

Ethical Discomforts Linked to Mental Health in Community Organizations

Jacques Quintin PhD

Nadine Larivière OT(C) PhD

Joelle Hassoun MD

Université de Sherbrooke,
Sherbrooke, Quebec, Canada

ABSTRACT

This qualitative study aimed to identify situations occurring in community organizations that raised ethical questions linked to mental health and illness. What seemed specific to these eight community organizations was perceiving a conflict between humanistic values and a frame of reference viewed as not humanistic. Practitioners and managers did not have prejudices about mental illness but wished they were more knowledgeable about it. Finally, teams in community organizations took the time to discuss issues and solve problems with a clinical lens.

Keywords: *community organizations, ethics, mental health, dialogue*

Introduction

In many industrialized countries, community organizations have grown quickly over the past 30 years (Jetté, 2008; Lachapelle, 2007; Rhéaume, 2007; Vaillancourt, 2002). Many of the clients of community organizations struggle with physical and mental health problems and live in poverty which makes them susceptible to being negatively judged and marginalized. It is a vulnerable population that can be perceived as “victims of society, the State, bureaucracies, even intolerance from other citizens” (Massé, 2004).

Administrators, employees, and volunteers in community organizations interact with these vulnerable persons, often intimately. Even if their desire to help is based on a belief in solidarity, justice, love, perseverance, civility, respect, and tolerance, their intent is often tainted by a social representation of mental illness that is prejudicial (Galand & Salès-Wuillemin, 2009). Their deliberations and decision-making could be based on false representations of mental illness without considering the

meaning of the lived experience of service users. This can have harmful effects “on those who are on the frontline, on the ground, battling against human suffering and vulnerability” (Beaulieu & Giasson, 2005), as well as on the relational quality inside the services and on the services delivered to the target population (Dallaire et al., 2008). There is documented stigmatization by human service workers, administrators, and volunteers, as by all healthcare professionals (Mental Health Commission of Canada, 2011). Furthermore, community organizations often embrace the antipsychiatry movement and defend the “disadvantaged” against society (Dimon, 2001). For human service workers, administrators, and volunteers, being confronted on a daily basis with poverty, mental and physical illness, solitude, and violence can lead to empathy fatigue (Ruszniewski, 2008).

Despite the fact that “autonomous community organizations are often searching, by their inner way of doing things and the condition of employment made to their employees, to achieve an ideal of democratic functioning” (Lamoureux, 1994), human service workers, administrators, and volunteers do not always have the opportunity to establish a dialogue and deliberate at critical times. “They risk to live a series of situations bearing suffering and [...] also to adopt practices and behaviors closed to collaboration, at a point that can put in danger relationships between peers” (Lancman et al., 2007). They are also at risk of becoming increasingly cynical, to such an extent as to see evil as commonplace and to believe in ethically questionable behaviours despite their usual and natural character (Lancman et al., 2007). Ultimately, they can experience a feeling of loss of meaning in their work. That can be explained in part, and this is the hypothesis of the researchers of this study, by a lack of conceptual tools linked to ethics that are needed to establish a real process of deliberation.

Bioethics, which were born in the 1960s, were traditionally limited to the field of life and human health, including major subjects such as abortion, euthanasia, genetic manipulations, and organ donation (Durand, 2005). In the 1980s, clinical ethics appeared to mitigate the decontextualized, formal, and abstract character of bioethics. Clinical ethics, as the name indicates, examine behaviours at the bedside of the sick. The emphasis is placed on the attitudes to

adopt, the information to be given, and the kind of dialogue to be established within the relationship between the health care professional and the sick person (Durand, 2005). There are also public health ethics centered on sets of laws, regulations, and behaviours addressing the entire population. In the context of community organizations, it is possible that ethics based on the bioethical model, clinical ethics, and public health ethics may not be the best approach. One of the purposes of this study was to explore an ethic that would be appropriate to community-based organizations. More specifically, the objectives of this study were: 1) to identify the main situations that triggered ethical questions and the lived experience of staff with their attendant representations of mental illness when facing these situations; 2) to describe the strategies used in these situations. A secondary objective was to assess participants' appreciation of reflective group discussions.

Methods

This research was an exploratory qualitative study inspired by phenomenology (Husserl, 1982) and principles of participatory action research (Larivière et al., 2014) in a context of lived ethics. According to Anadon and Savoie-Zajc (2007), participatory action research is characterized by its application to solving problems that arise from community actors' concerns, establishes a dialectical relationship between knowledge and action, includes the active and democratic participation of every actor by facilitating their expression in a public space, and reduces any kind of hierarchical relationship between researchers and participants, thus fostering a relationship based on equality. Group discussions were conducted in this study because they stimulate reflective thinking (Quintin, 2008), and problems can be solved by peers and better learning can occur (Watts, 2006).

The protocol, including the research questions, was initially developed with the consultation of the head of an association of community organizations in the targeted geographic region who also collaborated to link the researchers to local community groups. The human service workers and administrators were recruited on a voluntary basis. Each participating community organization was met with separately in three group meetings led by the authors. The purpose of the first meeting was to describe the mandates of the community organization and the context of practice, identify the main situations that triggered ethical questions, discuss the different lived experiences and representations of mental illness when facing these situations, and describe the effects of these situations on their lived experience as human service workers or administrators and the strategies used when facing these situations. The second meeting, which was held approximately two months after the first, consisted of looking at the participants' experience since the first meeting and discussing new situations that triggered ethical questions. Finally, the third meeting brought together all the participating community organizations to present and validate the results, especially strategies used for resolving ethical conflicts linked to mental illness. In addition, participants appreciated the use of reflective group discussions to address ethical questions and discomforts.

To capture the narratives about the participants' practices and ethical problems they encountered, the meetings were supported by

guides developed by the authors for the purpose of this study. The clarity and relevance of the themes and questions were validated by an external expert. The questions were mainly open-ended and covered the following: description of situations that raised ethical questions almost daily and were related to persons with mental illness; perception of the situation and of mental illness; feelings about this situation and their practice and consequences of this ethical question on the daily lived experience of the actors, their colleagues, and service users. The strategies used to manage these situations were also explored. The authors defined some concepts (for example, deontology, applied ethics) and provided illustrative examples to stimulate discussion. The three meetings were audiotaped and transcribed in full. Notes were taken and used to prepare subsequent meetings. The data analysis followed the method of Van Kaam adapted by Moustakas (1994), was organized using NVivo (version 9) and respected recognized qualitative research standards.

Overall, the first step was to analyze each meeting of an organization. Then, an analysis covering all the organizations was done. Each group meeting transcript was coded by the first two authors independently and then discussed, using a coding guide based on the interview themes and staying close to the words of the participants. The across organization analysis aimed to describe the nature and the structure of the experiences. The third author reviewed the final analysis. This study was approved by the CSSS-IUGS Research Ethics Committee.

Results

Context

Eight community organizations participated in the study, including 24 human service workers and six administrators. Five organizations had a specific mandate to help persons with mental health issues, one helped new immigrants to Quebec, one was specifically dedicated to youth, and one was exclusively for women.

The practical context of the community organizations had elements that influenced the themes addressed and the ethical questions raised. First of all, the following values were central in all organizations: 1) the importance of the relationship with the service user; 2) listening to the person; 3) availability of staff for their service users; 4) recognizing the person behind the psychiatric diagnosis; and 5) the importance of congruence between ostensible values and applied values. The mandates of the community organizations and the roles of the human service workers were sometimes fuzzy, with porous relational barriers. Also, many study participants indicated that collaboration with the healthcare system was difficult.

Most of the ethical questions raised revolved around concern for the person's well-being (values of caring, hospitality, beneficence), that conflicted with other values such as: equity; solidarity with colleagues; non-maleficence; respect for rules or mandates of the organization; ethical and deontological codes of professional bodies; respect for confidentiality and possible violations; good professional distance; and respect for freedom. Other ethical questions were also raised regarding the helping relationship,

such as where one sets limits in one's commitment and the concern about creating and preserving an alliance at all costs. Finally, questions were raised that implied a conflict of allegiance, that is, the gap between personal values and those of the organization as well as between personal values and those of the service user.

The ethical issues raised by living through delicate situations in their practice made the participants feel various negative feelings, such as a decrease in empathy, frustration, suffering, powerlessness, and tiredness. They worried about the acting out of service users, the onus of bearing sensitive information alone, the responsibility for life or death when facing suicidal states, and guilt if a service user became disorganized and they had to face behaviours perceived as dangerous and that could compromise their personal safety. In some cases, they also mentioned feeling both useless and used when service users had recurring demands or did not improve, regardless of solutions and advice offered. Finally, with respect to situations related to mental illness and relational issues, the participants sometimes felt incompetent and insecure due to a perceived lack of knowledge about mental health (Figure 1).

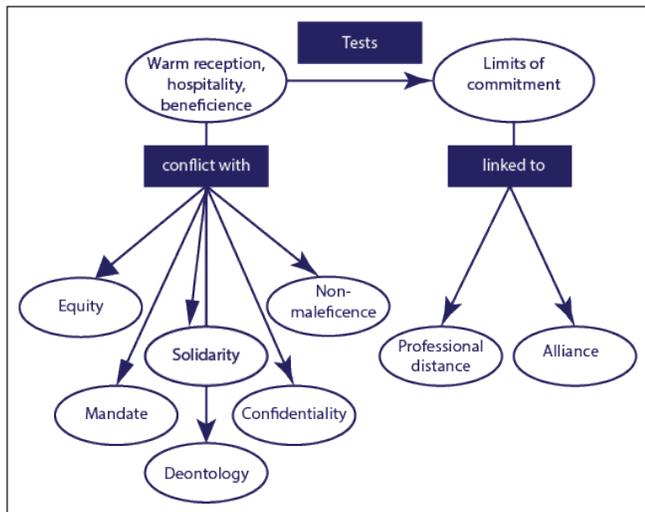


Figure 1: Main ethical issues raised

Conflict of values

The values of a warm reception, hospitality, and beneficence often appeared to conflict with equity. Human service workers questioned if their actions did not induce exclusion, create a precedent, or penalize other service users. For example, when a service user offered some help to the community organization and could be paid for it, the human service workers wondered: "to give money like that, is it worth \$10, am I exploiting the person? I don't know". The question was also raised when service users gave a voluntary monetary contribution for the services they received. "There's no question that the person can come back [even if she doesn't make a contribution], we will not refuse her here in our warm reception. We welcome every person who asks for help". Another context that triggered this type of conflict was when a service user frequently arrived late for the group session. "She disrupted my workshops a lot. And it disturbed the other participants ... She always

had a good reason and, according to her, we had to accept that. We owed that to her because we valued caring and open-heartedness".

When community organizations offered time-limited interventions, the participants raised the issue of who to prioritize. "When the program ends, I think that is where there is the discomfort... saying 'Yes, she still needs our services, I'd like to continue with this person.' But I also have my director's viewpoint telling me: 'I have a long waiting list, we must accept new individuals and there is nobody in the area that offers this kind of intervention'. This conflict between the person's well-being and the concern to be equitable also came up in a context where community organizations felt a duty to make exceptions to their rules and accept people who presented particular needs. "This service user, maybe we put him ahead of others to give him a positive experience".

Another discomfort emerged when there was a conflict between concern for the service user's well-being and the concern for solidarity with one or more work colleagues. For example, a human service worker witnessed a colleague's inappropriate demeanor. This human service worker was torn between two options with equal value: There is a problem, but if he does not react, he adds another problem and if he does react, he also creates another problem.

Several situations, such as when the service user's issues raised questions about having to contact Youth Protection or emitting strong body odor, highlighted a conflict between the concern for beneficence and the concern for non-maleficence. The participants wondered if their action contributed to well-being or, on the contrary, harmed the person and the helping relationship. To illustrate this, a human service worker expressed this conflict in a context where the service user was pregnant and abused substances: "There are two ways to intervene that are possible. One requires more energy, more effort, and then we are not sure of the end result. The other requires much less energy and the result consists of setting up the file [with Youth Protection]. At least, we know that the child will not be in misery, but he will not be with his mother". The concern about the service user's well-being also conflicted with respect for different ethical or deontological codes. To protect themselves, some human service workers came down on the side of respect for the deontological code even if they believed that it might harm the service user. However, in general, the participants were rather uncomfortable with setting hard-and-fast rules. They preferred to deliberate and operate on a case-by-case basis.

The participants wondered about the limits of intervention or at which point it was no longer within the organization's competencies. They were conflicted between concern for the service user's wellbeing and respect for the organization's rules or mandates. As one participant put it: "It is the hardest to intervene when the problematic situation does not occur within our walls but outside on our grounds. When this happens, we wonder: 'When can we intervene with a user, what is our role... where does our role stop and the role of another person begin?'".

The concern for beneficence often conflicted with the concern for confidentiality. The participants were not certain if they were helping the person by respecting confidentiality absolutely and rigidly. According to the workers, confidentiality was not always in the best interest of the service user. On the other hand, if the life of

the person or others was threatened, the workers did not hesitate to violate confidentiality. As illustrated by this participant: *“We know that he recruits young girls...at school. We were at a point where we were in agreement with that [violating confidentiality] because the lives of other people were in danger. It was the right thing to do that we shared this kind of information at that moment”*.

Limits of commitment in the helping relationship

In these community organizations, the concern for an alliance with service users was essential and took precedence over everything else. The different preoccupations were organized around the axis of alliance. For example, the workers and administrators agreed to compromise the alliance only if other people's safety became an issue. This alliance was challenged, however, with the issue of responsibility, professional distance and a conflict between personal values and those of the community organization. With regards to responsibility and its link to degree of commitment, an example was provided by one human service worker talking about a refugee with mental illness who refused psychiatric services: *“I am not there to live their life... I am there to help at the most. But it is them who must live their life”*. This question of degree of commitment was clearly brought up every time the participants were exposed to individuals in a suicidal state. They wondered about how to act without impinging on the service user's freedom. *“I accompanied a person who finally committed suicide... but I am not responsible for the lives of others. That it is something very clear that saves what I am as a human service worker. Maybe it's the fact that I have been a human service worker for a long time. I'm sure that some of my clients committed suicide...I find that a huge sadness, but I don't feel responsible for it. I do what I have to do, I do what I can, but I really respect people's choices”*.

Situations that challenged professional distance were brought up by several participants since their working environment often shared the daily and intimate life of service users. Workers often received invitations to spend time with users outside the context of service delivery. The daily friendliness could induce a reality that seemed like friendship. This blurred the role of service user and the role of the worker. In addition, the participants regularly wondered if they were too involved, doing too much. *“It is clear, I want more than him. It irritates me to desire more than him because I always said to myself that I must not desire more than him”*. This issue of degree of commitment was also found through the discomforts generated by the gap between the worker's expectations and those of the service user. What was difficult for some participants was *“accepting to accompany the everyday life of people and accepting no change, whereas you see the person's potential. Yes, you can learn not to wish for more than the other, but you must work on yourself”*. On the other hand, a few appeared comfortable in these situations. As one participant said: *“Personally... I go along with what the person wants. I don't have to decide what is good or not good for people... I don't have to desire for them things they don't ask for. So I wouldn't experience any discomfort with a person who never changes over many years”*.

Finally, the conflict between personal values and those of the community organizations can affect the degree of commitment. For example, one participant, despite her desire to help everyone, was confronted with her own personal limitations and those of the community organization when faced with a person with disturbing

behaviours who asked for a type of help that was beyond the community organization's mandate. She was not comfortable saying no: *“We work on that, saying no to someone, how, why. We say to ourselves that we have the right to say no. I remember that our lawyer said: ‘Listen, it is a matter of your credibility. Sometimes, you are obliged to say no because not all cases can be taken by you’”*.

Strategies

The participants used different strategies to deal with these situations that created ethical discomforts. For example, they set criteria, they tried to respect everyone's comfort zone, that is, workers, administrators as well as service users. All used a case-by-case approach to analyze these types of situations. Several participants allowed themselves to break the community organization's rules in favor of better action aimed at the service user's well-being. One repeated strategy was giving oneself time to reflect and talk: to service users, colleagues, and the person in charge. In certain cases, the human service worker transferred a person considered “difficult” to a colleague. Group discussions were a strategy generally used to review the situation, make decisions, give each other courses of action, and rally the team after reaching consensus; they focused mainly on problem solving. These discussions were reported to be useful in delineating the limits of commitment, responsibility, or professional distance. Other strategies consisted of referring service users to other appropriate services.

Implications for practice

This study aimed at making explicit the narratives around ethical problems linked to service users with mental illness as experienced by human service workers and administrators in community organizations. These problems are expressed through discomfort, uncertainties, doubts, conflicts, and suffering. In these lived situations of distress, the choice is not between good and bad, but between bad and worse (Quintin, 2011). The problems are ethical because the decision-making is difficult and complex and has repercussions on others. They involve negotiation between different values, norms, and rules that may conflict with each other in the field of action.

The findings show that ethical problems linked to people with mental illness faced by practitioners in community organizations are in many cases identical to those found in institutional settings. For example, in both types of settings, workers confront situations that challenge confidentiality and professional distance. In addition, they are concerned for people's well-being and safety and want to offer care fairly (Hoy & Feigenbaum, 2005; Szmukler, 1999; Watts & Priebe, 2002). However, even if the themes are similar, the context is different. For example, the greater closeness with service users in community organizations poses a more acute challenge to professional distance, confidentiality, and the degree of commitment. In short, because of the community context, there is a thin line between what is acceptable and what is not.

In institutional settings the parameters are often better established and embodied by the institution and its traditions, while in community organizations the parameters often need to be invented and require personal initiative for their interpretation and application. Legalism is less pronounced in community

organizations than institutional settings and thus there is greater freedom around understanding the situation and applying rules and ethical principles. However, this greater freedom adds to the weight borne by community workers. They bear the responsibility alone, which is a heavy burden. Community workers and administrators are often left to themselves when they face ethical issues. Because of this, one recommendation is to encourage community organizations to incorporate reflective dialogues in the ways used to resolve ethical issues. The last meeting with participants confirmed that earmarking periods of time for reflection in the work setting is appreciated by workers and administrators. The most important thing is to create spaces for dialogue to explore deeper meaning and not just solve problems. It is essential to create a space for reflection that is outside the institution's Ethics Committee (Davis, 2002). However, participants underlined the difficulty in having this reflective dialogue without an external ethics expert to lead the discussion. This led the authors to pose a new question: are discussion and reflection possible without an external viewpoint?

The findings from this study show that workers and administrators in community organizations are strongly motivated by humanistic values. When they were not nuanced, however, they sometimes conflicted with the idea that when the community organizations set limits and rules, they were not humanistic. For example, providing an unconditional warm reception was an important value. Any regulation or working structure that might compromise this ideal was poorly received. However, when applied strictly, this value could lead to feelings of disengagement. It is probably because of this unconditional warm reception that we did not observe prejudices, stigmatization, or exclusion aimed at people with or suspected of having a mental illness. However, there was a profound desire to be better equipped with theoretical and practical knowledge, even if such knowledge would not always help to resolve the discomforts with which they were confronted.

Because of its nature, this action research allowed us to recreate what could be a group for reflection, assuming that workers, administrators, and volunteers in community organization are experts in resolving ethical issues. It also allowed participants to realize the tragic nature of ethical issues insofar as, despite good intentions and the practice of reflection, these very uncertain situations remain uncertain. Therefore, this action research fostered normalization of uncertainty in a context that did not contain an optimal solution.

Conclusion

This study showed that for community workers and administrators, there are several contexts that make it difficult to apply at all costs their concern for a warm reception, hospitality, and beneficence toward people with mental illness using their services. This concern for a warm reception, hospitality, and beneficence comes into conflict with other values such as equity, solidarity, non-maleficence, confidentiality, respect for different deontological codes, and mandates of the community organization. It was clear that this gap between these different values tested the limits of commitment with regard to professional distance and the creation of an alliance.

The grand principles of medical ethics, such as autonomy, beneficence, nonmaleficence, and justice, were developed for the environment of the hospital and doctor's office, not for professionals working in community settings (Hoy & Feigenbaum, 2005; Szmukler, 1999; Watts & Priebe, 2002). It seemed that deontological codes needed to be enhanced by a frame of reflection that takes into account the circumstances in which the grand ethical principles find their limit (Jonson et al., 2006). This helped participants realize the importance of discussing freely between colleagues ethical issues emerging from the gap between the concern for a warm reception, hospitality, beneficence, and other values. The participants became aware that it is possible to resolve their difficulties through reflection in a group without referring to principlism and the importance of putting ethical questions in terms of limits. This awareness is a contribution of this study.

Given the results of this study, we recommend a follow-up investigation of these questions and ethical issues in other contexts of care or interventions that take place in the daily lives of service users (home, working environment), where healthcare professionals assist people in their personal lives or in an outreach context. It is possible that this type of context will raise similar discomforts as those that emerged from this first exploration of ethical issues in community organizations.

References

- Anadon, M., Savoie-Zajc, L. (2007). La recherche-action dans certains pays anglo-saxons et latino-américains : une formation de recherche participative. In *La recherche participative : multiples regards*, Québec, Presses de l'Université du Québec.
- Beaulieu, M., Giasson, M. (2005). L'éthique et l'exercice de l'autonomie professionnelle des intervenants psychosociaux œuvrant auprès des aînés maltraités, *Nouvelles pratiques sociales*, 18(1), 131-147.
- Dallaire, B., McCubbin, M., Carpentier, N., Clément, M. (2008). Representations of Elderly with Mental Health Problems Held by Psychosocial Practitioners from Community and Institutional Setting. *Social Work in Mental Health*, 7(1-3), 139-152.
- Davis, S. (2002). Autonomy Versus Coercion: Reconciling Competing Perspectives in Community Mental Health, *Community Mental Health Journal*, 38(2), 239-250.
- Dimon, M.-L. (2001). La folie au risque des discours institutionnels, *Topique*, 76(3), 141-157.
- Durand, G. (2005). *Introduction générale à la bioéthique. Histoire, concepts et outils*. Montréal, Fides.
- Galand, C., Sales-Wuillemin, É. (2009). Apports de l'étude des représentations sociales dans le domaine de la santé. *Sociétés*, 105(3), 35-44.
- Hoy, J., Feigenbaum, E., (2005). Ethics in Community Care. Making the Case for Ethics Consults in Community Mental Health Centers. *Community Mental Health Journal*, 41(3), 235-250.
- Husserl, E. (1982). *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy. First Book: General Introduction to a Pure Phenomenology*. The Hague, Nijhoff.
- Jetté, C. (2008). *Les organismes communautaires et la transformation de l'État-Providence*. Québec, Presses de l'Université du Québec.
- Jonson, A.R., Siegler, M., Winslade, W.J. (2006). *Clinical Ethics. A Practical Approach to Ethical Decisions in Clinical Medicine, 6th Edition*. New York, McGraw-Hill.

- Lachapelle, R. (2007). Renouveler l'État social: les enjeux de l'action communautaire au Québec. *Nouvelles pratiques sociales*, 19(2), 176-181.
- Lamoureux, H. (1994). Intervention communautaire : des pratiques en quête de sens. *Nouvelles pratiques sociales*, 7(1), 33-43.
- Lancman, S., Uchida, S., Idal Sznelwar, L., Andrade Jardim, T. (2007). Un agent de santé communautaire : un travail où l'on s'expose. *Travailler*, 17(1), 97-124.
- Larivière, N., Briand, C., Corbière, M. (2014). Les approches de recherche participatives: illustration d'un partenariat pour l'amélioration des pratiques de réadaptation en santé mentale au Québec. In Corbières, M. et al. *Méthodes qualitatives, quantitatives et mixtes : Dans la recherche en sciences humaines, sociales et de la santé*. Québec, Presses de l'Université du Québec.
- Massé, R. (2004). Les groupes communautaires comme espaces moraux. In F. Saillant et al., *Identités, vulnérabilités, communautés*. Montréal, Nota Bene.
- Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks, CA: SAGE.
- Quintin, J. (2011). La souffrance des médecins : un malaise éthique? In *Le Médecin du Québec*, 46(4), 51-55.
- Quintin, J. (2008). Enseignement de l'éthique : une approche socratique. *Pédagogie Médicale*, 9(3), 166-170.
- Rhéaume, J. (2007). Québec : une société communautaire? *Esprit critique*, 10(1), 1-14.
- Ricœur, P. (1992). *Oneself as Another*. Chicago, University of Chicago Press.
- Ruszniewski, M. (2008). *Face à la maladie grave. Patients, famille, soignants*. Paris, Dunod.
- Szmukler, G. (1999). Ethics in community psychiatry. *Australian and New Zealand Journal of Psychiatry*, 33, 328-338.
- Vaillancourt, Y. (2002). Le modèle québécois de politiques sociales et ses interfaces avec l'union sociale canadienne. *Enjeux publics*, 3(2), 1-52.
- Watts, J. (2006). Développement des compétences professionnelles et action communautaire. In J-L. Guyot & C. Mainguet, *La formation professionnelle continue*, Brussels, De Boeck.
- Watts, J., Priebe, S. (2002). A Phenomenological Account of User's Experiences of Assertive Community Treatment. *Bioethics*, 16(5), 439-454.

Funding and support: none

Acknowledgements: none

Competing interests: none

Address for Correspondence: Jacques.quintin@usherbrooke.ca

Date of Publication: August 3 2016