Understanding perceptions of community participation in persons with severe mental illness: A mixed-methods approach

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ABSTRACT

OBJECTIVES: This study aims to measure community participation in persons with severe mental illness (SMI) in Toronto, Ontario and outlines a methodological approach for understanding the dimensions of community participation.

METHODS: A mixed methods approach was used to define activity spaces through participatory mapping and a qualitative survey interview for participants ($N = 31$), selected through a stratified purposeful sampling strategy. Five neighbourhoods in Toronto were sampled in an attempt to obtain an ethnically diverse sample. Participants were interviewed over the study period and asked to draw maps indicating places that constituted their community. A qualitative interview was also administered to understand participants' perceptions of their communities. Point locations from the mapping exercise were used to measure and construct activity spaces using a mean circle approach; outlying locations were simultaneously recorded. Observed spatial patterns were then analyzed alongside the findings of the qualitative interviews.

RESULTS: There were no observed relationships between the number of locations reported by participants and the resultant activity space or outlier count. There were no quantitative relationships between activity space size and perceptions of community by participants. However, qualitative data revealed that a number of underlying factors (mental health status and associated stigma; relationships with friends and family; cultural background; income; and neighbourhood safety) influenced participants' activity spaces.

CONCLUSIONS: These results highlight the ways that community participation is influenced by an interplay of determinants, all of which have implications for service delivery and population-level interventions. They also point to the importance of mixed methods approaches in spatial analysis.

KEY WORDS: Mental health; community; schizophrenia; spatial analysis

La traduction du résumé se trouve à la fin de l'article.

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The term “community” is routinely used in policy and practice dialogues pertaining to severe mental illness (SMI), with SMI referring to major mental illness diagnoses attended by frequent contacts with services in key life domains.¹ Community and community participation (CP) in turn involve social and emotional connections constructed in physical spaces, movement across spaces, and the qualities of spaces.^{2–6} These connections are dynamic over time – shifting with considerations such as self-concept, socio-economic context and culture.⁷ In mental health literatures, community is framed as a resource (social and otherwise) – a place where recovery most readily occurs; and participating in communities is an often-cited treatment, service and system objective.⁷ What is almost absent in the mental health literature is adequate attention to the complexity of the community construct.⁷ This presents challenges for service provision and policy, which are subsequently often inadequately informed and run the risk of being ineffective. The relatively sparse level of attention to the concept of community in the mental health field is surprising given the complex discussions about community in allied research literatures, including community development, sociology, public health, and disability studies.^{8,9} Analyses in these literatures emphasize the multifaceted nature of community, including its social, physical and psychological dimensions.

Complex constructs such as community require research designs that employ triangulation as a function of data source and method of inquiry.⁵ One mixed-methods approach in this area combines geographic information systems (GIS) social resource mapping with qualitative inquiry.⁵ In literatures of community development, poverty, and welfare reform, combining mapping with qualitative inquiry has been found to be a highly effective way for people to describe their understanding of and participation in communities.^{4,10–12} One example of this type of approach for an SMI population is Townley et al.'s⁵ use of social mapping to examine sense of community and activity in the Southeastern United States. This study emphasized the salience of “home” as the most important activity location, and observed that those with a

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smaller radius of community activity had a stronger sense of community integration, though lower life satisfaction.⁵

The current study was designed to examine the perceptions of community and empirical use of space by individuals with SMI in the large urban centre of Downtown Toronto through a mixed-methods approach of participatory mapping and qualitative interviews, thereby addressing the following research question: How does a diverse group of individuals with SMI living in Metro Toronto experience community? This approach closely follows Townley et al.'s work and attempts to incorporate a closer examination of an ethnically diverse population.

METHODS

Sampling area and strategy

Figure 1 shows the boundaries of the five study neighbourhoods in the city of Toronto, namely Moss Park, Regent Park, Trinity-Bellwoods, Niagara and Parkdale. These five geographic spaces provide a broad spectrum of socio-economic and ethnocultural diversity, and are areas where many Toronto citizens with SMI reside as a function of income.

A stratified purposeful sampling strategy was used to select four groups of participants with psychosis-spectrum major mental illnesses in a manner addressing ethnocultural diversity.

Accordingly, balanced groups of participants of i) South Asian, ii) East Asian, iii) African Caribbean and iv) White European origin were recruited. Participants were approached through hospital-based and community organizations and through snowball sampling. Of a total sample of 31 participants, 8 came from Regent Park, 7 from Parkdale, 6 from Moss Park, 3 from Trinity-Bellwoods, 1 from Niagara, and 6 from adjacent communities. The age range of participants was 28–62 years. The sample consisted of 14 (46%) males, 15 (48%) females and 2 (6%) participants who did not conform to the gender binary. Six (19%) participants identified as White Canadian, 2 (6%) White European in origin, 1 (3%) African origin, 7 (23%) African Caribbean origin, 1 (3%) Indian Caribbean, 1 (3%) Latin American, 3 (10%) South Asian, 3 (10%) East Asian, 2 (6%) South East Asian, 1 (3%) Middle Eastern, and 3 (10%) identified with multiple origins. For further details on participants and recruitment, see Kidd et al. (2016).⁷

Study design

Three times over the course of 10 months, participants spent 6–8 hours completing i) in-depth interviews with a focus on the meaning of community, ii) a guided tour of their community and iii) a participatory mapping exercise to indicate the locations of their regular activity points. For the qualitative interview, a semi-structured qualitative interview guide was used, with “points of

Figure 1. Locations of the five study neighbourhoods within the City of Toronto showing average household incomes as reported in the 2006 Census of Canada^{13,14}

departure”¹² developed from community theory literatures^{7,15} that explored the use of (or avoidance; denial of access to), experiences in, and meanings ascribed to spaces ranging from home, to immediate vicinity and to the greater city. Audio-recorded interviews were complemented by field notes for ethnographic aspects of inquiry and the inquiry was iterative – following up on information shared earlier and inquiring about themes emerging in the analysis.

Participatory social mapping

During the interview process, participants took part in participatory mapping exercises in which they detailed their activity spaces. Participants drew maps and provided a list of the names and addresses (closest major intersection) of places that comprise their activity spaces. These addresses were subsequently geocoded using Esri’s ArcGIS® Online Geocoding Service for further spatial analyses.

Typically in studies examining the derivation of activity space areas, the Standard Deviation Ellipse (SDE) has been used to determine the directional distribution of a person’s use of spaces.^{16–19} While this approach provides a strong indication of the direction of a person’s activities within their proximal community, outlier activity points can lead to an overestimation of the size of activity space.^{20–24} To address this problem, the current study used a mean circle approach.^{17,19} The mean circle method represents one of the earlier attempts to define areas of importance based on the presence of point or line phenomena.^{18,19} This approach produces a circle around the activity points, based on a weighted centre; the radius of this circular area represents the average distance of all activity points from the weighted centre.

The current study estimated the activity space area for each participant using a mean circle analysis by calculating the average Euclidean distance travelled to an activity point from that person’s home address. This average distance was then used as a radius for a mean circle centred at the home address, whose area was subsequently used as an estimation of a participant’s activity space. Only locations within the city of Toronto (see Figure 1 inset) were used to calculate the average distance travelled. In their 2012 study, Boscoe et al.²³ observed a close correlation ($r^2 > 0.9$) in comparing Euclidean and network distances for travel times between community hospitals and sample point locations. Chan et al.²⁴ have compounded on the earlier work of Boscoe et al.²³ in the use of Euclidean distance measures in finding proximities of study participants’ homes to community features. Last, an outlier analysis was conducted to identify activity points that did not fall within a participant’s normal activity space. While a neighbourhood’s profile (demographic distribution, diversity, income, crime, employment) influences an individual’s use of space in their community, given the small sample size of this study, we did not look at correlations between resultant activity spaces and outlier count with specific neighbourhood characteristics. This would be an interesting avenue to explore in future studies.

The qualitative interview data were analyzed through an approach informed by grounded theory that focused on generating themes through multiple rounds of coding and with emergent themes being explored with participants in subsequent interviews.²⁵ A more detailed discussion of these methods is reported elsewhere.⁷

RESULTS

Activity points

From the participatory mapping component, participants reported an average of 20.13 activity points (range = 5–41, SD = 7.58). In examining the patterns of activity points for participants, there were no obvious commonalities within neighbourhoods. The activity points were grouped into six broad categories to summarize the types of activities that participants engaged in at those locations: a) *Daily life* (i.e., school, work, friends, family), b) *Health and welfare* (i.e., social services, food banks, mental and physical health services), c) *Food and social eating* (i.e., coffee shops, fast food outlets, restaurants, bars), d) *Shopping and amenities* (i.e., grocery stores, shopping malls, drugstores), e) *Leisure* (i.e., parks, movie theatres, gyms), and f) *Unspecified activities* (i.e., hairdressers, banks, meetings). Table 1 summarizes the counts of participants who reported these broad categories and the number of activity points reported for each category.

Within these broad categories, the most commonly visited activity points were sit-down restaurants (67 activity points). Grocery stores were the second most-frequented activity points in peoples’ lives (59), followed by social services organizations (54), shopping centres (43), coffee shops (40), and the Centre for Addiction and Mental Health (CAMH) (35). CAMH was assigned a separate code given the high involvement of these participants with CAMH compared to other social and health services.

Activity spaces

In using the mean circle method, activity space areas ranged from 1.81 to 111.91 km² with a mean area of 22.12 km² (SD = 25.42). The number of activity points per participant did not relate to the activity space area in any observable trend for all 31 participants, that is, participants with large numbers of points (and small numbers) had differing activity space areas.

Table 2 summarizes the activity space areas for the sample with respect to the number of activity points reported by the participant. The highest number of participants (29%) had activity space areas of <5 km², while the second largest proportion of the sample (19%) had activity space areas of >30 km². This suggests three prominent patterns of activity space use: a group of participants accessing community spaces very near to their home, a group of participants accessing community spaces across the city, and a group of

Table 1. Number of reported activity points for each activity type group, and number of participants reporting each group

Activity type group	Occurrence count ($N_{\text{activity points}} = 656$)	No. of participants who identified activity type group ($N_{\text{participants}} = 31$)
Daily life	64	31 (100%)
Unspecified category	65	29 (94%)
Leisure	102	27 (87%)
Shopping and amenities	129	31 (100%)
Health and welfare	144	30 (97%)
Food and social eating	152	28 (90%)

Table 2. Summary of activity space sizes, activity point counts and distance outlier ranges ($n = 31$)

Activity space area (km ²)	Number of participants	Activity point count range	Distance outlier count range
<5	9 (29%)	5–31	3–9
5.1–10	5 (16%)	13–25	4–10
10.1–15	2 (6%)	19–22	5–6
15.1–20	3 (10%)	9–30	2–13
20.1–25	1 (3%)	0–22	0–6
25.1–30	5 (16%)	9–30	3–13
>30	6 (19%)	14–41	3–11

participants (the majority) with an activity space in the mid-range. Interestingly, the groups with the largest and smallest activity spaces also had the largest range of activity point counts. These findings underscore that caution must be taken in assuming anything about a person's physical engagement with their community from the size of their activity space.

Table 2 provides the count of distance outliers identified for different ranges of activity spaces. Distance outliers are those activity points that fall outside the individual's activity space as calculated using the mean circle method. An interesting observation was that participants with the largest (>30 km²) and smallest (<5 km²) activity spaces showed similar ranges for the number of outliers identified (see Table 2).

Figure 2 shows two examples of derived activity spaces using the mean circle approach. In the case of these two examples, ID 2 shows that a close proximity of frequently visited activity points gives rise to a smaller mean distance travelled from home, while ID 12 shows a converse relationship. Additionally, Figure 2 highlights the broader finding that the number of points did not directly influence the activity space size.

Outlier results

Table 3 summarizes the counts of activity types that were identified as distance outliers and the number of participants for whom the activity group was identified as an outlier. The highest number of outlier activity points were found under the "Health and welfare" grouping, with 25% (54 points). This proportion of the identified outliers was attributed to reporting from 19 (61%) participants and reflects the significance of social services in participants' lives for multiple reasons, outlined in more detail below. Conversely, the lowest number of points was found under the "Daily Life" grouping, with a constituent 7% of the identified outliers. This group of outliers was only attributed to 10 (32%) participants.

Patterns in activity points: Meanings of common places

As a whole, the GIS results suggested that participants are engaging with a cross-section of community locations and are engaged with their communities at a physical geographical level (i.e., getting out

Figure 2. Examples of activity point distributions and activity spaces derived from the participatory mapping component

Table 3. Summary of counts of participants and outliers for activity type groups

Activity type group	Outlier occurrence count ($N_{\text{outliers}} = 215$)	No. of participants for whom activity type group was identified as an outlier ($N_{\text{participants}} = 31$)
Daily life	15	10 (32%)
Unspecified category	19	3 (10%)
Shopping and amenities	41	12 (39%)
Food and social eating	42	14 (45%)
Leisure	44	14 (45%)
Health and welfare	54	19 (61%)

of the house and being present in community spaces). The results also point to the particular importance of sit-down restaurants and service organizations in daily activity patterns. The qualitative data suggested that these two types of spaces are particularly important because participants used them in meeting basic needs and gaining practical supports, but that they also played an important role in feelings and perceptions of community participation and belonging.

Most participants described eating at restaurants for practical reasons, that is, they did not know how to cook, did not feel they had the energy to cook, or had limited access to cooking facilities (e.g., dirty shared kitchens in rooming houses, food handling legislation). Restaurants were used as an important source of pleasure for many of the participants, as a way to be out in the world and in the presence of others (even if dining alone), and as a way to briefly connect with the types of lives that many participants felt their illness and associated systemic barriers blocked them from having.

For many, social service spaces were an important source of support and interaction through relationships with peers and staff in those spaces. They also represented spaces where participants could spend time without spending money – an important feature given the high rates of poverty among the participants. For example, one participant commented, “When I go to CAMH, Queen Street, I know a lot of people and I’ve seen them at their worst and they’ve seen me at my worst” (ID 17). Another participant said that most of her friends were from CAMH because “well they know the struggles” (ID 18). Another participant echoes the sentiment that there is opportunity for a certain quality of connection in these spaces. “We can talk there [CAMH]. We can talk and so on.” “But outside of CAMH, it’s like no, ‘cause everybody’s in their own world. But at least it’s a place you can go and talk when you’re lonely” (ID 20). These perspectives suggest that health and welfare organizations have significance beyond their functional role for people diagnosed with schizophrenia in Toronto.

Patterns in outlier results: Understanding the search for community

While family and friend activity points represented only a small fraction of the total activity point data (9/656 and 16/656 activity points respectively) and the outlier counts, the percentage of these

activity points that were outliers was significant: 67% of the family and 19% of the friends activity points were outliers. This demonstrates that family members, particularly, often exist in a distinct spatial sphere from participants’ daily lives. Indeed, throughout the interviews, many participants cited complicated – and often strained – relationships with their families due to histories of hospitalization; “They are married, they are busy with their family.... I don’t see them very often” (ID 21).

Patterns in activity spaces: Understanding presence in the community

A qualitative analysis of participants’ activity spaces suggests that there are diverse factors influencing activity space sizes that cannot be captured by a strictly quantitative analysis. For example, factors influencing small activity spaces are sometimes contrasting. Seven of the nine participants in the smallest activity space size category (<5 km) have lives in these spaces that converge with traditional understandings of community: a physical presence in a geographic area that includes social contact with others and engagement with meaningful places. These participants were strongly connected to cultural or religious communities or social service organizations, which were located in close proximity to their home addresses (ID 15, 8, 4, 2, 16, 27, 28). For these participants, small activity spaces reflected social ties within a local geographic area, consistent with results from previous studies where people with smaller activity spaces were shown to experience a stronger sense of community.⁵ However, there were contrasting results for two other participants in this activity space size measure (<5 km). Despite occupying a local geographical area, these participants had minimal social ties or meaningful places nearby (ID 19). Both of these participants described distant, impersonal relationships with family and explained that safety in their neighbourhood affected their desire to go out. One participant viewed her neighbourhood as unsafe with “too much drugs,” which influenced her space use. “The apartment is not safe to be in right now, that’s what’s having an influence on my life right now” (ID 19). Quantitatively, the activity space sizes in this group of participants are similar, but qualitatively they are laden with distinct meanings.

There were more consistent commonalities among participants with the largest activity spaces (>30, $n = 6$). First, they all seemed to have close relationships in their lives. These relationships affected their space use; social contact was important to them and worth travelling for. Indeed, these results support Townley et al.’s⁵ findings, showing that larger activity space areas are linked with higher life satisfaction, albeit not necessarily community participation. However, in this study the qualitative data *do* suggest a high degree of community participation for those with large activity spaces. All of the participants with the largest activity spaces were from immigrant backgrounds, and some expressed challenges with language and cultural barriers in Toronto (ID 12, 13, 22, 24, 30, 31). All of these participants ($n = 6$) identified “pockets” of community in the city, which included cultural, linguistic and religious spaces (e.g., Chinatown, churches, specific restaurants). For example, one participant (ID 24) said she likes going to Chinatown because she likes being around people who speak Cantonese. Cultural and religious places played a significant role in activity space sizes – when cultural and religious places were

close to participants' home addresses, activity spaces were often small, as noted above; when they were farther from participants' home addresses, participants would travel farther to reach these activity points. These distances do not suggest disconnection from community, but rather a different form of community participation. These large activity spaces could represent new ways of thinking about community participation from a spatial perspective, particularly in ethnically diverse populations.

DISCUSSION

While serving the purpose of extending the line of inquiry begun by Townley and colleagues,⁵ this study has several limitations. Though having the study take place over 10 months and with 3 contacts allowed for greater depth of inquiry and verification of themes, it is of note that community participation processes unfold over longer periods. As such, this study was unable to examine this change over time. This study also relied primarily on self-report and took place downtown in a single urban centre, raising questions of generalizability and transferability. Finally, this study was not able to address the urban dynamics noted by others in which inner and outer suburbs are replacing the downtown core as places of residence for people with SMI as a function of gentrification.²⁶

However, this study does begin to highlight the ways that, for people living with SMI in Toronto, space use and community participation are influenced by an interplay of determinants, including mental health diagnosis and associated stigma; limited relationships with friends and family; cultural background; income; and neighbourhood safety. A methodological implication arising from this study is the depth of information gathered through the use of a mean circle approach coupled with an outlier analysis and qualitative inquiry to examine activity spaces.

The prominence of service spaces, such as a tertiary psychiatric facility, as a community space with implications beyond primary mental health care was striking. The role of discrimination was prominent in shaping this aspect of community participation, resonating with the intense stigmatization of psychoses.²⁷ Herein lies one of the central dilemmas in the field – whether service environments should cultivate a community ethos (as in early sanitarium models) or strictly emphasize out-of-hospital community participation. Indeed, enhancing community participation is clearly complex, as evidenced by the unclear benefits of public awareness campaigns designed to reduce discrimination.^{27,28}

A clear concern lies in the finding that small activity spaces were, for some, determined by fears of violence and victimization. Obviously relevant to SMI populations where trauma is common and there is a dose response relationship between victimization and illnesses such as psychosis,²⁹ it brings to light questions of human rights and the substandard living conditions being made available. Conversely, small activity spaces can indicate positive community connections, such as closeness with key relatives or contacts with communities of cultural relevance and resource. Herein lie implications for both a close assessment of safety and attending to same in clinical and policy domains as well as the clear need for a more nuanced understanding of barriers and resources in considering service design and interventions vis-à-vis community participation.⁷

Finally, it would be beneficial if future work took directions such as longitudinal analyses, attention to different geographic contexts (e.g., suburbs, rural settings) and locations (by country, size of city), and studies exploring in greater depth the unique features of subpopulations (e.g., by ethnicity, income level). This line of inquiry is in response to increasing calls for a better quality of information in this area and concerns that employing the concept of community without analysis will exacerbate the systemic problems faced by people with mental illness in poorly resourced and discriminatory community contexts.^{10,11} The scope and severity of this issue is amply evidenced in the history of failures in psychiatric de-institutionalization.

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RÉSUMÉ

OBJECTIFS : Notre étude vise à mesurer la participation communautaire de personnes atteintes d'une grave maladie mentale à Toronto (Ontario) et décrit une démarche méthodologique qui permet de comprendre les dimensions de la participation communautaire.

MÉTHODE : Nous avons utilisé une approche à méthodes mixtes pour définir des espaces d'activité, au moyen de la cartographie participative et d'un sondage par entretien qualitatif auprès des participants ($N = 31$), sélectionnés selon une stratégie d'échantillonnage intentionnel stratifié. Cinq quartiers de Toronto ont été échantillonnés afin d'obtenir un échantillon diversifié sur le plan ethnique. Les participants ont été interviewés au cours de la période de l'étude, et nous leur avons demandé de dessiner des cartes indiquant les endroits qui constituaient leur communauté. Nous avons aussi mené des entretiens qualitatifs pour connaître leurs perceptions de leurs communautés. Les emplacements des points obtenus par l'exercice de cartographie ont servi à mesurer et à construire des espaces d'activité selon l'approche du cercle moyen; les emplacements périphériques ont été enregistrés simultanément. Les structures spatiales observées ont ensuite été analysées côte à côte avec les constatations des entretiens qualitatifs.

RÉSULTATS : Nous n'avons observé aucun lien entre le nombre d'emplacements indiqués par les participants et le nombre résultant d'espaces d'activités ou d'emplacements périphériques. Il n'y avait pas de liens quantitatifs entre la taille des espaces d'activité et les perceptions de la communauté par les participants. Cependant, les données qualitatives ont révélé que des facteurs sous-jacents (l'état de santé mentale et la stigmatisation associée; les relations avec les amis et la famille; le contexte culturel; le revenu; et la sécurité du quartier) influençaient les espaces d'activité des participants.

CONCLUSIONS : Les résultats obtenus montrent que la participation communautaire est influencée par l'action réciproque de déterminants, lesquels ont tous des conséquences sur la prestation de services et les interventions en population. Ces résultats montrent aussi l'importance des approches à méthodes mixtes pour l'analyse spatiale.

MOTS CLÉS : santé mentale; communauté; schizophrénie; analyse spatiale