

Titre : Comprendre les seuils du vivre-ensemble dans l'action publique en santé mentale : des apprentissages transversales issues du Québec et du Brésil

Autrices : Isabelle Ruelland et Emmanuelle Khoury

Introduction

Specialized community mental health services have seen a rapid development internationally, particularly in Brazil and Canada (Onocko, 2012; MSSS, 2012; 2015; Rodriguez, 2011). Part of the continuum of mental health reforms in both countries, community mental health care offers the possibility to avoid potentially stigmatizing and traumatizing in-patient psychiatric care by placing the person and his or her living environment at the centre of care services.

We conducted research on these community-based mental health programs in Campinas and Montreal. We bring attention to the particular cities in which the programs were deployed rather than to their country since the particularities of the specific city space or territory will influence the nature of urban mobility. Both cities of Campinas (Sao Paulo state, Brazil) and Montréal (Québec, Canada) have invested in specialized mental health care that is community located with the goal of increasing the personal autonomy of the person in his or her community. They are cities with a different sociocultural, sociopolitical and socioeconomic backdrop, whose residents are facing different levels of social inequalities. Thus, several factors identified by Baldwin and King (2016) regarding social cohesion, health and well-being (eg. Public transit and infrastructure) differ vastly in these two cities. These differences are crucial to our development of a better understanding of the complex relationship service users have with their urban mobility. The present paper offers an exploration of mental health practice from the point of view of the people who are travelling to and from their homes to access the services and/or access resources identified in their intervention plans. Listening to what service users say about their urban mobility and observing the facilitators and barriers to their desired mobility, allowed us to identify the conditions that help or hinder them experiencing community life in their unique recovery process.

In these two studies, we focus on the comparison of experiences of community mental health care by outlining the situated actions, interactions and activities that lead to access and utilisation of community resources. This international and intercultural dialogue between Campinas (Brazil) and Montreal (Canada) allowed for a fresh look at what is happening in each city to better grasp and understand the subjective meaning of urban mobility and the spatial inequalities in both local realities and how this relates to an individuals personal recovery process. This psychosocial emphasis is less prominent in the contemporary literature on moving around in in the city space (Whitley and Prince, 2005, 2006; Thomas et al., 2007).

Methods

Our research was supported by the International Community University Research Alliance (CURA) for Mental Health and Citizenship (Rodriguez and Onocko, 2015) which was engaged in an international effort to renew practices and initiate social transformation so that people living with severe mental health issues could have the space and place to exercise their rights and live a life of quality in their community of choice. This is important for any discussion or research in this field because people living with mental health problems are particularly affected by structural and symbolic inequalities (Poirel, Weiss, Khoury & Clément, 2015; Ruelland, 2015). These inequalities often result in, and maintain, their situation of marginalization and social exclusion. Thus, a legitimate question would be: which conditions lead to improved access and use of community resources and inclusion in public spaces?

Using the narratives of two service users as particular cases in Montréal and Campinas, respectively, these two qualitative case studies examine and compare two community mental health models as both mental health policies at the macro level and organizational systems at the meso level that play a major role in facilitating or impeding urban mobility. Both research studies used a critical ethnographic approach, which allowed for an intimate explication of the inner workings of the respective community mental health teams. The case study approach, as a way to develop knowledge through detailed exploration of data sets, has been supported as a methodology that allows for reasoning through detailed in-depth data of a particular site, individual or phenomenon (Becker, 2014; Crowe et al., 2011; George & Bennet, 2005).

In addition to participant observation at both sites, individual semi-structured interviews lasting 30 minutes to 2 hours were conducted with a total of 16 service users and 49 professionals. The semi-structured interview guides were developed independently but both included questions about participants' perspectives regarding their experiences with the community mental health team in their neighbourhood, their social network, their satisfaction with their community contacts and their ability to access and utilise community resources.

Ethnographic analysis is never linear and is tangled up with every stage of the research process (O'Reilly, 2005). For both studies, coding followed a highly inductive approach that began with an open coding phase. Connections between these codes were ascertained (eg. Social network, medication supervision, community contacts) and led to the emergence of key, broad categories. To enhance rigour, analysis of interview findings and participant observation data was triangulated with documentary evidence from different sources.

For the current article, the authors subsequently re-examined the data from the 16 service user interviews through the lens of urban mobility, access to public spaces, resource utilisation, and wellbeing. The authors found a high level of concurrence in the results and key categories that emerged from the two research studies. A comparative approach allowed for an encounter between the two sites which highlighted the tensions and

paradoxes in attempts to develop recovery-oriented, community-based mental health practice.

Findings and discussion

The notion of special inequality is typically employed in economic and developmental discussions (Folmer, 1979; Grant, 2010; Kandbur & Venables, 2005; Kilroy, 2009) to demonstrate inequality in economic and social indicators of wellbeing across a geographical unit. It is referred to as a poverty trap by Grant (2010) and discussed as “self-perpetuating, embodying serious economic and social problems” (Kilroy, 2009). These spatial inequalities are rarely directly discussed in the literature on social determinants of health. However, participants commented regularly on their ability, or inability, to access resources based on the specific geographic territory they lived in.

It seems that it is not so much (or at least not only) interventions or sophisticated treatments that support or hinder a service user’s recovery journey or sense of empowerment as much as structural aspects such as access to transportation. This access seems to be related to the personal economic status, the personal network, the urban infrastructure and finally the interactions with a mental health professional but in Campinas and in Montreal.

The policy and practice emphasis on tertiary care mental health teams has created the possibility for mobility within the city space. Service users that were once relegated to the confines of a hospital room are now living in community housing or independent apartments and by virtue of their visit to the clinics or other appointments are more present in the public space than they would have been 10 years ago. Concurrently, their capacity to circulate and the opportunities to circulate and actively engage in the public space, especially beyond their immediate local surroundings, are mitigated by the ACT and CAPS programs. Returning to our previous discussion on mobility (Anderson & Baldwin, 2016; Baldwin & King, 2017; Baldwin, 2016) and time-space inequalities (Whitley and Prince, 2005, 2006) we believe that our case studies support their suggestion that access to transportation and changes in urban design can significantly impact social determinants of health.

There is also a variation in the ability to access different spaces within the immediate and wider environment in the two case studies. The Montreal case shows an increased use of public spaces and a more varied mobility (in terms of where, when and why) through the city where public transportation and urban design are more amenable to this. Also, the CAPS model is a one stop shop model, unlike the ACT model which provides psychiatric and some psychosocial services but then refers service users to other organisations for other needs or interests thus increasing their mobility and community contact. For example, if we think about Julio and his bike ride to the CAPS, this autonomy, is limited by the total lack of bike paths in the favela where he lives.

However, the availability and relative accessibility to public transportation and thus to a variety of community activities and services in Montréal does not necessarily reduce feelings of isolation. Participants consistently evoked the lack of a strong social network outside of the ACT team. In fact, many stated that the ACT was their only social network. Some referred to the treatment team as his “friends” and another participant, Other, referred to them as his “family”. They have the public means to circulate but it’s like if they circulate in a “track” controlled by third line service within society. If social network is part of the clinic then this liberty of mobility favours autonomy but is it used in a way that limits their mobility with new form of boundary reproducing hospital centric models. These two studies suggest that restrictions in how, when, where and why an individual circulates may play a role in the maintenance of hospital centric models that are not truly community focused and that retain the *status quo* of historical social and economic inequalities.

Conclusion

What we have observed by explicating the mobility within the city of individuals receiving medical and psychosocial services in community based tertiary care facilities in two cultural contexts is that the institution itself affects the ability to circulate but also determines it. On the one hand the ability to circulate depends on the case worker or treatment team to provide money for bus passes, to make referrals to community organisations or to provide car services. However, the ability to circulate also goes beyond the role of the treatment team; how, when, where and why an individual circulates is dependent on his personal preferences and interests and on structural facilitators and barriers such as proximity to public transportation, accessibility to public transportation and services or activities that are available in the community. It is at this juncture that the paradoxes inherent in the community based tertiary treatment model are evidenced.

To deal with this paradox within recovery process our researches invite to reinforce on basic questions about the person’s meaning of mobility: Where and why do you want to go? Can you go there? Yes, how you can go there? No, why and how can we act together to facilitate it? Those questions can even lead to political commons acts between users and treatment team for better urban infrastructure and for the right to choose and to experiment meaningful mobility within or without society (Corin, 2002).

Bibliography

Anderson, J and Baldwin, C (2016) ‘Building Wellbeing: Neighbourhood Flourishing and Approaches for Participatory Urban Design Intervention’, in R. Phillips, C. Wong (eds.), *Handbook of Community Well-Being Research*, International Handbooks of Quality-of-Life, Springer Publications. DOI 10.1007/978-94-024-0878-2_17

Anthony, W.A (1993). Recovery from Mental Illness: The guiding vision of the Mental Health Service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.

- Baldwin, C and King, R (2017) *What about the people? The socially sustainable resilient community and urban development*. Report.
- Baldwin, C (2015), 'Assessing Impacts on People's Relationships to Place and Community in Health Impact Assessment: An Anthropological Approach', *Impact Assessment and Project Appraisal (IAPA)*, 33(2): 154-159.
- Coleman, R. (2004). *Recovery: An Alien Concept?*. P&P Press, Wormit, Fife.
- Corin, E. (2002). Se rétablir après une crise psychotique: Ouvrir une voie? Retrouver sa voix?. *Santé mentale au Québec*, 27, (1), 65-82.
- Crowe et al. (2011). The Case Study Approach, *BMC Medical Research Methodology*, 11:100
- Cummins, S. (2007). Commentary: Investigating neighbourhood effects on health—avoiding the 'Local Trap'. *International Journal of Epidemiology*, 36(2), 355-357. doi: 10.1093/ije/dym033
- Deegan, P. (1988) 'Recovery: The lived experience of rehabilitation', *Psychosocial Rehabilitation Journal*, 6(4), 11-19.
- Deegan, P. (1997). Recovery and Empowerment for People with Psychiatric Disabilities. *Social Work in Health Care*, 25(3), pp. 11-24.
- Dorvil, H. (2005). Nouveau Plan D'action: quelques aspects médicaux, juridiques et sociologiques de la désinstitutionnalisation. Cahiers de recherche sociologiques, sous la direction de Marcelo Otero. Nouveau Malaise dans la civilisation. Regards sociologiques sur la santé mentale, la souffrance psychique et la psychologisation, 209-234.
- Drake, R.E. & Burns, B.J. (1995). Special Section on Assertive Community Treatment An Introduction. *Psychiatric Services*, 46(7), 667-668.
- Fleury, M-J. (2008). Santé mentale en première ligne. *Santé mentale au Québec*, 33(2), 19-34.
- Gélinas, D. (1997). Travail social et suivi intensif dans le milieu auprès des personnes souffrant de troubles mentaux graves et persistants, *Intervention* in Dorvil, H. (2005). Nouveau Plan D'action: quelques aspects médicaux, juridiques et sociologiques de la désinstitutionnalisation. Cahiers de recherche sociologiques, sous la direction de Marcelo Otero. Nouveau Malaise dans la civilisation. Regards sociologiques sur la santé mentale, la souffrance psychique et la psychologisation, 209-234.

- George AL, Bennett A. Case studies and theory development in the social sciences. Cambridge, MA: MIT Press; 2005.
- Government of Québec (ASSS). (2009). Les services de soutien d'intensité variable et de soutien intensif dans la communauté – trousse d'information.
- Government of Québec (MSSS). (2012). Évaluation de l'implantation, Plan d'action en santé mentale 2005-2010.
- Harding, C.M., Brooks, G.W., Ashikaga T., Strauss, J.S. & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness, II: long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry*, 144, pp. 727-735
- Hopper, K. (2007). Rethinking social recovery in schizophrenia: what a capabilities approach might offer, *Social Science and Medicine*, 65, 868-879.
- Pilgrim, D. (2008). 'Recovery' and current mental health policy', *Chronic Illness*, 4, pp. 295-304.
- Mead, S. & Copeland, M. E. (2000). What recovery means to us: Consumers' perspectives. *Community Mental Health Journal*, 36(3), 315-328.
- MHCC, Mental Health Commission of Canada. (2009). Toward Recovery and Wellbeing.
- MHCC, Mental Health Commission of Canada. (2016). Recovery-oriented practice guidelines.
- Ministerio, & Saude, d. (2004). *Saúde Mental no SUS: Os Centros de Atenção Psicossocial*. Brasília: Série F. Comunicação e Educação em Saúde.
- Rodriguez, L. (2011). Nouveaux paramètres pour l'élaboration des pratiques de soutien communautaire : contribution des organismes communautaires et alternatifs au Québec. *Santé mentale au Québec*, 36 (1), pp. 35-56.
- Ruelland, I., (2015) « Les dispositifs de délibération en santé mentale et la démocratisation des échanges entre les pairs : le cas de l'assemblée des usagers d'un Centre d'attention psychosociale au Brésil », *Revue Santé mentale au Québec*, vol. 40, n°. 1 :153-170.
- Starfield , B., 1998, Primary care visits and health policy, *Canadian Medical Association Journal* , 159, 795-796 in Fleury, M-J. (2008). Santé mentale en première ligne. *Santé mentale au Québec*, 33(2), 19-34.

- Thomas, H., Weaver, N., Patterson, J., Jones, P., Bell, T., Playle, R., Dunstan, F., Palmer, S., Lewis, G. and Aray, R. (2007). Mental health and quality of residential environment, *British Journal of Psychiatry*, 191, 500-505.
- Thomson, H., Kearns, A. & Petticrew, M. (2003). Assessing the health impact of local amenities: a qualitative study of contrasting experiences of local swimming pool and leisure provision in two areas of Glasgow, *Journal of Epidemiology and Community Health*, 57, 663-667 in Thomas, H., Weaver, N., Patterson, J., Jones, P., Bell, T., Playle, R., Dunstan, F., Palmer, S., Lewis, G. and Aray, R. (2007). Mental health and quality of residential environment, *British Journal of Psychiatry*, 191, 500-505.
- Wasylenki, D., Goering, P., Cochrane, J. & Prendergast, P. (2000). Tertiary mental health services: key concepts, *Canadian Journal of Psychiatry*, 45 (2), 179-184.
- Whitley, R., & Prince, M. (2005). Fear of crime, mobility and mental health in inner-city London, UK. *Social Science & Medicine*, 61(8), 1678-1688.
- Whitley, R., & Prince, M. (2006). Can urban regeneration programmes assist coping and recovery for people with mental illness? Suggestions from a qualitative case study. *Health Promotion International*, 21(1), 19-26.