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Experiencing Community: Perspectives of Individuals Diagnosed as Having Serious Mental Illness

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Abstract

Objective—Community integration is recognized as a crucial component of recovery from serious mental illness. Although the construct of community integration can be measured with structured instruments, little is known about the subjective and experiential meaning of community and community involvement for persons with serious mental illness.

Methods—In 2010, 30 individuals with serious mental illness treated in two public mental health clinics completed semistructured interviews that elicited the places and people that they associate with the experience of community and the larger meaning of community in their lives.

Results—Participants described four experiences as integral to their concepts of community: receiving help, minimizing risk, avoiding stigma, and giving back. Participants looked for communities that provide reliable support, and they described the need to manage community contact in order to protect themselves and others from their symptoms and from discrimination. Most participants experienced communities centered on mental health treatment or mentally ill peers as providing opportunities for positive engagement.

Conclusions—The experience of having a serious mental illness shapes preferences for and perceptions of community in pervasive ways. Participants describe community involvement not as a means to move away from illness experiences and identities but as a process that is substantially influenced by them. Mental health communities may help individuals with serious mental illness to both manage their illness and recognize and enjoy a sense of community. The findings indicate the need for further research on the relationship between community integration and outcome in serious mental illness.

Since the late 1950s and 1960s, it has become almost axiomatic that persons with serious mental illness are better off when they live in and are part of a community (1–6). More recently, community integration has been defined as an essential component of recovery for

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individuals with serious mental illness. Yet many basic questions about the community life of individuals with serious mental illness remain unanswered. Do persons diagnosed as having a mental illness have a distinct or shared experience of community? If so, what sorts of communities do they tend to seek? What barriers to community involvement—such as symptoms, stigma, or other factors (7–11)—are most consequential?

Although the construct of community integration can be measured with structured instruments (12,13), these instruments rely on an assumed definition of community that may be at odds with the lived experience of individuals with serious mental illness (14,15). Further, these instruments may not clarify why and how individuals with a serious mental illness come to experience a sense of community with certain people or in certain places.

Community—which usually connotes a locale for involvement as well as a nexus for social life (4,10,16–18)—tends to be described as an avenue that moves people away from illness. According to Bond and colleagues (1), "Community integration entails helping consumers to move out of patient roles, treatment centers, segregated housing arrangements, and work enclaves and enabling them to move toward . . . normal adult roles in community settings." That is, community integration "implies 'normalization,'" in which individuals with psychiatric diagnoses "live, work, play, and lead their daily lives without distinction from and with the same opportunities as individuals without disabilities."

Ware and colleagues (4), echoing this view, stated, "The meaning of social integration is not different for different people." They lamented that individuals diagnosed as having mental illness are "in the community, but not of it" because they may "live in neighborhoods alongside people without disabilities" but "remain, in a very real sense, socially excluded." These researchers stressed that persons diagnosed as having mental illness should no longer be considered a special population and deserve "increasing identification with groups not defined by mental illness." In other words, integration requires reducing barriers between those with and without mental illness and creating opportunities for participation in mainstream society (12,18,19).

Similarly, many researchers define community integration in contrast to the illness experience. McColl and colleagues (12) wrote that "community integration has been conceptualized as the opposite of handicap," and Davidson (20) said that recovery involves "minimizing, managing, or overcoming the effects of being a mental patient, including, but not limited to, rejection from family, peers, and society as a whole [and] loss of sense of self as an effective social agent."

Furthermore, prevalent definitions of community often rely upon a dichotomous distinction between inside and outside mental health institutions, a definition that may reflect the historical origins of the community mental health movement as a means to facilitate deinstitutionalization (1,5,21). As Bond and colleagues (1) said, community integration "is not immersion in worlds created by and managed by mental health professionals. . . . These settings are designed specially to pull consumers into treatment and away from community life."

However, studies that explore the experience of community living among persons with mental illness suggest that communal life can be fraught with challenges (10,22–27). Persons diagnosed as having psychotic disorders often report decreased interest, motivation, or tolerance related to interpersonal interactions and social activities (28–31). Although social contact can provide support, social interactions also can have negative effects, including discomfort, social undermining, or stigma experiences (32,33). For this reason, evidence-based interventions for serious mental illness include social skills training, supported employment, and other strategies that facilitate community integration. Ironically, because these programs can be time-intensive, they may also increase clients’ contact with mental health providers and peers with mental illness, integrating them into treatment rather than into the mainstream community.

To develop more robust theoretical models of community integration, we examined the ways in which individuals diagnosed as having serious mental illness define and evaluate the communities in their lives. We asked participants to talk about the experience of community, describe the attributes of the communities with which they feel involved, and comment on involvement with mainstream communities versus those defined by mental illness experiences. Here we describe how study participants define community, the kinds of communities they seek or avoid, and the processes through which communities gain intrinsic value for them.

Methods

Study design

This study used a grounded-theory approach to explore community integration. This approach involved inductive, iterative examination of qualitative data to generate a theoretical framework for understanding social-psychological phenomena (34,35). We used a maximally variant sampling frame and an open-ended interview design to capture the broadest range of responses.

The data are part of a longitudinal study funded by the National Institute of Mental Health that examines the impact of recovery-oriented system changes in Los Angeles County public mental health clinics. The parent study includes individuals (N=477) treated in intensive, outpatient therapy, similar to assertive community treatment, by case management teams and individuals matched for illness severity who are treated in usual, clinic-based, outpatient mental health care (one to four appointments per month).

Case managers of intensive, outpatient therapy have up to four treatment contacts per client per week and a low caseload (20 clients). Analyses using administrative data have shown that clients in intensive treatment receive about eight service hours per month compared with 2.5 service hours per month for clients in usual care. Participants completed a battery of instruments (36,37) upon enrollment in the parent study.

We derived our sample (N=30) from individuals enrolled at two of the six participating clinics (called by the pseudonym “Oak Ridge Mental Health Clinic” in this article). As a result of the matched sampling strategy, clients of both the intensive and the usual care programs demonstrated functional impairment at baseline, for example, Global Assessment of Functioning score <55 and recent homelessness or hospitalization. To capture an array of community experiences, we enrolled individuals from intensive and usual care treatment teams with varying race-ethnicity, primary diagnosis, and gender. During the recruitment phase, the team reviewed enrollment in an iterative process and adjusted sampling to maximize variation of the study groups and both treatment teams. Study team members remained blind to participants’ data from the parent study.

In all, we contacted 40 individuals and arranged appointments with 35. Between January and December 2010, we completed quantitative assessments with 33 and quantitative and qualitative assessments with 30; quantitative findings will be reported elsewhere. After the study was described, participants provided written informed consent. Sampling continued until preliminary data review suggested thematic saturation had been reached (38). No participant was lost to the study after consenting. The study was reviewed and approved by the institutional review board at the University of California, Los Angeles, and the Los Angeles County Department of Mental Health Human Subjects Committee.

Fourteen men and 16 women participated in interviews. Participants ranged in age from 26 to 53 years, with a mean±SD age of 38±8 years. Thirteen (43%) participants were African American, four (13%) were Caucasian, 12 (40%) were Hispanic, and one was Native American. Fourteen were enrolled in usual care, and 16 were enrolled in intensive treatment. Primary chart diagnoses included bipolar disorder (N=12), depression (N=4), and psychotic disorders (N=13). One participant had a severe anxiety disorder. Participants' mean±SD scores for items on the Behavior and Symptom Identification Scale (36) (1.6±.9 out of 4) and the Satisfaction With Life Scale (37) (1.6±.8 out of 4) were in the expected range for community-based samples of persons with serious mental illness (39–41) and were similar for participants in intensive treatment and usual care.

Structure of the interview

The semistructured interview guide is described in a box on page XXX. All interviews were conducted in English. Interviews were transcribed and checked against the audio recording by two authors (EB, SG). Two authors (EB, SG) conducted an inclusive tally of all communities named by participants as important in the past or present, even if participants described negative or ambivalent feelings about experiences in these communities, and compared and reconciled results. Then, using thematic data analysis, we looked for patterns in the way participants described community experiences. EB and SG analyzed transcripts independently to generate a list of preliminary themes and the narrative examples for each. These results were compared and discussed, and themes were refined. Next, themes and examples were reviewed with other members of the research team (JSB, BB, and RP) and refined further. Then EB and SG reviewed themes against the entire qualitative data set to search for disconfirming cases. The list of themes and narrative examples were reviewed with the study team (JTB, BB, and RP) and finalized. EB and SG then reviewed the entire data set to search for differences in the salience of these experiences across clients with different characteristics, such as treatment group, race-ethnicity, and gender.

Results

Participants described an approximately equal number of places and people as communities (Table 1). Many participants identified family (N=22) and the mental health clinic (N=19) as a community. More participants in intensive treatment than in usual care cited the clinic and mental health peers as communities, and more participants in usual care than in intensive treatment identified family. Twice as many Hispanic (N=8) as African-American (N=4) participants mentioned family as community.

Across the sample, participants described similar processes through which certain environments or people come to signify community. Four patterns of experience recurred in participants' concepts of community: receiving help, minimizing risk, avoiding stigma, and giving back. We did not observe significant differences in the salience of these themes between individuals enrolled in intensive versus usual care treatment programs. Few participants prioritized any one experience as most central to community, and most participants attributed more than one experience to a single community.

Receiving help

Participants most commonly described their communities as places where they receive help. When interviewers asked participants why they felt a sense of community from a given place or group, the most common response was, "They are there for me, and I can count on them," particularly in times of vulnerability. As one participant said about her family, "When I needed strength, they were there to pick me up and to give me good advice."

Many participants described receiving help as a key characteristic of communities found in mental health treatment settings. Asked why her mental health clinic community was important to her, one participant said, "Oh, [Oak Ridge Mental Health], they're amazing, they have pretty much everything you need. You just have to interact with the programs and everything. Just 'cause the office is closed doesn't mean that you can't get help, and to me that's beyond important, because there's several times I've had issues come up and I've called up my worker [Jane] and she's called me back. . . . They're my backbone when mine isn't working, so it's very important." Another participant described the importance of his 12-step community, saying he had stayed clean for months, "but my life still sucked . . . so I wanted to try to work the steps and see if my life would improve—and it has, slowly, but it's definitely better than without it."

Several participants described these experiences of receiving help also as an opportunity to identify with others. As one said, "I do feel a sense of community with Oak Ridge Mental Health. When I go to a group, I know that we are all battling a common monster. Everyone has their own demon, their own monster, but, hey, we're all basically on the same page. We're all seeking help and I feel comfortable." As another participant said about his residential treatment program, "It helped me to really understand more about what I was doing to myself, to get me to stop continuing down that road starting to use again, and then that made me want to stay sober. . . . Those meetings help. And all the support you get from all the people there, it's definitely a boost."

Some participants indicated that these experiences in mental health treatment settings or with others with mental illness influenced what they seek and value in other communities. One participant described a group of friends as an important community because, "we all have our backgrounds and we all struggle with, you know, emotional problems or whatever and so that kind of tightens us up. So it's more of like—it's also a support group." One participant described his church as an important community because of the help it provides in managing his mental illness. The church is "the foundation of my existence," he said. "I mean, when I'm in a crisis, I just go and I guess, you know, when I'm feeling a little down, I just go and pray a little and you know, that helps me to keep my sanity."

Several other participants described their mental health community as a gateway to other communities. One participant said his clinic team "gives you a place," to find support. He appreciates the team's encouragement of activity and social integration: "I mean, they go bowling every other week, get you out . . . go to picnics . . . different things. And that's just important because a lot of consumers, they just don't have no social network, they don't have no places to go. And like when I started going back to church, they said, 'Oh, that's good.' They encouraged me to keep doing what I was doing." A minority of participants described receiving help from communities not centered around mental health, such as communities at work or school and family.

Minimizing risk

Many participants described community as a place where they confront and manage risks to themselves and others. Most commonly, participants described their symptoms as posing risks in community contexts. Many worry that they will feel anxious or overwhelmed; they also worry that their symptoms will become threatening or irritating to others. Participants constructed their communities in ways that allow them to minimize these risks. As one said, "I dodge people. When they start calling me sometimes, and I don't know why, it might be part of what I'm dealing with in terms of depression or whatever, but I just don't want to deal with them sometimes."

Most participants described mainstream, public settings as risky. Many reported a pervasive need to limit the amount of contact there. For instance, one participant worries about the impact of her symptoms on those she sees in public. She restricts her contact with the public "because my moods go up and down. . . . Sometimes I'm not that pleasant. That doesn't make me feel like I'm part of something nice. . . . Sometimes I think I'm like a nightmare customer, so sometimes I feel bad . . . After I'm moody, I feel really bad about it." Another said, "I have a deadly temper. It can get real hostile, real fast . . . so I try to stay away. I don't visit malls. If I do, I go in, grab what I've got to grab, and get back out." A third shops at 5 a.m. to avoid being around too many other people.

Far from seeking to expand their community experiences, many participants prefer to keep to themselves and to familiar locations. Several participants described daily activities similar to those reported by one client: "Other than [group meetings], I'm at home. I don't [interact with the public]. I just, if I'm going to the store, I get what I'm going there for; if I sit at a restaurant I sit there and eat and leave." Even those participants who value positive experiences in mainstream communities did not describe a desire to be more integrated there.

Nonetheless, a few participants expressed a desire to strengthen ties to mainstream communities in order to overcome the disabilities caused by mental illness. These participants see mainstream community integration as a challenge or a risk, but one with high significance. For example, one participant described his city as an important community "because it's given me the opportunity to potentially go back to work. By getting some schooling in right now, I'm trying to get my life adjusted and figure out if I'm going to be well enough to go back to work."

Avoiding stigma

Almost all participants described painful experiences of stigma that led them to seek and value communities where they can minimize the potential for rejection. One participant said, "I feel like everybody is looking down on me, instead of looking at me like a person . . . like I'm considered an outcast." Another said, "I've known people that say, 'Oh, you go to [Oak Ridge]? Oh, wow, like stay away from you.' And even people around [the clinic] that I met . . . they're like, 'Are you part of the crazy crowd?'"

Participants' most frequent experiences of stigma were not from strangers but from family members and intimates. These episodes most commonly involved a loved one who is insensitive to the experience of living with a mental illness. Describing his family, one participant said, "They're the worst people. . . . They're very nice people, they're very lovely people. But they just don't understand me. . . . They just think, 'Just drink a tea and go to sleep.'" Another participant described a recent depression: "My roommate . . . wasn't there for me. . . . I was crying; she knew I'd been depressed . . . and they had to call the paramedics. . . . I guess since she's not mentally ill, she doesn't really understand bipolar." Another described family members who attribute all of his actions to mental illness. He said, "They were more sensitive to everything I was doing. Like, if I were to keep dropping a bottle of water, they would think it would have something to do with my illness, [rather] than me being clumsy. So if I do anything, it would be kinda like the illness, you know what I mean? Even if I got into an argument, they'll say it's my illness."

These experiences of feeling misunderstood or defined by their mental illness strongly shaped participants' expectations and preferences for community. Most commonly, participants avoided situations that they feared would elicit stigmatizing responses from others. One participant felt unwelcome in public settings because of his diagnosis: “For some reason, I think that they can see a sign on my forehead saying I have bipolar disorder.” One participant lamented that those with whom he interacts do not understand his illness. As he said, “If I was in a wheelchair, it's obvious what's wrong with that person. . . . I come across as being a very normal person. I'm articulate, I talk, and I seem very personable. So they don't understand that I have a disorder.” This experience of being misunderstood had left him with few friends and little desire to make more. One woman who values her church community does not socialize with those she meets at church, explaining, “I'm kind of shy about it now because of my mental illness. I'm kind of, like, not embarrassed, but just don't want them to know that I have the mental illness. I'm pretty sure they know; they're not going to judge me. But . . . I would be very, very heartbroken if they would find out and somebody would make a remark about it, then I'd rather not.”

Commonly, participants described communities as enclaves (6) they construct to avoid rejection. They described honing communities in ways that allow them to avoid stigma. For example, one participant said, “I would never disclose it at a job interview or a place of employment, unless it was in the field and it would benefit me that they know.” One subject said that when some people hear he has been diagnosed as having a mental illness, “Next thing I know, I don't hear from them anymore. . . . .For me, personally, it's better for me. I don't need people like that in my life.” Another keeps to familiar locales and reminds herself that some people are simply judgmental: “Sometimes I think I'm better off not to go there because a lot of people, when they hear somebody is having mental illness, they just think he's totally a lunatic and there's something wrong with you.” For many, the protective enclave is composed of others who understand what it is like to live with a mental illness. As one participant said, “Only somebody who goes through that knows what you're feeling.”

Giving back

Finally, several participants described a sense of community in situations that provide opportunities to respond generatively to past experiences. Participants described community as a place where they can give back. As one participant said, a church where he volunteers is important “because I've been at a point where I didn't have food or stuff like that. If you're at a point where you're doing better than you were, then you need to give back; so that's what I'm trying to do.” Another explained that, “I take friendship very seriously, partially because of what my background is. I've never had any reason to trust my family or relatives or anyone, so I take care of my friends.”

Many participants particularly value communities that allow them to put a painful past to use. For instance, one participant described the importance of his extensive online mental health community. He said this community is “a really big one for me . . . because I feel like my purpose being bipolar is to help people, not only through writing books and blogs and everything, but reaching out to people. And, you know, I have, like, for example, on Twitter I have a lot of mental health organizations . . . and I also have a lot of mental health consumers all over the world that I communicate with every day. . . . So that's very important to me in keeping my sanity because I feel like I want to give back. . . . It makes me feel like if I'm helping somebody. It makes me feel like a better person.”

Like other participants quoted above, this participant's experience in community shapes his identity and supports his esteem. In a similar way, another participant defines her identity in contrast to a mainstream community, where she feels she cannot productively contribute. She said she does not feel as though she belongs in the mainstream community “because I don't feel productive. I don't feel like I have something in common because I'm not working, I'm bipolar, I don't have money. So I don't feel productive. I don't feel like I have nothing to offer."

Discussion

This study explored the meaning and value of community for persons with serious mental illness. Overall, participants said they value communities that are helpful, low risk, nonstigmatizing, and facilitative of generativity and altruism. These findings run counter to some of the literature on community integration (1–5). For example, according to recovery-oriented definitions, community integration affords engagement with the mainstream public (21,23). In contrast, participants in this study often named places and groups comprising persons with mental illness as useful for forging identity, developing comfortable patterns of interpersonal interaction, and facilitating participation in communities (6,42). Participants most often experienced mainstream communities as stigmatizing or risky, and they most often described communities centered in mental illness experiences as helpful or as a source of protection from rejection (43,44). Compared with participants from usual care, participants from intensive clinical programs mentioned ties to mental health communities more often.

These findings had several limitations. Because our data were cross-sectional, we cannot determine whether participants' positive perceptions of mental health–related communities mark a stepping-stone in a longitudinal trajectory toward preferring mainstream communities. Because of our small sample size, we did not explore the impact of illness severity or neuropsychological factors that may impact perceptions of community (45). Finally, we conducted a majority of our interviews in a clinic environment, and we recruited from among a sample of individuals who were involved in the larger, parent study. This may have led to response bias that encouraged participants to elaborate on their ties to treatment settings and to others with mental illness. It may also have resulted in a sampling bias that skewed our sample toward those who are more engaged in the clinic.

Nonetheless, these findings raised questions about whether integration into the mainstream community ought to be a goal of recovery-oriented treatment. As Mandiberg (42) said, clinical services that prioritize mainstream involvement may present clients with a classic double bind: encouraging identification with a mental health community in one moment and signaling that progress entails leaving it in the next. By taking seriously these participants' experiences, development of a mental health community could be seen as a meaningful effect of treatment. However, if participants' descriptions of widespread rejection by mainstream communities, including families, are typical, the clinical community may be primarily compensatory, offering a second-tier "program citizenship" (46) that permits avoidance of richer community options and enables mainstream communities to continue exclusionary practices. Even so, providers and programs could acknowledge that the clinic community has value for clients at the same time as they work toward mainstream integration.

More research on community as a determinant of other clinical outcomes is needed. We lack data about how experiences and compositions of community relate to long-term outcomes of serious mental illness, such as symptoms, quality of life, social functioning, employment, and social capital. Does identification with a group or clinic related to mental health facilitate long-term progress, or do clinical communities foreclose mainstream opportunities and lessen quality of life? Further research could also aim to develop structured instruments that operationalize the four themes of community identified in this study.

Conclusions

Community integration has been described as a continuum of experiences characterized by degree of normalization, yet participants closely link their illness experiences to their understanding of and valuation of different communities. Rather than striving for normalcy per se, participants emphasize most often the need for reliable communities that provide consistent support and a safe haven. Further research is needed to set clinical and policy priorities related to community integration.

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Semistructured Interview Guide to Elicit Experiences of Community Among Persons With Serious Mental Illness

“I'd like to ask you about the idea of community. Some people think of community as a place where you live or hang out. That's part of it. But it can also be a group of people that you join with or feel a part of. So when I say the word community, tell me what you think of.”

[If participant names community] “Tell me about it.”

[If participant does not name community] “Do you have a community you feel like you belong to now?”

[If participant still does not name community] “Do you have a place where you can go where you feel like you belong now?”

[If participant still does not name community] “Did you ever in the past have a community you felt like you belonged to?”

[For each community, if not named, prompt] location of community, other members, relationship between participant and community, when participant visits, and other attributes relevant to community such as activities pursued or nature of relationships.

[If not named, prompt] “Is this community important to you? Tell me about that.”

[If not named, prompt] “I'd like to understand why this community is or is not so valuable to you.”

[For past communities, if not named, prompt] “Tell me why you are no longer a part of this community.”

“How about other communities? Do you have other communities in your life now?” [Repeat all prompts with each community.]

“What about another community: the mainstream public? By that I mean the people at the grocery store, at the bank, at a baseball game, in a restaurant, or just on the street.”

[If participant names community] “Tell me about it.”

[If not named, prompt] location of community, members, relationship between participant and community, when participant visits, and other attributes.

[If not named, prompt] “Is this community important to you? Tell me about that.”

[If not named, prompt] “I'd like to understand why this community is or is not so valuable to you.”

“Tell me a little more specifically about your interactions with people who DO NOT have a mental illness. Do you have a recent example that shows me what these interactions are like for you?”

“Have you heard of *stigma*?”

[If yes] “Tell me about your understanding of stigma.”

[If no] “Stigma is the experience of being judged ahead of time, or being seen as less valuable than other people, and perhaps being discriminated against, based on a characteristic of yours.”

“Have you had any experiences of stigma in your own life?”

[If yes] “Tell me more about this experience.”

[If no] “Tell me more about why you think you have not experienced stigma.”

Table 1

Communities named by clients in intensive treatment and usual care

Community	Examples	Total (N=30)	Intensive treatment (N=16)	Usual care (N=14)
Place				
Mental health clinic	Assertive community treatment program	19	11	8
Neighborhood or residence	City, mobile home park, board and care	15	9	6
Vocation	School, volunteer work, employment	9	4	5
Other location	Park, coffee shop, library	6	4	2
Religion or church	Specific churches, Islam culture	15	11	4
People				
Family	Siblings, parents, extended relatives	22	9	13
Mental health peers	Peers from 12-step and support groups	14	10	4
Non-mental health peers	Friends, acquaintances	14	8	6
Other group	Fundraising groups, diabetes support group	6	2	4
Racial or ethnic group	Mexican-American community	2	1	1