From prescription to listening: effects of gaining autonomy and medication on health workers

Da prescrição à escuta: efeitos da gestão autônoma da medicação em trabalhadores da saúde

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Abstract

The use of psychotropic drugs and rights related to the choice of prescribed treatments has been gaining ground in literature. This article reports aspects of a qualitative research that intervene in 10 health services (primary and secondary care) at two Brazilian cities (Campinas and Amparo, in São Paulo). Following the principle of Brazilian Psychiatric Reform, defending users' rights to decide about their treatment, we worked with the gaining autonomy and medication (GAM). GAM comes from Canada and proposes to "empower" users regarding the use of drugs in their therapeutic projects. This article aims to evaluate the impact's perception of the workers moderators of the GAM groups. Semi-structured interviews were conducted with the GAM Group's moderators before and after the intervention, narratives were constructed under the precepts of Gadamer's hermeneutics. Workers who experienced the strategy took a more critical role in relation to their clinical practices, and identified, in the horizontal methodology, group and directed to listening for the appreciation of the voice of users, an experience that could promote a more flexible clinic and conducive to the joint construction of actions. GAM's experimentation in the this research allowed to analyze it in relation to other Brazilian references to the field of collective health such as popular education and person-centered medicine, operating an interesting cultural hybridization.

Keywords: Mental Health Care Services; Decision-Making; Personal Autonomy; Gaining Autonomy and Medication; Psychotropic Drugs.

Resumo

O uso de psicotrópicos e os direitos relacionados à escolha dos tratamentos prescritos vêm ganhando espaço na literatura. Este artigo deriva de uma pesquisa qualitativa na qual se interveio em 10 serviços de saúde (Atenção Primária e Secundária) de dois municípios (Campinas e Amparo, SP). Seguindo os princípios da Reforma Psiquiátrica Brasileira de incluir os usuários nas decisões dos seus tratamentos, utilizou-se a gestão autônoma da medicação (GAM) como estratégia de intervenção; ela é originária do Canadá, e propõe "empoderar" usuários quanto ao uso de medicamentos em seus projetos terapêuticos. Este trabalho avalia a percepção dos trabalhadores que moderaram grupos de GAM. A partir de entrevistas semiestruturadas com esses moderadores, antes e depois da intervenção, construíram-se narrativas sob os preceitos da hermenêutica gadameriana. Os trabalhadores que experimentaram a estratégia assumiram papel mais crítico quanto a suas práticas clínicas, e identificaram, na metodologia horizontal, grupal e direcionada para a escuta de valorização da voz dos usuários, uma experiência capaz de promover uma clínica mais flexível e propícia à construção conjunta de ações. A experimentação da GAM nesta pesquisa permitiu analisá-la em relação a outros referenciais brasileiros da saúde coletiva, como a educação popular e a medicina centrada na pessoa, operando uma interessante hibridação cultural.

Palavras-chave: Serviços de Saúde Mental; Tomada de Decisões; Autonomia Pessoal; Psicotrópicos; Gestão Autônoma da Medicação.

Introduction

Brazilian Psychiatric Reform instituted a new mental health policy that had as one of its main resources the development of *Centros de Atenção Psicossocial* (Caps – Psychosocial Care Centers). However, despite the new arrangements in mental health, many challenges must be faced with regard to an effective change in care practices. One of them concerns the primacy of pharmacological treatment in the set of actions of mental health professionals, to such a degree that, many times, it is reduced only to psychotropic drugs. Hospitalization and "renewal of prescriptions" without face-to-face assessment of users are still common responses to the demands that arise in the system (Onocko Campos et al., 2011).

Other studies reinforce that the participation of users in decisions related to their treatments is often restricted to a simple report of symptoms (Lopes et al., 2012). This low personal and collective autonomy that users have in relation to their treatments, with little information and centralization of decisions in health professionals, makes clinical practice more vulnerable to market economy and to the medical-hospital complex (Conrad; Leiter, 2004).

Gaining autonomy and medication (GAM) is a proposal that came from the questions about the management of the use of psychoactive drugs in Quebec, Canada, in the 1990s. It emerged from the reflection carried out by social movements regarding the use of psychoactive drugs. The main questions were the lack of information about prescribed drugs, the undesirable effects resulting from the use of drugs, the persistence of suffering despite drug treatment, the difficulty in returning to the labor market and the desire of users to live without the drugs (Rodriguez; Perron; Ouellette, 2008).

GAM is a strategy to change power relations in order to guarantee users effective participation in decisions regarding their treatment, and it presupposes dialogue and exchange among people involved in them. In the beginning, the creators questioned the medication itself, but soon the argument shifted to the recognition

that there was suffering already existing before the medication. Thus, the axis was no longer the suspension of medication, but the sharing of the meaning of its use.

In a study that followed the adaptation of the GAM to the Brazilian reality (Onocko Campos et al., 2012), we also found a significant lack of spaces for information and reflection about the medication in the CAPS. This work also evidenced several difficulties of the workers to support the users in relation to a theme so relevant and impactful in daily life. Gravel, Légaré and Graham (2006) performed a meta-analysis on the barriers to practice clinical actions based on the sharing of decisions with users. Thirty-eight studies were included, with more than 3,000 subjects who indicated their perceptions regarding the barriers to the implementation of a shared clinic. The main factors described were: (1) the lack of time in visits; (2) the lack of clinical conditions of the user, in the evaluation of professionals; and (3) the lack of personal characteristics of users to enable sharing.

In the works related to this strategy, users brought the need to involve service workers in GAM – because, different from people of Québec, in the Brazilian context the balance of political forces was unfavorable to them (Gonçalves; Campos, 2017). They reported that it was not effective to be extremely certain of their rights if those who represent the state (in this case, health professional) were not supportive to them. For this reason, this research proposed to examine the effects of the participation of health professionals in GAM groups.

Methodology

This is an intervention research developed in the health networks of Campinas and Amparo, both in São Paulo, that is part of the list of participatory studies seeking to investigate the life of communities, assuming an intervention of a socioanalytic nature (Coimbra, 1995).

We developed the intervention by steps in the two municipalities. The first step was to present the concept of the GAM strategy to the workers of the two networks, with the support of the respective Health Secretariats for this purpose. Then, we gave a training course addressing the concepts of autonomy and sharing of decisions in treatment, delivered the history of the strategy and the GAM Guide to each student, with the group management approach and emphasis on its horizontal character. From 11 health services (five CAPS, 4 Basic Health Units in Campinas and 2 in Amparo), 61 people were interested in participating in the intervention research. In the agreement with each service about how the intervention research would be developed, and based on research that used the strategy previously, it was stipulated that the dynamics proposed by the Guide should be made between 18 and 22 meetings, making up a period of around six months. In addition, all the moderators of GAM groups held bi-monthly meetings to exchange experiences. Finally, each researcher involved in the project became a reference for a number of services in order to play a supporting role to these groups. We worked with the notion of facilitator in order to offer support, sustain and assistance to the developing groups. (Oliveira; Campos, 2015).

The question that guided the work was: "How much the use of the GAM groups by health workers is an instrument for the recognition of the autonomy of the mental health user?". The research subjects were submitted to semi-structured interviews at the beginning (T0) and the end (T1) of the experience of the strategy.

We used a semi-structured script in the interviews with the objective of understanding the perceptions of the interviewees, before and after their experience in GAM, regarding the concept of autonomy, the treatment of users of health services, the knowledge about rights, the knowledge about psychoactive drugs and how the experience of GAM affected the subjects. We recorded the material, transcribed it, and transformed into narratives. These were validated with the research's participants, allowing the subjects to recognize themselves or not (Figure 1).

The narratives were built from the hermeneutic approach, understood not as a methodology in itself, but as an interpretative posture that is sustained by the search for the understanding of a text or,

in a more general scope, of a human phenomenon, positioning itself between the explanation of nature and the understanding of history (Ricœur, 1990). We also rely on Onocko Campos (2005) and Onocko Campos and Furtado (2008), who work with narratives as an interpretative resource for the treatment of material produced in research. It aims, therefore, to understand in an interpretative way the processes of meaning construction and the universe of meanings located in a given context and historical moment, in addition to the way they share their own experience and meanings (Serpa Júnior et al., 2014).

Figure 1 – The construction of narratives
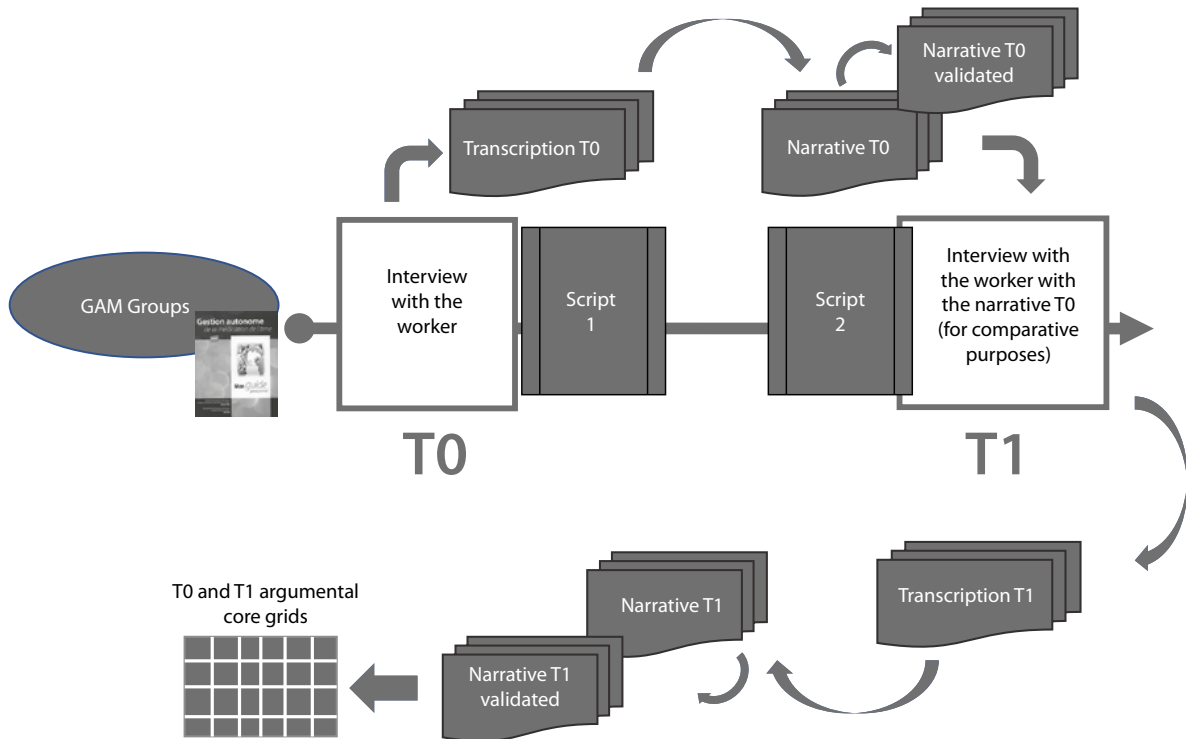
The study was evaluated by the Ethics and Research Committee (CEP) of the Faculdade de Ciências Médicas da Universidade Estadual de Campinas (Report No. 520/2011, CAAE: 0448.0.146.000-11), by the *Centro de Educação dos Trabalhadores da Saúde da Prefeitura de Campinas* (Health Worker Education Center of the Municipality of Campinas), the Health Department of Amparo and the *Núcleo de Educação Continuada do Serviço de Saúde Dr. Cândido Ferreira* (Center for Continued Education of the Health Service Dr. Cândido Ferreira).

Results and discussion

Twenty-five interviews were conducted at time 0 (before the intervention) and 17 after the intervention (at T1). Along the study trajectory, two services did not finish the groups, four workers did not complete the study due to dismissal from the services, and four did not finish the work, because they reported not feeling supported by their services to continue the activity. As for the 17 workers who participated in the study, both in T0 and T1, they were numbered in sequential order for identification and preservation of confidentiality; their characteristics are in Chart 1.

The workers who decided to try the GAM were differentiated by their prior consensus about the knowledge be democratized and accessible to all. They were workers with a previous history of greater acceptance of user knowledge as a fundamental point in the construction of

therapeutic projects of each one, and critics of the exclusive treatment with medications. Therefore, most of them, from the beginning, not tended to offer opposition and even support the user's decision, even if this was the stop of drug treatment. Despite the workers' previous posture approaching the precepts of GAM, they reported that such positions are difficult, causing insecurity in defending the autonomy. *Participating in the GAM group strengthened my opinion; the more I talk to users, the more I realize that they are intelligent, that the presence or absence of a psychosis will not make any difference if they do not want to take the drug.* (Worker 5, T1).

Chart 1 – Characterization of the moderators interviewed in T0 and T1

Worker	Place of work	Gender	Formation/Background	Length of service
1	Primary health care	F	Psychologist	More than 3 years
2	Primary health care	F	Nursing assistant	More than 3 years
3	Primary health care	F	Psychologist	More than 3 years
4	Primary health care	F	Occupational Therapist	More than 3 years
5	Primary health care	M	Nurse	Less than 3 years
6	Primary health care	F	Nursing assistant	More than 3 years
7	Primary health care	F	Psychologist	More than 3 years
8	Primary health care	F	Occupational Therapist	Less than 3 years
9	CAPS	F	Nursing assistant	More than 3 years
10	CAPS	F	Nursing assistant	More than 3 years
11	CAPS	F	Psychologist	Less than 3 years
12	CAPS	F	Nurse	Less than 3 years
13	CAPS	F	Occupational Therapist	Less than 3 years
14	CAPS	F	Occupational Therapist	More than 3 years
15	CAPS	F	Psychiatrist	Less than 3 years
16	CAPS	M	Psychologist	More than 3 years
17	CAPS	F	Occupational Therapist	More than 3 years

As for participation, GAM caused a surprise in a universe in which workers complain about the low adherence of users to the treatments offered. Unlike other groups, they identified great presence of users, they almost never forgot the Guide, and they were interested in continuing the proposal, even after it had ended.

Thus, for a good number of them, GAM was an experience of reaffirming the types of management and practices in which they believed. However, even in services where there was dialogue with the doctors, most of the burden of the decision to administer a drug against the will of the user, for example, was on medical responsibility. There were few spaces for this kind of discussion and, sometimes, this subject is a taboo.

Autonomy

In GAM groups, the construction of the concept of autonomy come from practical situations in which individuals faced issues about knowing themselves, self-care, knowing others, and taking care of others. Most of the workers, especially

those with higher education, reported that, in their previous backgrounds, they used to discuss the topic. However, they talked about the difference between discussing it in a speculative way, in classrooms, and experiencing it in practice, with real dilemmas, as in the case of the GAM strategy. They said that the themes related to autonomy were addressed in a theoretical way, without relation to the daily life of their practical steps.

> [What] *impressed me a lot during the GAM was the practical part of the discussion of autonomy: discussing the ways of accessing the support network, for example. It was very important for them to identify, recognize and know how to get to this network, regardless of being a neighbor, the family, a health service.* (Worker 6, T1)

The notion of dependence on the other people from the description of the networks, and from how each one can use it, became a positive use dimension, different from the negative charge that the word "dependence" brings. The narratives bring this point as one of those best discussed in the GAM groups: autonomy versus dependence versus independence. In several cases, the discussions converged on the concepts of interdependence and mutual dependence.

According to Norbert Elias (2001, p. 154), human beings live interacting in networks or "webs" of mutual dependence. He works with the concept of a network of permanent interaction, in which individuals or groups are connected to each other by a specific mode of reciprocal dependencies. These individuals would experience clustering processes via numerous invisible chains of relationships, whose interdependence supposes a flexible interweaving in constant movement (Elias, 2008, p. 32-36). Another aspect of autonomy was discussed more often in the interviews in T1 than in T0 was self-knowledge. The GAM Guide has several questions focused on the best knowledge of oneself, especially in the first two steps. The narratives pointed to the emergence, during the groups of information about users, of facts that most workers did not know: information about life histories and the territory in which they lived and testimonies that made sense

to the other participants. They also pointed out that the strategy contributed to a better knowledge of the users by the workers.

Knowledge about drugs

There was a recurrence, in the narratives, of insufficient training related to knowledge about drugs, both in higher and middle-level professionals. The workers reported that the knowledge about the drug is not as important as the knowledge about the effects it has on the subject. They said that listening to the user experience from the GAM groups revalued the popular knowledge, and they consider that knowledge today is more important than the way it is presented in books. They reported that they used gave greater value to technical knowledge, justifying that it was because, during their studies, regardless of the undergraduate course they did, this kind of knowledge is the most valued. In the comparison between T0 and T1, in the first one the user is also charged for "technical" knowledge about the drug and diagnosis. In T1, the narratives were more focused on the construction of knowledge involving experiential knowledge. *I found it very crazy, but also the fact that with GAM I was able to "discover" that they have the power to mess with the drugs.* (Worker 8, T1).

Where does the knowledge about medicines come from? It was the question that many participants began to do during the activities. Campos (2011) develops a critical reflection of contemporary common sense, reducing the relationship between knowledge and practice to its technological dimension. The technological reason imagines that human work and practices would be regulated by previously accumulated knowledge, preferably consolidated as science. This positivist trend is in the current cultural characteristics, when performance, productivism and individual results are valued. Thus, in recent scientific production, there is a predominant tendency to disregard or at least minimize personal accounts of illness, restricting them to the secondary place of mere illustration of the theory (Geekie; Read, 2009). Such an approach tends to exclude those who suffer from the discussion about the elaboration

and appointment of what afflicts each one. Thus, based on the question "where does knowledge about medicines come from?", some moderators expanded the reflection to "where does knowledge about ourselves come from?". Some narratives pointed to the dichotomy between experiential knowledge and technical-scientific knowledge coming from outside, asking about the validity and importance of one in relation to the other.

In this paradigm, the knowledge about the experience of illness and the use of medications is softened in pseudo dialogs, in which the user says what the doctor and the team expect to hear, preferably using medical terms, and these respond with a usual repertoire based on pharmaceutical instructions. Communication is reduced to the verification of symptoms and prescription of drugs, leaving aside the multiple unsaid of suffering (Rodriguez; Perron; Ouellette, 2008).

User rights

The majority of the interviewees brought the perception that many users do not know their rights. However, they said that they were unaware of their rights and few of them knew how to mention the sources, laws or places where they could access them. After living in GAM, the interviewees adopted positions of greater openness towards the user, to hear signs and meanings detached from the biomedical paradigm, which they most often learn in their training and replicate in the clinic's daily routine and in the services. Workers began to question the relationship between the prescriber and users from their point of view. Feeling like a user may have been one of the ways that led most of the interviewees to reflect, who were more sensitive to each other's citizenship and reported that the groups aroused various forms of criticism in the services where they work.

Several narratives pointed out that the influences that persisted in the services where the intervention occurred were almost nil, and that the effects of the GAM strategy were "isolated", in the words of many participants, from those who participated in the groups. The participants said that this created frustrations, because they worked on the logic of

inciting autonomy in the user, but it was barred by many teammates. Such resistance was nothing new and appeared in other researches with GAM (Onocko Campos et al., 2013). In these services, the lack of spaces for talking about drug treatment with the user and among the professionals of the teams themselves appeared. There was also a tension between doctors and the rest of the team, emphasizing that the doctors have difficulty in sharing knowledge about drugs, which makes the subject even cloudier. *We don't share information with the patient, sometimes because we don't have the knowledge, and many times we have it, but we don't pass it to the user because we think the well oriented user is a piece of work* (Worker1, T1).

Workers also listed possible barriers to the implementation of user rights in services in three categories: (1) the non-existence of information about the subject, (2) the non-existence of a structure or organization of the work process that enables the enforceability of rights, and (3) the personal and institutional resistance to the rights of others.

Another study corroborates this finding, also involving the approach with the GAM strategy, revealing the attitude of the teams when faced with the refusal of use of the drugs by users with the critical judgment preserved. The reactions ranged from non-acceptance and consequent disconnection from the service to acceptance with reservations. In these services, there remain spaces for control, domination, where the rights of users are inhibited or accepted with caution, indicating the existence of a fragile limit between the health care of users and the management of their lives (Onocko Campos et al., 2013). Another study indicates a prevailing contradiction in services, such as capture spaces, with the persistence of stigma and guardianship management that are still based on the supposed "lack of rationality" of critically ill patients (Figueiró; Dimenstein, 2010).

Vasconcelos (2007) relates the barriers to the application of rights in the field of mental health, both from the historical-social point of view and from the internal contradictions of the users' movement itself. This reflection is pertinent, because the GAM strategy, originating from the action and militancy of Canadian users, had as

background the social struggle for their rights. However, Brazilian social movements in the field of health are composed, almost entirely, of health professionals and state agents. There are few studies about these movements. Vasconcelos and Rodrigues (2010) point out that the growth of the participation of users and family members is slow, and even the associations with greater participation of those, in general, adopt a mixed configuration (users, family members and professionals), in which the latter have a more prominent and regular role, in a framework of organization, financial bases and political activism usually quite weakened.

In this context, it is understandable why the GAM strategy has found in Brazil support points in health workers and in state institutional spaces, in addition to anchorage for its implementation, something considered unthinkable by management proponents in Canada. We could ask, therefore, if the Brazilian arrangement is a limiting factor for the appropriation of knowledge and power of users. If, on the one hand, there is the risk of co-optation and bureaucratization of the strategy by the State, on the other hand, there is the possibility of reaching a public more inaccessible to a similar Canadian: the health worker.

Clinical practice after GAM

The workers who experienced the GAM groups reported feeling safer in their clinical practice. They talked about a change in relation to their posture within the service itself and the team, questioning more, including the doctor. They emphasized the openness of the possibility of better guidance to users, particularly in relation to medications, without the need to submit everything directly to the doctor or generate one more consultation only for doubts about drugs. In this way, they indicate greater safety in clinical practice, aimed at respecting the rights of users, something seen, for example, in the decision to use the drugs.

According to Campos (2000), the creation of new relationships between users and the health team, with shared care, allows a subjective repositioning of them. When the subject of knowledge becomes the citizen himself, and not only the scientific

accumulation knowing of the worker, it enables a new attitude in the therapeutic meeting. The participation of the user in decisions related to his treatment is no longer a novelty, at least not in the scientific literature of the last 20 years. In some countries, such as the United Kingdom, the scientific evidence and the individual values (including preferences, concerns, needs and desires) of users and their families (Fulford, 2011) are combined. The official guidelines of the English national system make it explicit that the sharing of the decision with the user must be an imperative condition for the follow-up of any treatment (Deegan; Drake, 2006).

Our group of hypertensive patients works like this: once a month, the patient goes, sits, and then the professional goes there and gives a class about something, without any construction. Before, I thought this was a group. GAM made me think about it to start running away from this. (Worker1, T1)

Because GAM has constructed in groups, it has enabled a different way of experiencing them than usual. The points that many brought, as good news of the strategy, were nothing more than basic precepts of good group practice, thus revealing that they were not part of the daily services. They identified the following points as elements that transformed the group into a more transversal space for exchange: (1) a pre-established script; (2) the groups a space for knowledge exchange; (3) listening and participating in the group without carrying the seal of resolution; (4) the perception of the need to develop a more accessible communication with the users and (5) the obligation to have a moment of planning the group. Finally, the participants evaluated it as a speech space, allowing the discussion of broader issues than those usually addressed in health services. It is a space with another time, allowing the access to other dimensions of the subject.

Final considerations

The design of the research used participatory precepts and favored the formation of subjects-intervener-researchers who were intertwined. The dynamics of the GAM Guide stimulated the search

for knowledge: the research of themselves, of their social networks, about the drugs, about the rights of each one.

As a limitation of the study, during the intervention, eight months on average, it was not possible to relate all the changes that appeared in the narratives exclusively to the experience of the GAM strategy, remembering that these are reflections and perceptions in the vision/voice of the workers. Another important point was the variety of group formats; despite the Guide works as a guide, the experiences varied according to the different management of each moderator and the results were dependent on the management and conduct of each group.

The intention of the research was to analyze and evaluate only the GAM strategy – however, it also examined the practices of the mental health services. This action permitted the raising of criticism in the face of the real inclusion of the voice of users in the local directions of health actions. Considering the Brazilian context, the process of Psychiatric Reform achieved significant advances, with investments in human resources, expansion of coverage of mental health services and care policies in the whole country. However, it continues to face challenges such as increasing the participation of users in the daily life of health services and overcoming guardianship practices for a greater production of autonomy.

The construction of a space that makes the experiences legitimate allowed the workers to reflect about their clinical actions. They indicated that they needed to have a more extensive listening, identified as reinforcing and expanding links between health professionals and users. This construction also allowed the moderators to experience a lighter and more flexible clinic, perhaps towards a possibility of sharing decisions.

When they got in touch with the singularities of each user, they realized that even the knowledge of effects and actions of medications was uncertain. It was interesting that, when certainties became uncertainties, the security of being able to include the others in decision-making increased. Once the foundations of the construction of scientific knowledge as the only legitimate knowledge are shaken, the belief in the others for the construction

of a new one is strengthened. Such bases allowed another way to discuss autonomy, users' rights, psychoactive drugs and the influence of these debates on the life of each one.

In the field of mental health, we can see that there are several paradigms that, although with different roots, guide clinical practices towards greater user's autonomy; among them, recovery, Brazilian psychosocial rehabilitation, clinic centered on the person, extended clinic, popular education in health and many others are part of the same field of opposition to the prevailing rationality in health. The original experience of GAM was to provide the emergence of practices with various aspects of the various theories cited, without pretending to be a theory.

In Brazil, GAM, even with the theory of recovery at its roots, is no longer a tool made by users and for users, and other traditions embraced it. It is closer to the clinic centered on the person, because it is a strategy built for health professionals. In Brazil, different from Canada, state agents, workers of the area, mostly conducted interventions in GAM. As we have seen, the clinical method centered on the person aims to expand listening and develop with the user a practical plan of prevention and promotion for a lifetime (Stewart et al., 2010).

With the experience of the group, the GAM approached the Brazilian tradition of popular health education, with historical influences from the margins of Brazilian society that converge in a pedagogy and world concept centered on dialogue, questioning and common action between professionals and population (Stotz; David; Wong Un, 2005). For popular health education, the learning processes happen in life and not only within the curricula and formal institutions. Through the principles of dialogue, respect for diversity and appreciation of collective subjects, it allows us to advance in a professional training focused on the daily construction of collective or individual projects (David; Acioli, 2010).

Finally, GAM, as a strategy born from the tradition of recovery, but which took shape in state health services, inevitably took on an evaluative feature of the institutions and their work processes. Movements described by Campos (2000, 2003),

in which the inseparability between clinical and management is evident, emerge by means of the GAM. The diversity of resistance of health services, perceived by workers, corroborates the results of other research about the strategy in Brazil (Onocko Campos et al., 2013; Passos et al., 2013). The notion that changes in mental health practices are still necessary is in evidence, especially with regard to the valuation of the user experience in their treatment. There is still a need to reform the care, within the Psychiatric Reform, so that the main concerns are no longer the diagnosis, the disease and the drug prescription. Thus, conditions are created for the user who, instead of occupying a place of dependence in the relationship with the service, has it as a space to resume the own place as a citizen.

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