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THE NEW PARADIGM OF RECOVERY FROM SCHIZOPHRENIA: CULTURAL CONUNDRUMS OF IMPROVEMENT WITHOUT CURE

ABSTRACT. This article is a qualitative investigation of the subjective experience of recovery from the perspective of persons living with schizophrenia-related disorders. An NIMH-sponsored ethnographic study of community outpatient clinics was completed for 90 persons taking second-generation antipsychotic medications. Research diagnostic criteria and clinical ratings were obtained in tandem with an anthropologically developed Subjective Experience of Medication Interview (SEMI) that elicits narrative data on everyday life and activities, medication and treatment, management of symptoms, expectations concerning recovery, and stigma. Ethnographic observations from diverse settings (clinics, public transportation, restaurants, homes) were also obtained. The primary findings are that recovery was experienced in relation to low levels of symptoms, the need to take medications to avoid hospitalization or psychotic episodes, and personal agency to struggle against the effects of illness. The majority of participants articulated their sense of illness recovery and expectation that their lives would improve. Improvement and recovery is an incremental, yet definitively discernable subjective process. Several problems were identified as part of this process surrounding cultural conflicts that generate the experience of ambivalence analyzed here as the "paradox of recovery without cure," irreconcilable "catch-22" dilemmas involving sacrifice (e.g., one must be "fat" or be "crazy"), and substantial stigma despite improvement in illness and everyday life experience.

KEY WORDS: culture, recovery, schizophrenia, psychopharmacology, atypical antipsychotics

In the great majority of cases the periods of improvement do not last longer than three years. . . . Among all the cases ultimately leading to dementia [praecox] the proportion of periods of improvement resembling recovery only amounted to about 2.6 percent . . . after the initial improvement [there is] a gradual deterioration of the psychic state.

—E. Kraepelin, 1919

We see that recovery is an important and fundamental phenomenon. . . . Although the phenomenon will not fit neatly into natural scientific paradigms, those of us who have been disabled know that recovery is real because we have lived it.

—Patricia E. Deegan, 1988

We envision a future when everyone with a mental illness will recover.

—U.S. Commission on Mental Health, 2003

INTRODUCTION

As these epigraphs illustrate, there has recently been a paradigmatic shift in the history of scientific expectations for the course of schizophrenia. Once typically regarded in psychiatry as an inherently chronic and deteriorating condition, current expectations concerning the course of schizophrenia-related conditions are more sanguine than conceptualizations of such problems a century ago. In tracing this extraordinary development, there are several issues to take into account. First, transnational studies have empirically demonstrated that course varies worldwide and that culture accounts substantially for much of this variability (Bebbington and Kuipers 1994; Hopper 2004; Jablensky et al. 1992; Warner 1994). Second, longitudinal and neurocognitive studies alike have demonstrated that schizophrenia-related disorders are not invariably deteriorating, chronic conditions (DeSisto et al. 1999; Good 1994; Harrison et al. 2001; Lieberman 1999). Third, the introduction of the atypical (also termed *second-generation*) antipsychotic medications has led to significant symptomatic improvement (Breier et al. 2000; Lieberman et al. 2003). Fourth, an increasing emphasis on the subjective experience of persons with such conditions has suggested particular dimensions of recovery for investigation (Hogarty et al. 1997; Jenkins and Barrett 2004; U.S. Department of Health and Human Services [USDHHS] 2003). Finally, there has recently been a methodological drive in the health sciences toward evidence-based approaches that incorporate qualitative methods and narrative analysis (Davidson 2003; Frese 2001; Good and Good 2000; Greenhalgh and Hurwitz 1999; Jenkins 1997; Kleinman 1988; National Institutes of Health 2001). These convergent developments, taken together, argue for studies that can empirically specify illness processes of exacerbation, improvement and recovery. This article examines this problem on the basis of a qualitative–quantitative anthropological investigation of cultural, psychosocial, and pharmacological factors that figure into these processes.

A recent U.S. mental health report (U.S. Department of Health and Human Services [USDHHS] 2003) defines recovery as "the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms." The concept of recovery has been conceived (1) as a process, outcome, or both (Liberman and Kopelowicz 2005; Mueser et al. 2002) and (2) along a continuum from more objectively to more subjectively based indicators of outcome (Liberman et al. 2001; Ridgway 2001; Turner-Crowson and Wallcraft 2002). While both kinds of data are ideally collected together, at this juncture it is remarkable that systematic qualitative studies based on large sample size have not been available. This study sought to address this shortcoming in the literature and is necessary to identify the shared and distinctive social and cultural contexts in which recovery

is transacted (World Health Organization [WHO] 2001). This gap in the health and social sciences literature is particularly noteworthy when one is seeking the perspectives of patients, families, advocacy groups, and mental health practitioners (Jacobson 2001; Jenkins and Schumacher 1999; Turner-Crowson and Wallcraft 2002).

Narrative studies have highlighted the significance of the self as a dimension of recovery. Davidson and Strauss' (1992) discussion of the "work of recovery" focuses on the reconstruction of an enduring sense of self. Davidson (2003) employs a phenomenological approach by highlighting first-person accounts of recovery. Despite the misperception that people with such illnesses are presumed to be less articulate, less verbal, and less socialized than other adults, Davidson avers that "schizophrenia provides a particularly appealing and potentially quite useful area for qualitative research" (9). His research underscores the diversity of experiences of schizophrenia and a full range of outcomes following a first episode of psychosis from a ethnopsychological model implicitly based on North American and European ethnopsychological selves (41).

To expand this approach to person-centered subjective perspectives on illness recovery with a cultural approach, an anthropological perspective need be brought to bear (Jenkins and Barrett 2004). An explicitly elaborated cultural approach to recovery is critical since empirical studies have established the role of culture in shaping not only symptomatology (Barrio et al. 2003; Lin and Kleinman 1988; WHO 1979), but also course and outcome (Bebbington and Kuipers 1994; Hopper 2004; Jenkins 1988b; Jenkins and Karno 1992; Karno et al. 1987; Leff and Vaughn 1985; WHO 1998). We argue that the process of recovery can be understood in relation to what Obeyesekere (1990) has termed "the work of culture," by which is meant the subjective process "whereby symbolic forms existing on the cultural level get created and recreated through the minds of people." This approach theorizes culture as both process and context of meanings that people create in the process of social interaction (Floersch 2002; Ortner 1996). In this way, self-processes in the "work of recovery" invariably involve the "work of culture" as cultural symbols (for example schizophrenia, conceived as a relatively nonstigmatizing condition such as *nervios* among Mexican-descent families [see Jenkins 1988b] or as a chronic disease or personality deficit such as "laziness" about which Euro-American kin are angry [see Jenkins 1988a]) that affect course of illness.

Pharmacological treatment through "atypical" or second-generation antipsychotic medications over the past two decades has resulted in the reduction of both psychotic symptoms and extrapyramidal effects relative to psychotropic drugs previously available (Awad and Hogan 1994; Weiden et al. 1996). These medications (including clozapine, olanzapine, quetiapine, and risperidone) may be efficacious with treatment-refractory patients as well as recent-onset patients

as an initial treatment that may result in a better long-term outcome (Andersson et al. 1998).

For some cases of schizophrenia, there were reports in the 1990s—in both the popular press[1] and the scientific literature—of substantial improvement and recovery on the order of the "awakenings" phenomena described by Sacks (1990) for survivors of encephalitis. These accounts of significant recovery among the previously persistently ill treated with newer medications have been heralded in the *Harvard Review of Psychiatry* by Duckworth and colleagues (1997), for example, as "often involv[ing] a fundamental reassessment of one's identity, relationships, and purpose in being. . . . The psychological reaction to dramatic pharmacological response is largely uncharted territory" (55). Reports of such dramatic changes in the subjective reactions and social relations of patients must be subjected to empirical scrutiny, however, since they are part of a clinical narrative premised on "miracle cures" and "wonder drugs" with a history in psychiatric discourse of initial hope and fervor, on the one hand, only to be followed by disappointment and subsequent discounting, on the other (Weiden and Havens 1994). As Hopper (2002) points out, sanguine, heroic stories of recovery may be inconsistent with the "'messy work' of putting disrupted lives back together again" (198).

Description of the SEACORA Study

This article reports on a NIMH-funded anthropological study, Subjective Experience and the Culture of Recovery with Atypical Antipsychotics (SEACORA), that contributes to the specification of the subjective experience and meaning of improvement and processes of recovery. The design of the study was a cross-sectional assessment of community outpatients through combination of standard clinical instruments (SCID-IV, BPRS, SANS) and qualitative techniques of interviewing and ethnographic observation. Informed consent was obtained in line with requirements of human subjects' protection. A specific interview, the Subjective Experience of Medication Interview (SEMI), was developed for this study, as an open-ended narrative exploration of everyday activities, dating, gender identity, social relations, medication and treatment, management of symptoms, expectations concerning recovery, stigma, and quality of life. Typically two interview periods (ranging one to two hours in length over one to three interview sessions) were carried out to complete the SEMI. Our central research questions are:

- What is the subjective experience of taking second-generation antipsychotics for patients with schizophrenia and schizoaffective disorders?
- What are the personal and cultural meanings of these medications from patients' points of view?

In addition to investigating recovery, the research was designed to expand on customary studies of medication characterized by many professionals as medication "compliance" or "adherence" from the perspectives of persons actually taking antipsychotic drugs (Budd et al. 1996; Hogan and Awad 1992). More broadly, this ethnographic study sought to provide an anthropological account of their everyday lived experience in the community.

We briefly outline the ethnographic context of this study. We worked at two outpatient psychiatric clinics in a major metropolitan area in the northeastern United States populated predominantly by people of European American and African American ancestry. The city is one whose mental health care establishment pioneered the use within the United States of clozapine, one of the earliest of the so-called atypical antipsychotic medications. Patients spent varying amounts of time in the clinics, and this was directly a function of which of the two clinics they attended. In the first, originally set up as a research site for clozapine, patient interaction was fairly intense, including daily visits during which they engaged in a variety of informal social activities, with occasional group discussion on topics of interest, guided by a nurse at the clinic. In the other, an older community mental health clinic with a less developed research focus, patients came briefly for biweekly or monthly medication checks. Although there may be a more fervent and explicitly elaborated psychiatric ideology regarding the efficacy of medication to treat disorders of the brain in the clozapine clinic, the *primacy* of medication as the most important treatment was common in both settings as indeed is currently the case widely throughout the country.

In briefly summarizing this research environment as an ethnographic setting, we note first an ambiguity in the sense that, properly speaking, schizophrenia patients do not constitute a community, although to some extent a clinical culture may be constituted in and outside the treatment setting in which outpatients interact with one another, and that insofar as patients talk among themselves based on common experience they share minimal elements of what sociolinguists call a speech community. For the most part psychiatric outpatients must be understood in relation to the ways they relate to the larger community, and in a major metropolitan area this community is far from homogeneous. At the same time there are certain modes of behavior common among patients, such as using public transportation and frequenting establishments such as fast food restaurants. We are currently working through observational data collected when project ethnographers followed patients into their homes and such community settings, as well as conducting comparative analyses along a variety of dimensions of patients treated in the two different clinical settings. In this article, we concentrate primarily on data from ethnographic interviews.

Transcripts of the SEMI were analyzed by the authors using an inductive approach to identify themes related to improvement and recovery. Improvement in

relation to atypical antipsychotic medications was coded for all participants and good ($\kappa = 0.69$) interrater reliability was established for the coding schema. For a detailed exposition of coding procedures please see Jenkins et al. (2005). Analysis of the SEMI also yielded many nuanced themes in relation to recovery, which were subsequently established through consensus between the authors. This article addresses both broad and subtler dimensions of recovery.

Methodological Orientation

In this article we focus on recovery from the point of view of persons diagnosed with schizophrenia-related illnesses. We attend to recovery as a process through a cultural approach that emphasizes both subjective experience and meaning. First, attention to subjective experience foregrounds "the active engagement of subjects in processes of cultural construction" (Jenkins and Barrett 2004: 9). Second, we take a meaning-centered approach as developed by Good and Good (1981) as a means to access and interpret personal and cultural understandings of recovery processes. This approach is new in the burgeoning scholarly literature on "recovery," which has already been substantially advanced through distinctions between recovery as process and recovery as outcome and, specifically, as one that requires, as Liberman and Kopelowicz (2005: 740) term it, "social validity" that urges a more expansive definition of recovery to incorporate a range of social norms, standards, and expectations. We urge that this be expanded further to locate explicitly the problem of recovery also to include prominently the *cultural* milieu in which the process is mediated. Thus, the meaning of recovery, from the perspective of persons actually engaged in the process, is constituted by both shared and personal meanings. Meaning-centered approaches seek to identify and to understand what is "at stake" (Kleinman 1999) for particular people at particular times in particular circumstances.

Sample Selection

Subject selection criteria included the following: (1) a diagnosis of schizophrenia or schizoaffective disorder assessed through the Structured Clinical Interview for DSM-IV (SCID) (First et al. 2002); (2) age 18–55; (3) elapsement of at least two years since first psychotic symptoms; (4) at least six months of treatment with an atypical antipsychotic; (5) absence of comorbid substance abuse or organic impairment; and (6) clinical stability sufficient to provide informed consent and participate in interviews.

The complete rosters of two community mental health outpatient facilities in a metropolitan area of the United States were obtained. Subject eligibility was assessed by treating psychiatrists and individual therapeutic managers to create a complete listing of all patients who met research diagnostic criteria. From this

complete listing, participants were then randomly sampled. When individuals did not meet the study criteria after administration of the SCID, or refusal to participate, these individuals were replaced by the next person on an SPSS-generated random sample listing until the desired sample ($N = 90$) was obtained. Toward the end of the recruitment process, an attempt was made to include subjects such that a balance would be achieved by sex and ethnicity across the two participating clinical sites. From the list of randomly selected subjects who met the inclusion criteria (167 subjects), 90 (54 percent) of those selected were included in the final sample, with 46.7 percent of these subjects refusing research participation. The overall high rate of refusal is not unusual for an American community outpatient sample such as this, with males (55.9 percent) significantly more likely than females (29.3 percent) to refuse participation (Fisher's exact, $p < 0.001$). Reasons for nonparticipation included general lack of interest in research (subjects stating simply that they "didn't want to") and a reluctance to provide time for interviews (due to work scheduling or preferences to spend time otherwise). In this light, it is likely that those who did participate in the study differed insofar as they were more motivated to participate in research, occasionally stating that they had an interest in contributing to anything that had potential to help in the understanding of others (or themselves). In this way, the sample may be more cooperative, be more functional, or have a better treatment experience than those in the group who declined research participation (as summarized in Jenkins et al. 2005).

RESULTS

Sociodemographic and Clinical Characteristics

Ninety persons participated in the study. Table 1 presents sociodemographic characteristics of the sample. These recruitment criteria (e.g., no comorbid substance abuse), sampling technique, and sociodemographic characteristics have been fully summarized elsewhere (Jenkins et al. 2005). The sample consisted of 49 (54.4 percent) men and 41 (45.6 percent) women. While most (84.4 percent of the sample overall) were never married, significantly more men (95.9 percent) than women (70.7 percent) had never married (Fisher's exact, $p < 0.01$) and more women (19.5 percent) than men (2.0 percent) lived with a partner/spouse ($p < 0.01$). Relatedly, 17.8 percent had children, with more women (36.6 percent) than men (2.0 percent) having children ($p < 0.001$). Overall, 40 percent of participants were working in half- or full-time employment. On the basis of years of education and occupation, there was a full range of social position within the sample, although the majority (73.3 percent) was of middle- and upper middle–class background, which is roughly representative of the sociodemographic characteristics of the mental health catchment area served by the community health clinics. There were

TABLE 1

Sociodemographic Characteristics of SEACORA
Participants ($N = 90$)

	Number	Percent
Gender		
Male	49	54.4
Ethnicity		
Euro-American	70	77.8
African American	20	22.2
Mean age (SD)	40.7 (7.9)	
Mean years of education (SD)	13.0 (1.9)	
Marital status		
Single	76	84.4
Married/partner	5	5.6
Divorced/widowed/separated	9	10.0
Living situation[a]		
Alone	23	25.6
Roommate	5	5.6
Group home	15	16.7
Relative/parent	38	42.2
Partner/spouse	9	10.0
Have children		
Yes	16	17.8
Work situation		
Not working	54	60.0
Half-time or less (<20 h)	20	22.2
Half- to full-time (≥ 20 h)	16	17.8

[a]Due to rounding, total percent may not equal 100.

no significant differences in socioeconomic status (SES) by gender or ethnicity (Euro-American or African American).

Table 2 lists the clinical characteristics of the research participants. The majority (81.1 percent) were diagnosed with schizophrenia, with 18.9 percent diagnosed with schizoaffective disorder. As has often been noted in the literature (Goldstein 1988), women ($M \pm SD = 22.6 \pm 9.1$) had a later age at onset than men ($M \pm SD = 18.9 \pm 4.9$; $t = -2.34$, $df = 88$, $p < 0.02$). The mean years of illness was 20.1 (SD = 8.4). The majority (56.7 percent) were taking clozapine as their current atypical antipsychotic medication. Other participants were taking risperidone (17.8 percent), olanzipine (16.7 percent), or other investigational (8.9 percent) atypical antipsychotic medications. Brief Psychiatric Rating Scale (BPRS) factor scores showed remarkably low levels of current symptomatology in the sample overall (Jenkins et al. 2005).

The particular sociodemographic and clinical characteristics of our study participants suggest that, relative to other community populations, our sample may be "doing better" than those who have less access to psychiatric care, financial resources, or family support or than those who also have comorbid substance

TABLE 2

Clinical Characteristics of SEACORA Participants ($N = 90$)

	Number	Percent[a]
Diagnosis		
Schizophrenia	73	81.1
Schizo-affective	17	18.9
Mean age at onset (SD)	20.6 (7.3)	
Mean years ill (SD)	20.1 (8.4)	
Admissions		
Mean (SD)	7.0 (7.0)	
Median	5.0	
Range	50.0	
Outpatient treatment[b]		
Mean (SD)	7.6 (4.5)	
Median	7.0	
Range	20.0	
Current atypical antipsychotic		
Clozapine	51	56.7
Risperidone	16	17.8
Olanzapine	15	16.7
Other	8	8.9
BPRS subscores	M ± SD	
Thought disorder	1.9 ± 0.88	
Withdrawal	1.9 ± 0.54	
Anxiety/depression	2.4 ± 1.0	
Hostility/suspicion	1.7 ± 0.65	
Activity	1.2 ± 0.32	

[a]Due to rounding, percent may not equal 100.
[b]Length of treatment at current clinical site in years.

abuse (the latter were excluded from the present study, which seeks to examine subjective experience of medications only, uncomplicated by such street drug use). Specifically, given the relatively high SES, proportion of the sample working, and available social support, as well as low levels of symptomatology that characterize participants in this study, we might expect this to be a particularly "improved" or "recovered" sample. Yet we are not inclined to consider these contextualizing features to be a limitation of the study. Rather, we find it notable that even among those who may arguably be "doing better" relative to their counterparts in the community, recovery is *still* fraught with deep personal and cultural ambivalence in ways (specified below) that remain highly problematic.

"Awakenings"

In this study, the experience of an "awakening" was reported if, in response to a direct interview question or spontaneously, persons made a narrative statement

during the SEMI to indicate that they had experienced a subjective sense of substantial and global transformation from a previous illness state. Only a minority of participants ($n = 22$, or 24.7 percent) reported having experienced an awakening, and among this group no one reported that this state had been sustained beyond a period of what they recall as a few weeks or months. Individuals with a schizoaffective diagnosis were significantly more likely (Fisher's exact, $p < 0.03$) to report having experienced an awakening (8 of 17) than those with a diagnosis of schizophrenia (14 of 72). For the proportion reporting an awakening, no significant differences were observed for gender or ethnicity.

Subtypes of awakenings were coded as "phenomenological" and "social." A phenomenological awakening was defined as the report of a substantial change in perception of one's reality, as in "coming out of a fog" or experiencing the world in a dramatically different manner. Of the 22 individuals who reported an awakening, 18 reported a phenomenological subtype. Below is an example described by a participant:

It's kind of hard. It's like trying to describe the color blue to someone who has never had sight. You know what blue is but you don't know how to say it to make them understand. . . . I just know that I'm benefiting from the way I am now versus the way I was before . . . now I know what reality is.

In contrast, a social awakening was defined as a substantial change (improvement) in relationships with family, friends, or other individuals. Four individuals—all women—reported this type of awakening, to highlight their sense of substantial improvement on the order of an awakening involving a strong, previously unrealized awareness of connection to family and friends. Although the number of respondents reporting a social awakening is small, it is noteworthy that phenomenological awakenings were split nearly evenly between men and women, with only women reporting the social subtype.

The Incremental Nature of the Process of Improvement

Narratives of improvement and recovery in association with the metaphor of awakenings appeared only among a minority of the SEACORA participants, who generally noted that such states were not sustained over time. Nearly all emphasized that the processes of illness management and improvement were gradual. Furthermore, these processes were subjectively observed as not necessarily a linear progression but rather one with occasional setbacks inherent to the process. Even so, when this North American sample was asked whether they expected the course of their illness to get better, stay the same, or get worse, the majority (80 percent) heartily expected their course of illness to improve. In response to a broader question of whether they expected their lives to get better, worse, or stay the same, most (70.6 percent) also conveyed that they indeed expected their

lives to get better. The rest thought that their illness would stay the same (14.1 percent) and their lives were likely to remain the same (25.9 percent). Strikingly, only a few expected that their illness would probably become worse (5.9 percent) and their lives likewise (3.5 percent). Our primary finding can be characterized through an understanding of recovery as an incremental process of improvement that occurs gradually, and is experienced subjectively over days, months, and even years. A narrative illustration of the central role of suffering (Kleinman 1999) in processes of recovery was widely evident in subjective comparisons to a previously severe and continuous illness state as expressed in the following narrative excerpt:

See, I've tried to explain in my poetry about how horribly suffering the psychosis is when you're in it, and I can't find the poem. There was a contest—today was the deadline. I sent some other poems, but I wrote this one poem saying that when I'd gone psychotic, the agony and the suffering would make Christ look like a teenage girl in bobby socks and saddle shoes and the Catholic girl skirt, with white blouse sitting at the drugstore soda fountain. [No. 63]

In sum, the phenomenology of recovery—following extraordinary suffering—can be best characterized as a *slow, incremental, but definitively discernible subjective process of improvement*.

Experience with and Faith in Medication as the Key to Improving

Considering the total sample of 84 participants who were taking atypicals after having taken older antipsychotics, the majority (77.4 percent) noted improvement, whereas 10.7 percent experienced no improvement. Some (8.3 percent) of the responses were contradictory or ambiguous and could not be coded owing at times to the lack of enough data to say in either case. Of the six persons who had received an atypical as their first medication and therefore had no basis for comparison between older and newer antipsychotics, five (83.3 percent) nonetheless affirmed that they had faith that the medication contributed to their improvement (Jenkins et al. 2005). One participant maintained that the medication provided a gradual improvement over time and that, for this reason, he took it "religiously."[2] There were no significant differences in these subjective reports in relation to clinical or sociodemographic characteristics.

While our African American subsample was not large, there was a tendency within that group to be even more likely to narrate improvement through medications than Euro-Americans. However, the overall subjective sense of the prominent role of medications to improvement was striking. Indeed, *medication occupies the most salient narrative position in the subjective sense of incremental recovery*. The usually long (several years) and excruciating process of trying a series of medications was typical in this sample of persons who had struggled with

schizophrenia-related conditions for two decades (Table 2). Within these bio-
graphical contexts, recovery was often relativized in relation to the severity of the
illness previously in one's life.

Improvement through "Personal Power and Control"

While medication is given a primary narrative placement in processes of recovery,
many participants were convinced that medication could not be relied on for all
of the "work of recovery." The narrative data in relation to felt personal power
and control showed that half (51.1 percent) experienced having the capacity or
will to struggle against the effects of illness. Those who felt they had "personal
power and control" made clear that although medications enabled them to improve
substantially, they must also do personal "work" as crucial to improvement and
recovery (Davidson 2003; Strauss and Carpenter 1977). Among those who expe-
rienced comparatively higher clinical and social functioning, the role of sustained
effort was often inexorably linked to social engagement, that is, personal efforts
were strongly contingent on engagement in social relations (Jenkins et al. 2005).

"Controlling" the Illness through Medication

One significant dimension of recovery is a cultural orientation to control.[3] In this
U.S. study, the theme of control has an array of quite different subjective mean-
ings as these are variously invoked across individuals: control over symptoms
surrounding thought, emotion, and behavior, control over life circumstances, con-
trol over hospitalization, control in social encounters, and control over appearance
and self-presentation. In this study, however, the narrative data highlight persons'
commonly shared sense that medication is the most important factor in relation to
gaining control over such problems for the self:[4]

I think it's under control now because of the medication. I think it's part of the Clozaril—
I wasn't able to control it, even if I wanted to I couldn't. And uh . . . I think the most
important thing is finding the right medication that starts to interact with the illness. And
it just takes a long time. You know, you have to be willing to invest the time, you know,
taking medications and waiting for it to . . . 'cause you can try—I mean I was on a number
of medications, and they didn't do anything for me. So it's—I think the first thing is trying
to find the right medication, and then that can take a long time. It took a long time for me
to finally find a medication. It took like eight years. [No. 76]

Thus regularly taking medications—with the help of a compatible doctor—
is one means for engaging the struggle to recover from schizophrenia. Several
studies have shown that regular medications and treatment can dramatically reduce
symptoms, relapse, and rehospitalizations (Lieberman 1996; USDHHS 1999).

"Controlling" the Illness through Activity, Leisure, and Distraction

Control of the illness involves other strategies as well, however, such as efforts to
"keep busy," to relax, and to distract oneself from otherwise disturbing symptoms.

R: It's better for me most of the time to keep busy, although, I need a little bit, or a bit or some time to myself. Where I can just sleep, or rest, or relax, just let myself do nothing or just about nothing. Any little bit at a time, I'm in that. But for the larger part, the largest part is keeping busy, and I keep busy.

 I: How do you think that helps you with your illness?

R: Uh, well, it keeps me occupied, and keeps me, helps me check on my energy, and, uh . . . uh, I don't know if you would call it a distraction from my own thoughts and feelings, or what you would. I'm not saying I'm trying to run away by doing these things. I assume some people might look at it that way, you know. . . . But I think, if you're doing something constructive and useful with all that, it has positive value to it, you know. [No. 03]

In addition to the role played by "everyday" sorts of distractions, others highlight the importance of religion in tandem with personal effort to control the illness:

Well, when I hear the voices, there's a combat in my head. You know, there's a struggle. And I have to fight 'em. And if I just go with the medicine, it doesn't work. You know, it takes, actually distracting myself and making the effort and cooking the meal, and sitting, trying to sit still and watch TV and going for a walk, that . . . 'cause if I just lay down, they won't go away. Until I fall asleep. . . . Also, going to church gives me spiritual strength, because when I didn't, it was worse. My whole life was worse when I didn't go to church and follow the, walk with the Lord. [No. 27]

Diet and exercise, along with avoiding street drugs, are also noted as being important for health:

 There's things you can do like I try taking an eight mile hike everyday. It makes you feel good physically, and in turn you feel better emotionally and mentally. Ah . . . eating on a regular basis as opposed to eating one fast food meal a day and then just going on caffeine and nicotine. The little stuff like that really adds up. . . as far as the power of positive thinking can affect it—no not really because it's . . . you can't maintain positive affirmations 24 h a day around the clock. I think that doing things that anyone could do for themselves regardless of whether they are schizophrenic or not can affect your health. Then there is the obvious staying away from drugs . . . but again that's something you have to do. [No. 66]

While the foregoing factors are cited as part of a daily process for control of the illness, "control" is enacted in highly personal ways in relation to individual needs and desires.

Self Processes in Relation to Recovery

Among participants, their experience can be characterized as a *palpable struggle* to situate themselves relative to their illness and medications. For participants, negotiating a sense of self involves teasing out the effects of their medication, symptoms of their illness, and aspects of their personality. This personal project simultaneously manifests and mediates the overlapping and polysemous mental, physical, and emotional dimensions of the perceived transformative process of recovery. Rendering the self entails both explicit and tacit negotiation of a sense of

"me" versus "not me." In contrast to previous studies (Estroff 1989) we do not, in the main, find among participants a fixed location for their subjective experience of illness identity. Instead, self processes among participants involve a substantial struggle and may be characterized as shifting and porous.

Personal Agency and De-emphasizing of Mental Illness

In the classic anthropologically informed formulation of psychiatric disorder as invariably located within particular social interactions, Harry Stack Sullivan (1962) set forth schizophrenia as a problem characterized by awareness and management of fragile self processes in specific situations. Our ethnographic data show that persons participating in the study often characterize their illness management as one in which medication cannot possibly be expected to do all of the complex and subtle "work" involved in the process of recovery. Numerous capacities of the self were invoked under a broad cultural framework of "control" with illness-specific concerns intersecting with "everyday" problems of making one's way in the world.

Many persons developed psychocultural strategies for struggle and control not through overcoming the illness or "fixing" the illness but, rather, through accommodating the illness. An accommodation or learning orientation to recovery stands in contrast to a problem-oriented approach that situates the illness as an enemy in relation to the self. Instead, by learning to deal with extraordinary experiences, both the illness and the self may be redefined in relation to one another. This redefinition may involve a conscious decision by individuals to adopt an affirmative perspective on their life circumstances. Some participants specifically reject viewing their lives or illnesses in negative or deficient terms. One person, for example, was adamant that despite the many difficulties she faced, she "liked her life," taking a directly offensive position to counter others who, from her perspective, appeared to view her situation as dismal. In another example, one person described how she accommodated the illness by allowing herself to experience symptoms:

I: So, do you feel like you have any personal power or control over your illness?
R: Yeah I do.
I: Yeah? How is that?
R: Because I can control the way I think.
I: Uh hm. And what do you try to do when you control what you think, how does that work?
R: Like, if I have a sick thought or something, I'll just allow myself to have the sick thought. But I'll recognize it as a sick thought. [No. 54]

In the above example, this person has taken an active stance in relation to her symptom experience. Instead of being a passive recipient of "sick thoughts," she chooses to recognize herself as an agent of those thoughts. By turning the tables on her symptoms, she acts as the author of her thoughts, manifesting control in both the act of thinking and the recognition of certain thoughts as problematic.

In this way, the illness is not external to the self for this participant but, rather, is incorporated into it as an aspect of self-experience. She experienced it as the re-creation of a new self.

"Normalizing" and "Relativizing" Illness

Normalizing the illness is achieved through strategies that situate the illness in relation to an integrated self-concept and engagement with the world. Recovery, for some participants, was experienced as a return to normality or to their "old selves." Returning to an "old self" or the creation of a newly reintegrated self suggests that persons develop a narrative strategy, creating an opposition between the ill (former) self and the recovering/recovered self. This opposition is also borne out in the strategy of relativizing the illness. The temporal dimension of this strategy is elaborated by participants who compare their current situation to the past, before the use of atypical antipsychotic medications.

Relativizing the illness is not limited to one's relationship to the ill self, but also occurs in relation to others. Like all persons, individuals with mental illness evaluate and assess their own behaviors through comparisons with others. This person distinguishes herself both temporally from her ill self and also from others with mental illness:

I think the hardest thing for people with mental illness to do is to socialize and make friends. A lot of people with mental illness don't have good social skills. I have good social skills now but I never used to. [No. 25]

Similarly, one person reflects on his frustration with being associated with other, lower-functioning individuals with mental illness:

Well, what they do is they bring these mentally ill people all together. And they bring them together and expect you to be friends. Just because of your illness. But there's much more to friendship than just sharing an illness. And I totally disagree with what they do, with bringing people together. It's very frustrating to me. 'Cause these people are all functioning on different levels. I'm on a pretty high level. A lot of these people in the program are pretty low functioning. And you know, they put me in there and expect me to gel with these people. I just can't do it. It just doesn't work. So I avoid them as much as I can. I play tennis with them on Sundays, you know. That's not that bad, but other than that, I kind of keep my distance. [No. 76]

In the above example, relativizing cuts doubly, functioning positively as a narrative strategy for recovery, but also serving to reproduce the stigma associated with mental illness through the creation of an "us" and "them" opposition. As such, stigma takes on a complex relationship to individuals with mental illness, as something to be managed as well as something capable of being co-opted by individuals with mental illness to perform the cultural work of recovery. Individuals co-opt and reproduce stigma through a narrative strategy that places

the ill self in opposition to the current recovering self, as well as drawing the distinction between the self and others who are less recovered. In expanding on Goffman's (1963) classic formulation, sociologist Link and colleagues (2001; Link and Phelan 2001) argue that the social and cultural study of various forms of stigma and the pernicious effects they produce in the case of mental illness is an especially critical research priority.

The Solace of Others

It is evident that recovery extends beyond transformation of the self and negotiation of personal identity "that combines the intimate or personal world with the collective space of cultural forms and social relations" (Holland et al. 1998: 5). Participants were often significantly supported by kin, friends, and health care providers in their struggle to recover. The types of interactions that appear to be helpful are remarkable for being utterly ordinary, illustrating that it does not require exceptional efforts to offer substantive support. In fact, such "everyday" and "normal" forms of connection may be some of the most important for the recovery process, allowing the individual to be treated as "just another person" rather than being marked as ill and excluded as such. This can be an effective counterweight to stigma, though not all social contact—including that with kin—is salubrious.

Living situation is one proxy of social contact and possible support. In this study (Table 1), the highest percentage of participants (52.2 percent) lived with family. One participant, a 27-year-old Euro-American man, describes his relationship with his mother in this way:

B: Do you, um, do you take care of your mom, would you say?
R: Well, I think we take care of each other. We have a very mutually supportive relationship. She's the reason I'm still here. [No. 01]

His mother was a very visible part of his everyday life and deeply involved in his recovery process, taking on the role of personal advocate for her son as well as being active within the National Alliance for the Mentally Ill (NAMI). A 26-year-old Euro-American woman identifies her brother as her "closest friend." In the following narrative example she describes her brother's role in caring for her during her illness:

When I was sick, they—my brother watched me. They had to watch me, and he'd take off work and stuff like that. [No. 27]

Her brother also makes it a point to include his sister in his social gatherings or outings, such as going to the movies. Her experience speaks to the need for support not only in the throes of an acute illness episode but also for continuing support in the recovery process. As noted above, however, not all social contact is positive. Decades of "expressed emotion" research have demonstrated that the

emotional climate of the familial and social environment in which patients live can have deleterious effects on the recovery process. It is therefore crucial to take into account the quality of social interactions in the context of recovery (Bebbington and Kuipers 1994; Jenkins and Karno 1992; Vaughn and Leff 1976). For example, an African American woman in this study appeared to be quite sensitive to her sister's refusal to speak to her about her illness experience or to include her in casual or intimate conversation alike. This seems to have had a negative impact on her everyday life as well as fluctuations in her psychotic symptoms.

 I: How do your friends, or say, [your sister] handle the problems that are associated with your illness?
R: Well, what gets on my nerves with her [my sister] is, she thinks I'm going to break, like everything. And it's like I have problems, if it's, when I do decide to discuss them with her, it's like she always tells me . . . to get that situation under control, you've got to control it. Which I know that because, don't get sickanymore, please don't get sick anymore. This mess, you think that everything is associated with me, and then I have a problem. She thinks I'm going to break. I'm not china, I'm not going to break. I just want to talk to you about what's bothering me. But the minute I talk about what's bothering me, she brings up as though, as though she keeps reminding me that something's wrong with me, you know. . . . I'm not going to break. You know, make me feel like I'm so fragile, that I can't get, or understand anything, you know?. I have a lot of responsibility and whatever. . . . But I'm not china. I mean, give me credit for something.

Responsibility for Others: Persons with Schizophrenia as Caregivers

In this study, we observed that, even among persons with mental illness, social support is a *reciprocal* process. It was striking that study participants took care of others in a variety of ways, from more casual "checking in" on others—roommates, friends, relatives—to being primary caregivers for elderly parents in ways mundane and exceptional alike. The finding is somewhat surprising given how little attention this social process has garnered in the literature. For many, in addition to being substantially supported in their recovery efforts by family and friends, they were also actively taking care of others, as illustrated below:

Well, my thoughts now are more settled on, taking care of my mother and thinking about how to take care of myself and what to do when she passes away. Um, taking care of the car, and my entire life is focused on responsibilities, obligations, chores. [No. 87]

One participant describes daily involvement in helping his roommate to take medications:

 I: Besides taking care of your own illness, are you taking care of anyone else right now, too?
R: Uh, kinda, yeah.
 I: And who is that?
R: Um, my roommate. I get out his pills for him at night. [No. 11]

Two other participants described their activities as parents:

I: And who else are you taking care of now? You're (saying you are) always taking care of somebody else?

R: Yeah, well . . . I, my son, he's 19. I guess you say I look, I'm taking care of him, cause um, I look after him. He tells me he's a man, but I look after him since he was a little kid. You know what I mean. I wash his clothes, I cook his meals. I even pick up behind him. [No. 33]

I: Uh hm, sounds like you have a lot to take care of with yourself, is there anyone else that you take care of too?

R: My daughter. She takes medication too. [No. 43]

These two narratives reflect the responsibilities of parenting, from the more pedestrian "picking up" after (adult) children to monitoring their health status and medication. Still other participants served as primary caregivers, describing this as a "full-time job" in caring, for example, a nephew and niece in this case:

I: For now, can you tell me if, besides managing your own illness, if you're taking care of anyone else, too, right now?

R: Yes, I babysit my two, my uh, my nephew and my niece. My nephew is four years old and my niece is one year old.

I: Uh hm.

R: I babysit them while both their parents work.

I: Okay.

R: They're over our house during the day because both their parents work.

I: Uh hm.

R: This is usually, at least, well, it's different every week. Some weeks it's three days a week, some weeks it's two days a week, some weeks it's maybe four or five days a week. It all depends on how busy their parents are, how [stutter] much other things they have to do when they can't watch their children.

I: Okay. How long have you been doing that?

R: Uh, let's see . . . ever since 1995.

I: Okay. And how many hours a day do you usually do that for?

R: Oh, maybe six or eight hours a day.

I: What kinds of things do you do when you're babysitting?

R: Make sure they get fed, make sure they get their rest, make sure they have something to do. See, they're both very active so you've got to keep up with them, see. . . .

I: Uh hm.

R: The one likes to go outside and play in the backyard so my grandfa—my father and I have to go in the backyard and play with them, you know.

I: Uh hm.

R: They keep you, you know, they keep you on your toes.

I: I bet.

R: Because, you know, you know, they are a handful, they always come in and want you to do something with them so, so . . . you're basically, it takes us full time. [No. 53]

Finally, one male participant describes in astonishing detail his responsibilities in caring for his elderly mother:

I: Um, well, besides managing your own illness, I know you're taking care of your mom too right now. Um, can you tell me a little bit about what you do for your mom? What kinds of things you do to help her?

R: Well, the day starts out, I give her, I check her blood sugar, all, every other day in the morning and then every other day in the afternoon. And then I fill up her syringe so she can give herself the insulin shot. And I um, fill up the inhaler, it's called a nebulizer which um, the little, comes in a little vial. The um, albuteral. And that turns into a steam mist which she breathes into her lungs. And so, I fill that up for her three times a day, then I fix her breakfast, lunch, and dinner. And um, do her laundry and um, take her um, prescriptions to the um, drug store when she needs those filled. And um, basically whatever else she needs done, I do her grocery shopping. And um, it takes two of us to take her to the doctor. My uncle um, comes and helps me, the wheelchair fits in his car. I've got two uncles. Her sister and her sister's- her brother, I mean. And her sister's ex, um, her sister's husband. Her sister's passed, so both of them help us take her to the hospital and her doctor's appointments.

I: Um, okay. Now, she has diabetes and pulmonary fibrosis and—

R: Rheumatoid arthritis, high blood pressure. Um, and um, now she's got the hematoma. She just recovered from having her artificial aorta put in. She has um, she's had numerous operations. Her wrist is wired together where it fell off when they were going to operate on it, from the arthritis. She had shoulder spurs, so she had operation on her shoulder. And um, she had operation on her knee, she can't bend her knee. Uh, she's got artificial knee. And did I mention her Achilles tendon came off the bone, so it took a while for that to knit together. She was in a wheelchair then. And now she's on oxygen, I'm here to let the oxygen man in. He comes in twice a week and pumps up her tank with liquid oxygen. Tuesdays and Fridays. And um, basically that's it. [No. 87]

The experiences of the individuals quoted above clearly illustrate the sometimes mundane, occasionally Herculean responsibilities undertaken by participants on a regular basis. While only 40 percent of the SEACORA sample were currently employed, in our view, wage labor is clearly a limited yardstick by which to assess either functionality or daily responsibilities. We advocate a more global view of work in light of the many study participants who occupy a crucial position within their families as caregivers for children and elderly parents. Although they themselves may not be producing income, their labor is nevertheless, in many cases, geared toward supporting the wage-labor of others.

It's the Little Things: Joie de Vivre in Life and Recovery

As for the finding of significant social support being provided by persons in this study, it is likewise remarkable how we have observed substantial joy in relation to "small" and "everyday" pleasures. Again, this is typically thought to be a domain of experience that is largely absent in the lives of persons with schizophrenia (see Jenkins [2004] for a discussion of the "otherizing" of persons with schizophrenia as "less than fully human").

The danger inherent in overly formalized and rigid investigations into recovery is overlooking the idiosyncratic—indeed, human—element in the experience and expression of recovery. Patient/client–based definitions of recovery may involve factors seemingly distant from the scope of mental health studies. As such, particular components of these definitions may overshadow the relative importance

of medications, symptoms, treatment, and work outcomes. Recovery in this sense creates an imperative to diminish the ideological, material, educational, and social gulf existent in the construct of "us"—as researchers and clinicians—and "them"—as individuals with mental illness.

Expanding definitions of recovery to include "the little things"—elements of the joie de vivre—demands at least a temporary decentering of the role of mental illness in the lives and identities of individuals. One participant waxed eloquent about "what he lives for:"

 I: Well, how would you describe what you live for?
R: A twenty dollar bill. Um, a canoe trip in Michigan. Um, sunscreen at the Kmart down in Florida. Uh, looking at quarters. Um. Tasting the ocean. Um. [pause] Birds.
 I: Birds?
R: Birds, yeah. Birds chirping. Um—okay. Um. Being a good Christian, stuff like that. [No. 40]

In contrast to the appeal of popular cultural discourses of overnight successes and dramatic triumphs over adversity, the subjective experiences of participants in the study speak to recovery as gradual and incremental, manifest in the mundane facets of everyday life. While the cultural force of Hollywood-esque narratives of "awakenings" is evident in participants' dissatisfaction with clinical discourses in their voiced desire for a cure, as opposed to management, for their illnesses, they nevertheless engage with the work of recovery on a daily basis, confronting the struggles and challenges of everyday life not uncommonly with steadfast fortitude.

Processes of recovery also hold implications for classical anthropological discourses on transformative processes. The process of recovery as observed in this study is by no means a rite of passage that produces a definitive transition from one state to another. Instead, the subjective experience of participants calls attention to the unfolding and partial character of *daily* rituals of recovery, often entailing such pedestrian efforts as getting out of bed, meeting with friends for a cup of coffee, taking care of others, and actively distracting oneself from annoying voices by gardening. These are not dramatic and highly culturally elaborated ritual processes, yet by engaging with the flow of daily life in such *incremental and additive rituals*, participants become agents of their own transformation.

Cultural Conundrums of Recovery

Ironies and contradictions.   In an overall analysis of participants of the SEA-CORA study, several specific problems (Table 3) were identified as part of processes of improvement to include cultural and structural conflicts that generate the experience of ambivalence that we characterized analytically as the "paradox of recovery without cure," irreconcilable "catch-22" dilemmas involving sacrifice whereby one must be "fat" (drool or have diminished sexual interest) in order not

TABLE 3

Competing Discourses Create Cultural Pardoxes of Lived Experience

- Recovery *without* cure
- Stigma *despite* recovery
- "Crazy" *or* "fat"
- Sexless and genderless *yet* desire and gendered conflicts
- Social developmental problems *yet* pharmaceutical "management" without psychotherapy
- Fault-free "biochemical imbalance" *yet* characterological "defect"
- Felt need for medication *in face of* fears of addiction, toxicity, and chronicity

to be "crazy," and confusion and stigma surrounding the meaning of living with a "chemical imbalance" for which one is expected to take medication for the rest of one's life. The all too familiar dehumanizing of persons with schizophrenia that leads to assumptions that they do not and should not date or be active sexually—certainly not to reproduce—is noted by participants in the SEACORA study as problematic. Many have, or would like to have, active sexual or romantic relationships and resent the subtle insinuation across a variety of social settings they encounter that, unlike their counterparts, they should not be involved in romantic entanglements, parental duties, or gendered identities.

Each of these ironies points to a direction for our continuing analyses of these data, but for the moment we elaborate briefly on only the first of these issues, the paradox of "recovery without cure." Notwithstanding recent national and international research reports, such as those noted earlier, for schizophrenia, unlike other diseases, everyday clinical and popular discourse is notably silent or pessimistic on the possibility of "cure." The perhaps metaphysical longing for cure is experienced as troubling to many in the SEACORA study, for whom "cure" was what they deeply desired. The elusiveness of cure can be painful indeed.[5]

One Euro-American woman (No. 4) drew pictures of herself before and after taking the newer medication. The last of the drawings was similar except for what she called her "extra gut," that is, the "sixty pounds she had gained on Risperdal." This self-drawing differed also from her earlier ones in that it did not have eyes—she crossed them out and wrote "self blinding"—which she further narrated as having "blinded herself to the fact that the medication could not 'cure' me." In another example, a Euro-American man conveyed his desire for and confusion surrounding a "cure" for schizophrenia:

I'd like to be healthy and I'd like my illness to be in remission. And I'd like to be cured of my illness if it's possible, and, uh, if, to the best of my knowledge, is that there's not a cure for schizophrenia. But, like I said, it depends on the doctor's philosophy, too. Some say there are cures for all illnesses, some say there aren't. And some say you can put illnesses in remission, and cure them, so I don't know.

For this group as well as others around the globe, medications alone simply cannot be expected to produce a cure. In the present context, this problem is

severe in contemporary psychiatric practice given the shortage of psychotherapy for such persons; however, in addition to the limitations placed on psychiatrists by managed care and insurance coverage for such services, also troubling has been the longstanding clinical perspective that psychotherapy is, in any event, of highly limited value for this population.

Processes of improvement as a moral "struggle."   The personal effort involved in recovery can be considered a kind of "moral struggle" in which people engage. The specific term *struggle* came up very frequently in the narrative data from the SEMI, and the term *moral* we invoke here in the sense that Kleinman (1999) uses it, as precisely "what matters" that provides experience with its moral mode as "the medium of engagement in everyday life in which things are at stake and in which ordinary people are deeply engaged stake-holders who have important things to lose, to gain, and to preserve" (362). Since what matters varies across diverse social settings, the moral modes of experience must vary, and this is a fundamental implication of Kleinman's contribution to moral theory— as applied to persons who have suffered profoundly and are now engaged in struggles long and deep to live under intersubjective conditions that alleviate oppression.

The social life of medication and side effects.   While a majority of persons (77.4 percent) subjectively experienced improvement in association with atypical antipsychotic medication, 90.8 percent of those experiencing improvement also noted one or more distressing side effect that they felt was due to the medication (Jenkins 2005). As reported in Table 4, participants considered the worst side effects to be weight gain, drooling, and tiredness/drowsiness. Gender differences were noted, with comparatively more women concerned about weight gain and men with sexual dysfunction. Reports of no troubling side effects are particularly noteworthy. Strikingly, 19.3 percent of the sample declined to cite a "worst side effect." This finding supports our sense that troubling side effects may have been underreported by participants in relation to factors straightforward and inchoate alike: (1) gratitude for medication for symptom control; (2) consideration that, relative to typical antipsychotics they had been taking, they experienced better symptomatic relief and fewer troubling side effects with atypicals, and thus deemed them "better," while also resigning themselves to a kind of relativistic "sacrificing;" and (3) a sense of oppression as socially stigmatized persons insofar as they did not feel "entitled" or morally worthy enough to launch complaints about medications that were less than ideal. The finding that the vast majority felt they must contend with serious side effects and yet remain committed to taking these medications to avoid symptom exacerbation and hospitalization thus implies

TABLE 4

Rank Order of Most Troubling Side Effect
(percent)[a]

	Overall (N = 88)[b]	Male (n = 48)	Female (n = 40)
Weight gain	18.2	14.6	22.5
Drooling[c]	17.0	14.6	20.0
Tired/drowsy	17.0	16.7	17.5
Tremor/stiff	10.2	10.4	10.0
Sexual dysfunction	5.7	10.4	0.0
Anxiety/fear	5.7	8.3	2.5
Gastrointestinal	3.4	4.2	2.5
Blood draws	3.4	2.1	5.0
None[d]	19.3	18.8	20.0

[a]Total percent may not equal 100 due to rounding.
[b]N < 90 due to nonresponse.
[c]Drooling reported significantly more for clozapine patients (Fisher's exact, $p < .001$). No significant differences by sociodemographic or other clinical variables.
[d]Response of "none" sometimes accompanied by statements such as "relative to older meds."

substantial ambivalence and contradiction in the face of this predicament. This problem complicates the meaning of recovery.

The study of medication experience must be expanded to go beyond the standard side effects typically listed in the pharmaceutical literature (and studied in clinical trials), to incorporate a great many other "effects" that alter subjective experience in a myriad of ways and entail sacrifices in the context of self-presentation and social interaction across a variety of settings. Recovery often involves negotiating the "catch-22" of the necessity of medication with the embarrassment of its effects. Effects of the medication, in this sense, must be understood more broadly to include the influence of medications on one's way of interacting with and inhabiting the world.

Stigma despite improvement.   As just outlined, improvement is a welcome experience relative to prior states of severe illness. Nevertheless, a pervasive problem faced by persons in the study was the dilemma of finding themselves the object of substantial social stigma *despite* their subjectively experienced improvement. Nearly all (96.0 percent) reported their experience of stigma daily across a variety of social settings. In this way, socially and culturally produced stigma, like the disease of schizophrenia, is a potent force against which they must struggle vigorously. This is true even though most subjects appear to endorse the notion that they have a "biochemical imbalance" that culturally is theoretically

"fault-free." Rather, many participants in the study apparently felt that having such an "imbalance" rendered them deficient, flawed.

De-emphasizing the illness offers a strategy in the management of stigma. Through normalizing and relativizing the illness, individuals may take an active stance against stigma. Participating in such a stance engages multiple psychocultural arenas, both illness- and non–illness-related. In this way, stigma cuts across dimensions of experience: employment, media, dating, side effects, class, gender, ethnicity, and religion. This complex intersection speaks to the need to situate and understand mental illness within the context of lived experience. The experience of stigma in such specific contexts underscores the complexity of the experiences of mental illness and recovery. A fuller account of the settings in which stigma is encountered and strategies for managing it, including hiding the diagnosis and medications, is given elsewhere (Jenkins and Carpenter-Song n.d.). The problem of stigma despite improvement calls attention to the significant sacrifices that mediate experiences of recovery for many participants.

DISCUSSION

In this study of 90 community residents taking second-generation antipsychotic medications for schizophrenia-related conditions, the levels of symptomatology were relatively low (in keeping with definitions as set forth by Liberman and Kopelowicz [2005]), while social and work functioning were relatively high among many participants. This is the first ethnographic study to systematically investigate a large community sample of persons taking second-generation antipsychotics, utilizing narrative and observational data to examine subjective experience.

In light of the finding that only a minority (24.7 percent) report having a sudden recovery that could qualify as an "awakening," it appears that hopeful hypotheses that the atypical antipsychotics might lead to relatively dramatic, substantial, and sustained recovery for most may not be empirically verifiable (Duckworth 1998; Duckworth et al. 1997; Stahl 1997). For those who did report such an experience, the finding of a subtype of awakening ("social" vs. "phenomenological") as gendered (albeit an infrequent occurrence) likely reflects cultural expectations that social engagement is an orientation of more concern to women (with or without schizophrenia alike). The observation that the awakenings phenomenon noted in the literature (Duckworth 1998; Duckworth et al. 1997; Stahl 1997) was not widely observed in the SEACORA project provides a cautionary note to avoid sensationalizing the nature of improvement as occurred for Sacks's (1990) Parkinson's patients.

Rather, analysis of the narrative data reveals that in this sample, participants' experience of improvement was observable as a gradual and incremental yet definitively discernible subjective process. This process does not typically proceed

in linear fashion but rather occurs in the context of a back-and-forth movement of slow yet steady improvement (Deegan 1988; Jenkins et al. 2005).

The striking finding that the majority of a sample of previously severely ill persons felt that their lives and illnesses had improved provides strong evidence to reject earlier clinical characterizations of schizophrenia as invariably chronic and degenerative (Kraepelin 1919). The common expectation for improvement in this study is likely due in part to the self-perceived efficacy of the atypical medications, on the one hand, and to distinctly American cultural and ethnopsychological orientations that produce narratives of optimism and progress through individual effort, on the other (Chang 2001; Shweder and Bourne 1984).

In this study, our finding of incremental improvement and recovery was subjectively considered to be due primarily to the efficacy of the atypical antipsychotic medications (77.4 percent). This was true despite the concomitant finding of an exceptionally high rate (90.8 percent) of one or (typically) more substantial side effects associated with these medications (such as weight gain, drooling, and fatigue). While there were no significant differences by gender or ethnicity in the extent to which persons considered that they had improved through atypical medications, it is noteworthy that African Americans tended to be somewhat more likely to report subjective improvement relative to Euro-Americans (76.6 vs. 94.1 percent). While our African American subsample is small ($N = 20$), the foregoing finding may serve to underscore the observation that, when available, medications considered useful may be expected to be subjectively appreciated across a variety of ethnic and cultural groups alike.

The finding for improvement in association with personal power and control was split relatively evenly insofar as 51.1 percent affirmed that they had personal power and control in relation to the illness whereas 48.9 percent did not. Preliminary review of these distinctively different views indicates various cultural logics, involving a complicated and uneasily separated triad of person/illness/meds (Fig. 1). As a matter of personal experience, it is at times difficult to detect where "I/me," the meds, and the illness can be differentiated. Different types of patterns were observed, however, in relation to how these three semantic fields tend to "go together:"[6] e.g., the subjective sense that one *has* personal power and control apart from or *because of* the medication, that one has *no* personal power or control *because* of the power of the medication or illness (or both), and that one's experience of stigma as demoralizing affects recovery adversely in contrast to those who actively reject stigma as part of their life and illness process (Fig. 2).

We are convinced that an absence of agency in terms of the illness is problematic insofar as such a stance may dissuade one from engaging psychocultural strategies for improvement (Deegan 1988), causing one to resign oneself to the prospect of having a "broken brain" about which one can do nothing. Broadly speaking with respect to a middle-class North American ethnopsychological orientation,
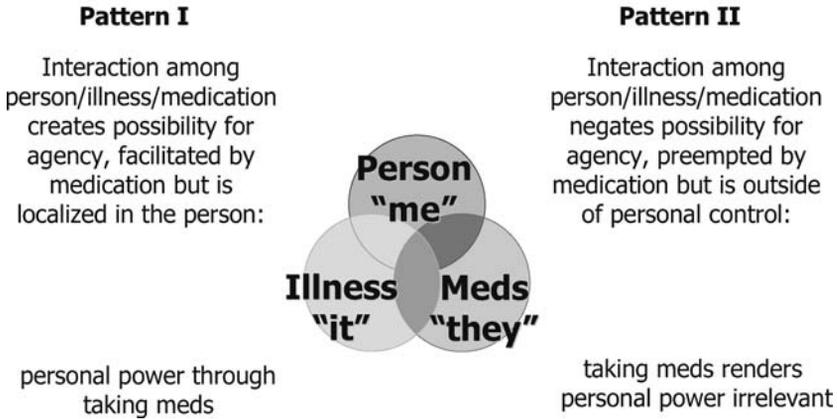
Person-Illness-Meds Experience

Pattern I

Interaction among person/illness/medication creates possibility for agency, facilitated by medication but is localized in the person:

Person "me"

Illness "it"   **Meds** "they"

Pattern II

Interaction among person/illness/medication negates possibility for agency, preempted by medication but is outside of personal control:

personal power through taking meds

taking meds renders personal power irrelevant

Figure 1. Person–illness–medications experience.

we might expect a certain resonance for personal "power and control," yet this may be less true in other societies. Nevertheless, personal agency is highly problematic even in the American case owing to psychiatric discourse on biochemical imbalances or deficits about which one can do little besides take medication.

Cultural Trouble with Biochemical Accounts of Mental Disorder

Biochemical discourses engage cultural dimensions of personal responsibility and agency problematically. On the one hand, a biochemical etiology removes
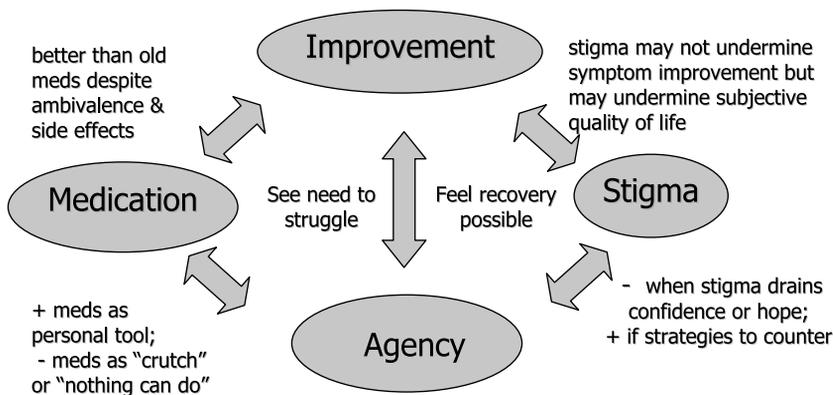
Improvement

better than old meds despite ambivalence & side effects

stigma may not undermine symptom improvement but may undermine subjective quality of life

Medication

See need to struggle   Feel recovery possible

Stigma

+ meds as personal tool; - meds as "crutch" or "nothing can do"

Agency

- when stigma drains confidence or hope; + if strategies to counter

Figure 2. Relationship among factors perceived by patients as being critical to improvement.

responsibility for the production of mental illness from individuals and their families. Linking mental disorders to imbalances and deficiencies of neurotransmitters ostensibly places them beyond the scope of families and, indeed, beyond culture. Conceptualizing schizophrenia as a biochemical imbalance—a disorder of the brain—places it in a "culture-free zone," free from blame.

Yet although biochemical and brain-based discourses are intended to do the undeniably good work of freeing families from blame and individuals from character flaws, the insidious pervasiveness of the twin problems of "deficient brains" and the invariably substantial stigma attached to such deficits underscores the therapeutic limitations of such approaches. Indeed, the intersection of biochemistry, mental illness, and responsibility requires further elucidation. As we probe deeper, it becomes clear that a biological etiology has the secondary consequence of removing personal agency from the experience of mental illness. This conflicts with discourses of recovery that emphasize personal control and accountability to self and to others as significant components of the improvement process. Instead, the emphasis on biochemistry might be seen to limit the scope of recovery to medication and treatment adherence, to the exclusion of other psychocultural realms.

Recognizing that the subjective experience of recovery is not limited in scope to the illness itself or to medication compliance creates a space for agency in recovery from schizophrenia. Individuals participate in the work of recovery, engaging as active participants in the process. The dimension of personal agency also extends the process of recovery away from the ill individual and into complex relationships with others. These social relations tend to de-emphasize illness, highlighting the fact that their problems, successes, sadnesses, and joys are not bounded by the illness but are, instead, informed by normatively imagined cultural orientations.

Concluding Remarks

The data lead us to conclude that, in this study, subjective reports of improvement can be accounted for in part by four factors: the subjectively perceived efficacy of the atypical medications, a clinical culture shared by fellow patients and clinicians that reinforces this perceived efficacy, a distinctly American ethnopsychological orientation that produces narratives of optimism and progress through individual effort, and, relatively speaking, good contextual factors of residing with or near kin or friends with economic or social resources to connect patients with psychiatric care within the community that is sustained. In addition, the fact that the persons in this study (by virtue of research inclusion criteria designed to focus on medication experience not complicated by active drug/alcohol abuse) were not currently burdened also with problems of substance abuse (although several had been in the past) or homelessness (although several had been in the past) undoubtedly

contributes to what can comparatively be considered a better outcome. Thus the factors key to recovery as identified for this mixed sample of low- to upper-income participants may only come into play given the presence of these structural features that can support basic needs and health care that clearly the majority of mentally ill persons do not generally have (i.e., those who are homeless, incarcerated, without health care, or entirely disenfranchised from friends and family). In this respect, the study is socioculturally specific to a group of persons who are relatively stable in the foregoing respects and is not broadly generalizable to all persons with mental illness in the absence of such relatively stabilizing features. However, the SEACORA participants do share a particular kind of social suffering with their (relatively) more disenfranchised mentally ill counterparts insofar as the structural poverty associated with being a mental "patient" or "consumer" in this case invariably involves the necessity of living on an extremely limited governmental allotment (SSI, Medicaid), the inability to afford a vehicle for transportation, and an array of other economically based logistical sustenances that others—albeit not among the very poor or low-income populations—take for granted.

To conclude, in this article, processes of recovery are complex, and often take on a sense of improvement at one turn and reversals at another, making for a considerably less than linear process. These incremental processes of improvement have been examined in relation to medication, personal power and control, and social stigma for the role they play in the subjective sense of recovery. The relative roles of these three domains were examined as (1) subjects' tenacious convictions that taking medications plays a critical role in managing symptoms and avoiding hospitalization, (2) active personal engagement in struggling against the effects of illness, and (3) perceptions of social stigma that attaches to their conditions despite their having improved substantially (compared to prior illness states).

We concur with other recovery studies on the importance of several key elements of the recovery process. First, in relation to our overarching finding regarding the gradual, incremental, and nonlinear process of recovery, our results are consistent with Hopper's (2002) characterization of recovery as complex and "messy." Our research project is, to our knowledge, the first to examine empirically the psychiatric and popular notion of "awakenings" from the perspective of persons who might (or, more likely, might not) experience them. In line with the observation that recovery from serious mental illness may indeed be messy, we find specifically that recovery often entails deep ambivalence and substantial sacrifice in the negotiation of impossible "catch-22" dilemmas. In particular, we have considered how "social medication effects" and psychiatric stigma create conditions in which participants must endure the "violences of everyday life" (Kleinman 2000) as they contend daily with embarrassment and discrimination in their struggle to get better in the wake of serious mental illness.

Second, this study affirms previous studies that foreground the importance of self processes for recovery (Davidson and Strauss 1992). However, in this study we specify multiplex ways in which individuals locate and situate the self in relation to illness and recovery, ranging from a sense of returning to an "old self," to a strict division between the "ill self" and the "well self," to the attempt to accommodate the illness as an aspect of the recovering self. In addition, our analysis reveals the complexity and ambiguity of agency in the recovery process. In particular, we have considered how biochemical discourses, which are common explanatory models for schizophrenia among study participants, complicate rather than resolve issues of personal power, control, and responsibility.

Third, in keeping with other studies (Davidson 2003; Salokangas 1997) we note the importance of social support for recovery processes. We observed social support as a *reciprocal* process. In addition, our approach to social support calls attention to recovery as a process that crucially implicates others beyond the mentally ill individual. In this regard, our study participants likewise articulate the observation common across the recovery literature that schizophrenia-related illnesses and recovery need to be situated in relation to multiple stakeholders (Meddings and Perkins 2002; Stein and Wemmerus 2001). As a shared social phenomenon we problematize notions of "social support" by illustrating it as something both received and given, both potentially positive and negative.

Fourth, the SEACORA study corroborates the critical salience of small, concrete details of everyday life to include social inclusion for recovery (see also Davidson 2003). Furthermore, in our study we observed joie de vivre, in contrast to broader cultural metanarratives of overnight success. Relatedly, we have considered how processes of recovery, as subjectively experienced by the study participants, diverge from traditional anthropological discourses regarding totalizing ritual conversion (Turner 1967) and, instead, suggest an *incremental, additive transformative process*.

In sum, it is clear that improvement and recovery from persistent and severe mental disorders occur in the complex context of interlocking personal, cultural, social, and pharmacological effects. Recognizing that the subjective experience of recovery is not limited in scope to the illness itself or to the problem of medication "compliance" creates a space for agency in recovery from schizophrenia. Individuals can and do participate in the work of recovery, engaging as active participants in the process. The dimension of personal agency also extends the process of recovery away from the ill individual and into complex relationships with others. Consequently, a significant aspect of recovery is success in diminishing the sway of illness by force of the momentum and rhythm of lives not constituted entirely in terms of illness.

The complexity and paradoxical nature of these relations as a matter of subjectivity suggests the continuing need to specify them more fully through ethnographic

methods. The goal is to generate new modes of conceptualizing recovery from schizophrenia in subjectively identified needs and desires of persons struggling to live ordinary lives after having passed through the portals of tremendous suffering (Jenkins and Barrett 2004).

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NOTES

1. "Many who treat schizophrenia believe clozapine is the most important medication to come along in 30 years. The press is so excited, it keeps using 'Awakenings' in headlines, conjuring images of film star Robert De Niro taking a new medicine suddenly going from comatose to superstar" (*New York Times*, September 9, 1992: 41).

2. The invoking of patently religious language and symbols in narratives on illness, suffering, recovery, and medication is a critical topic subject to separate analysis in a forthcoming publication on magic/science/religion in psychiatric discourse.

3. The salience of the cultural theme of control is by no means unique to Euro- and African Americans such as those included in this study. While "control" varies in cultural meaning across social settings, it emerges as prominent among many persons, their kin, and their community when examining the ethnographic materials available on this issue.

4. Such control by virtue of taking medications was considered by some to be preferably transacted in the context of a good relationship with one's doctor. For many, however, the primary narrative place of the medication in the absence of specific mention of patient–provider relationships was likewise noteworthy, highlighting the extent to which psychotherapeutic relations in medication management among this sample are either unavailable or underutilized (as is generally true in North America at this historical moment).

5. The metaphysical dimensions of desire for cure in the face of serious illness are critical yet beyond the scope of this article. I thank Don Tuzin for noting that this should be taken into account.

6. See Good's (1977) classic formulation of semantic fields of meaning and how these may symbolically tend to "go together" culturally.

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