

# Mental health care actions in the psychosocial care network viewed by users

## Ações de saúde mental na rede de atenção psicossocial pela perspectiva dos usuários

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### **Abstract**

This study was designed to analyze actions in mental health from the psychosocial care network through the perspective of users. Fourth-generation participatory methodology was used. The findings highlight the challenges of implementing mental health services in primary care and in different points of the psychosocial network, as users recognize the existence of a health network but indicate limited access to it, because, as they see it, actions could be undertaken in spaces that would facilitate their inclusion and integration with the community. There is weakness in the articulation and in the implementation of integrated care plans in services and, consequently, mental health needs to remain centralized in specialized services, showing strong inhibition of the work in the psychosocial care network. We concluded that the limits of working in networks present challenges in the daily life of service users and in the construction of new possibilities and progress towards social inclusion.

**Keywords:** Mental Health; Users; Primary Health Care; Psychosocial Care Network; Participative Evaluation.

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## Resumo

O objetivo deste artigo é analisar ações em saúde mental a partir da rede de atenção psicossocial pela perspectiva dos usuários. Usou-se metodologia participativa de quarta geração. De acordo com os resultados, os dados evidenciam desafios na implementação de ações de saúde mental na atenção básica e em diferentes pontos da rede psicossocial, visto que os usuários reconhecem a existência de uma rede de saúde, mas indicam acesso limitado a ela, pois entendem que as ações poderiam ser realizadas em espaços facilitadores de sua aproximação e inserção na comunidade. Há fragilidade na articulação e na efetivação de cuidados integrados nos serviços e, conseqüentemente, as demandas de saúde mental se mantêm centralizadas nos serviços especializados, demonstrando forte inibição do trabalho em rede. Conclui-se que os limites do trabalho em rede apresentam desafios no cotidiano dos usuários dos serviços e apontam outros desafios para a construção de novas possibilidades e avanços em direção à inserção social.

**Palavras-chave:** Saúde Mental; Usuários; Atenção Básica; Rede de Atenção Psicossocial; Avaliação Participativa.

## Introduction

The importance of following up the users of mental health services in their existential territories, starting from primary care, is in evidence (Vecchia; Martins, 2009; WHO, 2008). On the one hand, research shows that the organizational arrangement of work in health with reference teams and matrix support can produce teams' commitment in work processes and in the territories they work (Campos; Domitti, 2007, Dimenstein et al. Nunes; Jucá; Valentim, 2007), which could lead to the engagement of workers of different equipment in search of answers for a care plan articulated in the user's territory. On the other hand, the complexity of primary care, which meets 85% of health problems, requires greater efforts and technologies of care and promotes changes in health behaviors and lifestyles (Mendes, 2011). Territorial actions have constituted quite different interventions and powerful designs, with responses to concrete situations in people's lives (Silveira, 2012; Vecchia; Martins, 2009).

Regarding the structure of network services, in the design of the Reorientation of the Psychosocial Care Network (RAPS) proposed by the Ministry of Health (MS) in 2004, the organizational composition brought the Centers of Psychosocial Care (CAPS) as a central and articulating element of actions (Brasil, 2004). We can infer that this centrality contributed to the fact that the demands of mental health were directed primarily to the CAPS. In addition, these services were structured in order to respond to the different demands that came to them. In 2009, the proposal of the MS for the service to be used as an articulator indicated a path where the CAPS could facilitate mental health care, taking an organizing role in the actions constructed with the health network (Brasil, 2011).

From the RAPS, in 2011, the MS proposed a structuring of the health care model based on primary care actions in an expanded design, calling for the participation of different teams for an articulated work among the following equipment: primary health care (Primary Health Units, Offices in the Street teams), specialized psychosocial care, emergency and urgency care, transitional

residential care, hospital care, deinstitutionalization strategies, and psychosocial rehabilitation (Brasil, 2011).

From this current design, it is understood that, with the CAPS as a central articulating equipment, the users' needs and demands are guiding territorial actions that support for an integrated health care plan. Gradually, a proposed displacement in the national plan of inclusion of mental health actions was promoted in primary care starting from family health strategies. Regarding the attention and production of mental health care, this organization of networking aims at enhancing the performance of health teams included in primary care, allowing the exchange of knowledge among workers and greater articulation of the network of services, in view of the care extended to the users' needs.

However, different research have pointed out challenges for this ministerial proposal to be employed (Moura; Silva, 2015; Rodrigues; Moreira, 2012; Silveira, 2012). The evaluation of the quality of mental health users' access to primary care in a large city in the state of São Paulo (Onocko-Campos et al., 2014) indicated that, even though primary care is recognized as a gateway to the health system, access was still hampered by organizational and structural issues (and even by personal barriers), which hindered the intended or necessary care. The results indicate that, although there are many gains, there is no consolidation of the proposed model, and that there is oscillation of demands polarized between curative and preventive actions. Moreover, for many users, the idea of access is restricted to access to the physician.

User participation and perspective is crucial for a careful analysis about the public health policy in the country. In the 1990s, the English movement titled *Nothing About Us Without Us* presented users' denunciations of research practices that occurred without the participants' knowledge. In view of these denunciations, the movement claimed the involvement of users at all levels of services provided to them and in the surveys in which their lives are the object of analysis (Phillips, 2006).

Thus, the participatory model has been gaining strength and advancing rapidly, showing the

important role of researchers in the movements of users. Studies that are guided by this perspective (Lopes et al., 2012, Onocko-Campos et al., 2013, Passos et al., 2013, Serpa et al., 2014) indicate that, from the effective inclusion in research, the users' contractual and participatory power in general is increased, since this type of involvement challenges them to be more politically and civically active.

In addition, user participation helps induce changes in traditional research methods and the sector's way to intervene and theorize. Through different channels, the collaboration and the active participation of users have sought as an important advance in the debates beyond the assemblies and consultative moments. The experience of inclusion of users in a more organic way in academic research has been showing effects that extend to other aspects of life, such as the stimulation of citizenship as recognition of the capacity of the subjects to produce themselves (Passos et al., 2013; Pinheiro; Silva, 2011). These experiences have suggested other possible openings for participation in different spaces of academic life.

Considering the challenges of networking and the problematization about participatory research methods, this article is part of a study in which central point was an analysis performed by CAPS users on mental health actions in the psychosocial care network, with emphasis on primary health care actions. It is necessary to emphasize that, for this approach, the urgency to unveil the challenges of psychosocial care services from the perspective of their users was considered. Seldom invited to comment and report on their experiences, the participants in this study emphasized that they were never asked questions about how they perceived work, services, psychosocial care networks or the ways they build their relationships and their connections with the care plan designed or to be designed.

## Aim

To present the ways in which users of different psychosocial care centers perceive possible mental health actions in primary care based on the psychosocial care network.

## Method

The notion of participation in health research is quite polysemic and has expanded, especially in relation to the connection between participation and public policies. In order to avoid the degradation of State policies, forms of participation have been created and directed to processes of knowledge production and evaluation of public initiatives. According to this way of valuing the participant, there is a great accumulation and strong tradition of social research in which there is intense involvement of a population group in the production of data, with intense exchanges between expert and non-expert knowledge.

Action research is a model whereby a community works and makes decisions about a situation affecting them, taking group and individual growth as a principle. It is an essentially political way of doing research, which aims at the promotion of citizenship and focuses on the processes of social exclusion (Spink, 2007). Intrinsically associated with this model, there is participatory research, understood as “collective knowledge, based on a work that recreates, from the inside out, concrete forms for these people, groups and classes to participate in the right and power to think, produce and direct the uses of their knowledge about themselves” (Brandão, 1983, pp. 9-10). This way of research is considered by Spink (2007, p.9) as “an epistemological anticolonialism,” since, in search of a political re-signification in the form of knowledge production, it has been widely developed and disseminated in Brazil within the scope of community psychology.

In the health field, evaluative research has used a variety of ways of approaching the issues it addresses, with the inclusion of non-experts and different interest groups in evaluation processes (Minayo; Assis; Souza, 2005). For Guba and Lincoln (2011), evaluation is not a technical process of investigation and is not restricted to obtaining data. Hence, fourth-generation research encompasses the dynamic level of negotiation between people involved in different ways in a political, social, and value-driven process. Its results, therefore, represent significant constructions of the actors

to give meaning to the situations in which they are. Respectful health research centers construct their work from the participation and perspective of service users (Furtado et al., 2013; Onocko-Campos et al., 2008; Pinheiro; Martins, 2011).

In the mental health field, since the 1990s in England, health service users have been demanding greater participation in management decisions and production of knowledge about the reality in which they live. The “nothing about us without us” motto, created by users of mental health services, reflects the growing expectation – both in the movement of users and of research groups – for greater involvement and participation in research (Phillips, 2006). In Brazil, there are important contributions of participatory methodologies that confirm their importance for understanding the transformations resulting from the SUS structuring and the need to call up social movements to participate at various levels in the health system (Bosi; Mercado-Martinez, 2010; Furtado; Campos, 2008; Pinheiro; Martins, 2011; Serpa et al., 2014).

The research design used here was inspired by participatory assessments in which the invitation to service users to contribute with analyses aimed to overcome common processes where there is an evident gap between subjects and research participants (Laperrière, 2008; Pinheiro; Silva, 2011).

We sought to compose groups of participants who were users of different psychosocial care centers in the cities of Baixada Santista (SP). The invitations to participate were addressed to people who showed interest or curiosity about the subject and were made by one of the researchers in public meetings, social gatherings, social movements, protest events and various mobilizations. From these invitations, the proposal was presented and the participants could and were encouraged to invite other people voluntarily, with snowball sampling (Vinuto, 2014).

An open group was created, with twelve participants aged between 30 and 66 years, from different psychosocial centers located in the cities of São Vicente and Santos, on the coast of São Paulo. On a weekly basis, a total of five meetings were held in which focal groups were created (Iervolino; Pelicioni, 2001; Kruger; Casey, 2009; Miranda et al., 2008).

Focus groups are widely used in the education and health field, and are appropriate and relevant to the call for a participatory evaluation of services. They allow to bring up certain topics that arise in the group situation from the account of a participant who recalls a similar situation or event. In addition, the group situation provided a reading of the relationships between users of different services, with different life experiences and very different social and educational levels.

The initial meetings contributed to the building of connections and the survey of themes as contents for the focus groups. In this period of research presentation, the guiding questions were shown to the group, who debated freely on each of the themes.

To start the meetings, three guiding questions were asked to bring researchers closer to the reality lived by users. Participants were asked if they participated in the development of their unique therapeutic project in the CAPS, if they accessed other points of the RAPS, and what other spaces they used to attend. Subsequent meetings were based on the demands of issues brought by the users themselves, which originated in the initial meetings and permeated various themes, such as user welcoming, approach in crisis situations, hospitality, unique therapeutic plan, support to/from family, affective network, social and daily support in the community, among others.

The research design envisaged two distinct paths of user participation. While reflections on the central theme of this study were surveyed and produced - to understand how users of different psychosocial care centers perceive as possible the actions of mental health in primary care from the understanding of the psychosocial care network - a space for the production of new knowledge coming from the participant's knowledge was opened as well. From this mode of operation, we shared knowledge about the various topics suggested by users.

The analytical exercise began in an experience of joint construction of narratives (Miranda et al., 2008), so that at each meeting the narration itself became a means for new looks and element of new debate for the group. Following the design proposed by these surveys, the analysis required

an understanding of the users' personal itineraries and networks, as indicated by Ricoeur (1988), moving away from a mere interpretation of the data collected. We tried to overcome dichotomous explanatory models between understanding and explanation, in search of agency between the phenomena in a narrative construction. To this extent, time and action are not ordered chronologically in the linear description of the event or situation portrayed. The narratives, in turn, were understood as human narratives, constructed in a group by the research participants and written by the researchers. Thus, the analysis of the constructed narratives was presented to the participants and constituted fundamental material for a hermeneutic phenomenological analysis (Gadamer, 1997) presented at the beginning of each meeting.

This process allowed the users themselves to point out the most relevant themes, as well as the way to their better understanding, leaving the information production process closely interconnected to the analytical moment and providing the birth of new questions and objectives for subsequent moments.

This study was approved by the Ethics Committee of the Federal University of São Paulo under Opinion No. 777.148/2014, in accordance with Resolution No. 441/2011 of the National Health Council.

## Results and discussion

The scenario in which the research was developed was one of the coastal cities of São Paulo, in the Baixada Santista. Baixada Santista comprises nine municipalities located in the coastal region of São Paulo. One of the milestones of the beginning of the psychiatric reform in Brazil was the intervention at the Anchieta Clinic in 1989, when, with the closing of the doors of the psychiatric hospital, a welcoming network was set up for psychological suffering based on Psychosocial Support Groups (NAPS), with 24-hour care service in open and community system. This experience stimulated the creation of mental health services as an alternative to hospitalization in several municipalities in the region (Campos; Henriques, 1997).

Despite maintaining a wide network of health services, some cities of the Baixada Santista face challenges similar to those of other places in the country, as in recent years the region has been living with the devaluation and decharacterization of mental health services (Luzio; L'Abbate, 2006). However, structures remain, and services continue to function, even though they have not carried on the initial mental health project for which they were designed or produced the effect of their original work. Current investments are quite different across the cities of the Baixada Santista.

The older participants, some of them inpatients "from Anchieta" at the time of the intervention, since then cared for in the equipment implemented at the time of the reform, are aware of the transformations that occurred. These participants reported that their arrival in the services was through hospitalizations in psychiatric hospitals and that only later they had direct inclusion in the recently inaugurated CAPS. In different reports, the participants have pointed out positive aspects of the nascent services; they also understand that the transformation was very fast, with *lots of things going on at once*; therefore, they feel that sometimes the service was founded on the pressure for improvement, in the sense that one should do a lot of things, have willpower and get out of the crisis (P1), as exemplified in a user's report during the study. In analyzing this narrative extract, the group has reported that the inventive moment of the services (with several inaugurations, actions and intense work by the professionals for reintegration of the users) was an important moment of transformation.

The younger participants followed different paths and indicated that they knew the existence of a network of municipal services. One participant started treatment at a former mental health clinic, brought by his brother to the specialized service. Two other participants said they had "opened" the services of their municipalities, because they arrived directly at the CAPS of their city when it was being set up. More recently, three participants migrated from private health plans to the CAPS. One of the participants was admitted as inpatient to the general hospital before arriving at the Care Center. Another got to know the service through a

visit of the community agent of the neighborhood health center. The other three came directly to the services by spontaneous demand or brought by family and friends.

By highlighting a rich routine of meetings in the mental health services and an impoverished social life, users value the service as an important place of exchanges, as in these reports: *my routine is the CAPS and my home. At home it is getting up, bath, coffee, wait for lunch* (P5). Or in other words: *our space is restricted to our mind, our sick mind. So the world gets limited to our mind* (P3). Or this user's testimony for the group: *And we get restricted, but then comes... the CAPS, there are colleagues, there are people, different people, there is an intern, there are friends* (P7). And in this way, they describe that they attend the CAPS like someone who goes to a beach, a restaurant, a club; they confirm a way of life full of meetings with professionals and CAPS users, but poor in relations outside. And when referring to other services, they reported: *The unit? There's one close to home, I think it is. When I need a dentist, I should go there. I'm talking to the CAPS staff. They help me more.* Or in this report: *I have a back problem and I go there, but they sent me to the CAPS, but they have only head doctor, OT [occupational therapist] and psychologist there, right?* (P4)

The users evidenced the differences among them and how their life history changed when they reached CAPS and even after being included in it. That is why they indicated that they do not perceive the articulation between basic services after entering a specific mental health service. Thus, upon entering the CAPS, they appear to have left the health care network to never return. In their reports, the interviewees demonstrate that the CAPS has achieved few partnerships with primary care, and they feel the need for greater contact with their families and other equipment in their territories, which demonstrates the difficulty of articulating mental health actions in primary care. Faria and Guerrini (2012) have also pointed out limitations, indicating the existence of a hegemonic scientific paradigm in the approach to psychological distress that places integrality as a new epistemological problem in this field of knowledge.

In this study, users reported seeking care in different services without referring to other health equipment, fragmenting the understanding of their history and the process of psychological distress, as well as the effects on their lives (consequently, there was no continuity in the actions from one service to the other). Others, because of their own personal challenges, followed solitary and unsuccessful paths in search of care for their other health demands or any kind of help. Nunes, Jucá and Valentim (2007) state that, despite the closer actions of mental health and health in general and the narrowing of the mind/body relation indicate a certain change in the view of the health-illness-care process, fragmentation still seems very present. The challenges are presented in both directions, both from the CAPS to primary care and vice versa. One of the participants, a CAPS user from an early age, when the centers were inaugurated, recently suffered a CVA that left him with psychomotor sequelae. His report shows the fragmentation of the services:

*The funny thing is that they've never seen my pressure was high before in over twenty years. Now I take a lot more pills than before, it got so hard. Now, in this wheelchair, I'm going after a physical therapist to help me, but it was the CAPS who managed to make an appointment for me, I could not go there alone (P1).*

An analysis conducted by Silveira and Vieira (2009) showed that the coping strategies of mental health needs in primary care tend to the production of intramural care, which emphasizes the *locus* of the service due to the supremacy of the biomedical model in the organization of actions, which leads to the risk of expanding the psychiatric knowledge-power in people's lives. Perhaps because of this, and even if in another context, intramural care also reappears with importance in the perception of the users in this research, as they report that, currently, being longer inside the service is more "pleasant" than the exposures and invitations to different situations of social gatherings that were previously provided to them.

In the above account, the user refers to a CVA and says he attends a health service several days a

week that has never considered that he had elevated blood pressure, plus the regular use of multiple medications. A study by Rodrigues and Moreira (2012), which analyzed the interlocution of mental health in primary care from the workers' perspective, points out that the primary care professionals themselves and also the CAPS have revealed that they face challenges in the encounter between work processes and services. The arguments of the workers interviewed indicated that mental health issues were understood as specificity of the psi field answered by the psychologists and psychiatrists involved (Rodrigues; Moreira, 2012).

The perspective reveals the contradiction of understanding the individual in its entirety, since psychological distress comes to be understood as a demand for psychiatric treatment or medication. Although the workers understand that the inclusion of mental health in primary care should have a perspective of comprehensiveness and an expanded view of the individual, they continued to work at a specialized level of intervention and did not feel able to care for mental health cases. At other times, primary care professionals sought the matrix support of mental health in order to understand the diagnosis, treatment or referral, but without considering a plan of action to be implemented in the territory.

Participants had great difficulty telling what other spaces they sought for health care, or even pointing out where else their lives were happening, how they proceeded beyond the health equipment or what kind of integration they had in addition to the CAPS. In the following extract, this recognition by users becomes clear: *It's really just being in the CAPS, we are always there. But there comes a time when it no longer makes sense, but we don't have other places to go and stay only there (P5)*. This assertion appears in a debate where users report they cannot rid themselves from this pathway that they follow every day, going from home to the CAPS and from the CAPS home. They keep their core friends in the service, not going *anywhere else*. Especially when they try to find answers to health demands in general, they find themselves unassisted in the basic health units of their neighborhoods, remaining in the specialized service. Also in the

research conducted by Frateschi and Cardoso (2014), participants did not identify the basic unit as a reference for mental health care. They said that they used this service as a supportive alternative, but said they did not receive continued attention. Participants infer that the basic health units refer users to a specialized service without exploring the range of actions that corresponds to this level of care, which causes patients to circulate through the services without receiving the necessary assistance.

Participants yearn to broaden their lives beyond the Care Center; however, they feel socially inhibited, keeping restricted spaces of social exchange, as explained in this statement: *[My] life [is] restricted. I go to the CAPS and, apart from that, I do not go out much* (P3). They also list some possible settings for other exchanges, such as the beach, squares, sports centers, or newsstand and bakery. They also mention the Professional Rehabilitation Section, a division responsible for reinsertion into the world of work, as a space where they meet other people, also users of other health services.

The group also engaged in a reflection on the different dimensions of life, such as family, friendships, work, leisure, education and other spaces where they can expand the psychosocial network. The majority report having daily appointments in the service; few report responsibilities or chores outside. One of them goes to the beach with some frequency, another practices physical exercises in a gym, and another attends prayer groups. With this analysis, these participants point out that in a network restricted to health services, where the CAPS often remains the only space for social exchanges, their life does not expand across the territory. Pande and Amarante (2011) highlight a new chronicity as an important challenge to be faced by the Psychosocial Care Centers. For the authors, recognition of the challenges and critical awareness are elements that can favor the transformations in mental health.

From this analysis, we confirm the pressing need for greater integration in the territory, one that allows an encounter with life and concrete needs during everyday situations in which

psychological distress is present. It is a necessary move to get rid of isolated procedures, which remain away from the concrete reality of existential territories of service users and which serve as forms of control and law enforcement, leading to an impoverished existence in both users and professionals (Kinker, 2012). Therefore, it is imperative to overcome important pillars of the clinical model founded on notions of disease, treatment for healing, and remission of symptoms. We thus should make use of clinical assumptions that get closer to the actual lives of the people assisted and productions of ways of living that are possible to them. For this, it is essential to call up new actors to activate other forms of living together, of being together and living in society.

Some important considerations are directed to users' understanding of the work processes of teams, for recognizing the work and the burden on professionals with daily services, filled with unpredictability that makes them work in specific situations with tasks resolutions, where everything becomes an urgent case to be responded to, and the planning or the fulfillment of what was planned loses importance in the dynamics of "putting out fires." In these reports, the CAPS is full of demands, so many that often their new needs are diluted and are not understood in their care projects.

It is essential to be aware of this information, which brings two nodes that can contribute to the understanding of the place of psychosocial care service: by understanding the CAPS as a place of articulation and maintenance of the individuals in their territory, one can also predict the challenge of the construction of a care plan to prevent chronicity and to expand the view on the issue. In this regard, we emphasize the importance of listening directed to users so that they can point out possible directions, indicating paths to follow. For some of these participants, their protected exchanges within the Care Center are powerful and articulate with the way they are building their lives, contributing to maintain their daily lives without going through new destabilizing challenges.

We know it is a risk to bring this analysis, by indicating, for some users, that this is a protected space, as in the following reports: *I only go to the*



beach with the girls [of CAPS], only when they go. And I go to the CAPS (P2); I'm not going alone to places. Now I just come here because it's safe (P6); I do not stay home. I stay in the CAPS all the time, I only sleep at home... I didn't want to say it, but I'm very distrustful (P2). By bringing her continuing distrust of places and people somewhat related to his psychological distress, this account also allows us to appreciate the protected space that sometimes users feel as necessary. It is from this place that new meetings can keep happening and the individuals who experience intense psychological distress can go building their ways of living without feeling alienated from their relationships. If we consider the words of the users and how they are evaluating the work in the services they attend, we could point out that a major initiative to be carried out by CAPS workers may be advancing toward a broadening of relations from the interactions already constructed with the users, thus entering the ways of the territory to launch users into new possibilities and meetings.

Similarly, the protected space of the service could favor the sense of safety in other places by expanding the comfort felt with the workers from exchanges that could extend to other situations of everyday life in other social spaces. In this case, the group that was structured from the research went on to attend other places and started important relationships for the construction of new social exchange processes. However, this same information can suggest a user's dependence on the service if both become hostages of this *nice place* (P2) that was constructed, sometimes with great difficulty, to those who experience great difficulty being in ample spaces and maintaining social contacts. On the other hand, it may also become comfortable for the worker to repeat and accept this condition of a certain dependence on the service as the only possibility of space for working, restricting his/her intervention to the health equipment.

Users' reflections indicate a major contradiction that needs to be addressed, because, as the issue of scarce spaces for meetings was raised, participants problematized an ambiguity they detect and experience, since there are personal challenges merged to the challenges of the teams, as in

the memory stimulated by the song *Debaixo d'água* [underwater] by Arnaldo Antunes (2001). The song was brought by a participant (P8), recorded on her phone. It was sung, read and remembered several times, whenever the topic came up. Sometimes, it fulfilled the role of background music that expanded every time the subject was mentioned, as in the following reports: *Underwater for me is the CAPS, which is all cool, underwater, there. But we have to breathe. You have to go out of it and breathe. [...] This song has a lot to do with our life really* (P8); *underwater is like we get: safe, without sin. But I had to breathe. Inside the CAPS everything is as comfortable as underwater* (P10); *So, I had to breathe, I had to breathe* (P8).

Reports such as this one indicate that there is a long way to go, because in several accounts, users on the one hand value the friendships built in CAPS, the cozy place, the attention they receive from professionals and the intramural exchanges in different workshops and film sessions in which they have the company of other users or opening activities for public spaces; on the other hand, this place of comfort can also be a space of restriction for other possible exchanges, those indicated as trade in goods, messages and affects necessary to expand the autonomy (Kinoshita, 2001), more effective for psychosocial rehabilitation and enabled only by exposure to different places and social exchanges with others.

In this scenario, it would be crucial to think about how to produce projects that can be welcoming, challenging and able to intervene positively in the lives of users, in proposals that include consideration of the way psychological distress affects people's lives and, at the same time, produce new challenges in the construction of a wider space to live. Proposals, in short, that build new relationships from those already established.

In several reports, the participants in this study confirm that nosology still maintains the care plan and is what keeps them "connected" to the CAPS. Often the symptoms or illness code prevails over speech or over what they intend to bring to the professionals. Some important words, which could be considered as suggestions or even as indicative for a review of treatment plans, are

heard as laments, complaints, or as negative exacerbation of a clinical condition. Consequently, the team's actions often are directed to the need for symptomatic remission, and their words remain muted due to the consideration given to their symptoms. This suggests that the responses indicated by the teams are still supported by the medical-biological perspective of understanding the phenomena of mental suffering, which does not seem to match what should be the object of work in this new context: the existence-distress in relation with the social. As a mental health care plan is implemented, it may be recognized that the sense of care should be developed in such a way as to expand the spaces of existing and performing affective exchanges. This is a constant challenge for the design of unique treatment plans that seek to see that suffering will not inhibit people's lives.

Moreover, it could be recognized that the care sense should occur in any of the health network points and, above all, that this sense should be established as a way to take care and not abandon the people to their own suffering condition and, at the same time, avoid the imposition of desires and goals other than theirs, thus enabling the discovery of a way in which the lives of those who live with a psychological distress condition is placed in the center of all health work, regardless of the place where the person is bound. More than that, this sense triggers the need for methods of caring in which life projects are considered, so that from them it is possible to produce transformative actions not only of the dimensions of the lives of people affected by the experience of psychological distress, but also of the workers involved in the field. Perhaps this is the achievement of maximum ideals of social transformation and utopia of a possible reality in which life in freedom can also be therapeutic.

## Final remarks

As we started this research, we aimed to learn and analyze how users of different psychosocial care centers perceived the actions of mental health in primary care. However, because of the methodological path chosen to meet the claim of “nothing

about us without us,” the research led to daily challenges, and new horizons opened. In recurrent reports of users, it was shown that regardless of the health equipment in which the user is received, the person who experiences mental suffering still aspires to be seen as an ordinary citizen looking for answers to their different health demands, and not as a particular bearer of a given “illness.”

Even when they direct their health demands in general to CAPS workers (because of the trust), users seek to be understood in the different dimensions of their lives, affected by the condition in which they live.

The legacy of the hegemonic clinical model perpetuated in the points of attention indicate that simplistic paradigms of human suffering still predominate that empty the listening to the suffering and its consequences in the user's concrete life towards an overvaluation of diagnosis, in search of complaint-conduct answers.

One of the elements that can contribute to breaking with this clinical model would be the removal of ontological assumptions that conceive of life from stability and getting closer to understanding the complexity of mental suffering, its consequences for people's concrete lives and their context. From the reports, it can be said that the boundaries of the constituent work of a psychosocial care network can be understood as one of the major challenges encountered by users in the construction of new ways of life from the construction of new pathways and progress towards a broad social inclusion.

It is also important to note that, from a methodological point of view, the attempt to respond to a demand of the users to be present and participate in debates on issues that directly involve them enabled the construction of intense relationships. This insinuates that this perspective brings up very particular aspects and differs from traditional methods of health research, to the extent that, among its contributions, there is the desire for insertion in different spaces that enable exchanges of knowledge and collective productions aimed at understanding the lived and shared situations.

The research became increasingly relevant to the participants, who, by appropriating the themes

and knowing their theoretical aspects, felt more empowered to discuss, debate and defend their opinions even in meetings and assemblies. Thus, user involvement proved to be a basic principle so that we can ensure participation in the next steps in this research mode.

The work developed in this study indicated, in addition to a participatory evaluation process, the advancement of a methodology that maintains the emancipatory intention. This group has shown that their experience is the fundamental knowledge to be shared in search of reciprocity and training precepts required by research that aims to move beyond academic spaces. When presenting the final considerations of the process of participatory research, participant-users built life projects with proposals that are structured in new designs of expansive trajectories that they never imagined before, but which, from the experience they had, they could envisage as possible. These proposals were socialized and included in a biannual plan; beyond what they had already decided in the scope of this work, participants defined the continued participation as informants in other studies, also showing a desire to suggest topics, collect data, discuss results and produce new texts. In teaching, they expressed a desire to participate in mental health classes offered by the university, suggesting that these classes could take place in open spaces, outside the academic setting.

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#### Authors' contribution

Both authors contributed to the writing of this article.

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