Human rights and the use of psychiatric medication

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Abstract

Purpose – *Formal recognition of the human rights of people living with mental health problems has greatly progressed. We must ask ourselves, however, to what extent the formal recognition of these rights has transformed the culture of psychiatric care and improved their quality of life. Gaining Autonomy & Medication Management (GAM) is an approach that strives to empower service users and providers and promotes the exercise of users' rights by transforming their relationship with the central component of psychiatric treatment in community services: psychopharmacology. The purpose of this paper is to show how GAM highlights the issues surrounding the establishment of a culture of rights.*

Design/methodology/approach – *For this analysis qualitative data were collected in Brazil and in Quebec, Canada, through over 100 interviews done with people living with mental health issues and practitioners who participated in the different GAM implementation projects.*

Findings – *Issues, challenges and obstacles facing the instauration of a human rights culture in mental health services are presented. The profound changes that the understanding and exercise of users' rights bring to the lives of individuals are supported by excerpts illustrating recurring issues, situations and common experiences that appear in the various contexts of the two different countries.*

Research limitations/implications – *This is not a parallel study taking place into two countries. The methodologies used were different, and as a consequence the comparative power can be limited. However, the results reveal striking similarities.*

Originality/value – *There is scant research on human rights in mental health services in the community, and the issues surrounding the prescribing and follow-up of pharmacological treatment. The joint analysis of the researches in Brazil and in Canada, identified common challenges which are intertwined with the dominant approach of biomedical psychiatry.*

Keywords *Human rights, Mental health, Qualitative research,
Gaining Automony & Medication Management (GAM), Psychiatric medication, Quebec, Canada and Brazil*

Paper type *Research paper*

Since the advent of deinstitutionalization, formal recognition of the human rights of people living with mental health problems has greatly progressed. Today, judicial, legal and regulatory mechanisms exist to ensure their protection. The international mechanisms, together with the increased activism of citizens, have led to the implementation of policies promoting the development of community services (Weisstub and Arboleda-Florez, 2006) and the autonomy, recovery and participation of users in the organization of these services (McCubbin and Cohen, 1998; WHO, 2001). The increased awareness of their rights poses new challenges in terms of public policies, services and practices, but also with regards to the socio-cultural representations of mental disorders. This involvement, unthinkable a few years ago (WHO, 1993), is an indication of the change from the restrictive and reductionist identity of patient/beneficiary/user to that of active, responsible, critical citizen at the heart of society. To what extent, the formal recognition of these rights has transformed the culture of psychiatric care and improved the life of people in situations of great vulnerability?

The restoration of rights and the notion of participatory citizenship entail working toward "a life of quality in the community, rather than a life in quality services" (Rodriguez del Barrio et al., 2006). This implies the promotion of a culture of rights founded on the actions of service provider citizens and user citizens. The quality of services and public policies can thus be gauged by their ability to provide service users with the means to exercise their full rights and citizenship. However, this system is evolving in contradictory directions: on the one hand, it recognizes the individual's right to free and informed consent, and the right to refuse treatment considered intrusive or dangerous; but on the other hand, in some circumstances, make mandatory certain forms of community follow-up, which restrict in practice the possibility to refuse medical treatment (Rodriguez del Barrio et al., 2001).

In addition, inequities (social, political and economic), discrimination and stigma have profound effects on mental health. People who live with mental health problems are also at risk for economic insecurity, poverty, violence and homelessness (Morrow and Weisser, 2012; WHO, 2001; Mental Health Commission of Canada, 2009). The difficulty of taking into account the social dimensions of mental health problems, the centrality of the biomedical approach and the use of practices to control, also causes new forms of discrimination, stigma and violence (institutional and symbolic) among people who suffer more from the effects of social exclusion and inequality. In Canada (Quebec) the Commission on Ethics, Science and Technology states that "the lack of qualified personnel for home care, social workers and psychologists for non-drug therapies and family physicians is detrimental to the continuity of care and services and makes it more difficult to adequately respond to needs. [...] in this context, providers, not to mention the health care system itself, may contribute to medication taking on the role of substitute" (pp. 21-22) (Commission de l'éthique, de la science et de la technologie, 2009, cited by Rodriguez del Barrio et al., 2013).

We conducted research on the implementation of Gaining Autonomy & Medication Management (GAM) in Canada and Brazil. This approach promotes the exercise of users' rights by transforming their relationship with the central component of psychiatric treatment: psychopharmacology. Some legitimate questions would be: which conditions ensure that the use of medication in the treatment of mental health problems improve wellbeing and increase people's ability to act and exercise their rights or, contrariwise, which conditions serve to undermine their rights, dignity or physical and mental integrity, and intensify their experience of alienation and suffering? This paper describes how the introduction of GAM exposes the issues related to instilling a culture of rights in mental health services.

Rights and services in Canadian and Brazilian mental health policies

In keeping with international policy, Canadian and Brazilian reforms promote the development of services embedded in communities, which encourage user participation (Canada, 2009; Quebec Ministry of Health and Social Services, 2005). In Canada, where healthcare falls under provincial jurisdiction, the government of Quebec has created frontline mental health teams and services based on the model of Assertive Community Treatment (ACT). In Brazil, ambitious reforms have led to the establishment of psychosocial care centres (CAPS), and innovations in psychosocial and management practices to support the autonomy of users in the community.

In Quebec, the Act Respecting Health Services And Social Services recognizes the rights of service users (e.g. to have information about services and its access; to receive adequate services; to choose the practitioner or institution; to be informed of one's condition in order to be able to give free and informed consent; to participate in all decisions that affect one's health, etc.) (Quebec Ministry of Health and Social Services, 1991).

In 2001, the Brazilian psychiatric reform law (Law10.216/01) stipulated that treatment should be provided by community health services (CAPS) adopting a recovery approach (Brazil, 2001). The law also entrenched the right to access all information concerning treatment and health risks. The movement for mental health users' rights is still in its early stages. The first Brazilian charter of rights for health service users was approved only in 2006. The charter also guaranteed the right to access and choose alternative methods of treatment and the right to refuse a proposed treatment. The advances made have been tempered by existing social inequalities

(Onocko Campos *et al.*, 2011), and which make it more difficult to mobilize citizens . This context reinforces the need for innovations such as GAM to promote active citizenship and human rights (Paim *et al.*, 2011; Vasconcelos, 2007).

Research on GAM

GAM aims to empower both service users and providers with regards to psychiatric medication. This approach is based on the respect of the rights of the person, free will, and informed consent. It promotes an egalitarian relationship that facilitates the sharing of views with professionals. This process can allow individuals, in consultation with healthcare professionals, to determine the minimum effective dose of a medication required to ensure their quality of life (Rodriguez *et al.*, 2013).

GAM has in common with other approaches that address the issue of medication like shared decision making, the partnership philosophy, the sharing of expertise, and of point of views (Deegan and Drake, 2006; Drake *et al.*, 2010; Duncan *et al.*, 2010). In GAM terms, the "safe space of open dialogue" about the issue of mental health medication extends beyond the patient-doctor relationship and encompasses the different stakeholders: other providers and carers. Unique to GAM, are the recognition and practices surrounding the symbolic aspects or meanings that people attribute to medication. Often, the unspoken, taboos around psychiatric medication hold tremendous power and are not addressed (Estroff, 1981; Longhofer *et al.*, 2003; Rodriguez *et al.*, 2001). The complex issue of practices (provider and user) regarding psychiatric medication involve the varied input of all, and the different dimensions of the medication experience in order to foster informed consent.

The GAM approach was developed in Quebec through a participative process involving users, service providers from community-based alternative and advocacy organizations as well as researchers. Research teams in Brazil later joined in with the Quebec team to adapt the GAM practices for their public services. The development of this approach has been accompanied by several qualitative studies in both countries (Onocko Campos and Furtado, 2008). A better understanding was accomplished of the complex relationships of users with psychiatric medication, and the response of users, service providers to the implementation of the GAM approach. These studies help to evaluate mental health practices from the point of view of the people for whom they are intended (Rodriguez del Barrio *et al.*, 2013). Listening to what medication users have to express will allow us to identify the conditions that, from the perspective of those directly concerned, help or hinder them in regaining control over their lives and increase their ability to act meaningfully in the world, and thus break the cycle of exclusion.

In Brazil, the data analyzed were collected in two studies conducted in 2009-2011 and 2011-2012 (Onocko Campos *et al.*, 2012). For the first study, three focus groups were assembled, with users from three different CAPS, one per city, and one focus group with users from diverse mental health services. The focus groups were held at the start and at the end of GAM implementation period. For the second study we conducted 58 semi-structured interviews with 29 practitioners from ten public health service facilities in two different municipalities, before and after the introduction of GAM, over a six-month period. In Quebec, the data were collected over several studies of GAM implementation in three regions of Quebec in 2003-2006 and 2010-2013. These included: 35 in-depth interviews with people living with serious mental health problems; 60 reports of participant observation; 14 semi-structured interviews with managers and service providers from the public and community sectors, as well as carers. All the data from focus groups and interviews were recorded along transcribed and with the reports of participant observation, were transformed into a narrative validated by at least one other researcher, and compared with the original transcription or report. Our thematic analysis is based on these three sources of data.

The excerpts below were selected to illustrate recurring issues, situations and common experiences that appear in various contexts reflecting the different languages and cultures of the two countries. The country and status of each participant is identified in brackets (Q = Quebec-Canada, B = Brazil, U = user or P = practitioner).

Results

1. Difficulties and obstacles to the exercise of rights

When people come into contact with psychiatric services, their experiences are interpreted within the conceptual framework of the professionals. In general, they receive a diagnosis, and the central treatment provided is pharmacological. Psychiatric drugs are often the only available means to manage the experience of loss of meaning, internal chaos, and extreme suffering that lead people, or those close to them, to seek psychiatric help. From that point onward, medication plays a central role in patients' lives (Rodriguez et al., 2008).

Many people report feeling as though they were going around in circles and living in a maze of crises, hospitalizations and sometimes woefully inadequate pharmacological treatment, before finally finding their way to the resources and support they need to get well.

Information. One important complaint voiced by people with experience in the psychiatric system involves the lack of information about diagnoses, hospitalization, and medication:

> "I was back at the out-patient clinic. […] So I was no longer with schizophrenics. […] I was with the manic-depressives […] I said to myself: What am I doing here?" (UQ17). "I didn't know what my diagnosis was. I found out from a piece of paper they hand out at the welfare office […]" (UQ3).

> "They gave me medication without telling me anything about the side effects, no information, absolutely nothing." (UQ2); "We don't know if they don't give us information because they don't want to, or if the doctor thinks the person won't be able to understand" (UB1).

Sometimes patients are subjected to a change in medication, or dosage, without being fully informed and which may result in painful side effects, creating more confusion and suffering: "I took medication, I don't know which ones, and […] the psychiatrist stopped all the medication overnight. […] He wanted to see how I reacted […] I was like a lab rat" (UQ17). "One person in our group needed help during a very difficult moment […] she discovered her medication had been changed by the CAPS' doctor without her knowing it" (UB1).

Questioning medication. Professionals are unfamiliar with the legal and ethical frameworks that govern the services and the relationship between professionals and users. For example, in Quebec and Brazil, the code of ethics requires that in case of disagreement regarding treatment, the physician must refer the patient to a colleague to ensure continuity of services. In fact, users who consider some or all of their psychiatric medication as inadequate must consider the risk of losing their follow-up or support:

> "If you are taking medication and decide to stop, the psychiatrist can interpret this as a refusal of treatment. And there have been many cases […] which led to suspension of services." (PB2 – psychologist). "If you don't want to do what we say, don't come to see us" (UQ9).

In Brazil, most professionals will not accept the user's decision without consulting and obtaining the support of a physician, psychiatrist or other team members. A minority of stakeholders interviewed would, in a situation such as this, try to obtain written consent from the user in order to protect themselves professionally. Most professionals interviewed in Brazil were not sure of their ethical responsibilities in relation to the refusal of pharmacological treatment, and the process concerning free and informed consent: "I think users have the right to refuse medication, but I don't know of any legislation regarding that. There are the rights of the users of the universal system of health care, but there are no rights for mental health users" (PB3 – occupational therapist).

Obstacles within the healthcare system. In Brazil, structural problems in the public health system often lead to failure to ensure the rights of users. Consequently, even when professionals understand the rights of users, many of them are reluctant to address the issue of rights with their patients. They feel responsible for promoting the exercise of those rights but, at the same time, feel unable to do so:

> "Access to medication is a right, but what we need is not available at the public pharmacy. What can I do?" they (users) said (PB4 – physician).

"Users' rights are hardly respected at all. Neither are the workers' rights. We are afraid to act, because we feel we don't have the necessary support to uphold those rights" (PB5 – physician).

"I think we fall short of informing users about their rights. We have many opportunities to do so, we have the means to do it, but we don't do it, out of fear. It's kind of the same story as with GAM, and it's about users' rights, and if they know too much, they are going to ask questions. […] And in the end we are just talking, not giving" (PB6 – psychologist).

Users' participation. Users primarily question and contest the manner of administering medication that leaves no room for discussion and participation in the decision-making process. Many users complain about the authoritarian manner in which psychiatrists often prescribe medication, and the threats that are sometimes made. "They gave it to me by the shovelful […] If you refuse? 'We'll give it to you by injection'" (UQ4). "We couldn't talk and discuss it with our psychiatrists. We understand they are the bosses, not us. […] we have to change the country's vision of education, starting with the universities, to change the mindset of professionals […]" (UB8).

The narratives show that in Quebec, medication is used sometimes as a form of restraint without respecting protocols and users' rights: "[…] I hadn't slept for 7 days, so I go to the hospital […] they give me medication because I want to sleep […]. But I couldn't sleep during the night. […] I got up several times to tell the nurse that I couldn't sleep […] without acting violent. […] The third or fourth time I got up, she called a white code. […] They tied me to the bed and then she gave me a shot of some chemical […]. If she had told me she had an alternative to give to me, I would have said "perfect, give it to me. […] I don't know what the protocol is. […] It wasn't right" (UQ18).

Continuity and support after hospitalization. Patients can sometimes be hospitalized several times before feeling they have been given the support they need, provided with information on the choices, or referred to the proper resources. Support after hospitalization is often sorely lacking, if not neglected outright, and users develop a general feeling of abandonment and confusion: "I wasn't referred anywhere. They didn't give me any resources. I had a relapse." (UQ2); "In out-patient clinics, when you're done, there's no follow-up with your doctor […] Anyway, you see the psychiatrist for 15 minutes […] Then it's over" (UQ17).

Side effects and long-term use of psychiatric medication. Often, the effects of medication are disconcerting and contradictory for the person taking them, and also for the people around them. As part of a positive relationship with the treating physician, medication can help control symptoms and bring stability or calmness according to users' accounts (Rodriguez, 2008). Also, the stories users tell bear witness to the serious consequences of long-term use of psychiatric medication, with respect to its physical, mental, social and symbolic effects on patients' lives.

According to those participants interviewed, side effects constitute one of the most negative aspects of taking medication. The visible and stigmatizing side effects of some psychoactive drugs — including the inability to concentrate, facial rigidity, involuntary movements, and weight gain have an impact one's self-esteem and social integration. Thus, in too many cases, medication contributes to a patient's sense of confusion, stigmatization, and diminishes any hope of any possible recovery or improvement (Rodriguez *et al.*, 2008).

Medication can alter a patient's entire sense of self and body image. "It was a matter of conquering the medication … head all swollen, a distorted way of moving through space, not being able to be myself … a huge physical effect, a sort of handicap" (UQ16). "It's like it wasn't me leading my life" (UQ6). Many use terms like "numb" or "zombie" to describe the devastating effects: "They made me incredibly numb, … I was totally out of it, my memory was gone … I was almost a zombie … I was in bed for 7 or 8 months" (UQ1).

Patients on medication state that the regular or improper use of medication hindered "making contact with their inner selves." It also restricted the possibility of working on oneself, which is generally considered to be the most powerful source of personal transformation (Rodriguez *et al.*, 2008). The long-term effects of medication use can become sources of anxiety and problems comparable to the experience of crisis: "The medication is so unbearable, it's more unbearable than the illness" (UQ11).

Medication as the only answer to suffering. In this context, the dominant perception that drug treatment is the only answer to suffering and that it must continue for life, is often unbearable

from the patient's point of view. "And so at one point I took some medication […] I said: "It's time to end it. If I'm going to spend the rest of my days like that, I want to die". And I came close to poisoning myself" (UQ12). "The psychiatrist told some of us that we had to take medication for the rest of our lives. There was nothing left for us to say" (UB1). It comes as no surprise, after hearing comments such as these, that a number of the users interviewed attempted, at some point or another, to stop taking their medication, which too often resulted in further suffering (Hofer *et al.*, 2002; Lieberman *et al.*, 2005).

Beyond the recognition of formal rights to refuse treatment, we cannot but agree with Estroff that most clients of the mental health system are not offered enough non-pharmacological alternatives and are not encouraged to explore the few options available (Estroff, 1981). Many are unaware that they have a choice, so treatment is directed toward the control of medication.

2. The instauration of a culture of rights and its impacts

Access to information. The GAM process transformed how patients relate to their medication and increased their sense of control. Participants became increasingly aware of their rights to make choices, to give free and informed consent , and access to the means for exercising those rights. Many referred directly to the notion of empowerment: "It means being able to make your own decisions, make your own choices […] Once you realise you are able to make decisions you've taken a major step forward" (UQ17). GAM is "really knowing about your medication so you can deal with it. […] it's knowing the side effects, the other effects […] noticing if you have problems […]" (UQ5).

The GAM process cannot be reduced solely to providing access to technical information about medications. The information is put to use in a comprehensive manner, taking into account the way people make sense of their experience of suffering, of taking medication, and this requires dialogue and cooperation with healthcare professionals, providers, friends and family, and peers in a joint process of seeking the best ways to deal with problems and symptoms.

The GAM process also increased the awareness of practitioners concerning the rights of service users. This added understanding allowed for more flexibility on the part of most workers when negotiating with patients. "Before the introduction of GAM, I didn't negotiate with users about their treatment. Now, I take more time to make a decision like that, and I try to adapt a patient's treatment plan to his needs" (PB7 – nurse):

> "Before GAM, I was strict with users. I categorically insisted on refusing psychiatric drugs to those I thought didn't need them. But now, I'm much more tolerant. If a user really wants medication, […]), at least, I ask the doctor. […] I began to see that the issue of medication is not only the medication in itself, but the symbolic aspects that come with it" (PB6 – psychologist).

Following the recognition of rights, comes the challenge of exercising them, of overcoming the technical and scientific language so closely associated with treatment, of discussing one's doubts with healthcare professionals and taking one's place as an active citizen:

> "[…] Before, it was difficult to read the medication leaflets, […] but our discussions in the GAM group were helpful, because we talked about things like half-life, side effects and dosage" (UB8).

"*GAM*" *shared decision making.* We noted that with guidance and support, people tend to find a level of medication that suits them. The research shows that GAM encouraged people, in partnership with their physicians, to adjust their pharmacological treatment with the goal of improving quality of life and wellness. For some, this process involved a change in attitude and an acceptance of their treatment: "I was less rebellious […] I deliberately decided to take them and I saw the benefit of it. That's what GAM allowed me to do" (UQ3).

For others, changes in the types of drugs prescribed, the number of drugs they were taking, or the dosages (with the objective of reaching a "comfortable dose"): "… was the start of a new journey: I have not finished working on myself, but I could finally see a light at the end of the tunnel. […] My goal in coming here was to get off antidepressants completely. […] And she (the GAM counselor) was always there when I needed her. […] She never judged me, it was always my choice. […] She took every aspect of my life into account. […] That was absolutely extraordinary for my self-esteem, my healing, my dignity, being able to take back control of my

life, it made all the difference […] to me […] to have […] options open to me, the return of the word 'healing'" (UQ10).

And finally, for a minority of users, it meant a significant reduction or the complete cessation of psychoactive medications and the implementation of alternative strategies for dealing with the mental suffering and symptoms: "I'm off medication. And I feel ready for it, too. It's not a refusal to take my medication. […] And I don't hesitate to take it when I need it" (UQ2).

In Brazil, we ponder about strategies that would improve people's lives. In a context of extreme poverty and lack of resources and services, users find that CAPS do not offer many alternatives beside medication to improve their quality of life.

Considering oneself as a subject of rights

The introduction of users' rights at the heart of services and practices also brings major changes regarding the possibilities of rehabilitation, recovery, and quality of life in the community. We must not forget that the concept of rehabilitation is fundamentally associated with the culture of rights. Rehabilitating a person from a legal standpoint, means giving them access to all the rights enjoyed by every citizen.

Considering oneself as a subject of rights and a subject of treatment produce fundamental changes: "A light shone in the night. I was offered hope in a form other than pills. The hope of finally moving towards who I am, of finding a natural balance, an inner movement rather than that immutable state, that shaky equilibrium artificially maintained by chemicals. […] (The GAM approach) can be demanding, even painful at times. But for me it was a sort of necessary passage towards regaining my personal power, my dignity and my freedom to be and to act" (Dubois, 2009).

This implies that in the relationship between the professional provider and the user, the former must respect the latter's decisions concerning medication:

> "Nowadays, if someone talks about stopping his medication I can calmly discuss it with the patient. Even if I think he can get worse, I'm more at ease to deal with it. I have to deal with my frustration and be tolerant. If you accept this, someone may say you are an incompetent professional or that the patient will relapse, and you must have the serenity to know that is not true and that you are respecting the person's choices and autonomy. You must have self-assurance and affirm that the person has rights" (PB9 – psychologist).

Conclusion

International agreements and national legislation have directed public policies and social and health services very clearly toward the creation of a more inclusive society and have urged states to move from talk to action. The recognition of second-generation, positive rights opens the way to the free exercise of their rights by all citizens, including those in situations of extreme vulnerability (Weisstub and Arboleda-Florez, 2006).

It is, however, obvious that recognition and respect of these rights has not yet permeated the routine functions of mental health services. There is indeed reason to doubt whether the system even has the capacity to adopt a "culture of rights" in the present context of growing inequalities, the reassessment of public service mandates and budgetary constraints. These limit the impact positive rights can have on the development of public policy. We have seen it in our analysis of systemic obstacles in both countries.

This is not a parallel study taking place into two countries. The methodologies used were different, and as a consequence the comparative power can be limited. However, the perspectives of the different stakeholders, service users, providers and managers were explored by different qualitative means and the results reveal striking similarities.

People living with mental health problems do not immediately interpret what is happening to them in terms of rights, but the interviews we conducted revealed that the suffering of many people could easily be traced back to legislative deficiencies in the protection of patients' rights.

An analysis of users' statements furnishes a clear description of the confusion they feel, the insecurity, the doubts associated with self-stigmatization and the absence of support mechanisms adapted to their predicament. It is to be wondered if and how they can gain the necessary credibility and recognition of their perspective on the situation, to merit a consideration of their experiences from the point of view of rights.

We were also able to observe the consequences of pharmacological treatment on the psychological and physical integrity of patients when little information, continuity and individually tailored monitoring and support are provided. The centrality of psychiatric treatment, the powerful effects of medication and the lack of alternatives offered, can aggravate feelings of alienation and intense suffering.

The issue of rights is not immediately discernible to people. Training and an external viewpoint make it possible to identify the wrongs committed and the means of improving people's situations by providing them with the tools to change their relationships with healthcare providers and the system in general.

The lack of recognition of patients' rights is striking, both on the part of care providers and patients themselves and this holds true in both countries. But when recognized, they can be met by fear and resistance. Rights are often associated with a constraining normative framework, serving to identify and condemn situations, which are out of the ordinary (the negative perspective). This interpretation causes institutions and their representatives to develop mechanisms, contracts, intervention strategies and forms, which quickly devolve into mere bureaucratic measures of protection and control (Gagnon and Clément, 2013). This can lead to a certain rigidity in the services offered, an uninspired implementation of standardized protocols. This tendency alienates both users and providers, which, in the case of mental health services, can have dramatic consequences.

The analysis of the implementation of the GAM approach demonstrates that it is both possible and necessary to rethink the issue of rights. A culture of rights operating at the heart of the healthcare system would completely alter the relationship between patients and providers and would permit a dialogue to assess existing constraints and possibilities. To go from passive patient to subject of one's treatment, and of one's life has a definite therapeutic effect. It is undeniable that respect for patients' rights, as defined in existing agreements and legislation, must constitute an integral part of any treatment program and must be monitored closely by those institutions responsible for healthcare, the training of professional care providers and the welfare of their clients.

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