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ARTICLE

Ethno-Cultural Variations in the Experience and Meaning of Mental Illness and Treatment: Implications for Access and Utilization

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Abstract We conducted a study to investigate how understandings of mental illness and responses to mental health services vary along ethno-racial lines. Participants were 25 African American, Latino, and Euro-American inner-city residents in Hartford Connecticut diagnosed with severe mental illness and currently enrolled in a larger study of a community mental health center. Data were collected through 18 months of ethnographic work in the community. Overall, Euro-Americans participants were most aligned with professional disease-oriented perspectives on severe mental illness and sought the advice and counsel of mental health professionals. African-American and Latino participants emphasized non-biomedical interpretations of behavioral, emotional, and cognitive problems and were critical of mental health services. Participants across the sample expressed expectations and experiences of psychiatric stigma. Although Euro-Americans were aware of the risk of social rejection because of mental illness, psychiatric stigma did not form a core focus of their narrative accounts. By contrast, stigma was a prominent theme in the narrative accounts of African Americans, for whom severe mental illness was considered to constitute private "family business." For Latino participants, the cultural category of *nervios* appeared to hold little stigma, whereas

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psychiatric clinical labels were potentially very socially damaging. Our findings provide further empirical support for differences in symptom interpretation and definitions of illness among persons from diverse ethno-racial backgrounds. First-person perspectives on contemporary mental health discourses and practices hold implications for differential acceptability of mental health care that may inform variations in access and utilization of services in diverse populations.

Key words ethnicity • explanatory models • illness stories • race • severe mental illness • US

Introduction

In this article we examine how individuals diagnosed with severe mental illness understand mental health problems and respond to engagement with mental health services. The persons considered in this article lived in Hartford, Connecticut, a mid-sized city in the US, and came from diverse racial/ethnic[1] backgrounds. The first-person perspectives offered by these individuals illuminate orientations to mental health discourse and practice that vary along ethno-cultural lines. Their experiential accounts provide insight into how differential acceptability of mental health services may hold consequences for access and utilization of services among diverse populations.

Examining cultural variations in how mental health problems are experienced, expressed, and responded to, has been a key focus of research in medical anthropology and cultural psychiatry for decades. Culture affects how illnesses are identified, defined, and made meaningful; how they vary with respect to timing and onset, presenting symptoms, course, outcome, treatment utilization and responses (Jenkins, 1998; Jenkins & Barrett, 2004; Kleinman, 1988). Recently, the health sciences have echoed the importance of culture, exemplified by the “main message” that “culture counts” in the U.S. Surgeon General’s report *Culture, Race, and Ethnicity* (US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services [USDHHS], 2001).

Within the health sciences, much of the recent attention to matters of culture has arisen within the context of increasingly diverse patient populations (Betancourt et al., 2005) and increasing awareness of disparities in access to, and utilization of, mental health services among racial and ethnic minority populations in the United States (Smedley, Stith, & Nelson, 2003; USDHHS, 2001). Studies consistently find that African Americans and Latinos are significantly less likely than Euro-Americans to use and to receive mental health care (Alegria et al., 2002; Dobalian & Rivers, 2008; Lasser, Himmelstein, Woolhandler, McCormick, & Bor, 2002; Wells, Klap, Koike, & Sherbourne, 2001). Moreover, this situation does not appear to be improving (Cook, McGuire, & Miranda, 2007).

Disparities in mental health treatment are produced through a complex constellation of factors. Numerous pathways for the production and persistence of disparities have been proposed, including variations in symptom expression that may lead to underdetection of problems or misdiagnosis (Alegria et al., 2008; Borowsky et al., 2005; USDHHS, 2001); bias, prejudice, and stereotyping among providers and institutions (Balsa & McGuire, 2003; Snowden, 2003); psychiatric stigma (Gary, 2005; Nadeem et al., 2007); difficulties in accessing services due to the risk of missing work in low-wage jobs (Alegria et al., 2008; Dobalian & Rivers, 2008); and experiences of mistreatment that contribute to mistrust of mental health professionals (Diala et al., 2000; Whaley, 2001). It is important to note that this range of pathways includes patterns of response at the individual and group level as well as dynamics that reflect broad societal inequalities.

Although structural inequalities contribute to differential access and utilization of mental health services across racial/ethnic groups in the US, disparities are unlikely to be ameliorated without equal attention to how individuals and groups engage with, and respond to, mental health problems and treatment. Thomas and Snowden's (2001) finding that minority populations remain less inclined to use mental health services *even when covered by insurance* illuminates the complex underpinnings of differences in access and utilization. However, if we reduce the issue to one of "preference" by individuals and groups, this fails to acknowledge how choices to seek, use, and continue care may be shaped by broader forces of inequality and discrimination. Resistance toward, or acceptance of, mental health services occurs within an intersubjective and cultural milieu that shapes and constrains the responses of individuals and groups.

In this article, we focus on first-person perspectives of individuals from diverse backgrounds who were diagnosed with severe mental illness and were receiving community mental health services. Their perceptions and experiences of contemporary mental health discourses and practices hold implications for differential acceptability of mental health care across populations that may inform variations in access and utilization of services.

METHODS

ETHNOGRAPHIC SETTING

The narrative and observational data presented in this article are drawn from study participants who lived in Hartford, Connecticut, a mid-sized, relatively poor municipality in the northeastern US. According to the 2000

U.S. Census, the population of Hartford is composed primarily of persons of Hispanic/Latino origin (40.5%), Black/African American persons (38.1%), and White (non-Hispanic) persons (17.8%) (U.S. Census, 2000).[2] The Euro-American, African-American, and Latino populations of Hartford manifest some striking differences in life circumstances: mean education level, employment and labor force participation rates, poverty, language background, and household composition (U.S. Census, 2000). The African American and Latino participants in this study conformed to the demographic profile of the Hartford populations from which they come. The Euro-American study participants, by contrast, were unrepresentative of the city's Euro-Americans in that these participants tended to be poor, lived alone, and were unemployed.

Hartford has a comprehensive mental health system, offering a variety of psychosocial and vocational programs. The lead agency in Hartford, Capitol Region Mental Health Center (CRMHC), is operated by the Connecticut Department of Mental Health and Addiction Services. Participants in the study were all receiving services at CRMHC. This community-based mental health center serves clients from the Hartford metropolitan area with severe psychiatric disabilities and co-occurring substance use and mental illness.

Description of the Study

The ethnographic study, on which this article is based, was conducted within the context of a larger clinical trial of three approaches to vocational rehabilitation (Mueser et al., 2004). In the larger study, 204 individuals with SMI were randomly assigned to one of three vocational programs. (The vocational programs included Individual Placement and Support (IPS) supported employment, a "clubhouse" psychosocial rehabilitation program, and standard vocational rehabilitation services.) Eligibility criteria for the larger study included: (i) severe mental illness, defined as Axis I diagnosis or borderline personality disorder and severe impairment in psychosocial functioning or self-care (American Psychiatric Association [APA], 1994); (ii) lack of competitive employment; (iii) desire for competitive work; (iv) attendance at two research introduction meetings; and, (v) willingness and capability of providing informed consent to participate (Mueser et al., 2004). Participants in the larger study came from diverse racial/ethnic backgrounds: 46% African American, 30% Latino, and 24% "others" (most of whom were Euro-American). In the larger study, race/ethnicity was related to participation, with Latinos most likely to participate, followed by African Americans, followed by Euro-Americans (Mueser et al., 2004). After completing a baseline interview, participants were randomly assigned to one of three vocational programs, stratified by work history (competitive work in past five years or not), race/ethnicity, and gender (Mueser et al., 2004).

A sub-set of 25 participants from the larger study was selected to participate in the ethnographic study (27 were invited to participate; 2 declined). Participants in the ethnography were recruited on a random basis, stratified by the vocational program to which they had been assigned. The ethnographic study included participants who self-identified as Latino ($n = 10$), Euro-American ($n = 9$), and African American ($n = 6$). Table 1 presents the demographic and clinical characteristics of the ethnographic sample. Mean monthly income was about $700, ranging from $550 to $1300 (one person received a total monthly income from numerous sources of $1700). Income was mostly from Federal, State, and/or Municipal transfers, but some participants received monetary gifts or had informal employment arrangements (e.g., babysitting). In this sample, seven of the 25 exhibited at times delusional or incoherent talk. Thirteen had not held a competitive job in the past five years.

TABLE 1
Demographic and clinical characteristics of participants

Participant No.	*Sex*	*Age*	*Race/Ethnicity*	*Diagnoses*
1	M	43	African American	Schizoaffective Disorder Alcohol Abuse Cannabis Dependence
2	M	40	Latino	Schizophrenia Alcohol Abuse Polysubstance Dependence
3	M	69	Euro-American	Schizophrenia
4	F	55	Euro-American	Bipolar I Disorder Alcohol Dependence Post-traumatic Stress Disorder
5	M	34	African American	Schizoaffective Disorder
6	F	49	Euro-American	Psychotic Disorder NOS Alcohol Abuse
7	M	63	Euro-American	Schizophrenia
8	F	44	Latina	Major Depressive Disorder Post-traumatic Stress Disorder Obsessive Compulsive Disorder
9	M	41	African American	Schizophrenia Cannabis Dependence Cocaine Dependence
10	M	41	Euro-American	Schizophrenia Phencyclidine Dependence

TABLE 1
continued

Participant No.	*Sex*	*Age*	*Race/Ethnicity*	*Diagnoses*
11	F	50	African American	Schizophrenia
12	F	43	African American	Major Depressive Disorder Cocaine Dependence Cannabis Dependence
13	F	31	Latina	Bipolar I Disorder
14	F	51	Latina	Bipolar I Disorder
15	M	44	Latino	Schizophrenia Alcohol Abuse
16	M	36	Euro-American	Schizophrenia
17	M	36	Euro-American	Schizoaffective Disorder Cannabis Dependence
18	F	36	Latina	Schizoaffective Disorder Alcohol Dependence Cannabis Dependence
19	F	38	Latina	Major Depressive Disorder Post-traumatic Stress Disorder
20	F	44	Latina	Major Depressive Disorder Alcohol Dependence
21	M	39	Latino	Schizophrenia Cannabis Dependence Cocaine Abuse
22	F	58	Euro-American	Major Depressive Disorder
23	M	26	Euro-American	Schizoaffective Disorder
24	F	58	African American	Major Depressive Disorder
25	M	35	Latino	Delusional Disorder Alcohol Dependence Cannabis Dependence

Procedures

Over the course of 18 months we worked intensively with 25 participants. The principal method of data collection was participant observation (Spradley, 1980). Three field ethnographers shared in activities with study participants over at least one year at many of their regular haunts, engaging in observation and conversation in the many real-world contexts in which their lives, including mental illness, are situated and expressed. No interview schedules were used to elicit materials or to frame conversations that were largely participant directed. Their discourse reflected almost entirely what they wished to say, when they wished to say it.

The ethnographers wrote extensive field notes following their interactions with participants. These notes included details from conversations and observations across multiple community settings. Field notes were organized and analyzed with the aid of the software program, *Sonar: High Speed Text Retrieval 10* (Virginia Systems, 1998). Qualitative analysis proceeded iteratively and coding was done through consensus between the study supervisor (HSA) and research ethnographer (ECS). Participants' discourse ranged over many topics. For purposes of this analysis, we made a selection or culling from the total discourse corpus of all instances of "illness discourse," which we coded according to the following conjunctive criteria: (i) first-person accounts of life before illness, during the onset of illness, and consequent on illness, (ii) claimed effects of illness and interventions, (iii) observed and/or reported coping strategies, and (iv) observed and/or reported interactions with the treatment system.

The ethnography received approval from both the Dartmouth College and the State of Connecticut Institutional Review Boards, and all 25 individuals gave informed, written consent for their participation. All participant names in this article are pseudonyms. Participants did not receive monetary compensation for their participation. They did, however, receive meals with ethnographers, help with chores, and assistance with transportation by ethnographers.

RESULTS

In the present analysis we foreground patterns of variation that emerged between Latino, Euro-American, and African-American participants. By delineating these patterns we are not, and would argue strongly against, essentializing these demographic and cultural groups. Rather we align the present analysis with decades of anthropological and cultural psychiatric research that documents cross-cultural variations in the expression and experience of distress and engagement with treatment modalities. In addition, we note at the outset that population-level patterns, of the kind observed in this research, may not hold relevance at the level of individual experience.

We first present the broad contours of our argument using narrative examples from participants across the sample. We then turn to three ethnographic portraits to provide in-depth, contextualized knowledge of participants' experiences of, and perspectives on, contemporary community mental health services in a U.S. urban context.

Perspectives on Mental Health Services

Participants in the study exhibited a range of orientations to mental health services. Compared to Latino and African Americans in the study, Euro-American participants were strongly aligned with professional clinical interventions and mental health providers. In this section, we present participants' responses to two dimensions of contemporary mental health services: psychotropic medications and mental health providers.

Psychotropic Medications

Psychotropic medications occupy a central position in contemporary mental health services in the US and were a key locus of discourse across the participants. For Euro-Americans, these medications were viewed as central and necessary components of their treatment. Sarah credited clozapine with keeping her out of the hospital: "I haven't been in the hospital since '92 or '93. I'm doing better now. I used to be in and out [of the hospital.] This new medication clozaril seems to be working." (#6). Fred also noted the high stakes of taking medication: "I take the prolixin and decanote [sic] to keep me sane. They keep me from committing suicide. Now do you get it?" (#16).

Euro-Americans expressed that medications hold their mental illnesses at bay and that the balance between "stability" and "instability" is delicately achieved. As Fred observed: "My mental illness is so sensitive with the medication. If I'm off so much as a dose there's a complete change around." (#16). Similarly, Nora described what happens if she does not take the medications: "You feel pretty good for a while and then you crash." (#4). For Nora, and others, there was often a desire to be "medication free," but a sense of resignation that this was an impossibility: "Sometimes I think I'm doing better now and I can make it without the pills, but I'm afraid of landing in the hospital." (#4).

Among Euro-American participants, adjustments and changes to medications were viewed as key strategies in managing one's "ups" and "downs." As Nora explained: "I was really depressed on Saturday . . . I've just been so low. I really want to talk to my psychiatrist and get my meds changed. I just feel so low all the time." (#4).

Among Latino participants in the study, psychotropic medications were viewed as an unproblematic component of receiving services. Unlike psychosocial interventions, which were infrequently used (especially by men), Latino participants actively sought out psychotropic medications. For some, medications were viewed as instrumental in keeping them out of the hospital. As Mario explained: "I told [the doctor] not to [lower my dosage] 'cause there's no way I'm ever going back to the hospital. I mean, I'll do anything to stay out." (#21).

Although both Latinos and Euro-Americans link taking medication with staying out of the hospital there is a difference in their respective accounts. The Euro-Americans in the study attributed their ability to “stay sane” and out of the hospital to medications, which were understood to play a key role in mitigating psychiatric symptoms. Among the Latinos in the study, however, there was variability in the degree to which medications were viewed as helpful and necessary. For some participants, medications were seen as a potentially effective means of treating “nerves,” as Roberto stated: “I gotta talk to the psychiatrist and see if he can give me a new medication to make me less nervous.” (#25). Yet for others, medications “don’t do nothin’” and compliance with medication regimens was viewed as a necessary means of protecting oneself against a corrupt mental health system. As Mario explained:

> But you know they’d send me back for anything, and I’d just as soon keep taking my meds and stay out of there [the hospital.] I mean, they want to lower my meds, but that’s what happened last time and I don’t want to go back. They could have just raised my meds and kept me out of the hospital, but they just sent me back and I don’t want to go back. (#21)

Unlike the Euro-American and Latino participants, African Americans in the study were highly critical of psychotropic medications. Among these participants, there was a strong sense that mental health professionals’ principal concern is medication compliance. Tamara described a typical visit with her therapist as follows: “My visit usually last about fifteen minutes and his main topic is, ‘Am I taking my medication?’ and how I feel since I began taking the new medication.” (#11).

African-American participants voiced frustration with what they perceived as a narrow focus on medications. Gladys described a recent interaction with her vocational specialist:

> He don’t try to help me. He don’t try to help me find a job, yes. He don’t want to do his job. I beg him to help me. I beg him to help me, yes, and he didn’t. All he say is, “Are you taking your medication?” I say, “Yes, yes I take my medication.” I tell him I need work, he say, “Take your medication and you will find work.” (#24)

Unlike Euro-Americans, for whom adjustments to medications were expected and viewed as potentially helpful, African Americans became frustrated with ongoing changes to their medications. For some, switching medications cost them financially, as Gladys explained:

> I have to pay for a portion of my prescription. I’ve already paid $40 for my prescriptions and now they change them. [puts her hands to her forehead] I’m so sick of this mess . . . I don’t understand why they changed my medication. I didn’t sleep for a few nights and they just changed my medication just like that. (#24)

For others, changes to medications contributed to a feeling of being "experimented" on, as Jerome observed:

> They don't know what works and what don't work. First, they put you on a medication and when you tell them you don't need it anymore they just put you on another one. I get sick of taking pills, pills, pills. I don't need all this medication. They keep telling me I need medication but I don't. The medication is what makes me sick. I don't feel right when I take it anyway. (#1)

Jerome's assertion that he does not need medication was echoed by other African-American participants who called into question the necessity of taking psychiatric medications. Bernice felt that the antidepressant she had been prescribed was unnecessary:

> I told [my case manager] I was only depressed for about four or five days and I don't need medicine for depression because it didn't last. Everyone gets depressed and they don't take medication for it. Just because I have a mental illness doesn't mean I'm never going to get depressed. (#12)

In this narrative passage, Bernice normalizes her feelings of depression. In her view, it was inappropriate to pathologize transient feelings of sadness and she critiqued mental health services in which "doctors give you a pill for everything."

Mental Health Providers

Participants in the study offered a range of attitudes toward mental health providers. Euro-Americans frequently sought out the advice and counsel of mental health professionals. Nora (#4), for example, consulted with her therapist regularly on matters of daily life. Other Euro-American participants had become similarly attached to providers. Sherry (#22) noted that it was difficult for her to switch social workers. Although her current social worker is "nice," Sherry remembered her past social worker as a "wonderful girl" with whom she had a "bond." For Sarah (#6), her case manager was a frequent companion. They went shopping, ran errands, and even got their hair cut together. Whereas case managers and social workers were viewed as valued and trusted compatriots, psychiatrists and psychologists were often viewed with a critical eye. As Nora stated:

> Well, I don't like doctors. They don't treat you like people, like you're human. The social workers have helped me far more than the doctors . . . I don't know if it's because they're more educated – but they analyze you, they don't treat you like a person, they treat you like a case. [Social workers] are more caring, you know they're interested and they want to help you. (#4)

Euro-Americans in the study tended to accept the advice and suggestions of their mental health providers. Fred's decision to participate in the larger research study was influenced by his therapist: "[My therapist] told me about it. He suggested I try it out and learn to be social." (#16). Among these participants, their own desires and plans were subject to disruption or revision based on the perceived "professional" opinions of their providers. Randy had expressed to the ethnographer his desire to work at a local bus company. However, his plans were postponed after a meeting with his therapist: "They want me to get stabilized on the meds first and then get a job." (#23). Another time, he noted, "They don't think I'm ready [to get a job]." (#23).

Unlike Euro-Americans, for whom mental health providers occupied a central position in their everyday thoughts and actions, among many Latino participants, mental health professionals remained peripheral to their concerns of daily life. For the Latino men, in particular, mental health providers were viewed instrumentally – a means of obtaining medications or injections. Roberto (#25) explained the role of the psychiatrist as follows: "He just gives me medications." Another time, he clarified why he attends CRMHC as follows: "I just go there for my medications. I don't go there for psychiatric care." Latino men were aware that other services were available, but did not seek them out. As Mario stated:

> Yeah, they've got a lot of services [at CRMHC], that's why I go. They give me medications, and they have counseling though I haven't used that. And they have groups that you can go to. I haven't used that either because I don't think I need it, but I could go if I wanted. (#21)

In contrast, the Latina women tended to avail themselves of psychosocial interventions, including groups and therapy. Linda (#13) had been going to therapy "for years." Yet although Latina women were engaged with these forms of treatment, there was not the sense of personal connection with individual providers that was apparent, and deeply valued, among the Euro-American participants. Unlike their Euro-American counterparts, mental health providers were not sought out as a regular sounding board for "problems" among these participants. Instead, "meetings" with therapists were simply a part of the routine of receiving services. Among many Latino participants there was a sense of "going through the motions" with their providers. Among some Latino men, this sensibility was further intensified. As Mario stated proudly: "I'm not crazy. I just go to the club so I can get a check . . . I just started acting crazy, but I fooled them." (#21).

For Mario, his psychiatrist acted as a co-conspirator in an elaborate ruse. He noted that his doctor knows he "ain't crazy": "The doctor sees me anyway so he can make the big bucks . . . He just gives me a little bit [of medication] 'cause he knows I ain't crazy, so I take it." (#21).

Among the African Americans in the study there were pervasive critical accounts of mental health providers. African-American perspectives are perhaps best summed up by the sense that providers “don’t care.” After visiting the psychosocial clubhouse, Bernice shook her head in exasperation:

> Nothin’ changes – everything is the same and I just don’t have time for that . . . I’m trying to move on and do some positive things and they look like they are trying to keep people in the same ol’ spot . . . They really don’t have an interest in helping people, they are trying to help themselves keep a job and that’s what that’s about.
>
> *Do you really think they don’t care about the people who are at [the clubhouse]?*
>
> I was there so I know that they don’t care. Remember I *was* one of those people. (#12)

Jerome echoed this point:

> Why do I have to go talk to someone who don’t care about me or how I feel? I hate going to CRMHC. I have spent seventeen years going to see doctors that don’t really want to help. They get a paycheck and all they do is write prescriptions that don’t work. (#1)

Many participants similarly felt that providers “don’t listen.” As described earlier, many African Americans in the study were frustrated by what they viewed as a narrow focus on medications among mental health professionals. In the following narrative passage, the medication-centered focus of the clinician clashes with the focus of the participant. Jerome recounted how his case manager was not listening to his ongoing troubles with cockroaches in his apartment:

> I still got roaches in my apartment . . . Roaches all over everywhere. They even in my refrigerator. They be all over my wall, in the sink. When I open the cabinet they be everywhere. I keep tellin’ my case manager I want to move and they not listenin’. All they say at CRMHC is if you don’t take your medicine I’ll lose my benefits. It’s like they tryin’ to blackmail me. (#1)

Jerome’s experience reflects a more general complaint among African-American participants that providers do not help to solve problems. Gladys (#24), for example, felt that “no one wants to help me find work.” Tamara characterized her interactions with therapists in this way:

> They just ask questions and listen, they don’t provide any solutions. They are mainly concerned about you taking your medication. They ask if you’re sleeping all right and if you have any problems you want to talk about and that’s it. They don’t solve any of your problems for you even when you tell them what they are. (#11)

In a related vein, Bernice expressed her desire for someone to talk to and to help her solve problems: “If someone would just talk to me and help me figure out what’s wrong I’d be fine.” (#12).

Others expressed a desire to know "what's wrong": One participant stated: "No one could tell me what was wrong with me" (Tamara, #11). Another said:

> All these pills pills, I'm tired of taking all this medication. I wish somebody would find out what is really wrong with me and stop just giving me pills that don't do nothin'. They don't even try to find out what's wrong with you. They think it's all in your head. (Jerome, #1)

Again, providers' focus on psychotropic medications was configured as a barrier to forging a therapeutic connection. Finally, rather than being viewed as a helpful resource, some African Americans felt "controlled" by their mental health providers. Jerome was most adamant on this point:

> This is my life, this is my head. Why do I have to do what everyone else wants me to do? I'm not crazy and I'll never live a normal life if everyone is telling me what to do. (#1)

SALIENCE OF BIOMEDICAL PERSPECTIVES

Thus far, we have described variation in how individuals from diverse backgrounds engage with, and respond to, mental health services. We now turn our consideration to how participants understand and experience problems that are diagnosed as severe mental illness to argue that biomedical perspectives appear to hold limited salience among Latino and African-American participants relative to Euro-Americans in the study. We highlight that participants' various orientations to problems are shaped through interactions with their social worlds.

Conceptions of Problems

How participants understand and experience problems is another dimension of their experiences that bears on differential acceptability of mental health care. Euro-Americans appeared comfortable with professional biomedical understandings of problems. They were facile with diagnostic language and, unlike Latino and African-American participants, Euro-Americans readily applied clinical labels to themselves. As Fred stated:

> I have a pathology, ADT . . . it's not being able to concentrate. It's a personality disorder, get highs and lows and irritability and it's an anxiety disorder, it leaves me sexually dysfunctional . . . I watched a video tape about it and knew I had it. Then a doctor showed me what I had. (#16)

Likewise, Nora (#4) described herself as having "two conditions": "manic depressive disorder" and "rheumatoid arthritis." At times, Nora felt "unstable" and that she had a "lot of anxiety." She also identified herself as an "alcoholic." Euro-American participants sought out psychoeducational materials through which biomedical understandings were reinforced. Chronicity was also a feature of Euro-Americans' conceptualization of mental illness. These participants viewed mental illness as permanently disabling and subject to "management" through engagement with professional clinical interventions. In contrast to their Latino and African American counterparts, for whom mental health problems and treatment remained peripheral to everyday life, mental illness suffused the lives of the Euro-Americans in the study. As with other participants in the study, Euro-Americans also expressed a keen awareness of the stigma attached to psychiatric disorders and mental health treatment. Nora described her efforts to selectively disclose her illness, only revealing that information to others: "If they have some similar religious or hospital experience, if we exchange stories, or if someone seems like they're understanding and compassionate." (#4)

Latino and African-American participants gave voice to alternative, non-biomedical explanations for problems. Latino participants, in particular, resented diagnostic labels. Horacio (#2), for example, noted that "once they label you, they never look at you the same" and that a psychiatric label "changes you forever." Among many Latinos in the study, problems were often identified as "*nervios.*" Alicia (#14), for example, described herself as "*enferma de los nervios.*" Participants describe *nervios* as something that one "has" or is "sick with" for a long time (*hace mucho tiempo*), but that begins with a specific event. Pedro (#15) first experienced an "*ataque de nervios*" following the death of his grandmother. For others, problems were described more diffusely as "*problemas emocionales,*" "*problemas mentales,*" or "*debilidad mental.*" Among Latino participants there appeared to be little stigma attached to *nervios*. Psychiatric labels, however, were understood to carry the risk of social rejection, as Horacio explained: "I got labeled mentally retarded and a psycho by my friends and stuff when I got out [of the hospital]. I lost like all of my friends. It was rough." (#2)

Among African-American participants, explanations for problems included supernatural or demonological forces. Bernice (#12) confided to the ethnographer that she "didn't fit in" and was "always different," elaborating that she "used to see things" as a child. She continued:

> Even now as an adult I still see spirits. Sometime I see a hand on the table. They don't talk but I can hear what they are thinking . . . Ever since I was a little girl I could feel things, you know like a six sense. I could tell when things were going to happen and I could see things. I could see images of people but not see their faces. When I was younger I use to see an old woman, but I never saw her face. I could hear what she was saying but her face was covered. (#12)

In addition to supernatural explanations, African-American participants put forth characterological explanations, most notably, “laziness.” Psychiatric diagnoses and mental health treatment were seen to carry dire social consequences among African Americans in the study. These participants feared ridicule, disparagement, and even retaliation on account of mental illness. Bernice explained to the ethnographer why she would “never” tell her co-workers about receiving treatment at CRMHC: “Because they would pick on me. When you tell people you have a mental problem, they pick on you and blame everything on you because they know you have something wrong with you.” (#12). Because of the social danger of revealing one’s diagnosis or treatments, these participants were careful not to disclose these matters outside a small circle of trusted kin and friends. A strong recurrent theme in their narratives was the injunction not to air one’s “business” (including SMI) to those outside of the family.

Social Contexts of Distress

Knowledge concerning the nature, course, and consequences of problems is produced in a personal, familial, and sociocultural matrix that includes, but goes beyond, mental health services. Familial and social contexts are the crucible in which accounts of illness and problems are built up and through which experiences of distress unfold. Among African-American participants, we found family members providing explanations for visions and hearing voices that ran counter to standard biomedical interpretations of such phenomena as constituting visual and auditory hallucinations. Bernice (#12), for example, was told as a child by her mother that, “demons were around me. She would tell me that [they] wasn’t good spirits.” Another African-American participant’s mother invoked a constellation of demonological, characterological, and medical explanations for her son hearing voices:

> You hearin’ voices cuz it’s a demon inside you; an’ it inside you cuz you don’ be go-in-na preachin’ an’ prayin’ . . . You can’ find no job cuz you don’ be takin’ you med’cine, like the doctor done said; an’ you lazy.

As with African-American participants, the Latinos in the study were also intertwined within networks of family and friends. These participants supported or were supported by family. In both African-American and Latino families, participants remained incorporated within the normative patterns of behavior, expectations, and responsibilities of the household. Problems, including manifestations of mental illness, were viewed as interpersonal, with moral and material consequences for which participants could be held accountable according to local norms of family conduct. On the one hand, this may be experienced negatively. Among

African-American families, for example, it was not uncommon to hear family members accuse participants of having character flaws, such as "laziness." But on the other hand, this may be understood as a strongly "normalizing" strategy. Mental illness does not give one a "pass" regarding family or household obligations. In addition, among Latino families, the ill person was rarely excluded from circles of kin and friends on account of psychiatric symptoms.

Among some Euro-American participants, family members were also intertwined with the mental health system, reinforcing a clinical conceptualization of problems and an orientation toward acceptance of professional interventions. In Randy's (#23) family, for example, his mother "used to go to the hospital every year" when he was growing up. Overall, the Euro-American participants stood out for their isolation in comparison to the Latino and African American participants. Sarah felt that "nobody cares about me." (#6) Randy was "kicked out" by his sister because, as Randy's mother explained, "she doesn't understand Randy's illness." Similarly, Fred was hoping to "get some distance from my family," a point he elaborated as follows: "It's the blame and change syndrome. They think it's my fault that I'm mentally ill." (#16) Fred described how his family reacted when he was first diagnosed: "Fourteen years ago I was mentally ill and my father and my mother and my brother talked about me like a ladybug on a window. They talked in circles and then got angry at me." (#16)

Ethnographic Portraits

Having outlined the broad patterns regarding how mental illness and mental health treatments are variously experienced and interpreted across individuals in the study, we now turn to three ethnographic portraits. We intend for these portraits to provide "thick description" (Geertz, 1973) of how forms of distress and engagement with mental health services take shape in the lives of three individuals from diverse backgrounds. The individuals selected are emblematic of the patterns we observed across the sample and summarized above.

Portrait I

Bernice (#12), a 43-year-old African-American woman, lived with her mother and sister. She never married and had no children. She had experienced periods of homelessness in the past, having been forced to leave apartments on account of drug use. Homeless shelters and her mother's house have been her principal refuge from homelessness and life on the streets. Although she was grateful to have a haven from drugs and a stable home, Bernice also struggled with her mother and sister.

Bernice first became "sick" as a young girl. As a child she "always felt alone" and "like I wanted to die." In particular, she felt that her mother "never had enough time for me":

> I was really upset when I found out my mother was going to have another baby. She really didn't take enough time with me because [my sister] had problems with her speech, and my mother and father was always fighting all the time. I remember one day my mother and father was fighting and I got so upset I went into the bathroom and I went in the medicine cabinet and I took some pills.

After taking the pills, Bernice's mother took her to the hospital whereupon she stopped talking: "all I did was look out the window." As a young girl, Bernice also saw "spirits." One in particular was an old woman who would visit Bernice in the kitchen: "The old woman would tell me things to help me, but my mother said they were demons. They never tried to hurt me or tell me to do anything bad."

Bernice was cautious about to whom she revealed her psychiatric diagnosis and mental health treatment. She concealed her illness from her co-workers in the deli department at a local supermarket. Although she tended to become "nervous" interacting with demanding customers, she stated vehemently: "I would never tell them [about receiving treatment at CRMHC.] It's not their business. Oh no, I wouldn't tell them I have a problem." She expected to be ridiculed and rejected if others found out about her illness:

> People always act funny towards you when you have a mental disability . . . They whisper and talk about you; they call you names, you know, like, "she's crazy." They will call you stupid and make fun of you when you walk by them.

Bernice's mother was adamant that her daughter's problems were "family business" and, as such, were not to be discussed beyond the confines of close kin.

A common refrain in Bernice's experience of receiving mental health services was that her providers "don't care" about her. During an appointment with her psychiatrist, Bernice described having problems at home with her sister, who "picks" at her all the time. She expressed her desire to move into her own apartment, but that she is not is a position to do so at the moment. Her account received little acknowledgement from the psychiatrist, who redirected the conversation toward the topic of Bernice's medication. From Bernice's perspective, her psychiatrist's role was limited to dispensing medication – a role he appeared to fulfill. She did not expect to "feel better" as a result of her interactions with this clinician. In particular, she felt that clinicians' emphasis on medications came at the expense of trying to find a "reason" for her problems:

> I told the doctor I was depressed and he put me on Prozac. He put me on more medication when I don't need it . . . I'm not taking that medication because I was [simply] depressed and that was it . . . The doctor never took time to find out why I was depressed. All he said was, 'Oh, you're depressed; I'm gonna give you some medication for that.' . . . He never asked me anything; he just wrote the prescription out and gave it to me.

Likewise, she felt that medication-centered treatment prevented providers from helping her to solve her problems:

> Yeah, [the doctor] wants to get paid, but he doesn't care because we are poor and most of us are black and what does he care. It's a paycheck for him; it keeps him employed. They don't want to deal with the problem and try to help you solve it; they just want to give you medication and keep you coming back. If the problem doesn't get discussed it will never get solved.

Following another appointment with her psychiatrist, Bernice explained why she dislikes him:

> He doesn't answer my questions; and he doesn't explain what's wrong with me. I want him to break things down so I can understand what's going on with my body. He doesn't tell me anything and I hate that.

Bernice wished for a provider who would listen and felt that she would benefit from "someone to talk to." Yet this was difficult because of the high turnover of clinicians:

> Sometimes I talk to [my case manager.] But now I find out that [she] won't be my clinician anymore. They assigned me to a man . . . I have no intentions of talking to him about anything. I told you before: when you get comfortable with someone they change that person to another team or they leave. I don't feel like starting all over again and I sure as hell ain't talking to a man. I can't be building trust with someone new and then they get changed and then it's someone else new. I can't be pouring out my heart to everyone and they don't stay long enough to help me. I need someone to get to know me, I want them to know me, Bernice, so they can help me help myself.

Portrait II

Roberto (#25), a 35-year-old Latino man, lived with his mother, father, brother, and two sisters. He was born in Hartford and his parents migrated from Puerto Rico as young adults. His parents would like for him to move out of the house and become independent, however, they have not booted him out.

Roberto described himself as having a "mental disability" (*debilidad mental)* that manifested itself at a young age:

> When I was young my head didn't work right. I didn't think right. I was always doing things wrong . . . Like getting into trouble and stuff . . . My

> brother always used to pick on me. I think that traumatized me . . . I have this problem with concentrating. I have a lot of good knowledge, but I have trouble concentrating.

Roberto attributed these problems to tense familial interactions:

> My whole family is screwed up; they're always arguing and fighting. My parents, they fight a lot, too . . . My parents were fighting all the time. Ra! Ra! Ra! My dad, always screamin' . . .

Religion figured prominently in Roberto's experience. He was a Jehovah's Witness and regularly attended services at the local Kingdom Hall. From this religious standpoint, he felt strongly that doing drugs was morally wrong. However, he occasionally "fell off the path" out of "desperation." The same is true for alcohol and tobacco use. At one point, he was feeling "miserable" after smoking a cigarette and "polluting the Holy Spirit." He noted that, "I can go to see my psychiatrist, but none of that is going to be able to comfort me."

In general, Roberto did not expect to "feel better" through his interactions with mental health services. He found it difficult to connect with his mental health providers, who did not appear to listen to his perspectives and concerns. During an appointment with his psychiatrist and case manager, for example, the psychiatrist repeatedly insisted that Roberto had a "drug problem" despite Roberto's assertions that, "I don't do drugs." In the same encounter, Roberto struggled to have his perspectives on the nature of his struggles heard. When his case manager said, "You sounded really down when I called you yesterday. You were worried about dying and the end of the world," Roberto responded, "That stuff is true man. I'm not hallucinating. That stuff is going to happen . . . I'd just like some stronger medication." Roberto interpreted his experiences through a religious lens while his clinicians framed his worry about the end of the world as being "down" or, possibly, the result of a "drug problem." During the encounter, Roberto openly expressed his disagreement with the clinicians and was frustrated by their efforts "to make me look like I was having hallucinations." Roberto's self-assertion was not limited to this particular clinical context. At one point he recounted how:

> I'm very frustrated and upset . . . I met with [my vocational specialist] on Monday and I made a good display of that. I put on a pretty good show. I showed him how frustrated I was . . . There were some complaints that were not true – people making fabrications about me.

Such an "in your face" style of engagement with mental health professionals may be read as "acting out" (or worse, as symptomatic exacerbations) by providers whereas Roberto and others clearly demarcated such behaviors as normative, justifiable responses to perceived ridicule, dishonor, rudeness, disrespect, or neglect.

Portrait III

Nora (#4), a 55-year-old Euro-American woman, lived in a housing complex for the elderly and disabled. She had recently moved into the complex after having rented an apartment in a house in West Hartford for 20 years. Nora was divorced and raised her daughter on her own. Though they spoke on the phone, they did not see each other frequently. Within the complex, she had befriended a few residents, socializing with them when she does her laundry. She also had a few friends with whom she kept in contact outside of the housing complex. Still, she spent much of her time alone and spoke often of loneliness.

From Nora's perspective, she suffered from "two conditions": manic depressive disorder and rheumatoid arthritis. Mental illness and treatments constituted a core focus of Nora's conversations with the ethnographer. Regarding her illness, she stated, "I was diagnosed manic depressive when I was 22 – my first year in college. But I think I always knew." Nora linked feelings of "anxiety" and being "overwhelmed" to her illness. Much of what she knew regarding mental illness had come through library research and reading health-oriented magazines. Mental illness had touched others in her family. She revealed that her brother had been "manic depressive" and had committed suicide by jumping in front of a train. She attributed her brother's suicide to the fact that he was not taking his medications. Nora was careful about to whom she revealed her own illness and had only disclosed that she had a mental illness to one or two people in the complex.

Nora was closely intertwined with her mental health providers. "My therapist said . . ." constituted a common refrain in her conversations with the ethnographer. Nora viewed mental health services as central to her ability to "manage" her chronic illness. With tears welling up in her eyes, she said to the ethnographer one afternoon:

> I was really depressed on Saturday . . . I've just been so low . . . I really want to talk to my psychiatrist and get my meds changed. I just feel so low all the time . . . I want to get off these meds . . . I want more ups and downs like a normal person. I just always feel like a straight-line. [motioned her hand in a flat line across her body, then moved it up and down to show the highs and lows of a "normal" person] I'm going to the psychiatrist on Friday.

Nora's dissatisfaction with her current medications, however, did not encompass mental health services or providers generally. For her, the solution to her problem of feeling like a "straight line" was under the purview of professional psychiatry and would take the form of an adjustment or change in medication. In this regard, even though she generally disliked psychiatrists, they nevertheless occupied a central and important role in Nora's treatment through the management of her medications. Other providers, including her therapist, had been "more caring" from Nora's perspective. She worked very closely and assiduously with her therapist, frequently seeking out the woman's advice and counsel as a trusted resource in her care.

DISCUSSION AND CONCLUSIONS

In this article we have tried to show how individuals from diverse racial/ethnic backgrounds who were diagnosed and treated for SMI understand and respond to mental illness and mental health services. First-person perspectives offer insights into the complex processes of engagement with contemporary mental health discourse and practice. The patterns that we have identified point to how conceptions and experiences of distress and treatment vary among people of diverse backgrounds in a U.S. urban locale.

Participants across the sample expressed their expectations and experiences of psychiatric stigma. Stigma attached to psychiatric illness appears to be universal cross-culturally (Link, Yang, Phelan, & Collins, 2004; Pickenhagen & Sartorious, 2002). Yet stigma takes on significance in relation to particular local contexts (Coker, 2005; Kleinman, 1988; Yang et al., 2007). Within this study, Euro-Americans were aware of the potential for social rejection and distancing because of SMI, but stigma did not form a core focus of their discourse. Stigma, by contrast, was a very prominent theme in the narrative accounts of African Americans. SMI was considered by African-American participants and their families to constitute "family business" and, consequently, such information was to remain private. Their accounts expressed a strong rhetoric of the potential for information regarding SMI and clinical treatment to expose one to social rejection, disparagement, and ridicule. The strong injunction to conceal SMI may reflect awareness of the perception that individuals with mental illness are dangerous that previous scholars have found among African Americans (Anglin, Link, & Phelan, 2006; Rao, 2007; Whaley, 1997). For Latino participants, *nervios* appears to hold little stigma whereas clinical labels of SMI are potentially very socially damaging. This finding concurs with Jenkins (1988) who found among Mexican-American families that conceptualizing problems as *nervios*, rather than as schizophrenia, protected against psychiatric stigma and reinforced social relations characterized by *dignidad* and *respeto* (Jenkins, 1991).

Our findings regarding stigma are illustrative of the broader point that problems diagnosed and treated as SMI hold significance and take on meaning within interpersonal and cultural contexts. In this article we presented narrative data on how problems are conceptualized and responded to among family members. Families may introduce and reinforce non-biomedical interpretations of problems, as we found among the African-American and Latino participants. Our finding provides further empirical support for differences in symptom interpretation and definitions of illness among minority and non-minority families (cf. Guarnaccia, Deschamps, Milstein, & Argiles, 1992; Jenkins, 1988). Alternative conceptualizations of problems may, in some instances, mitigate stigma (cf. Jenkins, 1988). In addition, SMI did not constitute grounds for extrusion from the family among the African Americans and Latinos in the study, who remained embedded within their familial networks. Clearly, although Euro-Americans were, in many cases, saddened by their extrusion from their families, it is also the case that family contexts are not unequivocally salutogenic for individuals with SMI (cf. Karno et al. 1987; Leff & Vaughn, 1985).

Overall, Euro-Americans participants were most aligned with professional perspectives on severe mental illness. Their disease-oriented, individualistic understandings of problems correspond to how severe mental illnesses are conceptualized within contemporary biomedicine. Mental health professionals were generally viewed as valued and trusted. Euro-American participants sought the advice and counsel of their providers and tried to follow their suggestions. Euro-Americans' perspectives on psychotropic medications as integral to treatment aligns with professional perspectives on the centrality of psychopharmaceuticals. The Euro-Americans in the study inscribed themselves in a clinical narrative; the "illness story" suffused the "life story." Our narrative and observational data illustrating the strong alignment between Euro-American participants and mental health discourse and practice provide further empirical support for the argument that professional mental health services are embedded within a Euro-American cultural and ethnopsychological orientation (Atdjian & Vega, 2005; Gaines, 1992; Hampton, 2007; Kirmayer, 2007).

In contrast to the alignment between Euro-Americans and professional clinical perspectives, we observed substantial disconnection between Latino and African-American participants and mental health discourse and practice. Rather than thematizing SMI, as Euro-Americans tended to do, participants from these populations tended to downplay and normalize mental illness in their everyday lives. Individuals from Latino and African-American backgrounds voiced resistance towards mental health care. They offered alternative explanations for problems that do not resonate with biomedical perspectives. Latino participants called into question the helpfulness of certain forms of treatment, including "talk therapy.” African Americans in the study were highly critical of the perceived over emphasis on medications among clinicians. This reinforced a more general perception among African Americans that mental health providers “don’t care.” The resistant stances toward mental health care that we observed among Latinos and African Americans in the study may offer insights into reasons underlying the well documented variations in access and utilization of mental health services among minority populations in the US. As Newhill and Harris (2007) have found among African Americans, problems communicating with mental health providers were perceived by consumers to constitute a major obstacle to seeking services and engaging in treatment.

Engagement with mental health services and compliance with professional perspectives appears to be facilitated by the adoption of a “sick role” and a willingness to be a “patient,” as we observed among Euro-Americans in the study who relied on the advice and company of their mental health professionals and acquiesced to their wishes. As Good and colleagues have argued, physicians become “most caring of [those] patients who are willing to become part of the medical story they [doctors] wish to tell and the therapeutic activities they [doctors] hope to pursue” (Good, James, Good, & Becker, 2003, p. 595). Although the resistance toward mental health care manifest among Latino and African-American participants may complicate adherence to treatment plans and the utilization of services, such stances may also be interpreted as strongly normalizing assertions of agency. We believe that agentive stances, rather than being viewed as problematic, align with the paradigmatic shift in recent decades toward recovery-oriented mental health services (cf. Jenkins & Carpenter-Song, 2005). Personal effort has been considered central to what Davidson (2003) describes as the “work of recovery.” Mental health services that instead rely upon individuals with mental illness to assume dependence on providers may fail to engage those for whom such a role is unacceptable. Furthermore, what appears to be a successful connection between Euro-American participants and their mental health providers may mask troubling dynamics of dependence and come at a substantial cost, including resigning oneself to having a “broken brain” about which nothing can be done (Jenkins & Carpenter-Song, 2005, p. 403).

This study has brought to light how a small number of individuals from diverse ethno-cultural backgrounds variably experience and express wounds of mind and body that biomedicine appropriates, in part, as symptoms as signifiers of severe mental illness. The first-person accounts presented in this article suggest that each participant has a culturally informed, *individual* way of understanding mental illness, substance use, and life struggles, as well as a set of culturally specific preferences and styles for remediation and recovery. Common to almost all of the participants are culturally informed struggles to "make it," which often loom as large as coping with medically defined psychiatric symptoms. We see an opportunity for clinical alliances to take such existential struggles to heart, by expanding clinical discourse beyond symptom and medication-based exchanges. We propose that "seeing the world through the client's eyes" entails eliciting first-person perspectives on problems and treatment, facilitating an environment in which agentive stances by clients are supported, as essential steps in building trust, confidence, and true partnership that are, we aver, crucial for effective mental health care.

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NOTE

1. Racial/ethnic corresponds to current terminology of the U.S. Census Bureau. We stress that these categories are social constructions, taking on significance in the context of social interactions.
2. The categories, "Hispanic/Latino," "Black/African American," and "White" reflect the terminology of the U.S. Census Bureau. According to the U.S. Census Bureau, "'White' refers to people having origins in any of the original peoples of Europe, the Middle East, or North Africa. It includes people who indicated their race or races as 'White' or wrote in entries such as Irish, German, Italian, Lebanese, Near Easterner, Arab, or Polish. 'Black or African American' refers to people having origins in any of the Black racial groups of Africa. It includes people who indicated their race or races as 'Black, African American, or Negro,' or wrote in entries such as African American, Afro American, Nigerian, or Haitian. Hispanic/Latino is defined as 'a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race'" (Grieco & Cassidy, 2001).

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