

Socially Valued Roles, Self-Determination, and Community Participation among Individuals Living with Serious Mental Illnesses

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Highlights

- Our study examined community participation for individuals in recovery from serious mental illness.
- We conducted an in-depth examination of key stakeholder perspectives.
- Self-determination has important meaning in the psychological sense of community for this population.
- Community integration can be improved through special attention to motivational constructs.

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Abstract Decades after deinstitutionalization, individuals living with serious mental illnesses remain isolated, socially disengaged, and devalued members of communities. Burgeoning research and services need conceptual clarity to improve such social conditions. This qualitative inquiry used grounded theory and participatory approaches to conduct an in-depth exploration of community participation for individuals living with serious mental illnesses based on key stakeholder perspectives ($n = 45$). Results revealed that community participation is a multifaceted construct with layers of meaning for individuals living with serious mental illnesses. Overarching themes are contextualized in Self-Determination Theory and presented with deidentified illustrations. Implications for services, research, and policy are discussed.

Keywords Community participation · Serious mental illness · Psychiatric disabilities · Qualitative analysis · Participatory research · Rehabilitation

Introduction

The World Health Organization identified serious mental illnesses as the fifth leading cause of death and disability worldwide (Whiteford et al., 2013). In the United States, neuropsychiatric disorders (18.7%), a large percent of which includes mental and behavioral disorders (13.6%), are identified as the leading cause of disability, that is, percent of population with total number of years lost to illness, disability, or premature death (Murray et al., 2013). Serious mental illnesses is a term used to describe the experience of individuals diagnosed with a psychiatric condition of prolonged duration accompanied by significant impairments in a functional or role capacity that substantially limit one or more major life activities (Substance Abuse and Mental Health Services Administration [SAMHSA], 2016). Social functioning and community integration of individuals living with serious mental illnesses are often affected and impaired by debilitating symptoms and associated disruptions in important life stages (Rowe et al., 2012). On the other hand, community participation and integration harbors many benefits such as increased psychological well-being, perceptions of belonging and community connectedness, empowerment, independence, and expansion of social networks (Aubry, Flynn, Virley, & Neri, 2013). Despite stated benefits, this population faces profound challenges to community participation and integration (Nelson, Kloos, &

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Ornelas, 2014). In particular, there is a shortage of research on the measurement and facilitation of community participation among these individuals (Salzer, Brusilovskiy, Prvu-Bettger, & Kottsieper, 2014; Salzer, Brusilovskiy, & Townley, 2018).

Social Role Participation

Historically, individuals living with serious mental illnesses have experienced considerable devaluation in society, relegating their status to that of a socially marginalized group (Aubry et al., 2013). Wolfensberger (1983), widely recognized for his contributions to disability policy, described this experience in his theory of *Social Role Valorization*. He identified social roles as having prescribed values (*valued* vs. *devalued*) based on societal perceptions of what that role entails (Stenius, Veysey, Hamilton, & Andersen, 2005). In the early 20th century, people living with serious mental illnesses had limited social opportunities with minimal expectation of being productive and contributing members of society. While deinstitutionalization enabled this population to return to living in the community, the focus has largely remained on treatment and stabilization of psychiatric symptoms (Nelson et al., 2014). While long-standing debilitating symptoms (e.g., social anxiety) seriously impede community participation, individuals living with serious mental illnesses also contend with low expectations and the insidious nature of social stigma (Wong, Sands, & Solomon, 2010). Negative internalized perceptions result in fear, apathy, low self-esteem, and meaninglessness (Hinshaw & Cicchetti, 2000; Perlick, 2001). As a result, these individuals occupy devalued roles in society, remain isolated from mainstream society, and excessively rely on mental health professional caregivers for social connections (Argentzell, Leufstadius, & Eklund, 2014; Tsai, Desai, & Rosenheck, 2012).

Evidence accumulated over the past three decades demonstrates that people who experience serious mental illnesses are capable of occupying socially valued roles in the community through community living, work, and education (Silverstein & Bellack, 2008). In fact, these individuals conceptualize their communities as spaces where they receive help, minimize risk, avoid stigma, and give back (Bromley et al., 2013). Burgeoning recovery and rehabilitation services such as supported living, supported education, and supported employment, have been instrumental in promoting valued social roles and supporting citizenship (Drake & Bond, 2008; Gulcur, Tsemberis, Stefancic, & Greenwood, 2007; Rogers, Kash-MacDonald, Bruker, & Maru, 2010; Sylvestre, 2017).

Despite considerable progress, peers and community psychologists have criticized such efforts as largely

ameliorative. Ownership for ameliorating the problematic lack of community integration has been placed on the individuals with lived experience rather than the larger systemic forces that maintain the status quo (Nelson et al., 2014). Exercising the rights and responsibilities of citizens has been considered a reward contingent on individuals overcoming their mental health symptoms rather than a necessary precondition to their recovery (Pelletier et al., 2015). As a result, authors have been advocating for transformative change in community mental health to address these issues (Nelson et al., 2014). Transformative change in community mental health requires shifting the focus onto individual choice and control unfettered by external influence and interference.

Community Participation and Self-Determination

There is a pressing need for deeper understanding and conceptual clarity with regard to community participation (Salzer & Baron, 2014). Community participation is a complex and multidimensional construct which includes physical, psychological, social, and community experiences. The physical and social aspects of community participation have been most extensively studied (Min & Wong, 2015; Rowe et al., 2012; Townley & Kloos, 2009) while only recently have researchers been paying attention to the psychological aspects of the same (Pahwa & Kriegel, 2018). The psychological sense of community (Sarason, 1974), widely explored in community psychology, has a significant, positive, and moderately strong relationship with community participation (Talò, Mannarini, & Rochira, 2014). Both active community participation and a psychological sense of community have been associated with social empowerment and self-determination (Nelson & Prilleltensky, 2010). As a result, the field of mental health has increasingly been encouraging active participation with a strong focus on self-determination to ameliorate the consistent lack of social participation among individuals living with mental illnesses (Corrigan, Morris, Michaels, Rafacz, & Rüsich, 2012). In fact, leaders in the peer recovery movement have identified the basic needs of self-determination as fundamental to recovery from serious mental illnesses (Mancini, 2008; Onken, Craig, Ridgway, Ralph, & Cook, 2007).

Self-determination in community participation emphasizes individual choice and control (Wehmeyer & Shogren, 2016). However, as a consequence of socially devalued roles and societal barriers, self-determination is often an elusive experience among individuals living with mental illnesses. Low motivation, closely associated with disempowerment, has been linked to poor community participation and engagement among these individuals (Thomas, Luther, Zullo, Beck, & Grant, 2017). In a study by Brolin, Brunt, Rask, Syrén, and Sandgren (2016), individuals

living with serious mental illnesses described being deprived of self-determination in community living situations. Such experiences led to feelings of powerlessness, loss of meaning, and diminished self-esteem and self-worth (Brolin et al., 2016).

In order to understand the role of self-determination in the context of community participation, we felt it was necessary to lay the groundwork by unpacking the motivations of people experiencing serious mental illnesses with respect to community participation. Motivation is an essential psychological construct that underlies human behavior especially with respect to the decisions that these individuals make regarding housing, physical activity, employment, and health behaviors (e.g., Romain & Abdel-Baki, 2017). While these aspects are components of community participation that have been explored among individuals living with serious mental illnesses, we believed that the motivational aspects of community participation among these individuals as a whole needed further exploration. Recently, Sylvestre (2017) have called for the need to identify barriers to citizenship in the daily interactions of individuals living with serious mental illness as well as macro-level policies and laws. We believed that such explorations would help identify such barriers and provide important insights into the reasons for community participation among individuals living with serious mental illness and the role of important social networks, potentially informing further directions for service provision and research and facilitate the inclusion of psychological aspects of community integration.

Self-determination theory (SDT; Ryan & Deci, 2000) has been systematically utilized to understand the community activities of individuals living with serious mental illness (e.g., Moran, Russinova, Yim, & Sprague, 2014). Intrinsic motivation in SDT has been described as “*the inherent tendency to seek out novelty and challenges, to extend and exercise one’s capacities, to explore, and to learn*” (Ryan & Deci, 2000, p. 70). Debilitating symptoms and societal conditions of stigma and devaluation can stymie inherent tendencies and interfere with the satisfaction of basic and innate psychological needs that form the basis for self-motivation, that is, the needs for competence, relatedness, and autonomy.

The development of any comprehensive conceptual model of community participation for individuals living with serious mental illness begins with an exploration of related motivations for engaging with the community despite significant barriers. Theories of community integration of individuals who experience culturally devalued social roles need to be grounded in the principles of empowerment, social justice, critical consciousness, and emancipatory communitarianism (Nelson et al., 2014; Prilleltensky, 1996), especially since programs built from the “ground up” (i.e., by including community values,

indigenous knowledge, and key stakeholder perspectives) are progressively becoming standard practices and are likely to have more success and applicability (Feinberg, Bontempo, & Greenberg, 2008).

The purpose of this study was to explore the meaning of community participation and inclusion for individuals living with serious mental illness following a theoretically grounded, systematic, and comprehensive approach. We developed the research questions after reviewing existing literature and consulting with individuals with lived experience of serious mental illness. The study questions for this specific study were: (a) what are the perspectives on the community participation of individuals living with serious mental illness as viewed by individuals with lived experience and their network of natural and professional supports, and (b) what are the specific motivational factors influencing community participation among individuals with lived experience?

This study was nested within a large-scale qualitative inquiry into the meaning, facilitators and barriers to community participation to support and inform the development of a measure of community participation and a peer-led community participation intervention. Previous research with a similar purpose primarily focused on the first-person narratives of individuals living with serious mental illness (e.g., Chronister, Chou, Kwan, Lawton, & Silver, 2015; Davidson et al., 2001). Based on the recommendations of previous researchers (e.g., Magasi & Heinemann, 2009) in the context of measurement and service development in rehabilitation, we believed in the importance of the inclusion of multiple stakeholders in our exploratory study. Therefore, we sought to solicit diverse perspectives on community participation from individuals with lived experience and those who comprise the natural and professional support networks of these individuals.

Method

This exploratory investigation was designed as a qualitative study to explore the perspectives of community participation among individuals living with serious mental illness using a variety of data sources. Our study was informed by the principles of grounded theory (Charmaz, 2006) and aspects of community-based participatory research (CBPR; Smikowski et al., 2009). We followed a horizontal and a vertical approach to sample construction. Above all, we believed that the perspectives of individuals with lived experience were central to our study. We also believed that inclusion of the perspectives of individuals who comprise the proximal and distal supports of individuals with lived experience would provide additional depth to the information gathered. While family and mental

health providers have been identified by individuals with lived experience as their primary social network (Tsai et al., 2012), we wanted to include the perspectives of community leaders, that is, individuals with social influence and a professional interest in the inclusion of individuals with lived experience in the community. Finally, important differences in community participation have been found in urban and rural locations (Townley, Brusilovskiy, & Salzer, 2017). We took steps to ensure representation in terms of locations. In the selection of our research site to conduct all study procedures, we chose a mental health agency in the Northeast whose explicit mission is to improve community participation for adults with disabilities. This agency provided a wide variety of mental health and community-based services and programs for individuals living with serious mental illnesses. This study involved a one-time data collection for all participants involved after a brief screening process by phone to establish eligibility. All study procedures were reviewed and approved by the state and university Institutional Review Board.

Participants

A total of 69 individuals were recruited from rural, mid-sized, and urban communities. We collaborated with a single agency where we recruited four separate groups of participants, namely, consumers, family members, providers, and community leaders. Different sets of criteria were used for each selection of study participants. All participants in this study were required to be adults (i.e., above the age of 18) and have the ability to provide willing and knowing consent.

Consumer Participants

Eleven adults living with serious mental illnesses were recruited at two locations (rural and urban) of a mental health agency in the Northeast. These individuals participated in two ($n = 6$; $n = 5$) focus groups. Participants were paid \$40 for their time. All participants in the focus groups were White Americans. These individuals included six males and five females ranging in age from 24 to 55 years. Participants in this group required a mental health diagnosis. Among these individuals, five were diagnosed with schizophrenia or related disorders, three with post-traumatic stress disorder (PTSD), two with major depressive disorder, and one with bipolar disorder.

Provider Participants

Thirty-four mental health providers with experience serving individuals living with serious mental illnesses participated in five separate focus groups. Provider participants

selected were based on their affiliation with the mental health agency served their service recipients in varying capacity. The focus groups included two groups of community-based outreach providers ($n = 9$; $n = 8$), one group of peer providers ($n = 5$), one group of therapists at a community-based mental health clinic ($n = 9$), and staff at a clubhouse ($n = 3$). Participants included 26 females and eight males. These individuals included 27 White Americans, three Native Americans, two Latinx Americans, and one African American.

Family Member Participants

Five family members of individuals living with serious mental illnesses participated in individual interviews. These individuals had to have some experience either living with or attending to the needs of a family member with lived experience. All these participants were White Americans. Three were females and two were males. Three of these individuals were parents while two were siblings in relation to individuals with lived experience.

Community Leader Participants

Three community leaders were invited to participate in individual interviews based on their involvement as advisory board members of our collaborating agency. These individuals were White American males. One of these individuals identified as a peer. These individuals were recommended by the agency as community leaders with a keen interest in the community integration of individuals with lived experience by providing employment or developing essential programs.

Instruments

The instruments for this study included a demographic questionnaire and interview guides developed specifically for this study.

Demographic Questionnaire

The *demographic questionnaire* was designed to obtain basic demographic information (e.g., age, gender, race, marital status, education, etc.) and clinical characteristics of individuals living with serious mental illnesses (e.g., psychiatric diagnosis). These questionnaires were adapted for each key informant group.

Interview Guides

For focus groups and interviews, we developed a set of *Interview question guides*, which were semi-structured protocols with open-ended exploratory questions to address the primary questions on community participation

specific to each group of key informants in this study. We individualized our queries based on the participants' experience and expertise using an iterative process.

Procedures

Our overall approach to the qualitative research activities was based on grounded theory methodology and CBPR (Smikowski et al., 2009). Following the foundational principles of CBPR, we partnered with representative members of the population, that is, individuals with lived experience, at all stages of the project. Individuals with lived experience (i.e., peers) were involved in the development and design of the study (including questions in the interview guide), implementing key research procedures, analyzing study data, and interpreting the findings. In particular, a team of three peers consulted on the development of the study and the design of the interview guide. One peer was a key member of the research team, integrally involved in data collection (interviews and focus groups), data analysis, interpretation, and manuscript preparation. Finally, we sought consultation on the interpretation of our results from a well-established researcher and expert on this topic who identifies as peer. The study questions and purpose were too far removed from policy change to be considered "action research."

Data Collection

Individuals living with serious mental illnesses and family members were recruited through flyer distribution at the agency. Interested individuals completed a consent form giving research staff permission to contact them directly. Participants were paid in cash for their participation. For providers, we contacted the directors of the different teams of each group of providers within the agency and scheduled a brief informational session during their regular team meetings. Interested providers filled out a sign-up sheet and focus groups were conducted at a convenient time and location. We ensured representation of diverse groups of providers across urban, rural, and mid-sized communities. Individuals in leadership positions at the study site nominated the community leaders as participants. While we reached out to several more individuals, family members, and community leaders, we were only able to recruit those who responded to our request and attended their respective focus groups and interviews. Each group of participants was assigned a unique identification number (e.g., 101 for individuals with lived experience; 200 for providers, etc.)

Two facilitators were present for each focus group and interview. One facilitator conducted the interview while the other took notes verbatim and recorded nonverbal

responses. All focus groups and interviews were audio recorded and transcribed. The duration of the focus groups of adults diagnosed with serious mental illness was 90 minutes in length each. All participants completed demographic forms. Individuals living with serious mental illnesses also completed a form authorizing their providers to share their documented diagnosis. Focus groups conducted with providers met for a single session of 1 hour each. All focus group participants were engaged in a discussion centering on the meaning of community participation as well as facilitators and barriers to community living and participation for the adults living with serious mental illnesses. Providers of services were queried about their roles in the community participation of service recipients. All interviews/groups were audio recorded and transcribed.

Data Analysis

Analyses of the data from the transcribed interviews and minutes were informed by grounded theory methodology (Glaser & Strauss, 1967) to examine in-depth perspectives on community participation among individuals living with serious mental illness. Grounded theory is a widely used method to understand complex social phenomena in mental health (Bowling, 2014; Glaser & Strauss, 1967). In particular, Charmaz's (2006) grounded theory approach was used to explore the meaning of community participation from the "ground up" by including first-person perspectives and key stakeholder input.

Initial data analysis was conducted independently by three members of the research team including one doctorate-level psychologist and researcher, an individual with lived experience, and a master's level researcher. All members of the data analysis team had previous qualitative research experience and training.

Themes were developed from the research questions and from the comments and observations of research participants. To manage the volume of data, all deidentified data were uploaded into NVivo, a qualitative data analysis software package. Qualitative data were reviewed independently first by two researchers who developed an initial list of codes based on the study questions and recorded them in NVivo. We prioritized the perspectives of individuals with lived experience in the analysis, that is, initial coding schemes were developed on the consumer participants. Codes were reviewed independently by each team member who also independently documented her hypotheses regarding the relationships between codes, potential categories, and questions while also recording pertinent sources of bias. Research team members discussed their expectations and biases related to community participation to prevent undue influence on data analysis and interpretation. These discussions

occurred both prior to data analysis and during consensus meetings. In consensus meetings, two researchers categorized the data into meaningful units through a process of classifying and collapsing codes that fit together in patterns following an iterative process (Strauss & Corbin, 1998). The third member of the research team independently reviewed the data and provided feedback on all codes and categories developed by the first two members. In consensus meetings, all three team members discussed coding, collapsed categories, identified final categorization of data, and determined representative statements. NVivo provided the frequency of references to each theme and category. Deidentified results were presented to a peer consultant for clarification of themes obtained and for assistance in interpretation of the results.

Similar to previous qualitative studies (Millner et al., 2015; Moran et al., 2014) where established theoretical models were used to organize data, the research team assessed established theoretical frameworks for applicability to the data categories. Based on our review, we found that the central constructs of SDT appeared to fit already coded data (Ryan & Deci, 2000). This theoretical framework was used in the final presentation, description, and interpretation of the results.

Results

The results of this qualitative exploratory study aligned with three major themes of SDT (Deci & Ryan, 1985) each with distinct categories. These were (a) community participation fulfills the need for relatedness, (b) community participation relates to the need for competence, and (c) community participation is associated with the need for autonomy. Themes and categories are provided in Table 1.

Table 1 Results of qualitative analyses

Theme	Categories
Community participation fulfills the need for relatedness	Community means having a social network Community participation means breaking isolation Community participation provides a sense of belonging
Community participation relates to the need for competence	Community participation means having a valued role Community participation helps to overcome barriers
Community participation fulfills the need for autonomy	Community participation means doing activities independently Community participation enhanced by interest and willingness

Community Participation Fulfills the Need for Relatedness

The first theme was identified as *Community participation fulfills the need for relatedness* and included four categories, namely: (a) Community means having a social network, (b) Community participation means breaking isolation, (c) Community participation means engaging in community activities, and (d) Community participation provides a sense of belonging.

Community Means Having a Social Network

In the first category, many participants with lived experience provided descriptions of their community, including who and why they were their community. Participants described their community as their most immediate social network with whom they had regular interactions, for example, “family,” “partners,” “children,” “friends,” “neighbors,” “acquaintances,” “relatives.” Most participants referred to their community as being restricted to close and extended family members. But participants described limited social contact, as evident in a statement by a 28-year-old White American male diagnosed with obsessive compulsive disorder (OCD): “The people around you that are part of your life...For me, it’s mostly family. And some acquaintances, but that’s about it” [Participant #154]. Participants described their “peers” or other individuals with lived experience of mental health issues as their primary community.

For participants with lived experience, community meant those who were available to provide support and assistance, as expressed by a 28-year-old White American female diagnosed with bipolar disorder in her statement: “I think community is your support system and who’s around to help you. I think it’s not just where you live or what you do. It’s who’s there for you” [Participant #101]. Participants also described their community involvement through mental health service providers (e.g., clubhouses or residential activities. This is reflected in a statement provided below by a 57-year-old White female family member, whose brother was diagnosed with bipolar disorder:

In my mind, community for him is doing things in the community. He goes to the gym but [mental health agency] helps pay for his membership, they provide transportation there, the running club, the road races. All those are things that he does through them so I think that’s his big community center at the moment. [Participant #254]

One notable experience reflected the desire of participants with lived experience for meaningful connections

and the fragmentation that they have to deal with. The following is a quote by a 51-year-old White female diagnosed with PTSD who noted this important challenge:

I feel most comfortable with other people [who] also have mental health issues [...] It's a deeper connection with people. If I hang around with my family, most of the conversations [are] very surface level [...] It's kind of hard to mix the two. [...] I know people in programs and have interactions with them and I know some of my neighbors [without mental illness] and I have interactions with them, but the two don't sort of mix together very well ... people are extremely uncomfortable with anything mental illness.

[Participant #102]

These sentiments were also echoed by young adult, a 28-year-old White female diagnosed with bipolar disorder who stated: "For me it's hard to mix a group of friends with a group of supposedly mentally ill people. They don't want to interact with people who have mental illness. So it's hard to get a bunch of your young friends together and all hang out when some people, like, fear it" [Participant #101].

Community Participation Means Relieving Isolation

Participants also described community participation for individuals with lived experience in terms of relieving isolation and aloneness. For example, a 55-year-old White male diagnosed with schizoaffective disorder stated "Community to me is getting out and about. Just getting out and trying to be part of the outside" [Participant #152] and a 50-year-old White male diagnosed with OCD described community activities as "...talking to people, opening [up] to people rather than just isolating all the time. Getting into my own head" [Participant #153]. Provider participants similarly addressed these issues. For example, a 56-year-old White American female therapist reflected on the normalizing aspects of community engagement: "they feel like they're the only person in this world that has this problem [mental illness] and that they can't join everybody else because they're not normal. And once they're able to go out there and enjoy things, it's huge" [Participant #504].

Community Participation Provides a Sense of Belonging

Participants also described community participation in terms of fostering a sense of belonging that came not only through active engagement with community members but also by being valued by society at large. Participants in this category discussed the contribution of individual

members of society. For example, a 53-year-old White American female program coordinator shared an example of a community member who enhanced belongingness:

We have a community member, a store owner that is very welcoming to our individuals. I think [of] just his impact on the few that started going to that store. A lot of other individuals go to that store and it makes them feel good that he knows them by name. It makes them feel good and part of the community...I think having more social people in the community that are more welcoming like that, in each neighborhood makes our [clients] more comfortable.

[Participant #405]

These vivid descriptions emphasize the importance of the need for relatedness in the community activities of individuals living with serious mental illnesses.

Community Participation Relates to the Need for Competence

The second theme identified, *Community participation fulfills the need for competence*, included two categories, namely: (a) Community participation means having competence in holding a valued role, and (b) Community participation improved the ability to overcome barriers.

Community Participation Means Having a Valued Role

In the first category, participants made a number of references to community participation of individuals living with serious mental illnesses holding socially valued roles, particularly those not associated with their disability. For example, a 29-year-old White female community-based support provider described community participation as "Anything that's non-disabled. So, to define their community inclusion is to find things that are not disabled." [Participant 455]. The importance of having a valued role was further emphasized by another 28-year-old White American male community-based support provider, "We've had some people who have gone to AA for a while, and they just sit there and they don't talk. But they find [that] they're valued in that group of people when they're the ones who make the coffee for the group. That's a huge valued role, and they value that" [Participant #453].

Community participation experiences, such as employment, were described as being essential to competence and therefore more integrated in the community. This experience of needing to feel more competent through occupying socially valued roles were reflected in another statement by a 28-year-old White female diagnosed with bipolar disorder:

Working. I feel like when I walk down the street, even the people that are close to me, a lot of them, when I first met them, they couldn't even tell I had a mental illness until I told them [...] It's just about getting the will-power to get out there ... So I guess the whole working thing would be a really positive thing.

[Participant #101]

Occupying socially valued roles in the community allow individuals living with serious mental illnesses to be more accepted in the community. As a 58-year-old White American male community leader who employs individuals with lived experience at his automobile dealership stated in relation to these individuals, "if you have a purpose, and then you have the ability to be a little more self-sufficient, and you feel that you're valued by your employer and you have a place in life [Participant #903]." In our study, participants described feeling subject to societal stigma and prejudice, viewed as less competent and capable, and invalidated for their challenge in managing symptoms in reference to socially valued roles. For example, a 51-year-old White American female diagnosed with major depression and PTSD stated, "I feel like everything I do or don't do is sort of judged [negatively]. Well 'couldn't you just go to the grocery store, well, it's just the grocery store?' 'Couldn't you just do that?' 'It's just a job, just do it, it's an easy job, you can do that.' It's this judgment all the time that there's something wrong with me" [Participant #102]. In addition to being accepted, participants described community participation as helping not only the individual hold socially valued roles but being supported to do so as well. For example, a 58-year-old White American male community leader who employs individuals with lived experience at his automobile dealership stated, "Sometimes I have people working for me, [like] someone who cuts their wrists every other day ... it's important for me to just give him the assurance that I'm here for him. They come to you with their problems. They need to know that there's someone to lean on." [Participant #903].

Participants also emphasized that community integration implied that the mental health identity was either not as visible or as prominent. One of the ways to achieve this experience was through reciprocity, that is, contributing or giving back to society. The need for reciprocity as it contributes to the need for competence among their service recipients was described especially by providers. For example, one 29-year-old White female community-based provider described reciprocity as "I think it's the defining factor. Someone needs to feel important, or needed or wanted, or they're probably not going to continue to do something ... It's like sort of the feeling... like, the reciprocal relationship that activity has" [Participant #455].

Another provider, a 31-year-old White American female community-based support provider, described the experience of an individual with lived experience who would go to great lengths for reciprocity, "I have an individual here who loves gardening ... she volunteers at the greenhouse at the old state hospital. She will take this long treacherous journey switching buses ... and she'll spend all day up there pruning trees. They give her the flowers that are half dead and she'll bring them back to life at her apartment and plant them in her yard. Or donate them back to [program]" [Participant #408].

This concept of reciprocity was further explained by a 58-year-old White American male community leader as being an exchange that happens between equals. He stated,

There is need for people to be able to have relationships and experiences that were not enclosed within the client-provider model [which] is inherently unequal and not reciprocal. It's sort of a one-way relationship. . . To be able to have a relationship in which people can talk equally about their day, about their problems, about their, experiences, and strike a, a friendship is a very difficult thing to do because most of the experience that people with psychiatric disabilities have, outside of their own families are experiences that are, with [mental health] institutions. Even with de-institutionalized programs, there aren't that many relationships that people have, with members of the mainstream community.

[Participant #901]

Community Participation Improved the Ability to Overcome Barriers

In this category, participants described the impact of community participation activities on the experience of competence. First, participants described many barriers that individuals face in their community participation activities. For example, a 29-year-old White American female community-based provider stated, "Community inclusion is incredibly important, and it has a rehab element, itself. If you're not addressing some significant things or barriers in their life, it's going to be much harder, because they're struggling with very, very significant symptoms" [Participant #455]. Participants with serious mental illness reflected similar responses in relation to the insurmountable barriers, the description of which is beyond the scope of this paper. Participants simultaneously described the importance of willpower and determination to overcome these barriers. These statements related to competence in community participation despite the interference of symptoms. For example, a 54-year-old White American male diagnosed with schizophrenia stated "First of all, I get anxiety especially in groups—but now I try to fight it. Once a month I go to my [Community Leadership Council]. . . you

know, that's always anxiety-producing to me ... But it's something that I have to do, because I want to do it." [Participant #151]. Participants described community participation as creating opportunities for recovery and rehabilitation for this population. A 60-year-old White American female therapist went further and stated that "[community participation] is supportive. I think it relieves isolation for them, and that, in turn relieves depression, if depression is the client's problem. That feeling that they're connected" [Participant #501].

Participants described the importance of community participation to the self-esteem and self-worth of individuals in their recovery from mental health conditions and their perceived competence. Community activities have a strong influence on the self-efficacy of these individuals and how they perceive their ability in engaging in community activities and how they viewed themselves. Being involved in the community further improved their competence in engaging in the community. This was reflected in a statement by 29-year-old White American female therapist:

Once they get out into the community I see a real improvement in self-esteem and the ability to make good choices and [desire] to do other things later, and even coming in with ideas of things we could explore during the sessions, which seems to make a big difference.

[Participant #504]

Participants described the role of providers in fostering their competence of a 28-year-old White American female diagnosed with bipolar disorder described the development of motivation and competence from encouragement and support by providers: "Being pushed for four years to do things, got me to explore what I liked. New things that I liked and stuff, so I guess it got me out there ... my own personal will helped me stay motivated" [Participant #101].

Providers also reinforced clients' motivation to engage in community activities by focusing on what might be considered small and minor achievements in fulfilling the need for competence. These descriptions are reflected in a statement by a 56-year-old White male peer provider, "I think it's great to see them get excited about what their accomplishment was no matter how small. And it's nice for me to see them at the end of the meeting for them to say, 'oh I got this done,' and 'I was over here' and it's nice to see them getting excited about an accomplishment" [Participant #302].

Community Participation Fulfills the Need for Autonomy

The third and final theme identified, *Community participation fulfills the need for autonomy*, included two categories, namely: (a) community participation means doing

activities independently, and (b) Community participation enhanced by interest and willingness.

Community Participation Means Doing Activities Independently

Family member and provider participants made various references to the importance of independent engagement in community participation. Providers pointed to the over-reliance of individuals on mental health providers for support in their community activities. These were reflected in statements such as the following, made by a 56-year-old White American male peer provider: "We want people to be fully integrated but if they can only be fully integrated with [reliance on] the practitioner, we still have a problem" [Participant #302]. Others emphasized the importance of reliance on alternative sources of support and connection. For example, a 27-year-old White American female community-based services support provider-described community participation as "finding a connection where they can go and look, without the other people they see all day (i.e., peers), and work with people who are NOT part of the mental health system, I think that is the biggest struggle that I always face" [Participant #452].

Providers described the process of attaining independence and autonomy in community participation. They emphasized the importance of independent or self-initiated help seeking and ascribed value to independent requests for help from their mental health service providers. For example, a 63-year-old White American male peer provider described his goal for his client in his statement: "I'm hoping that in time [the client] will say something like, 'will you help me?' Or maybe she'll talk to a staff and say, 'what do I do, can I get a staff to do this with me?'" [Participant #301]. In another example, a 57-year-old White male provider described the process that individuals with lived experience go through:

I have a [client] that we always meet at [coffee shop] to get her out of the house. And for the longest time she couldn't order for herself so she would have me do it. After a couple of weeks of coaching and positive feedback, last week she went up to the counter and ordered for herself and paid and it's a small thing, but to her it was a big deal.

[Participant #303]

This example also emphasized providers' attention to seemingly minor accomplishments. Such small achievements were described by providers as independently accomplishing basic tasks like taking public transportation, opening a bank account, attending a doctor's appointment, doing laundry, or ordering coffee at a shop.

Providers also described the psychological benefits of achieving independence in community activities. These included enjoyment, empowerment, vitality, pride, accomplishment, and self-worth. For example, a 53-year-old White American female community-based support provider described the link between independent completion of tasks and the experience of personal competence and self-worth. She stated, “I think that when we do get people connected and are out in the community, not supported anymore, they feel so much more valued and good about themselves, and less about their illness . . . I think it’s important for them in terms of their own internal self-worth” [Participant #405]. Participants with lived experience also made similar statements. They described their community activities with pride and stated that such activities were opportunities for family members to feel proud of them socially, especially in contexts where they believed their family was disappointed with them.

Community Participation Enhanced by Consumer Interest and Willingness

Another aspect of autonomy mentioned in participant interviews was the importance of community participation activities being driven by the interests and willingness of individuals of living with serious mental illnesses. Participants reported on the engagement of these individuals in activities of their choice such as art, music, games (e.g., bowling, billiards, baseball, etc.), physical activities (e.g., running, swimming, etc.), involvement in one’s religious community, outdoor activities (e.g., gardening), group activities, (e.g., trips to the park or the beach, etc.), volunteering, and even activities related to education and employment.

Providers described the enjoyment of community activities as motivating individuals living with serious mental illnesses to get engaged in the community. This was shared by a 45-year-old White American female therapist who stated, “They have something to offer. I have one client in particular who is really getting engaged at the clubhouse, and has a purpose over there now. That’s really helped him a lot” [Participant #502]. However, many of the activities described were organized by or through the mental health programs where these individuals received services. The programs also created opportunities for such activities. Mental health providers viewed their role as helping individuals living with serious mental illnesses explore and identify their areas of interest, as evident in the following quote by a 27-year-old White American female community-based support provider, “I feel like my role is kind of like getting everybody into [a] meaningful activity . . . I really get to work with them one-on-one and figure out what their likes and dislikes and strengths are” [Participant #457].

Participants also discussed the importance of motivation in community participation. Individuals living with serious mental illnesses experience considerable barriers to community participation in relation to their symptoms (e.g., fear, anxiety, etc.). However, these individuals also described an intrinsic drive which helps them engage in the community despite their symptoms and related barriers. Individuals living with serious mental illnesses described the experience as “I think my own personal will to get out there. . . I mean, not wanting to get back into my old ways. It just helped me, like my own personal will helped me stay motivated so it helps me get out there” [Participant #101].

These reports by individuals living with serious mental illnesses were supported by the experiences shared by providers who actively worked on identifying the motivational factors related to engaging in community activities among individuals served. Providers described how they attempt to affect motivation. For example, a 45-year-old White American male peer provider stated:

In certified peer specialist training, what we’re all talking about is called the satisfaction for change. We work with people to get a sense of whether people are dissatisfied with the situation they are in and what the risk is. The fear of the activity is there . . . ‘I’m afraid of taking the bus, but I’m less afraid of taking the bus than I am pissed off that I can’t do this. I want this more than I am afraid of the bus, so I’ll take the bus.’ We do that balancing act.
[Participant #304]

These results indicate the varying perspectives on the satisfaction of psychological needs that form the basis for self-determined community participation among individuals living with serious mental illnesses.

Discussion

This qualitative study was designed to explore the meaning of community participation of individuals living with serious mental illnesses by including multiple perspectives and key stakeholder input. The results of the study clustered around three main themes that reflected the basic needs underlying motivation as posited by Self-Determination Theory (Ryan & Deci, 2000). Debilitating symptoms and societal conditions of stigma and devaluation can serve to stymie such inherent tendencies and interfere with the satisfaction of basic innate psychological needs that form the basis for self-motivation, that is, the need for competence, relatedness, and autonomy.

In our study, overall, individuals living with serious mental illnesses described the physical (e.g., proximity),

emotional, psychological, and social aspects of community participation. Consistent with previous literature (e.g., Bromley et al., 2013), our sample described community as comprising of people or groups of people with whom they had the most interactions, from whom they received help, or with whom they felt most valued. Notably, these individuals identified community both psychologically and in terms of proximity, that is, with the individuals who they are most likely to interact with. They described the importance of being valued members of the community, engaging with the outside world, having meaningful social relationships, and being able to contribute to society. These are reflected in their experiences, or lack thereof, of self-determination. As a disabling condition where individuals are unable to fulfill socially valued roles, mental illness affects motivation through difficulties in satisfying the inherent psychological desire for relatedness, competence, and autonomy. Participant descriptions of the psychological meaningfulness of community participation addressed each of these innate needs.

Relatedness was the first and foremost construct that emerged in our study. Relatedness is associated with meaningful relationships and their psychological benefits in the lives of individuals with lived experience (Prezza, Amici, Roberti, & Tedeschi, 2001). In our study, participants described the importance of relatedness and the ways in which they satisfy this basic need. Isolation and limited community engagement have been the long-term issues of this population (Davidson, Chinman, Sells, & Rowe, 2006). Individuals in our study reported on the prevalence of isolation and highlighted the significance of breaking their isolation and reducing the restrictions on their community participation activities. When they described their community, they highlighted family, peers (i.e., other individuals with lived experience), and their mental health providers as their primary social network. While this has been established in the literature (e.g., Tsai et al., 2012), individuals in this study described the ways in which these individuals make an important contribution to their need for social relatedness. For some individuals, family members were a source of discomfort and superficial relationships. For others, family provided an important source of support. Most notably, individuals with lived experience reported greater friendship, comfort, and meaningful contact with those who shared their lived experience of having mental health challenges. Peer relationships provide unique and essential social contact for individuals with lived experience who are characterized by compassion and reciprocity which may not otherwise be available for these individuals (Davidson et al., 2006).

Despite descriptions of individuals who form their social network, the references to a sense of fragmentation in participants' psychological sense of community were

noteworthy. Participants described their experience of having to navigate and maintain separate social worlds, that is, keeping their community of peers separate from those who did not have lived experience of mental illness. Such fragmentation may be reflective of the unique and chronic traumatic stress that is a result of public stigma of mental illness (Kira et al., 2014). Individuals with lived experience separation in their social networks as a result of the social impact of mental illness stigma (Wong et al., 2010) experienced at the personal level through marginalization and devaluation and at a systematic level in the lack of inclusion in normative settings with equal access to social, legal, political, and economic opportunities (Aubry et al., 2013; Wolfensberger & Thomas, 1983). Therefore, individuals in our sample described the importance of feeling socially valued as an important facilitator to community participation.

The importance of valued community roles in relatedness was also reflected in the need for competence for this population. Competence allows individuals with lived experience to regain valued roles in their communities (Hunt & Stein, 2012). The development of personal competencies is essential to the enhancement of socially valued roles (Wolfensberger & Thomas, 1983). Such community activities normalize experience, reduce the internalization of social stigma, and improve self-efficacy in coping and managing illness (Prince & Prince, 2002). In this context, participants described their experiences of community participation in terms of their competence in occupying socially valued roles, for example, as a student, worker, etc. Participants also described the relationship of their mental health recovery to their perceptions and investment in their social roles and community activities (Hunt & Stein, 2012). As previously established, symptoms and the social constraints impede the ability of these individuals in fulfilling their social roles (Padgett, Henwood, Abrams, & Drake, 2008). Despite such barriers, these individuals lived experience continue to engage in the community, even describing community participation as therapeutic and intrinsic to their recovery. These results support a common finding in literature that valued social roles are associated with higher levels of well-being and less psychological symptomatology (Hunt & Stein, 2012). Our results also extend this understanding by identifying the mechanism through which community participation enhances well-being, that is, by improving one's competence in social situations. With increased social activities, individuals with lived experience develop greater confidence and mastery experiences that enable continued participation.

The final construct reflected in our study pertained to the need for autonomy in community participation. Autonomy has been identified as a critical component of

recovery from mental illness. Autonomy refers to the independent ability to make choices and have responsibility. In ideal terms, community participation was described as participation in independent and autonomous community activities, that is, activities independent from the mental health system. Participants stated that greater independence in community participation for individuals with lived experience resulted in increased self-worth, pride, and vitality. Independent engagement in community participation was cited as an importance source of self-worth and pride and created opportunities for important others (e.g., family members) to value their accomplishments.

Participants in this study described the process of achieving independence and autonomy as being one that can only occur in the presence of support. From a recovery and rehabilitation perspective, community-based supports are essential for the community integration of individuals living with serious mental illnesses. In the recent past, the treatment of these individuals (e.g., forced hospitalizations) has significantly infringed upon their independence and autonomy (Mancini, 2008). These systems of care often secluded these individuals and fostered dependence rather than autonomy. Individuals with lived experience who were socialized in such systems of care experienced overreliance on the mental health system. Provider participants in this study reflected on the process of unlearning such overreliance as a goal of community integration. They identified the mechanism of change in this process and emphasized support as a necessary part of this transition to gaining greater autonomy. Providers asserted that individuals with lived experience frequently required support and assistance for their community-based activities and that they conscientiously maintained focus on the goal of independent community participation for the individuals they served. Providers described strategies that they used to measure the progress of service recipients toward their community participation goals. These included focusing on self-determination of community participation needs, independent assertion of assistance required from mental health providers, reinforcement of minor independent accomplishments, and satisfaction for change. These results show that competence is necessary for the enhancement of devalued social roles (Wolfensberger & Thomas, 1983), and autonomy provided the mechanism through which the psychological sense of competence was achieved.

The overall results of this study identified the various psychological and motivational aspects of community participation for individuals living with serious mental illnesses, highlighting the experiences of need fulfillment in their social roles. While the three conditions of competence, relatedness, and autonomy in SDT (Deci & Ryan, 1985) are necessary to facilitating optimal functioning in

the community for individuals with lived experience, equal availability of opportunities to fulfill these needs was not evident in our data. There was a predominance of social needs as the source of motivation, such as diversifying social connections, giving back to society, engaging with communities of choice, and being acknowledged and known by others in valued roles. Our data also highlighted the psychological benefits of community participation through the importance of finding meaning and purpose, increasing motivation, and improving self-esteem, sense of belonging, self-worth, etc. As mentioned earlier, self-determination is a crucial concept to rethinking the recovery process for individuals living with serious mental illnesses (Onken et al., 2007).

Implications for Theory, Practice, and Research

We believe that our study findings have important implications for theory, practice, and research. First, we believe that there needs to be intentional discourse on the applicability of motivational theories such as SDT for individuals living with serious mental illnesses. Second, our results support the need for a more complex understanding of the motivational factors that influence community participation for this population. These factors intersect with external facilitators and barriers to community participation for this population at multiple systemic levels including family, providers, and the community-at-large. In order to facilitate transformative change, these aspects need to be comprehensively assessed. Third, the results of this study are expected to directly contribute to: (a) the development of a new measure of community participation that includes motivational aspects, and (b) the development of a new peer-led intervention to improve the community participation of individuals living with serious mental illnesses. This intervention has benefited from a focus on empowerment and socially valued roles, identifying specific areas of need fulfillment in self-determination, and bolstering self-efficacy in social participation. These aspects are essential to the psychological health and well-being of this population (Talley, Kocum, Schlegel, Molix, & Bettencourt, 2012).

It is difficult to generalize the findings in this study to all individuals living with serious mental illnesses due to the sampling method and the demographic limitations of participants. There was a small number of participants with lived experience compared to the number of stakeholders who shared their input. The samples were geographically diverse but limited to a single agency, which limited our ability to predetermine specific participant characteristics and numbers. The diversity in terms of race, culture, and ethnicity, social class, and the functional abilities of individuals living with serious mental illnesses was

significantly limited. This considerably limits the generalizability of our results. Additional methodological limitations pertained to the exploratory design of the study and post hoc application of SDT, which may have yielded different results from a confirmatory design querying participants specifically on SDT theory constructs. Future studies may benefit from attending to these sampling and methodological concerns and by examining populations with more diverse demographic characteristics.

Overall, results of this qualitative, participatory-oriented research demonstrated the value in applying motivational constructs to the community living and participation of individuals living with serious mental illnesses. Our findings yielded complex information that is expected to be useful for mental health providers, peer and consumer advocates, and future researchers. We consider this study to be an important but preliminary exploration of the motivational factors that underlie the community integration needs of this population, allowing greater clarity and coherence in providing community-based support and services to individuals living with serious mental illnesses.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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