Gaining Autonomy & Medication Management, from Quebec to Brazil: a participatory commitment

Gestão Autônoma da Medicação, do Quebec ao Brasil: uma aposta participativa

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ABSTRACT This article presents the context and construction of the Brazilian version of the Gaining Autonomy & Medication Management Guide (GAM-BR) compared to Quebec's original Guide. The GAM-BR Guide resulted from a partnership between Brazil and Canada, which transposed the Quebec instrument to the Brazilian context through multicenter research to empower mental health users in the negotiation of their drug treatment. This process was more than an adaptation as it transformed the original Guide into a Brazilian instrument. The main changes were replacing 'I' with 'you' as the subject of the statements in the Guide, further developing the theme of rights, suppressing the guidelines for the progressive withdrawal of medication. Additionally, the group device became immanent to the Brazilian GAM strategy. Far from being a betrayal, this set of changes remains loyal to the participatory and co-managerial process that oriented the elaboration of the GAM at its origin as an embodiment of Quebec's typical democratic and citizen experience. Therefore, this article aims to analyze the production of the GAM strategy's effects of in Brazil, considering its democratic experience and the psychiatric reform in the country.

KEYWORDS Medication therapy management. Mental health. Community participation.

RESUMO *Este artigo apresenta o contexto e os modos de construção da versão brasileira do Guia da Gestão Autônoma da Medicação (Guia GAM-BR), comparativamente ao Guia originário do Quebec. O Guia GAM-BR foi resultado de parceria estabelecida entre Brasil e Canadá que, por meio de uma pesquisa multicêntrica, transpôs ao contexto brasileiro o instrumento quebequense, a serviço dos usuários da saúde mental, visando ao aumento do seu poder de negociação em seus tratamentos medicamentosos. Tal transposição implicou mais do que 'adaptação': tratou-se da 'transformação' do Guia originário em um instrumento brasileiro. Entre essas transformações, destacam-se: substituição do 'eu' pelo 'você' como sujeito do enunciado das questões apresentadas pelo Guia; maior desenvolvimento do tema dos direitos; supressão das orientações para retirada progressiva da medicação. Além disso, o dispositivo grupal fez-se imanente à estratégia GAM brasileira. Longe de significar traição, tais transformações mantêm-se fiéis à forma participativa e cogestiva que orientou a elaboração da GAM na sua origem, como encarnação da experiência democrática e cidadã própria ao Quebec. Assim, o artigo busca colocar em análise a produção dos efeitos da estratégia GAM em solo brasileiro, na consideração à experiência democrática e ao processo de reforma psiquiátrica no Brasil.*

PALAVRAS-CHAVE *Conduta do tratamento medicamentoso. Saúde mental. Participação da comunidade.*

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Introduction

We turn our attention to the historical elements of our nation, whose effects persist to this day, affecting the relationships established between health professionals and mental health users, to achieve the specifics of the mental health experience in the Brazilian territory covered by this article. Brazil has one of the worst income distribution rates in the world[1,2], responsible for the blatant social inequality – with repercussions on indicators such as schooling levels and access to cultural goods[3] – affecting the impoverished majority of the population and, more severely, the black majority. The accumulation of wealth comes hand in hand with a high degree of power concentration, excluding most of its adult population from the political and institutional life of the country, which, thus, remains sidelined and distant from the established spaces of the polis. At the same time, the ruling class understands the exercise of political power as part of its inalienable privileges[4] – which is also a colonial heritage that establishes the power of the patriarchal family at the expense of a democratic state of law.

The definition of 'courteous man', coined by Sérgio Buarque de Holanda[5] to define the nature of Brazilian social relations, is the expression of this familiarist use of spaces of power, based on personal interests: courteous subjects regulate, for themselves and their loved ones, benefits and privileges, ignoring the meanings and universality inherent to the concepts of democracy, citizenship, political freedom, and the public sphere. Added to this is the slave heritage perpetuated and refreshed in the naturalized inequality and racism, which is denied but is a structuring factor in Brazilian society, upholding white supremacy at all levels[6]. Elitist economic and political domination is thus exercised with extreme coercion and brutality, even when permeated by gestures of familiarity and intimacy. This is the political outlook of Brazil, which has repeatedly and forcefully imposed a short existence on the popular democratic experiences of its recent republican life, which does not mean the absence of population struggles and resistance.

Indeed, the anti-asylum movement has emerged in the late 1970s in a context of mobilization as one among many expressions of the struggle for the country's re-democratization. In the 1960s and 1970s, while movements for the reform of psychiatric institutions and the deinstitutionalization of madness were erupting in the Western world, Brazil's civil-military dictatorship exponentially increased the population in the asylums and multiplied the number of private psychiatric hospitals associated with the State. Thus, the movement of mental health workers emerged against this reality, leading to the anti-asylum struggle[7]. In the wake of the health reform movement, which ensured the inclusion of health as people's right and duty of the State and the creation of the Unified Health System (SUS) in the text of the 1988 Constitution, the anti-asylum struggle movement achieved the implementation of a national, reformist mental health policy at the community and psychosocial levels[8].

However, these gains did not reach all the radicality of their principles in the political arena in which they were disputed, at the crossroads between re-democratization and neoliberalism[2]. The comprehensive, universal, and equitable SUS coexists with privatist supplementary health care. Furthermore, one of its basic principles, popular participation in defining the direction of the national health policy, struggles to materialize: what has been referred to as "social control", as a general rule, has been restricted to spaces of health councils and conferences, whose organization tend to prevent the participation of the most frequent users of health services[9] if not equipped by the State. Concerning mental health, the network of services, devices, and programs proposed by the national policy replacing the asylum rationale coexists with the maintenance of a still significant part of the old

asylum compound and its psychiatric public or private hospitals. It was unable to reverse the emphasis or the vertical, non-participatory form of drug treatments. Thus, despite the expanded clinic proposed by the reformist movements, mental health care is often limited to drug treatment, without users knowing the reasons or deciding about it[10].

Focusing on this last aspect, a partnership established between Brazil and Canada (The International Research Alliance University-Community – Mental Health and Citizenship, Aruci/SMC) from 2009 to 2014 prepared the Brazilian version of the Gaining Autonomy & Medication Management Guide (GAM-BR) – an instrument at the service of mental health users aiming at increasing their bargaining power regarding their drug treatments with their treating professionals. While reiterating the right to informed consent for the use of psychotropics, the GAM recognizes the knowledge deriving from the experience of using the medication, embodied by the users' bodies[11].

The GAM approach was developed in the 1990s in Quebec by community bodies – alternative mental health services and user rights groups – in partnership with the university. It was a long process of reflection, research, and action, involving users, workers, and researchers in different stages until its consolidation and the establishment of a network of knowledge transfer, monitoring, and support to the GAM experiences between the so-called alternative services in Quebec and the public sector[12].

In turn, its Brazilian version was realized in the partnership between the university, the association of users and family members, and services of the public mental health network, particularly the Psychosocial Care Centers (Caps). Building the GAM-BR Guide involved multiple translation efforts between Quebec and Brazil and between the different Brazilian states and research groups participating and between academics, workers, and users: from one language to another, one culture to another, and one viewpoint to another[13]. Also, socioeconomic and cultural differences between the two countries made an effort to adapt the GAM Guide to the Brazilian reality a radical experience[10], which would no longer be called an 'adaptation'; instead, it was a question of 'transforming' the Quebec's Guide into a Brazilian instrument.

Indeed, GAM is not a model to be applied, but a strategy that updates its principles when opening spaces of speech: recognizing subjects' dignity and respecting their rights; affirming the right to refuse the proposed treatment without giving up care; and claiming access to alternative mental health practices. Transforming the GAM Guide, as occurred in Brazil, was remaining faithful to the principles that guided its creation, carried out in a participatory and co-managerial way, as an embodiment of Quebec's democratic and citizen experience, at the crossroads of the common and the singular, between the subject of rights and subject of desire.

This article aims to present the context and construction process of the GAM-BR Guide, signaling its differences vis-à-vis the original Guide and analyzing its effects on Brazilian soil, considering the particularities of the Brazilian democratic experience. Thus, the dialogue established between Quebec and Brazil, which is the basis for the metabolization of GAM in our country, continues in a dialogical movement analogous to that in which participatory democracies are forged, with discussion channels enabling popular participation in political decision-making.

Material and methods

The process of translating and transforming the GAM Guide for the Brazilian context included two interconnected research stages, following Brazilian human research regulations, with approval 222/2009 by the Research Ethics Committee of the Faculty of Medical Sciences, State University of Campinas.

The first stage of the research was conducted from 2009 to 2011. It prepared a first

Brazilian version of the Guide, based on the translation and adaptation of the original text. This initial adaptation preceded the intervention stage in mental health services and was held in monthly face-to-face meetings with the participation of six researchers from the universities involved and academics linked to them, including some workers of the mental health network of Campinas (research headquarters); five users from Campinas and two from Rio de Janeiro, participating in social movements and cultural projects spearheaded by mental health users. Based on two independent translations of the original Guide compared at these meetings, the text was read and debated among the three segments gathered. Fundamental changes in its content were already proposed at this stage.

The GAM Guide thus translated and adapted was used in intervention groups carried out in three Caps in the states of São Paulo (SP), Rio de Janeiro (RJ), and Rio Grande do Sul (RS), respectively, with the participation of users and moderation of researchers and service workers. A fourth group was held at the university, with members of the association of users and family members and moderated by researchers and workers in the mental health network of Campinas.

The first version of the GAM-BR Guide was built from this experience of using the Guide preliminarily translated and adapted, its critical evaluation, and the modifications proposed by the participating users, workers, and researchers, which were discussed in monthly multicenter meetings, with the presence of these three segments, originating from the three centers part of the research[10].

The second stage of the research, from 2011 to 2014, followed the use of the GAM Guide in the version finally established by the first stage. Its development varied from one research center to another, but it continued to occur in mental health services and groups, inviting its various actors to dialogue in the three states (RS, SP, and RJ). The critical evaluation of this experience resulted in a final review of the Guide and the formulation of the 'Moderator's Guide', with guidelines for its use in group processes. The final version of the GAM-BR Guide[14] and the Moderator's Guide[15] were made available online for free use.

Results and discussion

The above report was intended to be brief but does not live up to the enormous challenge involved in the effort to proceed with the multiple translations required for the '*Brazilianization*' of the GAM Guide built in Quebec. It is worth noting that, although at least one of the transformations of GAM on Brazilian soil has taken place due to the adaptation to the situation, the remaining have imposed themselves as an expression of the participatory and co-managerial perspective guiding the strategy itself.

However, Guerini[13] warns of the danger of succumbing to a homogenizing project of society to adapt. According to the author, resisting this project involves conducting intercultural translation towards creating a shared, non-uniform, and universalizing plan, "always vulnerable and threatened by closure trends"[13(63)]; it also involves transiting between different worlds produced by each perspective from which a subject emerges.

This challenge followed the research and guided our perspective when seeking to identify what makes the Brazilian version of the GAM Guide unique compared to the Quebec's Guide. We organized our presentation into two topics, referring to the two tool transformation stages: before and after the experience of the intervention groups.

Previous text transformation: language and community, rights and citizenship

More substantial changes to the text of the GAM Guide were made at the inaugural moment of the research, before the

intervention groups, with the participation of academics, workers, and users, as mentioned above. These modifications mainly concerned the subject of the statements, the theme of rights, and instructions for the progressive withdrawal of medication.

Transposing the French text into Portuguese implied a first and more immediate decision-making: replacing 'I' by 'you' as the subject of the statement of the Guide's questions. The original Guide is constructed as a tool for self-reflection, which justifies the use of the 'I' in the proposed questions and the possessive that accompanies the title on the cover: *'Mon guide personnel'*[16].

After the Brazilian Portuguese title equivalent to 'Gaining Autonomy & Medication Management', the GAM-BR[14] Guide opens space for users to take ownership of this instrument, filling in their name in the blank space reserved for them: 'This Guide belongs to _____'. We think that assuming your name and inscribing it on the cover of the Guide – making it your own – is, in itself, an act of citizenship, especially significant for some Brazilians deprived of assets and access to cultural goods. However, the change announced on the cover already signals the change of perspective with which the questions contained in the text are enunciated, shifting from a self-reflective to a dialogic position: the GAM Guide does not speak out as a voice of conscience but users' interlocutor, asking them questions and making them think about their daily life and relationship with the medication experience. Thus, for example, the first part of the Guide, in the Brazilian version, is called 'Your quality of life' instead of *'Ma qualité de vie'* ('My quality of life'), and questions such as *'De quelle façon je prends soin de moi?'* ('How do I take care of myself?') changed to 'How do you take care of yourself?'. It should be noted that, while in the edition of the Quebec GAM Guide on which we base our translation and adaptation, the dialogical perspective is called into question only on page 3, entitled *'Ton guide'* ('Your Guide'), in the updated edition published in 2017 in Quebec[17], we observe an alternation between self-reflection and dialogue throughout the Guide, as a reverberation of the modification made by the Brazilian experience.

In Brazil, such a change was proposed by academic researchers at the onset of the translation adaptation work and immediately agreed by workers and users without it becoming an object of discussion. We could list several reasons that led us immediately to make this change. A decisive factor leads us to the previous definition of the experimentation forms and context of the translated Guide: in a group process with Caps users, to be developed in the service. The group was a fundamental device through which it operated the GAM strategy in the Brazilian context – the construction of groupality is one of the primary themes addressed in the 'Moderator's Guide'[15]. We are interested in highlighting the linkage between language and community, for which the idea of a monological discourse does not apply. Bakhtin[18] teaches us that any enunciation is the product of society's dialogical interaction: no one text does not allude to others that preceded it, which does not incite others to come. In this sense, the voice of the other, the discourse of otherness, inhabits and populates each other's voice; even a monologue in the first person carries a polyphony of voices[19]. However, it seemed essential to us to make this dialogue explicit in the statement of the questions proposed by the GAM Guide, giving rise to an exercise of thought, a reflection of oneself, which is realized in shared presence, together and alongside others. In the Brazilian context, this shared presence was an essential factor for mutual learning and encouragement among users participating in the GAM groups to defend their rights and exercise citizenship in their daily relationships with health services and their families.

Regarding rights, we considered that Brazilian democracy has been insufficient to cover the entire population. Furthermore, it is fragile and subject to recurring blows.

Citizenship and rights are abstract terms to many Brazilians and do not materialize in their daily lives, much in the same way as users of mental health services. Let us remember that the most significant volume of public investments in mental health was directed to psychiatric hospitals[20] until 2005, despite the network of open and territorialized services that SUS and a mental health policy have advanced. The experience of Caps treatment was a new thing to many of these users who had previously only been able to know the injunctions of medical and hospital treatment. Therefore, it was necessary to provide them with instruments that would allow them to understand that this novelty represented a right more than the benevolence of professionals. It was necessary to inform them which rights were assured to them as health system users. Therefore, besides the shared presence materialized in the dialogical form of the Guide's text and the collectivization of its use, it was essential to stress the theme of rights, which was reduced to one page in the Quebec Guide. We should also mention here that the updated edition of the Quebec Guide[17] significantly expanded the theme of Rights, bringing it, however, to the front as the first step of the Guide, while it is the third step in the Brazilian Guide, which addresses the support networks and the expanded autonomy.

Finally, one modification addresses a crucial point in the proposal of the Quebec GAM Guide, which is excluding, in the Brazilian version, the part that, in the original Guide, provides instructions based on the user's decision-making to progressively and safely reduce the number of drugs ingested, until its elimination. The Brazilian version

> shifted the focus from the withdrawal or reduction of the medicine to that of bargaining. The second part of the Guide was rewritten to increase users' participation in the management of their treatment[10(972)].

On the one hand, the apparent reasons for this change point to the position expressed by the participating users since the first stage of the research, which was that the issue was not *"the right to stop the use of medicines, but the right to access them"* (users voiced their awareness of citizenship right here – that of access to the goods necessary for life – which was not assured); on the other hand, the choice to research within the State; that is, in mental health services linked to the SUS, implying negotiation whereby "it is granted to the State while the State is forced to grant"[21(28)]. Considering the mental health policy national setting, whose reformist project did not prevent the pharmacological treatment from maintaining a central and often exclusive place among therapeutic offerings despite its advances, the researchers estimated that research would become unpractical in the service network if the proposed original Guide were kept in its entirety. Concerning research psychiatrists, we feared that the Medical Council, the supervisory body of the profession with an eminently conservative character, would react badly to the proposed Guide, promptly imputing to them the accusation of 'unethical exercise' of the profession.

We can affirm that we, Brazilian researchers, yielded to the State by abandoning the assertion of the possibility – the most radical and concrete – of users deciding to withdraw the medication; and we forced, or intended to force, the State, in the figure of its agents – professionals and health services – to grant the recognition of users' rights, their effective participation in the formulation of their therapeutic project, and the exercise of citizenship in the daily routine of services.

The elements found in the Brazilian health reform's ideology, namely, rights, participation, and citizenship, forge the ideas of autonomy and empowerment – of workers and users – in the SUS, clashing with the State's regulatory and population control function. However, we inevitably run the risk of a catch. Thus, in a neoliberal and privatizing health perspective, the idea of empowerment or autonomy flows into the subjects' responsibility for their illness

and caring for their health. Based on the 'care logic', as mentioned by Annemarie Mol[22], the decision to stop the use of psychiatric drugs is a shared responsibility that requires professional monitoring. By excluding the second part of the original GAM Guide from the Brazilian version, we save the services and their teams from making contact with it, freeing them from having to respond collectively to the prospect of withdrawing medications – users become solely responsible for this decision, according to what Mol will call the privatizing, individualistic[22] 'logic of choice'.

Ten years after this decision was taken, we believe that we now have enough knowledge to put into experimentation, in the Brazilian context, the guidelines for reducing or withdrawing the medication, completing the full exercise of rights provided for in the Bill of Rights of SUS Users[23]. Thus, in 2018, a multicentric project involving several public universities in the country was submitted to a public support notice for this purpose (while excellent per peer review, it did not obtain funding for its realization).

Among Brazilians: conflicts and negotiation

Subsequent modifications proposed to the GAM Guide – based on the experimentation of its translated and previously transformed version – focused primarily on the choice and adequacy of terms and the arrangement of questions. The dynamics of discussions were particularly marked by the intervention of users in decision-making. In general, the interventions imposed themselves from a singular sense of experience, disrupting the established rationale of thought or the sometimes-vicious circle of discussions between academics and, eventually, workers. Such was also the case with the word 'Guide', which has given this instrument its name since its origin in Quebec. Workers at one of the Caps participating in the survey questioned the use of this term, arguing that the experience of psychosis could lead users to take the word 'guide' from an imperative perspective, determining absolutely the steps to follow. Instead, they suggested the word 'notebook', which, in turn, was rejected by academics and workers present at the multicenter meeting of this debate, under the argument that this term would refer to the school context, which was not pertinent and could sound like infantilized use. The discussion threatened to become endless were it not for the timely intervention of one of the users present who, hitting the table as if to express the desire to speak, said loud and clear: "A notebook is blank, and a book is written. In the guide we read but also write. So, it's a guide!"[10(972)]. The other users nodded: the concern with the word Guide did not reverberate in the experience they had had. At first glance, untimely and randomly, the user's intervention introduced a third term in the conversation – 'book' -, hitherto unprecedented but capable of shifting the poles of the discussion. Thus, 'guide' became the median term of a new polarity involving 'notebook' and 'book'. It was a precise and timely intervention, which sealed the dispute.

However, ending the discussion did not mean avoiding the semantic multiplicity of the term 'guide', and bearing it was the first step. Interestingly, Jorge Melo's[24] thesis, when constructing the narrative of a first GAM group encounter (in the second stage of the research), presents us with a user playing with the semantics of the term 'guide', while the researchers answered that it is 'just a notebook', seeking to resume control of the situation. The direct citation of his text makes this point explicit and provides the clues of group dynamics that enlivens the Brazilian GAM experience, introducing elements of local, aphrodiasporic culture, traversing the wheel and its participants.

> FIRST MEETING. These foreigners continue to speak the way they do, with a know-it-all attitude, asking whether we knew what we are doing there. We know that we are there to talk

about medicines, which is a study, research, but we are still a little unsure about what to do there and how. Doctors say that they have a guide to help both users and the Caps. Next door, a companion begins to display a face of astonishment. She gets up suddenly, very nervous, and wants to know what this guide business was. Isn't it a macumba thing? It will not be possible to stay there, it's not for that, the macumba business. Almost without pause, the companion rushes to the center of the circle and begins to dance as if she were in a *terreiro* (African Brazilian religious worshipping yard), her arms in alternating semicircles alternating back and forth, her legs crossing in equally alternating steps, under the curved body. Dragged by muffled drums, we burst out laughing all over the circle. In a temporary situation, the group shows its proximity to what the circle underlies, that is, with the wheel, which is immediately transformed into a *terreiro*. Without any constraint, the companion steps forward and temporarily occupies the center of an area of influence, with which she seems to have no problem handling. She has fun with it while entertaining others. Wiping tears of laughter away, some try to compose themselves. They then ask for respect for their beliefs because they don't play with it: it's something to be careful about! Somewhat lost in the field of a game that is played otherwise, the researchers just smile and reassure the group that it was not a macumba, but only a notebook with information and questions to help them think about the topic of medication[24(68-69)].

Another expression put up for discussion was the sentence 'I am a human being, not a disease' that starts the text of the original Guide[16]. Some scholars argued that the sentence contained a dichotomy – 'human being or disease' – that perhaps did not make sense to users, which was overturned by a female user's eloquent testimony about the relevance of that sentence in her life, reinforced another user's comment that "it cannot be denied that there is a disease"[10 (973)].

However, the participation of users did not occur only to preserve the proposed text. Their attention was drawn to the little emphasis given to the themes of work and sexual and loving relationships in the original text, which they deemed crucial in their lives and were very much affected by the experience of illness and medicalization. Thus, they proposed the inclusion of specific questions on these topics. Regarding relationships, they took care to express 'sexual life' and 'love life' in the formulation of the question as two distinct spheres of experience (but that could be united), which were affected by the drugs' side effects.

Finally, the concern with simplifying the text, avoiding long sentences and difficult words since the preliminary modifications of the Guide's translation continued operating in preparing this version of the GAM-BR Guide, and in its critical review in the next stage of the research, as already reported. Indeed, the low schooling level and access to reading typical of the Brazilian population pose fundamental challenges in understanding the written text and some terms that are dear to the psychiatric reform, such as autonomy and empowerment. The group device was also crucial in facing the reading or literacy hardships of many users, who, alongside literates, could feel themselves to be readers: of the Guide, the contexts of life, and their experiences.

GAM effects on Brazilian soil

The acceptance of research at the Caps was facilitated by the researchers involved in the long history of working in mental health. However, the stated theme – 'Gaining Autonomy & Medication Management' – was new, raising diverse expectations and fears by users and workers. Some believed that it promoted self-medication, while others assumed that it was researching a new drug with substantial funding from a pharmaceutical laboratory. As the misunderstandings were undone, despite the initial receptivity and, sometimes, the

positive signaling or expression of interest to carry out the research in the services contacted, the intervention groups did not develop smoothly, requiring continued negotiation with the teams. While the workers involved in conducting these groups with the researchers were very touched by the experience, capable of transforming both users and themselves, the other professionals of the teams remained either unaware or suspicious of what was happening there.

If some of these could recognize positive changes in the attitude of the group users, who were more aware of their rights and attempted to participate more in decisions regarding their treatments, others either did not perceive these changes or considered them undesirable. However, the effects produced between workers and users in the inaugural stage of the research enabled its replication in the next stage, including a more significant number of services and participation of users, workers, and residents in the moderation of the intervention groups.

Also, since 2013, when the GAM-BR Guide was made available to the public via the internet and in the State of Rio Grande do Sul (Brazil) at the initiative of the State Health Secretariat, distributed to regional coordinators for use by interested services, experiences have multiplied with varying spaces, forms, and participants, also reaching users of alcohol and other drugs, children, and adolescents[25]. In some cases, similar to the initial misunderstandings with the expression 'gaining autonomy and medication management', the expectation of workers when proposing a GAM group is to produce adherence to drug treatments – and autonomy is identified here as users' ability to take their medications without the help from third parties. However, other effects have been collected from the users' experience, where users have greater knowledge about the effects of medicines and are aware of their rights.

An analysis of the first Brazilian publications of the GAM survey reveals that users showed greater knowledge about their medication and started to recognize in themselves knowledge derived from experience after participating in the intervention groups. Both the doctors and users had authority over drug treatment. However, they continued to consider the professionals as a superior authority, with the power to decide on treatment. In all fields of research, mobilized and encouraged by discussions in the GAM groups, some users sought their doctors to adjust their medication. In general, the intention was reducing, yet not withdrawing the medication. Drug prescription remained paramount in the formulation of the therapeutic project; users would rather endure side effects than live without medications, even if they identified their limitations and harm: "If we don't take medicine, we get worse"[10,26(120),27].

Furthermore, although they could express their ideas and claim their rights to workers through the GAM, users argued that this did not mean that they were heard. They perceived that their increased demands regarding treatment produced tensions and confrontations with the teams, concerning which they affirmed the need to be better prepared to address the negotiation of each therapeutic project. The GAM experience sparked users' budding effort to participate in the decisions regarding their treatments while putting them in touch with the limit of services to receive and give way to this participation, especially regarding the drug treatment. This experience also revealed the lack of knowledge about drugs falling on non-prescribing professionals, who also identified difficulties in the relationship with doctors to obtain more information about the users' drug treatment. The GAM experience also made users look critically at how the treatment concept was equated with the regular use of medications at the Caps. While other resources were mentioned, they did not reach the same value given to pharmacological treatment[21,28].

Users referred to the GAM group as a space for exchanging experiences about the

medicine, in which people could tell their unique experience with the medication and experiential knowledge to be recognized. The GAM experience contrasted with the communication of the professionals who served them and which the users could then criticize: the language was technical and insufficient to clarify their doubts. According to them, doctors gave little guidance on drug treatment, leaving them with their fears, such as that the use of multiple drugs could kill or cause permanent coma[28].

Finally, the GAM experience also made users invest interest in rights, previously absent from the universe of their concerns. They began to recognize the right to participate in decisions regarding their treatment, read their medical records, and obtain the necessary information. They began to participate more often in the management of the services in which they were served. Furthermore, they expanded the discussion on rights regarding health, living conditions, and access to housing. However, in general, the Caps established a strict demarcation of the spaces for users to exercise their rights – as a rule, 'assemblies' and user associations. According to users, participation in these spaces was supported and respected, but they were hardly heard when managing their treatment. In particular, the right to refuse treatment was not respected, with attitudes such as forced medication, oral or injectable, or, during hospitalization, physical restraint, threats of transfer to a "worse place"[10,27,28(2896),29] or triggering a crisis, if they rejected the prescribed treatment.

Final considerations

We point out the inseparable link between GAM and the exercise of rights and citizenship, which highlighted its potential and its limitations in the experience with Brazilian public health services. We saw that GAM was a space for exercising users' rights, but this exercise did not reverberate as expected among professionals or in the services' decision-making processes. In total affinity with SUS principles, the deeply participatory nature of the GAM strategy goes against a centralized power and hierarchical knowledge culture that has long been ingrained in society, in which the user-derived knowledge is not valued. The lack of value of this knowledge is also rooted in the extreme social inequality, which imposes distance between some of the health workers and the users concerning the conditions of access to cultural goods, even in the face of the growing instability of these workers.

Thus, although the Brazilian health policy professed to its users the right to speak, be respected as a person, refuse or question the proposed treatment, and the possibility of a more egalitarian relationship between users and workers; although these precepts could be indeed applied in many of the services replacing the asylum rationale proposed by the Brazilian mental health policy; we find ourselves, not infrequently, with workers and services attached to old models, repeating old undemocratic and hierarchical forms of relationship with users – that are replicated in different spheres of Brazilian society.

Through GAM, these users gained an unprecedented experience of citizenship, which acquired a sense of dignified life, as a status change: from inhuman to human and from object to subject. This is unparalleled by the Quebec GAM experience, whose democracy has acquired sufficient reach and stability, securing fundamental rights for all. Certainly, psychic illness and life medicalization generate stigma and loss of rights, but citizenship and respect for the subject are experiences accessed before illness and treatment, which are being rescued. With an uneven and interrupted democracy, citizenship is an experience to be invented in Brazil. For mental health users, participation in a GAM group can be a glimpse of this invention, which gains transformative momentum – in this case, due to its common management, lateralized relationships, and shared experiences, the group is part of the

Brazilian strategy, a catalyst of its transforming force[15]. However, suppose the gradient of democracy and citizenship is an essential marker of Quebec and Brazil's difference: in that case, we are faced with the fact that the GAM trajectory in Quebec or Brazil – both institutional and personal – faces the same challenges to increase the power of users in decisions regarding their drug treatment. GAM bumps against the same wall: stigmatizing diagnoses, biomedical reductionism, and life medicalization.

Regardless of the country, we risk saying that the reform movements have failed to reform drug treatment. The biomedical discourse imposes itself as a transnational entity at the service of body control and the pharmaceutical industry. The partnership between Quebec and Brazil around GAM finds reasons to follow on for the right to life, more democracy, and non-medicalizing alternatives for mental health care.

Collaborators

Palombini A (0000-0002-8332-8292)* contributed to the design, planning, analysis, and interpretation of the data, elaboration of the draft, and the final version of the manuscript.

Del Barrio LR (0000-0002-4451-8237)* contributed to the design, planning, analysis, and interpretation of the data, critical review of the content, and preparation of the final version of the manuscript. ■

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