http://dx.doi.org/10.1037/ort0000269

A Developmental Study of Community Participation of Individuals with Serious Mental Illnesses: Implications for Policy and Practice

Abstract

Understanding age-related expectations for community participation can aid mental health providers and policy makers in the design and tailoring of age-appropriate services to better meet consumers' participation needs. This study seeks to describe and compare the amount, importance, and sufficiency of community participation in younger adult, middle-aged adult, and older adult consumers. Participants were 879 adults with serious mental illnesses who completed the Temple University Community Participation Measure as part of several studies (only baseline data were analyzed). One-way analysis of variance tests and chi-square analyses were used to evaluate the effect of age group on community participation outcomes. The amount and importance of participation in specific participation areas differed across age groups in developmentally appropriate ways. For older adults, a greater percentage of areas considered important were done enough, and fewer participation days were needed in certain areas for participation to be considered sufficient. Consumers reported participating in the community to meet basic needs (e.g., running errands), but participation appeared lower in areas typically identified as important to various age groups across the lifespan (e.g., working). Results support the use of developmental frameworks for delivering mental health services, and identify particular areas of community participation that policy and practice efforts might focus on to help individuals participate to a greater degree in areas that are important to them. Implications for policy-making, program evaluation, and individual interventions are discussed.

Public Policy Relevance: Little is known about mental health consumers' preferences for community participation across the lifespan. This study demonstrates that the participation preferences of younger adult, middle-aged adult, and older adult groups of individuals with serious mental illnesses are consistent with theories of human development. Therefore, it is important that policy makers support the application of these developmental theories to the

delivery of mental health services in order to better promote community integration and inclusion.

Keywords: community integration; community inclusion; psychiatric disabilities; lifespan development

Introduction

Community participation is the "choice and action that individuals make to be active in valued roles in the communities of their choice, across a variety of domains in their life" (Burns-Lynch, Brusilovskiy, & Salzer, in press). At the core of community participation is self-determination, the ability to act autonomously, to make informed decisions about how to behave, to have a sense of personal efficacy and agency, and to capitalize on knowledge of personal strengths and limitations (Wehmeyer, Kelchner, & Richards, 1996). According to the World Health Organization's International Classification of Functioning, Disability, and Health framework (World Health Organization, 2001), community participation includes engagement in activities to meet basic needs (e.g., shopping); involvement in social relationships; education and employment; and religious, civic, and leisure participation. A number of studies document the importance of community participation for psychological and physical health-related outcomes in people in general (Kachan et al., 2015; Kim, Heo, & Lee, 2015; Sato, Du, & Inoue, 2016). Individuals with serious mental illnesses are no different; for those who experience these mental health conditions, community participation is positively related to recovery, quality of life, and life meaning (Burns-Lynch et al., in press; Kaplan, Salzer, & Brusilovskiy, 2012). As individuals with serious mental illnesses often experience disproportionately fewer opportunities for full and personally meaningful engagement in settings of their choosing (Salzer, Baron, Menkir, & Breen, 2014), enhancing community participation has become a priority for mental health systems that serve them (Hogan, 2003).

Quantitative and qualitative changes in community participation naturally occur as individuals age. Theories of human development highlight roles that people tend to value at different points in time, providing context for variability in the amount and type of participation

over the lifespan. For example, according to Erikson's stages of life development and Vaillant's theory of developmental tasks, young adulthood is characterized by a desire for intimacy during which individuals seek relationships with others; middle adulthood is typically when individuals focus on employment; and older adulthood is a time when individuals search for a sense of integrity, deriving meaning from what has been done earlier in life (Agronin, 2014). Empirical findings of age-related community participation largely support this developmental perspective. The American Time Use Survey (ATUS), which provides an overview of the types of activities Americans engage in across the lifespan, shows that younger adults spend slightly more time in educational activities, while middle-aged adults spend the most time in work-related activities. As individuals age, time spent in organizational (e.g., volunteering), civic (e.g., voting) and religious activities (e.g., going to a place of worship) also increases (Bureau of Labor Statistics, 2016).

While it can be expected that individuals with serious mental illnesses would value certain areas of community participation like everyone else, personal and environmental challenges associated with having a mental health condition may impact actual participation or alter participation expectations. First, mental health-related difficulties and environmental constraints can interrupt, or at least delay, the pursuit of participation interests and goals. For example, the onset of serious mental illnesses typically occurs in the late teens to early thirties, which may prolong the attainment of educational achievements needed for competitive employment (Dudley, Nicholson, Stott, & Spoors, 2014). Similarly, because of public stigma and discrimination against those with serious mental illnesses, individuals face greater difficulty securing and maintaining employment (Henry & Lucca, 2002). Second, according to Motivational Theory of Life-Span Development (Heckhausen, Wrosch, & Schulz, 2010), as

personal and contextual challenges to goal-striving become more prevalent, individuals resort to certain control strategies (e.g., shifting expectations and values) so that these challenges do not result in a loss of motivation for goal attainment. As individuals with serious mental illnesses experience obstacles and environmental constraints to participation, especially as they age, they may choose to focus their efforts on other areas or may become more satisfied with less participation in valued areas over time.

Although research has broadly evaluated time use in the general population (Bureau of Labor Statistics, 2016) and among individuals with disabilities (Anand & Ben-Shalom, 2014), surprisingly few studies have examined community participation of individuals with serious mental illnesses across the lifespan. Particularly needed are studies that clarify how the service needs of older adults with serious mental illnesses may differ from those who are younger (Al Jurdi, Rej, & Sajatovic, 2014). Understanding expectations for community participation at various life stages can aid in the development of age-appropriate services and supports. Among the available evidence, a European study indicated that individuals with serious mental illnesses spend the most time in personal care (e.g., sleeping, eating) and passive leisure (e.g., watching television), with younger people reporting more time in social activities and older individuals reporting more time in passive leisure (Shimitras, Fossey, & Harvey, 2003). Another study (Kaplan et al., 2012) demonstrated that emerging adults with serious mental illnesses were more likely to be students and spend time with friends, while maturing adults were more likely to be parents and participate in spiritual and self-help/mutual support activities. Finally, while it did not compare age groups, a study of the time use of individuals with psychosis across the illness career found that time spent in structured activity decreased with greater illness chronicity and that individuals without psychosis were more likely to spend time in work, housework and

childcare, and structured leisure activities than individuals with psychosis (Hodgekins et al., 2015).

The present study utilizes a large dataset involving a reliable and valid measure of community participation in individuals with serious mental illnesses, the Temple University Community Participation (TUCP) measure (Burns-Lynch et al., in press; Salzer, Brusilovskiy, Prvu-Bettger, & Kottsieper, 2014), to describe participation across various age groups and test three hypotheses about age-related differences:

1) There will be differences in amount of community participation in specific participation areas across age groups. Consistent with developmental theories (Agronin, 2014) and findings from the general population (Bureau of Labor Statistics, 2016), young adults (YAs) are expected to spend more time in educational areas, middle-aged adults (MAs) in work-related areas, and older adults (OAs) in organizational, civic, and religious areas.
2) Based on previous research and theory about age-related preferences for participation, it is expected that differences in importance of community participation in specific domains will be found across age groups. Specifically, educational areas will be most important to YAs, work-related areas will be most important to MAs, and organizational, civic, and religious areas will be most important to OAs.
3) In accordance with Motivational Theory of Life-Span Development (Heckhausen et al., 2010), we expect that as individuals age, they will experience a greater sufficiency ratio and a lower sufficiency threshold (as defined in Methods).

Methods

Participants

Baseline data from 923 adults (over 18 years of age) were appended from six research studies conducted between 2008 and 2013. Individuals had a primary schizophrenia-spectrum or major affective disorder diagnosis, based on mental health provider or self-report. All were English speaking. Studies assessed community participation in the context of intervention evaluation (e.g., self-directed care intervention; online parent support intervention), program or service evaluation (e.g., publicly-funded vs. non-publicly-funded services; supports provided by a Center for Independent Living), naturalistic observation (e.g., ascertaining community participation needs and supports of formerly incarcerated individuals), or psychometric evaluation of the TUCP. All studies were approved by the Institutional Review Board of the researchers' academic institution, and the Institutional Review Board of the local municipality when necessary. All participants provided informed consent.

Of these 923 participants, 44 were excluded: 19 due to missing age; 10 due to missing TUCP data; and 15 due to likely unreliable responses (i.e., reporting an implausible amount of participation). The final sample consisted of 879 individuals.

Measures

Community participation. The TUCP (Salzer et al., 2014) is a self-report measure of independent participation in community-based areas during the month preceding assessment. Individuals report the number of days of participation in each area without a staff person (amount), whether each participation area is personally important ("yes/no;" importance), and whether they consider their participation in each area to be "enough," "not enough," or "too much" (sufficiency). We used the 22 item version of the measure. The following outcomes were extracted to assess overall community participation and participation by specific area (i.e., by TUCP item):

1) Amount: (a) number of participation days overall; (b) number of participation days in specific participation areas.
2) Importance: (a) number of participation areas considered important; (b) number of individuals who considered each participation area important.
3) Sufficiency: (a) a "sufficiency ratio" was calculated by dividing the number of participation areas considered important and done enough by the number of important participation areas; (b) "sufficiency thresholds" in specific areas were defined as the number of participation days in these areas for individuals who considered them important and done enough. We assume that participation days at and above the mean for each age group indicate sufficient levels of participation.

Statistical Analysis

Individuals were separated into three age groups: YAs (ages 18-30 years), MAs (ages 31-55 years), and OAs (56 years and older). Age classifications were consistent with age ranges discussed in the literature (Nichols, Rogers, Fisk, & West, 2001). A series of one-way analysis of variance (ANOVA) tests with Tukey's post-hoc comparisons were used to evaluate the effect of age group on continuous participation outcomes (e.g., participation days). Given that sufficiency ratio data were approximately normally distributed, we assumed that general linear models would be appropriate. When Levene's Test of homogeneity of variances was significant, we used Welch's adjusted *F* ratio and Games-Howell's post-hoc comparisons. Chi-square analyses were used to examine the relation between age groups and categorical participation outcomes (e.g., specific participation areas considered important). All analyses were conducted using SPSS version 22.

Results

Participant Characteristics

Of the 879 participants, 554 (63%) were female, 322 (37%) were male, and 1 (<1%) was transgender. Average age was 45.27±10.69 years. Four hundred thirty one (49%) were Black, 394 (44%) were White, 46 (5%) were Native American, 12 (1%) were Asian, 6 (<1%) were Native Hawaiian or Pacific Islander, and 33 (4%) were other (racial categories were not mutually exclusive); 43 (5%) identified their ethnicity as Latino or Hispanic. The majority (n=361, 41%) reported having postsecondary education [298 (34%) had high school education or GED, 219 (25%) had less than high school education].

Age categories were comprised of 105 (12%) YAs, 612 (70%) MAs, and 162 (18%) OAs. No significant differences existed across age groups by gender (male versus female; χ^2=1.46, df=2, p=.48), race/ethnicity (white only versus non-white; χ^2=.76, df=2, p=.69), or education level (χ^2=5.50, df=4, p=.24).

Across all participants, the average number of participation days was 58.18±42.95, the average number of important participation areas was 15.16±4.73, and the average sufficiency ratio was .39±.25, which means that participants reported enough participation in approximately 40% of areas that were important to them.

Community Participation by Age Group

Amount. Table 1 shows areas with the greatest and least participation days by age group (e.g., using public transportation and running errands vs. going to a zoo/garden/museum), and results from ANOVA tests.

Regarding age group comparisons (hypothesis 1), the effect of age group on number of participation days overall was non-significant (YAs: 62.56±46.15; MAs: 56.94±41.38; OAs: 60.01±46.51; F=.95; df=2,876; p=.39). However, there were differences across age groups in specific areas (Table 1). Post-hoc comparisons demonstrated that OAs had fewer days working

for pay than YAs (p=.001) and MAs (p<.001). OAs also had fewer days going to school than YAs (p=.04) and MAs (p=.03). The effect of age group on participation days attending a political event was significant; however, post-hoc comparisons did not reveal significant differences between age groups. YAs had more days going to a movie than OAs (p=.02). MAs had more days going to a social group than YAs (p=.01).

Importance. Table 2 shows areas with the greatest and fewest number of individuals considering them important by age group (e.g., shopping vs. attending a political event or going to watch a sporting event), and results from chi-square analyses.

In terms of age group comparisons (hypothesis 2), the effect of age group on overall number of important participation areas was non-significant (YAs: 14.21±4.27; MAs: 15.22±4.82; OAs: 15.52±4.63; F=2.64; df=2,873; p=.07). However, a greater percentage of YAs considered working for pay and going to school to earn a degree/certificate to be important compared to MAs and OAs. A greater percentage of MAs considered going to a community fair to be important compared to YAs and OAs. A greater percentage of OAs considered going to a restaurant/coffee shop, using public transportation, running errands, shopping, and attending a political event to be important compared to YAs and MAs. A greater percentage of MAs and OAs compared to YAs considered going to a zoo/garden/museum to be important (Table 2).

Sufficiency. Table 3 shows areas with the highest and lowest sufficiency thresholds by age group (e.g., using public transportation vs. attending a political event), and results from ANOVA tests.

With respect to age group comparisons (hypothesis 3), there was a significant difference in sufficiency ratios across age groups (YAs: .36±.25; MAs: .38±.24; OAs: .43±.26; F=3.71; df=2,872; p=.03), with post-hoc comparisons revealing that OAs had a higher sufficiency ratio

than YAs (p=.04) and MAs (p<.05), meaning that a greater percentage of areas considered important were done enough.

When comparing sufficiency thresholds in specific areas (Table 3), post-hoc comparisons revealed that YAs had a higher sufficiency threshold for going to a zoo/garden/museum than MAs (p<.04), meaning that they needed more participation days for participation to be considered sufficient. OAs had lower sufficiency thresholds for working for pay (p=.01) and going to school to earn a degree/certificate (p=.04) than MAs, suggesting that they needed fewer participation days for participation to be considered sufficient.

Discussion

To our knowledge, this is the first study documenting independent community participation and interests by age groups in a large sample of individuals with serious mental illnesses. Hypotheses about the amount, importance, and sufficiency of participation were generally supported. Differences in participation across the lifespan inform the design and tailoring of mental health services and supports in developmentally appropriate ways.

Similar to findings from the general population (Bureau of Labor Statistics, 2016), YAs and MAs were more likely than OAs to participate in employment and to engage in education-related activities. There was a trend toward increased participation in organizational, civic, and religious activities among older participants, but most differences in participation in these areas across age groups were non-significant. An exception was that MAs were more likely to attend a social group than were YAs. This may reflect age-related interpretation of the item. MAs may attend more organized/official social gatherings, whereas YAs may ‘hang out’ in less structured groups. An alternative interpretation is that MAs may be more likely to participate in recovery-

oriented groups in an effort to sustain or grow in their recovery. Thus, data partially support hypothesis 1.

Supporting hypothesis 2, there were age-related differences in the importance of participation in certain areas. More YAs valued working and training activities, more MAs valued leisure-type activities (e.g., going to zoo/botanical garden/museum, or community fair), and more OAs valued purchasing goods/services (e.g., using public transportation, shopping), certain leisure activities (e.g., going to zoo/garden/museum) and civic participation. The relative importance of educational activities to YAs and civic participation to OAs follows the pattern of time use in the general population. Working appeared to be more important to YAs than MAs, which was unexpected. A qualitative analysis of the work-related experiences of younger and older individuals with serious mental illnesses may provide insight into this finding, as younger people were most likely to identify working as a life goal while those older tended to be concerned about perceived work-related barriers, such as loss of disability benefits (Millner et al., 2015). YAs are in a life stage in which career identity is developing (Clark & Unruh, 2009), have had less exposure to disincentive messages about work, and may consequently place greater value on work. Another interesting finding was a greater percentage of MAs and OAs considered certain leisure areas to be important (e.g., going to a zoo/garden/museum). However, one should not conclude that YAs are uninterested in leisure, as they tended to value spending time with family and friends. As suggested by developmental theories and previous research (Kaplan et al., 2012; Shimitras et al., 2003), the social aspect of leisure activities may be more valuable to YAs than the particular type of activity performed.

Several notable findings about sufficiency of participation emerged. First, participants' sufficiency thresholds for work-related activity appeared to be lower than the number of days

that most people work in the general population (Bureau of Labor Statistics, 2016). The easiest interpretation is that individuals with serious mental illnesses desire less than full time employment; a more thoughtful analysis considers how their employment expectations may be shaped by their environments. In countries with high unemployment rates, employed individuals experienced greater life satisfaction despite the desire to work more (Baslevent & Krimanoglu, 2016). Given the high rates of unemployment among individuals with serious mental illnesses (Baron & Salzer, 2002), satisfaction may be based more on having a job than the amount of participation. Second, supporting hypothesis 3, OAs had a higher sufficiency ratio than their counterparts, indicating that they were participating enough in important areas to a greater degree. Consistent with their life stage, OAs also had a lower sufficiency threshold in work and school areas. We interpret the finding that OAs experienced greater sufficiency of participation in light of Motivational Theory of Life-Span Development (Heckhausen et al., 2010), although we acknowledge that other explanations are possible and that this study was not designed to answer questions about predictors of sufficiency. This is an area for future research.

It is also interesting to note that in many community participation areas, there were consistencies in aspects of participation across age groups. For example, when examining importance of participation, it may be observed that there were several areas with a large percentage of individuals rating them as important and no group differences. These included going to a barbershop/salon; going to a place of worship; going to a gym, health, or exercise club; entertaining/visiting family or friends in the home; and getting together in the community or attending an event or celebration with family or friends. These findings suggest particularly meaningful areas of community participation despite age, and may be useful when planning supports.

Several limitations to this study merit discussion. First, the TUCP may not adequately capture areas of importance for YAs. Development of a community participation measure designed for YAs with psychiatric disabilities is recommended. Second, the TUCP may underestimate participation levels, as it assesses participation without the support of a mental health provider. However, knowing how often individuals independently participate in personally meaningful areas in the community can inform efforts to support the community integration and inclusion of mental health consumers. Third, potential confounds, such as geographic or neighborhood characteristics (Byrne et al., 2013) and psychiatric symptoms (Davis, Townley, & Kloos, 2013), may have produced differences in community participation. Since these other considerations were not a focus of the studies from which the data originated, we could not control for them but recommend that future research explore their potential role.

Despite these limitations, this study makes an important contribution to the literature by supporting the use of developmental frameworks for delivering mental health services and supports. Application of developmental frameworks that consider age-related expectations: (a) promotes a more holistic understanding of the people who receive mental health services by taking into account typical values, roles, and behaviors; (b) encourages service engagement, particularly for difficult to engage groups like young adults (Lucksted et al., 2015); (c) enhances treatment efficacy (Davis, Koroloff, & Ellison, 2012); and (d) facilitates community integration and inclusion by helping consumers participate in areas most salient to their life stage. Findings demonstrate that theories of human development, particularly Erikson's stages of life development and Vaillant's theory of developmental tasks (Agronin, 2014), may be especially useful when designing and tailoring services and supports.

Historically, mental health service systems have been poorly equipped to assist youth with the transition to adulthood, especially in relation to preparing them to participate in adult roles in the community (Furstenberg, 2015). Since the seminal Recovery After an Initial Schizophrenia Episode (RAISE) study (Kane et al., 2016), increased funding for early psychosis treatment programs has allowed for the widespread implementation of services for YAs with psychotic disorders. These services especially target work and school-related participation (Mueser et al., 2015). In addition to providing empirical support for YAs' interests in these areas, this study highlights the need for services that promote social integration in this age group in order to fulfill the developmental need for intimacy and relatedness. Therefore, it is important that policy makers and providers also support approaches that help YAs build and sustain healthy relationships in their communities. For example, managed care companies might include funding for programs that target these areas. As both personal and environmental challenges contribute to the poor social relationships of individuals with mental illnesses (Davidson et al., 2004; Stier & Hinshaw, 2007), efforts to promote social integration should not only focus on supporting YAs with their relational goals, but on making community settings as welcoming and inclusive of these individuals as possible. Policy makers and providers are also encouraged to apply lessons learned from the RAISE study to systems of care that are available to YAs without psychotic disorders.

With regard to MAs, services that target occupational functioning, such as supported employment (Modini et al., 2016), might place a greater emphasis on evaluating expectations for employment and correcting misperceptions about work so that individuals are able to participate to a greater degree in this developmentally appropriate area. A study of a vocational intervention program that was designed to address defeatist beliefs and work-related amotivation

demonstrated that individuals in the experimental group experienced an improvement in work performance and a higher supported employment retention rate compared to those who did not receive the intervention (Mervis et al., 2016). Interventions such as these might be particularly helpful and should be encouraged in routine practice. For example, policy makers could allocate research funding to programs that utilize these interventions so that they may be systematically studied.

Finally, services for OAs might especially focus on helping individuals derive meaning and purpose from their lives while encouraging continued participation in areas that are important to them. Recently, there has been increased interest in the use of photovoice interventions in the context of mental health treatment. These interventions use narrative therapy principles to help individuals construct empowering stories based on their life experiences, and demonstrate promise for improving empowerment, positive identity, and community integration (Mizock, Russinova, & DeCastro, 2015). While not specifically designed for OAs, interventions such as photovoice might assist individuals with accomplishing the developmental tasks associated with older age.

The present findings also highlight areas of community participation that require additional attention in order to close the gap between what consumers express as important to them and what they actually do. A review of participation areas indicates that consumers participate in the community to meet basic needs (e.g., running errands); however, participation appears lower in areas typically valued by different age groups across the lifespan (e.g., spending time with family/friends, working, civic engagement). These findings are consistent with research documenting reduced participation in important domains of community living in individuals with serious mental illnesses (Baker & Procter, 2014; Baron & Salzer, 2002; Pratt,

2012). Further, less than half of the sample reported participating enough in areas that were important to them. The disconnect between the amount and importance of participation became less pronounced as individuals aged, but this may reflect a shift in expectations as a consequence of experiencing the numerous personal and environmental barriers to participation that those with serious mental illnesses frequently face. Results suggest that policy and practice efforts might especially focus on reducing barriers to participation in work and school-related activities in YAs, recreation and leisure in MAs, and civic involvement in OAs.

Finally, this study has implications for program evaluation and specific interventions in mental health settings. For example, these data may be used to evaluate services offered in comparison to consumer interest and age-normed participation. Agencies could also periodically evaluate sufficiency ratios to determine if consumers are increasing overall satisfaction with participation. As social comparison is often how individuals prioritize activities (Festinger, 1954), providing information to consumers about age-matched peers may especially help those who identify few interests or have difficulty prioritizing activities.

Conclusions

More frequently, mental health services aim to support consumers to engage in personally meaningful and diverse life roles. However, little research has explored how consumers with serious mental illnesses spend their time in the community independent of these services, and how community participation may differ by age. By reporting on the amount, importance, and sufficiency of community participation in different age groups of adults with serious mental illnesses, this study addresses a significant gap in the extant literature and may assist providers and policy makers with age-tailoring mental health services and supports.

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