

Community Participation Differences Between Adults With or Without Serious Mental Illness

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Objective: This study aimed to clarify the extent of community participation by individuals with serious mental illnesses in comparison with the general population.

Methods: Participants with serious mental illnesses (N=300) were recruited from 21 outpatient mental health organizations throughout the United States, and the participants without serious mental illnesses (N=300) were recruited from a stratified sample from across the United States. All participants completed the Temple University Community Participation Measure.

Results: The groups differed in community participation amount, number of important areas, breadth, and sufficiency

of community participation. Differences between groups in amount of participation were not evident after analyses controlled for income and car ownership. However, differences in number of important areas, breadth of participation, and sufficiency remained after analyses controlled for demographic and economic factors.

Conclusions: Car ownership and income are important factors in amount of community participation, but differences in other areas remain, plausibly affecting the health and wellness of persons with serious mental illnesses.

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The International Classification of Functioning, Disability, and Health deems community participation—such as in work, social relationships, and religious engagement—as an important aspect of health. Accordingly, mental health researchers are paying increased attention to this issue (1). Participation in community life is associated with positive physical, cognitive, and mental health and wellness outcomes for everyone, including people with serious mental illnesses (2–5). The limited and often dated information about the participation of adults with a serious mental illness indicates lower labor force participation (6), lower educational attainment (7), and less engagement in activities such as walking in a park and going to a place of worship compared with the general population (8–10). However, information based on narrow coverage of participation domains with a sole focus on the amount of participation is somewhat limited. What is missing is more detailed information about possible disparities in the amount of participation in a broader range of areas, the number of areas of participation that are important to them, and the extent to which there are differences in satisfaction with their level of participation across a wide range of areas.

We also lack information about differences in participation between adults with and without a serious mental

illness. There are many possible explanations for comparatively lower levels of participation in a broad range of areas among adults with serious mental illnesses, including physical, psychological, cognitive, and behavioral factors, as well as environmental factors—especially prejudice, discrimination, and poverty—that limit opportunities for participation (5, 11–13). Comparative data about participation are valuable in identifying potential additional pathways for how their health may be affected. Moreover, findings of diminished depth, breadth, and satisfaction with participation can plausibly provide additional intervention priorities and directions.

HIGHLIGHTS

- Compared with the general population, individuals with serious mental illnesses had significantly less community participation by amount, breadth, and sufficiency.
- Although economic factors explained the difference in participation amount between individuals with and without serious mental illnesses, economic factors did not fully explain the differences in breadth and sufficiency of participation.

METHODS

Participants with serious mental illnesses were recruited between April 2014 and July 2015 from 21 outpatient community mental health centers (CMHCs) located in 15 states. These CMHCs were selected on the basis of geographic diversity. Inclusion criteria were as follows: adults had to be 18–65 years old and have a self-reported diagnosis of either a major mood disorder or a schizophrenia spectrum disorder. Exclusion criteria were as follows: having a legal guardian and inability or unwillingness to provide informed consent. A total of 451 individuals expressed an interest, and 300 were screened and determined to be eligible and were enrolled.

The participants without serious mental illnesses were recruited during approximately the same period (September 2014 and December 2015) from the Truven Health Analytics' PULSE Survey, which is the largest privately funded phone-Web survey in the United States, which resulted in a geographically stratified random sample of the U.S. population who did not report having a mental illness, who were between ages 18 and 65, and who spoke English. Research staff randomly contacted individuals from a list of 1,481 who agreed to provide contact information until 300 interviews were completed.

All participants provided informed consent and received \$20 for completing the survey. The research protocol was approved by the institutional review boards of the partnering universities.

Community participation was measured with the 22-item version of the Temple University Community Participation Scale (TUCP) (1). The scale measures the number of days of independent participation during the past 30 days in 22 areas, such as working for pay, going to school for a degree, volunteering, going to a place of worship, going to a library, going to a park, meeting with a social group, and hosting or visiting family or friends. For each item, the participant is also asked whether the activity was important to them (answers were “yes” or “no”) and whether they felt that they had done the activity enough (answers were “enough,” “not enough,” or “too much”). The TUCP has demonstrated good reliability (1, 14).

Participation amount was calculated as the sum of participation days across all 22 areas. Importance was calculated by summing the number of areas out of 22 that the participant indicated were important. Breadth of participation was calculated as the number of these important areas where the participant had at least 1 day of participation. Sufficiency of participation was calculated by taking the total number of areas that were deemed important and done enough and dividing by the total number of important areas.

Demographic information such as sex, race, education, housing, personal income, employment, car ownership, and living in an urban block group were also measured.

Differences in demographic variables between the CMHC and the general population samples were examined with chi-square and *t* tests. Community participation amount,

importance, breadth, and sufficiency were examined with *t* tests. Then, analyses of covariance (ANCOVAs) were performed to examine whether any differences remained significant after we controlled for demographic characteristics that were identified as being associated with the dependent variables for both samples.

RESULTS

The CMHC sample (*N*=300) comprised individuals with a mood disorder (57%, *N*=171) or schizophrenia spectrum disorder (43%, *N*=128). The mean±SD age was 46.30±11.23 years; 60% (*N*=178 of 297) were female; 60% (*N*=179) were white, 25% (*N*=76) were Black, 1% (*N*=2) were Asian, 4% (*N*=12) were Hispanic, 1% (*N*=3) were Native American, and 9% (*N*=28) identified as other; and monthly income was \$752±\$494. For the general population sample (*N*=300), age was 51.50±11.33 years, 55% (*N*=165) were female, personal income was \$2,336±\$2,003, and 79% (*N*=236) were white, 10% (*N*=29) Black, 1% (*N*=4) Asian, 3% (*N*=9) Hispanic, 1% (*N*=4) Native American, and 6% (*N*=17) other. Age, personal income, and white and Black racial composition differences between samples were statistically significant. In addition, the CMHC sample had statistically lower educational attainment and labor force participation, and fewer lived in independent housing and owned a car. (A table showing these data is available as an online supplement.)

The amount of participation was 50.58±40.32 days in the CMHC sample and 62.67±32.63 days in the general population sample, a difference that was statistically significant (*t*=−4.03, *df*=597, *p*<0.001). (Group differences in participation days at the item level can be found in the online supplement.) The CMHC respondents participated less in the areas of shopping, going to a restaurant or coffee shop, going to a theater or cultural event, running errands, going to a gym, going to a barber shop, and working for pay. They participated more in the use of public transportation and taking a class for leisure. The analyses of demographic variables found that race and gender had no relation to the amount of participation in either sample; living in an urban block group had a positive association in the CMHC sample only; and higher education, living in independent housing, and younger age had positive associations in the general population sample only. Personal income and car ownership were found to have positive associations in both groups and were included as covariates in an ANCOVA model. After analyses controlled for personal income (*F*=15.62, *df*=1, 571, *p*<0.001) and car ownership (*F*=8.81, *df*=1, 571, *p*=0.003), the adjusted mean participation days were 56.97±2.48 in the CMHC sample and 55.01±2.57 in the general population sample, with no statistically significant difference.

The number of important areas was 14.98±4.46 in the CMHC sample and 14.03±4.16 in the general population sample. These differences were statistically significant (*t*=2.71, *df*=593, *p*<0.001). Age, gender, personal income, car ownership, urbanicity, and living in independent housing

were not related to the number of important participation areas in either group. Nonwhites had more important participation areas in the CMHC sample; in the general population sample, the number of important participation areas was associated with higher levels of education. No ANCOVA was run, because no demographic variables had a relationship with the number of important participation areas in both groups.

Breadth of participation was 6.95 ± 3.38 in the CMHC sample and 8.67 ± 3.45 in the general population sample. Age, race, and gender were not significantly associated with breadth of participation in either group; urban block groups had a positive association in the CMHC sample only; and higher education, living in independent housing, and car ownership had positive associations in the general population sample only. Only personal income was positively associated with breadth of participation in both samples. After analyses controlled for personal income ($F=22.87$, $df=1$, 574 , $p<0.001$) in an ANCOVA model, the adjusted mean of breadth of participation was still higher in the general population sample (8.35 ± 0.21) compared with the CMHC sample (7.29 ± 0.21 ; $F=11.86$, $df=1$, 574 , $p<0.001$).

Sufficiency of participation was $42\% \pm 26\%$ in the CMHC sample and $59\% \pm 24\%$ in the general population sample. Education, car ownership, and urbanicity were not related to sufficiency of participation in either group. Males and individuals with higher personal income had greater sufficiency of participation in the CMHC sample only; older individuals, whites, and those living in independent housing had greater sufficiency in the general population group only. No ANCOVA was run, because no demographic variables had a relationship with sufficiency of participation in both groups. The results of the *t* test indicated that differences between the CMHC sample and the general population sample were significant ($t=-8.50$, $df=597$, $p<0.001$). (Group differences in sufficiency at the item level can be found in the online supplement.) The CMHC respondents had lower levels of sufficiency in 19 of the 22 areas.

DISCUSSION

This study is the first to comprehensively compare community participation amount, importance, breadth, and sufficiency between individuals with and without serious mental illnesses across a wide range of participation domains. Results suggest overall differences in amount of participation between the CMHC and general population samples across the domains. These differences did not remain after we controlled for car ownership and income, which suggests that the lower levels of participation among individuals with serious mental illnesses may be primarily due to their much lower incomes and degree of car ownership. The CMHC sample was found to have slightly more areas that they rated as important to them, which was statistically significant. However, their breadth of participation was lower, as was their sufficiency, or satisfaction, with the amount of

participation they had overall, as well as at the individual item level. These latter differences were not due to any demographic differences between the groups. Overall, the CMHC sample participated less and was less satisfied with their amount of participation across nearly all areas.

These results are consistent with previous research on the participation of adults with serious mental illnesses and adds new knowledge about their level of dissatisfaction with the degree to which they participate overall and in any particular area compared with the general population. The differences in community participation cannot be explained entirely by poverty, in that economic factors did not explain differences in participation breadth and sufficiency. Previous studies have argued that factors such as negative symptoms and internalized stigma may decrease participation interests and desires (8, 11), but our findings about importance and sufficiency suggest that people with serious mental illnesses may have even more areas of participation that are important to them and clearly desire more participation, plausibly to the same degree as other citizens. The potential explanations for the differences that are found clearly seem worthy of further exploration, especially given the importance of participation to overall health and well-being.

Implications of these findings include clinicians increasing their assessment of and conversations with consumers about what they are doing and would like to do and developing treatment plans that include supporting their participation in the community. Policy-level actions can increasingly target prejudice and discrimination that limit opportunities for participation. Even more frequent and effective campaigns to combat these factors would help individuals with serious mental illnesses to engage in activities that they value. Efforts that address poverty, which may include increased funding for supported education and employment, can also be made to increase the availability of affordable community activities in which people may engage. Finally, more research is needed to better document the effect of participation on the health of individuals with serious mental illnesses, as well as the individual and societal interventions that may be needed to increase opportunity for participation.

This study had many strengths, including national samples of individuals with and without a serious mental illness who had demographic characteristics that approximated those of the general population and who were fairly comparable in most areas, with the exception of expected differences in income and car ownership. The phone survey was conducted only in English, which might have failed to include those who had low English proficiency and thus might be a cause of fewer Latinx and Asian respondents in our samples. Although urbanicity was controlled in the analyses and showed no consistent influence on community participation, the different recruitment methods might have caused unmatched locations, which could not rule out geography as a confounding factor. Another limitation pertains to the measure used in this study. Self-report instruments

that require retrospective recall are susceptible to recall bias. However, potential bias caused by memory impairments that are common among individuals with serious mental illness (15) may not be severe, given that the measure has evidence of high correlation between 30-day recall and daily checklist (14).

CONCLUSIONS

In conclusion, this study found that individuals with serious mental illnesses had lower amounts of community participation, less breadth of participation in important areas, and less sufficient participation or satisfaction with the degree to which they participate compared with individuals without serious mental illnesses. The differences are at least partially explained by the lack of financial resources; however, this factor does not explain differences on all dimensions examined here. The most notable difference between individuals with and without serious mental illnesses was the sufficiency of participation. Further research is needed to examine the mechanisms behind these differences to inform interventions aimed at increasing opportunities for the participation and inclusion of individuals with serious mental illnesses.

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