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Gaining Autonomy & Medication Management: methodological innovations in the public health field


Gestão Autônoma da Medicação: inovações metodológicas no campo da saúde pública

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This dossier presents case reports on implementation and monitoring of the effects of the Gaining Autonomy & Medication Management (GAM) strategy, highlighting the methodological challenges faced by the studies conducted in the mental health field using the strategy, the device, and the GAM tool. GAM is a strategy in the mental health field initially developed in Quebec, Canada, in the 1990s, based on group devices using the *Personal guide for Gaining Autonomy & Medication Management*, formulated by associations of psychotropic users to promote discussion and production of autonomy in the use of psychiatric drugs. The theme of autonomy is central in the renewal movement of mental healthcare models, encouraging initiatives such as the psychosocial care that guides the public health system in Brazil.

In a global scenario of increasing medicalization of the population, especially regarding the use of psychotropic drugs, the end of the 20th century in French Canada had an interesting problematization movement of psychiatric drug use. As a social movement of users, this resistance to medication practices was justified by the lack of information about the medications prescribed to people with mental illness; by the undesirable effects of psychotropic drugs; by the suffering that usually remains despite the pharmacological treatment; by the difficulty of the users of the medication treatments to resume their capacity of social contractuality and labor market insertion; by the users' desire to live without remedies. However, the sudden and unassisted interruption of medication has led many people to be admitted to hospitals where they came out more medicated than before. Alternative mental health services and human rights

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advocacy groups in Quebec have engaged in this critical movement to the biomedical care model.

To respond to the legitimate need for information about psychotropic drugs, in 1995, the Association of Care Groups in the defense of Mental Health Rights in Quebec (AGIDD-SMQ) published the *Critical Guide of Remedies of Soul*, a text directed to people who use this type of medication and that provides information so they can sign the informed consent form for psychiatric treatment. In 1997, AGIDD-SMQ elaborated the *Other Side of the Tablet*, directly inspired by the *Critical Guide of Remedies of Soul* and disclosed it in several regions of Quebec, primarily with those diagnosed with mental health problems.

Since 1999, Quebec's alternative mental health services have begun to develop GAM experiences. Members of Quebec's alternative Mental Health Services Group (RRASMQ), a hundred services from different regions of Quebec and with diversified care models, have pledged to use GAM in their practices. The respect to questions critical to "medicalization" practices (Caliman; Passos, Machado, 2016) and to the needs of the diagnosed individuals guides these practices. A collective space for discussion of medication is opened, and a clinical-political guideline for mental health treatment is defined. To value users experience and knowledge, foster their protagonism in treatment management, experiment with other forms of care beyond medication were alteration vectors of both the care model and the management of mental health practices (Onocko-Campos et al., 2013).

In 1999 the pilot project was carried out with ten members of the alternative services of RRASMQ, with the collaboration of AGIDD-SMQ. Researchers from the Mental Health and Culture Research and Action team (ÉRASME) evaluated the implementation of GAM (Rodriguez del Barrio; Corin; Poirrel; 2001). It was within this pilot project that *My Personal Guide* emerged, a booklet containing texts and questions to assist users of psychiatric treatments in the problematization and modification of their relationship with psychotropic drugs.

The adaptation of the GAM Guide to the Brazilian reality resulted from the partnership between Brazil

and Canada with the seal of Community-University Research Alliance (Aruc) of the University of Montreal. Aruc supported studies on the subject of mental health and citizenship, the training of researchers, and the transfer of technology to the community and health services from multicentric and international projects. In 2009/2010, the multicentric project Evaluative Research of Mental Health: Instruments for the Qualification of the Use of Psychotropic Drugs and Human Resources Training: GAM-BR was developed, elaborated by the Universidade Estadual de Campinas, Universidade Federal Fluminense, Universidade Federal do Rio de Janeiro and Universidade Federal do Rio Grande do Sul (CNPq - 2009), which had as objectives: (1) translate, adapt and test, in Psychosocial Care Centers in the cities of Rio de Janeiro (RJ), Novo Hamburgo (RS) and Campinas (SP), the *Gaining Autonomy & Medication Management Guide* (GGAM),¹ with patients with severe mental disorders; and (2) to evaluate the impact of this instrument on the training of mental health professionals (psychiatrists and non-medical professionals).

GGAM was translated and adapted to our reality, with the aim of strengthening the Brazilian psychiatric reform (Campos et al., 2012). In the public health field, we have discussed the advances and challenges to be faced for the continuity of the democratization movement of health practices according to the ideals of the Brazilian National Health System (SUS). The constituent process that culminated in the Constitution of 1988 had a strong participation of the Brazilian sanitary reform, a movement in the health field that fought for the democratization of health. The proposal was the alteration of care and management models of the health work process, decentralization and social control in the management of the public health system, respect for the rights of health services users, considering the knowledge involved in the health production process. The constitutional text of 1988 advanced in the defense of the right to health, preparing the institutional ground for the SUS's definition in 1990. The universality of access to health goods, the integrality of the health system and

1 An English version of the GAM guide can be found at <<https://bit.ly/36AydxF>>.

the fairness of the offerings of this system became the basis of the democratization of health in Brazil that exceeded the authoritarian shadow of the years of the civil-military dictatorship.

As to the public mental health domain, the psychiatric reform and the fight-anti-asylum movement were the theoretical and militant arms of the Sanitary Reform in the field of care practices with those diagnosed with mental disorders. Mental health care in the territory became not only a motto, but, above all, state politics from the 1990s, which indicates a tune with what was experienced in Quebec. Although the movement of the psychiatric reform was important in the alternative services, in Brazil, the bet was in the substitutive services to the asylum that compose the public network of psychosocial care. This difference, however, does not compromise the harmony between our experiences of changing the model of mental health care aiming at the autonomy and protagonism of users.

We are certainly advancing in the changes. However, the topic of medication is still a blind spot or the unreformed face of psychiatric reform (Sugimoto, 2012). It is verified that, in the daily life of mental health services (Caps and ambulatories) or that has any interface with them, as is the case of primary care (family health and Street Outreach clinic team), there is still a centrality of drug treatment and, consequently, medical prescription, health practices that are predominantly hierarchical, specialized and with low inclusion of users' experience.

The theme of participation, fundamental to SUS, gains importance in this context, whether in relation to the change of care and management models in the health work process, or in the formulation of methodologies of knowledge production in the health field, including the perspective of the subjects participating in the organization and analysis of the research data. The university, in its commitment to the expectations of society, is called upon to develop methodologies of knowledge production at the height of the democratizing aspirations of SUS.

Hence the bet of GAM researches in participatory methodologies in which we designate participatory research-intervention. The co-authors of this dossier have been working on the construction of interventional and participatory methodology, most of them as members of the research group Enativos: Knowledge and Care, linked to Universidade Federal Fluminense. The Enativos group were initially focused on the cognition field, particularly investigating the "false memories," a phenomenon that puts into question the strictly representational character of cognition. In our investigation, we understand that this cognitive phenomenon forces us to include, as data from the study and as a perspective of analysis of these information, the alterity of the experience of the one who remembers, which prevents an easy separation between what is a true and what is a false memory² (Passos et al., 2018; Silva et al., 2006, 2010). The inclusion of the alterity of the subjects' experience led us to build the methodological approach of participatory research-intervention, which proved pertinent to the public health field.

When we turn our studies to the GAM proposal, we also encounter a problem related to experience and alterity: the individual and institutional processes related to the use of psychotropic drugs - the prescription, the dispensation, the experience of their clinical and collateral effects, the definition and adjustment of dosages, that is, the management of medication practices - are carriers of controversies and singularities that hinder (and problematize) the constitution of universal judgments. As we approach the experience of using psychotropic drugs, we perceive that this is a carrier of alterity, so that knowledge cannot be restricted to the established and stereotyped formulas common in users and/or workers of mental health services such as Caps, for example: the medicine is the best (or the only) treatment; the knowledge about the remedy is always on the doctor's side; such remedy is necessarily good or bad. Users often possess a knowledge, anchored in experience, about non-pharmacological actions that help them feel better, about ambivalent effects of

2 In false memories, a subject has a memory that, objectively, does not correspond to what was agreed in the social collective as having happened (Stein, 2010). However, the account of remembrance is true, as those who narrate tell the truth about their mnemonic experience; it is not perjury (Loftus; Hoffman, 1989).

remedies, about the most appropriate dosage, but this knowledge is usually not recognized (not even by users themselves) and ends up not counting for treatment. The ethical problem, related to the inclusion of the alterity of the experience with psychotropic drugs, unfolds in a methodological problem related to the practices of health production, as well as the practices of knowledge production in health.

The challenge is to leave and abandon the abstract of the dualistic and generalist positions, as Varela (2003) would say, to reenchant the concreteness of experience. The experience involved in medication practices often presents a polysemia that prevents the constitution of a single reference to represent it. The approach and inclusion of this polysemia requires, therefore, another cognitive policy (Kastrup; Tedesco; Passos, 2008): knowledge not as representation of reality *a priori*, but rather as co-creation or coemergence of oneself and the world, as the enactive approach affirms (Varela, 2003). GAM presupposes this enactive cognitive policy. The questions that compose GGAM, for example, do not aim to obtain correct answers, but rather open and broaden the points of view regarding the use of psychotropic drugs. It is necessary to lean towards the experience to listen to what is shown not as an index of an object to be represented, but as alterity that interposes us and draws us from the centrality in the production of knowledge - leaving an hierarchical and vertical attitude (typical of subject-object relationship), to lateralize in a subject-subject relationship (Passos; Eirado, 2009).

In the participatory research-intervention methodology that we built, the relational or interactive dimension of the study gains primacy. The act of researching is necessarily linked to the act of intervening in the investigated reality, based on the appreciation of the points of view of the participants who leave the position of objects of knowledge for the position of cognizant subjects. Researchers and participants are implicated, which gives a sense of care to the research - both mutually transform each other during the investigation process, they are coemergent effects of this process. Knowledge is defined by its collective autonomy (Passos et al., 2018), because it takes place in the reception of alterity, which is equivalent to recognizing the

interdependence between me and others: being autonomous is not acting independently and alone, but rather considering the bonds that constitute us. The research process is, at the same time, participative and interventive. Participation is not limited to the choice between options already given, nor is restricted to the spaces previously defined for this purpose, but it presupposes the manufacture of new alternatives, reinventing the limits of oneself and the world.

GAM is part of this participatory and interventive bet in the mental health field, where the challenge is the democratic inclusion and fostering of the protagonism of health services users. These individuals diagnosed with mental illness are often deprived of their condition as subjects of rights, citizens of social contractuality (Kinoshita, 2001). To ensure participation in the management of the treatment itself does not necessarily represent self-management or independence in relation to health services. The co-management proposal (Campos, 2000; Passos et al., 2013) in the health production processes allows the verticality (hierarchy in the relationship with workers themselves and between them and the users) and the horizontality (corporativism) give way to the transversality in the institutional relations (Passos, 2017; Passos; Carvalho, 2015). To transversalize is to change the communicational pattern in institutions by putting different side-by-side in the management of a common good. If the hierarchy distributes the different ones in a vertical relationship of command and obedience and if the corporativism gathers the equals side by side in defense of what they possess, the transversality presupposes lateralizing the different ones without refusing the heterogeneity in the relations of knowledge and power, but by putting into analysis the political concentrations, the epistemological hegemonies, the authoritarianism of the centers of power and knowledge. To conduct a mental health investigation betting on laterality among researchers, workers and users or relatives interferes in the investigated reality, conferring to the study its interventional character.

GAM is guided by the methodological principle of transversality. As a strategy, the promotion of collective autonomy, the distributed protagonism and the co-management guideline are ways of

doing that can be presented in different devices for attention or management of work in health, whether in practices of knowledge production and participative intervention studies. This strategy is present in GAM devices, which are heterogeneous groups integrated by workers and users, or by workers and relatives, possibly with the presence of university researchers, where GGAM is discussed, a tool that directs a GAM group. GAM, therefore, is strategy, device and tool, being presented from its most abstract version to the most concrete.

In the work of the GAM research, the reading of GGAM in a group device led us to define it as a collective interview (Sade et al., 2013). The use of interview techniques was not fortuitous, it is a way of investigating the experience with emphasis on the relational dimension. The GAM group, as a collective interview, was for us a way to construct devices that would allow us to establish new modalities of encounter with the participants. In the GAM group, we cartographed its dynamics, monitoring the processes and movements of the participants' experience, intensive and qualitative aspects, which required interview procedures equally procedural (Renault; Passos; Eirado, 2016; Tedesco; Sade; Caliman, 2013). We are inspired by the concept of cartography formulated by Deleuze and Guattari (1995), from which we developed, in collaboration with other researchers, methodological clues for conducting qualitative research (Passos; Kastrup; Escóssia, 2009; Passos; Kastrup; Tedesco, 2014). The collective interview is not constituted for us as a means of collecting information immediately available. This is a non-directive interview, which sustains an attitude of openness and experimentation, using relaunch techniques, sensitive to what happens during dialogue with the participants of the group and that seek to evoke their concrete experience with broad questioning. With the support of GGAM and the collective interview, we guide the participants in a nondirective way to their own experience, providing time for the emergence of a content that is not given beforehand.

The collective interview of GAM is not confused with a focal group (Sade et al., 2013). The interview's handling does not aim at focusing the group's speeches, which could restrict the spectrum of

discussion, monitoring not only the focus of the conversation, but also what is out of focus. The group is the effect of a dynamic of co-management handling (Mello et al., 2015), with coordination initially centered on a leader who has the task of fostering the distributed protagonism, aiming at the handling decentralization. Decisions about the conduct of the group can only be taken on a case-by-case basis by sharing the participants' experience on the part of the leader. Guided by the principle of transversality, co-management handling is receptive to different perspectives, which makes the participants feel a sense of belonging and co-responsibility, sharing the protagonism of the group, assuming a collaborative and creative position. The GAM group is not only participative, it fosters participation. The effect sought is that of the contraction of a group that is more than a gathering of people, to the extent that a dynamic of collective autonomy is achieved, that is, the group starts to operate as a generator of norms for themselves: normative group and not a normal group (Passos; Carvalho; Maggi, 2012) that operates the medication co-management. The work of the participatory research-intervention does not separate itself from the implementation process of the GAM device.

We are interested in presenting research experiences that discuss the technological innovation of the implementation of GAM in the services and their reverberations beyond the specialized mental health care. The texts gathered for this dossier should be considered in the problematic field based on two axes: (1) methodological innovations in health production practices in the public health field - GAM as a group device for promoting co-management in mental health care; support as a direction in health management practices; the health workers' forum; (2) methodological innovations in public health research - the research narrative policy; participation in data analysis; the research-support. These axes are transversal to the texts presented, since they are all located in the relationship between research and experience, between research and intervention. However, we can locate the articles gathered here as being more predominantly on one axis or another. Health production practices encompass the

dimensions of attention, management, promotion and prevention, taken as distinct and inseparable.

In the axis of methodological innovations in public mental health practices, two articles discuss the GAM strategy and the inseparability between the management of work processes and mental health care processes.

In the article “Gaining Autonomy & Medication Management (GAM) as a psychosocial care device in primary care and support to mental health care,” Eduardo Caron and Laura Feuerwerker problematize an experience of building devices of psychosocial attention in primary care, based on the GAM proposal. These devices, guided by the co-management guideline and sharing of experiences, were constituted in basic health units through groups that gathered users of psychiatric medication. In the context of the massive prescription of psychotropic drugs in primary care and the centralization of sanitary responsibility in mental health in specialized care services, the authors discuss the strategic importance of intervention methodologies that foster autonomy in power relations between health teams, between workers and users, and among the types of knowledge involved in health production practices.

In the article “Institutional support for the Forum of São Pedro da Aldeia Mental Health Network as a dimension of the Gaining Autonomy & Medication Management research,” Everson Rach Vargas, Eduardo Passos, Beatriz Prata Almeida and Lorena Guerini present an experience of institutional support to a collective of workers in the municipality of São Pedro da Aldeia, in Rio de Janeiro. This experience, which emerges in the participatory research-intervention process that implanted and validated the GAM device in the Caps of the city, had as one of its effects the construction of a forum of workers of the Psychosocial Care Network (Raps) in São Pedro da Aldeia, as a device to care for the caring experience in the mental health field. The text highlights the relationship between the research process and the institutional support technology, emphasizing the methodological modulations implicated in this process, both regarding the practice of research

regarding the practice of health production in the Raps of the municipality.

If in the first part of this dossier the reported experiences express the effects of the participatory research-intervention methodology on health production practices, the second part presents the effect the innovations of the inclusion of experience and alterity in health production practices has on research methodologies.

The encounter between research and field is the motto of the text “Intervention research as research-support a support research: the case of POP RUA,” by Iacã Macerata, José Guilherme Neves Soares, and André Miranda de Oliveira. In this article, the authors develop the concept of research-support as a modulation of participatory research-intervention in the health field, based on a case report of the experience of a research about the care practice of a Street Outreach Clinic team, in Rio de Janeiro. In this research, the problems of the psychosocial care field to the homeless population shed light on the challenges of the methodological approach of GAM research.

In the article “Narrative policy in participatory research-intervention,” Christian Sade and Jorge Melo discuss the narrativity in participatory research-intervention related to GAM. The authors take as a starting point the premise that listening and legitimizing the users’ experience is a key point for GAM. The production of narratives evidences the necessary legitimation of different points of view commonly excluded: both users and the researcher, a viewpoint that is hegemonically hidden in the pretense neutrality of the researcher.

In the article “Participating in the analysis, analyzing the participation: methodological aspects of a participatory research-intervention on mental health,” Letícia Renault and Júlia Ramos discuss the articulation between the themes of participation and data analysis from the viewpoint of the methodology in participatory research-intervention linked to GAM. In this research-intervention, all participants are, to some extent, researchers, which alters the comprehension of the ways of doing research analysis. The authors propose a circular relationship between participation and analysis, where participation depends on the collective

realization of the analysis, and the analysis allows the identification and transformation of different qualities of participation.

The experiences and propositions reported here result from the problematic field of Gaining Autonomy & Medication Management. With the number of texts we want to make public the experience of this collective of research and highlight the methodological challenges that arise when we value the participants' experience, whether in health practices or in health research. We want to emphasize the relationship of distinction and inseparability between knowledge production and care production, which tunes our research practices with work in healthcare.

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