MULTICENTER ADAPTATION OF THE GUIDE AUTONOMOUS MANAGEMENT OF MEDICATION


I Departamento de Saúde Coletiva, Faculdade de Ciências Médicas, Universidade Estadual de Campinas. Rua Tessália Vieira de Camargo, 126, Cidade Universitária. Campinas, SP, Brasil, 13083-887. <rosanaoc@mpc.com.br>
II, VII Departamento de Psicanálise e Psicopatologia, Instituto de Psicologia, Universidade Federal do Rio Grande do Sul.
III, IV Departamento de Psicologia, Instituto de Filosofia e Ciências Humanas, Universidade Federal Fluminense.
V Faculdade de Medicina (campus Macaé) Universidade Federal do Rio de Janeiro.
VI Instituto de Psiquiatria, Universidade Federal do Rio de Janeiro.
VIII, IX, XII, XIII, XIV Departamento de Saúde Coletiva, Faculdade de Ciências Médicas, Universidade Estadual de Campinas.
XI Fundação de Saúde Publica de Novo Hamburgo e Residência Integrada em Saúde Mental Coletiva, Universidade Federal do Rio Grande do Sul.

ABSTRACT

Rising psychotropic prescriptions and low empowerment of mental health users hamper qualified delivery of mental health services in Brazil and countries providing universal healthcare. This multicentric study performed in three Brazilian cities aimed to develop the Brazilian translation and adaptation upon the Quebecoise-Canadian Gaining Autonomy and Medication (GAM) Guide; and to evaluate the impact of its use on mental health workers education. Intervention Groups (IGs) were held to provide experience sharing on medication as relevant issues were brought up by the guide. Pre- and post- IGs focus groups were held. Major changes to the original text of the Quebecoise handbook were necessary according to the Brazilian scenario. Results show the Brazilian version as a powerful strategy to promote users' participation in decision making concerning treatment as well as the mental health services they are in treatment at. The handbook also has a positive impact on staff education.
Keywords: mental health; personal autonomy; qualitative research; psychotropic drugs; learning.

Introduction

In Brazil, the Psychiatric Reform has enabled a transition from the hospital-centered model to a community-based mental health model. Thus, it has expanded the field of the clinic, promoting psychosocial care and redefining the meaning of health on the border between individual and collective. However, even in this context the pharmacological treatment continues to predominate, and in a non-critical way. Many times, the mental health treatment is reduced to psychotropics, and the communication between health professionals and users about the treatment is deficient (Santos, 2009). The latter usually ignore the reason for or the duration of drug therapies, and have low level of autonomy to decide on their own treatment. Therefore, the qualification of the utilization of psychotropics, as well as staff qualification, have been sensitive points in the expansion of the services network (Furtado, Onocko, 2008).

The increasing use of psychotropics – greater than what is recommended in the literature (Hull, Aquino, Cotter, 2005), in terms not only of quantity, but also duration – is inadequate and associated with socioeconomic factors (Maragno et al., 2006). The prevalence of medication is associated with individuals of great social vulnerability, low level of schooling and low per capita income (Regier et al., 1984). An equal process has been observed in the European primary care, with psychotropic prescription rates that reach 8% of the population (Vedia et al., 2005). The INCB (International Narcotics Control Board) (2010) points that, globally, between 2002 and 2008 the production of benzodiazepines increased from 19 to 30 million S-DDD (defined daily doses for statistical purposes) per year. Even in municipalities equipped with mental health services in considerable quantity and quality, there are high psychotropic prescription rates. In the city of Campinas (Southeastern Brazil), in the first half of 2010, 65,758 people received prescriptions of psychotropics in the public network of drugstores, which is equivalent to 6.5% of the population (Campinas, 2010). In addition to the increasing medication of the population, its medicalization can also be perceived, a phenomenon of transformation of trivial situations into objects of medical treatment. In both situations, one of the effects that is produced is the reduction of people’s singular experiences to mere biochemical phenomena.

Another facet of this problem involves the low empowerment that the services’ users have in relation to their treatment, with little appropriation of information and the centralization of power on the health professionals, which makes the clinic become more vulnerable to the market economy and to the medical-hospital complex. According to Winter (2007), only 39% of the interviewees from primary care services in Canada were informed by their doctor of possible side effects of the prescribed medication, and only 23% of these patients were informed of alternatives to the use of psychiatric drugs (Rodriguez, Perron, Ouellette, 2008).
In this context, since 1993, in Quebec, Canada, a strategy has been developed to rescue active participation in decisions about medication: Gaining Autonomy and Medication (Rodriguez, Perron, Ouellette, 2008). In this experience, users and technicians who initially questioned the use of drugs formed debate groups. The issue quickly moved to the recognition of a suffering that preceded this use; thus, the axis of work centered no longer on the suspension of the medication, but on sharing the signification of its utilization.

The *Gaining Autonomy and Medication Guide* was designed in 2001. Targeted at users with severe mental disorders, it has given visibility to the plurality of positions regarding medication. In addition, it recognized the right to free and clarified consent for the utilization of psychotropics, as well as the need to share the decision between professionals and users. According to the Guide, the person is invited to make a balance of his/her own life to determine the aspects that can be improved, aiming at quality of life. Medication may or may not be included as one of these aspects, and information on indications, side effects, interactions and therapeutic doses are provided. In the second part, the Canadian guide proposes, for those who want it, a method of progressive reduction in medication, to be undertaken in collaboration with a doctor. Therefore, it stimulates people to search for, with the person who prescribes the drug, access to information and the necessary help to perform the adjustment, reduction in or suspension of medication. As a way of monitoring this process, the Guide includes tools for self-observation and identification of support networks, contributing to the (re)appropriation of the decision-making power by psychotropic users. One of the central conceptions in the Guide is that mental health treatment is more than the use of drugs and that people are more than a disease; therefore, they cannot be reduced to its symptoms.

Understanding that this resource would enable to tackle the non-critical utilization of drugs also in Brazil, this study aimed to, on the one hand, design the *Guia Brasileiro da Gestão Autônoma da Medicação* (GGAM-BR - Brazilian Gaining Autonomy and Medication Guide) based on the translation and adaptation of the Canadian Guide and its application at *Centros de Atenção Psicossocial* (CAPS – Psychosocial Care Centers) of three Brazilian cities; on the other hand, it aimed to evaluate the effects of the use of the GGAM in the education of mental health services workers. Finally, it aimed to investigate whether the Brazilian context would require important adaptations of the Canadian material or whether it would apply in the way it is to the Brazilian reality.

**Field of the study**

This study involved four Brazilian public universities, in the areas of medicine, public health and psychology, and was carried out in the cities of Rio de Janeiro (State of Rio de Janeiro), Campinas (State of São Paulo) and Novo Hamburgo (State of Rio Grande do Sul). The cities were chosen due to their different cultural and regional trajectories and healthcare networks. As it is a multicentric research, each field had the participation of head researchers and their teams, including Master’s students, doctoral students, undergraduate students, interns (in Psychiatry and multiprofessionals) and professionals of the mental health network of each city, and also users with active participation in all the stages of the research process (Table 1).

**Table 1:** Characteristics of the field of study.
<table>
<thead>
<tr>
<th>Field</th>
<th>Population-2010 (IBGE)</th>
<th>Number of CAPS</th>
<th>Therapeutic Home Services</th>
<th>Outpatient clinics or Mental Health Teams in Primary Care</th>
<th>Urgency, Emergency and Support Services in Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campinas-SP</td>
<td>1,080,999 inhab.</td>
<td>10 (6 CAPS 24h, 2 CAPS AD and 2 CAPS i)</td>
<td>38 homes with 206 enrolled users</td>
<td>32 mental health teams in primary care and 2 psychiatry outpatient clinics</td>
<td>2 Emergency Wards, one Psychiatric SAMU, 30 beds in a general hospital and one psychiatric hospital</td>
</tr>
<tr>
<td>Rio de Janeiro-RJ</td>
<td>6,323,037 inhab.</td>
<td>16 (11 CAPS, 2 CAPS AD and 3 CAPS i)</td>
<td>31 homes and 16 care homes with 146 enrolled users</td>
<td>53 psychiatry outpatient clinics</td>
<td>3 Emergency Wards and 10 psychiatric hospitals</td>
</tr>
<tr>
<td>Novo Hamburgo-RS</td>
<td>239,051 inhab.</td>
<td>5 (3 CAPS, 1 CAPS AD and 1 CAPS i)</td>
<td>Non-existent</td>
<td>One psychiatry outpatient clinic</td>
<td>10 beds in a general hospital</td>
</tr>
</tbody>
</table>

Source: Municipal Health Departments

**Methodology**

Initially, the material produced in Quebec (*Gestion autonome de la médicacion de l’âme*) was translated and adapted to the Brazilian reality, in a process in which all the segments involved in the research participated. This first version was used in the intervention groups (IGs), with the participation of seven to nine users in each group. Three IGs were carried out at CAPS (one in each field), and a fourth IG took place at *Universidade de Campinas* (Unicamp), with users who performed representation activities at different CAPS in the city of Campinas. The IGs occurred simultaneously in the three fields, during ten months, through weekly or fortnightly meetings, totaling an average of twenty meetings in each IG. Besides the services users, the groups were formed by: scientific initiation students; one to three interns (psychiatry or multiprofessional interns); one CAPS worker; one or two researchers as group operators – a function to which it was required, besides the handling of the research, also the perspective of a clinical handling, necessary to holding group works with people who suffer from severe mental disorders. The inclusion criteria of the users were: having a severe mental disorder, having been using psychotropics for more than one year, and manifesting the desire to participate in the group. The exclusion criteria were: refusal to participate or to sign the consent document and presence of severe cognitive limitation. To the group held at Unicamp, another inclusion criterion was the capacity to circulate in the city and in the services network, and a trajectory of political participation in the mental health field.

Each IG participant received a copy of the GGAM. Diverse reading and discussion dynamics were employed. The application of the GGAM occurred simultaneously to its critical appraisal, in such a way that suggestions of alterations to the text, sequence or to the way of using it were made by users as each one of its steps were being followed. Suggestions and comments made by users and researchers were registered in field diaries; after the IGs were concluded, they were revisited in multicentric meetings with the participation of academic researchers, workers and users, aiming at the final design of the GGAM-BR. (Figure 1)
Besides the IGs, focal groups (FG) were held with users and family members, and interviews were conducted with managers and workers, before (FG0) and after (FG1) the intervention groups, in an attempt to get closer to the participants’ experience, focusing on the following themes: use of psychiatric drugs in the relation to users’ autonomy and rights; valuation of the user’s context; capacity for managing and sharing decisions (user and team); user rights, especially concerning medication (access, information, refusal); user’s voice in the service and in the doctor/patient relationship; experience in the use of psychotropics.

The focal groups and interviews were integrally audio-recorded and transcribed. These transcriptions originated narratives (Onocko, Furtado, 2008). The field diaries of the IGs were also organized as narratives. The narratives were constructed by the individuals who had conducted each group and/or interview, and were subsequently validated by another researcher. The validated narratives of the FG0 and FG1 were submitted to the users for a final validation – which we have been calling hermeneutic focal group (Onocko Campos, 2012), based on the formulations of Ricoeur (1990) about the narrative’s function (Ricouer, 1997). The users, in the encounter with the text produced with their voices, judged whether their accounts had been portrayed there, thus contributing to the researchers’ understanding.

First, the research teams in each field analyzed the material coming from their field and organized it by voices (users, workers, managers, family members and interns). In a second
stage, a meta-analysis was performed of all the fields by voice and, subsequently, a comparison was drawn among the contributions of the different fields, complying with the hermeneutical precept of passing many times by the same place, but with a different understanding (Gadamer, 1997).

The research, approved by the Ethics Committee (CEP opinion no. 222/2009 and CAAE: 0975.1.000.146-09), respected the ethical and legal aspects implied in the work with people, especially as they are users of the mental health network.

Results

We initially present the main modifications required by the GGAM-BR, as the final product of the research process, in relation to the Canadian guide, from the adaptations introduced before the IGs until the modifications agreed in the multicentric meetings. Then, we bring the interpretation of the research voices about the experience of medication and of the application of the GGAM to the intervention groups in the services.

GGAM-BR

The Canadian material, Gestion autonome de la médicacion de l’âme, is presented in six steps and divided into two parts, which are preceded by an introduction that situates the context in which the Guide was designed and invites the reader to engage in the proposed work. The statement “I’m a person, not a disease”, initiates the first step. In the sequence (“Observations of myself”), the reader is invited to observe his quality of life: his daily routine, the conditions in which he lives (including the relationship with close people, with the place in which he lives, with the money he has), the people around him, his health, the medicines he takes, why he takes them, positive and negative effects. Step 3 (“Recognizing”) aims to recognize “basic needs”, as well as resources and support networks they can count on to meet these needs. It also approaches “my rights” and provides objective information on the medicines (prescription, families of drugs, drug interactions, desired and undesirable effects etc.). The fourth step proposes, to the reader that has arrived at this stage, that he makes a decision, based on his self-observation and on the information obtained about his medicines, adopting a critical and participatory posture in relation to his treatment. The next two steps form the second part of the Guide. In the first one, the objective is to set the conditions to start a process of reduction or discontinuation of the medicines (which includes contact with the doctor, emergency contacts in case of a crisis, survey of his social network, and acquisition of healthy life habits). In the second step, there are objective guidelines to perform a gradual reduction in the medication. The entire Guide is permeated with questions (formulated in the first person), objective information and guidelines about the approached themes.

The process of production of the GGAM-BR started with the translation of the Canadian guide. Two independent translations were made and then compared in the multicentric meetings, and the final version was altered due to the process of preliminary adaptation of the text, which was also undertaken in the multicentric meetings, with the participation of the diverse segments of the research. The adaptation attempted to take into account the Brazilian context of mental health (especially the movement of the Psychiatric Reform and the Sistema Único de Saúde (SUS – Brazilian National Health System)), and focused on the rights of the users of health and mental health services in Brazil. It also included fragments of discourses of Brazilian users regarding the experience with the medication (Onocko
Campos, 2012), replacing the testimonies of Canadian users. And, finally, it modified integrally the content of the second part of the Canadian guide, which instructed to reduce or interrupt the use of the medicine. Among other reasons, it was noted that this theme was not important for the Brazilian users. On the contrary, users who participated in this stage of the research emphasized that access to medicines was what was crucial to them, and manifested their desire to talk more to their doctors and receive more explanations about the reasons for the medication. Thus, the preliminary Brazilian version of the Guide (GGAM) moved the focus from the discontinuation of or reduction in the medicine to negotiation, and the second part of the Guide was re-written, aiming to increase user participation in the management of his treatment.

In fact, the shared management of the treatment was related to the concept of autonomy implied in the movement of the Brazilian Psychiatric Reform, which involves a collective perspective of sharing and negotiating among its different players, imbued with distinct values and perspectives. The higher number of bonds and the larger the network of relations that people establish, the greater their autonomy (Kinoshita, 1996). Thus, the adaptation of the Canadian Guide to the Brazilian context was oriented by the understanding that the decision regarding the best treatment is made within a composition between the knowledge of the user and of the reference team, in a shared management of care, an exercise of co-management that engenders autonomy processes (Campos, Onocko, 2005; Campos, 2000). The same understanding determined that the experience of the use and evaluation of the adapted Guide should occur in group works, through the IGs, in each one of the research fields.

The construction of the final version of the GGAM-BR was based on the modifications proposed to the GGAM in each field, debated in multicentric meetings with the presence of researchers, workers and users from the three fields. To process the set of suggestions coming from the different fields, the work was divided among the research groupings (Campinas, Rio de Janeiro and Rio Grande do Sul). Each group worked with the memories of the four intervention places referring to one part of the Guide and was responsible for presenting a unified proposal to the part in question, so that decisions could be made in a multicentric meeting. In this stage, the multicentric meetings had the participation of users from each one of the fields who had undergone the experience of working with the GGAM in the IGs - up to this moment, the multicentric meetings had only the participation of users who represented the AFLORE - Associação Florecedo a Vida de Familiares, Amigos e Usuários de Serviços de Saúde Mental de Campinas (Association Flourishing the Life of Relatives, Friends and Users of Mental Health Services of Campinas).

In this process, some of the words and phrases contained in the translated and adapted Guide caught the participants’ attention, mobilized intense discussions and required negotiations among the involved segments. Thus, the word “guide”, which is part of the title of the material, was questioned by the team of one of the participant CAPS, with the argument that some users, due to the characteristics of the mental illness, might view “guide” as something absolute which would determine their paths in an imperative way. Instead, they proposed to name it “notebook”, a term refused by some of the participants because they believed that the word “notebook” recalled a traditional learning context that was not coherent with the group’s proposal. The impasse was resolved only when the users entered the discussion. The concern about the word “guide”, expressed by one of the segments, found no echo in the experience they had had, and one of them argued: “the notebook comes with nothing written on it, the book comes fully written, and the guide we
read, but we also write on it, so it’s a guide”. Also, the sentence “I’m a person, not a disease” was the object of discussions, as some researchers wanted to remove it, arguing that it led to a dichotomy operated by the technicians (workers and scholars) that maybe would not make sense to the users. Then, one user gave an account on the importance of this sentence to the reflection that she could make on herself, while another user pondered that it is not possible to deny that there is a disease. Among pros and cons, it was decided to maintain the sentence. Ensuring a certain identity with the Canadian movement, which had this sentence as its motto, was one of the arguments to maintain it, but the main reason was the users’ belief that it was an important saying for them. Another term that generated an impasse was “basic needs”. During the IGs, the users, having been informed of the meaning of the term, had the opportunity to participate actively in the proposed debate. It was one part of the guide in which the users indicated what they understood as their basic needs and which ones were being met or not. However, some of the researchers in the group have been questioning the use of this concept in the area of public health for many years, because they defend that there is something beyond needs when we think about the human existence. The decision, in this case, took into account especially the researchers’ impressions (protagonism). The term “basic needs” was replaced by “what you need to live” (Marques, 2012).

Generally speaking, the final version included suggestions of additions and alterations, simplification of phrases and words and formulation of open questions – in order to allow users to express the knowledge they gained with their experience and to enable that, with the provision of the pertinent information, exchanges and reflections were established among the participants in an intervention group with the use of the guide.

The need of cultural adaptation called our attention, especially with regard to three aspects: citizenship rights, the impact of medication on loving and sexual relationships and the access to work and income generation. Concerning the first aspect, the non-recognition of oneself as the subject of rights required further details to the Brazilian users, regarding what was configured as their rights in the context of the treatment, from, for example, the right to access the leaflet of the drug that was administered to them to the right to refuse the proposed treatment. As for the second and third aspects, the Brazilian users insisted on the importance of these themes (loving and/or sexual relationship and work or income generation) and on their inclusion in a prominent way in the Guide, as the illness and the medication deprived them of the possibility of fully exercising these aspects of life. In relation to work, they valued not only the perspective of financial gain, but also the experience of feeling useful. Regarding relationships, they took into account both their affective and lasting dimension and the conditions for a satisfactory sexual performance.

The final version of the GGAM-BR also required an important adaptation of the written structure: short and simple sentences that were easy to understand were valued. This aspect emphasizes the distance between Canadian and Brazilian users concerning the educational profile.

The different voices in the experience of the IGs

Users
The lack of information about the medication permeated all the FG0 narratives. The users reported difficulties and fear to talk to the doctors, seen as the ones who have the authority. After the IGs (FG1 narratives), they showed that they had acquired more knowledge about
what they take and what for and started to recognize that they, too, have authority (deriving from experience), not only the doctors. However, they continued to believe that the professionals are superior and have the power to decide about the treatment. They questioned especially the way in which they are assisted, and identified reasons for the difficulties they face, focusing not only on the doctor’s posture, but also on the instituted work dynamics. And, in all the fields, during the IGs, there were users who, mobilized by the group discussions, attempted to talk to the doctors, aiming to perform adjustments in the use of some medicine.

Concerning the personal experience related to the medication, in FG0 the users identified that the medication helps to combat the diseases and enables the performance of daily activities, but they emphasized the annoyance they felt due to the side effects, as well as the concern about the large amount of drugs they use. In FG1, they manifested that the medication could be reduced, but not discontinued. The priority of the drug prescription in the formulation of the therapeutic project persisted, even though the narratives mentioned its limits and damages.

In FG1, an interest in the theme of rights was perceived, which had been absent from the FG0 discussions. They mentioned the recognition of the right to participate in the treatment, to see their medical records and to obtain information. After the IGs, the users tried to participate in the management of their services more frequently. Moreover, they stated that the GGAM helped to amplify the discussion about their rights beyond health, including life conditions and access to housing.

The users valued the role of the family, friends and of the CAPS in supporting the treatment. However, they mentioned that they face stigmatization on the part of these same players. Two aspects emerged as determinants of the stigma situations: being seen as a psychiatric patient and experiencing the loss or reduction in the capacity for dealing with the daily situations of their lives.

**Workers**

Differences among the professional categories participating in the IGs made the voices of this segment become particularly heterogeneous. All the workers reported that the decisions about the therapeutic project are made by the team and that they respect what has been agreed, sustaining this positioning with the families and users. However, it was also mentioned that the decision about the adequate medication is made exclusively by the doctor, in a non-shared way. The professionals who are not doctors reported not having knowledge about the medication and its effects, and manifested, on this theme, less elaborate doubts than those of the users themselves and of their families. Nevertheless, they criticized the fact that the relationship between doctor and patient is limited to the drug prescription and to the patient’s duty to accept it.

As for the inclusion of the user, of his context and territory in the process of shared clinical management, in one of the fields it was emphasized that the team had difficulties in performing this inclusion. In another field, however, the user’s context was considered an essential aspect to be taken into account in the treatment. The doctors stated that the valuation of the context – when this can be done – changes the way of medicating, as it expands the understanding about the user’s life.

Generally speaking, the psychiatrists agreed that, in case the user insists on not using psychotropics, he must be heard. However, one professional disagreed, defending the medical hegemony and Psychiatry’s knowledge, and alleging that only the use of drugs can
prevent crises. In the service in which this professional worked, there was an institutional rule according to which the user who refused to take the medication or to participate in the activities indicated in his therapeutic project would be disconnected from the service.

The theme of rights was not much commented by the workers, who just focused on the choice of taking the medicines or not, accepting the proposed therapeutic project or not. Sentences like: “the right not to use medication cannot be regarded as if the patient could do whatever he wants” indicated the difficulty in dealing with a population that is more conscious and critical concerning their rights. There was the recognition that, at the CAPS, the collective spaces that were adequate to the questions about rights, like general assemblies, had little or no participation of their workers; therefore, the theme of rights was not incorporated into the services’ routine.

Family members

There were differences in the way in which this segment was accessed in the fields, due to contingencies of each place. In Campinas, the FG0 had the participation of family members in the two IGs. In Rio de Janeiro, only one group was held at the beginning of the process and, in Novo Hamburgo, groups with family members were not held. The narratives expressed the desire of knowing better and participating more actively in the treatment proposed to their relative. The family members resented the absence of spaces where they could be heard and where decisions could be shared. They considered that the closeness among the team, users and the family inhibited possible complaints on the part of the family members regarding the provided care. This care was seen as a favor, not as a right, which can be linked to a type of bond that has a paternalistic character, which is common in the Brazilian society.

About the experience of the medication, they manifested doubts and uncertainties concerning either its indication (“why do schizophrenics take medicines for epileptics?”), or the effects, in old age, of its prolonged use. They also emphasized the family’s suffering due to the mental disorder that affects one of its members, and they agreed about the importance of the offer of psychotherapeutic treatment to the family group.

As for the influence of family relations on users’ process of becoming ill, we verified the denial of this influence and also its recognition, passing by the hypothesis of hereditary diseases. The denial of any correlation between the quality of the family relations and the mental disorders was recurrent in the narratives.

Concerning the valuation of the life context, they agreed about its importance for the users’ wellbeing. However, sometimes they emphasized a context of relations that gave importance to the religious spaces (Rio de Janeiro’s field), and sometimes they mentioned social meetings and events that were not necessarily connected with religion (Campinas’s field), which may point to cultural and political differences between the cities-fields of the present study. Such differences between the fields also emerged in relation to the theme of users’ rights: while one of the groups (Campinas’ field) revealed to have knowledge about the matter - although they emphasized that there was a distance between knowing about a right and being able to truly exercise it -, in the other group (Rio de Janeiro), the theme raised little conversation, revealing lack of interest on the part of a significant portion of the participants.

Managers
The contact with the management of the different services respected the availability and the management arrangements of each field: two focal groups were held with the Management Board of the CAPS of Campinas; two interviews were conducted with the manager of the CAPS of Novo Hamburgo; and, in Rio de Janeiro, only one interview was conducted with the CAPS’ manager.

There was a consensus about the importance of the service’s decision-making be constructed with the participation of the team members, but they did not mention an effective participation of users and their families. In this sense, only the users’ rights that do not generate great confrontations with the team were recognized: the access to the services is a right; the refusal to take the medication, not always.

The narratives manifested ethical and clinical concerns, regarding the construction of spaces that potentialized the bond with the user when he makes decisions about his medication without negotiating with the team. They mentioned management strategies in the cases of users who suspend the medication. They referred to users who, having decided not to take medications, could remain under treatment (without medication) with the team, and also to users to whom the medication was imposed as a way of guaranteeing their physical integrity or that of the people around them. Furthermore, they mentioned strategies to guarantee and aid the use of the medicine for those who did not do it because of difficulties in handling the tablets: daily doses at the service, individual doses to take home, etc.

Resources to reduce the distance between the workers and the users’ reality were valued, like the home visits, although these resources are almost completely operated by the nursing team.

According to the managers, a group that aims to discuss the medication favors the questioning of forms that have already been naturalized in the relationship with the users and, at the same time, it constitutes an action on the border between care and control.

**Interns**

The narratives of the FGs of Campinas (four Psychiatry interns of Unicamp, attending the first year) and Novo Hamburgo (two interns of the Public Mental Health program of UFRGS, also attending the first year, who had just started Internship) were considered.

All the interns were of the opinion that, when the user interrupts the medication, this should not cause the interruption of the treatment. On the one hand, they stated that, in these cases, it is necessary to rethink the proposed treatment, but on the other hand, they indicated as the work direction the search for strategies that led the user to resume taking the medication.

In the theme of co-management of the therapeutic project, multiprofessional interns reported it to the empowerment of the team, and not of the user, while the psychiatry interns defended the inevitability of the asymmetry in the doctor-patient relationship, arguing that the doctor has a (technical) knowledge that the user lacks.

All of them mentioned the importance of the family’s involvement and monitoring. The psychiatry interns, however, brought reflections that were specific to the practice of the person who prescribes and differentiated the psychotic users from the others in the question of autonomy, conditioned, in this case, to the quality of the patient’s “judgment”. On the other hand, they manifested their uneasiness in relation to the side effects that affected important aspects of the patient’s life. They stated that, in their education, they were led to consider the user’s context – family, house, way of life, culture and history – but in a limited or disconnected way from experience.
In FG1, multiprofessional interns expanded the notion of context, understanding that the family and the user’s entire network of relations in the territory are part of the health-disease process; the psychiatry interns, in turn, mentioned the importance of the context for drug prescription, when it is necessary to evaluate whether the user has economic conditions to acquire some specific medication. There was a discrepancy in the narratives about the theme of rights between the two groups of interns. Psychiatry interns stated, both in FG0 and in FG1, that the doctor and the family have, by law, the right and the obligation to decide against the user’s will, when it is evaluated that he does not have autonomy and puts his life and/or others’ lives at risk. However, they argued that the user has the right to complain about the doctor’s conduct, and, in FG1, they could specify the places where they can do this. As for the multiprofessional interns, although they recognized that the users have rights in relation to their treatment, they ignored which legislation deals with these rights. All of them recognized the IGs as an adequate place for hearing, in which they had access to aspects of the users’ lives that they did not know about and which they started to take into account in their practice. The multiprofessional interns understood the users’ experiences as knowledge to be included in the therapeutic project. The psychiatry interns, in turn, mentioned that the GAM experience provided them with a more open hearing, attentive to the user’s context, but did not mention his participation in the construction of the therapeutic project (Otanari, 2011).

Discussion

The two years of experience and adaptation of the GGAM have offered us the opportunity to deepen the discussion on barriers to the use of psychotropics in the Brazilian CAPS. We could unveil some subtle (and not so subtle) forms in which the services control the users and their bodies and the difficult access to citizenship and to the full exercise of rights. During the research, fundamental differences between the Canadian and the Brazilian social-cultural scenarios obliged us to focus our efforts on the work of adapting the Guide to the Brazilian reality. However, we could verify that the GGAM-BR may become an important tool in the qualification of the use of psychotropics in the CAPS. The diverse voices that we heard reveal differences that say something about their position as group of interest or narrative post (Onocko, Furtado 2008), and the persistence of a stigmatizing view about madness, which permeates workers, managers, family members and the users themselves – the latter, in all the fields, were surprised at first and then appropriated their rights, as a consequence of the work with the GGAM. The lack of formal spaces in the services to provide information for the users about the medication was naturalized, in a first moment, by the users themselves. Teams and managers also naturalized the doctor’s exclusive competence regarding these questions, which configures one more challenge in the search for a better quality of the assistance, of integral nature. This lack of qualification and even of interest in the medication on the part of the professionals who are not doctors becomes a barrier to the qualification of the assistance, and indicates a thematic field that is not discussed in the CAPS. This contrasts with some international experiences, including the one that originated the instrument that we have translated and adapted (Rodriguez, Corin, Poirier, 2001).

Considering that the medication mentioned here does not cure; rather, it controls the symptoms, it is important to ask: in what moment would its use become “optimal” for a
given subject who is suffering? Which symptoms should be suppressed or relieved and to which degree? Which undesired effects would a given subject be willing to tolerate and for how long? And how can we answer these questions without the participation of the user? How can we work adequately with the pharmacological resource without having some level of analysis of the experience of its use? How can we approach this experience, which belongs to the other, without opening ourselves to his words?

**Final Remarks**

In the present study, we verified a significant lack of spaces for information and reflection on the medication at the CAPS that participated in the research, as well as the low qualification, generally speaking, of the workers of these services to support users in relation to such a relevant theme that has such a great impact on their daily routine. We could also reveal the tension or contradiction prevailing in the services, with the persistence of the stigma and of tutelary managements that still lean on the supposed “lack of rationality” of critically ill patients. The GGAM proved to be powerful to institute spaces where it is possible to talk about the medication, and called the attention of the team and of the managers about the importance of this theme. Coping with it is not restricted to the clinic, as it has ethical and political consequences. It reassured the rights of the users, bringing their discussion to light among users, their families and teams. And, finally, it also provided, for the relationship with the user, a dynamic approach, plastically adapted to the singular moment of the life of each individual.

The relevance and comprehensiveness of its effects indicate that the GAM is not reduced to the use of the guide as a technical instrument, as a protocol of steps to guide the discussion about medication and users’ rights. The GGAM-BR should be understood as a complex device, which involves the mental health service as a whole, in its several dimensions, from policies to management, to care, ambience and social control, considering health care as a relational process.

Thus, we are interested in monitoring the way in which the main product of this research will be henceforth utilized, in agreement with the ideas and the work process that originated it. The GAGM-BR resulted from a collective construction, in which the trajectory of the Canadian group was added to that of the diverse Brazilian research groups that participated in the process, in interlocution with managers, workers, interns, users and their families. We intend that its use continues to occur in the services and in groups, in the perspective of the active participation of all the individuals involved, summoning all the players to the dialog. With this concern, after this research we initiated a new investigation at different CAPS in Campinas, in the metropolitan region of Porto Alegre and in Rio de Janeiro, in intervention groups with the use of the GGAM-BR. Our purpose was to validate this instrument and to build strategies to disseminate it in the mental health services, preserving its participatory and co-managerial character – among these strategies, the writing of a manual for the use of the guide. To this purpose, we considered that it is fundamental that the Guide is available at the spaces for the education of health workers, like medical and multiprofessional internships and permanent education processes.

To conclude, as it was a qualitative research, we do not present its possible biases; rather, its limitations. Among them, the fact that we could not have a field in the North/Northeast region of Brazil has not allowed us to cover a greater diversity of the cultural and political trajectories that compose the national territory. Also, the participation of interns in the
GAM groups was smaller than what had been planned, due to the difficulty in conciliating the research timetable with that of the respective internships. In addition, some differences among the fields point to the complexity and the challenge of conducting a multicentric qualitative research, as the standardization succumbs in view of the singularities of each field. Thus, the conditions of entrance into the services, of recruiting participants, among others, necessarily varied according to the configuration of the services in each city and to the researchers’ negotiation capacity. However, the findings were so coincident in relation to the aspects pointed as results that we considered to have achieved a saturation degree that was adequate to the object of this investigation.

Finally, we highlight that the adaptation of a material that is internationally recognized does not happen without a long development process. Mere translations and tests may not serve to adapt these instruments to the Brazilian reality or to that of other developing countries. Factors like level of schooling and income, degree of validity of rights in terms of citizenship, cultural issues like the value attributed to sensuality, as shown by our research subjects, indicate that qualitative adaptations have a path to be explored in public health. In this sense, it is important to consider that perhaps the incorporation of advances produced by our colleagues from more developed countries should always require a certain dose of anthropophagy.

Collaborators

The authors worked together in all the stages of the manuscript. Although the first four authors started to outline the paper, subsequently all of them contributed to it, as the paper was read and discussed among all of them during meetings and in e-mail lists.

References


1 Departamento de Saúde Coletiva, Faculdade de Ciências Médicas, Universidade Estadual de Campinas. Rua Tessália Vieira de Camargo, 126, Cidade Universitária. Campinas, SP, Brasil, 13083-887.

Translated by Carolina Siqueira Muniz Ventura.