Challenges faced by users of mental health services: reflections on narratives about labor inside and outside workshops projects of income generation

Desafios enfrentados por usuários da saúde mental: reflexões sobre narrativas acerca do trabalho dentro e fora de oficinas de geração de trabalho e renda

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ABSTRACT: This article is extracted from a master's thesis, whose objective was to understand the labor experience of users of mental health services in workshops projects of income generation in Campinas, São Paulo. This is a qualitative research, from the perspective of social research, in which focus groups were formed with the participants of workshops from the Center for Workshops and Labor (Núcleo de Oficinas e Trabalho – NOT) – all six participants had labor experience previous to their entry in the workshop and brought some experiences of violence, humiliation and submission in work situations within the capitalist model. In this article, we show the narratives of these participants, which allowed us to learn the daily work in the workshops on labor and income generation from the perspective of users participants. Capitalist work does not contribute to the inclusion of socially vulnerable people. Understanding the work of users of mental health services as a citizenship right and the encounter between the principles of the psychiatric reform and solidarity economy is fundamental for the construction of worthy work spaces and for overcoming prejudice and stigma.

KEYWORDS: Mental health; Employment/psychology; Work/psychology; Social facilitation; Sheltered workshops/manpower; Narration.

RESUMO: Este artigo é extraído de pesquisa de mestrado cujo objetivo foi conhecer a experiência de trabalho de usuários da saúde mental em oficinas de geração de trabalho e renda na cidade de Campinas, São Paulo. Tratou-se de pesquisa qualitativa, dentro da perspectiva da pesquisa social, foram realizados grupos focais com participantes das oficinas do NOT (Núcleo de Oficinas e Trabalho), todos os seis participantes tiveram experiências de trabalho anteriores a entrada nas oficinas e trazem algumas experiências de violência, humilhação e submissão em situações de trabalho dentro do modelo capitalista. Neste artigo traremos as narrativas de oficineiros, que nos possibilitam conhecer o cotidiano de trabalho nas oficinas de geração de trabalho e renda na perspectiva dos usuários participantes. O trabalho, nos moldes capitalistas, não contribui para a inclusão de pessoas em processo de vulnerabilidade social. O entendimento do trabalho dos usuários da saúde mental como direito de cidadania e o encontro dos princípios da reforma psiquiátrica e da economia solidária, são fundamentais para a construção de espaços de trabalho dignos e de superação do preconceito e estigma.

DESCRITORES: Saúde mental; Emprego/psicologia; Trabalho/psicologia; Facilitação social; Oficinas de trabalho protegido/recursos humanos; Narração.

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INTRODUCTION

To understand the importance of labor for users of mental health services, we will briefly contextualize the Brazilian psychiatric reform, its interface with the psychosocial rehabilitation and its encounter with the solidarity economy.

The Brazilian psychiatric reform has the ethical principles of inclusion, solidarity and citizenship, and it is perceived as a complex social process that produces new subjects, human rights-holders[1].

To speak of the citizenship of people with mental disorders is to speak of the construction of substantial rights linked to the access to affective, relational and material exchanges, to the access to housing and production (producing goods and values). The guidelines proposed in psychosocial rehabilitation can indicate one of the possible ways to expand social interactions and, consequently, acquire citizenship, that is, the possibility of achieving the social contractuality of subjects[4].

The right to work has been restricted to "crazy" people for more than one century, through the irreversibility of hospitalization in psychiatric institutions, ensuring thus the control over inclusion and exclusion processes of these people in the labor market, using the inability and chronicity of the mental disorder as excuses[2]. This exclusion from the labor market created the need for the intervention and construction of real work spaces that allow the validation of their skills and knowledge, sharing the risks of being in a social structure[3].

In this context, initiatives of social inclusion through work are created for users of mental health services, composing the network of psychosocial care, with the objective of increasing the awareness of users and family members in the exercise of citizenship through initiatives articulated with the local resources, in the working fields/solidarity economy, qualification, education, culture and health[5].

Solidarity economy proposes an alternative to the capitalist mode of production, and its principles include the collective or associative property of capital and the right to individual liberty, in addition to self-management. The application of these principles results in unity, solidarity and equity[6]. There is a common matrix between the solidary economy and the psychiatric reform. Both come from the strength of social movements, in the struggle to develop a more inclusive and caring society, and in the search for strategies for coping with adverse market conditions that exclude socially vulnerable people[7].

In the last survey of supportive economic enterprises and strategies of labor and income generation developed in the field of mental health in Brazil, performed in 2013, a total of 1,008 initiatives were identified, being 352 from the Southeast region of the country. Of these experiences, 177 are located in the state of São Paulo.

After this overview of the process of psychiatric reform, psychosocial rehabilitation, the encounter between mental health and the solidarity economy movement, and the dimension of networks of enterprises that generate work and income linked to mental health, a few theoretical contributions will be shown regarding job and income generation in mental health.

Theoretical contributions of the field of labor and income generation

In a theoretical study performed on labor and income generation in mental health, with the objective of learning the meaning attributed to these projects by the users themselves, their family members and workers of the mental health network, it is noticeable that the workshops on labor and income generation and the enterprises can be important spaces in the emancipation process of users, improving self-esteem, self-awareness and expanding the social contractuality of these individuals. These workshops face the difficulty of formalization, due to the lack of a legal framework for social cooperativism in the country, which hinders the autonomy of experiences and its possible disconnection from health services.

Aranha and Fonseca[9] point out that work, by overcoming the place of treatment, is associated with social contractualities, with the access to a different social place, more inclusive and civic, and it becomes an alternative and an opportunity to develop a productive activity.

Delevati and Palazzo[10], after interviewing businesspeople in Rio Grande do Sul, conclude that the entrepreneurs have prejudiced opinions of irreconcilability and dangerousness and are favorable to the social restriction of mental health users.

Pacheco[11] points out the weaknesses in the conceptual and legal frameworks and in the mental health and solidarity economy public policies, which, in the daily life of these work and income experiences, bring challenges regarding the increase in income and the improvement of the living conditions of working users. The findings show that the cooperative and supportive work is a potential device for expanding and strengthening the contractual power, autonomy and social inclusion of the working users[11].

Lussi studied the conceptions about work produced by participants of Brazilian experiences of income generation and of an Italian social cooperative. The results showed that,

in the participants' conception, working is an important tool to social emancipation, as well as a resource that promotes self-knowledge, self-realization, right acquisition, citizenship and life production. However, these experiences are still fragile, isolated and with few conditions to generate income. The author says that projects that come from the context of health services may keep users in the condition of assisted participants instead of promoting emancipation and autonomy in the process of work. His conclusion is that projects of labor insertion should be emancipated from mental health services but work in parallel with the therapeutic treatment of users in health services[12-13].

Nicácio et al.[14] also point out the need to overcome the forms of intervention guided by the conception of "therapeutic work" and by the "protected work" logic. They place social cooperatives as a possible alternative in the effective inclusion of people who are at a disadvantage, both in social exchanges and in the production of values, rights and emancipation.

These theoretical explanations give clues about the importance of these work spaces for users of mental health services and the challenges yet to be overcome by these projects of social inclusion through work.

Keeping in mind the relevance of the right to associated and cooperative work of mental health patients, this article aims to discuss the challenges faced by them inside and outside workshops on labor and income generation.

Methodology

A qualitative study was conducted adopting the perspective of social research. Focus groups were developed as a tool to collect data, and the enunciation analysis was applied, which is considered, among the content analysis techniques, one of the most adequate to the qualitative health investigation.

In the enunciation analysis, the speech is conceived as word in act, and communication is a process in which, at the same time, senses are elaborated, and transformations are carried out. The analysis seeks to understand the meaning, the connection between the topics discussed and its production process[15-16].

The field of research was performed with workshoppers (users) that participate in workshops from NOT, located in Campinas, São Paulo. The experience of formation of the mental health network in Campinas, although contemporary to the experiences from the cities of São Paulo and Santos, occurs not only in the governmental sphere, but also through partnerships with other institutions,

which is the case of the Health Service Dr. Cândido Ferreira, currently responsible for the management of most services available in the municipality's mental health network. In 1990, with Law no. 6,215, the Municipal Health Secretariat signed a co-management agreement with the psychiatric hospital Dr. Cândido Ferreira, which became a mental health service with the proposal of reformulating the assistance and the creation of new services, being one of the oldest networks of care in the Brazilian process of psychiatric reform[17-18].

The workshops from NOT were created in 1991 from the occupational therapy sector of the day hospital in the Health Service Dr. Cândido Ferreira, where handicraft activities were developed. The first workshops developed agricultural, cooking and handicraft activities. In 1993, with the growth of the users demands for activities of labor and income generation, the workshop supply was extended, and the creation of an association was required to give legal, technical and financial support[17-19], which assisted in the financial administration of the workshops, the marketing of products, purchase of materials, issuance of receipts, as well as the payment of the workshop stipend(as the divisions of the profit generated by the selling of the products are called).

Currently, NOT has 13 workshops on labor and income generation. In total, 300 workshoppers attend these activities are identified as "workshoppers" because they learn a profession and, by participating in the workshops, they take on a new role – craftsmen –, besides the one of mental health patients.

The technical staff from NOT consists of workshop coordinators, with university degrees in health and nutrition, and by monitors with secondary education. These professionals are responsible for the workshop administration, the care of workshoppers, for teaching techniques to manufacture products and for organizing the production. All the workshops follow common guidelines to calculate products, the workshop stipend, the organization of groups and to conduct rounds of conversation for shared workshop management. The users receive a referral by the mental health network, of health and social assistance from the municipality for inclusion in the project. The management of the workshops has a democratic proposal, performed by the coordinators, monitors and workshoppers of each group according to the principles of the psychiatric reform and solidarity economy.

The research aimed to know the working daily routine in the NOT workshops on labor and income generation from the perspective of the participants. Six workshoppers participated in this research; five men and one woman, aged from 21 to 60 years. Regarding the

participants' education, two of them attended school until the fourth grade of elementary school, two until the eighth grade, and two completed high school. Three of them are being treated in CAPS III, one of them in CAPS A/D, and the other two in Health Centers. The participation time in the workshops varied from 7 months to 11 years. All participants reported work experience previous to their entry in NOT, in which they performed diversified activities.

This study counted with the collaboration of a user-researcher, who participated as an observer of the focus groups. She participated in meetings held before the groups, in which the research project proposed was discussed, as well as the objectives, the methodology that would be used, the dynamics of conducting focus groups and the guiding questions. In addition, she also contributed by giving her the notes and perceptions on the topics that stood out in the group discussions.

Presentation of data and discussion

After reading the transcribed material, it was possible to identify the main topics and the meanings of the participants' narratives. The topics that appeared intensely were the suffering generated by the illness and the great implications of personal and work relationships, in addition to the social stigma.

All six participants had work experience previous to their entry in the NOT workshops and reported situations of violence, humiliation and submission at work, with consequent physical and emotional exhaustion. A participant attributes his illness to these situations of stress and violence experienced at work.

The narratives also showed the diversity of meanings and the labor operation in workshops, as well as the differences in organization, management and in the relationships established in the workshops. After identifying the main topics in the participants' narratives, they were worked and transformed into basic units in an attempt to build work experiences in the workshops. Those basic units were organized in the following categories: a) illness and work; b) meanings attributed to the workshops; c) work management and organization in the workshop daily routine; d) self-perception and overcoming of illness and stigma.

Illness and work

The concepts of dangerousness and incapacity are attributed to mental illness, which only increases the stigma and the segregation of people with this diagnosis in work spaces.

"where I work, I had an outbreak once, people said, the man trusts this madman, and if I have an outbreak, they think you're not supposed to trust people with problems" (P4).

"I had postpartum depression. I was hospitalized, had my head shocked fourteen times, lost my memory, could not recognize anyone, it was a long process. Today, my son is already 11 and now I can say that I got a lot better, but I got better for my son. I was a health agent, then I got sick and was transferred to be an administrative assistant" (P3).

Violence in the workplace appears with intensity in the participants' reports, as they describe moments of humiliation and submission suffered to keep their job and ensure the family subsistence. One participant identifies situations of tension, violence and stress suffered in the workplace, with factors that contributed to the illness.

"in order to work, for those with a family, you have to humiliate yourself, because you need that job, you need the money, they humiliate you and you have to be quiet" (P1).

"I used to work as a security guard, and at night there are lots of robberies, lots of things, and then I got sick, I had a very strong depression, I even attempted suicide" (P6).

The relation between work and illness shows the responsibility of society and of psychiatry in the process of exclusion of people with mental health issues. The diagnostic labeling not only identifies a suffering condition and the belief in the impossibility of reversing the state described by the diagnosis, but also diminishes people's capacities. Any action from a person, read by the lens of the disease, "authorizes" the exclusion[2], which demonstrates the importance of the encounter between Brazilian psychiatric reform movements and the solidarity economy, regarding the expansion of associated and cooperative work, as an alternative to the exclusion of people with mental disorders from work relations.

Meanings attributed to the workshops

Regarding the work performed in workshops on job and income generation linked to the mental health network, the meanings given to this work in daily life appear in the narratives. This work, when compared with works developed prior to their entry in the workshops, is described as a less competitive and less stressful space.

"Outside NOT there are envious people, everyone wants to go over each other's head, they do not accept differences and are more stressed. In NOT, people are more relaxed, you don't see so much competition" (P5).

The therapeutic sense stands out, especially when the financial gain is low and the value of the exchanges in the group, the well-being, the reduction of idleness appears as justifications for the participation in the workshop. The perception of the workshops as a workplace increases as the work becomes registered, or the value of the stipend becomes more substantial – when they need to handle a large order, for example.

This participant reports the insufficiency of the stipend to his subsistence, stressing the importance of the workshop for his treatment.

"We do not come here because of the money, because, if you think about it, the money does not compensate for the stipend you get, it compensates a lot more for your treatment, for your head, for your mind." (P6)

However, another report shows that considering the workshop as therapy and as a source of income are not experiences that exclude each other.

I went there for the money as well, I wanted to get payed, to start working, but the therapy has been very good, it reunited me and my mother to talk about what was happening and we solved the problem, it was one of the best conversations I ever had, so, for me, money was important, but the therapy has been a bit more important than the money" (P5).

The following report points out that the stipend, by bringing real income and registration in the work card, can change the value family members give to the workshops, transforming the role of the workshopper, who starts being recognized by their relatives as someone who contributes to household expenses, as a worker.

"Before, my family did not accept this work, they thought it was a job for bums, that they didn't know anything. At that time I received a stipend, now I'm registered, I get my food parcel, I make a good amount of money, which helps at home, and I also receive some stipend money. Nowadays, they see how much things have changed, they are giving me strength and I feel good, the friendships are good" (P1).

Work management and organization in the workshop daily routine

In the workshops, the differences in rhythm regarding learning and participation in productive processes appear as a challenge to the work developed. This issue is an important factor of appreciation or depreciation of roles played by workshoppers, since there are tasks and functions that are not considered "work" by some participants – such as simpler activities, not related directly to the workshop production. This situation generates a lack of solidarity and empathy with one's suffering, who is disqualified for performing such tasks.

"some people there don't do anything, not that they don't do anything, they make some coffee, sweep, we notice that some people just can't do anything else, they just do that, and we let them, not us, the coordinator, the monitor lets them, let's leave them alone, they are nice people, let's leave them." (P5)

Another participant makes a counterpoint regarding the workshop operation, saying that, in his workshop, everyone organizes, cleans, makes coffee, regardless of the function. If someone has a hard time in the workshop, the subject is discussed and solved by everyone, which brings the connotation of a more cooperative labor, and people with any difficulty are not neglected.

"I work as an electrician in the workshop, but I do everything in the workshop, I sweep, make coffee, everything, we work as a community there, we are friends, nobody is neglected there, when something's up we make rounds of conversations, if somebody has a problem we solve it, it's always solved among us, so we don't have this kind of problem" (P6).

The narratives show that changes in the way of thinking work processes in the workshop can work around the issue of difficulty and "incapacity" of some people, developing cooperative work and providing evidences that respect, being recognized as workers, freedom of creation, discussions, making decisions in group and guiding the work by the principles of solidarity economy can provide more collaborative and participatory groups, in addition to making the processes more horizontal and more democratic in the operation and management of the workshops.

Self-perception and overcoming of illness and stigma

Prejudice and stigma appear in the narratives as consequences of the mental illness diagnosis and are the main challenges to build processes of empowerment and social inclusion for these subjects. The reports show the belief that prejudice can be linked to the old forms of treatment.

> *"because they see the treatment as it used to be, they don't see that the psychiatric reform has changed a lot, I think that's why they have this vision. When they say Cândido Ferreira hospital, they already imagine a place for people that are hospitalized, that are being observed, just like a psychiatric hospital, they don't know there's a workshop here" (P2).*

Another report points out that a way to reduce prejudice is by knowing the activities performed in the workshops, that the quality and beauty of the products manufactured demystifies the "crazy" image and would put them in the role of workers, of people that are finding alternatives to the problems they have had.

> *"To know the project, how the workshops work, to invite them to go there and see what we do, so they can leave and comment something very different, so they can see that our work is well done, so they don't arrive in the bus stop and say, look at the crazies, this is really bad for us" (P6).*

The participants discuss the importance of the anti-asylum fight movement, aiming at the end of asylums, the increase in investments in the mental health policies and a good management of these investments, improving the mental health networks.

> *"there's still a lot of asylums, where the person is locked inside, tied with chains, there's still a lot of those, that's why the anti-asylum fight needs to combat this, I don't know who's in there, who's going to take care of it, I don't know if it's going to be the same thing, if it's going to get better or worse" (P6).*

The participants report the power of the stigma and the need to face it. To this end, respect and dignity are essentials, in addition to the recognition that they are citizens and workers. Still on overcoming the stigma, there are statements about the extinction of asylums, which, according to the reports, should cease to exist both physically and in the imagination of people; about the investment in public policies; and about the choice of representatives in the public power.

CONCLUSION

Understanding the work of users of mental health services as a right of citizenship and the encounter between the principles of the psychiatric reform and solidarity economy are fundamental for the construction of decent work spaces and for overcoming prejudice and stigma.

The study shows the importance of an institutional democracy for the construction of a more autonomous life. "To provide health is necessarily to provide meetings focused on the connection of people, not by their pathologies, but by the experimentation of art and work"[20].

Social cooperatives and solidarity economic enterprises represent possible paths to include people with mental health issues, turning them into workers based on the logic of associated and supportive work.

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