UC San Diego
UC San Diego Previously Published Works

Title

Subjective Experience of Recovery from Schizophrenia-Related Disorders and Atypical Antipsychotics

Permalink

https://escholarship.org/uc/item/6928n8ck

Journal

International Journal of Social Psychiatry, 51(3)

ISSN

0020-7640 1741-2854

Authors

Jenkins, Janis H
Strauss, Milton E
Carpenter, Elizabeth A
et al.

Publication Date

2016-07-27

DOI

10.1177/0020764005056986

Peer reviewed

I|J|S|P

SUBJECTIVE EXPERIENCE OF RECOVERY FROM SCHIZOPHRENIA-RELATED DISORDERS AND ATYPICAL ANTIPSYCHOTICS

JANIS H. JENKINS, MILTON E. STRAUSS, ELIZABETH A. CARPENTER, DAWN MILLER, JERRY FLOERSCH & MARTHA SAJATOVIC

ABSTRACT

Aims: This article investigates the subjective experience of the process of improvement and recovery from the point of view of persons diagnosed (according to research diagnostic criteria) with schizophrenia and schizo-affective disorders.

Methods: A community study of persons using psychiatric services was conducted for a sample of ninety subjects taking atypical antipsychotic medications. Sociodemographic data and clinical ratings were collected to complement the qualitatively developed Subjective Experience of Medication Interview (SEMI), which elicits narrative data on everyday activities, medication and treatment, management of symptoms, expectations concerning recovery, stigma, and quality of life.

Results: Recovery was observed through: (1) relatively low ratings of psychiatrically observed symptomatology through BPRS scores; (2) the subjective sense among the majority (77.4%) of participants that taking medication plays a critical role in managing symptoms and avoiding hospitalization; and (3) the subjective sense articulated by the vast majority (80%) that they would recover from their illness and that the quality of their lives would improve (70.6%).

Conclusion: The overall quality of improvement and recovery is best characterized as an incremental, yet definitively discernable, subjective process.

INTRODUCTION

A recent report from a commission on mental health (Commission on Mental Health, 2003, p. 5) has defined 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 fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms'. In a conceptual overview, Mueser and colleagues (2002) note first, that recovery has been conceived as a process, outcome, or both; and second, that while illness management and recovery are intertwined, nearly all research on services and treatment has been confined to illness management.

The conceptualization and assessment of recovery can be thought to fall along a continuum from more objectively to more subjectively based indicators of outcome (WHO, 1979; Lin & Kleinman, 1988; Warner, 1994; Torgalsboen & Rund, 1998; Davidson *et al.*, 2001; Harrison *et al.*, 2001; Markowitz, 2001; Liberman *et al.*, 2002; Noordsy, *et al.*, 2002; Spaniol *et al.*, 2002; Turner-Crowson & Wallcraft, 2002; Hopper, 2004). Objective measures typically reflect symptomatic and functional outcomes indexed as work and social relationships whereas more subjectively oriented studies seek to shed light on qualitative dimensions of processes and factors associated with recovery (Leff & Vaughn, 1985; Karno *et al.*, 1987; Jenkins, 1988; Kleinman, 1988; Jenkins & Karno, 1992; Salokangas, 1997; Torgalsboen & Rund, 1998; Frese, 2001; National Institute of Health (NIH), 2001; Ridgway, 2001; Liberman *et al.*, 2002; Noordsy *et al.*, 2002; Spaniol *et al.*, 2002; Davidson, 2003). While both objective and subjective indicators are ideally are collected together, it is clear that systematic qualitative studies of considerable sample size are vitally needed at this stage in the investigation of recovery. Such studies are necessary to identify the various social and cultural contexts for recovery in the community (Jenkins, 1997; WHO, 1998; Floersch, 2002;), to include the perspectives of patients/consumers, families, advocacy groups, and service providers (Davidson & Strauss, 1992; Salokangas, 1997; Jenkins & Schumacher, 1999; Tohen 2000; Jacobson, 2001a, 2001b; Markowitz, 2001; Turner-Crowson & Wallcraft, 2002; Corring, 2002; Meddings & Perkins, 2002).

In the last two decades, pharmacological treatment through 'atypical' antipsychotic medications has led to reduction of both symptoms and extrapyramidal effects compared to conventional medications (Awad & Hogan, 1994; Weiden *et al.* 1996; Andersson *et al.*, 1998; Rosenheck *et al.*, 1998; Breier *et al.*, 2000; Dinakar *et al.*, 2002; Lieberman *et al.*, 2003). Andersson *et al.* summarize evidence that atypical drugs are used efficaciously with previously treatment-refractory patients and recent onset patients such that 'use of atypical antipsychotics as a first line treatment may result in better long-term clinical outcome' (Andersson *et al.*, 1998). While use of atypical medications among treatment refractory patients may be associated with symptom reduction and participation in psychosocial rehabilitation treatments in the case of clozapine (Rosenheck *et al.*, 1998), these effects have yet to be demonstrated in the case of other atypicals. It may be that the atypical agents are associated with greater patient satisfaction due to fewer extrapyramidal symptoms, reduced relapse, and, perhaps cognitive functioning (Awad & Hogan, 1994; Weiden *et al.*, 1996; Andersson, Chakos, Mailman, *et al.*, 1998; Rosenheck, *et al.*, 1998; Breier *et al.*, 2000; Lieberman *et al.*, 2003). At present, the literature is unclear whether atypicals are better than conventional antipsychotics (Velligan, *et al.*, 2003).

Our research group aimed to investigate the subjective experience of improvement and recovery processes as outlined by the U.S. Commission in social contexts of everyday life in the community from the vantage point of persons taking atypical antipsychotic medications (Hogan & Awad, 1992; Budd *et al.*, 1996; Cuffel *et al.*, 1996). This paper serves as background to more fully anthropological analyses to follow.

METHODS

Sample selection

The research project, 'Subjective Experience and the Culture of Recovery with Atypical Antipsychotics' (SEACORA), is a study of persons ($N = 90$) with schizophrenia-related disorders according to research diagnostic criteria. Data collection was carried out September 1999–June 2002. All research participants were taking atypical antipsychotic medications, the majority of whom had been designated as previously treatment refractory in relation to other antipsychotic drugs; however, some subjects ($N = 6$) were prescribed atypical antipsychotic drugs as their first psychopharmacological treatment.

Subject selection criteria included:

(1) diagnosis of schizophrenia or schizo-affective disorder assessed through the Structured Clinical Interview for DSM-IV (SCID) (First *et al.*, 2002);
(2) age 18–55;
(3) at least two years since first psychotic symptoms;
(4) at least six months of treatment with an atypical antipsychotic;
(5) absence of co-morbid 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 US 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 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 inclusion criteria (167 subjects), 90 (54%) of those selected were included in the final sample, with 46.7% of these subjects refusing 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 refuse participation (Fisher's Exact, $p < .001$). Reasons for non-participation included a general lack of interest in research (stating simply they 'didn't 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, functional or likely to have had a positive experience with medication or their clinical providers than those in the group who declined research participation.

Procedures

The subjective experience of schizophrenia was studied though ethnographic interviewing and observations, and questionnaires. The primary qualitative interview developed for the current study on the basis of prior research (Jenkins, 1997) was designed to obtain narrative data using a semi-structured, open-ended anthropological interview guide, the Subjective Experience of Medication Interview (SEMI). The SEMI inquires into the experience of medication and treatment, living situation, everyday activities, illness management, social relations, gender identity, stigma, and expectations concerning recovery and quality of life. The duration of these interviews was generally 1.5–2 hours over 1–3 interview sessions. The expanded 24 item Brief Psychiatric Ratings Scale (BPRS) for symptom severity (Overall & Gorham, 1962), along with other procedures to include the Ratings of Medication Influence (Weiden *et al.*, 1994; the Scale for the Assessment of Negative Symptoms (SANS) (Andreasen, 1989) and the Bem Sex Role Inventory (Bem, 1974), and ethnographic naturalistic observations of clinic, community, and home settings.

The data in this article include the sociodemographic and clinical characteristics of the sample and SEMI data for subjectively perceived improvement and recovery. All SEMI interviews were transcribed verbatim from audiotape and entered into a qualitative software program, Atlas.ti (Scientific Software Development, 1997), to code and analyze qualitative data systematically (Good, 1994; Luborsky, 1993).

Coding of improvement through medication

Subjectively improved status on the basis of medication was determined in response to the following SEMI questions: 'Did you take other medication before? What is the difference between that medication and what you're taking now?' Responses to these questions were coded in relation to the difference between previous and current medications. When no response could be determined from these specific questions, transcripts were reviewed for spontaneous statements of comparison between previous and current medication. Cases in which no response could be determined were coded as missing data. All individual responses were coded according to the following rules:

(1) has the subject been treated with older neuroleptic medication? If the subject has had atypical antipsychotic medication as the only course of treatment, there is no basis for comparison and that individual is not included in this assessment;

(2) if coded affirmatively, does the subject articulate a difference between previous and current (atypical) medication? If the subject does not articulate an improvement or change between previous and current medication, this constitutes no improvement; and

(3) does the subject describe atypical antipsychotics as better than previous medications? Responses to this question were coded as yes, no, or ambiguous. Responses were coded as ambiguous in the case of contradiction, when a response was highly qualified, or a 'don't know'.

Inter-rater reliability was good ($\kappa = .69$) for the coding schema above. One pair of raters independently coded 20 randomly selected responses.

Coding of improvement through personal power and control
Subjectively perceived personal power and control was addressed in relation to the following interview question: 'Do you have any power or control over your illness?' Responses were coded affirmatively or negatively. Qualified responses that indicated some degree of control over illness were coded affirmatively. Inter-rater reliability was very good ($\kappa = .88$) for the coding schema above. One pair of raters independently coded 20 randomly selected responses.

RESULTS

Descriptive sociodemographic and clinical characteristics
Table 1 presents sociodemographic characteristics ($N = 90$). The sample consisted of 49 (54.4%) men and 41 (45.6%) women. The majority (77.8%) were Euro-American and 22.2% African-American. The mean age was 40.7 ($SD = 7.9$). The mean number of years of education was 13.0 ($SD = 1.9$). On the basis of an independent-sample t-test, men ($M \pm SD = 13.4 \pm 2.2$) had more years of education than women ($M \pm SD = 12.6 \pm 1.6$; $t = 2.00$, $df = 86.6$, $p < .05$). While the vast majority (84.4% of sample overall) had never married, significantly more men (95.9%) than women (70.7%) had never married (Fisher's Exact, $p < .01$). Relatedly, while most (42.2%) lived with a relative or parent, more women (19.5%) than men (2.0%) lived with a partner/spouse (Fisher's Exact, $p < .01$). In addition, 17.8% had children, with more women (36.6%) than men (2.0%) having children (Fisher's Exact, $p < .001$). Overall, 40% was working either half or full time. In addition to these income producing activities, 29 (32.2%) were engaged in volunteer activities (e.g. a nursing home), 10 (11.1%) in educational activities (e.g. college or vocational courses), and 20 (22.2%) in caretaking of a family member. Besides the 6% of the sample who were in marital situations, 20 (23.5%) were in a dating relationship, and approximately one-half (55.1%) of participants report satisfaction in the domain of social relations with friends.

As calculated by the Hollingshead index of social status (Unpublished manuscript), there was a full range of background by class. These social class designations were representative of the clientele of the two mental health sites for subject recruitment. Although there were no significant differences in socioeconomic status by gender, more men (36.7%) than women (22.0%) were in upper socioeconomic classes (Classes I–II). There were no significant differences in socioeconomic status by ethnicity.

Table 2 shows clinical characteristics. The majority (81.1%) were diagnosed with schizophrenia, 18.9% diagnosed with schizo-affective disorder. The mean age at onset was 20.6 ($SD = 7.3$). As often found in the literature (Goldstein, 1988; Seeman, 1995), an independent-sample t-test showed that women ($M \pm SD = 22.6 \pm 9.1$) had a later age of onset than men ($M \pm S = 18.9 \pm 4.9$; $t = -2.34$, $df = 88$, $p < .02$). The mean years ill was 20.1 ($SD = 8.4$). The mean number of admissions was 7.0 ($SD = 7.0$). The mean length of outpatient treatment, defined as the length of treatment at current clinical site, was 7.6 years ($SD = 4.5$). An independent-sample t-test showed that Euro-Americans ($M \pm SD = 8.1 \pm 4.5$) had been in outpatient treatment significantly longer than African-Americans ($M \pm SD = 5.8 \pm 4.0$; $t = 2.0$, $df = 88$, $p < .05$). There were no other significant differences by gender or ethnicity. The majority (56.7%) were taking clozapine as their current atypical antipsychotic medication.

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 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*		
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
Working situation*		
Not working	54	60.0
Half time or less (< 20 hours)	20	22.2
Half to full-time (20+ hours)	16	17.8
Hollingshead 4-Factor SES**		
Class I	8	8.9
Class II	19	21.1
Class III	39	43.3
Class IV	23	25.6
Class V	1	1.1

* Due to rounding, percent may not equal 100
** From highest (I) to lowest (V)

The other subjects were taking risperidone (17.8%), olanzapine (16.7%), or other (8.9%) atypical medications. The mean duration of treatment with atypical antipsychotics for the sample overall was 6.9 years ($SD \pm 4.1$). Duration of treatment with atypicals ranged from a minimum of 6 months to a maximum of 15 years.

Finally, BPRS scores show relatively low levels of symptomatology in the sample overall. Confirmatory factor analysis suggests a five-factor structure in samples of persons with long-standing schizophrenia, such as this one (Burger *et al*, 1997). Scores on each factor were divided by the number of items constituting each variable to place all scores on the same scale of measurement. The factors are thought disorder (five items to include grandiosity, hallucinations, unusual thought content, conceptual disorganization, bizarre behavior), anxiety/depression (five items to include somatic concerns, anxiety, depression, guilt, suicidality),

Table 2
Clinical characteristics of SEACORA participants ($N = 90$)

	Number	**Percent (%)***
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 **		
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	$M \pm SD$	
Thought disorder	1.9 ± .88	
Withdrawal	1.9 ± .54	
Anxiety/depression	2.4 ± 1.0	
Hostility/suspicion	1.7 ± .65	
Activity	1.2 ± .32	

* Due to rounding, percent may not equal 100
** Length of treatment at current clinical site

activity (five items to include tension, excitement, mannerisms and posturing, distractibility, motor hyperactivity), hostility/suspicion (three items to include hostility, suspiciousness, uncooperativeness), and withdrawal (six items to include disorientation, blunted affect, emotional withdrawal, motor retardation, elevated mood, and self-neglect). The level of symptomatology in this sample was quite low; the five factor scores ranged from 1.23 (activity) to 2.09 (anxiety/depression). As depicted in Table 2, mean scores for BPRS factors were as follows: thought disorder ($M \pm SD = 1.9 \pm .88$); withdrawal ($M \pm SD = 1.9 \pm .54$); anxiety/depression ($M \pm SD = 2.4 \pm 1.0$); hostility/suspicion ($M \pm SD = 1.7 \pm .65$); and activity ($M \pm SD = 1.2 \pm .32$). On the basis of an independent-sample t-test, men had significantly greater thought disorder ($M \pm SD = 2.1 \pm .95$) than women ($M \pm SD = 1.7 \pm .75$) ($t = 2.16$, $df = 86.9$, $p < .04$).

Given the possibility of specific findings in relation to antipsychotic medications (Awad & Hogan, 1994; Weiden *et al.*, 1996; Andersson *et al.*, 1998; Rosenheck *et al.*, 1998), we investigated whether any differences could be observed for subjects treated with clozapine compared with all other atypical antipsychotics, and significant differences were noted with respect to symptomatology. Based on independent-sample t-tests, subjects taking clozapine

had significantly lower scores for three BPRS factors: individuals taking clozapine had significantly lower thought disorder scores ($M \pm SD = 1.76 \pm .80$) than individuals not taking clozapine ($M \pm SD = 2.17 \pm .94$) ($t = -2.23$, $df = 87$, $p < .03$); individuals taking clozapine had significantly lower anxiety/depression scores ($M \pm SD = 2.05 \pm .86$) than individuals not taking clozapine ($M \pm SD = 1.05 \pm .17$) ($t = -3.44$, $df = 87$, $p < .002$); individuals taking clozapine had significantly lower hostility/suspicion scores ($M \pm SD = 1.45 \pm .55$) than other atypicals ($M \pm SD = 1.91 \pm .69$) ($t = -3.50$, $df = 87$, $p < .002$).

Improvement through medication

Table 3 illustrates that of the 84 participants taking atypicals after having taken older neuroleptics, 77.4% indicated improvement on atypicals, 10.7% indicated no improvement, and 8.3% were ambiguous. Of the six individuals who had received atypical antipsychotics as their initial treatment and thus had no basis for comparison between older neuroleptics and atypical antipsychotics, five (83.3%) indicated they felt the atypical medications were helping. There were no significant differences in reported improvement in relation to clinical (including type of atypical) or sociodemographic characteristics. While the African-American sub-sample is not large, there is a tendency within that group for African-Americans to be slightly more likely to report improvement through medications relative to the Euro-Americans.

Overall, participants did widely endorse their subjective sense of the critical role of medications in contributing to improvement. Indeed, it is clear that medication subjectively occupies the most prominent role in the incremental process of recovery as illustrated in a narrative that invokes metaphor to convey the subjective effect of the medication as:

> A mental dam that stops the flow of schizophrenia . . . The most important thing is finding the right medication that starts to interact with the illness. And it just takes a long time. (quote from study participant)

Table 3
Improvement with changeover to atypical antipsychotic medications ($N = 81$)*

	No Improvement		Ambiguous		Improvement**	
	N	%	N	%	N	%
All participants	9	11.1	7	8.6	65	80.3
Male ($N = 45$)	6	13.3	2	4.4	37	82.2
Female ($N = 36$)	3	8.3	5	13.9	28	77.8
Euro-American ($N = 64$)	8	12.5	7	10.9	49	76.6
African-American ($N = 17$)	1	5.9	0	0.0	16	94.1
Schizophremia ($N = 68$)	8	11.8	5	7.4	55	80.9
Schizo-affect ($N = 13$)	1	7.7	2	15.4	10	76.9

* 84 subjects took atypical antipsychotics after switching from older neuroleptics. 3 (3.6%) responses insufficient to code. For subjects taking atypicals as initial medication ($N = 6$), 5 reported symptom improvement vs. pre-medicated states
** No significant differences by sociodemographic or clinical characteristics

This process of trying a series of medications until the current point of relative satisfaction was typical since most had struggled with their illness for two decades ($M \pm SD = 20.1 \pm 8.4$). In this context, a subjective sense of recovery is experienced relative to the severity of the illness at an earlier time in one's life; an important narrative feature of recovery is to relativize one's condition now compared to a far worse situation in the past.

Improvement and side effects

While the data clearly indicate that a majority (77.4%) of individuals in the sample subjectively perceived improvement as a result of treatment with atypical antipsychotic medication, 90.8% of those reporting improvement also report one or more disturbing side effects that they attribute to atypicals. As depicted in Table 4, individuals reported their perception of the most troubling side effect resulting from treatment with atypical antipsychotic medication. The three most commonly reported side effects perceived to be the worst in the sample overall were weight gain (18.2%), drooling (17.0%), and tiredness/drowsiness (17.0%). Patients taking clozapine (28.0%) were significantly more likely than patients taking other atypical antipsychotics (2.6%) to report drooling as their perceived most troubling side effect (Fisher's Exact, $p < .001$). Quite noteworthy are reports of no troubling side effects. In fact, 19.3% of the sample declined to cite a 'worst side effect'. This observation supports our sense that this table under-reports troubling side effects perhaps in relation to (a) gratitude for meds for symptom control (b) relative to typical antipsychotics they had been taking, they considered that they had relatively fewer troubling side effects, and thus deemed atypicals as 'better' in relation to improvement.

The fact that such an overwhelming majority report serious side effects points to a crucial dilemma of lived experience of the atypical medications, that is, while most persons in the study are tenacious in their conviction of the necessity to take these medications to avoid symptom exacerbation and hospitalization, they nonetheless evince considerable ambivalence and contradiction surrounding this predicament. While the atypical antipsychotic

Table 4
Rank-order of most troubling side effect

	Overall $N = 88$ (%)	Cloz. $N = 50$ (%)	Other atyp. $N = 38$ (%)
Weight gain	18.2	16.0	21.1
Drooling	17.0	28.0[†]	2.6
Tiredness/drowsiness	17.0	16.0	18.4
Tremors/stiffness	10.2	6.0	15.8
Sexual dysfunction	5.7	6.0	5.3
Anxiety/fear	5.7	6.0	5.3
Gastrointestinal	3.4	2.0	5.3
Blood draws	3.4	6.0	0.0
None	19.3	14.0	26.3

$N < 90$ due to non-response
[†] Drooling reported significantly more for clozapine patients (Fisher's Exact, $p < .001$)
May not equal 100% due to rounding; no sig. differences by sociodemographic or clinical variables

drugs are generally associated with a more benign adverse effect profile compared to the older neuroleptic agents, other adverse effects such as weight gain, hyperprolactinemia, glucose dysregulation and prolonged QTc interval remain problematic for some patients (Mortimer, 2003). This is an important issue for an effective recovery process to include attention to individual perception of adverse effects.

Improvement through personal power and control

Despite the subjective salience of medication in the recovery process, participants emphasized that medication could not do all the 'work of recovery'. Analysis of the narrative data surrounding personal power and control (Table 5) revealed that 51.1% subjectively experienced having the capacity or will to struggle against the effects of illness. Individuals who felt they had a cultural sense of 'personal power and control' in relation to the illness underscored that while medications have allowed them to make great improvements in reducing illness symptoms, they needed not only to rely on medications but also to do personal 'work' as crucial to improvement and recovery (Strauss & Carpenter, 1977; Davidson, 2003). The psychocultural work required for recovery is evident in the following statement:

> I don't think it's easy for anybody, you know. Somebody said it's a full time job, you know, living with it, and I agree with that. You have to be working at it all the time.

An example of the 'work of recovery' came in response to the interview question 'What can't medications do?', as reported by a participant concerned with individual effort and the doctor-patient relationship:

> Well, you have to have a lot of responsibility for yourself, too, because there's nobody there watching you take it. And that tells you something – they know that they're trusting you.

In this and other narrative SEMI materials obtained, the role of sustained personal effort was often inexorably linked to social engagement, that is, personal efforts were contingent on engagement in social relations.

Table 5
Personal power and control over illness (N = 90)

	N	%*
All participants	46	51.1
Male	28	57.1
Females	18	43.9
Euro-American	36	51.4
African-American	10	50.0
Schizophrenia	39	53.4
Schizo-affective	7	41.2

* No significant differences by sociodemographic or clinical characteristics

Recovery as incremental process of improvement

Overall, subjectively perceived improvement and recovery in relation to the metaphor of 'awakenings' was endorsed by only a minority of the SEACORA sample, who likewise noted that such states were transitory. In either case, nearly all participants agreed that illness management and improvement were gradual processes. They acknowledged occasional relapses and set-backs as inherent to this process. Nevertheless, when participants were also asked whether they expected the course of their illness to get better, stay the same, or get worse, the majority (80%) fully expected an improved course of illness. When asked whether they expected their lives to get better, worse, or stay the same, a majority (70.6%) likewise conveyed that they expected their lives to get better. The remainder expected their illness to stay the same (14.1%) and that their lives would likewise similarly stay the same (25.9%). Only a fraction expected their illness would actually get worse (5.9%) and that their lives would deteriorate (3.5%).

Incremental recovery is defined as a process of improvement occurring gradually, experienced *subjectively* in temporal terms of days, months, and even years. An example of the subjective sense of getting better on a daily basis through taking medication came in response to the SEMI question, 'Do you think you're getting better?'

> Oh, definitely. I think a day doesn't go by without my getting a little bit better. That's the nice thing about Clozaril. You do improve over time, you know, if you continue to take it. I take it religiously.

Another narrative example of the difficulty of recovery, particularly when compared to a previously severe and continuously present illness, is the following:

> I'm doing much better than I was (before), yeah. Finally. It was a long time coming. It was hard, hard as hell. I mean, I don't expect hell to be that hard. You know, that tough to stand. And it was just nonstop from the second I woke up to the second I went to bed. So it was really a nightmare.

Taken together with expectable set-backs, this subjective process is not experienced as a progression that necessarily proceeds in linear fashion. In sum, the overall quality of self-perceived recovery can be characterized as a slow, incremental, but definitively discernable subjective process of improvement and recovery.

DISCUSSION

Among this sample ($N = 90$) of community residents taking atypical antipsychotic medications for schizophrenia-related conditions, the level of observed symptomatology was relatively low compared with similarly constituted samples who were taking conventional neuroleptics (Jenkins, 1997; Karno *et al*., 1987) and particularly when compared with participants' own subjective assessment of their symptom levels prior to taking atypical antipsychotic medications. This finding for improvement in symptomatology in relation to the atypicals has been reported elsewhere on the basis of psychiatric ratings of symptomatology

(Breier *et al.*, 2000; Dinakar *et al.*, 2002). However, this is the first study to do so systematically utilizing a large community sample from the perspective of patients themselves based on narrative data of subjective experience. Factors associated with relatively better course of illness (age of onset, schizo-affective diagnosis, social functioning to include marriage, children, and family residence) among women (Goldstein, 1988; Seeman, 1995) were likewise observed in this study. The finding for lower BPRS scores on three factor scores among those taking clozapine compared with all other atypicals may suggest that treatment-refractory patients' symptomatic improvement is even more observable for those taking clozapine.

The observation that 40% worked in half or full time employment can be taken as an indicator of improvement; however, the fact that the majority of the sample was not employed may indicate either that most were actually unable to work in income-producing jobs or that appropriate employment was not available to them. This latter possibility may be due to financial restrictions placed on persons working (who may forfeit disability and other governmental assistance necessary to pay for prescribed medications). In addition, as noted by several in the study, supportive employment that is geared to diverse levels of functioning is often unavailable.

Analysis of narrative data reveals that participants' experience of improvement was observable as an *incremental yet definitively discernable subjective process*. This incremental process is one of improvement in both expected course of illness and own's life more generally. Similarly noteworthy was the small fraction who expected their illness would actually get worse or that their lives would deteriorate. This is a striking finding in a sample of previously severely ill persons, calling into question early clinical characterizations of schizophrenia as invariably chronic and degenerative (Kraepelin, 1919). These expectations for improvement are likely due in part to the perceived efficacy of the atypical medications, on the one hand, and to American cultural and ethnopsychological orientations that highlight optimism and forward-moving progression of the individual, on the other (Shweder & Bourne, 1984; Chang, 2001). The results must be interpreted also, however, in relation to relatively 'advantaged' persons compared to their counterparts with fewer economic, social, and treatment resources. In addition, this sample reported being fairly regular in taking medication and might not be similar to those who either do not take medication regularly or have not had as positive an experience relative to this sample. Within this data set, however, there were no differences between the middle and upper class subjects and those of lower socioeconomic status with respect to positive regard for their medication. Nevertheless, limitations of the present study include the following:

(1) potentially limited application beyond Euro-American, African-American, poor social resources, homelessness, or substance abuse;
(2) research subjects who agreed to participate may have had a better experience with medication and providers, leaving poorer responders understudied;
(3) while there is utility in comparing heterogeneous second-generation atypicals, the large number of treatment-refractory patients taking clozapine in this sample may have had distinctive illness histories;
(4) the limited involvement in psychotherapy and non-pharmacologic treatments may have contributed to a subjective emphasis on medications; and

(5) family perspectives not captured in the present study which focused rather on patients' perspectives.

Given these limitations, our findings allow us to demonstrate that, from patients' perspectives, incremental improvement and recovery are subjectively discernable. This is significant given the history of psychiatry that has tended to conceptualize schizophrenia as an inherently chronic, degenerative condition. Also, the incremental improvement was considered by the patients to have been due primarily to the effects of the atypical antipsychotic medications. While there were no significant differences by gender or ethnicity in the extent to which subjects 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%). This suggests the future relevance of investigating further the subjective experience of medications in relation to ethnicity and social class.

The finding for improvement and recovery in relation to personal power and control was split relatively evenly insofar as 51.1% affirmed that they had personal power and control in relation to the illness whereas 48.9% did not. This is a complex with various possibilities. For example, one may consider that they have personal power and control conferred to them by taking the medications or conversely that they have no personal power or control because they are taking medications that have effects independent of anything that they might think or do. We are inclined to think that the cultural sense that one has no personal power or control over the illness is problematic insofar as such a stance may discourage active strategies for improvement and recovery (Deegan, 1988; Hogarty, 2002), resigning oneself to the prospect of having a 'broken brain' about which one can do nothing, on the one hand, yet alleviating unhelpful personal and familial guilt about etiology and course of illness, on the other. Yet another critical consideration for interpretation of these findings is an American culturally specific orientation that from a cross-cultural perspective might be hypothesized as relatively 'high' in relation to the notion of 'personal power and control'. In other societies, religious and supernatural orientations might be expected to be vital to the process of recovery and the idea that individuals would figure prominently into recovery from illness might appear strange. A leading cultural theorist (Geertz, 1984) makes this point broadly:

> The Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgement, and action organized into a distinctive whole and set contrastively both against other such wholes and against a social and natural background is, however incorrigible it may seem to us, a rather peculiar idea within the context of the world's cultures. (p. 126)

Understanding the finding for the role of personal power and control in this American sample as a cultural matter highlights the necessity of providing integrated care for schizophrenia to combine culturally competent psychosocial and pharmacological interventions (Hogarty, 2002; Lenroot *et al.*, 2003). While at present there are insufficient studies available to state with confidence that the research participants in this sample are broadly representative of those taking atypical antipsychotics, it is clear that other studies have likewise reported

patients' positive regard for atypicals in the case of clozapine despite adverse experiences (Waserman & Criollo, 2000) and that a combined approach toward services and treatment is in order (Hogarty, 2002; Mueser *et al.*, 2002; Davidson, 2003; Lenroot *et al.*, 2003).

CONCLUSION

In this community study of persons with schizophrenia and schizo-affective disorders taking atypical antipsychotics, the vast majority articulated their subjective sense of improvement and recovery from their illness. The overall quality of improvement and recovery is best characterized as an incremental, yet definitively discernable subjective process. The study of incremental recovery thus constitutes a critical area for empirical investigation that takes into account the subjective experience of processes of improvement according to systematically collected narrative materials.

In this article, incremental processes of improvement were examined in relation to the subjective sense of the critical role that taking medications plays in managing symptoms and avoiding hospitalization. In sum, improvement and recovery from persistent and severe mental disorders occur in the complex context of interlocking personal, cultural, social, economic, and pharmacological effects (Waserman & Criollo, 2000; Dinakar *et al.*, 2002; Lenroot *et al.*, 2003; Jenkins & Barrett, 2004; Sajatovic *et al.*, 2005). The complexity of these relations as a matter of subjectivity suggests the theoretical and methodological requirement to specify these processes more fully through in-depth qualitative approaches that can complement standardized scalar techniques of investigation (Davidson, 2003). Such a complementary approach can contribute to the development of new strategies for treatment, prevention, and community management of schizophrenia in line with the subjectively determined preferences and goals of persons struggling to recover and to live ordinary lives under extraordinary circumstances (Jenkins, 2004).

ACKNOWLEDGEMENT

REFERENCES

ANDERSSON, C., CHAKOS, M., MAILMAN, R. & LIEBERMAN, J. (1998) Emerging roles for novel antipsychotic medications in the treatment of schizophrenia. *Psychiatric Clinics of North America*, **21**, 151–179.
ANDREASEN, N.C. (1989) The scale for the assessment of negative symptoms (SANS): conceptual and theoretical foundations. *British Journal of Psychiatry*, **155**, 49–52.

AWAD, A.G. & HOGAN, T.P. (1994) Subjective response to neuroleptics and the quality of life: implications for treatment outcome. *Acta Psychiatrica Scandinavica*, **89**, 27–32.

BEM, S.L. (1974) The measurement of psychological androgyny. *Consulting & Clinical Psychology*, **42**, 155–162.

BREIER, A., BUCHANAN, R.W., IRISH, D. & CARPENTER, W.T. (2000) Clozapine treatment of out-patients with schizophrenia: outcome and long-term response patterns. *Psychiatric Services*, **51**, 1249–1253.

BUDD, R.J.H., IAN, C.T., & SMITH, J.A. (1996) Health beliefs and compliance with antipsychotic medication. *British Journal of Clinical Psychology*, **35**, 393–397.

BURGER, G.K., CALSYN, R.J., MORSE, G.A., KLINKENBERG, W.D. & TRUSTY, M.L. (1997) Factor structure of the expanded brief psychiatric rating scale. *Journal of Clinical Psychology*, **53**, 451–454.

CHANG, E.C. (Ed.) (2001) *Optimism and Pessimism: Implications for Theory, Research, and Practice*. Washington, DC: American Psychological Association.

COMMISSION ON MENTAL HEALTH (2003) Achieving the Promise: Transforming Mental Health Care in America. Executive Summary. DHHS Pub. No. SMA-03-3831. Rockville, MD: DHHS.

CORRING, D. (2002) Quality of life: perspectives of people with mental illnesses and family members. *Psychiatric Rehabilitation Journal*, **25**, 350–358.

COVELL, N.H., FRISMAN, L.K. & ESSOCK, S.M. (2003). Rates of refusal to participate in research studies among men and women. *Psychiatric Services*, **54**, 1541–1544.

CUFFEL, B.J., ALFORD, J., FISCHER, E.P. & OWEN, R.R. (1996) Awareness of illness in schizophrenia and outpatient treatment adherence. *Journal of Nervous Mental and Disease*, **184**, 653–659.

DAVIDSON, L. (2003) *Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia*. New York: New York University Press.

DAVIDSON, L. & STRAUSS, J.S. (1992) Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, **65**(2),131–145.

DAVIDSON, L., STAYNER, D.A., NICKOU, C., STYRON, T., ROWE, M. & CHINMAN, M. (2001) 'Simply to be let in': inclusion as a basis for recovery. *Psychiatric Rehabilitation Journal*, **24**, 375–388.

DEEGAN, P.E. (1988) Recovery: the lived experience of rehabilitation. *Psychosocial Rehabilitation*, **11**, 11–19.

DINAKAR, H., SOBEL, R., BOPP, J.H., DANIELS, A. & MAURO, S. (2002) Efficacy of olanzapine and risperidone for treatment-refractory schizophrenia among long-stay state hospital patients. *Psychiatric Services*, **53**, 755–757.

FIRST, M.B., SPITZER, R.L., GIBBON, M. & WILLIAMS, J.B.W. (2002) *Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Research Version, Patient Edition. (SCID-I/P)* New York: Biometrics Research, New York State Psychiatric Institute.

FLOERSCH, J. (2002) *Meds, Money, and Manners: The Case Management of Mental Illness*. New York: Columbia University Press.

FRESE, F.J. (2001) Integrating evidence-based practices and the recovery model. *Psychiatric Services*, **52**, 1462–1468.

GEERTZ, C. (1984) On the nature of anthropological understanding. In *Culture Theory: Essays on Mind, Self, and Emotion*. (eds. R.A. Shweder & R.A. LeVine). Cambridge: Cambridge University Press.

GOLDSTEIN, J.M. (1988) Gender differences in the course of schizophrenia. *American Journal of Psychiatry*, **145**, 684–689.

GOOD, B.J. (1994) *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge and New York: Cambridge University Press.

HARRISON, G., HOPPER, K., CRAIG, T., LASKA, E., SIEGAL, C. & WANDERLING, J. (2001) Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry*, **178**, 506–517.

HOGAN, T.P. & AWAD, A.G. (1992) A self-report scale predictive of drug compliance in schizophrenics: a re-examination comparing two measures. *Psychological Medicine*, **22**, 347–352.

HOGARTY, G. (2002) *Personal Therapy for Schizophrenia and Related Disorders: A Guide to Individualized Treatment*. New York: Guilford Press.

HOLLINGSHEAD, A. (n.d) *Four Factor Index of Social Status*. Yale University, Department of Sociology, New Haven: Unpublished manuscript.

HOPPER, K. (2004) Interrogating the meaning of 'culture' in WHO international studies of schizophrenia. In *Schizophrenia, Culture, and Subjectivity: The Edge of Experience* (eds. J.H. Jenkins & R.J. Barrett). New York: Cambridge University Press.

JACOBSON, N. (2001a) Experiencing recovery: a dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal*, **24**, 248–256.

JACOBSON, N. (2001b) What is recovery? A conceptual model and explication. *Psychiatric Services*, **52**, 482–485.

JENKINS, J.H. (1988) Ethnopsychiatric interpretations of schizophrenic illness: the problem of nervios within Mexican-American families. *Culture, Medicine and Psychiatry*, **12**, 301–329.

JENKINS, J.H. (1997) Subjective experience of persistent psychiatric disorder: schizophrenia and depression among U.S. Latinos and Euro-Americans. *British Journal of Psychiatry*, **170**, 20–25.

JENKINS, J.H. (2004) Schizophrenia as a paradigm case for understanding fundamental human processes. In *Schizophrenia, Culture, and Subjectivity: The Edge of Experience*. (eds. J.H. Jenkins & R.J. Barrett). New York: Cambridge University Press.

JENKINS, J.H. & BARRETT, R.J. (2004) (eds.) *Schizophrenia, Culture, and Subjectivity: The Edge of Experience*. New York: Cambridge University Press.

JENKINS, J.H. & KARNO, M. (1992) The meaning of 'expressed emotion': theoretical issues raised by cross-cultural research. *American Journal of Psychiatry*, **149**, 9–21.

JENKINS, J.H. & SCHUMACKER, J.G. (1999) Family burden of schizophrenia and depressive illness: specifying the effects of ethnicity, gender, and social ecology. *British Journal of Psychiatry*, **174**, 31–38.

KARNO, M. JENKINS, J.H., DE LA SELVA, A., SANTANA, F., TELLES, C. & LOPEZ, S. (1987) Expressed emotion and schizophrenic outcome among Mexican-American families. *Journal of Nervous and Mental Disorders*, **175**, 143–151.

KLEINMAN, A. (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.

KRAEPELIN, E. (1919) *Dementia Praecox and Paraphrenia*. Edinburgh: E. & S. Livingstone.

LEFF, J. & VAUGHN, C. (1985) *Expressed Emotion in Families*. New York: Guilford Press.

LENROOT, R., BUSTILLO, J.R., LAURIELLO, J. & KEITH, S.J. (2003) Integration of care: Integrated treatment of schizophrenia. *Psychiatric Services*, **54**, 1499–1507.

LIBERMAN, R.P., KOPELOWICZ, A., VENTURA, J. & GUTKIND, D. (2002) Operational criteria and factors related to recovery from schizophrenia. *International Review of Psychiatry*, **14**, 256–272.

LIEBERMAN, J.A., TOLLEFSON, J.A., TOHEN, M. GREEN, A.I., GUR, R.E. & KAHN, R. (2003) Comparative Efficacy of Atypical and Conventional Antipsychotic Drugs in First-Episode Psychosis: a Randomized, Double-Blind Trial of Olanzapine versus Haloperidol. *American Journal of Psychiatry*, **160**, 1396–1404.

LIN, M. & KLEINMAN, A. (1988) Psychopathology and clinical course of schizophrenia: a cross-cultural perspective. *Schizophrenia Bulletin*, **4**, 555–567.

LUBORSKY, M.R. (1993) The identification and analysis of themes and patterns. In *Qualitative Methods in Aging Research*. (ed. J. Gubrium & A. Snakar). New York: Sage Publications.

MARKOWITZ, F. (2001) Modelling processes in recovery from mental illness: relationships between symptoms, life satisfaction, and self-concept. *Journal of Health and Social Behavior*, **42**, 64–79.

MEDDINGS, S. & PERKINS, S. (2002) What 'getting better' means to staff and users of a rehabilitation service: an exploratory study. *Journal of Mental Health*, **11**, 319–325.

MORTIMER, A.M. (2003) Antipsychotic treatment in schizophrenia: atypical options and NICE guidance. *European Psychiatry*, **18**, 209–219.

MUESER, K.T., CORRIGAN, P.W., HILTON, D.W., TANZMAN, B., SCHAUB, A. & GINGERICH, S. (2002) Illness management and recovery: a review of the research. *Psychiatric Services*, **53**, 1272–1284.

NATIONAL INSTITUTE OF HEALTH (2001) *Qualitative methods in health research: Opportunities and considerations in application and review*. Bethesda: NIH.

NOORDSY, D., TORREY, W., MUESER, K., MEAD, S., O'KEEFE, C. & FOX, L. (2002) Recovery from severe mental illness: an intrapersonal and functional outcome definition. *International Review of Psychiatry*, **14**, 318–326.

OVERALL, J.E. & GORHAM, D.R. (1962) The brief psychiatric rating scale. *Psychological Reports*, **10**, 799–812.

RIDGWAY, P. (2001) Restorying psychiatric disability: learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, **24**, 335–343.

ROSENHECK, R., TEKELL, J., PETERS, J., CRAMER, J., FONTANA, A. & XU, W. (1998) Does participation in psychosocial treatment augment the benefit of clozapine? *Archives of General Psychiatry*, **55**, 618–625.

SAJATOVIC, M., JENKINS, J., STRAUSS, M., BUTT, Z. & CARPENTER, E. (2005). Gender identity among men and women with schizophrenia. *Psychiatric Services*, **56**(1), 96–98.

SALOKANGAS, R.K. (1997) Living situation, social network and outcome in schizophrenia: a five-year prospective follow-up study. *Acta Psychiatrica Scandinavica*, **96**, 459–468.

SCIENTIFIC SOFTWARE DEVELOPMENT (1997) ATLAS/ti. Berlin, Germany.

SEEMAN, M. (1995) *Gender and Psychopathology*. Washington, DC: American Psychiatric Press.

SHWEDER, R.A. & BOURNE, E.J. (1984) Does the concept of the person vary cross-culturally? In *Culture Theory: Essays on Mind, Self, and Emotion* (ed. R.A. Shweder & R.A. LeVine). Cambridge: Cambridge University Press.

SPANIOL, L. WEWIORSKI, N.J., GAGNE, C. & ANTHONY, W.A. (2002) The process of recovery from schizophrenia. *International Review of Psychiatry*, **14**, 327–336.

STRAUSS, J.S. & CARPENTER, W.T. (1977) Prediction of outcome in schizophrenia III: five-year outcome and its predictors. *Archives of General Psychiatry*, **34**, 159–163.

TOHEN, M. STRAKOWSKI, S.M. & ZARATE, C. (2000) The McLean-Harvard first-episode project: 6-month symptomatic and functional outcome in affective and nonaffective psychosis. *Biological Psychiatry*, **48**, 467–476.

TORGALSBOEN, A.K. & RUND, B.R. (1998) 'Full recovery' from schizophrenia in the long term: a ten-year follow- up of eight former schizophrenic patients. *Psychiatry*, **61**, 20–34.

TURNER-CROWSON, J. & WALLCRAFT, W. (2002) The recovery vision for mental health services and research: a British perspective. *Psychiatric Rehabilitation Journal*, **25**, 245–254.

VELLIGAN, D.I., LAM, F., ERESHEFSKY, L. & MILLER, A.L. (2003) Psychopharmacology: perspectives on medication adherence and atypical antipsychotic medications. *Psychiatric Services*, **54**, 665–667.

WARNER, R. (1994) *Recovery from Schizophrenia*. New York: Routledge.

WASERMAN, J. & CRIOLLO, M. (2000) Subjective experiences of clozapine treatment by patients with chronic schizophrenia. *Psychiatric Services*, **51**, 666–668.

WEIDEN, P., AQUILA, R., & STANDARD, J. (1996) Atypical antipsychotic drugs and long-term outcome in schizophrenia. *Journal of Clinical Psychiatry*, **57**(Suppl. 11), 53–60.

WEIDEN, P., RAPKIN, B., MOTT, T., *et al.* (1994) Rating of Medication Influences (ROMI) scale in schizophrenia. *Schizophrenia Bulletin*, **20**, 297–310.

WORLD HEALTH ORGANIZATION (1998) *Schizophrenia and Public Health*. Geneva: World Health Organization.

WORLD HEALTH ORGANIZATION (1979) *Schizophrenia: an International Follow-up Study*. Chichester: John Wiley and Sons.

Janis H. Jenkins, PhD, Departments of Anthropology and Psychiatry, Case Western Reserve University, Cleveland, USA.

Milton E. Strauss, PhD, Department of Psychology, Case Western Reserve University, Cleveland, USA.

Elizabeth A. Carpenter, MA, Department of Anthropology, Case Western Reserve University, Cleveland, USA.

Dawn Miller, MA, Department of Anthropology, Case Western Reserve University, Cleveland, OH, USA.

Jerry Floersch, PhD, Mandel School of Social and Applied Sciences, Case Western Reserve University, Cleveland, USA.

Martha Sajatovic, MD, University Hospitals of Cleveland and Case Department of Psychiatry, Cleveland, USA.

Correspondence to Janis H. Jenkins, PhD, Departments of Anthropology and Psychiatry, Case Western Reserve University, 10900 Euclid Avenue, Cleveland, OH, 44106 USA.
Email: jhj4@case.edu