Narrative policy in participatory research-intervention
A política de narratividade na pesquisa-intervenção participativa

Abstract

This paper aims to discuss the narrative policy in participatory research-intervention related to Gaining Autonomy & Medication Management (GAM). Listening and legitimizing the experience of users of mental health services is a key point for GAM, as well as for participatory research-intervention. The appreciation of the research participants’ experience unfolds in the problem of narratives as a medium of access and inclusion of the experience. This article is based on two research projects already completed, carried out in Psychosocial Care Centers of inland cities of the state of Rio de Janeiro. We talk about narrativity policy as the production of narratives evidences the necessary legitimation of commonly excluded points of view. Such policy concerns, on the one hand, the operation of intervention groups with users, workers and researchers as spaces for sharing experiences and discussing about medication. On the other hand, it concerns the translation of this dialogue in the form of written texts, related to the research register (memories) and to the restitution of the knowledge produced in narrative groups, in which the participants are called to produce knowledge in co-authorship. We highlight that there is a narrative policy of GAM characterized by mobilizing and sustaining a dialogue based on the alterity of the experience.

Keywords: Mental Health; Research Methodology; Participatory Research-Intervention; Narrative Policy; Gaining Autonomy & Medication Management.
Resumo

Este artigo visa discutir a política de narratividade em pesquisas-intervenção participativas relacionadas à gestão autônoma da medicação (GAM). Escutar e legitimar a experiência dos usuários de saúde mental é um ponto-chave para a GAM, assim como para as pesquisas-intervenção participativas. A valorização da experiência dos participantes da pesquisa se desdobra no problema das narrativas como meio de acesso e inclusão da experiência. O artigo se baseia em dois projetos de pesquisa já concluídos, realizados em Centros de Atenção Psicossocial de municípios do interior do Rio de Janeiro. Falamos de política de narratividade na medida em que a produção de narrativas evidencia a legitimação necessária de pontos de vista comumente excluídos. Tal política diz respeito, por um lado, ao funcionamento dos grupos de intervenção com usuários, trabalhadores e pesquisadores como espaços de compartilhamento de experiências e discussão sobre o tema da medicação. Por outro, diz respeito à tradução deste diálogo em textos escritos, relativos ao registro da pesquisa (memórias) e à restituição do conhecimento produzido em grupos narrativos, nos quais os participantes são chamados a produzir o conhecimento em coautoria. Destacaremos que há uma política de narratividade da GAM que se caracteriza por mobilizar e sustentar um diálogo com base na alteridade da experiência.

Palavras-chave: Saúde Mental; Metodologia de Pesquisa; Pesquisa-Intervenção Participativa; Política de Narratividade; Gestão Autônoma da Medicação.

Introduction

Since 2009, the research group Enactives: Knowledge and Care (Enativos: Conhecimento e Cuidado), linked with the Universidade Federal Fluminense, has been working on research projects related to Gaining Autonomy & Medication Management (GAM) in different Psychosocial Care Centers (CAPS) and cities in the state of Rio de Janeiro. GAM is a strengthening strategy for the Brazilian psychiatric reform by an approach to the recognition and inclusion in drug treatment, from the user’s unique point of view, multiple forms of suffering, and its various meanings. The user of mental health has an embodied, experience-based knowledge about what helps or hinders the treatment. However, this knowledge is usually delegitimated and excluded. Without this appreciation of the user’s experience, drug prescription becomes a blind spot in the Brazilian psychiatric reform (uncorrected aspect of the reform), for drug treatment relies only on external observation, usually restricted to the description of physiological or behavioral signs, and its management is limited to the prescription of the psychiatrist (Campos et al., 2012, 2013). Aligned with the GAM strategy, the projects of participatory research-intervention of the Enactives group seek to investigate and include the experience of users, family members, and workers, classifying them as inseparable in the care process. Listening and legitimizing these experiences is fundamental to GAM, as is to the methodology of participatory research-intervention. Thus, the importance of a reflection about the place of narratives in the research process that considers the form of experience inclusion from the point of view of knowledge production, as well as the production of care.

We will consider as base two research projects: one conducted between 2011 and 2012 in the CAPS of the municipality of São Pedro da Aldeia (RJ) and the other carried out between 2014 and 2018 in the CAPS of the municipality of Rio das Ostras (RJ). The first project aimed to validate the GAM Guide1, while

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1 The GAM Guide was originally conceived as part of a social movement composed of users, workers and human rights defenders in Quebec, Canada in the early 1990s, and adopted as an important resource for mental health treatment in Quebec services. In 2009, the Guide was translated and adapted to Brazilian services by the multicenter research project Evaluative Mental Health Research: Tools for the Qualification of Psychopharmaceutical Use and Human Resource Training (CNPq, 2009). It is available from: <http://www.redecaps.org/s/acrovo-geral/cs8s>. An English language version of the GAM guide can be found at <http://www.rrasmq.com/GAM/documents/GuideGAM-EN-2019.pdf>.
the second project aimed to implement and assess the impacts of the GAM device on the Rio das Ostras CAPS. What we call GAM device refers to intervention groups gathering researchers, users, and workers of CAPS to build collective reflections on the use of psychoactive drugs based on the GAM Guide and co-management handling. The GAM groups had weekly frequency, with meetings of one hour and a half. Besides the fulfillment of the GAM groups, we will discuss other methodological tools and procedures developed throughout the participatory research-intervention process: memories of the meetings and narrative groups.

Research with the GAM device has shown how medication is not only a blind spot, but, a deaf and mute point of the Brazilian psychiatric reform. In general, users of mental health services experience silencing in society, often in the health services themselves. In the words of some participants of the GAM groups: no one ever listened to me, just listen to them, no one listened to me; get your case, pack it up, go to Niterói Street, there are a lot of nail salons hiring manicures and watch your mouth! Be quiet. This silencing can be either in the form of a “shut up” or a “nobody listens to me”. Often users refer to their difficulty talking to the psychiatrist: I’m ashamed to talk with Dr. Celso’ cause he is so serious. I’m afraid to say something that makes him not want to arrange appointments with me anymore. Then I just mind my own business!

On the other hand, GAM groups provide a speaking space for users. Speaking in the GAM group is, according to participants, different from answering questions in an appointment, for example. The participants themselves, when introducing the GAM group to beginners, say that this is a place where we talk about everything, family, medicine, religion: a group to share problems. Some people said that in the GAM group, we leave our problems and go home lighter. Another participant said she gets anxious to the GAM day as she “let it all out”. This idea of “letting it all out” was very present and demonstrates the relationship with a space where users felt listened and understood.

The participants’ narratives are fundamental as manners to access the experience. In our view, much of the power of the GAM device as a strengthening strategy for the Brazilian psychiatric reform lies in its ability to produce narratives, to help participants freely talk about their experiences, building a meaning for them associated with other people equally interested in this process. This is the highlight point, the GAM device presupposes a narrative policy (Passos; Benevides, 2009) that needs to be studied and included in participatory research-intervention (Melo, 2015). Our objective, is to discuss and present this narrative policy, clarifying how it was present in our research projects.

We will distinguish two moments of narrative production. The first refers to the dialogism of the GAM device. Supported by the GAM guide and co-management handling, participants become narrators of their experiences to the group. The second moment refers to the construction of memories and narrative groups, in which researchers look for translate the group process into a collective narrative, which constitutes research data and basis for the return of their results to participants. In the first topic of the text, we will expose which narrative policy is functional in the GAM device, considering the support of a dialogue based on the alterity of the experience. In the second topic, we will discuss the construction of memories and narrative groups, highlighting how the research assumes a narrative policy searching to translate the group’s experience and strengthen their participation in the construction of knowledge.

Experience and alterity: the dialogism of the GAM device

The research experience in GAM groups is marked by an irreducible alterity. It is important to emphasize the interference of what is characteristic of the field of Mental Health, the experience with madness. In group discussions we find ourselves facing strange narrative constructions, unexpected word substitutions, subversion of meaning,
neologisms, delusional and polyphonic narratives, displacing the centrality of the logical and rational exposition of experiences. This group dynamics often tends to extrapolate the research focus – the issue of treatment and medication management. Issues related to health services, transportation in the city, politics and religion, family or love relationships, relationship with the doctor, stigma and discrimination, all sorts of themes come up in the discourses, expanding the field of intervention and exposing the complexity of psychotropic drug use experience, which extends beyond problems restricted to body and consciousness. It is as if access to the experience of drug use opened to us a “gateway” to a whole network of interactions that, in the group’s reasonless discourse, often emerges in a confusing and delusional manner. The challenge is to transform this intense production of narratives in a medium of accessing and holding experiences, connecting such heterogeneous discourses without annulling singularities, contributing to legitimize the participants’ experience and avoid their isolation. The GAM device is both a medium of knowledge production and a medium of care. We understand that the GAM Guide, with its respectfully interrogating experience, and co-management handling – which strengthens group participation – contribute to this dual function by promoting a narrative policy in which the expression and listening of otherness are encouraged and lived as invitations to dialogue.

The GAM Guide is aimed at users of psychotropic drugs to produce a critical assessment of the drug use experience. It is composed of open-ended questions, broad questions about specific daily actions (“What is it like to take medicine?”, “Who can you count on during hard times?”, “What do you do to take care of your health?”). Throughout its six steps, the guide questions help us to access users’ experiences and knowledge about medication use and the treatment in general. Despite the focus on psychiatric medication, the Guide steps address general themes of users’ lives. The six steps in the Guide are: (1) Talking a little about you; (2) Observing yourself (your daily life, your health, your relationship with money, etc.); (3) Expanding their autonomy (which helps participants to identify and build a support network of people, services or social groups); (4) Talking about medicines (which gathers some information and enhance users’ experience using psychotropic drugs); and the last two steps, which aim to build an action plan to consolidate the gains of the previous steps. The Guide helps participants to talk about medication through relationships with various themes, always focused on the concrete experience.

Collective reading of the guide requires a GAM narrative policy. Understanding the guide concepts and information often requires collective building. For example, what do you mean by “Autonomous Drug Management”? And by “shared management”? At the beginning, we heard participants say I mean, it’s up to us to decide which medicine we’ll take, how much, the time and which reaction we wanna from the medicine, and that “shared” means taking each other’s medicine. The understanding of what GAM proposes is not preconceived, it is not immediate. It is based on the joint construction that the notion of something we do together gradually helps us to make decisions in a shared way.

The guide is dedicated to presenting the most commonly used drugs in psychiatry, as well as providing information on the diagnoses for which medications are usually indicated. Contact with such information led one user to comment that we were discovering each participant disease; another participant, saying she did not know what was wrong with her; someone else, revealing some disagreement with the psychiatrist’s diagnosis. These statements demonstrate how information demands a work of collective and personal construction of meaning, rendering the guide a kind of narratives trigger in the group. It is about inviting the reader to dialogue, to construct meanings and to elaborate new logics, supporting the experience of madness. The understanding is fundamental so users can position themselves and exert some role in their lives, recognizing themselves as subjects of rights. This process of constructing meaning from reading concepts and information enabled the groups to be seen as learning spaces: here at GAM I feel like in the
classroom, I better understand what I’m doing here at CAPS: how should I deal with my limitations and helping other people, I’m not alone in this boat.

We highlight that there is one GAM narrative policy, which, in addition to the importance of information, leads a meaningful discussion among the participants, inviting them to narrate their experiences. As Benjamin (2018) says, storytelling is not limited to reporting facts. The information contained in a newspaper today no longer matters the next day. On the other hand, good stories can surprise us, causing astonishment and reflection even after a long time. They do not lose their ability to breed other stories. When asked “How do you describe your daily experience of taking medications?”, this is a non-directive question inviting the reader to speak based on their daily experience. It is different, for example, from the question, “What psychiatric medications do you take?” The first question invites us to tell a story, the second asks us to report a fact: “I take Diazepam!”, “I take Risperidone” etc. With the support of the GAM guide, some participants told us that taking medicine is bad for them, others stressed its relevance to prevent a psychotic attack. The drug helps to lessen the suffering, the voice hearing, depression, to behave calmly, but it also produces many side effects: the bitter taste in mouth, thinning of hair, people who get fat and lose weight “weight cycling all the time” etc. Evidencing the subjective senses of the psychotropic drugs use can contribute both to the qualification of their prescription and to increase the users’ participation in the treatment, considering their greater appropriation on the effects of each drug. There are users who would like to change their medication, but they receive no voice. Some would just like to decrease the dose, others to remove it. There are those comfortable with their pills and those who complain about problems for which they have not found a remedy. Moreover, there is always some frustration for – although the medicine helps – the suffering does not disappear completely.

The experience with psychotropic drugs appears in the GAM group, always carrying many ambiguities, such as a pharmakon, which carries both a sense of medicine and poison. Its polysemy prevents the dialogue from ending with totalization. According to Larrosa (2016), the concrete experience is irreducible to information or opinion. To inform is to restrict polysemy. The more informed and opinionated, the more unavailable we become to be touched by an experience, which, in Larrosa’s words, is something that happens to us, that changes us. Therefore, GAM narrative policy implies a gesture of listening and openness to the experience. Communicating an experience by narratives is connected to our ability to let words touch us differently. Such as discussing the side effects of drugs, someone said I’m feeling like a potatoes sack, triggering a whole set of reactions in the group: people who felt heavy, injured, tight, a burden to others, suffocated, inert, or sleepy.

GAM favors the presence of experience in the narrative. More than a talk about experience, at a distance, narratives express the experience in discourse. It is no longer a “no man’s language,” a neutral language, “no blemishes, no shadows, no wrinkles, no body, an unpopulated language” (Larrosa, 2016, p. 85-86). As Vermersch (1994) says, it is an “incarnate discourse”: Since I was a child I felt a lack of fulfillment, then I became nervous…; I lost my mind, I’m not healed, but I’m better; we may not be able to get the psychological offended, so… suffered; there are people who understand, but there are people who don’t, because there is not much outburst. Incarnate discourse often provides a creative form to the narrative, such as a user, sharing with us her experience of the psychotic attack, exclaimed: I feel a monster inside me! When experience appears in discourse, it cannot be elaborated in the usual language of information nor reason, but it requires a language “crossed with passion”, capable of incorporating uncertainty into “uniquely enunciating the singular” (Larrosa, 2016, p. 69).

Therefore, GAM narrative policy is not primarily characterized by the transmission or collection of information. The GAM Guide is not confused with a questionnaire. Rather than answering the guide questions, our goal is to deepen the issues, collectively construct meaning, holding the polysemy of experience.
The guide is less a tool for collecting than for “data harvesting” (Sade et al., 2013). Whereas it also serves to convey and gather information, for example about side effects or possible interactions with other substances, this is not the primary purpose or major contribution of GAM narrative policy. The cultivation and harvesting of the field of sense in the group’s own time matters to the research methodology, which is also a care practice. Therefore, they always said: you have a lot of patience with us.

In addition to the guide, the GAM device is composed of co-management handling, as we call the know how that characterizes the GAM strategy (Melo et al., 2015) and whose demand is evidenced by the collective reading of the guide. Handling is initially centered on the leader (one of the researchers), who actively conducts the group. However, the conduction itself emanates an attitude of decentralization, thus, the handling aims at co-managing. The leader conducts the reading of the guide, ensuring that experiences are welcomed, valued and shared. The listening and the language of co-management handling should be aligned with and foster GAM narrative policy, being careful not to seize participants’ statements only in their informational aspect, but also in what they express. When a user says he cannot talk to the psychiatrist, what happens then? What does he express without saying? Once we talked to a newcomer that we were discussing about medication. She promptly asked if we were doing meditation, said she was “into” yoga and meditation, and told us excitedly how she was doing her practice. What initially was a disconnected discourse, for a more attentive listening and open to experience, presented another manner of care. For the user, meditating was taking care of herself, improving her quality of life. If the handling listening was focused on collecting information, it would not contribute to holding and reaching the multiplicity of experience. Therefore, co-management handling needs to follow the discourse experience rather than discourse about an experience.

The pragmatic approach to language studies, by highlighting the inseparability between the planes of expression and content, helps us to understand this point (Austin, 1990; Deleuze; Guattari, 1995; Tedesco; Sade; Caliman, 2013). According to this approach, signs should not be taken as constituting an abstract, neutral plane independent of the empirical plane, but as an instance that suffers and reacts to the interference of experience. Language variations, which accompany intonation, height variations, speed, silences, repetitions, body gestures, the use of grammatical transgressions, and neologisms are direct effects of the presence of discourse experience. There is no experience in itself, external to saying, waiting to be represented by the signs. Language carries the experience itself and is affected by it, as in the above examples, of incarnate discourse. To follow the discourse experience, the listening of co-management handling implies opening up to what Petitmengin (2007) calls felt meaning, a kind of “intuitive sense,” which occurs in contact with the affective, intensive, and intuitive dimension of experience, in which the sense and the sensible intersect.

The inseparability between the planes of expression and content, posed by pragmatics, presupposes not only the interference of the empirical plane of contents over expression, but also expression over content, as it is circularity (Austin, 1990; Deleuze; Guattari, 1995; Tedesco; Sade; Caliman, 2013). The expression extends over the contents and enables the signs to act on the experience. According to pragmatics, the word is a practice, an act of discourse and, as such, has a performative dimension of production and transformation of meaning. Every statement is the realization of an act that establishes a new reality, nonexistent before its own occurrence — for example, “I now pronounce you husband and wife,” “I promise to pay you tomorrow.” The performativity of the language of co-management handling, as well as the language of the GAM guide, is not restricted to the transmission of information. As in the guide, handling narrativity is also poorly directive, supporting an attitude of openness and experimentation. Rather than pre-defined questions, the handling uses relaunch techniques (Vermersch, 1994), sensitive to what occurs during group conversation, seeking to evoke
the participants’ concrete experience with broad questions, and having time for the emergence of unexpected content (Sade et al., 2013). GAM narrative policy search to pave the way for experience by moving and differentiating issues rather than closing or concluding them.

Co-management handling, associated with the GAM guide, provokes and sustains a dialogue based on the alterity of the experience. In this way, participants can realize that, despite their differences, they are side by side, forming a group. One of the success rates of co-management handling is precisely its decentralization, so that the other participants feel protagonist and lead the group. The ethos of openness and non-directivity of handling aligns with its co-management characterization. Originating from the field of collective health, the concept of co-management incorporated the guideline of institutional democratization of the Brazilian National Health System, recommending that power can be shared among different stakeholders in care management (Campos, 2000). Initially located in a researcher, co-management handling looks for its decentralization. Paradoxically, the location of handling is often important for its distribution. The group can pass by moments of great disorganization, and it is important to have a center that will restart the conversation, returning to its most relevant points and including what appears to be going out of focus.

At a GAM meeting, some participants said that they preferred to be called patients instead of users. For us from the university and interested in keeping the psychiatric reform, this discourse was surprising. However, despite this initial discomfort, we noticed that users (or patients, as they preferred) were indicating us to another direction, which alters the modes of identification. We ask: “What does the word ‘patient’ mean, what remind you when we say that?”; “And what is being a user?” The answers to these questions led us to a long and intense discussion about what is drug and what is medicine – User is those doing drugs, there is no drug patient. It was necessary to wonder if the medicine they take in CAPS is a drug, if there was a difference between medicine and drug. One user commented that when someone has a disease which has no cure, they must take medicine for the rest of their life. Then, she asked if this medicine is a drug since it generates addiction. Another user was more direct: I’m dependent on medicine. And when someone stated that used to smoke a joint to avoid stress when talking with their grandmother, one user agreed that the effect is really similar to Clonazepan, and other people start to recollect other calming solutions, such as passion fruit juice, balm tea etc.

The initial estrangement of the preference for being calling as patient led us to collectively build knowledge about drugs and medicines. It is common in the GAM group to access experiences that we cannot clearly discern on the beginning, which causes us some strangeness. These meanings become clearer as the handling revisits the experience, relaunching the narratives to the guide questions or to a specific theme. As if one says, “come back,” “let’s go back to the experience.” This is what drives the dialogism of the GAM device. It is a dialogue essentially based on the alterity of the experience. More than the personality of a group participant, it is the intersubjectivity experience which is embodied by the discourses, emphasizing the perspective of care taken collectively. The GAM guide also regards to a personal experience; however, reading the guide in the GAM group, gathering different users, workers and researchers, produces a collective co-management experience, whose access and otherness depend on relationships.

As alterity, the experience is presented in its procedural and genetic face, in which the meaning is not completely discretized in fixed and isolated points of view (Passos et al., 2018; Petitmengin, 2007), but carries loose lines that lead to polyphony. Different themes do scramble from the otherness of experience, as well as the self-other distinction – what is my discourse and what is the other’s discourse – often becomes difficult in dialogue. The voices mingle with each other and no participant works in isolation as the source of discourse or as a generator center of idea. In synchrony with co-management handling, GAM narrative policy promotes co-authoring narrative production.
The Bakhtinian notion of free indirect discourse helps us to explain this notion of co-authoring. Bakhtin (2006) shows how dialogic processes are present in every discourse and can be heard in a single word, as if every discourse had in itself a kind of “free indirect discourse” (FID). It has the ability of overcoming the binary between first (direct discourse) and third person (indirect discourse), in a bivocal composition promoted by the mixture between these two modes of enunciation. The author expresses the interference of another’s word on the narrator’s discourse, as if passing the words of the other through their mouth.

The narrated discourse infiltrates the narrator’s discourse, creating a special kind of bond between the discourses, in which authorship is less interesting than the expression of its indeterminacy and the outcomes of new meanings construction. By pushing the notion of free indirect discourse to its limit, we speak not only about the articulation of two subjects, but about many discourse chains. As a set, each statement interferes with the others, alters their senses. Sometimes, what we often experience in the first place as a scattered and meaningless voices, achieve – using the concept of free indirect discourse – the positive sense of manifestation of the genetic and common plane of experience (Kastrup; Passos, 2013). One participant stated once: The reverend told me that I shouldn’t take that, that it was the enemy, he told me. Then my friends, my neighbors told me to take, that it would make me better, be fine, and I was asking myself what should I do, what God wants for me. Dialogism demonstrates the friction and unusual composition resulting from the presence of another’s discourse in the self-discourse, it refer us to a conception of enunciation as free indirect discourse or, speaking as Deleuze and Guattari (1995, p. 17), as “collective assemblages of enunciation,” established in the heterocyte composition among social agents.

The similarity between the experience of madness experienced by the participants of the GAM groups and the FID led us to rename it as “folly indirect discourse.” GAM narrative policy, characterized by its opening to the otherness of experience, brings us closer to the experience of madness. It brings language in the GAM group closer to a tragic and literary experimentation of overcoming the limits instituted by rationality (Foucault, 2016). With the GAM device, we built a narrative of mental health care that includes the experience of madness. It is a matter of creating conditions for a co-participation in this experience to interfere on it, holding its ambiguities and unusual senses, by narratives that perform care. The practical dimension of the participatory research-intervention carries fundamental clues for the second moment of narrative production.

Narrating the meetings and sharing knowledge: memories and narrative groups

Our research projects predicted that field experience would be recorded as field diaries and recordings. Based on this material, the researchers wrote the memories of the meetings. In our practice, the field diary was often confused with memories, which are usually written by those in charge of the groups. At each meeting a memory was produced. The problem posed was: how to express the experience of the meeting in a written narrative? How to narrate it?

GAM studies accept a challenge by proposing to access the experience of users and workers of Mental Health. When a user says “I feel a monster inside me” or “I lost my mind,” we access experiences which escape rationality but reveal unique forces of madness. These forces ask for passage, claiming for listening and recognition of their otherness, and we look for provide them expression. Our research experience in GAM groups is in line with the challenge that psychiatric reform poses to society: to develop another approach to madness. Instead of repressing it, how to listen and legitimize its experience? How to talk to it? How to let it talk to us?

According to Roberto Machado (2000, p. 20-21), Foucault sought to adopt, in his initial research, a language free of psychiatric terminology to “let madness speak its own language.” This movement
is enabled by Foucault finds in Nietzsche’s tragic philosophy a distinct syntax of reason. The tragic gesture denies the radical separation between reason and unreason, separation on which psychiatric knowledge is founded as knowledge about madness. Foucault intended to be where the relation to madness can no longer be of exteriority: sovereign reason on the one hand and illusion, error or disease on the other. How to convey to writing a narrative style that evokes an experience of closeness to madness, not separation?

I commented that other people had also said they heard voices. “So do I!” “That’s awful!” were some of the almost immediate comments that popped up in the whole group, simultaneously with the nodding. A mate’s voice boomed out in the murmur, telling us the story of a notebook she was chatting with. I swear I was looking at a person! I remembered that many users used to call the guide “notebook.” “I used to talk to him,” she said. It was imaginary, but there were times when she talked a lot, alone... as if she was with someone. I asked how she perceived it was imaginary, but it was a fellow who answered. He used to go to the person and when he found out they were not calling or saying anything, he got scared. The fellow had not finished speaking when a third person, who was acting as such to be holding back to speak, took the floor. She related something very odd that happened to her, which made her wonder if she was going crazy. Once, when she had finished a course at SEBRAE and needed to get her diploma. A voice told her to go immediately and get the diploma, but when she arrived there, she saw a handsome and gorgeous boy as every woman appreciates, who said to her “Here is your beautiful and wonderful diploma as you like!” The boy remained in her mind as if he was married to her and she went back after him. She remembered him getting into a beautiful car, which made her think he had a lot of money. But she never saw the boy again.

In this passage, FID performs the approximation between narrator and participants. The experience of madness is legitimized in this gesture of implication, important from both clinical and research point of view: GAM research lies on the frontier between knowledge production and care. Producing knowledge with subjects who have an experience with madness requires from us the possibility of providing expression to their disruptive forces, enhancing their “sayability” through narratives. GAM narrative policy addresses this problem and provide to it a guide with its dialogism. Folly Indirect Discourse (FID) provides to us the path to include the experience of GAM groups in memories. The research narrative assumes the quality of a discourse with – not a discourse about or a discourse by.

Inspired by FID, we understand that in the writing of memories the alleged author must lose his primacy to express the group’s dialogism, in which multiple voices coexist and interact. Narrative can express the experience of GAM meetings since it becomes able to include participants’ statements, including the narrator’s own, into the same polyphonic discourse. The researchers must pay attention to the experience in the discourse and to develop a writing that adopts as a procedure the composition of a narrative composed of the participants’ narratives, transmitting their interference to the narrative itself. In this second narrative moment of the research, we built a kind of second order polyphony, in which the discourse of each participant becomes a discourse of the group, of the collective. In the memories, we seek to produce a narrative style that expresses the meeting in its collective dimension.

We search to relive the density of the experience of GAM meetings in memories, not considering them as mere transcription. It is a task of translation: to access what is untranslatable in the meeting and, to draw a narrative in co-participation with the group’s experience. Translating encounters are a work of creating “equivalences without identity” (Ricoeur, 2012, p. 47). Translation is also an analytical experience (Renault; Barros, 2013), with an epistemological meaning: foreigner and familiar do not remain identical to themselves but broaden their horizons and open themselves to new possibilities (Ricoeur, 2012). In the GAM group, given the otherness of the experience, we
often encountered the problem of translating a “foreign language.” With memories, the challenge is to translate polyphony, to keep present in the construction of the text of memory the collective dimension of the GAM meeting.

In the memories, we narrate the meetings revealing their tensions, the acting forces, the dialogism of the experience, but we also include the “out-of-text”: we express our difficulties with the group’s agreement, we highlight the relationships between the participants, we express feelings in regard to discourses and interventions, we report events that occur in other spaces, as the kitchen or the reception of CAPS, we mark unexpected moments, we describe the way researchers deal with each situation:

Today the room was crowded. We had three new participants: Elias, about fifty years old, retired stevedore, said he sometimes stops taking his medication and does not go to CAPS, but returns when he needs help; Hélio, a quiet and quite lucid gentleman; and a third whose name I can’t remember, perhaps not randomly, since it was the most committed and difficult to understand. This is an important force that I feel in myself and in the other members of the group: we kind of pay more attention to less committed users.

The memories of the participatory research-intervention assume a policy of narrativity that does not elaborate impartial representations, but, by reliving the group’s experience, retakes its dialogism. This methodological choice provides access to the group’s experience, which is complete in the restitution of the narratives to the participants. It is the need for this feedback as a form of data validation that incline us to choose a specific device: the narrative group.

Narrative groups (Miranda et al., 2008) constitute a moment of feedback based on the point of view of researchers to users and workers, fundamental for research participants to appropriate of the process, to dialogue with researchers’ assessments, as well as to confirm or refute certain analyzes. It occurs at different moments of the research-intervention process, consisting of a moment of collective reading of a narrative of the process elaborated by the researchers. For this meeting, we extracted from the memories the main theme of a research period, such as the experience of medication use, the means of care, the relationship with society and family, the experience of illness, etc. From these themes, we built a narrative aimed to express and to consolidate the collective care experience of the GAM group. With the narrative group, we sought to include the perspective of the participants in the data analysis, since the narrative is read and discussed with the group, generating collective reflection effects of the research process. The returned narrative highlights the conversation and the different points of view of the group, in order to recognize, value and include them:

Often, some have shown a willingness to be healed. “Am I going to be okay?” One participant asked. We discussed a lot about what is “to be healed” and we hear a lot of opinions about what healing truly is. For some, being healed is returning to the life they had before the first psychotic attack, for others be healed is taking less medicine, having a better quality of life. Many participants would like to work, to have a salary and not depend on help alone. We talked a lot about the difficulty of getting a job.

The narrative encourages dialogue. Sometimes, participants corroborate what is written, and sometimes refute the researchers’ point of view. Participants actively contribute by proposing changes to sentences, completing passages. At this moment there is an important task of translation, as academic language usually is far from the social reality, often meaningless to others. The polyphony of the text seeks to make it more an expression of the collective protagonism. One effect of narrative groups is the increasing degree of participation and appropriation of participants, since it is offered the possibility of recalling their discourses and discussions they generated. With narrative groups, the participation of users and workers is increased, as they help us to rewrite the presentation text of the research partial results. The co-authoring narrative emphasizes the participatory and interventional methodology.
Final considerations

We aimed to show how the policy of narrativity has implications for the dual function of a participatory research-intervention in Mental Health, which aims to produce knowledge and care. GAM narrative policy seeks to investigate and include the experience of users, as well as family members and workers, strengthening shared and participatory co-management of experience associated with the use of psychotropic drugs. Listening and legitimizing these experiences is fundamental for both GAM and participatory research-intervention itself.

Based on the point of view of this policy of narrativity, the production of research data enables the shared construction of knowledge, which produces care effects for the service and its users. Thus, participatory research-intervention is not only co-managed, but also co-authored with the participants, contributing to their protagonism as subjects of rights.

References


Authors’ contribution
Both authors conceived the project, participated in the research that supports the article, one in the CAPS of São Pedro da Aldeia and the other in the CAPS of Rio das Ostras, and both wrote the manuscript.

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