turn against themselves” (p. 16).

Social-cognitive processes such as stereotyping figures prominently as ways in which “in group” members affirm positive and individualistic traits of themselves in contrast to “out group” members, who are portrayed homogeneously and negatively (Hinshaw and Stier, 2008). Such basic social psychological processes are considered to account, in part, for a degree of “automatic” and “inevitable” stigma that subsequently becomes intensified by the “threat” posed by disordered behavior and mental illness labels (Hinshaw and Stier, 2008). In this regard, social psychological models conceptualize stigma as a process whereby certain “attributes” or “marks” are associated with a “devaluing social identity” or “discrediting disposition” in the context of social interactions (Crocker et al., 1998; Jones et al., 1984). Such formulations echo Goffman (1963), who defines stigma as rooted in an “undesired difference,” an “attribute that is deeply discrediting” and that results in a “spoiled identity.” The complex ways in which individuals navigate their social worlds—how to manage information regarding one’s condition, contending with the expectation of stigma, efforts to pass—constitute the “moral career” of the stigmatized.

Keusch et al. (2006) have recently called for a reinvigoration of the “science of stigma” and advocate building upon the insights set forth by Goffman (1963) to examine stigma as a “cultural disease that marks its victims as morally tainted” (Keusch et al., 2006, p. 526). Although Goffman’s formulation emphasizes stigma as a social construction, social psychological frameworks tend to reduce
stigma to processes occurring at the individual cognitive level in response to social stimuli. As Yang et al. (2007) have noted, although such social psychological mechanisms are relational in structure: “analysis of these models reveals that they primarily regard the social aspects of stigma as a psychological variable (i.e., ‘social identity’ as applied to an individual), as an environmental stimulus that the individual appraises as threatening to, or as societal or cultural stereotypes. Further, these models restrict the range of coping responses to the stigmatized individual’s reactions (e.g., cognitive coping strategies) and the harmful outcomes of stigma to individual self-processes (e.g., psychological well-being). These models suffer from limiting conceptualization of the social to those environmental elements of stigma that ‘impinge upon’ the individual sufferer, who is then viewed as the primary locus in which stigma processes take place” (p. 1525).

Link and Phelan (2001) summarize recent social psychological research to show that people construct cognitive categories and then customarily link those categories to preexisting stereotyped notions. Going beyond this well-known association, they make a convincing case for understanding stigma as a set of social components that includes labeling, separation, status loss, and discrimination (see also, Sartorius, 1998). These elements, they aver, unfold in the context of unequal social, economic, and political power. Accordingly, the process of stigmatization is such that persons with mental illness are socially identified as different, this difference is ranked and linked to negative social stereotypes facilitating the construction of individuals with mental illness as “others,” which, in turn, provides a rationale for devaluing, rejecting, and excluding them. Furthermore, Link and Phelan (2001) identify 2 key problems in current literature on stigma: (1) an overemphasis on individual attributes derived from social psychological research methods that rely on scalar instruments; and (2) a notable absence of research on the lived experience of persons who struggle daily with stigma. A literature review by Link et al. (2004) offers evidence that research conducted from the standpoint of individuals with mental illness or their close associates accounts for a minority of studies, and qualitative methodologies of interviewing and participant observation are uncommon.

The Experience of the Stigmatized

Moving toward an approach that takes into account the lived experience of stigma as an interactive phenomenon, Corrigan and Watson (2002) developed a situational model of personal response to stigma that varies substantially in relation to the person’s perception of its legitimacy as applied to them. Camp et al. (2002) investigated whether low self-esteem was an inevitable consequence of stigma among a group of 10 women using qualitative analysis, revealing that while these women considered that they had a mental illness, they did not accept society’s unfavorable representations of them on that basis (cf. Link et al., 2001). Sajatovic et al. (2005) highlight an additional dimension of the relationship between stigma and the self in their investigation of gender identity and gender role performance among individuals with schizophrenia-related disorders. They note that while individuals with schizophrenia are likely to experience lowered self-esteem in relation to the stigmatizing effects of mental illness, it is also likely that specific disturbances in gender identity and gender role performance likewise confer negatively upon sense of self-esteem. In their recent review of stigma related to mental disorders Hinshaw and Stere (2008) observe that stigma involves stereotypes, prejudice, and discrimination that limit the life chances of those stigmatized. Yet they also observe that stigma processes are not reducible to these phenomena in light of the often all-encompassing nature of stigmatizing characterizations, the shame experienced by the stigmatized, and the crippling effects of stigma on social interactions that become shadowed by hostility, rejection, and anxiety (Hinshaw and Stere 2008).

Aside from the literature constituted by memoirs of individuals living with mental illness (Deegan, 1988; Gallo, 1994), there has also been a slowly accumulating literature that has incorporated first-person perspectives on psychiatric stigma. For the most part these studies have been based on data from focus groups, surveys, and questionnaires (Corrigan et al., 2003; Perlack et al., 2001; Schulze and Angermeyer, 2003; Wahl, 1999) or from semi-structured interviews with small samples sizes (N ≤10) (Camp et al., 2002; Knight et al., 2003). These studies point to multiple pathways for the constitution of the self and self-worth, and have important implications in the illness recovery process which requires self-management and reintegration of the individual into the community (Davidson, 2003). The findings of Dinon et al. (2004) based on their study of 46 individuals with mental illness align well with our findings of the pervasive awareness of stigma and the importance of managing illness information among persons with schizophrenia. However, from an anthropological perspective, Dinon et al. (2004) do not adequately situate the experiences of the individuals they interviewed within their interactive context. Indeed, ethnographic data on the immediate contexts of stigma in the community are in short supply (Phelan et al., 1998).

Against this conceptual and empirical background, and with an understanding of stigma as an interactive phenomenon with its locus in lived experience, we ask two questions in this article. First, to what extent is stigma pervasive in the lives of the afflicted? Answering this question requires specifying the range of contexts in which people encounter stigma, and in which stigmatizing behavior might take different forms. Second, how do people afflicted with schizophrenia perceive and experience stigma? An approach attuned to stigma as an interactive phenomenon will not be satisfied with a global notion of “spoiled identity,” but will identify how differentness and otherness are constituted in instances of being snubbed, teased, rejected, talked about, or even looked at in an unusual way. This is all the more salient among a population such as that examined herein, among whom symptom levels are relatively well controlled and social functioning is relatively high. Our data on stigma are drawn from a broader anthropological study entitled “Schizophrenia and the Experience of the Culture of Recovery through Atypical” (SEACORA), which examined the subjective experience and meaning of illness and either worsening or improvement/recovery among 90 persons diagnosed with schizophrenia-related disorders and taking “atypical” or “second generation” antipsychotic medications (Jenkins et al., 2005; Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song 2008).

METHODS

Sample Selection

In a northeastern US metropolitan area, we obtained the complete rosters of 2 community mental health outpatient facilities that served Euro-American and African-American ethnic groups. The first clinic is affiliated with an academic research community and was developed specifically to deliver clozapine treatment. Those attending the clinic often spent significant amounts of time on site, ranging from every day visits to once or twice per month. The second clinic had a relatively less developed research focus, and patients came briefly for biweekly or monthly medication checks. Study 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, some subjects in the study (N = 6) were prescribed atypical antipsychotic drugs as their first psychopharmacological treatment.
Selection criteria included: (1) diagnosis of schizophrenia or schizoaffective disorder assessed through the Structured Clinical Interview for DSM-IV (First et al., 2002); (2) age 18 to 55; (3) at least 2 years since first psychotic symptoms; (4) at least 6 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. Eligibility was assessed by treating psychiatrists and therapeutic managers, and resulted in a complete list of all patients who met research diagnostic criteria. From this list, 167 eligible participants were randomly sampled. Of those selected, 90 (54%) were included in the final sample, with 46.7% declining research participation. The overall high rate of refusal is not unusual (Covell et al., 2003) for an American community out-patient sample such as this, with males (55.9%) significantly more likely than females (29.3%) to decline participation (Fisher exact test, p < 0.001). Reasons for nonparticipation included lack of interest in research (stating simply they “did not want to”) or a reluctance to provide time for interviews (due to 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 were more interested in research, sometimes stating that they had an interest in cooperating with anything that might benefit others (or themselves) in future. In this regard, the sample may be more cooperative and less symptomatic, more socially functional, or potentially more likely to have had a positive experience with medication or their physicians than those in the group who declined participation (see also, Jenkins et al., 2005).

Procedures
For this study of subjective experience of schizophrenia, we employed techniques of ethnographic interviewing, naturalistic observation, and procedures for research diagnostic criteria (Structured Clinical Interview for DSM-IV) and symptom severity (Brief Psychiatric Rating Scale [BPRS]). The research psychiatrist for the project was trained in the reliable administration of both of the latter instruments. This article, however, is based on stigma-related data generated by the ethnographic interview. The ethnographic interview, the “Subjective Experience of Medication Interview” (SEMI), is a semi-structured, open-ended qualitative procedure adapted from interviews used in prior research (Jenkins, 1997). As a qualitative procedure, the SEMI serves as an interview guide in which there is flexibility in the administration of interview questions. If a subject is highly responsive and generates narrative on a topic of interest, the predesignated interview questions may be used sparingly. On the other hand, if a respondent is not highly responsive in generating narrative on their own initiative, the interviewer may use questions and follow-up probes more extensively in an effort to obtain the persons’ point of view. The substantive domains covered by the SEMI include the experience of medication and treatment, living situation, everyday activities, illness management, social relations, gender identity, expectations concerning recovery and quality of life, and stigma. Qualitative data on any topic, including stigma, might be generated at any point of the interview. Examples of specific questions posed to eliciting stigma-related data were as follows: “Do you tell people that you have (diagnosis)? That you’re on medication? Who do you tell?” and “What kinds of things do you try to do to keep people from finding out?” “Does anybody act different toward you because of your illness, or because you take medication?” “For yourself, do you prefer friends or dating relationships among people who also have a mental illness or those who do not have a mental illness?”

The duration of the SEMI interviews was generally 1.5 to 2 hours over 1 to 3 interview sessions. Interviews were conducted by the Principle Investigator and a team of 4 doctoral students in medical anthropology. All SEMI interviews were transcribed verbatim from audiotape and entered into the Atlas.ti qualitative software program (Scientific Software, 1997) which is designed to code and analyze qualitative data systematically (Good, 1994; Luborsky, 1993). The 90 SEMI interview transcripts, averaging 92 double-spaced pages, were read and coded by the two authors (J.J. and E.C.S.). A grounded theory approach in which thematic categories are inductively derived (Strauss and Corbin, 1990), yielded 34 substantive categories, of which “stigma” was one. In any instance in which content of a text segment was in question, relevance of that text segment to stigma was confirmed or disproven through review and consensus between the 2 coders, as customarily required for systematic qualitative analysis of large volume textual data (NIH, 2001; Taylor and Bogdan, 1998; Warren, 2002). We coded data “yes” for awareness of stigma if at least 1 of the following conditions was met: (1) the subject indicated that people react negatively toward them in response to the direct questions listed above; (2) the subject volunteered information about awareness or experience of psychiatric stigma in any other part of the SEMI interview. Coding a “no” response cannot be considered as a definitive determination that the subject did not perceive or experience stigma, but only that the response reflects absence of any report of stigma in the interview transcript. Reports of perceived stigma were secondarily coded by the same 2 coders to identify the contexts in which subjects experience stigma, yielding the categories of social relations and identity domains shown in the results below.

Sample Characteristics
Sociodemographic and clinical characteristics of the 90 SEACORA participants have been more fully summarized elsewhere (Jenkins et al., 2005). In brief, males constituted 54.4% and females 45.5% of the sample. Euro-Americans accounted for 77.8% and African-Americans for 22.2%. 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% single, 5.6% married or living with a partner, and 10% divorced, widowed, or separated. Those living alone accounted for 25.6%, those living with a roommate or in a group home for 22.2%, those with a relative or parent 42.2%, and those with a partner or spouse 10%. Fully 60% were unemployed, 22.2% were working half time or less, and 17.8% were working from half to full time.

Diagnostically, 81.1% participants had schizophrenia and 18.9% 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 1–7, absent to severe, respectively) on the 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/depression (see, Jenkins et al., 2005 for fuller discussion). There were no significant differences in socioeconomic status by ethnicity.

RESULTS
Nearly all persons in the study (80% or 96.0%) reported perception of stigma across a variety of social settings that they encounter on a daily basis. In general, the low symptomatology among study participants (Jenkins et al., 2005) does not appear to afford these individuals any considerable measure of protection from the blows of stigma. In fact, for some participants, improvement may create the conditions for a subjective discernment of pervasive stigma to be felt with greater acuity, what we refer to as the paradox of stigma despite recovery.
TABLE 1. Awareness of Stigma

<table>
<thead>
<tr>
<th>Social relations</th>
<th>%</th>
<th>N</th>
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</thead>
<tbody>
<tr>
<td>Anonymous social interactions</td>
<td>47.7</td>
<td>41</td>
</tr>
<tr>
<td>Work relations</td>
<td>36.0</td>
<td>31</td>
</tr>
<tr>
<td>Dating relations</td>
<td>32.6</td>
<td>28</td>
</tr>
<tr>
<td>Family relations</td>
<td>22.1</td>
<td>19</td>
</tr>
<tr>
<td>Acquaintance relations</td>
<td>12.8</td>
<td>11</td>
</tr>
<tr>
<td>Friendship relations</td>
<td>11.6</td>
<td>10</td>
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Identity domains

| Medication use                           | 44.2 | 38 |
| Popular culture                          | 24.4 | 21 |
| Gender                                   | 19.8 | 17 |
| Self presentation                        | 18.6 | 16 |
| Social class and ethnicity                | 5.8  | 5  |

*Total number of subjects equals 86 who indicated awareness of stigma; 4 responses were judged as lacking or insufficient to code presence of awareness of stigma.

A 39-year-old Euro-American woman living with her parents in a lower middle class suburban neighborhood, who has been ill for 21 years, attempts to de-emphasize her illness and does not reveal her illness to people other than close friends and family. Otherwise, she says:

R: Well, the people I do know, already know. Like the relatives and friends of the family probably know I have problems, but someone like a stranger, someone I wouldn’t know. Or like when I go to welfare. The lady at welfare knows I’m on disability, and um, sometimes I feel that she’s looking at me in a different way. I just try to carry myself in a proper way not to let people know that there’s something wrong with me. Because then, like I say, I’m funny about that.

I: Uh hm. Yeah. And what is the proper way?

R: Well, I, some people just come out and say, you know, I’m sick or you know, I got a problem. I’ll just try to, try to hide it. (Uh hm.) I would just try not to make it obvious. (Uh hm.) Because some people can be really cruel, you know. Um, they can say, ‘well what’s wrong with her, you know? You know how people are. They, they can just kinda get funny about that kind of stuff.’

She expressed anxiety and discomfort as common for her when walking on the street, a situation in which she felt people were staring at her for appearing strange.

Work Relations

Overall, 36.0% were aware of stigma in the context of social interactions related to work. As expectable, those working currently (36 or 40%) were significantly more likely to report stigma in relation to work (50.0%) than those not currently working (24.1%) (Fisher exact test, p < 0.02). While it is obvious that those currently working would be more preoccupied with stigma in this context, its salience in the context of previous or prospective employment was also noteworthy. Transactions in the workplace included the perception of hostile or fearful attitudes, teasing, violation of confidentiality, discrimination and unfair treatment, pejorative stereotyping or insensitivity by coworkers/supervisors, as well as the fear of either not being hired or being fired on the basis of mental illness. Finally, negative reactions by others because one does not have a job were also noted.

One illustration of stigma encountered at the workplace was provided by a 36-year-old Euro-American woman living with her parents. She works as a salesperson in a department store, where she fears people know about her condition. The sources of her fear are her own behavior as well as that of others. For her part, she says that she sometimes becomes confused about when employee breaks are scheduled, a potential problem since these must be negotiated and coverage of the various departments had to be ensured. She imagines that her confusion may have given coworkers reason to surmise she is ill. Nevertheless, she makes a point of not revealing her illness to people at work, a sore spot in light of a recent action on the part of a store manager.

“Um, no, I generally, most of the time I don’t, like especially at work. I figure it’s really none of their business. I have a sneaking suspicion that some people might know or have guessed (mental illness). Because one time there was a manager, over in another department, I had mentioned that I had to see my Medicaid lady to her. And then we were in the hallway, and I had either clocked out for the day or was about to, and I talked to her about that appointment. And she says something about blah, blah, blah, you know, about your disability and it was, there was still a lot of people around, and I don’t know. They might have known or have guessed.”

Another example of the way in which stigma and symptomatic worsening are reciprocally related comes from a 39-year-old

(Jenkins and Carpenter-Song, 2008). The remainder of our analysis will consist of specification of this social matrix of contexts of subjective awareness of stigma.

The diversity of contexts in which there is a heightened awareness of stigma underscores the pervasiveness of stigma within the everyday experiences of individuals with schizophrenia-related disorders and illuminates the ways in which stigma surrounding the illness shapes nearly all aspects of everyday experience. The contexts of the awareness of stigma constitute 2 categories: (1) social relations and (2) domains of identity (Table 1). In the category of social relations, study participants identified differences in the perception of stigma in anonymous interactions, work relations, dating relations, family relations, interactions with acquaintances, and interactions with friends. The category of identity domains includes gender, self-presentation, social class, and ethnicity. We also include popular culture as an individual may define him/herself in relation to a media-derived social context, and medication use insofar as our earlier analysis demonstrated the considerable extent to which persons identified themselves in relation to reliance on psychotropic medication (Jenkins and Carpenter-Song, 2005). In sum, although it is not surprising that people report stigma across these varied social relations and identity domains, our purpose here is (1) to point to the quality of stigma as lived experience in each of the contexts, and (2) to indicate how the set of contexts constitutes a comprehensive framework of the struggle to recover from psychotic illness.

Social Relations

Anonymous Social Interactions

The category of stigma in “anonymous interactions” occurred among strangers in public, commercial, or bureaucratic social settings. This included settings such as the street, bus, library, parks, drug and grocery stores, restaurants and coffee shops; and governmental and welfare offices. The ways in which persons felt the presence of social stigma in these diverse settings included discomfort over the sense that verbal and nonverbal communications were directed toward them to signal identification and labeling of them as mentally ill, strange, frightening, or of lesser intellectual and social capacity. Besides the perception of disapproving and derisive messages, people in the study also reported the sense from strangers that they could be patronized on the basis of one’s condition, on the one hand, or a target of vulnerability, on the other.

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African American man who lives alone in a condominium purchased for him by his parents. Recently hired to work in a hospital setting, he began to feel uncomfortable in the work setting because he was taking medication. This led to a series of events beginning with his decision to stop taking medication, ensuing difficulties with his supervisor, and subsequent suspension.

"When I was working in the hospital, I stopped taking the medication a couple of weeks or so after I got hired because I felt bad about having to take medication and having an illness and being diagnosed as schizophrenic. And um, instead of educating myself or educating other people about it, I chose to just stop taking it. And um, that was bad. And then I was, had a fell out with my boss and got put on suspension. And, even though when I came back they paid me for the times I missed, they understood that I have a sickness, and illness. And when I came back I was on the medication and I really didn’t know what to say to people or what to, how to explain it, what was going on. And I felt like I was under a magnifying glass and it was really uncomfortable. That was really hard for me."

This example of stigma in the workplace interrelates with the identity domain of medication examined below whereby disapproval of the self is unwittingly conjoined by social disapproval by others.

**Dating Relations**

Dating is an area of social relations that participants identified as a source of unease. About one-third (32.6%) described either being rejected by potential dating partners because of mental illness or acknowledged not wanting to date another person with mental illness. As for the above social relations, people described reluctance to reveal illness or medications because of fear of frightening others, fear of rejection, stereotyping, teasing, and fear of mistreatment and vulnerability in relation to dating. In addition, while weight gain in women and personal appearance constituted an impasse to the prerogative to date for women and men alike, women tended to worry somewhat more about such limitations. For their part, men were more preoccupied that they could not meet cultural expectations that they have money, a car, and perform sexually. Overall, women (41.5%) were more likely to speak about such limitations compared with men (22.4%).

An interview exchange with a 35-year-old African American woman illustrates the problem of feeling disallowed to date on the basis of mental illness: I: So are there particular difficulties for people with mental illness, or with schizophrenia in particular? R: Oh, yeah, for me there is, quite a bit. You know, that’s the thing, you know, I think that there’s really, only, not much choice in the way of, you know, dating people because I think if you’re a girl that has mental problems, or whatever, you know, well at least I know, normal guys don’t look twice at me. They don’t!

The following interview interchange with a 39-year-old Euro-American woman illustrates what she felt is at stake if you have a mental illness and get involved in a romantic relationship:

I: Do you think that love is difficult?
R: Love is very difficult. Love is difficult because you risk—you risk everybody laughing at you if you love somebody.

I: Everyone laughing at you? And why is that? Why would they be laughing?
R: Someone [told me] once, um—it’s impossible for people—for schizophrenics to actually love. I go why? "Because your head gets involved with everything." I don’t know.

I: What do you think about that?
R: I don’t—it’s pretty hard. Take advantage of, thinking that maybe I’m—you’re not good enough for this person, you’re not good enough for that person. Something like that. Thinking I’m not good enough to be with that person. That you’re crazy and stuff.

Finally, a 47-year-old Euro-American man who lives alone in an apartment conveyed ambivalence on the subject of dating by saying that “Sometimes I feel strongly that I’d like to meet somebody, and sometimes I don’t, you know.” His sense of dating as “very risky” was borne out by this comment that “there’s no guarantees that it’s going to work out the way you want it to.” In addition, he viewed dating as not realistic given his illness, physical appearance, and financial constraints such that he could only become interested if things were different than they currently are:

“Right now, you know, I don’t have that much money and its not real practical. I can’t imagine a healthy woman being interested in, particularly interested in a schizophrenic person my age and my big fat stomach [he laughs] and my gray hair and all that, you know. It’s not impossible but I don’t really, it’s not high on my agenda right now.”

**Family Relations**

Participants also describe avoidance or exclusion by family, denial of illness by family members, and the perception that family members are embarrassed or ashamed on the basis of mental illness. A sense of exclusion and unfavorable attention within one’s family was more commonly the subject of commentary by women (34.1%) than men (10.2%, Fisher exact test, p < 0.01) in the study.

A divorced 43-year-old Euro-American woman described family relations as characterized by 2 recurring patterns: either as attempts to avoid her or as efforts to make her into a kind of family scapegoat who could be pointed to as an example of someone who had more problems and was “more ill” than anyone else.

“Either they don’t want to be around you or (it’s) where you can’t even have any privacy without, you know, it’s like they mention your name all the time in their conversation. And either that or they don’t want to be around you. Because you know why, they don’t want to look at themselves. They might see something in themselves that might disturb them . . . (this is) my family, mostly. They’d rather avoid you. It’s a defense mechanism.”

Another illustration of how families may exclude members with mental illness from participation in family activities comes from a 44-year-old Euro-American woman:

“I feel in a lot of ways mom and dad are maybe ashamed of me for some reason . . . they are kind of hesitant and everything and . . . it’s a feeling, you know, they don’t know that I’ve come a long ways from what I used to be. It just seems like I’m still the same way that they think I am. You know, they just don’t realize it hurts when they go some place . . . ah . . . they don’t ask me . . . they just don’t want me to go. It kind of hurts.”

For this woman, the sting of being left out of family interactions reinforces her perception that her parents do not acknowledge her considerable sense of improvement, with stigma persisting in spite of having come a long way. A 42-year-old Euro-American man who lives alone in a condominium, detailed how his entire family shunned him for being unemployed and did not seem to comprehend his illness condition. Ultimately, his parents came to understand and accept him (after having obtained employment) but this was not true of his siblings:

“My folks are very understanding and supportive, especially now. But my brothers and sisters don’t stay in touch. They don’t write. They don’t call. They don’t visit. And I have been in the hospital 19 times, and not once did they come to visit me, you know. 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. I—it bothered me a lot. I used to be jealous, I know some people where their families are really close, you know, and I don’t have that.”

524 | www.jonmd.com © 2009 Lippincott Williams & Wilkins

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Acquaintance Relations

A realm of less intimate social relations is that of acquaintances in which encounters may be less regular but nonetheless hold significance for one’s overall social experience. This may be the neighbor who lives down the street who occasionally waves in front of your house when walking his dog or the schoolmates who usually say “hello” but never actually converse or make social overtures. In one case, a European-American woman said that someone down the street called her “mentally retarded,” a comment which she says really hurt her. When asked for detail regarding how this occurred, she elaborated that the offending man had not said this directly to her but to her next door neighbor within her earshot. Her response was “just let it go,” reasoning that people do not understand but in any event do not intend to hurt her.

Intended or not, a 32-year-old European-American woman recalled her experience at an exclusive private girls preparatory school as intolerable. As seniors, students were allowed to go for lunch off campus but in her case she saw felt “isolated” and was “cut out” because no one ever asked her to lunch. She says that although she is pleased with what she regards as currently good health, she nonetheless is unhappy and has thoughts of killing herself: “There’s nothing I can do about it. I get so tired of being cut off, and it’s like I’m really really frightened of it [being cut off].” She feels that she never learned to socialize properly and that she is generally avoided or excluded. Some years later, she continues to feel left out of things yet seems resigned to this situation as she says, “I’ve never fit in and I never belong.” For her, perceived stigma from persons she does not know well is so incisive to her experience of not “belonging” that it can fuel a desperate need to end her life quite distinct from the above proclivity to “just let it go.”

A generalized sense of degradation was articulated by a divorced 56-year-old African American woman who responded to an interview question about whether women or men were treated differently in a situation of schizophrenia.

I: Do you think that people react any differently to men and women with schizophrenia?

R: No, they gonna treat you the same regardless. They treat you, umm . . . when you have mental illness. I try not to let them know that I have a mental illness, because the minute you do, that’s it. They gonna not be bothering, they’re gonna talk about you, they’re gonna downgrade you. It’s gonna cause you problems, so, you know, if I go out the door and I see a neighbor, he’ll say, “Oh, how you doing?” And I don’t say, I let them know the least about me as possible, and ‘cause I don’t talk about nothing out there except the weather or whatever. Because, you know, I know I have problems, whatever. And the minute they get to know me and maybe I don’t have a good day or whatever and they’re going to know something ain’t right with this lady. And then even if they won’t be bothered, they won’t be bothering me after that. It’s just a stigma and it hurts me.

Likewise, a 47-year-old divorced Euro-American man conveyed his sense of stigmatizing attitudes in the following exchange:

I: Does anybody act differently towards you because of your illness or because you’re taking medication?

R: Well . . . yes. I mean, I’m coming out of that, of feeling, um, literally negative vibes or attitudes from like, neighbors. And that, for a while, it just really upset me, I could feel it, I knew it was reliable . . . I just had to deal with it. (How?) Get on with it. And not, like, get all bummed out. (Hm). Feel sorry for myself.

Friendship Relations

Compared with other types of social relations, friends were mentioned least frequently with regard to stigma. As an elective social relation, there may be 2 scenarios specific to friends that shed light on their lesser salience: (1) they may be inclined to evince support and acceptance; and (2) they may be scarce in the lives of people in the study. As an example of the first scenario is a 26-year-old Euro-American woman who indicated that she felt friends were supportive:

I: Um, how do your friends handle problems that are associated with your illness? Do those ever come up?

R: [she laughs]. It’s funny, because um, Tony, a good friend and Paul. 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.

Another illustration of friends who do not stigmatize came with precision from a 49-year-old Euro-American woman who noted that her friends tended to downplay or explain away her mental illness such that stigma was something not only to elude but also to refuse:

“My friends don’t treat me like a lower status person . . . They treat me like I’m intelligent. I often feel like Ronald Reagan the president when it comes to my mental illness: I feel like I have Teflon, it just rubs off me. People don’t see me that way. And I don’t have a stigma, I always say no to their stigma ‘cause you have to put a stigma on yourself. I don’t accept the stigma, and I don’t accept the stigma, and that’s how I feel, and if they treated me differently they probably wouldn’t be my friends. I probably wouldn’t be comfortable around them.”

In the second scenario, of having few friends, the following 2 illustrations from a 50-year-old Euro-American woman and a Euro-American woman of 46 years provide a sense of the insecurity and uncertainty surrounding loss of a friend due to one’s illness condition:

R: And, well, I had this good friend, long, long time ago. We used to get out and do all kind of things together. And she quit hanging around me, I don’t really know why. But she said something about me wanting to get a job. (Uh hm.) Because, that she didn’t want to see me any more.

I: Wow. Now, was she also someone with an illness . . . ?

R: No, So, I don’t. I let bygone be bygones. [laughs] I don’t need friends like that, do I?

I: Oh, that’s alright. Um, do you ever feel like you’re avoided?

R: By certain people? (Uh hm.) Well, I’m sure. It’s very possible. (Uh hm. Uh hm.) I’m sure it’s very possible, yeah. I have not, um, there’s a lot of people since this happened that I used to work with who have never called to the what happened. And that’s it. And the work, and that’s gone on, people that I thought were my real friends. So yeah, I’d have to say yes. (Uh hm.) Some people have avoided me. And it’s not my imagination. It’s the real thing.

Identity Domains

Medication Use

Of the domains surrounding identity that we analyze here, medication was by far the most common. The rationale for analyzing medication as an “identity” domain is drawn from previous publications (Jenkins and Carpenter-Song, 2005) in which being “a person who takes medication” and having to take such “for the rest of your life” converts to a key dimension of one’s identity. Stigma associated with taking antipsychotic medications was manifested as a reluctance to acknowledge to others that one is taking medication, hiding medication or taking it only in privacy, and great dissatisfaction with one’s physical appearance in relation to medication side effects. That one was taking psychotropic medication was widely thought to instill fear in others that would invariably lead to avoidance and rejection. Examples of stigma associated with medication cross-cuts other domains of analysis presented here as illustrated above for the social relations of work, dating, and acquaintances.
The expectation of rejection and fear in relation to taking medication is illustrated further in a 25-year-old Euro-American woman's imagining of what it would be like to divulge the illness: "It would be interesting to see. I think they might back away. That's what I think. Unless I explained it in such a way that everybody has some disability and this is just one of them and I talked about it and explained it. But if I just said 'I'm schizophrenic, I take medicine' they might back away. In a nice way, if I explained what it was and why I take it, but still I think most people would be frightened about it."

Individuals often find themselves in a "catch-22" situation wherein their experience has shown that they need to take medication to improve or remain well, yet by taking medication they become vulnerable to the judgment of others. To protect against this, one woman described being quite discreet about taking her medication: "I don't announce that I'm taking it. I try to take it very discreetly when I do . . . I don't need someone saying, ooh what are you taking, what are you taking?"

A 47-year-old Euro-American woman described a differential practice of hiding her medication in her home: "If somebody comes over to the house, I may put my medication away, like it's in a cabinet now, I may hide it. The blood drawing thing (for clozapine), I hide that. Actually, when I was with Randy, a while ago, I think it was a couple weeks ago, he's the priest's nephew, I didn't hide it from him, but he asked whether I, I was easily bruised, (since) they bruised the hell out of my arm. But I told him it was, uh, it was some kind of a blood test. 'Cause I have this hemochromatosis thing where my body doesn't get rid of iron. So I have to, uh, have blood drawn, like every week, and that reduces my iron level, cause the iron's used to make new blood. So I told him it was from that. And he didn't question it, really, that much."

Regarding fear and lack of familiarity with antipsychotic medication widely encountered by participants, one woman alluded to the shortcoming of the approach to mental illness through reference to the adage to simply "pull yourself up by your bootstraps": "Some people can do things on their own without taking pills, sometimes you need a boost. Some people don't really need boosts for a long period of time, they just need to get over a hump. Um, some people react more adversely than normal to grief, to the loss of a loved one. I've seen people in psych wards because somebody died. If they were taking some medication and most doctors do offer when somebody dies, they can prevent that. A lot of people are afraid of medication, they have a stoic attitude. And they think everybody should pull themselves up by their own boots. Some people don't have any boots, you know? Those who have boots, fine, but those who don't, they need medication. That's how I feel."

Her vigorous response to people she considered "uneducated" about medications extended to a friend who opined that an acquaintance diagnosed with chronic fatigue syndrome stayed in bed because she "wanted" to do so: "R: I removed myself from her life for months because that's where I drew the line. She said umm, I told her about somebody who was in bed for about fourteen years with chronic fatigue and she said that's 'cause they wanted to be. And I said something about, 'well you know my psych drugs make me tired too.' Which I think they do . . . [She said] 'Well you need to get off those! Well I just didn't speak to her for months and months, because I thought somebody with an attitude like that, uh uh . . .'

I: Was not a friend?
R: Yeah, I thought that's a dangerous thing to tell. She should be in my shoes, would you like to hallucinate? Or be suicidal? (right) Have voices tell her to hang herself? And this person is somebody whose education . . . she should've known better (uh him). So we got back together and she doesn't say things like that any more so I guess she figured it out on her own.

Popular Culture

Narrative statements coded as popular perceptions of individuals with mental illness included statements that articulate attitudes perceived to be held by the general public as well as media portrayals of mental illness, particularly with respect to images of individuals with mental illness as prone to violence. Of those who talked about the experience of stigma 24.4% reported stigma associated with popular perceptions or portrayals of schizophrenia. The following from a 43-year-old Euro-American woman illustrates how public perceptions of schizophrenia as unpredictable or violent can overshadow individual identity: "People are ignorant when it comes to mental illness. All they see is someone on the news that someone felt threatened and took an assault rifle and started shooting people. Because he didn't take his medication, that's what they see."

In this respect, stigma attaches not simply to an individual, but to a social category. Another example of popular cultural stereotypes that confer stigma is the following response to an interview question about what she thought would happen if people found out she had a mental illness: "They would probably, um, probably think I'm kind of weird, or, if I was, uh, watching television and make a reference to people's schizophrenia, and the reference they use, is that it's, uh multiple personality, multiple personality, which makes me angry, because it's not that at all. And it's not that you're crazy, you know, and I think a lot of people think, 'Oh God, she a nut.' You know, and she . . . you know, people have a, uh, you know, bad connotation of it and everything."

With respect to the stereotype of violence as associated with mental illness, a 34-year-old African American man confirmed his experience of this problem as follows: "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."

Gender

Awareness of stigma was identified by one-fifth (19.8%) of subjects in relation to gender differences, with some subjects reporting greater difficulty for men whereas others reported greater difficulty for women. More women (31.7%) than men (8.2%) reported stigma in relation to gender (Fisher exact test, \( p < 0.007 \)). Individuals diagnosed with schizoaffective (41.2%) were more likely than those with schizophrenia (13.7%) to report perceptions of the occurrence of gender-related stigma (Fisher exact test, \( p < 0.02 \)). In several cases, stigma was defined by a perceived inability of individuals with mental illness to live up to culturally normative gender roles. For example, a 27-year-old Euro-American man, describes the particular difficulties faced by men with schizophrenia: "I think, um, maybe what I'm trying to get at is that it may be for the men it is hard, because the illness sort of emasculates them. Because I think, in men, there is a need to be on top of things. Um, to have certain responsibilities. To look good, to have a significant other, and somehow schizophrenia sort of puts a brake on all of this. They can't fulfill all these, these obligations. All these ideals of, of manhood and masculinity. And I think that makes it hard for them." A parallel although contrasting view was noted by some participants regarding the difficulty of keeping up with feminine gendered expectations. A 39-year-old Euro-American woman demonstrated a preoccupation with her femininity throughout all our research contacts, voicing the view that mental illness may be more difficult for women due to self-perceived lost or wanting physical.
attractiveness: "[Men] probably don’t worry about their image, as much as maybe I would. Well, I think they probably just maybe don’t. It doesn’t really, you know, bother them." In addition to repeatedly asking for reassurance that she was "attractive" she worried about her "image" and the possibility of making mistakes.

Self-Presentation

We found that the experience of stigma in relation to self-presentation could be coded into 3 domains: (1) appearance, in which an individual indicates that she/he looks different from others on the basis of mental illness, was identified by 18.6% of participants; (2) side-effects, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others because of medications side-effects was identified by 10.5%; and (3) overweight, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others specifically because of the side-effect of weight gain resulting from the medications was identified by 15.1%. More individuals diagnosed with schizophrenia (35.3%) than those diagnosed with schizophrenia (9.6%) reported stigma in relation to overweight (Fisher exact test, p < 0.02).

In response to an interview question regarding which side effect was most bothersome, a 41-year-old Euro-American man cited drooling, a side effect particularly associated with clozapine: "It gets all over my mouth and everything. Like if I’m making love to a woman at night, I get her all ... wet." Another participant, a 40-year-old Euro-American man, emphasized the problem of weight gain:

"I’ve been gaining a lot of weight ... about fifty pounds. (I’m) like a fat slob. I don’t think I’ll get involved with a woman until I lose weight."

Given the central role that medications play in participants’ improvement, embarrassing side effects is yet another manifestation of the dilemma of “stigma despite recovery” (Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song, 2008).

Social Class and Ethnicity

Only a fraction of subjects (5.8%) reported stigma in relation to social class but nearly a quarter (23.3%) reported stigma in relation to ethnicity. Experiences of stigma in relation to ethnicity occurred in approximately equal proportions in Euro-Americans (21.4%) and African-Americans (25.0%). Narrative statements in which individuals articulated social exclusion, negative attitudes, stereotyping, or discrimination because of a lack of money, poor housing, lack of their own transportation, or on the basis of receiving social security disability income or other government benefits were coded as reflecting stigma in relation to social class. In addition, the perception of stigma often seems to result from an inability to live up to expectations of traditional masculinity and sexuality in relation to low income. Men do not cite schizophrenia itself as a reason not to date, but rather make use of other social and cultural yardsticks to determine their "readiness" to date. These cases reveal the inadequacy of narrow, symptom-based definitions of recovery, and speak to the fact that individuals with mental illness face constellations of constraints such that life chances are reduced not only by the presence of schizophrenia but also significantly by dimensions of social class refracted through gender.

We defined perceptions and experiences of stigma related to ethnicity as either (1) articulations of an especially negative reaction to mentally ill persons among members of a particular ethnic group or (2) articulations of mental illness being particularly difficult for individuals of a given ethnic group. In the following example, a 35-year-old African-American man articulates his perception that African-Americans are less sympathetic than other (unspecified) ethnic groups with respect to mental health problems:

"I don’t think they’re as open-mindedness about it. I think they are a little more prejudiced against mental illness than other people might be. Because of their culture ... I think a lot of blacks think there is something wrong with me, like, there’s something bad about it."

The moral dimension of this response—that others think there is something "bad"—about his illness suggests the possible salience of characterological explanations for mental illness among African-Americans.

DISCUSSION

In contrast to viewing stigma as a process whereby negative social stereotypes and attitudes are imposed upon the stigmatized, the anthropological approach we have adopted in this analysis begins with a concept of stigma as an interpersonal process. Our intent has been to redress the over-emphases on individual attributes in studies conducted using scalar instruments (Link and Phelan, 2001) and on attitudinal measures as the sole indicators of stigma (Hinshaw and Stier, 2008; Lee et al., 2005) by examining the social contexts in which individuals with psychotic illness become aware of stigma as manifest in both overt forms of discrimination as well as in tacit forms of rejection and distancing. The data we have presented contribute to a growing literature that incorporates first-person perspectives on psychiatric stigma and, as such, is positioned to offer a further corrective to the "conspicuously absent" voices of mental health consumers in previous research on stigma (Wahl, 1999).

In one respect the population with which we worked represents a limiting case for the study of stigma insofar as for the most part their symptom levels are relatively well controlled, social functioning is relatively high, and living conditions are stable. They are articulate, coherent and socially engaged, hence more attuned to the nuances of experience associated with stigma and susceptible to the paradoxical situation that we have described as "stigma despite recovery." The data indicate a significant degree of reflectiveness on their part, and very little ambiguity about whether they are subject to stigma and the character of that stigma across different types of situation. This awareness of stigma may be related to the almost uniform recognition among these subjects that they have a mental illness from which, relative to their previous states of acute psychotism, they have improved. Perhaps this awareness of having a long-term disorder conduces to assimilation of and susceptibility to a popular cultural image of mental illness as a state of reduced social status and credibility. They are able to make comparisons between themselves and others, and exhibit distinctive styles of personal expression. Their expectations and attitudes toward life are not dictated by their illness, but are conditioned by it in terms of whether they can "live up to" goals that they take to be no different than those held by "normal" people. Their comments about stigma show that it is constituted interactively, and it has an emotional tone without being characterizable as either flat or histrionic.

Yet while participants revealed a good deal about stigma in their lives, talk about stigma may be limited by reluctance to acknowledge personally painful and socially detracting events which call into question one’s moral status. Across all content domains of our qualitative interviews, discussion of stigma in particular tended not to be extensively elaborated but rather tentative and indirect. That women reported "more" stigma (i.e., spoke about it more) than men in our interviews may represent a gender difference with respect to artfulness, but not necessarily experience. It may also reflect the fact that all the interviewers in the SEACORA project were women, and that male participants were less comfort-
able than their female counterparts in discussing stigma related issues with female interviewers.

It is noteworthy that the first person accounts that constitute our data come in 2 forms. One is opinions about stigmatizing behavior and stigmatizing circumstance that consist of background knowledge, social attitudes, and stereotypes—including stereotypes about mental illness and the mentally ill. The other is brief narrative accounts of actual instances of experiencing stigma. It is relevant to hypothesize that these opinions and experiences are not independent of one another, and future research could productively be directed at how this takes place among persons in recovery from major mental disorder. Not every individual reports experiences of stigma across every one of the categories of social relations and identity domains, but insofar as these domains form a framework of possibilities for experiencing stigma, it is likely that people can imaginatively project themselves into other situations and form impressions based on what they hear about others’ experiences. Thus for them stigma is not a discontinuous set of isolated occurrences or a feature of an isolated kind of situation, but implicitly an atmosphere permeating everyday life.

A final aspect of the data requires reflection on the encompassing nature of the framework itself. It is no accident that the inductive categories that emerged from our qualitative data are of 2 types, and that broadly speaking the category of social relations has everything to do with what one does, and the category of identity domains has everything to do with who one is. With respect to social relations, our analysis anticipated that frequency of reported stigma would vary according to degree of intimacy. Our actual results (Table 1) suggest the alternative, or perhaps additional, interpretation that frequency of stigma varies according to the social proximity and experienced intensity of the social situation. By this interpretation, our finding that stigma is perceived as coming most often from strangers may occur in relation to fear (realistic or imagined) that people who one does not know are more likely to judge harshly or dismissively. Anonymous interactions among persons with mental illness are the most intense and have most at stake because they are the most ambiguous, whereas for those not afflicted anonymous situations might be more easily written off as relatively inconsequential. With respect to identity domains, the category itself does not cohere without the interpretation that for this population medication use—the ambivalent tradeoff of controlling symptoms against unpleasant side effects, of embracing and rejecting it at different moments, and of thinking of it as tool or crutch—is indeed an element of identity, whereas for those not afflicted medication use is episodic and not necessarily mind-altering. Under this interpretation it is not surprising that social class and ethnicity receive so little mention, appearing as ancillary or as afterthought to the stigma of mental illness. From the standpoint of our data, psychiatric stigma associated with the identity of being a medication user appears to “trump” the stigma of race or social class, though the latter may exacerbate or have an additive effect.

CONCLUSION

The paradoxical life circumstance of many study participants 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 framework of contexts identified by mentally ill persons themselves in which they are aware of stigma may be relatively stable across cultural boundaries or categories of illness, but individuals in-depth anthropological investigations involving a large sample size such as the present study are required in the future to determine variations in how the experience of stigma is played out across this framework. We may speculate, however, that given the widely documented existence of stigma in relation to mental illness worldwide (Kleinman, 1988; WHO, 2001), future research will find a broad concordance of an awareness of stigma as a matter of everyday lived experience, while the cultural meanings of the specific contexts of stigma experience are likely to vary in several respects (e.g., with respect to diagnosis, medications, or distancing of social relations) yet be similar in others (e.g., dating prospects, popular perceptions of fear). In this article, we have outlined categories of social relations and identity domains in which patients are aware of stigma, and have taken the additional step of specifying the quality of that awareness. In this light, psychiatric stigma is clearly not a monolithic force against which individuals must struggle. Indeed, we suggest that knowledge of the particularity of lived experiences of stigma may aid the efforts of mental health professionals to anticipate where and under what circumstances individuals may experience the blows of stigma. The data presented in this article contribute to understanding stigma as a product of intersubjective, reciprocal social processes and not something “out there” that is imposed upon an individual. Individuals with mental illness play an active role in contending with, resisting, and sometimes reproducing stigma. Attending to the complex social fields of stigma encourages rethinking individuals with mental illness in ways beyond vulnerability and victimhood.

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REFERENCES


Awareness of Stigma Among Persons With Schizophrenia

Marking the Contexts of Lived Experience

Janis Hunter Jenkins, PhD,* and Elizabeth A. Carpenter-Song, PhD†

Abstract: This article investigates the subjective experience of stigma attached to schizophrenia-related disorders. We examine data from anthropological interviews from a community sample of 90 out-patients residing in a metropolitan area of the United States. Patients were under treatment with atypical antipsychotic medication, and their symptoms were for the most part relatively well controlled. Overall, 96% of participants reported an awareness of stigma that permeated their daily life. Based on an understanding of stigma as a product of interpersonal, reciprocal social processes, we identify 6 types of social relations and 5 identity domains in which social stigma is routinely encountered by participants. We describe the experience of stigma in each of these 11 subcategories, and suggest that taken together they constitute a framework of social and personal factors involved in the struggle to recover from psychotic illness. Among types of social relations, anonymous social interactions most commonly generated an awareness of stigma. Among identity domains, being a person who regularly takes medication was most commonly associated with an awareness of stigma. The finding that multiple forms of stigma are encountered irrespective of substantial symptomatic, functional, and subjectively perceived improvement creates a complex situation of stigma despite recovery.

Key Words: Stigma, schizophrenia, subjective experience, antipsychotic medication, recovery, qualitative methods.

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Stigma is increasingly recognized as a global public health problem across a range of illness conditions (Green, 1995; Keusch et al., 2006; World Health Organization, 2001). The global impact of stigma on health care systems, economic productivity, and society at large is extensive and is a very persistent predicament in the lives of persons affected by it" (Link and Phelan, 2001, p. 9). Stigma associated with mental illness appears to be a cross-cultural universal (Link et al., 2004; Pickenhagen and Sartorius, 2002; Yang et al., 2007). In spite of increased public knowledge about mental disorder, findings from attitudinal surveys suggest that psychiatric stigmatization is pervasive (Angermeyer and Dietrich, 2006; Bhugra, 1989; Rabin, 1974) and has increased in the United States, particularly with respect to the perception that individuals with psychotic illnesses are violent and frightening (Link et al., 1999; Phelan et al., 2000). Corrigan et al. (2003) conducted a survey of 1824 persons with serious mental illness on perceptions of discrimination applied to mental illness compared with other social characteristics such as ethnicity, gender, or sexual orientation. Over half report experienced discrimination and the most frequent source of this discrimination occurred in relation to mental disability. Such findings are particularly disturbing when coupled with the observation that surveys of explicit attitudes toward those with mental illness may underestimate the pervasiveness of stigma due to socially desirable response tendencies (Link and Cullen 1983).

THE PROCESS OF STIGMATIZATION

Much of the social psychological scholarship on stigma concerns specifying the mechanisms underlying stigmatization. Measures of implicit attitudes—so-called "unconscious" attitudes or biases—are a recent development intended to avoid the pitfall of socially desirable responses. A study by Teachman et al. (2006), employing the Implicit Association Test demonstrated negative implicit attitudes toward mental illness, with 58% to 78% of participants associating the concepts "bad," "blameworthy," and "helpless" with mental illness. Explicit and implicit attitudinal measures are useful in documenting broad societal orientations toward persons with mental illness. Yet these studies do not examine the impact of stigmatizing attitudes on those with mental illness (Hinshaw and Stier, 2008; Link et al., 2004). Thormicroft et al. (2007) have recently noted that attitudinal and social distance research has "generally focused on hypothetical rather than real situations, neglecting emotions and the social context, thus producing very little guidance about interventions that could reduce social rejection" (p. 193). Moreover, research by Corrigan and Watson (2002) highlights that psychiatric stigma does not manifest solely in public attitudes. Corrigan and Watson (2002) have usefully distinguished public stigma, "the reaction that the general population has to people with mental illness," from self-stigma, defined as "the prejudice which people with mental illness turn against themselves" (p. 16).

Social-cognitive processes such as stereotyping figure prominently as ways in which "in group" members affirm positive and individualistic traits of themselves in contrast to "out group" members, who are portrayed homogeneously and negatively (Hinshaw and Stier, 2008). Such basic social psychological processes are considered to account, in part, for a degree of "automatic" and "inevitable" stigma that subsequently becomes intensified by the "threat" posed by disordered behavior and mental illness labels (Hinshaw and Stier, 2008). In this regard, social psychological models conceptualize stigma as a process whereby certain "attributes" or "marks" are associated with a "devaluing social identity" or "discrediting disposition" in the context of social interactions (Crocker et al., 1998; Jones et al., 1984). Such formulations echo Goffman (1963), who defines stigma as rooted in an "undesired differentness," an "attribute that is deeply discrediting" and that results in a "spoiled identity." The complex ways in which individuals negotiate their social worlds—how to manage information regarding one's condition, contending with the expectation of stigma, efforts to pass—constitute the "moral career" of the stigmatized.

Keusch et al. (2006) have recently called for a reinvigoration of the "science of stigma" and advocate building upon the insights set forth by Goffman (1963) to examine stigma as a "cultural disease that marks its victims as morally tainted" (Keusch et al., 2006, p. 526). Although Goffman's formulation emphasizes stigma as a social construction, social psychological frameworks tend to reduce
stigma to processes occurring at the individual cognitive level in response to social stimuli. As Yang et al. (2007) have noted, although such social psychological mechanisms are relational in structure: “analysis of these models reveals that they primarily regard the social aspects of stigma as a psychological variable (i.e., ‘social identity’ as applied to an individual), as an environmental stimulus that the individual appraises or responds to, or as societal or cultural stereotypes. Further, these models restrict the range of coping responses to the stigmatized individual’s reactions (e.g., cognitive coping strategies) and the harmful outcomes of stigma to individual self-processes (e.g., psychological well-being). These models suffer from limiting conceptualization of the social to those environmental elements of stigma that ‘impinge upon’ the individual sufferer, who is then viewed as the primary locus in which stigma processes take place” (p. 1525).

Link and Phelan (2001) summarize recent social psychological research to show that people construct cognitive categories and then customarily link those categories to preexisting stereotyped notions. Going beyond this well-known association, they make a convincing case for understanding stigma as a set of social components that includes labeling, separation, status loss, and discrimination (and also, Sargent, 1998). These elements, they aver, unfold in the context of unequal social, economic, and political power. Accordingly, the process of stigmatization is such that persons with mental illness are socially identified as different, this difference is ranked and linked to negative social stereotypes facilitating the construction of individuals with mental illness as “others,” which, in turn, provides a rationale for devaluing, rejecting, and excluding them. Furthermore, Link and Phelan (2001) identify 2 key problems in current literature on stigma: (1) an overemphasis on individual attributes derived from social psychological research methods that rely on scalar instruments; and (2) a notable absence of research on the lived experience of persons who struggle daily with stigma. A literature review by Link et al. (2004) offers evidence that research conducted from the standpoint of individuals with mental illness or their close associates accounts for a minority of studies, and qualitative methodologies of interviewing and participant observation are uncommon.

The Experience of the Stigmatized

Moving toward an approach that takes into account the lived experience of stigma as an interactive phenomenon, Corrigan and Watson (2002) developed a situational model of personal response to stigma that varies substantially in relation to the person’s perception of its legitimacy as applied to them. Camp et al. (2002) investigated whether low self-esteem was an inevitable consequence of stigma among a group of 10 women using qualitative analysis, revealing that while these women considered that they had a mental illness, they did not accept society’s unfavorable representations of them on that basis (cf. Link et al., 2001). Sajatovic et al. (2005) highlight an additional dimension of the relationship between stigma and the self in their investigation of gender identity and gender role performance among individuals with schizophrenia-related disorders. They note that while individuals with schizophrenia are likely to experience lowered self-esteem in relation to the stigmatizing effects of mental illness, it is also likely that specific disturbances in gender identity and gender role performance likewise confer negatively upon sense of self-esteem. In their recent review of stigma related to mental disorders Hinshaw and Stier (2008) observe that stigma involves stereotypes, prejudice, and discrimination that limit the life chances of those stigmatized. Yet they also observe that stigma processes are not reducible to these phenomena in light of the often all-encompassing nature of stigmatizing characterizations, the shame experienced by the stigmatized, and the crippling effects of stigma on social interactions that become shadowed by hostility, rejection, and anxiety (Hinshaw and Stier 2008).

Aside from the literature constituted by memoirs of individuals living with mental illness (Deegan, 1988; Gallo, 1994), there has also been a slowly accumulating literature that has incorporated first-person perspectives on psychiatric stigma. For the most part these studies have been based on data from focus groups, surveys, and questionnaires (Corrigan et al., 2003; Perlick et al., 2001; Schulze and Angermeyer, 2003; Wahl, 1999) or from semi-structured interviews with small samples sizes (N < 10) (Camp et al., 2002; Knight et al., 2003). These studies point to multiple pathways for the constitution of the self and self-worth, and have important implications in the illness recovery process which requires self-management and reintegration of the individual into the community (Davidson, 2003). The findings of Dinos et al. (2004) based on their study of 46 individuals with mental illness align well with our findings of the pervasive awareness of stigma and the importance of managing illness information among persons with schizophrenia. However, from an anthropological perspective, Dinos et al. (2004) do not adequately situate the experiences of the individuals they interviewed within their interactive context. Indeed, ethnographic data on the immediate contexts of stigma in the community are in short supply (Phelan et al., 1998).

Against this conceptual and empirical background, and with an understanding of stigma as an interactive phenomenon with its locus in lived experience, we ask two questions in this article. First, to what extent is stigma pervasive in the lives of the afflicted? Answering this question requires specifying the range of contexts in which people encounter stigma, and in which stigmatizing behavior might take different forms. Second, how do people afflicted with schizophrenia perceive and experience stigma? An approach attuned to stigma as an interactive phenomenon will not be satisfied with a global notion of “spoiled identity,” but will identify how difference and difference are constituted in instances of being snubbed, teased, rejected, talked about, or even looked at in an unusual way. This is all the more salient among a population such as that examined herein, among whom symptom levels are relatively well controlled and social functioning is relatively high. Our data on stigma are drawn from a broader anthropological study entitled “Schizophrenia and the Experience of the Culture of Recovery through Atypicals” (SEACORA), which examined the subjective experience and meaning of illness and whether worsening or improvement/recovery among 90 persons diagnosed with schizophrenia-related disorders and taking “atypical” or “second generation” antipsychotic medications (Jenkins et al., 2005; Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song 2008).

METHODS

Sample Selection

In a northeastern US metropolitan area, we obtained the complete rosters of 2 community mental health outpatient facilities that served Euro-American and African-American ethnic groups. The first clinic is affiliated with an academic research community and was developed specifically to deliver clozapine treatment. Those attending the clinic often spent significant amounts of time on site, ranging from every day visits to once or twice per month. The second clinic had a relatively less developed research focus, and patients came briefly for biweekly or monthly medication checks. Study 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, some subjects in the study (N = 6) were prescribed atypical antipsychotic drugs as their first psychopharmacological treatment.
Selection criteria included: (1) diagnosis of schizophrenia or schizoaffective disorder assessed through the Structured Clinical Interview for DSM-IV (First et al., 2002); (2) age 18 to 55; (3) at least 2 years since first psychotic symptoms; (4) at least 6 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. Eligibility was assessed by treating psychiatrists and therapeutic managers, and resulted in a complete list of all patients who met research diagnostic criteria. From this list, 167 eligible participants were randomly sampled. Of those selected, 90 (54%) were included in the final sample, with 46.7% declining research participation. The overall high rate of refusal is not unusual (Covell et al., 2003) for an American community out-patient sample such as this, with males (55.9%) significantly more likely than females (29.3%) to decline participation (Fisher exact test, p < 0.001). Reasons for nonparticipation included lack of interest in research (stating simply they “did not want to”) or a reluctance to provide time for interviews (due to 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 were more interested in research, sometimes stating that they had an interest in cooperating with anything that might benefit others (or themselves) in future. In this regard, the sample may be more cooperative and less symptomatic, more socially functional, or potentially more likely to have had a positive experience with medication or their physicians than those in the group who declined participation (see also, Jenkins et al., 2005).

Procedures

For this study of subjective experience of schizophrenia, we employed techniques of ethnographic interviewing, naturalistic observation, and procedures for research diagnostic criteria (Structured Clinical Interview for DSM-IV) and symptom severity (Brief Psychiatric Rating Scale [BPRS]). The research psychiatrist for the project was trained in the reliable administration of both of the latter instruments. This article, however, is based on stigma-related data generated by the ethnographic interview. The ethnographic interview, the “Subjective Experience of Medication Interview” (SEMI), is a semi-structured, open-ended qualitative procedure adapted from interviews used in prior research (Jenkins, 1997). As a qualitative procedure, the SEMI serves as an interview guide in which there is flexibility in the administration of interview questions. If a subject is highly responsive and generates narrative on a topic of interest, the predetermined interview questions may be used sparingly. On the other hand, if a respondent is not highly responsive in generating narrative on their own initiative, the interviewer may use questions and follow-up probes more extensively in an effort to obtain the persons’ point of view. The substantive domains covered by the SEMI include the experience of medication and treatment, living situation, everyday activities, illness management, social relations, gender identity, expectations concerning recovery and quality of life, and stigma. Qualitative data on any topic, including stigma, might be generated at any point of the interview. Examples of specific questions posed to elicit stigma-related data were as follows: “Do you tell people that you have (diagnosis)? That you’re on medication? Who do you tell?” and “What kinds of things do you try to do to keep people from finding out?” “Does anybody act differently toward you because of your illness, or because you take medication?” “For yourself, do you prefer friends or dating relationships among people who also have a mental illness or those who do not have a mental illness?”

The duration of the SEMI interviews was generally 1.5 to 2 hours over 1 to 3 interview sessions. Interviews were conducted by the Principle Investigator and a team of 4 doctoral students in medical anthropology. All SEMI interviews were transcribed verbatim from audiotape and entered into the Atlas.ti qualitative software program (Scientific Software, 1997) which is designed to code and analyze qualitative data systematically (Good, 1994; Luborsky, 1993). The 90 SEMI interview transcripts, averaging 92 double-spaced pages, were read and coded by the two authors (J.J. and E.C.S.). A grounded theory approach in which thematic categories are inductively derived (Strauss and Corbin, 1990), yielded 34 substantive categories, of which “stigma” was one. In any instance in which content of a text segment was in question, relevance of that text segment to stigma was confirmed or disconfirmed through review and consensus between the 2 coders, as customarily required for systematic qualitative analysis of large volume textual data (NIH, 2001; Taylor and Bogdan, 1998; Warren, 2002). We coded data “yes” for awareness of stigma if at least 1 of the following conditions was met: (1) the subject indicated that people react negatively toward them in response to the direct questions listed above; (2) the subject volunteered information about awareness or experience of psychiatric stigma in any other part of the SEMI interview. Coding a “no” response cannot be considered as a definitive determination that the subject did not perceive or experience stigma, but only that the response reflects absence of report of stigma in the interview transcript. Reports of perceived stigma were secondarily coded by the same 2 coders to identify the contexts in which subjects experience stigma, yielding the categories of social relations and identity domains shown in the results below.

Sample Characteristics

Sociodemographic and clinical characteristics of the 90 SEACORA participants have been more fully summarized fully elsewhere (Jenkins et al., 2005). In brief, males constituted 54.4% and females 45.5% of the sample. Euro-Americans accounted for 77.8% and African-Americans for 22.2%. 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% single, 5.6% married or living with a partner, and 10% divorced, widowed, or separated. Those living alone accounted for 25.6%, those living with a roommate or in a group home for 22.2%, those with a relative or parent 42.2%, and those with a partner or spouse 10%. Fully 60% were unemployed, 22.2% were working half time or less, and 17.8% were working from half to full time.

Diagnostically, 81.1% participants had schizophrenia and 18.9% 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 1–7, absent to severe, respectively) on the BPRS revealed remarkably low levels of symptomatology overall for a sample such as this (Burger et al., 1997). Factor scores for the BPRS ranged from a low of 1.23 for features such as psychomotor agitation to a high of 2.09 for anxiety/depression (see, Jenkins et al., 2005 for fuller discussion). There were no significant differences in socioeconomic status by ethnicity.

RESULTS

Nearly all persons in the study (86 or 96.0%) reported perception of stigma across a variety of social settings that they encounter on a daily basis. In general, the low symptomatology among study participants (Jenkins et al., 2005) does not appear to afford these individuals any considerable measure of protection from the blight of stigma. In fact, for some participants, improvement may create the conditions for a subjective discernment of pervasive stigma to be felt with greater acuity, what we refer to as the paradox of stigma despite recovery.
TABLE 1. Awareness of Stigma

<table>
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<tr>
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<th>%</th>
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<tbody>
<tr>
<td>Social relations</td>
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</tr>
<tr>
<td>Anonymous social interactions</td>
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<td>41</td>
</tr>
<tr>
<td>Work relations</td>
<td>36.0</td>
<td>31</td>
</tr>
<tr>
<td>Dating relations</td>
<td>32.6</td>
<td>28</td>
</tr>
<tr>
<td>Family relations</td>
<td>22.1</td>
<td>19</td>
</tr>
<tr>
<td>Acquaintance relations</td>
<td>12.8</td>
<td>11</td>
</tr>
<tr>
<td>Friendship relations</td>
<td>11.6</td>
<td>10</td>
</tr>
<tr>
<td>Identity domains</td>
<td></td>
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<tr>
<td>Medication use</td>
<td>44.2</td>
<td>38</td>
</tr>
<tr>
<td>Popular culture</td>
<td>24.4</td>
<td>21</td>
</tr>
<tr>
<td>Gender</td>
<td>19.8</td>
<td>17</td>
</tr>
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<td>16</td>
</tr>
<tr>
<td>Social class and ethnicity</td>
<td>5.8</td>
<td>5</td>
</tr>
</tbody>
</table>

*Total number of subjects equals 86 who indicated awareness of stigma; 4 responses were judged as lacking or insufficient to code presence of awareness of stigma.

(Jenkins and Carpenter-Song, 2008). The remainder of our analysis will consist of specification of this social matrix of contexts of subjective awareness of stigma.

The diversity of contexts in which there is a heightened awareness of stigma underscores the pervasiveness of stigma within the everyday experiences of individuals with schizophrenia-related disorders and illuminates the ways in which stigma surrounding the illness shapes nearly all aspects of everyday experience. The contexts of the awareness of stigma constitute 2 categories: (1) social relations and (2) domains of identity (Table 1). In the category of social relations, study participants identified differences in the perception of stigma in anonymous interactions, work relations, dating relations, family relations, interactions with acquaintances, and interactions with friends. The category of identity domains includes gender, self-presentation, social class, and ethnicity. We also include popular culture insofar as an individual may define him/herself in relation to a media-derived social context, and medication use insofar as our earlier analysis demonstrated the considerable extent to which persons identified themselves in relation to reliance on psychotropic medication (Jenkins and Carpenter-Song, 2005). In sum, although it is not surprising that people report stigma across these varied social relations and identity domains, our purpose here is (1) to point to the quality of stigma as lived experience in each of the contexts, and 2) to indicate how the set of contexts constitutes a comprehensive framework of the struggle to recover from psychotic illness.

Social Relations

Anonymous Social Interactions

The category of stigma in “anonymous interactions” occurred among strangers in public, commercial, or bureaucratic social settings. This included settings such as the street, bus, library, parks, drug and grocery stores, restaurants and coffee shops, and governmental and welfare offices. The ways in which persons felt the presence of social stigma in these diverse settings included discomfort over the sense that verbal and nonverbal communications were directed toward them to signal identification and labeling of them as mentally ill, strange, frightening, or of lesser intellectual and social capacity. Besides the perception of disapproving and derisive messages, people in the study also reported the sense from strangers that they could be patronized on the basis of one’s condition, on the one hand, or a target of vulnerability, on the other.

A 39-year-old Euro-American woman living with her parents in a lower middle class suburban neighborhood, who has been ill for 21 years, attempts to de-emphasize her illness and does not reveal her illness to people other than close friends and family. Otherwise, she says:

R: Well, the people I do know, already know. Like the relatives and friends of the family probably know I have problems, but someone like a stranger, someone I wouldn’t know. Or like when I go to welfare. The lady at welfare knows I’m on disability, and um, sometimes I feel that she’s looking at me in a different way. I just try to carry myself in a proper way not to let people know that there’s something wrong with me. Because then, like I say, I’m funny about that.

I: Uh hm. Yeah. And what is the proper way?

R: Well, I, some people just come out and say, you know, I’m sick or you know, I got a problem. I’ll just try to, try to hide it. (Uh hm.) I would just try not to make it obvious. (Uh hm.) Because some people can be really cruel, you know. Um, they can say, ‘well what’s wrong with her, you know? You know how people are. They, they can just kinda get funny about that kind of stuff.’

She expressed anxiety and discomfort as common for her when walking on the street, a situation in which she felt people were staring at her for appearing strange.

Work Relations

Overall, 36.0% were aware of stigma in the context of social interactions related to work. As expectable, those working currently (36 or 40%) were significantly more likely to report stigma in relation to work (50.0%) than those not currently working (24.1%) (Fisher exact test, p < 0.02). While it is obvious that those currently working would be more preoccupied with stigma in this context, its salience in the context of previous or prospective employment was also noteworthy. Transactions in the workplace included the perception of hostile or fearful attitudes, teasing, violation of confidentiality, discrimination and unfair treatment, pejorative stereotyping or insensitivity by coworkers/supervisors, as well as the fear of either not being hired or being fired on the basis of mental illness. Finally, negative reactions by others because one does not have a job were also noted.

One illustration of stigma encountered at the workplace was provided by a 36-year-old Euro-American woman living with her parents. She works as a salesperson in a department store, where she fears people know about her condition. The sources of her fear are her own behavior as well as that of others. For her part, she says that she sometimes becomes confused about when employee breaks are scheduled, a potential problem since these must be negotiated and coverage of the various departments had to be ensured. She imagines that her confusion may have given coworkers reason to surmise she is ill. Nevertheless, she makes a point of not revealing her illness to people at work, a sore spot in light of a recent action on the part of a store manager.

“Um, no, I generally, most of the time I don’t, like especially at work. I figure it’s really none of their business . . . I have a sneaking suspicion that some people might know or have guessed (mental illness). Because one time there was a manager, over in another department, I had mentioned that I had to see my Medicaid lady to her. And then we were in the hallway, and I had either clocked out for the day or was about to, and I talked to her about that appointment. And she says something about oh no, oh my, oh know, about your disability and it was, there was still a lot of people around, and I don’t know. They might have known or have guessed.”

Another example of the way in which stigma and symptomatic worsening are reciprocally related comes from a 39-year-old
African American man who lives alone in a condominium purchased for him by his parents. Recently hired to work in a hospital setting, he began to feel uncomfortable in the work setting because he was taking medication. This led to a series of events beginning with his decision to stop taking medication, ensuing difficulties with his supervisor, and subsequent suspension.

“When I was working in the hospital, I stopped taking the medication a couple of weeks or so after I got hired because I felt bad about having to take medication and having an illness and being diagnosed as schizophrenic. And um, instead of educating myself or educating other people about it, I chose to just stop taking it. And um, that was bad. And then I was, had a fell out with my boss and got put on suspension. And, even though when I came back they paid me for the times I missed, they understood that I have a sickness, and illness. And when and when back I was on the medication and I really didn’t know what to say to people or what to, how to explain it, what was going on. And I felt like I was under a magnifying glass and it was really uncomfortable. That was really hard for me.”

This example of stigma in the workplace interrelates with the identity domain of medication examined below whereby disapproval of the self is unwittingly conjoined by social disapproval by others.

**Dating Relations**

Dating is an area of social relations that participants identified as a source of unease. About one-third (32.6%) described either being rejected by potential dating partners because of mental illness or acknowledged not wanting to date another person with mental illness. As for the above social relations, people described reluctance to reveal illness or medications because of fear of frightening others, fear of rejection, stereotyping, teasing, and fear of mistreatment and vulnerability in relation to dating. In addition, while weight gain in women and personal appearance constituted an impasse to the prerogative to date for women and men alike, women tended to worry somewhat more about such limitations. For their part, men were more preoccupied that they could not meet cultural expectations that they have money, a car, and perform sexually. Overall, women (41.5%) were more likely to speak about such limitations compared with men (22.4%).

An interview exchange with a 35-year-old African American woman illustrates the problem of feeling disallowed to date on the basis of mental illness.

I: So are there particular difficulties for people with mental illness, or with schizophrenia in particular?

R: Oh, yeah, for me there is, quite a bit. You know, that’s the thing, you know, I think that there’s really, only, not much choice in the way of, you know, dating people because I think if you’re a girl that has mental problems, or whatever, you know, well at least I know, normal guys don’t look twice at me. They don’t!

The following interview interchange with a 39-year-old Euro-American woman illustrates what she felt is at stake if you have a mental illness and get involved in a romantic relationship:

I: Do you think that love is difficult?

R: Love is very difficult. Love is difficult because you risk—you risk everybody laughing at you if you love somebody.

I: Everyone laughing at you? And why is that? Why would they be laughing?

R: Someone [told me] once, um—it’s impossible for people—for schizophrenics to actually love. I go why? “Because your head gets involved with everything.” I don’t know.

I: What do you think about that?

R: I don’t—it’s pretty hard. Take advantage of, thinking that maybe I’m—you’re not good enough for this person, you’re not good enough for that person. Something like that. Thinking I’m not good enough to be with that person. That you’re crazy and stuff.

Finally, a 47-year-old Euro-American man who lives alone in an apartment conveyed ambivalence on the subject of dating by saying that “Sometimes I feel strongly that I’d like to meet somebody, and sometimes I don’t, you know.” His sense of dating as “very risky” was borne out by this comment that “there’s no guarantees that it’s going to work out the way you want it to.” In addition, he viewed dating as not realistic given his illness, physical appearance, and financial constraints such that he could only become interested if things were different than they currently are:

“Right now, you know, I don’t have that much money and its not real practical. I can’t imagine a healthy woman being interested in, particularly interested in a schizophrenic person my age and my big fat stomach [he laughs] and my gray hair and all that, you know. It’s not impossible but I don’t really, it’s not high on my agenda right now.”

**Family Relations**

Participants also describe avoidance or exclusion by family, denial of illness by family members, and the perception that family members are embarrassed or ashamed on the basis of mental illness. A sense of exclusion and unfavorable attention within one’s family was more commonly the subject of commentary by women (34.1%) than men (10.2%, Fisher exact test, p < 0.01) in the study.

A divorced 43-year-old Euro-American woman described family relations as characterized by 2 recurring patterns: either as attempts to avoid her or as efforts to make her into a kind of family scapegoat who could be pointed to as an example of someone who had more problems and was “more ill” than anyone else.

“Either they don’t want to be around you or (it’s) where you can’t even have any privacy without, you know, it’s like they mention your name all the time in their conversation. And either that or they don’t want to be around you. Because you know why, they don’t want to look at themselves. They might see something in themselves that might disturb them . . . (this is) my family, mostly. They’d rather avoid you. It’s a defense mechanism.”

Another illustration of how families may exclude members with mental illness from participation in family activities comes from a 44-year-old Euro-American woman:

“I feel in a lot of ways mom and dad are maybe ashamed of me for some reason . . . they are kind of hesitant and everything and . . . it’s a feeling, you know, they don’t know that I’ve come a long ways from what I used to be. It just seems like I’m still the same way that I think I am. You know, they just don’t realize it hurts when they go some place . . . ah . . . they don’t ask me . . . they just don’t want me to go. It kind of hurts.”

For this woman, the stigma of being left out of family interactions reinforces her perception that her parents do not acknowledge her considerable sense of improvement, with stigma persisting in spite of having come a long way. A 42-year-old Euro-American man who lives alone in a condominium, detailed how his entire family shunned him for being unemployed and did not seem to comprehend his illness condition. Ultimately, his parents came to understand and accept him (after having obtained employment) but this was not true of his siblings:

“My folks are very understanding and supportive, especially now. But my brothers and sisters don’t stay in touch. They don’t write. They don’t call. They don’t visit. And I have been in the hospital 19 times, and not once did they come to visit me, you know. 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. It—bothered me a lot. I used to be jealous, I know some people where their families are really close, you know, and I don’t have that.”
Acquaintance Relations

A realm of less intimate social relations is that of acquaintances in which encounters may be less regular but nonetheless hold significance for one's overall social experience. This may be the neighbor who lives down the street who occasionally tarries in front of your house when walking his dog or the schoolmates who usually say "hello" but never actually converse or make social overtures. In one case, a Euro-American woman said that someone down the street called her "mentally retarded," a comment which she says really hurt her. When asked for detail regarding how this occurred, she elaborated that the offending man had not said this directly to her but to her next door neighbor within her earshot. Her response was to "just let it go," reasoning that people do not understand but in any event do not intend to hurt her.

Intended or not, a 32-year-old Euro-American woman recalled her experience at an exclusive private girls preparatory school as intolerable. As seniors, students were allowed to go for lunch off campus but in her case she says felt "isolated" and was "cut off" because no one ever asked her to lunch. She says that although she is pleased with what she regards as currently good health, she nonetheless is unhappy and has thoughts of killing herself: "There's nothing I can do about it. I get so tired of being cut off, and it's like I'm really really frightened of it [being cut off]." She feels that she never learned to socialize properly and that she is generally avoided or excluded. Some many years later, she continues to feel left out of things yet seems resigned to this situation as she says, "I've never fit in and I never belong." For her, perceived stigma from persons she does not know well is so incisive to her experience of not "belonging" that it can fuel a desperate need to end her life quite distinct from the above proclivity to "just let it go."

A generalized sense of degradation was articulated by a divorced 56-year-old African American woman who responded to an interview question about whether women or men were treated differently in a situation of schizophrenia.

I: Do you think that people react any differently to men and women with schizophrenia?

R: No, they gonna treat you the same regardless. They treat you, umm...when you have mental illness. I try not to let them know that I have a mental illness, because the minute you do, that's it. They gonna not be bothering, they're gonna talk about you, they're gonna downgrade you. It's gonna cause you problems, so, you know, if I go out the door and I see a neighbor, he'll say, "Oh, how you doing?" And I don't say. I let them know the least about me as possible, and 'cause I don't talk about nothing out there except the weather or whatever. Because, you know, I know I have problems, whatever. And the minute they get to know me and maybe I don't have a good day or whatever and they're going to know something ain't right with this lady. And then even if they won't be bothered, they won't be bothering me after that. It's just a stigma and it hurts me.

Likewise, a 47-year-old divorced Euro-American man conveyed his sense of stigmatizing attitudes in the following exchange:

I: Does anybody act differently towards you because of your illness or because you're taking medication?

R: Well...yes. I mean, I'm coming out of that, of feeling, um, literally negative vibes or attitudes from like, neighbors. And that, for a while, it just really upset me, I could feel it, I knew it was reliable...I just had to deal with it. (How?) Get on with it. And not, like, get all bummed out. (Hm.) Feel sorry for myself.

Friendship Relations

Compared with other types of social relations, friends were mentioned least frequently with regard to stigma. As an elective social relation, there may be 2 scenarios specific to friends that shed light on their lesser salience: (1) they may be inclined to evince support and acceptance; and (2) they may be scarce in the lives of people in the study. As an example of the first scenario is a 26-year-old Euro-American woman who indicated that she felt friends were supportive:

I: Um, how do your friends handle problems that are associated with your illness? Do those ever come up?

R: [She laughs.] It's funny, because um, Tony, a good friend and Paul, 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.

Another illustration of friends who do not stigmatize came with precision from a 49-year-old Euro-American woman who noted that her friends tended to downplay or explain away her mental illness such that stigma was something not only to elude but also to refuse:

"My friends don't treat me like a lower status person...They treat me like I'm intelligent. I often feel like Ronald Reagan the president when it comes to my mental illness: I feel like I have Teflon, it just rubs off people. People don't see me that way. And I don't have a stigma, I always say no to their stigma 'cause you have to put a stigma on yourself. I don't accept the stigma. It's an illness, that's how I feel, and if they treated me differently they probably wouldn't be my friends. I probably wouldn't be comfortable around them."

In the second scenario, of having few friends, the following 2 illustrations from a 50-year-old Euro-American woman and a Euro-American woman of 46 years provide a sense of the insecurity and uncertainty surrounding loss of a friend due to one's illness condition:

R: And, well, I had this good friend, long, long time ago. We used to get out and do all kind of things together. And she quit hanging around me, I don't really know why. But she said something about me wanting to get a job. (Uhm hm.) Because, that she didn't want to see me any more.

I: Wow. Now, was she also someone with an illness...?

R: No, So, I don't. I let bygone be bygones. [Laughs] I don't need friends like that, do I?

I: Oh, that's alright. Um, do you ever feel like you're avoided?

R: By certain people? (Uhm hm.) Well, I'm sure. It's very possible. (Uh hm. Uhm hm.) I'm sure it's very possible. Yeah. I have not, um, there's a lot of people since this happened that I used to work with, who have never called to see what happened. It's an illness, that's gone on, people that I thought were my real friends. So yeah, I'd have to say yes. (Uhm hm.) Some people have avoided me. And it's not my imagination. It's the real thing.

Identity Domains

Medication Use

Of the domains surrounding identity that we analyze here, medication was by far the most common. The rationale for analyzing medication as an "identity" domain is drawn from previous publications (Jenkins and Carpenter-Song, 2005) in which being "a person who takes medication" and having to take such "for the rest of your life" converts to a key dimension of one's identity. Stigma associated with taking antipsychotic medications was manifested as a reluctance to acknowledge to others that one is taking medication, hiding medication or taking it only in privacy, and great dissatisfaction with one's physical appearance in relation to medication side effects. That one was taking psychotropic medication was widely thought to instill fear in others that would invariably lead to avoidance and rejection. Examples of stigma associated with medication cross-cuts other domains of analysis presented here as illustrated above for the social relations of work, dating, and acquaintances.
The expectation of rejection and fear in relation to taking medication is illustrated further in a 25-year-old Euro-American woman’s imagining of what it would be like to divulge the illness:

"It would be interesting to see. I think they might back away. That’s what I think. Unless I explained it in such a way that everybody has some disability and this is just one of them and I talked about it and explained it. But if I just said ‘I’m schizophrenic, I take medicine’ they might back away. In a nice way, if I explained what it was and why I take it, but still I think most people would be frightened about it."

Individuals often find themselves in a “catch 22” situation wherein their experience has shown that they need to take medication to improve or remain well, yet by taking medication they become vulnerable to the judgment of others. To protect against this, one woman described being quite discreet about taking her medication:

“I don’t announce that I’m taking it. I try to take it very discreetly when I do . . . I don’t need someone saying, oh what are you taking, what are you taking?”

A 47-year-old Euro-American woman described a differential practice of hiding her medication in her home:

“If somebody comes over to the house, I may put my medication away, like it’s in a cabinet now, I may hide it. The blood drawing thing (for clozapine), I hide that. Actually, when I was with Randy, a while ago, I think it was a couple weeks ago, he’s the priest’s nephew, I didn’t hide it from him, but he asked whether I, I was easily bruised, (since) they bruised the hell out of my arm. But I told him it was, uh, it was some kind of a blood test. ‘Cause I have this hemochromatosis thing where my body doesn’t get rid of iron. So I have to uh, have blood drawn, like every week, and that reduces my iron level, cause the iron’s used to make new blood. So I told him it was from that. And he didn’t question it, really, that much.”

Regarding fear and lack of familiarity with antipsychotic medication widely encountered by participants, one woman alluded to the shortcoming of the approach to mental illness through reference to the adage to simply “pull yourself up by your bootstraps”:

“Some people can do things on their own without taking pills, sometimes you need a boost. Some people don’t really need boosts for a long period of time, they just need to get over a hump. Um, some people react more adversely than normal to grief, to the loss of a loved one. I’ve seen people in psych wards because somebody died. If they were taking some medication and most doctors do offer when somebody dies, they can prevent that. A lot of people are afraid of medication, they have a stoic attitude. And they think everybody should pull themselves up by their own boots. Some people don’t have any boots, you know? Those who have boots, fine, but those who don’t, they need medication. That’s how I feel.”

Her vigorous response to people she considered “uneducated” about medications extended to a friend who opined that an acquaintance diagnosed with chronic fatigue syndrome stayed in bed because she “wanted” to do so:

R: I removed myself from her life for months because that’s where I drew the line. She said umm, I told her about somebody who was in bed for about fourteen years with chronic fatigue and she said that’s because they wanted to be. And I said something about, well you know my psych drugs make me tired too. Which I think they do . . . [She said] Well you need to get off those! Well I just didn’t speak to her for months and months, because I thought somebody with an attitude like that, uh uh . . .

I: Was not a friend?

R: Yeah, I thought that’s a dangerous thing to tell. She should be in my shoes, would you like to hallucinate? Or be suicidal? (right) Have voices tell her to hang herself? And this person is somebody whose education . . . she should’ve known better (uh hm). So we got back together and she doesn’t say things like that any more so I guess she figured it out on her own.

**Popular Culture**

Narrative statements coded as popular perceptions of individuals with mental illness included statements that articulate attitudes perceived to be held by the general public as well as media portrayals of mental illness, particularly with respect to images of individuals with mental illness as prone to violence. Of those who talked about the experience of stigma 24.4% reported stigma associated with popular perceptions or portrayals of schizophrenia. The following from a 43-year-old Euro-American woman illustrates how public perceptions of schizophrenia as unpredictable or violent can overshadow individual identity:

“People are ignorant when it comes to mental illness. All they see is someone on the news that someone felt threatened and took an assault rifle and started shooting people. Because he didn’t take his medication, that’s what they see.”

In this respect, stigma attaches not simply to an individual, but to a social category. Another example of popular cultural stereotypes that confer stigma is the following response to an interview question about what she thought would happen if people found out she had a mental illness:

“They would probably, um, probably think I’m kind of weird, or, if I was, uh, watching television and make a reference to people’s schizophrenia, and the reference they use, is that it’s, uh multiple personality, multiple personality, which makes me angry, because it’s not that at all. And it’s not that you’re crazy, you know, and I think a lot of people think, ‘Oh God, she a nut.’ You know, and she . . you know, people have a, uh, you know, bad connotation of it and everything.”

With respect to the stereotype of violence as associated with mental illness, a 34-year-old African American man confirmed his experience of this problem as follows:

“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.”

**Gender**

Awareness of stigma was identified by one-fifth (19.8%) of individuals in relation to gender differences, with some subjects reporting greater difficulty for men whereas others reported greater difficulty for women. More women (31.7%) than men (8.2%) reported stigma in relation to gender (Fisher exact test, p < 0.007). Individuals diagnosed with schizoaffective (41.2%) were more likely than those with schizophrenia (13.7%) to report perceptions of the occurrence of gender-related stigma (Fisher exact test, p < 0.02). In several cases, stigma was defined by a perceived inability of individuals with mental illness to live up to culturally normative gender roles. For example, a 27-year-old Euro-American man, describes the particular difficulties faced by men with schizophrenia:

“I think, um, maybe what I’m trying to get at is that it may be for the men it is hard, because the illness sort of emasculates them. Because I think, in men, there is a need to be on top of things. Um, to have certain responsibilities. To look good, to have a significant other, and somehow schizophrenia sort of puts a brake on all of this. They can’t fulfill all these, these obligations. All these ideals of, of manhood and masculinity. And I think that makes it hard for them.”

A parallel although contrasting view was noted by some participants regarding the difficulty of keeping up with feminine gendered expectations. A 39-year-old Euro-American woman demonstrated a preoccupation with her femininity throughout all our research contacts, voicing the view that mental illness may be more difficult for women due to self-perceived loss of femininity.
attractiveness: “[Men] probably don’t worry about their image, as much as maybe I would. Well, I think they probably just maybe don’t. It doesn’t really, you know, bother them.” In addition to repeatedly asking for reassurance that she was “attractive” she worried about her “image” and the possibility of making mistakes.

**Self-Presentation**

We found that the experience of stigma in relation to self-presentation could be coded into 3 domains: (1) appearance, in which an individual indicates that she/he looks different from others on the basis of mental illness, was identified by 18.6% of participants; (2) side-effects, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others because of medications side-effects was identified by 10.5%; and (3) overweight, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others specifically because of the side-effect of weight gain resulting from the medications was identified by 15.1%. More individuals diagnosed with schizophrenia 

more patients with schizophrenia (9.6%) reported stigma in relation to overweight (Fisher exact test, p < 0.02).

In response to an interview question regarding which side effect was most bothersome, a 41-year-old Euro-American man cited drooling, a side effect particularly associated with clozapine: “It gets all over my mouth and everything. Like if I’m making love to a woman at night, I get her all . . . wet.” Another participant, a 40-year-old Euro-American man, emphasized the problem of weight gain:

“I’ve been gaining a lot of weight . . . about fifty pounds. (I’m) like a fat slob. I don’t think I’ll get involved with a woman until I lose weight.”

Given the central role that medications play in participants’ improvement, embarrassing side effects is yet another manifestation of the dilemma of “stigma despite recovery” (Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song, 2008).

**Social Class and Ethnicity**

Only a fraction of subjects (5.8%) reported stigma in relation to social class but nearly a quarter (23.3%) reported stigma in relation to ethnicity. Experiences of stigma in relation to ethnicity occurred in approximately equal proportions in Euro-Americans (21.4%) and African-Americans (25.0%). Narrative statements in which individuals articulated social exclusion, negative attitudes, stereotyping, or discrimination because of a lack of money, poor housing, lack of their own transportation, or on the basis of receiving social security disability income or other government benefits were coded as reflecting stigma in relation to social class. In addition, the perception of stigma often seems to result from an inability to live up to expectations of traditional masculinity and sexuality in relation to low income. Men do not cite schizophrenia itself as a reason not to date, but rather make use of other social and cultural yardsticks to determine their “readiness” to date. These cases reveal the inadequacy of narrow, symptom-based definitions of recovery, and speak to the fact that individuals with mental illness face constellations of constraints such that life chances are reduced not only by the presence of schizophrenia but also significantly by dimensions of social class refracted through gender.

We defined perceptions and experiences of stigma related to ethnicity as either (1) articulations of an especially negative reaction to mentally ill persons among members of a particular ethnic group or (2) articulations of mental illness being particularly difficult for individuals of a given ethnic group. In the following example, a 35-year-old African-American man articulates his perception that African-Americans are less sympathetic than other (unspecified) ethnic groups with respect to mental health problems:

“I don’t think they’re as open-mindedness about it. I think they are a little more prejudiced against mental illness than other people might be. Because of their culture . . . I think a lot of blacks think there is something wrong with me, like, there’s something bad about it.”

The moral dimension of this response—that others think there is something “bad”—about his illness suggests the possible salience of characterological explanations for mental illness among African-Americans.

**DISCUSSION**

In contrast to viewing stigma as a process whereby negative social stereotypes and attitudes are imposed upon the stigmatized, the anthropological approach we have adopted in this analysis begins with a concept of stigma as an interpersonal process. Our intent has been to redress the over-emphases on individual attributes in studies conducted using scalar instruments (Link and Phelan, 2001) and on attitudinal measures as the sole indicators of stigma (Hinshaw and Stier, 2008; Lee et al., 2005) by examining the social contexts in which individuals with psychiatric illness become aware of stigma as manifest in both overt forms of discrimination as well as in tacit forms of rejection and distancing. The data we have presented contribute to a growing literature that incorporates first-person perspectives on psychiatric stigma and, as such, is positioned to offer a further corrective to the “conspicuously absent” voices of mental health consumers in previous research on stigma (Wahl, 1999).

In one respect the population with which we worked represents a limiting case for the study of stigma insofar as for the most part their symptom levels are relatively well controlled, social functioning is relatively high, and living conditions are stable. They are articulate, coherent and socially engaged, hence more attuned to the nuances of experience associated with stigma and susceptible to the paradoxical situation that we have described as “stigma despite recovery.” The data indicate a significant degree of reflectiveness on their part, and very little ambiguity about whether they are subject to stigma and the character of that stigma across different types of situation. This awareness of stigma may be related to the almost uniform recognition among these subjects that they have a mental illness from which, relative to their previous states of acute psychosis, they have improved. Perhaps this awareness of having a long-term disorder conduces to assimilation of and susceptibility to a popular cultural image of mental illness as a state of reduced social status and credibility. They are able to make comparisons between themselves and others, and exhibit distinctive styles of personal expression. Their expectations and attitudes toward life are not dictated by their illness, but are conditioned by it in terms of whether they can “live up to” goals that they take to be no different than those held by “normal” people. Their comments about stigma show that it is constituted interactively, and it has an emotional tone without being characterizable as either flat or histrionic.

Yet while participants revealed a good deal about stigma in their lives, talk about stigma may be limited by reluctance to acknowledge personally painful and socially detractions events which call into question one’s moral status. Across all content domains of our qualitative interviews, discussion of stigma in particular tended not to be extensively elaborated but rather tentative and indirect. That women reported “more” stigma (i.e., spoke about it more) than men in our interviews may represent a gender difference with respect to articulateness, but not necessarily experience. It may also reflect the fact that all the interviewers in the SEACORA project were women, and that male participants were less comfort-
able than their female counterparts in discussing stigma related issues with female interviewers.

It is noteworthy that the first person accounts that constitute our data come in 2 forms. One is opinions about stigmatizing behavior and stigmatizing circumstance that consist of background knowledge, social attitudes, and stereotypes—including stereotypes about mental illness and the mentally ill. The other is brief narrative accounts of actual instances of experiencing stigma. It is relevant to hypothesize that these opinions and experiences condition one another, and future research could productively be directed at how this takes place among persons in recovery from major mental disorder. Not every individual reports experiences of stigma across every one of the categories of social relations and identity domains, but insofar as these domains form a framework of possibilities for experiencing stigma, it is likely that people can imaginatively project themselves into other situations and form impressions based on what they hear about others' experiences. Thus for them stigma is not a discontinuous set of isolated occurrences or a feature of an isolated kind of situation, but implicitly an atmosphere permeating everyday life.

A final aspect of the data requires reflection on the encompassing nature of the framework itself. It is no accident that the inductive categories that emerged from our qualitative data are of 2 types, and that broadly speaking the category of social relations has everything to do with what one does, and the category of identity domains has everything to do with who one is. With respect to social relations, our analysis anticipated that frequency of reported stigma would vary according to degree of intimacy. Our actual results (Table 1) suggest the alternative, or perhaps additional, interpretation that frequency of stigma varies according to the social proximity and experienced intensity of the social situation. By this interpretation, our finding that stigma is perceived as coming most often from strangers may occur in relation to fear (realistic or imagined) that people who one does not know are more likely to judge harshly or dismissively. Anonymous interactions among persons with mental illness are the most intense and have most at stake because they are the most ambiguous, whereas for those not afflicted anonymous situations might be more easily written off as relatively inconsequential. With respect to identity domains, the category itself does not cohere without the interpretation that for this population medication use—the amenable tradeoff of controlling symptoms against unpleasant side effects, of embracing and rejecting it at different moments, and of thinking of it as tool or crutch—is indeed an element of identity, whereas for those not afflicted medication use is episodic and not necessarily mind-altering. Under this interpretation it is not surprising that social class and ethnicity receive so little mention, appearing as ancillary or as afterthought to the stigma of mental illness. From the standpoint of our data, psychiatric stigma associated with the identity of being a medication user appears to “trump” the stigma of race or social class, though the latter may exacerbate or have an additive effect.

CONCLUSION

The paradoxical life circumstance of many study participants can be summarized as follows: the “good” news is that we 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 framework of contexts identified by mentally ill persons themselves in which they are aware of stigma may be relatively stable across cultural boundaries or categories of illness, but in-depth anthropological investigations involving a large sample size such as the present study are required in the future to determine variations in how the experience of stigma is played out across this framework. We may speculate, however, that given the widely documented existence of stigma in relation to mental illness worldwide (Kleinman, 1988; WHO, 2001), future research will find a broad concordance of an awareness of stigma as a matter of everyday lived experience, while the cultural meanings of the specific contexts of stigma experience are likely to vary in several respects (e.g., with respect to diagnosis, medications, or distancing from social relations) yet be similar in others (e.g., dating prospects, popular perceptions of fear).

In this article, we have outlined categories of social relations and identity domains in which patients are aware of stigma, and have taken the additional step of specifying the quality of that awareness. In this light, psychiatric stigma is clearly not a monolithic force against which individuals must struggle. Indeed, we suggest that knowledge of the particularity of lived experiences of stigma may aid the efforts of mental health professionals to anticipate where and under what circumstances individuals may experience the blows of stigma. The data presented in this article contribute to understanding stigma as a product of intersubjective, reciprocal social processes and not something “out there” that is imposed upon an individual. Individuals with mental illness play an active role in contending with, resisting, and sometimes reproducing stigma. Attending to the complex social fields of stigma encourages rethinking the relationships with mental illness in ways beyond vulnerability and victimhood.

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REFERENCES


Awareness of Stigma Among Persons With Schizophrenia

Marking the Contexts of Lived Experience

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Abstract: This article investigates the subjective experience of stigma attached to schizophrenia-related disorders. We examine data from anthropological interviews with a community sample of 90 out-patients residing in a metropolitan area of the United States. Patients were under treatment with typical antipsychotic medication, and their symptoms were for the most part relatively well controlled. Overall, 96% of patients reported an awareness of stigma that permeated their daily life. Based on an understanding of stigma as a product of interpersonal, reciprocal social processes, we identify 6 types of social relations and 5 identity domains in which social stigma is routinely encountered by participants. We describe the experience of stigma in each of these 11 subcategories, and suggest that taken together they constitute a framework of social and personal factors involved in the struggle to recover from psychotic illness. Among types of social relations, anonymous social interactions most commonly generated an awareness of stigma. Among identity domains, being a person who regularly takes medication was most commonly associated with an awareness of stigma. The finding that multiple forms of stigma are encountered irrespective of substantial symptomatic, functional, and subjectively perceived improvement creates a complex situation of stigma despite recovery.

Key Words: Stigma, schizophrenia, subjective experience, antipsychotic medication, recovery, qualitative methods.

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Stigma is increasingly recognized as a global public health problem across a range of illness conditions (Green, 1995; Keusch et al., 2006, World Health Organization, 2001). The global impact of stigma on health care systems, economic productivity, and society at large is extensive and is "a very persistent predicament in the lives of persons affected by it" (Link and Phelan, 2001, p. 9). Stigma associated with mental illness appears to be a cross-cultural universal (Link et al., 2004; Pickenhagen and Sartorius, 2002; Yang et al., 2007). In spite of increased public knowledge about mental disorder, findings from attitudinal surveys suggest that psychiatric stigmatization is pervasive (Angermeyer and Dietrich, 2006; Bhugra, 1989; Rabkin, 1974) and has increased in the United States, particularly with respect to the perception that individuals with psychotic illnesses are violent and frightening (Link et al., 1999; Phelan et al., 2000). Corrigan et al. (2003) conducted a survey of 1824 persons with serious mental illness on perceptions of discrimination applied to mental illness compared with other social characteristics such as ethnicity, gender, or sexual orientation. Over half reported experiences with discrimination and the most frequent source of this discrimination occurred in relation to mental disability. Such findings are particularly disturbing when coupled with the observation that surveys of explicit attitudes toward those with mental illness may underestimate the pervasiveness of stigma due to socially desirable response tendencies (Link and Cullen 1983).

THE PROCESS OF STIGMATIZATION

Much of the social psychological scholarship on stigma concerns specifying the mechanisms underlying stigmatization. Measures of implicit attitudes—so-called "unconscious" attitudes or biases—are a recent development intended to avoid the pitfalls of socially desirable responses. A study by Teachman et al. (2006), employing the Implicit Association Test demonstrated negative implicit attitudes toward mental illness, with 58% to 78% of participants associating the concepts "bad," "blameworthy," and "helpless" with mental illness. Explicit and implicit attitudinal measures are useful in documenting broad societal orientations toward persons with mental illness. Yet these studies do not examine the impact of stigmatizing attitudes on those with mental illness (Hinshaw and Stier, 2008; Link et al., 2004). Thornicroft et al. (2007) have recently noted that attitudinal and social distance research has "generally focused on hypothetical rather than real situations, neglecting emotions and the social context, thus producing very little guidance about interventions that could reduce social rejection." (p. 193) Moreover, research by Corrigan and Watson (2002) highlights that psychiatric stigma does not manifest solely in public attitudes. Corrigan and Watson (2002) have usefully distinguished public stigma, "the reaction that the general population has to people with mental illness," from self-stigma, defined as "the prejudice which people with mental illness turn against themselves" (p. 16).

Social-cognitive processes such as stereotyping figure prominently as ways in which "in group" members affirm positive and individualistic traits of themselves in contrast to "out group" members, who are portrayed homogeneously and negatively (Hinshaw and Stier, 2008). Such basic social psychological processes are considered to account, in part, for a degree of "automatic" and "inevitable" stigma that subsequently becomes intensified by the "threat" posed by disordered behavior and mental illness labels (Hinshaw and Stier, 2008). In this regard, social psychological models conceptualize stigma as a process whereby certain "attributes" or "marks" are associated with a "devaluing social identity" or "discrediting disposition" in the context of social interactions (Crocker et al., 1998; Jones et al., 1984). Such formulations echo Goffman (1963), who defines stigma as rooted in an "undesired difference," an "attribute that is deeply discrediting" and that results in a "spoiled identity." The complex ways in which individuals navigate their social worlds—how to manage information regarding one's condition, contending with the expectation of stigma, efforts to pass—constitute the "moral career" of the stigmatized.

Keusch et al. (2006) have recently called for a reinvigoration of the "science of stigma" and advocate building upon the insights set forth by Goffman (1963) to examine stigma as a "cultural disease that marks its victims as morally tainted." (Keusch et al., 2006, p. 526). Although Goffman's formulation emphasizes stigma as a social construction, social psychological frameworks tend to reduce...
stigma to processes occurring at the individual cognitive level in response to social stimuli. As Yang et al. (2007) have noted, although such social psychological mechanisms are relational in structure: "analysis of these models reveals that they primarily regard the social aspects of stigma as a psychological variable (i.e., 'social identity' as applied to an individual), as an environmental stimulus that the individual appraises or responds to, or as societal or cultural stereotypes. Further, these models restrict the range of coping responses (e.g., the stigmatized individual's cognitive coping strategies) and the harmful outcomes of stigma to individual self-processes (e.g., psychological well-being). These models suffer from limiting conceptualization of the social to those environmental elements of stigma that 'impinge upon' the individual sufferer, who is then viewed as the primary locus in which stigma processes take place" (p. 1525).

Link and Phelan (2001) summarize recent social psychological research to show that people construct cognitive categories and then customarily link those categories to preexisting stereotyped notions. Going beyond this well-known association, they make a convincing case for understanding stigma as a set of social components that includes labeling, separation, status loss, and discrimination (see also, Link, 1995). These elements, they aver, unfold in the context of unequal social, economic, and political power. Accordingly, the process of stigmatization is such that persons with mental illness are socially identified as different, this difference is ranked and linked to negative social stereotypes facilitating the construction of individuals with mental illness as "others," which, in turn, provides a rationale for devaluing, rejecting, and excluding them. Furthermore, Link and Phelan (2001) identify 2 key problems in current literature on stigma: (1) an overemphasis on individual attributes derived from social psychological research methods that rely on scalar instruments; and (2) a notable absence of research on the lived experience of persons who struggle daily with stigma. A literature review by Link et al. (2004) offers evidence that research conducted from the standpoint of individuals with mental illness or their close associates accounts for a minority of studies, and qualitative methodologies of interviewing and participant observation are uncommon.

The Experience of the Stigmatized

Moving toward an approach that takes into account the lived experience of stigma as an interactive phenomenon, Corrigan and Watson (2002) developed a situational model of personal response to stigma that varies substantially in relation to the person's perception of its legitimacy as applied to them. Camp et al. (2002) investigated whether low self-esteem was an inevitable consequence of stigma among a group of 10 women using qualitative analysis, revealing that while these women considered that they had a mental illness, they did not accept society's unfavorable representations of them on that basis (cf. Link et al., 2001). Sajatovic et al. (2005) highlight an additional dimension of the relationship between stigma and the self in their investigation of gender identity and gender role performance among individuals with schizophrenia-related disorders. They note that while individuals with schizophrenia are likely to experience lowered self-esteem in relation to the stigmatizing effects of mental illness, it is also likely that specific disturbances in gender identity and gender role performance likewise confer negatively upon sense of self-esteem. In their recent review of stigma related to mental disorders Hinshaw and Ster (2008) observe that stigma involves stereotypes, prejudice, and discrimination that limit the life chances of those stigmatized. Yet they also observe that stigma processes are not reducible to these phenomena in light of the often all-encompassing nature of stigmatizing characteristics, the shame experienced by the stigmatized, and the crippling effects of stigma on social interactions that become shadowed by hostility, rejection, and anxiety (Hinshaw and Ster, 2008).

Aside from the literature constituted by memoirs of individuals living with mental illness (Deegan, 1988; Gallo, 1994), there has also been a slowly accumulating literature that has incorporated first-person perspectives on psychiatric stigma. For the most part these studies have been based on data from focus groups, surveys, and questionnaires (Corrigan et al., 2003; Perlick et al., 2001; Schulze and Antomazuvogel, 2003; Wahl, 1999) or from semi-structured interviews with small to medium sample sizes (N < 100) (Camp et al., 2002; Knight et al., 2003). These studies point to multiple pathways for the constitution of the self and self-worth, and have important implications in the illness recovery process which requires self-management and reintegration of the individual into the community (Davidson, 2003). The findings of Dinos et al. (2004) based on their study of 46 individuals with mental illness align well with our findings of the pervasive awareness of stigma and the importance of managing illness information among persons with schizophrenia. However, from an anthropological perspective, Dinos et al. (2004) do not adequately situate the experiences of the individuals they interviewed within their interactive context. Indeed, ethnographic data on the immediate contexts of stigma in the community are in short supply (Phelan et al., 1998).

Against this conceptual and empirical background, and with an understanding of stigma as an interactive phenomenon with its locus in lived experience, we ask two questions in this article. First, to what extent is stigma pervasive in the lives of the afflicted? Answering this question requires specifying the range of contexts in which people encounter stigma, and in which stigmatizing behavior might take different forms. Second, how do people afflicted with schizophrenia perceive and experience stigma? An approach attuned to stigma as an interactive phenomenon will not be satisfied with a global notion of "spoiled identity," but will identify how differentness and otherness are constituted in instances of being snubbed, teased, rejected, talked about, or even looked at in an unusual way. This is all the more salient among a population such as that examined herein, among whom symptom levels are relatively well controlled and social functioning is relatively high. Our data on stigma are drawn from a broader anthropological study entitled "Schizophrenia and the Experience of the Culture of Recovery through Atypicals" (SEACORA), which examined the subjective experience and meaning of illness and either worsening or improvement/recovery among 90 persons diagnosed with schizophrenia-related disorders and taking atypical or "second generation" antipsychotic medications (Jenkins et al., 2005; Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song, 2008).

METHODS

Sample Selection

In a northeastern US metropolitan area, we obtained the complete rosters of 2 community mental health outpatient facilities that served Euro-American and African-American ethnic groups. The first clinic is affiliated with an academic research community and was developed specifically to deliver clozapine treatment. Those attending the clinic often spent significant amounts of time on site, ranging from every day visits to once or twice per month. The second clinic had a relatively less developed research focus, and patients came briefly for biweekly or monthly medication checks. Study 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, some subjects in the study (N = 6) were prescribed atypical antipsychotic drugs as their first psychopharmacological treatment.
Selection criteria included: (1) diagnosis of schizophrenia or schizoaffective disorder assessed through the Structured Clinical Interview for DSM-IV (First et al., 2002); (2) age 18 to 55; (3) at least 2 years since first psychotic symptoms; (4) at least 6 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. Eligibility was assessed by treating psychiatrists and therapeutic managers, and resulted in a complete list of all patients who met research diagnostic criteria. From this list, 167 eligible participants were randomly sampled. Of those selected, 90 (54%) were included in the final sample, with 46.7% declining research participation. The overall high rate of refusal is not unusual (Covell et al., 2003) for an American community outpatient sample such as this, with males (55.9%) significantly more likely than females (29.3%) to decline participation (Fisher exact test, p < 0.001). Reasons for nonparticipation included lack of interest in research (stating simply they “did not want to”) or a reluctance to provide time for interviews (due to 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 were more interested in research, sometimes stating that they had an interest in cooperating with anything that might benefit others (or themselves) in future. In this regard, the sample may be more cooperative and less symptomatic, more socially functional, or potentially more likely to have had a positive experience with medication or their physicians than those in the group who declined participation (see also, Jenkins et al., 2005).

Procedures

For this study of subjective experience of schizophrenia, we employed techniques of ethnographic interviewing, naturalistic observation, and procedures for research diagnostic criteria (Structured Clinical Interview for DSM-IV and symptom severity (Brief Psychiatric Rating Scale [BPRS]). The research psychiatrist for the project was trained in the reliable administration of both of the latter instruments. This article, however, is based on stigma-related data generated by the ethnographic interview. The ethnographic interview, the “Subjective Experience of Medication Interview” (SEMI), is a semi-structured, open-ended qualitative procedure adapted from interviews used in prior research (Jenkins, 1997). As a qualitative procedure, the SEMI serves as an interview guide in which there is flexibility in the administration of interview questions. If a subject is highly responsive and generates narrative on a topic of interest, the predesignated interview questions may be used sparingly. On the other hand, if a respondent is not highly responsive in generating narrative on their own initiative, the interviewer may use questions and follow-up probes more extensively in an effort to obtain the persons’ point of view. The substantive domains covered by the SEMI include the experience of medication and treatment, living situation, everyday activities, illness management, social relations, gender identity, expectations concerning recovery and quality of life, and stigma. Qualitative data on any topic, including stigma, might be generated at any point of the interview. Examples of specific questions posed to elicit stigma-related data were as follows: “Do you tell people that you have (diagnosis)? That you’re on medication? Who do you tell?” and “What kinds of things do you try to do to keep people from finding out?” “Does anybody act differently toward you because of your illness, or because you take medication?” “For yourself, do you prefer friends or dating relationships among people who also have a mental illness or those who do not have a mental illness?”

The duration of the SEMI interviews was generally 1.5 to 2 hours over 1 to 3 interview sessions. Interviews were conducted by the Principle Investigator and a team of 4 doctoral students in medical anthropology. All SEMI interviews were transcribed verbatim from audiotape and entered into the Atlas.ti qualitative software program (Scientific Software, 1997) which is designed to code and analyze qualitative data systematically (Good, 1994; Luborsky, 1993). The 90 SEMI interview transcripts, averaging 92 double-spaced pages, were read and coded by the two authors (J.J. and E.C.S.). A grounded theory approach in which thematic categories are inductively derived (Strauss and Corbin, 1990), yielded 34 substantive categories, of which “stigma” was one. In any instance in which content of a text segment was in question, relevance that text segment to stigma was confirmed or disconfirmed through review and consensus between the 2 coders, as customarily required for systematic qualitative analysis of large volume textual data (NIH, 2001; Taylor and Bogdan, 1998; Warren, 2002). We coded data “yes” for awareness of stigma if at least 1 of the following conditions was met: (1) the subject indicated that people react negatively toward them in response to the direct questions listed above; (2) the subject volunteered information about awareness or experience of psychiatric stigma in any other part of the SEMI interview. Coding a “no” response cannot be considered as a definitive determination that the subject did not perceive or experience stigma, but only that the response reflects absence of report of stigma in the interview transcript. Reports of perceived stigma were secondarily coded by the same 2 coders to identify the contexts in which subjects experience stigma, yielding the categories of social relations and identity domains shown in the results below.

Sample Characteristics

Sociodemographic and clinical characteristics of the 90 SEACORA participants have been more fully summarized fully elsewhere (Jenkins et al., 2005). In brief, males constituted 54.4% and females 45.5% of the sample. Euro-Americans accounted for 77.8% and African-Americans for 22.2%. 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% single, 5.6% married or living with a partner, and 10% divorced, widowed, or separated. Those living alone accounted for 25.6%, those living with a roommate or in a group home for 22.2%, those with a relative or parent 42.2%, and those with a partner or spouse 10%. Fully 60% were unemployed, 22.2% were working half time or less, and 17.8% were working from half to full time.

Diagnostically, 81.1% participants had schizophrenia and 18.9% 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 1–7, absent to severe, respectively) on the 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/depression (see, Jenkins et al., 2005 for fuller discussion). There were no significant differences in socioeconomic status by ethnicity.

RESULTS

Nearly all persons in the study (86 or 96.0%) reported perception of stigma across a variety of social settings that they encounter on a daily basis. In general, the low symptomatology among study participants (Jenkins et al., 2005) does not appear to afford these individuals any considerable measure of protection from the blows of stigma. In fact, for some participants, improvement may create the conditions for a subjective discernment of pervasive stigma to be felt with greater acuity, what we refer to as the paradox of stigma despite recovery
A 39-year-old Euro-American woman living with her parents in a lower middle class suburban neighborhood, who has been ill for 21 years, attempts to de-emphasize her illness and does not reveal her illness to people other than close friends and family. Otherwise, she says:

R: Well, the people I do know, already know. Like the relatives and friends of the family probably know I have problems, but someone like a stranger, someone I wouldn’t know. Or like when I go to welfare. The lady at welfare knows I’m on disability, and um, sometimes I feel that she’s looking at me in a different way. I just try to carry myself in a proper way not to let people know that there’s something wrong with me. Because then, like I say, I’m funny about that.

I: Uh hm. Yeah. And what is the proper way?

R: Well, I, some people just come out and say, you know, I’m sick or you know, I got a problem. I’ll just try to, try to hide it. (Uhm.) I would just try not to make it obvious. (Uhm.) Because some people can be really cruel, you know. Um, they can say, ‘well what’s wrong with her, you know? You know how people are. They, they can just kinda get funny about that kind of stuff.’

She expressed anxiety and discomfort as common for her when walking on the street, a situation in which she felt people were staring at her for appearing strange.

### Work Relations

Overall, 36.0% were aware of stigma in the context of social interactions related to work. As expected, those working currently (36 or 40%) were significantly more likely to report stigma in relation to work (50.0%) than those not currently working (24.1%) (Fisher exact test, p < 0.02). While it is obvious that those currently working would be more preoccupied with stigma in this context, its salience in the context of previous or prospective employment was also noteworthy. Transactions in the workplace included the perception of hostile or fearful attitudes, teasing, violation of confidentiality, discrimination and unfair treatment, pejorative stereotyping or insensitivity by coworkers/supervisors, as well as the fear of either not being hired or being fired on the basis of mental illness. Finally, negative reactions by others because one does not have a job were also noted.

One illustration of stigma encountered at the workplace was provided by a 36-year-old Euro-American woman living with her parents. She works as a salesperson in a department store, where she fears people know about her condition. The sources of her fear are her own behavior as well as that of others. For her part, she says that she sometimes becomes confused about when employee breaks are scheduled, a potential problem since these must be negotiated and coverage of the various departments had to be ensured. She imagines that her confusion may have given coworkers reason to surmise she is ill. Nevertheless, she makes a point of not revealing her illness to people at work, a sore spot in light of a recent action on the part of a store manager.

“Um, no, I generally, most of the time I don’t, like especially at work. I figure it’s really none of their business . . . I have a sneaking suspicion that some people might know or have guessed [mental illness]. Because one time there was a manager, over in another department, I had mentioned that I had to see my Medicaid lady to her. And then we were in the hallway, and I had either clocked out for the day or was about to, and I talked to her about that appointment. And she says something about blah, blah, blah, you know, about your disability and it was, there was still a lot of people around, and I don’t know. They might have known or have guessed.”

Another example of the way in which stigma and symptomatic worsening are reciprocally related comes from a 39-year-old...

### TABLE 1. Awareness of Stigma

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<tr>
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<td>Dating relations</td>
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<td>Social class and ethnicity</td>
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*Total number of subjects equals 86 who indicated awareness of stigma; 4 responses were judged as lacking or insufficient to code presence of awareness of stigma.

(Jenkins and Carpenter-Song, 2008). The remainder of our analysis will consist of specification of this social matrix of contexts of subjective awareness of stigma.

The diversity of contexts in which there is a heightened awareness of stigma underscores the pervasiveness of stigma within the everyday experiences of individuals with schizophrenia-related disorders and illuminates the ways in which stigma surrounding the illness shapes nearly all aspects of everyday experience. The contexts of the awareness of stigma constitute 2 categories: (1) social relations and (2) domains of identity (Table 1). In the category of social relations, study participants identified differences in the perception of stigma in anonymous interactions, work relations, dating relations, family relations, interactions with acquaintances, and interactions with friends. The category of identity domains includes gender, self-presentation, social class, and ethnicity. We also include common culture as an individual may define him/herself in relation to a mediated-derived social context, and medication use as an isolated analysis demonstrated the considerable extent to which persons identified themselves in relation to reliance on psychotropic medication (Jenkins and Carpenter-Song, 2005). In sum, although it is not surprising that people report stigma across these varied social relations and identity domains, our purpose here is (1) to point to the quality of stigma as lived experience in each of the contexts, and 2) to indicate how the set of contexts constitutes a comprehensive framework of the struggle to recover from psychotic illness.

### Social Relations

#### Anonymous Social Interactions

The category of stigma in “anonymous interactions” occurred among strangers in public, commercial, or bureaucratic social settings. This included settings such as the street, bus, library, parks, drug and grocery stores, restaurants and coffee shops, and governmental and welfare offices. The ways in which persons felt the presence of social stigma in these diverse settings included discomfort over the sense that verbal and nonverbal communications were directed toward them to signal identification and labeling of them as mentally ill, strange, frightening, or of lesser intellectual and social capacity. Besides the perception of disapproving and derivative messages, people in the study also reported the sense from strangers that they could be patronized on the basis of one’s condition, on the one hand, or a target of vulnerability, on the other.
African American man who lives alone in a condominium purchased for him by his parents. Recently hired to work in a hospital setting, he began to feel uncomfortable in the work setting because he was taking medication. This led to a series of events beginning with his decision to stop taking medication, ensuing difficulties with his supervisor, and subsequent suspension.

“When I was working in the hospital, I stopped taking the medication a couple of weeks or so after I got hired because I felt bad about having to take medication and having an illness and being diagnosed as schizophrenic. And um, instead of educating myself or educating other people about it, I chose to just stop taking it. And um, that was bad. And then I was, had a fall out with my boss and got put on suspension. And, even though when I came back they paid me for the times I missed, they understood that I have a sickness, and illness. And when I came back I was on the medication and I really didn’t know what to say to people or what to, how to explain it, what was going on. And I felt like I was under a magnifying glass and it was really uncomfortable. That was really hard for me.”

This example of stigma in the workplace interrelates with the identity domain of medication examined below whereby disapproval of the self is unwittingly conjoined by social disapproval by others.

**Dating Relations**

Dating is an area of social relations that participants identified as a source of unease. About one-third (32.6%) described either being rejected by potential dating partners because of mental illness or acknowledged not wanting to date another person with mental illness. As for the above social relations, people described reluctance to reveal illness or medications because of fear of frightening others, fear of rejection, stereotyping, teasing, and fear of mistreatment and vulnerability in relation to dating. In addition, while weight gain in women and personal appearance constituted an impasse to the prerogative to date for women and men alike, women tended to worry somewhat more about such limitations. For their part, men were more preoccupied that they could not meet cultural expectations that they have money, a car, and perform sexually. Overall, women (41.5%) were more likely to speak about such limitations compared with men (22.4%).

An interview exchange with a 35-year-old African American woman illustrates the problem of feeling disallowed to date on the basis of mental illness:

**R:** Oh, yeah, for me there is, quite a bit. You know, that’s the thing, you know, I think that there’s really, only, not much choice in the way of, you know, dating people because I think if you’re a girl that has mental problems, or whatever, you know, well at least I know, normal guys don’t look twice at me. They don’t!

The following interview interchange with a 39-year-old Euro-American woman illustrates what she feels is at stake if you have a mental illness and get involved in a romantic relationship:

**I:** Do you think that love is difficult?

**R:** Love is very difficult. Love is difficult because you risk—you risk everybody laughing at you if you love somebody.

**I:** Everyone laughing at you? And why is that? Why would they be laughing?

**R:** Someone [told me] once, um—it’s impossible for people—for schizophrenics to actually love. I go why? “Because your head gets involved with everything.” I don’t know.

**I:** What do you think about that?

**R:** I don’t—it’s pretty hard. Take advantage of, thinking that maybe I’m—you’re not good enough for this person, you’re not good enough for that person. Something like that. Thinking I’m not good enough to be with that person. That you’re crazy and stuff.

Finally, a 47-year-old Euro-American man who lives alone in an apartment conveyed ambivalence on the subject of dating by saying that “Sometimes I feel strongly that I’d like to meet somebody, and sometimes I don’t, you know.” His sense of dating as “very risky” was borne out by this comment that “there’s no guarantees that it’s going to work out the way you want it to.” In addition, he viewed dating as not realistic given his illness, physical appearance, and financial constraints such that he could only become interested if things were different than they currently are:

“Right now, you know, I don’t have that much money and its not real practical. I can’t imagine a healthy woman being interested in, particularly interested in a schizophrenic person my age and my big fat stomach [he laughs] and my gray hair and all that, you know. It’s not impossible but I don’t really, it’s not high on my agenda right now.”

**Family Relations**

Participants also describe avoidance or exclusion by family, denial of illness by family members, and the perception that family members are embarrassed or ashamed on the basis of mental illness. A sense of exclusion and unfavorable attention within one’s family was more commonly the subject of commentary by women (34.1%) than men (10.2%, Fisher exact test, p < 0.01) in the study.

A divorced 43-year-old Euro-American woman described family relations as characterized by 2 recurring patterns: either as attempts to avoid her or as efforts to make her into a kind of family scapegoat who could be pointed to as an example of someone who had more problems and was “more ill” than anyone else.

“Either they don’t want to be around you or (it’s) where you can’t even have any privacy without, you know, it’s like they mention your name all the time in their conversation. And either that or they don’t want to be around you. Because you know why, they don’t want to look at themselves. They might see something in themselves that might disturb them . . . (this is) my family, mostly. They’d rather avoid you. It’s a defense mechanism.”

Another illustration of how families may exclude members with mental illness from participation in family activities comes from a 44-year-old Euro-American woman:

“I feel in a lot of ways mom and dad are maybe ashamed of me for some reason . . . they are kind of hesitant and everything and . . . it’s a feeling, you know, they don’t know that I’ve come a long ways from what I used to be. It just seems like I’m still the same way that they think I am. You know, they just don’t realize it hurts when they go some place . . . ah . . . they don’t ask me . . . they just don’t want me to go. It kind of hurts.”

For this woman, the sting of being left out of family interactions reinforces her perception that her parents do not acknowledge her considerable sense of improvement, with stigma persisting in spite of having come a long way. A 42-year-old Euro-American man who lives alone in a condominium, detailed how his entire family shunned him for being unemployed and did not seem to comprehend his illness condition. Ultimately, his parents came to understand and accept him (after having obtained employment) but this was not true of his siblings:

“My folks are very understanding and supportive, especially now. But my brothers and sisters doesn’t stay in touch. They don’t write. They don’t call. They don’t visit. And I have been in the hospital 19 times, and not once did they come to visit me, you know. 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. I sit bothered me a lot. I used to be jealous, I know some people where their families are really close, you know, and I don’t have that.”
Acquaintance Relations

A realm of less intimate social relations is that of acquaintances in which encounters may be less regular but nonetheless hold significance for one's overall social experience. This may be the neighbor who lives down the street who occasionally tarries in front of your house when walking his dog or the schoolmates who usually say "hello" but never actually converse or make social overtures. In one case, a Euro-American woman said that someone down the street called her "mentally retarded," a comment which she says really hurt her. When asked for detail regarding how this occurred, she elaborated that the offending man had not said this directly to her but to her next door neighbor within her earshot. Her response was "just let it go," reasoning that people do not understand but in any event do not intend to hurt her.

Intended or not, a 32-year-old Euro-American woman recalled her experience at an exclusive private girls preparatory school as intolerable. As seniors, students were allowed to go for lunch off campus but in her case she says felt "isolated" and was "cut off" because no one ever asked her to lunch. She says that although she is pleased with what she regards as currently good health, she nonetheless is unhappy and has thoughts of killing herself: "There's nothing I can do about it. I get so tired of being cut off, and it's like I'm really really frightened of it [being cut off]." She feels that she never learned to socialize properly and that she is generally avoided or excluded. Some many years later, she continues to feel left out of things yet seems resigned to this situation as she says, "I've never fit in and I never belong." For her, perceived stigma from persons she does not know well is so incisive to her experience of not "belonging" that it can fuel a desperate need to end her life quite distinct from the above proclivity to "just let it go."

A generalized sense of degradation was articulated by a divorced 56-year-old African American woman who responded to an interview question about whether women or men were treated differently in a situation of schizophrenia.

I: Do you think that people react any differently to men and women with schizophrenia?

R: No, they gonna treat you the same regardless. They treat you, umm... when you have mental illness. I try not to let them know that I have a mental illness, because the minute you do, that's it. They gonna not be bothering, they're gonna talk about you, they're gonna down-grade you. It's gonna cause you problems, so you know, if I go out the door and I see a neighbor, he'll say, "Oh, how you doing?" And I don't say. I let them know the least about me as possible, and 'cause I don't talk about nothing out there except the weather or whatever... Because, you know, I know I have problems, whatever. And the minute they get to know me and maybe I don't have a good day or whatever and they're going to know something ain't right with this lady. And then even if they won't be bothered, they won't be bothering me after that. It's just a stigma and it hurts me.

Likewise, a 47-year-old divorced Euro-American man conveyed his sense of stigmatizing attitudes in the following exchange:

I: Does anybody act differently towards you because of your illness or because you're taking medication?

R: Well... yes. I mean, I'm coming out of that, of feeling, um, literally negative vibes or attitudes from like, neighbors. And that, for a while, it just really upset me, I could feel it, I knew it was reliable... I just had to deal with it. (How?) Get on with it. And not, like, get all bummed out. (Hm). Feel sorry for myself.

Friendship Relations

Compared with other types of social relations, friends were mentioned least frequently with regard to stigma. As an elective social relation, there may be 2 scenarios specific to friends that shed light on their lesser salience: (1) they may be inclined to evince support and acceptance; and (2) they may be scarce in the lives of people in the study. As an example of the first scenario is a 26-year-old Euro-American woman who indicated that she felt friends were supportive:

I: Um, how do your friends handle problems that are associated with your illness? Do those ever come up?

R: (she laughs). It's funny, because um, Tony, a good friend and Paul. 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.

Another illustration of friends who do not stigmatize came with precision from a 49-year-old Euro-American woman who noted that her friends tended to downplay or explain away her mental illness such that stigma was something not only to elude but also to refuse:

"My friends don't treat me like a lower status person... They treat me like I'm intelligent. I often feel like Ronald Reagan the president when it comes to my mental illness: I feel like I have Teflon, it just rubs off me. People don't see me that way. And I don't have a stigma, I always say no to their stigma 'cause you have to put a stigma on yourself. I don't accept the stigma. It's an illness, that's how I feel, and if they treated me differently they probably wouldn't be my friends. Probably wouldn't be comfortable around them."

In the second scenario, of having few friends, the following 2 illustrations from a 50-year-old Euro-American woman and a Euro-American woman of 46 years provide a sense of the insecurity and uncertainty surrounding loss of a friend due to one's illness condition:

R: And, well, I had this good friend, long, long time ago. We used to get out and do all kind of things together. And she quit hanging around me, I don't really know why. But she said something about me wanting to get a job. (Uh hm). Because, that she didn't want to see me any more.

I: Wow. Now, was she also someone with an illness...?

R: No. So, I don't. I let bygone be bygones. [laughs] I don't need friends like that, do I?

I: Oh, that's alright. Um, do you ever feel like you're avoided?

R: By certain people? (Uh hm.) Well, I'm sure. It's very possible. (Uh hm. Uh hm.) I'm sure it's very possible, yeah. I have not, um, there's a lot of things that happened that I used to work with who have never called to see what happened. What's gone on, people that I thought were my real friends. So yeah, I'd have to say yes. (Uh hm.) Some people have avoided me. And it's not my imagination. It's the real thing.

Identity Domains

Medication Use

Of the domains surrounding identity that we analyze here, medication was by far the most common. The rationale for analyzing medication as an "identity" domain is drawn from previous publications (Jenkins and Carpenter-Song, 2005) in which being "a person who takes medication" and having to take such "for the rest of your life" converts to a key dimension of one's identity. Stigma associated with taking antipsychotic medications was manifested as a reluctance to acknowledge to others that one is taking medication, hiding medication or taking it only in privacy, and great dissatisfaction with one's physical appearance in relation to medication side effects. That one was taking psychotropic medication was widely thought to instill fear in others that would invariably lead to avoidance and rejection. Examples of stigma associated with medication cross-cuts other domains of analysis presented here as illustrated above for the social relations of work, dating, and acquaintances.
The expectation of rejection and fear in relation to taking medication is illustrated further in a 25-year-old Euro-American woman’s imagining of what it would be like to divulge the illness:

“It would be interesting to see. I think they might back away. That’s what I think. Unless I explained it in such a way that everybody has some disability and this is just one of them and I talked about it and explained it. But if I just said ‘I’m schizophrenic, I take medicine’ they might back away. In a nice way, if I explained what it was and why I take it, but still I think most people would be frightened about it.”

Individuals often find themselves in a “catch 22” situation wherein their experience has shown that they need to take medication to improve or remain well, yet by taking medication they become vulnerable to the judgment of others. To protect against this, one woman described being quite discreet about taking her medication:

“I don’t announce that I’m taking it. I try to take it very discreetly when I do. I don’t need someone saying, oh what are you taking, what are you taking?”

A 47-year-old Euro-American woman described a differential practice of hiding her medication in her home:

“If somebody comes over to the house, I may put my medication away, like it’s in a cabinet now, I may hide it. The blood drawing thing (for clozapine), I hide that. Actually, when I was with Randy, a while ago, I think it was a couple weeks ago, he’s the priest’s nephew, I didn’t hide it from him, but he asked whether I, I was easily bruised, (since) they bruised the hell out of my arm. But I told him it was uh, it was some kind of a blood test. ‘Cause I have this hemochromatosis thing where my body doesn’t get rid of iron. So I have to uh, have blood drawn, like every week, and that reduces my iron level, cause the iron’s used to make new blood. So I told him it was from that. And he didn’t question it, really, that much.”

Regarding fear and lack of familiarity with antipsychotic medication widely encountered by participants, one woman alluded to the shortcoming of the approach to mental illness through reference to the adage to simply “pull yourself up by your bootstraps”:

“Some people can do things on their own without taking pills, sometimes you need a boost. Some people don’t really need boosts for a long period of time, they just need to get over a hump. Um, some people react more adversely than normal to grief, to the loss of a loved one. I’ve seen people in psych wards because somebody died. If they were taking some medication and most doctors do offer when somebody dies, they can prevent that. A lot of people are afraid of medication, they have a stoic attitude. And they think everybody should pull themselves up by their own boots. Some people don’t have any boots, you know? Those who have boots, fine, but those who don’t, they need medication. That’s how I feel.”

Her vigorous response to people she considered “uneducated” about medications extended to a friend who opined that an acquaintance diagnosed with chronic fatigue syndrome stayed in bed because she “wanted” to do so:

R: I removed myself from her life for months because that’s where I drew the line. She said umm, I told her about somebody who was in bed for about fourteen years with chronic fatigue and she said that’s because they wanted to be. And I said something about, ‘well you know my psych drugs make me tired too.’ Which I think they do...[She said] ‘Well you need to get off those! Well I just didn’t speak to her for months and months, because I thought somebody with an attitude like that, uh uh...’

I: Was not a friend?

R: Yeah, I thought that’s a dangerous thing to tell. She should be in my shoes, would you like to hallucinate? Or be suicidal? (right?) Have voices tell her to hang herself? And this person is somebody whose education...she should’ve known better (uh hm). So we got back together and she doesn’t say things like that anymore so I guess she figured it out on her own.

Popular Culture

Narrative statements coded as popular perceptions of individuals with mental illness included statements that articulate attitudes perceived to be held by the general public as well as media portrayals of mental illness, particularly with respect to images of individuals with mental illness as prone to violence. Of those who talked about the experience of stigma 24.4% reported stigma associated with popular perceptions or portrayals of schizophrenia. The following from a 43-year-old Euro-American woman illustrates how public perceptions of schizophrenia as unpredictable or violent can overshadow individual identity:

“People are ignorant when it comes to mental illness. All they see is someone on the news that someone felt threatened and took an assault rifle and started shooting people. Because he didn’t take his medication, that’s what they see.”

In this respect, stigma attaches not simply to an individual, but to a social category. Another example of popular cultural stereotypes that confer stigma is the following response to an interview question about what she thought would happen if people found out she had a mental illness:

“They would probably, um, probably think I’m kind of weird, or, if I was, uh, watching television and make a reference to people’s schizophrenia, and the reference they use, is that it’s, uh multiple personality, multiple personality, which makes me angry, because it’s not that at all. And it’s not that you’re crazy, you know, and I think a lot of people think, ‘Oh God, she a nut.’ You know, and she...you know, people have a, uh, you know, bad connotation of it and everything.”

With respect to the stereotype of violence as associated with mental illness, a 34-year-old African American man confirmed his experience of this problem as follows:

“Yeah 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.”

Gender

Awareness of stigma was identified by one-fifth (19.8%) of subjects in relation to gender differences, with some subjects reporting greater difficulty for men whereas others reported greater difficulty for women. More women (31.7%) than men (8.2%) reported stigma in relation to gender (Fisher exact test, p < 0.007). Individuals diagnosed with schizoaffective (41.2%) were more likely than those with schizophrenia (13.7%) to report perceptions of the occurrence of gender-related stigma (Fisher exact test, p < 0.02). In several cases, stigma was defined by a perceived inability of individuals with mental illness to live up to culturally normative gender roles. For example, a 27-year-old Euro-American man, describes the particular difficulties faced by men with schizophrenia:

“I think, um, maybe what I’m trying to get at is that it may be for the men it is hard, because the illness sort of emasculates them. Because I think, in men, there is a need to be on top of things. Um, to have certain responsibilities. To look good, to have a significant other, and somehow schizophrenia sort of puts a brake on all of this. They can’t fulfill all these, these obligations. All these ideals of, of manhood and masculinity. And I think that makes it hard for them.”

A parallel although contrasting view was noted by some participants regarding the difficulty of keeping up with feminine gendered expectations. A 39-year-old Euro-American woman demonstrated a preoccupation with her femininity throughout all of our research contacts, voicing the view that mental illness may be more difficult for women due to self-perceived lost or waning physical
attractiveness: "[Men] probably don’t worry about their image, as much as maybe I would. Well, I think they probably just maybe don’t. It doesn’t really, you know, bother them." In addition to repeatedly asking for reassurance that she was "attractive" she worried about her "image" and the possibility of making mistakes.

Self-Presentation

We found that the experience of stigma in relation to self-presentation could be coded into 3 domains: (1) appearance, in which an individual indicates that she/he looks different from others on the basis of mental illness, was identified by 18.6% of participants; (2) side-effects, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others because of medications side-effects was identified by 10.5%; and (3) overweight, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing labeling, or discrimination by others specifically because of the side-effect of weight gain resulting from the medications was identified by 15.1%. More individuals diagnosed with schizoaffective disorder (35.3%) than those diagnosed with schizophrenia (9.6%) reported stigma in relation to overweight (Fisher exact test, p < 0.02).

In response to an interview question regarding which side effect was most bothersome, a 41-year-old Euro-American man cited drooling, a side effect particularly associated with clozapine: "It gets all over my mouth and everything. Like if I’m making love to a woman at night, I get her all . . . wet." Another participant, a 40-year-old Euro-American man, emphasized the problem of weight gain:

"I’ve been gaining a lot of weight . . . about fifty pounds. (I’m) like a fat slob. I don’t think I’ll get involved with a woman until I lose weight."

Given the central role that medications play in participants' improvement, embarrassing side effects is yet another manifestation of the dilemma of "stigma despite recovery" (Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song, 2008).

Social Class and Ethnicity

Only a fraction of subjects (5.8%) reported stigma in relation to social class but nearly a quarter (23.3%) reported stigma in relation to ethnicity. Perceptions of stigma in relation to ethnicity occurred in approximately equal proportions in Euro-Americans (21.4%) and African-Americans (25.0%). Narrative statements in which individuals articulated social exclusion, negative attitudes, stereotyping, or discrimination because of a lack of money, poor housing, lack of their own transportation, or on the basis of receiving social security disability income or other government benefits were coded as reflecting stigma in relation to social class. In addition, the perception of stigma often seems to result from an inability to live up to expectations of traditional masculinity and sexuality in relation to low income. Men do not cite schizophrenia itself as a reason not to date, but rather make use of other social and cultural yardsticks to determine their "readiness" to date. These cases reveal the inadequacy of narrow, symptom-based definitions of recovery, and speak to the fact that individuals with mental illness face constellations of constraints such that life chances are reduced not only by the presence of schizophrenia but also significantly by dimensions of social class refracted through gender.

We defined perceptions and experiences of stigma related to ethnicity as either (1) articulations of an especially negative reaction to mentally ill persons among members of a particular ethnic group or (2) articulations of mental illness being particularly difficult for individuals of a given ethnic group. In the following example, a 35-year-old African-American man articulates his perception that African-Americans are less sympathetic than other (unspecified) ethnic groups with respect to mental health problems:

"I don’t think they’re as open-mindedness about it. I think they are a little more prejudiced against mental illness than other people might be. Because of their culture . . . I think a lot of blacks think there is something wrong with me, like, there’s something bad about it."

The moral dimension of this response—that others think there is something "bad"—about his illness suggests the possible salience of characterological explanations for mental illness among African-Americans.

DISCUSSION

In contrast to viewing stigma as a process whereby negative social stereotypes and attitudes are imposed upon the stigmatized, the anthropological approach we have adopted in this analysis begins with a concept of stigma as an interpersonal process. Our intent has been to redress the over-emphases on individual attributes in studies conducted using scalar instruments (Link and Phelan, 2001) and on attitudinal measures as the sole indicators of stigma (Hinshaw and Stier, 2008; Lee et al., 2005) by examining the social contexts in which individuals with psychotic illness become aware of stigma as manifest in both overt forms of discrimination as well as in tacit forms of rejection and distancing. The data we have presented contribute to a growing literature that incorporates first-person perspectives on psychiatric stigma and, as such, is positioned to offer a further corrective to the "conspicuously absent" voices of mental health consumers in previous research on stigma (Wahl, 1999).

In one respect the population with which we worked represents a limiting case for the study of stigma insofar as for the most part their symptom levels are relatively well controlled, social functioning is relatively high, and living conditions are stable. They are articulate, coherent and socially engaged, hence more attuned to the nuances of experience associated with stigma and susceptible to the paradoxical situation that we have described as "stigma despite recovery." The data indicate a significant degree of reflectiveness on their part, and very little ambiguity about whether they are subject to stigma and the character of that stigma across different types of situation. This awareness of stigma may be related to the almost uniform recognition among these subjects that they have a mental illness from which, relative to their previous states of acute psychotism, they have improved. Perhaps this awareness of having a long-term disorder conduces to assimilation of and susceptibility to a popular cultural image of mental illness as a state of reduced social status and credibility. They are able to make comparisons between themselves and others, and exhibit distinctive styles of personal expression. Their expectations and attitudes toward life are not dictated by their illness, but are conditioned by it in terms of whether they can "live up to" goals that they take to be no different than those held by "normal" people. Their comments about stigma show that it is constituted interactively, and it has an emotional tone without being characterizable as either flat or histrionic.

Yet while participants revealed a good deal about stigma in their lives, talk about stigma may be limited by reluctance to acknowledge personally painful and socially detracting events which call into question one’s moral status. Across all content domains of our qualitative interviews, discussion of stigma in particular tended not to be extensively elaborated but rather tentative and indirect. That women reported "more" stigma (i.e., spoke about it more) than men in our interviews may represent a gender difference with respect to articulateness, but not necessarily experience. It may also reflect the fact that all the interviewers in the SEACORA project were women, and that male participants were less comfort-
able than their female counterparts in discussing stigma related issues with female interviewers.

It is noteworthy that the first person accounts that constitute our data come in 2 forms. One is opinions about stigmatizing behavior and stigmatizing circumstance that consist of background knowledge, social attitudes, and stereotypes—including stereotypes about mental illness and the mentally ill. The other is brief narrative accounts of actual instances of experiencing stigma. It is relevant to hypothesize that these opinions and experiences condition one another, and future research could productively be directed at how this takes place among persons in recovery from major mental disorder. Not every individual reports experiences of stigma across every one of the categories of social relations and identity domains, but insofar as these domains form a framework of possibilities for experiencing stigma, it is likely that people can imaginatively project themselves into other situations and form impressions based on what they hear about others’ experiences. Thus for them stigma is not a discontinuous set of isolated occurrences or a feature of an isolated kind of situation, but implicitly an atmosphere permeating everyday life.

A final aspect of the data requires reflection on the encompassing nature of the framework itself. It is no accident that the inductive categories that emerged from our qualitative data are of 2 types, and that broadly speaking the category of social relations has everything to do with what one does, and the category of identity domains has everything to do with who one is. With respect to social relations, our analysis anticipated that frequency of reported stigma would vary according to degree of intimacy. Our actual results (Table 1) suggest the alternative, or perhaps additional, interpretation that frequency of stigma varies according to the social proximity and experienced intensity of the social situation. By this interpretation, our finding that stigma is perceived as coming most often from strangers may occur in relation to fear (realistic or imagined) that people who one does not know are more likely to judge harshly or dismissively. Anonymous interactions among persons with mental illness are the most intense and have most at stake because they are the most ambiguous, whereas for those not afflicted anonymous situations might be more easily written off as relatively inconsequential. With respect to identity domains, the category itself does not cohere without the interpretation that for this population medication use—the ambivalent tradeoff of controlling symptoms against unpleasant side effects, of embracing and rejecting it at different moments, and of thinking of it as tool or crutch—is indeed an element of identity, whereas for those not afflicted medication use is episodic and not necessarily mind-altering. Under this interpretation it is not surprising that social class and ethnicity receive so little mention, appearing as ancillary or as afterthought to the stigma of mental illness. From the standpoint of our data, psychiatric stigma associated with the identity of being a medication user appears to “trump” the stigma of race or social class, though the latter may exacerbate or have an additive effect.

CONCLUSION

The paradoxical life circumstance of many study participants 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 framework of contexts identified by mentally ill persons themselves in which they are aware of stigma may be relatively stable across cultural boundaries or categories of illness, but in-depth anthropological investigations involving a large sample size such as the present study are required in the future to determine variations in how the experience of stigma is played out across this framework. We may speculate, however, that given the widely documented existence of stigma in relation to mental illness worldwide (Kleinman, 1988; WHO, 2001), future research will find a broad concordance of an awareness of stigma as a matter of everyday lived experience, while the cultural meanings of the specific contexts of stigma experience are likely to vary in several respects (e.g., with respect to diagnosis, medications, or distancing of social relations) yet be similar in others (e.g., dating prospects, popular perceptions of fear).

In this article, we have outlined categories of social relations and identity domains in which patients are aware of stigma, and have taken the additional step of specifying the quality of that awareness. In this light, psychiatric stigma is clearly not a monolithic force against which individuals must struggle. Indeed, we suggest that knowledge of the particularity of lived experiences of stigma may aid the efforts of mental health professionals to anticipate where and under what circumstances individuals may experience the blows of stigma. The data presented in this article contribute to understanding stigma as a product of intersubjective, reciprocal social processes and not something “out there” that is imposed upon an individual. Individuals with mental illness play an active role in contending with, resisting, and sometimes reproducing stigma. Attending to the complex social fields of stigma encourages rethinking individuals with mental illness in ways beyond vulnerability and victimhood.

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REFERENCES


Awareness of Stigma Among Persons With Schizophrenia

Marking the Contexts of Lived Experience

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Abstract: This article investigates the subjective experience of stigma attached to schizophrenia-related disorders. We examine data from anthropological interviews from a community sample of 90 out-patients residing in a metropolitan area of the United States. Patients were under treatment with atypical antipsychotic medication, and their symptoms were for the most part relatively well controlled. Overall, 96% of participants reported an awareness of stigma that permeated their daily life. Based on an understanding of stigma as a product of interpersonal, reciprocal social processes, we identify 6 types of social relations and 5 identity domains in which social stigma is routinely encountered by participants. We describe the experience of stigma in each of these 11 subcategories, and suggest that taken together they constitute a framework of social and personal factors involved in the struggle to recover from psychotic illness. Among types of social relations, anonymous social interactions most commonly generated an awareness of stigma. Among identity domains, being a person who regularly takes medication was most commonly associated with an awareness of stigma. The finding that multiple forms of stigma are encountered irrespective of substantial symptomatic, functional, and subjectively perceived improvement creates a complex situation of stigma despite recovery.

Key Words: Stigma, schizophrenia, subjective experience, antipsychotic medication, recovery, qualitative methods.

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Stigma is increasingly recognized as a global public health problem across a range of illness conditions (Green, 1995; Keusch et al., 2006; World Health Organization, 2001). The global impact of stigma on health care systems, economic productivity, and society at large is extensive and is "a very persistent predicament in the lives of persons affected by it" (Link and Phelan, 2001, p. 9). Stigma associated with mental illness appears to be a cross-cultural universal (Link et al., 2004; Pickenhagen and Sartorius, 2002; Yang et al., 2007). In spite of increased public knowledge about mental disorder, findings from attitudinal surveys suggest that psychiatric stigmatization is pervasive (Angermeyer and Dietrich, 2006; Bhugra, 1989; Rabkin, 1974) and has increased in the United States, particularly with respect to the perception that individuals with psychotic illnesses are violent and frightening (Link et al., 1999; Phelan et al., 2000). Corrigan et al. (2003) conducted a survey of 1824 persons with serious mental illness on perceptions of discrimination applied to mental illness compared with other social characteristics such as ethnicity, gender, or sexual orientation. Over half reported experience with discrimination and the most frequent source of this discrimination occurred in relation to mental disability. Such findings are particularly disturbing when coupled with the observation that surveys of explicit attitudes toward those with mental illness may underestimate the pervasiveness of stigma due to socially desirable response tendencies (Link and Cullen 1983).

THE PROCESS OF STIGMATIZATION

Much of the social psychological scholarship on stigma concerns specifying the mechanisms underlying stigmatization. Measures of implicit attitudes—so-called "unconscious" attitudes or biases—are a recent development intended to avoid the pitfall of socially desirable responses. A study by Teachman et al. (2006), employing the Implicit Association Test demonstrated negative implicit attitudes toward mental illness, with 58% to 78% of participants associating the concepts "bad," "blameworthy," and "helpless" with mental illness. Explicit and implicit attitudinal measures are useful in documenting broad societal orientations toward persons with mental illness. Yet these studies do not examine the impact of stigmatizing attitudes on those with mental illness (Hinshaw and Stier, 2008; Link et al., 2004). Thornicroft et al. (2007) have recently noted that attitudinal and social distance research has "generally focused on hypothetical rather than real situations, neglecting emotions and the social context, thus producing very little guidance about interventions that could reduce social rejection " (p. 193). Moreover, research by Corrigan and Watson (2002) highlights that psychiatric stigma does not manifest solely in public attitudes. Corrigan and Watson (2002) have usefully distinguished public stigma, "the reaction that the general population has to people with mental illness," from self-stigma, defined as "the prejudice which people with mental illness turn against themselves" (p. 16).

Social-cognitive processes such as stereotyping figure prominently as ways in which "in group" members affirm positive and individualistic traits of themselves in contrast to "out group" members, who are portrayed homogeneously and negatively (Hinshaw and Stier, 2008). Such basic social psychological processes are considered to account, in part, for a degree of "automatic" and "invaluable" stigma that subsequently becomes intensified by the "threat" posed by disordered behavior and mental illness labels (Hinshaw and Stier, 2008). In this regard, social psychological models conceptualize stigma as a process whereby certain "attributes" or "marks" are associated with a "devaluing social identity" or "discrediting disposition" in the context of social interactions (Crocker et al., 1998; Jones et al., 1984). Such formulations echo Goffman (1963), who defines stigma as rooted in an "undesired differentness," an "attribute that is deeply discrediting" and that results in a "spoiled identity." The complex ways in which individuals navigate their social worlds—how to manage information regarding one's condition, contending with the expectation of stigma, efforts to pass—constitute the "moral career" of the stigmatized.

Keusch et al. (2006) have recently called for a reinvigoration of the "science of stigma" and advocate building upon the insights set forth by Goffman (1963) to examine stigma as a "cultural disease that marks its victims as morally tainted" (Keusch et al., 2006, p. 526). Although Goffman's formulation emphasizes stigma as a social construction, social psychological frameworks tend to reduce
stigma to processes occurring at the individual cognitive level in response to social stimuli. As Yang et al. (2007) have noted, although such social psychological mechanisms are relational in structure: "analysis of these models reveals that they primarily regard the social aspects of stigma as a psychological variable (i.e., 'social identity' as applied to an individual), as an environmental stimulus that the individual appraises or responds to, or as societal or cultural stereotypes. Further, these models restrict the range of coping responses to the stigmatized individual's reactions (e.g., cognitive coping strategies) and the harmful outcomes of stigma to individual self-processes (e.g., psychological well-being). These models suffer from limiting conceptualization of the social to those environmental elements of stigma that 'impinge upon' the individual sufferer, who is then viewed as the primary locus in which stigma processes take place" (p. 1525).

Link and Phelan (2001) summarize recent social psychological research to show that people construct cognitive categories and then customarily link those categories to preexisting stereotyped notions. Going beyond this well-known association, they make a convincing case for understanding stigma as a set of social components that includes labeling, separation, status loss, and discrimination (see also, Sartorius, 1998). These elements, they aver, unfold in the context of unequal social, economic, and political power. Accordingly, the process of stigmatization is such that persons with mental illness are socially identified as different, this difference is ranked and linked to negative social stereotypes facilitating the construction of individuals with mental illness as "others," which, in turn, provides a rationale for devaluing, rejecting, and excluding them. Furthermore, Link and Phelan (2001) identify 2 key problems in current literature on stigma: (1) an overemphasis on individual attributes derived from social psychological research methods that rely on scalar instruments; and (2) a notable absence of research on the lived experience of persons who struggle daily with stigma. A literature review by Link et al. (2004) offers evidence that research conducted from the standpoint of individuals with mental illness or their close associates accounts for a minority of studies, and qualitative methodologies of interviewing and participant observation are uncommon.

The Experience of the Stigmatized

Moving toward an approach that takes into account the lived experience of stigma as an interactive phenomenon, Corrigan and Watson (2002) developed a situational model of personal response to stigma that varies substantially in relation to the person's perception of its legitimacy as applied to them. Camp et al. (2002) investigated whether low self-esteem was an inevitable consequence of stigma among a group of 10 women using qualitative analysis, revealing that while these women considered that they had a mental illness, they did not accept society's unfavorable representations of them on that basis (cf. Link et al., 2001). Sajatovic et al. (2005) highlight an additional dimension of the relationship between stigma and the self in their investigation of gender identity and gender role performance among individuals with schizophrenia-related disorders. They note that while individuals with schizophrenia are likely to experience lowered self-esteem in relation to the stigmatizing effects of mental illness, it is also likely that specific disturbances in gender identity and gender role performance likewise confer negatively upon sense of self-esteem. In their recent review of stigma related to mental disorders Hinshaw and Stere (2008) observe that stigma involves stereotypes, prejudice, and discrimination that limit the life chances of those stigmatized. Yet, they also observe that stigma processes are not reducible to these phenomena in light of the often all-encompassing nature of stigmatizing characterizations, the shame experienced by the stigmatized, and the crippling effects of stigma on social interactions that become shadowed by hostility, rejection, and anxiety (Hinshaw and Stere 2008).

Aside from the literature constituted by memoirs of individuals living with mental illness (Deegan, 1988; Gallo, 1994), there has also been a slowly accumulating literature that has incorporated first-person perspectives on psychiatric stigma. For the most part these studies have been based on data from focus groups, surveys, and questionnaires (Corrigan et al., 2003; Perlick et al., 2001; Schulze and Angermeyer, 2003; Wahl, 1999) or from semi-structured interviews with small samples sizes (N ≤10) (Camp et al., 2002; Knight et al., 2003). These studies point to multiple pathways for the constitution of the self and self-worth, and have important implications in the illness recovery process which requires self-management and reintegration of the individual into the community (Davidson, 2003). The findings of Dinos et al. (2004) based on their study of 46 individuals with mental illness align well with our findings of the pervasive awareness of stigma and the importance of managing illness information among persons with schizophrenia. However, from an anthropological perspective, Dinos et al. (2004) do not adequately situate the experiences of the individuals they interviewed within their interactive context. Indeed, ethnographic data on the immediate contexts of stigma in the community are in short supply (Phelan et al., 1998).

Against this conceptual and empirical background, and with an understanding of stigma as an interactive phenomenon with its locus in lived experience, we ask two questions in this article. First, to what extent is stigma pervasive in the lives of the afflicted? Answering this question requires specifying the range of contexts in which people encounter stigma, and in which stigmatizing behavior might take different forms. Second, how do people afflicted with schizophrenia perceive and experience stigma? An approach attuned to stigma as an interactive phenomenon will not be satisfied with a global notion of "spoiled identity," but will identify how difference and otherwise are constituted in instances of being smubbed, teased, rejected, talked about, or even looked at in an unusual way. This is all the more salient among a population such as that examined herein, among whom symptom levels are relatively well controlled and social functioning is relatively high. Our data on stigma are drawn from a broader anthropological study entitled "Schizophrenia and the Experience of the Culture of Recovery through Atypicals" (SEACORA), which examined the subjective experience and meaning of illness and either worsening or improvement/recovery among 90 persons diagnosed with schizophrenia-related disorders and taking "atypical" or "second generation" antipsychotic medications (Jenkins et al., 2005; Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song 2008).

METHODS

Sample Selection

In a northeastern US metropolitan area, we obtained the complete rosters of 2 community mental health outpatient facilities that served Euro-American and African-American ethnic groups. The first clinic is affiliated with an academic research community and was developed specifically to deliver clozapine treatment. Those attending the clinic often spent significant amounts of time on site, ranging from every day visits to once or twice per month. The second clinic had a relatively less developed research focus, and patients came briefly for biweekly or monthly medication checks. Study 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, some subjects in the study (N = 6) were prescribed atypical antipsychotic drugs as their first psychopharmacological treatment.
Selection criteria included: (1) diagnosis of schizophrenia or schizoaffective disorder assessed through the Structured Clinical Interview for DSM-IV (First et al., 2002); (2) age 18 to 55; (3) at least 2 years since first psychotic symptoms; (4) at least 6 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. Eligibility was assessed by treating psychiatrists and therapeutic managers, and resulted in a complete list of all patients who met research diagnostic criteria. From this list, 167 eligible participants were randomly sampled. Of those selected, 90 (54%) were included in the final sample, with 46.7% declining research participation. The overall high rate of refusal is not unusual (Covell et al., 2003) for an American community out-patient sample such as this, with males (55.9%) significantly more likely than females (29.3%) to decline participation (Fisher exact test, p < 0.001). Reasons for nonparticipation included lack of interest in research (stating simply they “did not want to”) or a reluctance to provide time for interviews (due to 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 were more interested in research, sometimes stating that they had an incentive in cooperation with anything that might benefit others (or themselves) in future. In this regard, the sample may be more cooperative and less symptomatic, more socially functional, or potentially more likely to have had a positive experience with medication or their physicians than those in the group who declined participation (see also, Jenkins et al., 2005).

Procedures

For this study of subjective experience of schizophrenia, we employed techniques of ethnographic interviewing, naturalistic observation, and procedures for research diagnostic criteria (Structured Clinical Interview for DSM-IV) and symptom severity (Brief Psychiatric Rating Scale [BPRS]). The research psychiatrist for the project was trained in the reliable administration of both of the latter instruments. This article, however, is based on stigma-related data generated by the ethnographic interview. The ethnographic interview, the “Subjective Experience of Medication Interview” (SEMI), is a semi-structured, open-ended qualitative procedure adapted from interviews used in prior research (Jenkins, 1997). As a qualitative procedure, the SEMI serves as an interview guide in which there is flexibility in the administration of interview questions. If a subject is highly responsive and generates narrative on a topic of interest, the predesignated interview questions may be used sparingly. On the other hand, if a respondent is not highly responsive in generating narrative on their own initiative, the interviewer may use questions and follow-up probes more extensively in an effort to obtain the persons’ point of view. The substantive domains covered by the SEMI include the experience of medication and treatment, living situation, everyday activities, illness management, social relations, gender identity, expectations concerning recovery and quality of life, and stigma. Qualitative data on any topic, including stigma, might be generated at any point of the interview. Examples of specific questions posed to elicit stigma-related data were as follows: "Do you tell people that you have (diagnosis)? That you're on medication? Who do you tell?" "And what kinds of things do you try to do to keep people from finding out?" "Does anybody act differently toward you because of your illness, or because you take medication?" "For yourself, do you prefer friends or dating relationships among people who also have a mental illness or those who do not have a mental illness?"

The duration of the SEMI interviews was generally 1.5 to 2 hours over 1 to 3 interview sessions. Interviews were conducted by the Principle Investigator and a team of 4 doctoral students in medical anthropology. All SEMI interviews were transcribed verbatim from audiotape and entered into the Atlas.ti qualitative software program (Scientific Software, 1997) which is designed to code and analyze qualitative data systematically (Good, 1994; Luborsky, 1993). The 90 SEMI interview transcripts, averaging 92 double-spaced pages, were read and coded by the two authors (J.J. and E.C.S.). A grounded theory approach in which thematic categories are inductively derived (Strauss and Corbin, 1990), yielded 34 substantive categories, of which "stigma" was one. In any instance in which content of a text segment was in question, relevance of that text segment to stigma was confirmed or disconfirmed through review and consensus between the 2 coders, as customarily required for systematic qualitative analysis of large volume textual data (NIH, 2001; Taylor and Bogdan, 1998; Warren, 2002). We coded data “yes” for awareness of stigma if at least 1 of the following conditions was met: (1) the subject indicated that people react negatively toward them in response to the direct questions listed above; (2) the subject volunteered information about awareness or experience of psychiatric stigma in any other part of the SEMI interview. Coding a “no” response cannot be considered as a definitive determination that the subject did not perceive or experience stigma, but only that the response reflects absence of report of stigma in the interview transcript. Reports of perceived stigma were secondarily coded by the same 2 coders to identify the contexts in which subjects experience stigma, yielding the categories of social relations and identity domains shown in the results below.

Sample Characteristics

Sociodemographic and clinical characteristics of the 90 SEACORA participants have been more fully summarized elsewhere (Jenkins et al., 2005). In brief, males constituted 54.4% and females 45.5% of the sample. Euro-Americans accounted for 77.8% and African-Americans for 22.2%. 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% single, 5.6% married or living with a partner, and 10% divorced, widowed, or separated. Those living alone accounted for 25.6%, those living with a roommate or in a group home for 22.2%, those with a relative or parent 42.2%, and those with a partner or spouse 10%. Fully 60% were unemployed, 22.2% were working half time or less, and 17.8% were working from half to full time.

Diagnostically, 81.1% participants had schizophrenia and 18.9% 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 1–7, absent to severe, respectively) on the 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/depression (see, Jenkins et al., 2005 for fuller discussion). There were no significant differences in socioeconomic status by ethnicity.

RESULTS

Nearly all persons in the study (86 or 96.0%) reported perception of stigma across a variety of social settings that they encounter on a daily basis. In general, the low symptomatology among study participants (Jenkins et al., 2005) does not appear to afford these individuals any considerable measure of protection from the blows of stigma. In fact, for some participants, improvement may create the conditions for a subjective discernment of pervasive stigma to be felt with greater acuity, what we refer to as the paradox of stigma despite recovery.
TABLE 1. Awareness of Stigma

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<tr>
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<th>%</th>
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<tr>
<td>Social relations</td>
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<tr>
<td>Anonymous social interactions</td>
<td>47.7</td>
<td>41</td>
</tr>
<tr>
<td>Work relations</td>
<td>36.0</td>
<td>31</td>
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<tr>
<td>Dating relations</td>
<td>32.6</td>
<td>28</td>
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<td>Family relations</td>
<td>22.1</td>
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<td>Acquaintance relations</td>
<td>12.8</td>
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<td>Friendship relations</td>
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| Identity domains              |     |    |
| Medication use                | 44.2| 38 |
| Popular culture               | 24.4| 21 |
| Gender                        | 19.8| 17 |
| Self presentation             | 18.6| 16 |
| Social class and ethnicity    | 5.8 | 5  |

*Total number of subjects equals 86 who indicated awareness of stigma; 4 responses were judged as lacking or insufficient to code presence of awareness of stigma.

(Jenkins and Carpenter-Song, 2008). The remainder of our analysis will consist of specification of this social matrix of contexts of subjective awareness of stigma.

The diversity of contexts in which there is a heightened awareness of stigma underscores the pervasiveness of stigma within the everyday experiences of individuals with schizophrenia-related disorders and illuminates the ways in which stigma surrounding the illness shapes nearly all aspects of everyday experience. The contexts of the awareness of stigma constitute 2 categories: (1) social relations and (2) domains of identity (Table 1). In the category of social relations, study participants identified differences in the perception of stigma in anonymous interactions, work relations, dating relations, family relations, interactions with acquaintances, and interactions with friends. The category of identity domains includes gender, self-presentation, social class, and ethnicity. We also include popular culture insofar as an individual may define him/herself in relation to a media-derived social context, and medication use insofar as our earlier analysis demonstrated the considerable extent to which persons identified themselves in relation to reliance on psychotropic medication (Jenkins and Carpenter-Song, 2005). In sum, although it is not surprising that people report stigma across these varied social relations and identity domains, our purpose here is (1) to point to the quality of stigma as lived experience in each of the contexts, and (2) to indicate how the set of contexts constitutes a comprehensive framework of the struggle to recover from psychotic illness.

Social Relations

Anonymous Social Interactions

The category of stigma in “anonymous interactions” occurred among strangers in public, commercial, or bureaucratic social settings. This included settings such as the street, bus, library, parks, drug and grocery stores, restaurants and coffee shops, and governmental and welfare offices. The ways in which persons felt the presence of social stigma in these diverse settings included discomfort over the sense that verbal and nonverbal communications were directed toward them to signal identification and labeling of them as mentally ill, strange, frightening, or of lesser intellectual and social capacity. Besides the perception of disapproving and derisive messages, people in the study also reported the sense from strangers that they could be categorized as a victim of one’s condition, on the one hand, or a target of vulnerability, on the other.

A 39-year-old Euro-American woman living with her parents in a lower middle class suburban neighborhood, who has been ill for 21 years, attempts to de-emphasize her illness and does not reveal her illness to people other than close friends and family. Otherwise, she says:

R: Well, the people I do know, already know. Like the relatives and friends of the family probably know I have problems, but someone like a stranger, someone I wouldn’t know. Or like when I go to welfare. The lady at welfare knows I’m on disability, and um, sometimes I feel that she’s looking at me in a different way. I just try to carry myself in a proper way not to let people know that there’s something wrong with me. Because then, like I say, I’m funny about that.

I: Uh hm. Yeah. And what is the proper way?

R: Well, I, some people just come out and say, you know, I’m sick or you know, I got a problem. I’ll just try to, try to hide it. (Uh hm.) I would just try not to make it obvious. (Uh hm.) Because some people can be really cruel, you know. Um, they can say, ‘well what’s wrong with her, you know? You know how people are. They, they can just kind of get funny about that kind of stuff.’

She expressed anxiety and discomfort as common for her when walking on the street, a situation in which she felt people were staring at her for appearing strange.

Work Relations

Overall, 36.0% were aware of stigma in the context of social interactions related to work. As expected, those working currently (36 or 40%) were significantly more likely to report stigma in relation to work (50.0%) than those not currently working (24.1%) (Fisher exact test, p < 0.02). While it is obvious that those currently working would be more preoccupied with stigma in this context, its salience in the context of previous or prospective employment was also noteworthy. Transactions in the workplace included the perception of hostile or fearful attitudes, teasing, violation of confidentiality, discrimination and unfair treatment, pejorative stereotyping or insensitivity by coworkers/supervisors, as well as the fear of either not being hired or being fired on the basis of mental illness. Finally, negative reactions by others because one does not have a job were also noted.

One illustration of stigma encountered at the workplace was provided by a 36-year-old Euro-American woman living with her parents. She works as a salesperson in a department store, where she fears people know about her condition. The sources of her fear are her own behavior as well as that of others. For her part, she says that she sometimes becomes confused about when employee breaks are scheduled, a potential problem since these must be negotiated and coverage of the various departments had to be ensured. She imagines that her confusion may have given coworkers reason to surmise she is ill. Nevertheless, she makes a point of not revealing her illness to people at work, a sore spot in light of a recent action on the part of a store manager.

“Um, no, I generally, most of the time I don’t, like especially at work. I figure it’s really none of their business . . . I have a sneaking suspicion that some people might know or have guessed (mental illness): Because one time there was a manager, over in another department, I had mentioned that I had to see my Medicaid lady to her. And then we were in the hallway, and I had either clocked out for the day or was about to, and I talked to her about that appointment. And she says something about blah, blah, blah, you know, about your disability and it was, there was still a lot of people around, and I don’t know. They might have known or have guessed.”

Another example of the way in which stigma and symptomatic worsening are reciprocally related comes from a 39-year-old
African American man who lives alone in a condominium purchased for him by his parents. Recently hired to work in a hospital setting, he began to feel uncomfortable in the work setting because he was taking medication. This led to a series of events beginning with his decision to stop taking medication, ensuing difficulties with his supervisor, and subsequent suspension.

"When I was working in the hospital, I stopped taking the medication a couple of weeks or so after I got hired because I felt bad about having to take medication and having an illness and being diagnosed as schizophrenic. And um, instead of educating myself or educating other people about it, I chose to just stop taking it. And um, that was bad. And then I was, had a, fell out with my boss and got put on suspension. And, even though when I came back they paid me for the times I missed, they understood that I have a sickness, and illness. And when I came back I was on the medication and I really didn’t know what to say to people or what to, how to explain it, what was going on. And I felt like I was under a magnifying glass and it was really uncomfortable. That was really hard for me."

This example of stigma in the workplace interrelates with the identity domain of medication examined below whereby disapproval of the self is unwittingly conjoined by social disapproval by others.

**Dating Relations**

Dating is an area of social relations that participants identified as a source of unease. About one-third (32.6%) described either being rejected by potential dating partners because of mental illness or acknowledged not wanting to date another person with mental illness. As for the above social relations, people described reluctance to reveal illness or medications because of fear of frightening others, fear of rejection, stereotyping, teasing, and fear of mistreatment and vulnerability in relation to dating. In addition, while weight gain in women and personal appearance constituted an impasse to the prerogative to date for women and men alike, women tended to worry somewhat more about such limitations. For their part, men were more preoccupied that they could not meet cultural expectations that they have money, a car, and perform sexually. Overall, women (41.5%) were more likely to speak about such limitations compared with men (22.4%).

An interview exchange with a 35-year-old African American woman illustrates the problem of feeling disallowed to date on the basis of mental illness:

I: So are there particular difficulties for people with mental illness, or with schizophrenia in particular?

R: Oh, yeah, for me there is, quite a bit. You know, that’s the thing, you know, I think that there’s really, only, not much choice in the way of, you know, dating because I think if you’re a girl that has mental problems, or whatever, you know, well at least I know, normal guys don’t look twice at me. They don’t!

The following interview interchange with a 39-year-old Euro-American woman illustrates what she felt is at stake if you have a mental illness and get involved in a romantic relationship:

I: Do you think that love is difficult?

R: Love is very difficult. Love is difficult because you risk—you risk everybody laughing at you if you love somebody.

I: Everyone laughing at you? And why is that? Why would they be laughing?

R: Someone [told me] once, um—it’s impossible for people—for schizophrenics to actually love. I go why? “Because your head gets involved with everything.” I don’t know.

I: What do you think about that?

R: I don’t—it’s pretty hard. Take advantage of, thinking that maybe I’m—you’re not good enough for this person, you’re not good enough for that person. Something like that. Thinking I’m not good enough to be with that person. That you’re crazy and stuff.

Finally, a 47-year-old Euro-American man who lives alone in an apartment conveyed ambivalence on the subject of dating by saying that "Sometimes I feel strongly that I’d like to meet somebody, and sometimes I don’t, you know." His sense of dating as "very risky" was borne out by this comment that "there’s no guarantees that it’s going to work out the way you want it to." In addition, he viewed dating as not realistic given his illness, physical appearance, and financial constraints such that he could only become interested if things were different than they currently are:

"Right now, you know, I don’t have that much money and its not real practical. I can’t imagine a healthy woman being interested in, particularly interested in a schizophrenic person my age and my big fat stomach [he laughs] and my gray hair and all that, you know. It’s not impossible but I don’t really, it’s not high on my agenda right now."

**Family Relations**

Participants also describe avoidance or exclusion by family, denial of illness by family members, and the perception that family members are embarrassed or ashamed on the basis of mental illness. A sense of exclusion and unfavorable attention within one’s family was more commonly the subject of commentary by women (34.1%) than men (10.2%, Fisher exact test, p < 0.01) in the study.

A divorced 43-year-old Euro-American woman described family relations as characterized by 2 recurring patterns: either as attempts to avoid her or as efforts to make her into a kind of family scapegoat who could be pointed to as an example of someone who had more problems and was “more ill” than anyone else.

"Either they don’t want to be around you or (it’s) where you can’t even have any privacy without, you know, it’s like they mention your name all the time in their conversation. And either that or they don’t want to be around you. Because you know why, they don’t want to look at themselves. They might see something in themselves that might disturb them . . . (this is) my family, mostly. They’d rather avoid you. It’s a defense mechanism."

Another illustration of how families may exclude members with mental illness from participation in family activities comes from a 44-year-old Euro-American woman:

"I feel in a lot of ways mom and dad are maybe ashamed of me for some reason . . . they are kind of hesitant and everything and . . . it’s a feeling, you know, they don’t know that I’ve come a long way from what I used to be. It just seems like I’m still in the same way that they think I am. You know, they just don’t realize it hurts when they go somewhere . . . ah . . . they don’t ask me . . . they just don’t want me to go. It kind of hurts."

For this woman, the sting of being left out of family interactions reinforces her perception that her parents do not acknowledge her considerable sense of improvement, with stigma persisting in spite of having come a long way. A 42-year-old Euro-American man who lives alone in a condominium, detailed how his entire family shunned him for being unemployed and did not seem to comprehend his illness condition. Ultimately, his parents came to understand and accept him (after having obtained employment) but this was not true of his siblings:

"My folks are very understanding and supportive, especially now. But my brothers and sisters don’t stay in touch. They don’t write. They don’t call. They don’t visit. And I have been in the hospital 19 times, and not once did they come to visit me, you know. 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. I - it bothered me a lot. I used to be jealous, I know some people where their families are really close, you know, and I don’t have that."
Acquaintance Relations

A realm of less intimate social relations is that of acquaintances in which encounters may be less regular but nonetheless hold significance for one's overall social experience. This may be the neighbor who lives down the street who occasionally tarries in front of your house when walking his dog or the schoolmates who usually say "hello" but never actually converse or make social overtures. In one case, a Euro-American woman said that someone down the street called her "mentally retarded," a comment which she says really hurt her. When asked for detail regarding how this occurred, she elaborated that the offending man had not said this directly to her but to her next door neighbor within her earshot. Her response was to "just let it go," reasoning that people do not understand but in any event do not intend to hurt her.

Intended or not, a 32-year-old Euro-American woman recalled her experience at an exclusive private girls preparatory school as intolerable. As seniors, students were allowed to go for lunch off campus but in her case she says felt "isolated" and was "cut off" because no one ever asked her to lunch. She says that although she is pleased with what she regards as currently good health, she nonetheless is unhappy and has thoughts of killing herself: "There's nothing I can do about it. I get so tired of being cut off, and it's like I'm really really frightened of it [being cut off]." She feels that she never learned to socialize properly and that she is generally avoided or excluded. Some many years later, she continues to feel left out of things yet seems resigned to this situation as she says, "I've never fit in and I never belong." For her, perceived stigma from persons she does not know well is so incisive to her experience of not "belonging" that it can fuel a desperate need to end her life quite distinct from the above proclivity to "just let it go."

A generalized sense of degradation was articulated by a divorced 56-year-old African American woman who responded to an interview question about whether women or men were treated differently in a situation of schizophrenia.

R: No, they gonna treat you the same regardless. They treat you, umm . . . when you have mental illness. I try not to let them know that I have a mental illness, because the minute you do, that's it. They gonna not be bothering, they're gonna talk about you, they're gonna down-grade you. It's gonna cause you problems, so, you know, if I go out the door and I see a neighbor, he'll say, 'Oh, how you doing?' And I don't say, I let them know the least about me as possible, and 'cause I don't talk about nothing out there except the weather or whatever . . . Because, you know, I know I have problems, whatever. And the minute they get to know me and maybe I don't have a good day or whatever and they're going to know something ain't right with this lady. And then even if they won't be bothered, they won't be bothering me after that. It's just a stigma and it hurts me.

Likewise, a 47-year-old divorced Euro-American man conveyed his sense of stigmatizing attitudes in the following exchange:

I: Does anybody act differently towards you because of your illness or because you're taking medication?

R: Well . . . yes. I mean, I'm coming out of that, of feeling, um, literally negative vibes or attitudes from like, neighbors. And that, for a while, it just really upset me, I could feel it, I knew it was reliable . . . I just had to deal with it. (How?) Get on with it. And not, like, get all bummed out. (Hm). Feel sorry for myself.

Friendship Relations

Compared with other types of social relations, friends were mentioned least frequently with regard to stigma. As an elective social relation, there may be 2 scenarios specific to friends that shed light on their lesser salience: (1) they may be inclined to evade support and acceptance; and (2) they may be scarce in the lives of people in the study. As an example of the first scenario is a 26-year-old Euro-American woman who indicated that she felt friends were supportive:

I: Um, how do your friends handle problems that are associated with your illness? Do those ever come up?

R: [she laughs]. It's funny, because um, Tony, a good friend and Paul. 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.

Another illustration of friends who do not stigmatize came with precision from a 49-year-old Euro-American woman who noted that her friends tended to downplay or explain away her mental illness such that stigma was something not only to elude but also to refuse:

"My friends don't treat me like a lower status person . . . They treat me like I'm intelligent. I often feel like Ronald Reagan the president when it comes to my mental illness: I feel like I have Teflon, it just rubs off me. People don't see me that way. And I don't hurt, a stigma, I always say no to their stigma 'cause you have to put a stigma on yourself. I don't accept the stigma. It's an illness, that's how I feel, and if they treated me differently they probably wouldn't be my friends. I probably wouldn't be comfortable around them."

In the second scenario, of having few friends, the following 2 illustrations from a 50-year-old Euro-American woman and a Euro-American woman of 46 years provide a sense of the insecurity and uncertainty surrounding loss of a friend due to one's illness condition:

R: And, well, I had this good friend, long, long time ago. We used to get out and do all kind of things together. And she quit hanging around me, I don't really know why. But she said something about me wanting to get a job. (Uh hm.) Because, that she didn't want to see me any more.

I: Wow. Now, was she also someone with an illness . . . ?

R: No. So, I don't. I let bygone be bygones. [laughs] I don't need friends like that, do I?

I: Oh, that's alright. Um, do you ever feel like you're avoided?

R: By certain people? (Uh hm.) Well, I'm sure. It's very possible. (Uh hm. Uh hm.) I'm sure it's very possible, yeah. I have not, um, there's a lot of things that happened that I used to work with who have never called to see what's up. It's an illness that's gone on, people that thought were my real friends. So yeah, I'd have to say yes. (Uh hm.) Some people have avoided me. And it's not my imagination. It's the real thing.

Identity Domains

Medication Use

Of the domains surrounding identity that we analyze here, medication was by far the most common. The rationale for analyzing medication as an "identity" domain is drawn from previous publications (Jenkins and Carpenter-Song, 2005) in which being "a person who takes medication" and having to take such "for the rest of your life" converts to a key dimension of one's identity. Stigma associated with taking antipsychotic medications was manifested as a reluctance to acknowledge to others that one is taking medication, hiding medication or taking it only in privacy, and great dissatisfaction with one's physical appearance in relation to medication side effects. That one was taking psychotropic medication was widely thought to instill fear in others that would invariably lead to avoidance and rejection. Examples of stigma associated with medication cross-cuts other domains of analysis presented here as illustrated above for the social relations of work, dating, and acquaintances.
The expectation of rejection and fear in relation to taking medication is illustrated further in a 25-year-old Euro-American woman’s imagining of what it would be like to divulge the illness:

“It would be interesting to see. I think they might back away. That’s what I think. Unless I explained it in such a way that everybody has some disability and this is just one of them and I talked about it and explained it. But if I just said ‘I’m schizophrenic, I take medicine’ they might back away. In a nice way, if I explained what it was and why I take it, but still I think most people would be frightened about it.”

Individuals often find themselves in a “catch 22” situation wherein their experience has shown that they need to take medication to improve or remain well, yet by taking medication they become vulnerable to the judgment of others. To protect against this, one woman described being quite discreet about taking her medication:

“I don’t announce that I’m taking it. I try to take it very discreetly when I do [...]. I don’t need someone saying, oh what are you taking, what are you taking?”

A 47-year-old Euro-American woman described a differential practice of hiding her medication in her home:

“If somebody comes over to the house, I may put my medication away, like it’s in a cabinet now, I may hide it. The blood drawing thing (for clozapine), I hide that. Actually, when I was with Randy, a while ago, I think it was a couple weeks ago, he’s the priest’s nephew, I didn’t hide it from him, but he asked whether I, I was easily bruised, (since) they bruised the hell out of my arm. But I told him it was, uh, it was some kind of a blood test. ‘Cause I have this hemochromatosis thing where my body doesn’t get rid of iron. So I have to uh, have blood drawn, like every week, and that reduces my iron level, cause the iron’s used to make new blood. So I told him it was from that. And he didn’t question it, really, that much.”

Regarding fear and lack of familiarity with antipsychotic medication widely encountered by participants, one woman alluded to the shortcoming of the approach to mental illness through reference to the adage to simply “pull yourself up by your bootstraps”:

“Some people can do things on their own without taking pills, sometimes you need a boost. Some people don’t really need boosts for a long period of time, they just need to get over a hump. Um, some people react more adversely than normal to grief, to the loss of a loved one. I’ve seen people in psych wards because somebody died. If they were taking some medication and most doctors do offer when somebody dies, they can prevent that. A lot of people are afraid of medication, they have a stoic attitude. And they think everybody should pull themselves up by their own boots. Some people don’t have any boots, you know? Those who have boots, fine, but those who don’t, they need medication. That’s how I feel.”

Her vigorous response to people she considered “uneducated” about medications extended to a friend who opined that an acquaintance diagnosed with chronic fatigue syndrome stayed in bed because she “wanted” to do so:

R: I removed myself from her life for four months because that’s where I drew the line. She said umm, I told her about somebody who was in bed for about fourteen years with chronic fatigue and she said that’s because they wanted to be. And I said something about, ‘well you know my psych drugs make me tired too.’ Which I think they do [...]. [She said] ‘Well you need to get off those! Well I just didn’t speak to her for months and months, because I thought somebody with an attitude like that, uh uh [...]’

I: Not a friend?
R: Yeah, I thought that’s a dangerous thing to tell. She should be in my shoes, would you like to hallucinate? Or be suicidal? (right) Have voices tell her to hang herself? And this person is somebody whose education [...]. She should’ve known better (uh hm). So we got back together and she doesn’t say things like that any more so I guess she figured it out on her own.

Popular Culture

Narrative statements coded as popular perceptions of individuals with mental illness included statements that articulate attitudes perceived to be held by the general public as well as media portrayals of mental illness, particularly with respect to images of individuals with mental illness as prone to violence. Of those who talked about the experience of stigma 4.4% reported stigma associated with popular perceptions or portrayals of schizophrenia. The following from a 43-year-old Euro-American woman illustrates how public perceptions of schizophrenia as unpredictable or violent can overshadow individual identity:

“People are ignorant when it comes to mental illness. All they see is someone on the news that someone felt threatened and took an assault rifle and started shooting people. Because he didn’t take his medication, that’s what they see.”

In this respect, stigma attaches not simply to an individual, but to a social category. Another example of popular cultural stereotypes that confer stigma is the following response to an interview question about what she thought would happen if people found out she had a mental illness:

“They would probably, um, probably think I’m kind of weird, or, if I was, uh, watching television and make a reference to people’s schizophrenia, and the reference they use, is that it’s, uh multiple personality, multiple personality, which makes me angry, because it’s not that at all. And it’s not that you’re crazy, you know, and I think a lot of people think, ‘Oh God, she a nut.’ You know, and she ... you know, people have a, uh, you know, bad connotation of it and everything.”

With respect to the stereotype of violence as associated with mental illness, a 34-year-old African American man confirmed his experience of this problem as follows:

“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.”

Gender

Awareness of stigma was identified by one-fifth (19.8%) of subjects in relation to gender differences, with some subjects reporting greater difficulty for men whereas others reported greater difficulty for women. More women (31.7%) than men (8.2%) reported stigma in relation to gender (Fisher exact test, p < 0.007). Individuals diagnosed with schizoaffective (41.2%) were more likely than those with schizophrenia (13.7%) to report perceptions of the occurrence of gender-related stigma (Fisher exact test, p < 0.02). In several cases, stigma was defined by a perceived inability of individuals with mental illness to live up to culturally normative gender roles. For example, a 27-year-old Euro-American man, describes the particular difficulties faced by men with schizophrenia:

“I think, um, maybe what I’m trying to get at is that it may be for the men it is hard, because the illness sort of emasculates them. Because I think, in men, there is a need to be on top of things. Um, to have certain responsibilities. To look good; to have a significant other, and somehow schizophrenia sort of puts a brake on all of this. They can’t fulfill all these, these obligations. All these ideals of, of manhood and masculinity. And I think that makes it hard for them.”

A parallel although contrasting view was noted by some participants regarding the difficulty of keeping up with feminine gendered expectations. A 39-year-old Euro-American woman demonstrated a preoccupation with her femininity throughout all our research contacts, voicing the view that mental illness may be more difficult for women due to the self-perceived lost or waning physical
ATTRACTIVENESS: "[Men] probably don't worry about their image, as much as maybe I would. Well, I think they probably just maybe don't. It doesn't really, you know, bother them." In addition to repeatedly asking for reassurance that she was "attractive" she worried about her "image" and the possibility of making mistakes.

**Self-Presentation**

We found that the experience of stigma in relation to self-presentation could be coded into 3 domains: (1) appearance, in which an individual indicates that she/he looks different from others on the basis of mental illness, was identified by 18.6% of participants; (2) side-effects, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others because of medications side-effects was identified by 10.5%; and (3) overweight, in which an individual articulates negative reactions/insensitivity, exclusion/rejection, teasing, labeling, or discrimination by others specifically because of the side-effect of weight gain resulting from the medications was identified by 15.1%. More individuals diagnosed with schizophrenia (35.3%) than those diagnosed with schizoaffective disorder (9.6%) reported stigma in relation to overweight (Fisher exact test, p < 0.02).

In response to an interview question regarding which side effect was most bothersome, a 41-year-old Euro-American man cited drooling, a side effect particularly associated with clozapine: "It gets all over my mouth and everything. Like if I’m making love to a woman at night, I get her all... wet." Another participant, a 40-year-old Euro-American man, emphasized the problem of weight gain:

"I’ve been gaining a lot of weight... about fifty pounds. (I’m) like a fat slob. I don’t think I’ll get involved with a woman until I lose weight."

Given the central role that medications play in participants’ improvement, embarrassing side effects is yet another manifestation of the dilemma of "stigma despite recovery" (Jenkins and Carpenter-Song, 2005; Jenkins and Carpenter-Song, 2008).

**Social Class and Ethnicity**

Only a fraction of subjects (5.8%) reported stigma in relation to social class but nearly a quarter (23.3%) reported stigma in relation to ethnicity. Experiences of stigma in relation to ethnicity occurred in approximately equal proportions in Euro-Americans (21.4%) and African-Americans (25.0%). Narrative statements in which individuals articulated social exclusion, negative attitudes, stereotyping, or discrimination because of a lack of money, poor housing, lack of their own transportation, or on the basis of receiving social security disability income or other government benefits were coded as reflecting stigma in relation to social class. In addition, the perception of stigma often seems to result from an inability to live up to expectations of traditional masculinity and sexuality in relation to low income. Men do not cite schizophrenia itself as a reason not to date, but rather make use of other social and cultural yardsticks to determine their "readiness" to date. These cases reveal the inadequacy of narrow, symptom-based definitions of recovery, and speak to the fact that individuals with mental illness face constellations of constraints such that life chances are reduced not only by the presence of schizophrenia but also significantly by dimensions of social class refracted through gender.

We defined perceptions and experiences of stigma related to ethnicity as either (1) articulations of an especially negative reaction to mentally ill persons among members of a particular ethnic group or (2) articulations of mental illness being particularly difficult for individuals of a given ethnic group. In the following example, a 35-year-old African-American man articulates his perception that African-Americans are less sympathetic than other (unspecified) ethnic groups with respect to mental health problems:

"I don’t think they’re as open-minded about it. I think they are a little more prejudiced against mental illness than other people might be. Because of their culture... I think a lot of blacks think there is something wrong with me, like, there’s something bad about it."

The moral dimension of this response—that others think there is something "bad" about his illness suggests the possible salience of characterological explanations for mental illness among African-Americans.

**DISCUSSION**

In contrast to viewing stigma as a process whereby negative social stereotypes and attitudes are imposed upon the stigmatized, the anthropological approach we have adopted in this analysis begins with a concept of stigma as an interpersonal process. Our intent has been to redress the over-emphases on individual attributes in studies conducted using scalar instruments (Link and Phelan, 2001) and on attitudinal measures as the sole indicators of stigma (Hinzman and Stier, 2008; Lee et al., 2005) by examining the social contexts in which individuals with psychotic illness become aware of stigma as manifest in both overt forms of discrimination as well as in tacit forms of rejection and distancing. The data we have presented contribute to a growing literature that incorporates first-person perspectives on psychiatric stigma and, as such, is positioned to offer a further corrective to the "conspicuously absent" voices of mental health consumers in previous research on stigma (Wahl, 1999).

In one respect the population with which we worked represents a limiting case for the study of stigma insofar as for the most part their symptom levels are relatively well controlled, social functioning is relatively high, and living conditions are stable. They are articulate, coherent and socially engaged, hence more attuned to the nuances of experience associated with stigma and susceptible to the paradoxical situation that we have described as "stigma despite recovery." The data indicate a significant degree of reflectiveness on their part, and very little ambiguity about whether they are subject to stigma and the character of that stigma across different types of situation. This awareness of stigma may be related to the almost uniform recognition among these subjects that they have a mental illness from which, relative to their previous states of acute psychotism, they have improved. Perhaps this awareness of having a long-term disorder conduces to assimilation of and susceptibility to a popular cultural image of mental illness as a state of reduced social status and credibility. They are able to make comparisons between themselves and others, and exhibit distinctive styles of personal expression. Their expectations and attitudes toward life are not dictated by their illness, but are conditioned by it in terms of whether they can "live up to" goals that they take to be no different than those held by "normal" people. Their comments about stigma show that it is constituted interactively, and it has an emotional tone without being characterizable as either flat or histrionic.

Yet while participants revealed a good deal about stigma in their lives, talk about stigma may be limited by reluctance to acknowledge personally painful and socially detracting events which call into question one’s moral status. Across all content domains of our qualitative interviews, discussion of stigma in particular tended not to be extensively elaborated but rather tentative and indirect. That women reported "more" stigma (i.e., spoke about it more) than men in our interviews may represent a gender difference with respect to articulateness, but not necessarily experience. It may also reflect the fact that all the interviewers in the SEACORA project were women, and that male participants were less comfort-
able than their female counterparts in discussing stigma related issues with female interviewees.

It is noteworthy that the first person accounts that constitute our data come in 2 forms. One is opinions about stigmatizing behavior and stigmatizing circumstance that consist of background knowledge, social attitudes, and stereotypes—including stereotypes about mental illness and the mentally ill. The other is brief narrative accounts of actual instances of experiencing stigma. It is relevant to hypothesize that these opinions and experiences condition one another, and future research could productively be directed at how this takes place among persons in recovery from major mental disorder. Not every individual reports experiences of stigma across every one of the categories of social relations and identity domains, but insofar as these domains form a framework of possibilities for experiencing stigma, it is likely that people can imaginatively project themselves into other situations and form impressions based on what they hear about others’ experiences. Thus for them stigma is not a discontinuous set of isolated occurrences or a feature of an isolated kind of situation, but implicitly an atmosphere permeating everyday life.

A final aspect of the data requires reflection on the encompassing nature of the framework itself. It is no accident that the inductive categories that emerged from our qualitative data are of 2 types, and that broadly speaking the category of social relations has everything to do with what one does, and the category of identity domains has everything to do with who one is. With respect to social relations, our analysis anticipated that frequency of reported stigma would vary according to degree of intimacy. Our actual results (Table 1) suggest the alternative, or perhaps additional, interpretation that frequency of stigma varies according to the social proximity and experienced intensity of the social situation. By this interpretation, our finding that stigma is perceived as coming most often from strangers may occur in relation to fear (realistic or imagined) that people who one does not know are more likely to judge harshly or dismissively. Anonymous interactions among persons with mental illness are the most intense and have most at stake because they are the most ambiguous, whereas for those not afflicted anonymous situations might be more easily written off as relatively inconsequential. With respect to identity domains, the category itself does not cohere without the interpretation that for this population medication used—the ambivalent tradeoff of controlling symptoms against unpleasant side effects, of embracing and rejecting it at different moments, and of thinking of it as tool or crutch—is indeed an element of identity, whereas for those not afflicted medication use is episodic and not necessarily mind-altering. Under this interpretation it is not surprising that social class and ethnicity receive so little mention, appearing as ancillary or as afterthought to the stigma of mental illness. From the standpoint of our data, psychiatric stigma associated with the identity of being a medication user appears to “trump” the stigma of race or social class, though the latter may exacerbate or have an additive effect.

CONCLUSION

The paradoxical life circumstance of many study participants 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 framework of contexts identified by mentally ill persons themselves in which they are aware of stigma may be relatively stable across cultural boundaries or categories of illness, but in-depth anthropological investigations involving a large sample size such as the present study are required in the future to determine variations in how the experience of stigma is played out across this framework. We may speculate, however, that given the widely documented existence of stigma in relation to mental illness worldwide (Kleinman, 1988; WHO, 2001), future research will find a broad concordance of an awareness of stigma as a matter of everyday lived experience, while the cultural meanings of the specific contexts of stigma experience are likely to vary in several respects (e.g., with respect to diagnosis, medications, or distancing of social relations) yet be similar in others (e.g., dating prospects, popular perceptions of fear).

In this article, we have outlined categories of social relations and identity domains in which patients are aware of stigma, and have taken the additional step of specifying the quality of that awareness. In this light, psychiatric stigma is clearly not a monolithic force against which individuals must struggle. Indeed, we suggest that knowledge of the particularity of lived experiences of stigma may aid the efforts of mental health professionals to anticipate where and under what circumstances individuals may experience the blows of stigma. The data presented in this article contribute to understanding stigma as a product of intersubjective, reciprocal social processes and not something “out there” that is imposed upon an individual. Individuals with mental illness play an active role in contending with, resisting, and sometimes reproducing stigma. Attending to the complex social fields of stigma encourages rethinking individuals with mental illness in ways beyond vulnerability and victimhood.

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REFERENCES


