Community Partnership in Response to Hoarding Disorder in Montreal

Yuliya Bodryzlova, M.D., M.Sc., Kieron O'Connor, Ph.D., Veronique Vallée, B.Sc., Natalia Koszegi, D.Ps., Marie-Josée Dupuis, M.Sc.

Clinical management of hoarding disorder is challenging because of the weak insight of people with hoarding disorder, the lack of available tools for disease management in the health care system, and the absence of communication between health care and primary responders. To tackle this communication gap and, hence, improve clinical management of hoarding disorder, a community partnership initiated by people with hoarding disorder took place in Montreal. This initiative could profitably offer guidelines for other communities facing hoarding disorder challenges.

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Hoarding disorder is a persistent difficulty in discarding or parting with possessions, regardless of the value that others may attribute to them (1). Hoarding disorder provokes serious clutter, which leads to the faster deterioration of a building and an infestation of living areas with insects and rodents, and it creates important fire hazards (2). Evictions, institutionalization, and homelessness are frequent outcomes of hoarding disorder (3). Its prevalence is estimated at 1.3% (4).

Even though it is a significant and quite frequent mental health problem, hoarding disorder remains underresourced in the health care system. A key reason is the lack of insight in people with hoarding disorder, which makes them rarely seek formal help. Some people with hoarding disorder are oblivious to the clutter and unsanitary conditions of their houses and therefore do not consider their hoarding behavior to be unusual or abnormal. Initial complaints may come from neighbors, landlords, family members, health professionals who are treating these people for other health conditions, and municipal service employees (e.g., housing, building security, fire prevention, police) (5).

Municipal services have few tools to deal with such a truly complex mental health problem. They treat cases as if the solution to the unsanitary or fire security issue, due to hoarding disorder, only depended on the willing cooperation of the affected person. Decluttering is usually coercive and carried out under threat of eviction. People with hoarding disorder describe this intervention as "violent," "forceful," "inhuman," and "threatening" (6). This intervention is not efficient, as it causes significant distress and trauma, which may worsen symptoms of hoarding. A further obstacle in treatment is the lack of resources available within the health care system to deal with hoarding disorder. Even when seeking help, a person can rarely receive tailored care. Interventions—namely, assisted decluttering, psychoeducation, and cognitive-behavioral therapy—are rarely available in the public health care system because of a lack of specialized training among health care professionals (5).

Community partnerships have been proven to be effective in situations in which health outcomes depend on the coexistence of multiple social, cultural, political, biological, and economic challenges (7). Partnerships affect health care policies and resource allocation, as well as logistics within and beyond the health care system. In addition, they inform beliefs, improve attitudes, create trust and mutual aid between collaborators, and improve the social capital of the involved communities (8, 9). The burden of hoarding disorder can be diminished if the people with the disorder and their families can be educated about the disorder and can be

HIGHLIGHTS

- Community partnerships can guide the efforts of the health care system to develop adapting mental health services.
- People with mental disorders could be drivers of change by narrowing the gap between their needs and health care services.
- The openness of the health care system to communication can encourage people with mental disorders and other actors to share their expertise and preoccupations to make health care services more responsive to their needs.

referred, in a timely fashion, to mental health services or to social care.

To achieve this, these services must be adequately equipped with management tools, and there needs to be collaboration between municipal workers and health care professionals. Also, people with hoarding disorder and the intervention team have to create a constructive, realistic, and respectful framework for decluttering. Evidently, given that the complexity of a hoarding situation involves all three groups of actors, the best way to find a solution is to combine efforts. Professionals from the health care system and municipalities could share a vision of the problem and adopt a common language to describe cases. They might display convergent attitudes toward people with hoarding disorder and share similar expectations in terms of case management. In addition, they could be made aware of their mutual responsibilities and limitations. Collaboration with service users could help professionals maintain a focus on the needs of the person with hoarding disorder rather than on reducing the consequences of hoarding.

The objective of this report is threefold: to describe the partnership created to improve the current situation through the clinical management of hoarding disorder in Montreal; to analyze partnership-proper and context-proper factors that favor its success; and, finally, to discuss the generality of this experience.

Montreal Experience

In 2011, four service users in southwestern Montreal with hoarding disorder, but who were only receiving outpatient help for comorbid mental health conditions, noted the lack of tailored services. They decided to form a partnership to work together. With the help of a community organizer at a local primary care facility, the first meeting brought together professionals and people with hoarding disorder. The discussion revealed that health care and social service professionals felt poorly equipped and were often only called upon in crisis situations and that service users who were willing to change their situation could not receive formal structured assistance in mental health services or the proper accompaniment to declutter. In the winter of 2015, the Montreal Compulsive Hoarding Enlarged Committee (MCHEC) was formed. The MCHEC brought together some 30 partners: service users, health care and social work professionals from the public and nonprofit sectors, and municipal services providers and researchers. Among the partners, there were such powerful actors as Montreal's Public Health Department, Montreal City Hall, and the OCD Spectrum Study Centre at the University Institute of Mental Health in Montreal (Centre d'Études sur les Troubles Obsessionnels-Compulsifs et les Tics, or CETOCT). The primary care facility of southwestern Montreal hosted the MCHEC. In the beginning, the MCHEC was funded through a subvention awarded by the Montreal City Council. Subsequently, it has received a grant from the Canadian Institutes of Health Research and has managed to receive external funding. The MCHEC fixed the following objectives: to raise awareness of hoarding disorder, to transmit good intervention practices, to create partnerships between the various actors, and to construct a specialized intervention team.

To depict the current situation with the clinical management of hoarding disorder in Quebec, the MCHEC conducted a survey among primary care mental health professionals dealing with hoarding in Quebec in autumn of 2015 (5). A 19-item questionnaire was developed by the project team and widely discussed during several MCHEC meetings between service users, clinical psychologists, municipal workers, frontline mental health team managers, and an invited epidemiologist. Of 98 primary mental health teams, 85 responded to the survey. The results elucidated the pathway of a person with hoarding disorder in the health care and municipal security systems, described barriers and facilitators of efficient clinical management of hoarding disorder, and revealed the tools most needed for hoarding disorder management at the primary care level (5).

Members of the MCHEC decided that the development and provision of training programs covered most of their objectives. The training would advocate comprehensive interventions in all sectors dealing with hoarding and facilitate the development of further collaborative strategies in Montreal and Quebec. The content of the 6.5 hours of training was designed by clinical psychologists, a social worker, a psychoeducator, an urbanist, social housing workers, fire prevention officers, and service users. The program was evaluated and accepted for continuing education credits by Quebec's Order of Social Workers and Familial and Marital Therapists. This training has, so far, been offered three times: in April 2016, October 2016, and April 2017. The total number of participants was 458 people, of which 34% participated via videoconference. Health care and social work professionals (77% of attendees) were represented by psychologists, social workers, occupational therapists, psychoeducators, and community workers. Specialists from other sectors were represented by social housing and building security managers (17%) and fire prevention and police officers (2%). Researchers, students, and friends and family members of people with hoarding disorder accounted for 3% of the attendees. The first videoconference training session was provided in nine cities, and the second was provided in 16 cities, in the province of Quebec. In several cities, municipal workers attended the training at health care facilities.

The provincewide colloquium on hoarding disorder took place in March 2018, in Montreal. More than 300 professionals attended two panel sections and two of six parallel workshops ("Friends and Family," "Resources," "Housing," "Research," "Healthcare System," and "Intersectoral Actions"). Attendees were represented mostly by community organization members (39%), municipal services (29%), and health and social services (20%). Despite the considerable price (250 Canadian dollars), the places were sold out

3 weeks before the event. The colloquium was widely covered in the local media (see the online supplement).

A bilingual (English and French) documentary film about the daily routines of people with hoarding disorder, *Object Relations* (*Les Biens Aimés*, in French), was released in August 2019. Created in collaboration with award-winning Canadian Broadcasting Corporation director Anne Henderson, the documentary avoids the sensationalism with which the media often discuss hoarding disorder, and it promotes a holistic and humanitarian approach to people with hoarding disorder. The film is available for purchase for educational purposes. The trailer is available at https://youtu.be/HHSK_8gpd58.

The current activities of the MCHEC include support for four peer-led support groups for people with hoarding disorder and their family members and support for peer-assisted decluttering; the support of a Web site; and training for health care and social services and for municipal services on hoarding disorder. In autumn 2019, the committee started the development of guidelines for the community management of hoarding disorder.

Discussion

From a formal point of view, the MCHEC is an example of an effective partnership: it brings together various actors within and beyond the health care system; it contributes to the creation of a common language, attitudes, and expectations among the professionals dealing with hoarding; and it provides the best clinical practices for treatment and advocates for the dignity of the people affected by hoarding disorder. The MCHEC has managed to become self-funding. Several factors explain the success of this partnership.

First, the health care system in Quebec is responsive to the demands of the community. There are full-time specialists in primary health care facilities whose duties are to organize a dialogue with community members to ensure balanced and respectful solutions to delicate health care problems such as, in this case, mental health conditions. Second, the partnership-proper success factor offers a leading role for people with hoarding disorder in the organization and management of the MCHEC. The active participation of people with hoarding disorder has drastically changed the dynamics of training sessions by preventing their objectification as well as any blaming, patronizing, or condescending attitudes toward them. They have adopted new roles as a primary source of knowledge about hoarding disorder and the primary judge of the quality and acceptability of interventions. This new role has reinforced their nonhoarding identities and has changed their position in the community. Finally, the problem is important both for the health care professionals and for the municipal workers involved. During the training sessions, there were several emotional testimonials from primary responders about their experience with hoarding, and the need for collaboration was extensively discussed.

This project faces several shortcomings and challenges. First, we do not use all the institutional capacities of our partners to build structural changes that improve the management of hoarding disorder. These changes could address a new regulation that would facilitate the case transfer between the health care system and municipal services, including intervention on hoarding in the basic training agenda of mental health, social work, and municipal security professionals and the institutionalization of peer-assisted decluttering in primary mental health care. The involvement of participants from higher levels of governance is needed to enable sustainable systemic changes. Second, although the MCHEC is currently self-funding, the initiative is not sustainable and depends on the current action plan of the hosting health care facility. The participation of institutional actors also depends on the current objectives of their institutions. Third, the current rules on social aid impede wider participation of service users in training and peer-guided activities. The probable compensation for the time spent by service users on the MCHEC would have affected their handicap and social aid payment plans. Finally, the sustainable running of the partnership is threatened by the fact that it relies on individual leadership and a wide network of professional contacts of several partners.

The generality of the experience depends, therefore, on the coexistence of these three factors: the response of the health care system to the demands of the community; the nonformal active role of community members in organizing and managing the partnership; and the perception by the involved specialists (e.g., health care, municipal, and social services professionals) of the importance of the problem. The response of the health care system is the most important factor of generality. The leading role of the health care system in community partnerships should be institutionalized. A paid specialist with formal education in public health, and with strong communication and conflict management skills, might be a part of each primary mental health facility team. This specialist would facilitate communication between health care professionals, other sectors (municipal workers, social housing, police, education, etc.), and the community. As well, specialists from other sectors should be compensated for their time consulting with health care workers. Finally, the rules for social aid should be reviewed to allow service users to be compensated for their participation in training and peer-leadership activities.

Conclusions

The experience of the MCHEC is not necessarily generalizable to a larger scale. However, some insight can be obtained from the response of the health care system to the demands of the community to find a balanced and respectful approach to delicate health care problems, such as mental health conditions, and from community initiatives that can guide the efforts of the health care system in developing

and adapting services through community partnerships. Taken together, the response of the health care system and community initiatives reinforce each other by enabling a better delivery of care in the health care system and by creating new roles and new identities for community members.

AUTHOR AND ARTICLE INFORMATION

École de la Sante Publique de l'Université de Montréal, Montreal (Bodryzlova); Montreal Mental Health University Institute Research Centre, Montreal (O'Connor, Koszegi); Clinique Communautaire de Pointe-Saint-Charles, Montreal (Vallée); Installation St.-Henri Centre Intégré Universitaire de Santé et Services Sociaux du Centre-Sud-de-l'Île-de-Montréal, Montreal (Dupuis). Debra A. Pinals, M.D., and Marcia Valenstein, M.D., M.S., are editors of this column. Send correspondence to Dr. Bodryzlova (yuliya.legkaya@umontreal.ca).

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REFERENCES

1. Obsessive Compulsive and Related Disorders. Arlington, VA,American Psychiatric Association, 2013. https://www.aging.pa.gov/publications/policy-procedure-manual/Documents/Obsessive%20Compulsive%20Disorders%20Fact%20Sheet.pdf.
2. Tolin DF, Frost RO, Steketee G, et al: Family burden of compulsive hoarding: results of an internet survey. Behav Res Ther 2008; 46:334–344
3. Snowdon J, Shah A, Halliday G: Severe domestic squalor: a review. Int Psychogeriatr 2007; 19:37–51
4. Nordsletten AE, Reichenberg A, Hatch SL, et al: Epidemiology of hoarding disorder. Br J Psychiatry 2013; 203:445–452
5. Bodryzlova Y, O'Connor K: Factors affecting the referral rate of the hoarding disorder at primary mental health care in Quebec. Community Ment Health J 2018; 54:773–781
6. Gibson EJ: Perceptions of Determining Factors: A Case Study of Eviction Risks of People Who Hoard in Waterloo Region. Waterloo, Ontario, Canada, Wilfrid Laurier University, 2015. https://scholars.wlu.ca/cgi/viewcontent.cgi?article=2822&context=etd
7. Koelen MA, Vaandrager L, Wagemakers A: What is needed for coordinated action for health? Fam Pract 2008; 25(suppl 1):i25–i31
8. Corbin JH, Jones J, Barry MM: What makes intersectoral partnerships for health promotion work? A review of the international literature. Health Promot Int 2018; 33:4–26
9. Gillies P: Effectiveness of alliances and partnerships for health promotion. Health Promot Int 1998; 13:99–120

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