Short Communication

Narratives of Users with Severe Mental Illness on Psychotropic Medication Use: Stigma and Identity

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Abstract

This study took place within a large Brazilian city, with users of Psychosocial Care Centers (CAPS) with the objective of evaluating the effects of experimentation of the Autonomous Medication Management guide (GAM) in the relation among these users, their treatments and their political participation. This instrument was originated in Canada from the acknowledgement of the lack of conscious use of medication during mental treatment, and recognition of the symbolic value of the medication in the users’ lives. The guide respects the right to free and informed consent for medication use and the necessity of shared decisions between professionals and users. The use of the guide was proposed by means of an intervention group including mental health users of who carry severe mental disorder and have political participation in the field of health. Focus groups and in-depth interviews were also conducted. The transcripts were transformed into narratives through the extraction of their argumentative cores. The categories of analysis were: subjects of extreme suffering experiences; experiences with medication; user rights; political participation and militancy. After the experimentation of the GAM guide, users demonstrated a wider knowledge of the medications they take, and began to acknowledge authority in themselves. They questioned the way they were treated and some sought to talk to their doctors aiming at a change in treatment. Also, they strengthened their participation as mental health militants.

INTRODUCTION

In Brazil, the Psychiatric Reform (PR) consolidated a new mental health policy not centered on the disease, but on integral health care. However, there are still challenges to overcome the biomedical model and the psychiatric hospital, on which health care is still centered [1,2]. Within these models, there is a relation of dominance of the professional over the patient [3,4] and a scarce construction of horizontal care devices and more autonomous promoters [5].

In addition, there has been a rising medicalization [6-8] of the populace, a phenomenon of transformation of common situations into objects treatable by medicine and one of the produced effects is the reduction of singular experiences to mere biochemical phenomena. These factors favor the low participation and little knowledge of the users in relation to their respective treatments, which produces an abusive and counterproductive consumption of biomedical services, creating excessive dependence and alienation [9]. There has also been a strong process of “medicamentation” [10-14]: problems that, in the past were treated in their complexity and singularity today are classified as diseases, deficits or disorders and (in) appropriately medicated in order to “fix” the affliction.

It is in this context that there has been a significant increase of psychoactive drugs prescriptions in Brazil and the world [15-19]: the use and prescription of such drugs has increased, not only in quantity but also in duration of use, for periods sometimes longer than that recommended by the specialized literature [20]. There is a wide and uncritical privilege of pharmacological treatment conducted by health teams, which, besides health problems, intend to take care of social and economic issues by means of medication prescription [21].

The matter in question is not the use or non-use of psychiatric medication, but the way it is prescribed and the significance of this use for the users’, who barely or not at all participate in decisions on their treatments. The users’ participation often restricts itself to the mere act of information of their symptoms, putting aside the unsaid multiples of the suffering [22-24]. The experience of
sickness [25-29] and the significance of the use of psychotropic medication for the person involved continue to be rarely taken into consideration [30-32], producing a new type of exclusion in relation to severe patients, since they can never discuss the kind of life they are willing to take and what is the place in their lives they wish to give the medication with the professionals who treat them.

The reformist movements in the area of mental health seek to empower bearers of mental disorders and the addition of their contractual power in society by means of psychosocial rehabilitation proposals that go through the exercise of autonomy and citizenship in an effort to recover these people who have been stigmatized for centuries [33]. However, we asked ourselves in what level has it been possible to increase the contractual power when difficulty is found, still present in the services, for removing the disease from focus and effectively consider the experience of sickness and its relationship with the use of medication. Some studies [34-37] determined the asymmetry present in the relations between professionals and users, which point to processes that still constrain the protagonist and favour the continuation of the historic passivity of mental health users. These studies also show that disputes of interest, hierarchization of power relations and solidification of the manner of participative process conduction can reduce or make impossible the possibilities of protagonism in mental health. These issues evoke the importance that mental health users need increasingly more access to information about their rights, but also about empowerment devices, whilst understanding empowerment as an exercise of power sharing [38].

While recognizing the context uncritical medication use in mental health treatment, as also the symbolic value of the medication for those who use it, a new interventional approach named *Autonomous Medication Management* (GAM) developed in Canada since 1993. The ethical principle of this approach is to defend and support people weakened by the experience of mental health problems and, sometimes, unfortunately, also by the kind of offered mental health treatment. The actions and interventions of the GAM aim at the creation of spaces where the users can express themselves and decide on their treatments and quality of life, benefiting an active relation and not passive in relation to pharmacological treatment [39-41]. One of the tools used by the approach is the GAM Guide. The Guide respects the right to free and informed consent for the use of medication and the need of shared decisions between professionals and users and one of its objectives is to make information about medications available (side effects, therapeutic doses, etc.). Therefore, we experiment this instrument and evaluate the effects of the experience in a group comprised of mental health users who have a record of political participation in this area.

**MATERIALS AND METHODS**

The use of the guide was proposed by means of an Intervention Group including mental health users who carry severe mental disorder and have political participation in the field of health’s right fights in a large Brazilian city. The aim was to evaluate the experimentation effects of the guide on the relation between these patients and their respective treatments, and on their militant actions. The Intervention Group was conducted through bi-monthly meetings between researchers and users, in a total of 18 meetings. The group was put together through an articulation of the researchers alongside members of an association of mental health users, families and friends of users of the mental health network of the mentioned city. The inclusion criteria were: to suffer from severe mental disorder, to use psychoactive medication for more than one year, will to make part of the group, be able to have good movement in the city and in the mental health network and to have a record of political participation in mental health. The exclusion criteria were: refusal to participate or severe cognitive limitations. Focus Groups were also conducted with the users, before and after the Intervention Groups, seeking to become more familiar to the experience of the participants in relation to psychoactive medication use. After the first focal group, the speech transcripts of each one, narratives were put together by isolating the argumentative cores. These narratives were presented to the participants of the group (hermeneutic moment) for a final confirmation through reading the constructed narratives [42, 43]. This allowed the changes noticed as effects of the Intervention Groups to be discussed encouraging the validation and participation in data analysis. In-depth interviews were also conducted with the seven users. A constructivist and interpretive paradigm was used, inserted within the qualitative approaches. In order to analyze and interpret the data, the construction of narratives was done as proposed by Ricoeur [44-46] and used by Onocko Campos and Furtado [44]. Questionnaires and quantitative indicators were not used.

**RESULTS AND DISCUSSION**

The categories identified in this study will be presented below.

**Patients of extreme experiences of suffering**

In this category a tension between the construction and reproduction of an ill identity versus the legitimacy of the singularity of user experience appears. In general, users showed the diagnosis of the disease as the recognition of their experience of severe suffering, which helped them to give positive meaning to the experience, since family and society in general began to see them as people who suffer. However, often this ill identity would always make them see themselves bound to a place of incapable subjects or a discourse that makes them hostages of many attributions that mental illness carries. If on one side, the mental health user conditions permit access to symbolic goods and social benefits; in other aspect they also reinforce the stigma [47]. In the struggle for assurance of a legitimate place in society, the diagnosis offered by medical discourse as recognition of the experience of suffering recalls the construction of identity that they are mentally ill. When the disease becomes the identity, it ignores the uniqueness of the radical suffering experience that afflicts each one of these people, and therefore, the subject becomes an ideal patient, standardized, without history, inserted within a relation of dominance leaving only the affirmation of the necessity of medication, in the absence of contextualizing the society in which that necessity (of so many medications) is imperative. The recognition of which these users spoke of seems to be connected to symptom identification which must fit into
Central etc. It is a paradox concerning the coexistence of the civil rights benefits, special job schemes, free pass on public transport and illness and to retrieve their civil capacity to manage their lives. Users struggle against segregation and stigmatization of mental and competence as a criterion for access. On behalf of civil rights, social rights may conflict and weaken other struggles in the field of mental health relates to the fact that claims for special empowerment strategies and specific claims [48,49]. However, despite the researchers’ view based on the users’ narratives, in which the appointment with the professional is a space of little exchange, for the users the act of being diagnosed and medicated seemed to be taken as a response to the recognition of the singularity of the experience of suffering. “A person who does not believe in the illness, who says you don’t have anything, is worse” (sic).

Experiences with medication

Although the majority of users established an apparent reaction of submission to medical prescription, many times they also auto-managed the use, against the medical prescription: they controlled the dosage, increasing or decreasing it as they saw fit and would suspend the use in situations they judged it would be favorable. After the IG meetings, users realized how inappropriate they were for the medication they were taking and its effects. Also, they realized how they had gotten used to the lack of availability of professionals who work at the CAPS to ask questions, criticize and show their dissatisfaction in relation to the treatment. They showed a wider knowledge of what medication they take and what does it do. Also, they began to recognize the knowledge gained by their experience with the medication, not only the doctors’ knowledge. They questioned the way they were treated. Some users, encouraged by the group discussions, sought to talk to their doctors, aiming at adjustments of some medication.

Mental health user rights

The mental health users realized they had many rights, but did not make use of them effectively. This discussion gained emphasis when connected to the acknowledgement of the right to labor and to access social monetary benefits for being ill, stressing how much the ill identity becomes prejudice and creates difficulties when accessing the labor force. They believe that one right eliminates the other: if they receive the social benefits, they cannot work; if they can work, they cannot receive the benefits, even if the payment they get is considered insufficient for livelihood.

The topic of rights and citizenship has been appropriated by contemporary social movements for the formulation of empowerment strategies and specific claims [48,49]. However, an issue that has been relevant to the movement of users in the field of mental health relates to the fact that claims for special social rights may conflict and weaken other struggles in the civil rights field, the fight against discrimination. Therefore, the stigma eventually strengthens the conventional medical model and competence as a criterion for access. On behalf of civil rights, users struggle against segregation and stigmatization of mental illness and to retrieve their civil capacity to manage their lives. Although, they fight for special social rights also, as pecuniary benefits, special job schemes, free pass on public transport and etc. It is a paradox concerning the coexistence of the civil rights and social rights struggles. A survey of mental health users of a large Brazilian city [50], shows that users accessed their basic rights from the illness process. The paradox is precisely the defense of equal rights and, at the same time, individual ones, reconciling the universality of civil rights with the specificity of certain segments of the population, as users of mental health, considering what makes them unique.

Political participation and militancy

In general, the users showed to value participation not only in their treatments, but also in their political lives. An important space of militancy recognized by the Group was the Association of which five of the seven members of the IG are part. Users recognized it as a space of belonging and support as well as a supervisory function and militancy against the asylums and psychiatric practices. They said that during the development of the research they learned to value themselves, since during the process they felt as if what they had to say was important and pointed out the desire to take the discussions initiated by the guide to other users of the mental health services network by means of a project they built with the objective of creating discussion groups of mental health, using the same GAM approach.

CONCLUSION

The experience with the GAM Guide pointed out a certain naivety and docility of the users in relation to their treatments. The importance of investment in sharing spaces between users of an “experiential knowledge” of their experiences of illness and use of medicine devices was pointed. Our study also reinforced the GAM Guide as a device with the ability to empower users to their treatments, highlighting the importance of the GAM as device that can enlarge the autonomy and the self-management of severe mentally ill patients [51].

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