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J H Jenkins

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# Subjective experience of persistent schizophrenia and depression among US Latinos and Euro-Americans

JANIS HUNTER JENKINS

**Background** The aims were to investigate cross-culturally the subjective experience of long-term psychiatric patients to determine whether or not they would define their current life situation predominantly in terms of illness.

**Method** The design is a two-by-two comparison by ethnicity (Latino and Euro-American) and diagnosis (schizophrenia and unipolar depression) of 80 subjects for DSM-III-R criteria according to the SADS. Patients were interviewed using a semi-structured interview (Context of Illness Experience) yielding data coded for qualitative and quantitative analyses.

**Results** While significant ethnic differences were observed, nearly half the sample did not include illness in their description of their life situation. Other domains (e.g. activities, events) and the extent to which patients perceived themselves as in- or out-of-step with the "rhythm of life" were identified as central patient concerns.

**Conclusions** Empirical research on the subjective experiences and representations of the life situation of patients offers clues to the course and treatment of persistent psychiatric disorder.

What can we learn from the study of the subjective experience of mental disorder? The answer is evident in so far as subjectivity is often configured as suffering, and appreciation and alleviation of suffering is our primary objective. Even so, the relevance of subjective patient accounts has seemed far from obvious to clinicians and researchers, for whom subjective experience interferes with scientific objectivity. As psychiatry has increasingly come to be dominated by advances in psychopharmacology, brain localisation and genetics, research on experience, subjectivity and suffering has receded to the periphery.

## RESEARCH ON SUBJECTIVITY

While advocates of the scientific study of subjectivity are rare, it is worth noting two researchers who are exceptional in this regard: Arthur Kleinman and John Strauss. Kleinman (1980) distinguished between suffering conceived as the experiential essence of illness and the social conditions of that suffering (Kleinman, 1995). In this view illness is not the function of an isolated subjectivity, but the product of inter-subjective participation in local moral worlds and macrosocial political processes (Kleinman, 1995). That patients play an active role in shaping the course of illness led Strauss (1994) to a concern with their subjective experience. His work has moved from a conceptualisation of course in terms of patient-environment interaction which maintained a primary interest in the disorder, to a conceptualisation in terms of patient-disorder interaction, with primary interest in the experience – agency, emotion, and enactment of psychological regulatory mechanisms (Strauss, 1989; Strauss & Estroff, 1989).

The subjective experience of mental disorder can serve as a starting point for several research questions. Firstly, subjective experience may offer clues about the course of mental disorder. There are different kinds or dimensions of course, the importance of

which vary depending on the subjective focus of the patient. These include success in social relationships, occupational functioning, symptom level, and forms of distress or suffering. For example, our research and that of others has shown that the construct of 'expressed emotion' (that is, reliably obtained measurements of subjective data on criticism, hostility and over-involvement within the family) is significantly predictive of clinical relapse (Leff & Vaughn, 1985; Karno *et al*, 1987; Jenkins & Karno, 1992; Bebbington & Kuipers, 1994). Secondly, culturally valid psychiatric assessment of subjective data remains critical to diagnosis. The Committee on Culture and Diagnosis for DSM-IV (American Psychiatric Association, 1994) concluded that psychiatric assessment of subjective states should be determined through culturally valid criteria, as outlined in the manual's general cultural formulation and the specific cultural considerations for each individual disorder (Karno & Jenkins, 1997, in press). Thirdly, the relevance of subjective experience is strongly implicit in the recent recognition of the role played by negative symptoms. For example, while a common term such as 'flat affect' may accurately describe expressive behaviour, it may not capture rich variations in experiential dimensions of emotional life across persons and cultures (Kring *et al*, 1993; Jenkins, 1994). The research of Corin (1990) has demonstrated that social withdrawal may be negative when subjectively experienced as exclusion, but positive when experienced as protective detachment. Finally, the afflicted person is not identical with the disorder. The development and onset of disease processes are shaped by the active engagement of the person (Strauss, 1989) in a cultural milieu (Kleinman, 1988a).

There are several conceptual and methodological challenges for a scientific study of subjectivity. First is the problem of cultural validity, that is, the issue of whether particular research constructs (e.g. the diagnostic categories of schizophrenia and major depression) and instruments can be meaningfully employed across cultural contexts. Although such concerns may dissuade some from comparative work, others have argued that it is important to put such constructs as schizophrenia to the test to determine their validity in particular cultural contexts (Good, 1992). This problem of cultural validity is not, however, unique to cross-cultural studies of subjectivity but is of general relevance in psychiatric research (Kleinman, 1988a). A

second problem concerns how subjectivity may be manifested. The cultural meanings of 'psychological' and 'somatic' presentation may vary. Thus, some cultural groups (or genders) may tend to express distress with emotion words as opposed to somatic complaints. Thirdly, the accounts of subjective experience and interpretations of those accounts are both variable. Patient accounts are often subject to revision both over time and across situations. Interpretation can be carried out according to a number of varieties of narrative analysis (Good, 1994), each predicated on a conceptualisation of the relation between experience and the representation of that experience.

This paper reports on empirical findings for one domain of subjectivity, patients' representations of their everyday life experience. Questions addressed are: (a) to what extent does characterising one's life situation in terms of illness organise one's experience? (b) Does this organisation of experience appear to vary in relation to culture and type of major mental disorder?

## METHOD

### Sociocultural factors and persistent mental disorder

The data reported here are part of a five-year National Institute of Mental Health (NIMH) study consisting of ethnographic interviews and observations carried out in the homes and communities of psychiatric out-patients. The purpose of the study is to examine relationships among psychosocial and cultural factors relevant to the experience of major mental disorder across ethnic and diagnostic groups. These factors will be examined in relation to indices of chronicity (symptom severity/impairment, work and social life, person and family-based assessments of the quality of everyday life) in order to assess the question of whether there are common or culture and illness-specific pathways to chronicity and recovery.

The specific questions raised here originated with the anthropological finding that conceptions of mental illness vary cross-culturally. Our research group's interest in the nature and meaning of indigenous conceptions also stems from the idea that such conceptions may mediate not only the felt flow of everyday experience, but also the course and outcome of psychiatric disorder. This is because indigenous conceptions of 'psychiatric disorder' – such as *nervios* (nerves) or personality deficits (e.g. laziness) – are determinants of expressed

emotion and therefore play a substantial role in mediating the course and outcome of mental disorder (Jenkins, 1988; Jenkins & Karno, 1992).

Beginning with patients reliably assessed according to research diagnostic criteria and recently released from hospitalisation for an acute psychotic episode (Karno *et al*, 1987), we took a step toward subjectivity by asking whether they considered themselves to have any illness or disability. Specifically, we decided to ask 'neutral' questions such as "How would you describe your problem?". By not specifying that we thought the problem was mental disorder, we thought we had broadened response possibilities enough to include indigenously defined distress and symptom clusters such as *nervios*, mental illness and the like (Jenkins, 1988). However, framing the question in this way still potentially skewed the responses by presupposing that everyone would agree that they had a 'problem'. In our current research with out-patients diagnosed with depression or schizophrenia, we tried to remedy this by asking how they would characterise their current life situation, leaving open the question of whether it would be framed in terms of a problem or illness.

### Sociodemographic, cultural and clinical characteristics of the sample

Participants were recruited from out-patient facilities of northeastern Ohio in the USA. The sample consisted of 80 subjects divided between ethnic (Latino and Euro-American) and diagnostic (schizophrenia and depression) groups, for a total of 20 subjects in each of four cells. The designation of 'Latino' is currently preferred by Spanish-speaking ethnic groups in the USA. The designation 'Euro-American' is meant to refer to an ethnically heterogeneous group of English-speaking US residents whose heritage is traced to Europe. All suffered from persistent major mental disorders of either schizophrenia or (non-psychotic) unipolar depression for at least two years. Patients were diagnosed as suffering from schizophrenia or major depressive disorder according to DSM-III-R criteria on the basis of a Schedule for Affective Disorders and Schizophrenia (SADS; Spitzer & Endicott, 1978) interview administered by trained mental health professionals. Patients were currently receiving out-patient psychiatric treatment, were aged between 20 and 55 years, and living with or in regular weekly contact with family member(s). Prospective study participants

with clinically significant substance misuse or organic conditions were excluded.

Selected sociodemographic and clinical characteristics are presented in Table 1. As might be expected from epidemiological and service-use studies, this naturalistic community study found that women predominate in the depressed group and men predominate in the schizophrenic group; this is the case for both Latinos and Euro-Americans. Across the four groups, the mean length of illness was 17 years since the time of first onset of psychotic or depressive symptoms. Thirty-eight (95%) of the Latino patients were Puerto Rican (80% born on the island), one was Cuban and one Honduran. The majority (73%) were primarily or only Spanish-speaking and were found to be relatively unacculturated, with a mean score of 1.95 (s.d.=0.78) on our adapted five-point scale developed by Cuellar *et al* (1980). The vast majority of the Euro-American families had resided in the USA for several generations, and all spoke English as their primary language.

### Interview and qualitative coding

The research interview, the Context of Illness Experience Interview (CIEI) developed by the author, elicits narrative and subjective data on the patient's everyday experience of illness and life in the community. The first question posed to the study participants was "How would you describe your current life situation?". The question was intended to elicit the broadest possible range of characterisations of the person's current life circumstances. Early pilot research had demonstrated the validity of this question for the ethnic groups under consideration. Analyses were conducted from the transcribed verbatim texts of the audio-taped interviews, using coding categories derived from the major topics referred to by the patients and devised to be as inclusive as possible. We first determined whether each patient: specified a type of illness (mental, physical, or *nervios/nerves*, shown as the first three categories in Table 2); acknowledged explicitly but non-specifically that they had an illness or sickness (illness unspecified, shown as category four in Table 2); made no mention of illness, disease, or disorder, yet mentioned that they had received treatment in the form of medication, psychotherapy or hospitalisation (illness implicit, the fifth category in Table 2); or did not include illness at all in their description (non-illness responses, the sixth category in Table 2).

**Table 1** Sociodemographic and clinical characteristics of patients (n=80)

	Latino		Euro-American	
	Schizophrenia (%) <sup>1</sup>	Depression (%) <sup>1</sup>	Schizophrenia (%) <sup>1</sup>	Depression (%) <sup>1</sup>
Gender				
Female	35	75	35	70
Male	65	25	65	30
Mean age (s.d.)	37.5 (9.1)	42.9 (9.4)	34.0 (7.7)	39.8 (8.6)
Marital status				
Single	70	30	50	25
Married/partner	15	55	15	65
Divorced/widowed	15	15	35	10
Household type				
Parental	55	5	30	5
Marital/partner	15	55	15	65
Sibling	20	5	0	0
Offspring	5	25	10	10
Non-relative	0	5	30	5
Alone	5	5	15	15
Social class (median)	5	5	5	3
Mean age at onset (s.d.)	20.8 (7.9)	23.7 (9.9)	21.4 (5.0)	21.2 (9.1)
Mean years ill (s.d.)	16.8 (7.3)	19.3 (9.5)	12.6 (5.9)	18.6 (9.7)
Mean admissions (s.d.)	4.2 (2.8)	1.1 (1.6)	4.8 (2.1)	1.9 (2.8)
Out-patient treatment				
< 1 year	5	15	5	30
1–5 years	30	40	40	30
> 5 years	65	45	55	40
Recent medication				
Yes	95	90	100	100
No	5	10	0	0
Adherence to recent medication				
Regular	80	65	80	95
Somewhat irregular	15	20	15	0
Very irregular	0	5	5	5
Not applicable	5	10	0	0

1. n=20.

## RESULTS

### Illness and non-illness categories

Several findings can be drawn from the data in Table 2. Firstly, Euro-Americans are significantly more likely than Latinos to characterise their life situation in terms of mental illness, and this was notably more pronounced for Euro-American schizophrenic than depressed patients. Yet given that all had been diagnosed and treated for a major mental disorder, perhaps the most prominent observation is that overall, only 13 (16.3%) of 80 patients explicitly and without prompting invoked the category of mental illness. Secondly, in no instance did

Latinos describe their life situation in terms of physical illness, whereas a portion of Euro-Americans in both diagnostic categories did invoke physical illness. Thirdly, and in sharp contrast to the responses for physical illness, no Euro-Americans invoked the category of nerves, while for both Latino groups, and especially the schizophrenic group, *nervios* was a popular category. (The category of 'nerves' does hold some cultural salience for English patients, however (Helman, 1995).) When these three categories of specified illness are combined, there is little apparent cross-cultural difference: roughly 35–40% of people with schizophrenia specified some

form of illness, while roughly 20–30% of depressed patients invoked one of these categories. Finally, unspecified illness was non-occurrent only for depressed Euro-Americans but otherwise rare among the other three groups. There were no statistically significant differences in responses by diagnostic groups.

The most striking finding was that, even given these generous coding rules, 49% of diagnosed psychiatric out-patients *did not include illness in their description of their life situation*. Patients who did not volunteer illness as the framework for describing their life situation spoke instead primarily in terms that could be broadly and reliably coded as affect, activities, events, accomplishments, and relationships, or some combination of these (Table 3). This observation remains noteworthy despite the fact that, upon further questioning using a forced-choice method, all patients did acknowledge having a health problem of some sort. Thus illness does *not* dominate the description of life situation for a substantial proportion of the sample.

### Characterisation of life situation

What then are the dominant experiential domains for these patients from their own points of view? The responses of patients who did include illness in the description of their life situations tended to be dominated or organised by that fact. For example, one depressed Puerto Rican male described his life situation as: "Not bad. I can't say I'm well because of my problem. It bothers me, my illness. I worry sometimes because I can't be well, that I can't be like I was before." And from a Euro-American male with schizophrenia: "In the past ten years I've lost two jobs. I think it's because of my mental illness. I worked one job about four years and then started getting ill and then they put me on medication. And the person who I worked with wouldn't work with me because I was taking pills 'retarded' people take."

The data in Table 3 suggest that for those who did not characterise their life situation in illness terms, the most salient domain was that of emotion, most often negative, but without explicit conceptualisation in symptomatic or pathological terms. Indeed, emotional distress in this category was often articulated in the language of suffering and anguish. Second most common was the domain of life activities, either in terms of concern over how their activities are restricted or in terms

**Table 2** Open-ended description of current life situation, by ethnicity

	Latino (n=40) <sup>1</sup>		Euro-American (n=40) <sup>2</sup>		All (n=80)	
	n	(%)	n	(%)	n	(%)
Mental illness	3	(7.5)	10	(25.0)	13	(16.3)*
Physical illness	0	(0)	4	(10.0)	4	(5.0)*
Nervios/nerves	8	(20.0)	0	(0)	8	(10.0)**
Illness unspecified	5	(12.5)	2	(5.0)	7	(8.8)
Illness implicit	3	(7.5)	7	(17.5)	10	(12.5)
Non-illness responses	21	(52.5)	18	(45.0)	39	(48.8)
Missing data	1	(2.5)	0	(0)	1	(1.3)
Total illness responses <sup>3</sup>	18	(45.0)	22	(55.0)	40	(50.0)

1. One case coded for both 'Mental illness' and 'Nervios/nerves'.

2. One case coded for both 'Mental illness' and 'Physical illness'.

3. Total number of cases giving at least one illness response.

\*P < 0.05; \*\*P < 0.01.

**Table 3** Open-ended description of life situation in non-illness terms

	Latino (n=21)	Euro-American (n=18)	All (n=39)
Affect	12	12	24
Activities	7	7	14
Events	4	4	8
Accomplishments	2	3	5
Relationships	2	3	5

The response of some individuals was coded for more than one category. The total number of responses thus exceeds the 39 respondents.

of preoccupation with certain types of activity. Third was the domain of life events, such as geographical moves, assaults or robberies, or the illness or death of a family member. Less common was concern with various types of accomplishment and achievement, and explicit concern over the state of their social relationships. Since these five categories are in themselves rather general, brief examples will convey a better sense of their subjective nature.

Among those who define their life situation in affective terms, one example is a 31-year-old Puerto Rican woman diagnosed with schizophrenia who described her life briefly in terms of feeling "very sad and alone". (This response was also coded in terms of relationships.) With daily recollections of a childhood poisoned by physical and sexual abuse (her father taught her how to drink rum in bed as a precursor to his sexual assaults on her, aged 8–12), she is preoccupied with guilt over rapes too numerous to count and the fear that her father does not love her. A 41-year-old Puerto Rican woman diagnosed with depression, also sexually abused as a child and now married with a family, responded

that "I feel unable to move on with my life. I've had so much suffering, so much anguish. Sometimes it makes me cry. It's just the way I feel." Other patients described their lives in terms of positive affect. A 39-year-old Euro-American widower diagnosed with schizophrenia reported "I have a good life. I feel good and can think clearly, and can cope with people. I like myself." Restricted activity and negative feelings was the focus of a depressed Euro-American woman who is a married mother of four: "It's sort of driving me nuts. I don't do anything. I need to find something to do. I . . . that's about it. Everything else is OK . . . I get bored and anxious."

Life events dominated the narrative presentation of a 31-year-old Puerto Rican woman diagnosed with depression who dramatically recounted car chases, gunfights and stabbings. In addition, she described how numerous instances of betrayal by others have also come to characterise her current life situation. Rather than referring to her life as coloured by illness, she maintains that problems (defined by her as external events) follow her no matter where she is. In her view, she has had multiple and

unrelenting painful life experiences for which there is little alternative but to "swallow" (*un trago amargo*) them. For example, the regular appearance of migrant relatives who seek temporary housing from her is a recurring event that she experiences as stressful in itself, and for which she does not feel properly acknowledged or appreciated.

A patient who was clearly concerned with accomplishments and goals is a 34-year-old lower middle-class Euro-American depressed male who lives with a partner. In his description of his life situation he provided a quantitative assessment: "On a scale from one to ten, probably a two. I do not have any specific career goals. Financially I am not stable. Relationship-wise, I have nothing going. So, it seems like all the things that society forces you to accept – I am not having trouble accepting it. The fact that I used to strive for the American dream, I have just – I guess I am just not interested. And as a result I have not accomplished what this society feels is acceptable – a home, two cars, a wife, two children, \$50 000 a year job."

### Rhythm of life

Despite their usefulness, we found that the straightforward coding of categories fell somewhat flat with respect to capturing adequately the holistic sense and meaning of the patients' narrative responses. As framed by Kleinman (1988b), the question became whether the illness narratives reveal what is "at stake" for these patients. Accordingly, in a second analytical pass we attempted to identify an overarching qualitative sense of the responses that went beyond the determination of whether a person represented his or her life situation with reference to illness or the other categories of Tables 2 and 3. A theme that emerged across ethnic and diagnostic groups was a subjective sense of engagement in what can be termed the 'rhythm of life'. Often there appeared to be a moral struggle either to maintain or find anew one's sense of rhythm or involvement in the flow of everyday activities. Patients articulated their suffering over having lost or been thwarted from ever finding a sense of rhythm, given the persistent or recurring context of major mental disorder. While some patients claimed they were unable to remember or imagine their lives in so-called 'normal' terms, they had lost neither the desire nor the hope that somehow things might change

for the better. Although this sense of hope and faith was implicitly or explicitly articulated among both ethnic groups, it was more apparent among the Latinos.

In summary, the sense of self which allows for purposeful action and immersion in the daily flurry of behavioural routine is the central process which appears to be very much at stake. Patients' sense of rhythm in life was experienced as being jeopardised by the subjective competition between persistent suffering, monotony and detachment, on the one hand, and the desire to hold fast to one's vital energy, sense of self and social connection, on the other. Sadly, many of the patients' imaginings or remembering of a life as free from suffering and illness were pale and poorly defined.

## DISCUSSION

Given the above analysis, we are faced with the question of how it is that so many of these patients described their lives in terms that exclude either explicit or implicit reference to illness. Certainly, patients' conceptualisation of their situation in terms *other* than illness is echoed in a variety of work in social psychiatry, whether the focus be on poverty, poor housing and lack of education (Lewis, 1968; Brown & Harris, 1978), family socialisation practices (Scheper-Hughes, 1979), or "problems in living" (Laing, 1967). However, several objections could be raised against the results reported here. Firstly, it could be argued that the finding may be an artefact of method, in so far as when the same patients are asked directly if they are ill they will acknowledge as such. Indeed, in our 1980s research only about a third of Mexican immigrants diagnosed with schizophrenia volunteered, when asked, to describe their 'problem', but this went up to two-thirds in response to a subsequent direct inquiry as to whether their problem might be *nervios*, a culturally acceptable and non-stigmatising term for distress and illness among Latinos (Jenkins, 1988). We are using comparable probes for each of the illness categories described here, and are in fact finding a similar pattern of response (Coehlo, 1995); thus, the rhetorical decision to represent one's current life situation in terms other than those of illness may be partially mediated by strategic attempts to eschew the stigma and marred identity which so frequently accompany mental disorder. Secondly, it is conceivable that patients who have been more

frequently hospitalised would be more likely to describe their life situation spontaneously in illness terms. However, our analyses revealed that this appears simply not to be the case. Thirdly, it is known that a symptom of schizophrenia itself is "lack of insight", referring to denial or unwillingness to acknowledge mental disorder. However, this symptom appears most often in patients in an active, acute psychotic episode, which was rarely the case in those we interviewed. Moreover, it is a symptom typically reported in about 30% of cases of schizophrenia, yet a full 85% of all our schizophrenic and depressed patients failed to invoke any notion of mental illness. Fourthly, some sociodemographic characteristic other than ethnic group membership could account for the difference, for example, gender, socioeconomic status or age. Again, our analyses suggest that this is not the case. Similarly, clinical variables such as mean years ill or length of treatment were not significantly associated with the responses we obtained.

In my view, more likely to account for the strong tendency to describe life situations in terms other than illness are the following four features of patients' perceptions of the nature of illness and disability. First is the overarching salience of subjective themes, such as that identified here as the rhythm of life. Existential themes these may be, and suffering they may entail, but they may not necessarily be medicalised, and indeed may not best be expressed in medical terms. Second is the experience of *temporality*. The phenomenology of feeling ill may have the temporal form of flashes, moments, or waves that come and go and are not objectified as enduring conditions or identities. Third and perhaps most evident is the strategic attempt to represent to self and others that one is not marked by the stigma of mental disorder. Thus the category of physical illness appeals to Euro-American patients, that of *nervios* to Latinos, and the categories of unspecified and implicit illness appeal variously to both. Fourth is implicit or explicit hope for recovery. As Good (1994) has observed with reference to patients afflicted by epilepsy in Turkey, "illness stories . . . portray a 'subjective world', one in which healing was an open possibility even if miracles were necessary." The subjunctive state of distress, misfortune and illness is particularly impressive in the illness stories of Latino respondents, for whom cure and recovery are distinct possibilities.

## CONCLUSIONS

What is the value of asking open-ended questions concerning patients' lives as opposed to their symptom levels or conceptions of psychiatric disorder? I will suggest three ways in which it may be informative. Firstly, I think it is validated by the simple finding that in a sample of chronic psychiatric out-patients, only about half describe their life situation in terms of illness. In this respect Strauss (1994) has proposed the idea of elaborating specific themes of a person's 'story' as the most useful way to bridge subjective and objective descriptions of illness processes. Secondly, within the kind of design we have presented (i.e. comparing across both diagnostic and ethnic groups), the data generated by this question support anthropological theory and research aimed at accounting for variability in illness experience. Thirdly, such a patient-centred focus constitutes a research progression from disease problems to subjectively assessed situations, and consequently from illness conceptualised to life conceptualised, as part of our efforts to understand the course of persistent mental illness.

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## CLINICAL IMPLICATIONS

- To enhance patient–doctor rapport, it may be beneficial to recall that patients' concerns are not restricted to symptom, illness or treatment issues but often centre on everyday themes.
- An overarching theme for patients is their sense of being tuned into or severed from the "rhythm of life".
- Cross-cultural comparison reveals that the subjective experience of major mental disorder in the course of everyday life is socioculturally constituted.

## LIMITATIONS

- An overall report for a sample of 80 patients does not allow for a more contextualised account of culture, mental disorder and subjective experience.
- The data analysis does not fully take into consideration the issue of intra-cultural variability.
- As a naturalistic, community mental health study of out-patients, patients were in varying stages of clinical remission with differing types of residual symptoms, which may have affected their responses.

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JANIS HUNTER JENKINS, PhD, Russell Sage Foundation, 112 East 64th Street, New York, NY10021, USA

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