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Mental health and solidary economy: the family in the inclusion through work

SAÚDE MENTAL E ECONOMIA SOLIDÁRIA: A FAMÍLIA NA INCLUSÃO PELO TRABALHO

SALUD MENTAL Y ECONOMÍA SOLIDARIA: LA FAMILIA EN LA INCLUSIÓN LABORAL

Carmen Lúcia Alves Filizola¹, Iraí Maria de Campos Teixeira², Débora Brechesi Milioni³, Sofia Cristina Iost Pavarini⁴

ABSTRACT

The Psychiatric Reform raises the issue of social inclusion through work from the perspective of Solidary Economy and family involvement. In city in the interior of São Paulo, a solidary enterprise of users of the Psychosocial Care Center was created. This qualitative study was performed with the following objective: to identify the composition and relationships of the families of members of the referred enterprise; to know the perception of the family members about inclusion of the users through work and the possibility of the family taking on a major role in this process. Interviews were performed using the genogram and ecomap of the Calgary Family Assessment Model as well as open questions about the families' perceptions, based on content analysis. Result show that most families are nuclear, headed by women. Most users do not have and family conflicts and those who do refer having conflict with their parents. They recognize the importance of work as a space for creating meanings and new relationships and point at several forms for co-involvement to take place.

DESCRIPTORS

Deinstitutionalization
Mentally ill persons
Family
Work
Rehabilitation nursing

RESUMO

A Reforma Psiquiátrica traz à tona a inclusão social pelo trabalho na perspectiva da Economia Solidária e envolvimento familiar. Em município do interior paulista foi criado empreendimento solidário de usuários do Centro de Atenção Psicossocial. Esta pesquisa qualitativa teve como objetivos: identificar a composição e relações das famílias de integrantes desse empreendimento; conhecer as percepções dos familiares sobre a inclusão pelo trabalho dos usuários e a possibilidade de protagonismo da família nesse processo. Foram realizadas entrevistas, utilizando o genograma e ecomapa Modelo Calgary de Avaliação da Família e questões abertas sobre as percepções das famílias, pautadas na análise de conteúdo. Os resultados mostram que a maioria das famílias é nuclear, chefiada por mulheres. A maior parte dos usuários não apresenta relação familiar conflituosa e os que relatam apresentar, referem-se aos pais. Reconhecem a importância do trabalho como espaço de criação de sentidos e novas relações e apontam várias formas para o co-envolvimento.

DESCRIPTORES

Desinstitucionalização
Pessoas mentalmente doentes
Família
Trabalho
Enfermagem em reabilitação

RESUMEN

La Reforma Psiquiátrica trae a tono la inclusión social laboral en la perspectiva de la Economía Solidaria y la involucración familiar. En municipio del interior paulista se creó emprendimiento solidario de usuarios de Centro de Atención Psicossocial. Esta investigación cualitativa objetivó: identificar composición y relaciones de familias de participantes del emprendimiento; conocer percepciones de familiares sobre inclusión laboral de usuarios y posibilidad de protagonismo familiar en el proceso. Se realizaron entrevistas utilizando genograma y ecomapa Modelo Calgary de Evaluación Familiar y preguntas abiertas sobre percepciones familiares, pautadas en análisis de contenido. Los resultados muestran que la mayoría de las familias es nuclear y matriarcal. La mayoría de los usuarios no presenta relación familiar conflictiva, los que las relatan se refieren a los padres. Reconocen la importancia del trabajo como espacio creativo de sentidos y nuevas relaciones, aportan varias formas de involucración participativa.

DESCRIPTORES

Desinstitucionalización
Enfermos mentales
Familia
Trabajo
Enfermería en rehabilitación.

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INTRODUCTION

The Psychiatric Reform ongoing in Brazil has entailed a new conceptual framework, which is psychosocial rehabilitation. More than a technique, this constitutes a set of principles and strategies to guide care for people in psychic suffering⁽¹⁻²⁾. Rehabilitation is also understood as a process that facilitates the restoration of people with limitations to the best possible level of autonomy and exercise of their functions in the community⁽²⁾.

The Psychiatric Reform process envisions the creation/construction of a substitutive service network for asylums and Psychosocial Care Centers (CAPS) constitute the axis of this network, aiming for users' social reinsertion through leisure, work, development of citizenship and strengthening of family bonds⁽³⁾. In this sense, the psychosocial rehabilitation process reveals the challenges of family involvement and social inclusion through users' work.

Social inclusion through work from the Solidary Economy perspective constitutes a new step in the Brazilian Psychiatric Reform process. The articulation between Mental Health and the Solidary Economy represents a recent construction that gained strength through a range of articulations between the Ministries of Health and Work, strengthened in the accomplishment of the *Income Generation and Work Experience Workshop of Mental Health Service Users*, held in November 2004⁽⁴⁾.

In this scenario, Inter-ministerial Decree No. 353/2005 was created, which established the *Workgroup on Mental Health and the Solidary Economy*. Among the guidelines appointed in this workgroup's final report, experiences are emphasized that permit the emancipation process of people with mental disorders, favor the participation of people from the community, encourage self-management and democratic participation and permit these people's inclusion in trading networks, opportunities and solidary economy forums⁽⁵⁾.

The Solidary Economy is born as an alternative to the capitalist economy, mainly as a way to generate work and income for those segments excluded from the population, as a mode for production and even social and cultural organization, with cooperativism as its main exponent⁽⁶⁻⁷⁾. The following are values of this other production and organization mode: solidarity, voluntary and informed adherence, collective democratic participation, self-management, cooperation, inter-cooperation, promotion of human development, attention for nature, attention to the community, ethical production and consumption⁽⁶⁾.

Although the Solidary Economy has stood out in Brazil in recent decades, there are countless inquiries about the contradictory and challenging nature of solidary enterprises.

At the center of this debate is the promotion of social emancipation, which is supposed to occur to the extent that, besides changes in the living conditions of the population inserted in the enterprises, the social fields are expanded in which non-capitalist values and organization modes exist. This perspective underlines the need to reinvent social emancipation, going beyond the economic sphere. Hence, it does not only involve the production, distribution and consumption mode, but the constitution of meanings that permit the reorganization of the human activities proposed by their alternative practices⁽⁷⁾.

In our context, in view of the emergent articulation between Mental Health and the Solidary Economy and the lack of concrete experiences of social inclusion through the work of users with mental disorders, in August 2006, a group was created for the production and trading of recycled paper. This group comprises users from the city's CAPS, who decided to call it Recriart.

The concretization of this group results from the partnership between the CAPS and the Federal University of São Carlos - UFSCar (Nursing Department and Incubator of Popular Cooperatives – INCOOP). This support comes from a team of CAPS workers and university members.

When providing support to the group, in accordance with the guidelines of the psychiatric reform, the support team has attempted to involve the family, as it can be a great partner in this process. The family can play the role of facilitator in encouraging the users, or even provide help/support in certain situations, such as: accompanying the family member to events/spaces of articulation among different actors in the process or participation in fairs to trade manufactured products.

In this context, the following questions guide the research development: how has the family perceived the user's participation in the enterprise? Would he be willing/able to participate and be a protagonist in the process? Who are these families? What is their composition and life context? Investigating this theme is relevant due to the lack of literature date on the family's involvement in the process of social inclusion through work and, what is more, from the perspective of Mental Health and the Solidary Economy.

OBJECTIVES

- To identify the composition and family relations of participants in the solidary enterprise Recriart;
- To get to know the family members' perceptions on the inclusion of users through work and the possibility of the family's protagonism in this process.

METHOD

The research is based on the premises of the qualitative research method, which applies to the study of history, relations of representations, beliefs, perceptions and opinions, products of interpretations human beings develop about how they live, construct their artifacts and themselves, feel and think⁽⁷⁾.

Operationalization and data collection

Place – the study context

This research was carried out in the Recriart Group. Today, 31 CAPS users are part of the group, whose production happens from Monday to Thursday, in the afternoon, in a building (Residue Center) at UFSCar. At least two support team members accompany both product production and trading activities. The later takes place at fixed points (at the university and in the city) and on community fairs. Sales revenues are divided monthly among users, according to the total number of hours worked. Group assemblies for collective discussion and decision-making are held monthly at the city's Public Center for Solidary Economy since its inauguration in 2008.

With a view to approaching the families to this experience, the support meeting held two meetings to present the functioning of the enterprise, its focus on the Solidary Economy and the products the group manufactured.

Subjects

Study subjects were the thirty families of the 31 CAPS users in São Carlos (SP) who were members of the Recriart group (two users are brothers). To invite them, CAPS workers were requested to indicate the relatives that were most present/close to the service. Before contacting the family, information on the research was reinforced, about the visit that would be made to their home and its objective.

In the end, 21 families participated in the research, as the others could not be contacted during the data collection period. At the time of the interviews, 25 relatives and 8 users were present. Most (15) relatives were women between 19 and 76 years of age and the relationship with the user varied between mothers, fathers, partners, brothers/sisters, niece, sister-in-law and daughter-in-law.

The interview

The interview with the families followed a two-step script. The first was the family's assessment, based on the Calgary Family Assessment Model (CFAM), a methodological framework proposed by researchers from the University of Calgary, Canada and emphasized as an important model in Brazilian mental health studies⁽⁸⁻¹⁰⁾. The CFAM comprises three main assessment categories: Structural, Functional and Developmental, with assessments accomplished through semistructured interviews⁽¹¹⁾.

The Structural Assessment, with data on family composition, internal relations and context, is carried out through the construction of two instruments, the genogram and the ecomap⁽¹¹⁾.

The genogram is a family tree that represents the internal family structure and provides rich data on relationships, health, education, occupation, religion, ethnic origin, migration, income and housing of family members. In the genogram, family members are included in horizontal series that indicate generation lines⁽¹¹⁾. Up to three generations were surveyed for each family. The ecomap aims to represent the family members' relationships with the broader systems and demonstrates the resource flow or lack and the family's privations. The primary value of the ecomap is its visual impact⁽¹¹⁾.

Functional Assessment refers to details of how individuals relate with one another and covers two aspects: the instrumental (related to daily life routines) and the expressive (related to circular communication among members). In Developmental Assessment, it is analyzed which of the five phases of families' lifecycle the family has reached. According to the CFAM, families go through five phases: leaving home, the couple's union through marriage, families with small children and adolescents, forwarding the children to leave home and families at the end of life⁽¹¹⁾.

The second step of the interview attempted to understand the family members' perception on the social inclusion process through work. It started with the following guiding question: *How do you see your relative's participation in the Social Inclusion Project through work?* To the extent that this question was answered, others were formulated, such as: *How have you perceived his/her involvement? What are the difficulties/facilities for his/her participation in the project?* And, finally: *Can the family contribute/participate in this process?*

The mean duration of the interviews was one hour each. They were tape-recorded and later transcribed for analysis. To guarantee the subjects' anonymity, all users' names were replaced by fruit names. For family members' names, only the first three letters were maintained, followed by flower names. The families were numbered from one to twenty-one and the interviews only took place after the signing of the Informed Consent Term.

Ethical procedures

All ethical care was taken. Approval for the Project was obtained from the Institutional Review Board at UFSCar - Opinion No 290/2007 - CAAE 2652.0.000.135-07.

Data analysis and results

To identify the families' internal structure and relations, each family's genogram and ecomap were elaborated. For the genograms, data show the family structure, living conditions and some social indicators, such as income and hous-

ing conditions. The ecomaps show the families' internal relations and support network.

To analyze family assessment data, the genograms and ecomaps made with each family were first digitalized and described. Then, analysis started, adding up data and transforming them into simple percentages. In this process, with a view to the research problem, the researchers attempted to highlight data on the family structure, internal relations and relations with the context, and privilege the families' living conditions and some social indicators, such as income and housing conditions.

As for the families' perception and possible protagonism in this process, the data collected during the interviews were submitted to thematic content analysis, considering the three basic steps: pre-analysis, exploration of the material and treatment and interpretation of the collected data⁽¹²⁾.

RESULTS AND DISCUSSION

Characterization of families under analysis

Based on the structural and developmental assessment, apprehended through the interviews and genograms and ecomaps, it was verified that most families (33%) are nuclear, headed by women (19%) and living in their own house (76%) and a prevalence of three to four people per house (30%). Large numbers of separations and fathers and mothers raising their children alone were found. As for income, most families (48%) gained up to two minimum wages, 43% more than two minimum wages and 9% did not provide this information.

The families under analysis reflect changes in the contemporary family, with new formats and a need for increasing subtitles to translate its current formation. This fact occurs be-

cause, even if still predominant, the traditional family, with the couple and children, is losing ground to non-traditional families with new arrangements. Among these are the following, with increasing percentages: consensual union, fathers and mothers raising children alone and divorces⁽¹³⁾.

The families' functional analysis also revealed that fifteen women (mothers, sisters or sisters-in-law), whom the users have a strong relation with, take charge of the greatest care responsibility. Despite the countless and critical transformations that have occurred in the past, women still assume the responsibility and demand for the socially attributed roles of procreating and raising healthy children who are prepared for the professional market and joint life⁽¹⁴⁾.

Regarding the internal relations and with the context, it was verified that most users (63%) do not present any conflicting relation with any family member, and, if present, the conflicting relation is with the parents, with whom most users (49%) live. As for the families' relations with the context, it is important to highlight the strong relation with the CAPS and, hence, with Recriart, besides the inferior use of leisure resources.

The family core is considered the first social network available to people in mental suffering and cannot be separated from the expanded network, as suffering in the former interferes in the latter and vice-versa⁽¹⁾. In that sense, intervening to improve the family core generates improvements in the expanded network, which is why bonding with the support networks has been emphasized to relieve the caregivers' overload and enhance these users' contact and social interaction⁽¹⁵⁾.

The genogram and ecomap of **Family 20, Pequi's family**, shown in Figures 1 and 2, together with their descriptions, exemplify the structure and relations of one of the families under analysis.

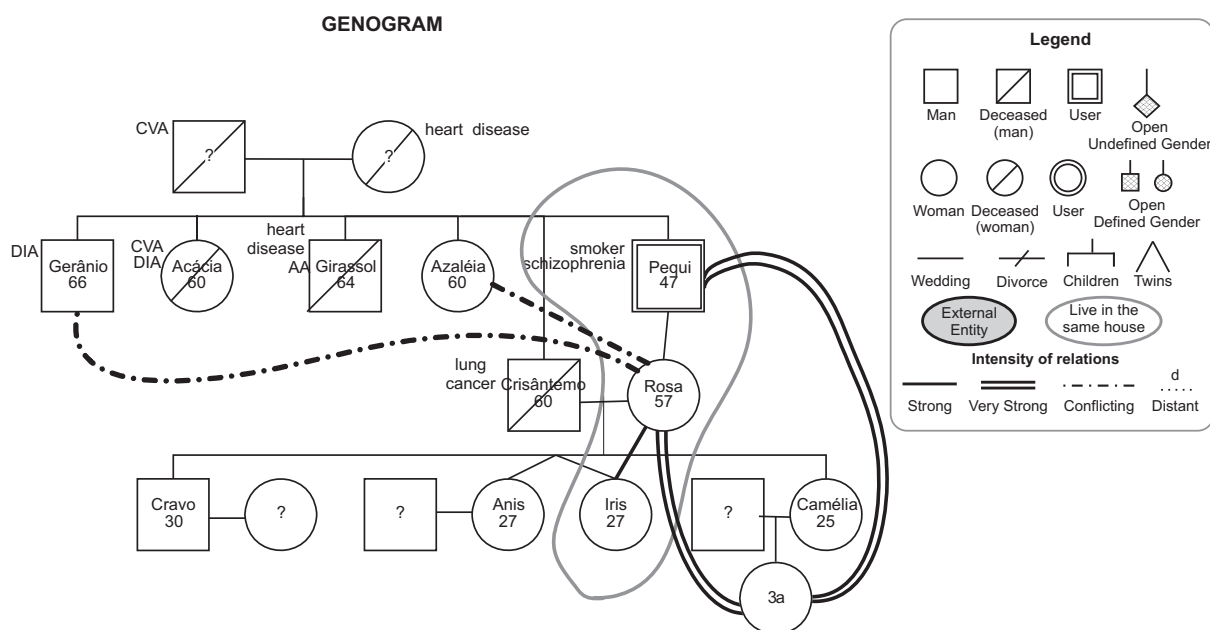


Figure 1 - Genogram of Pequi Family

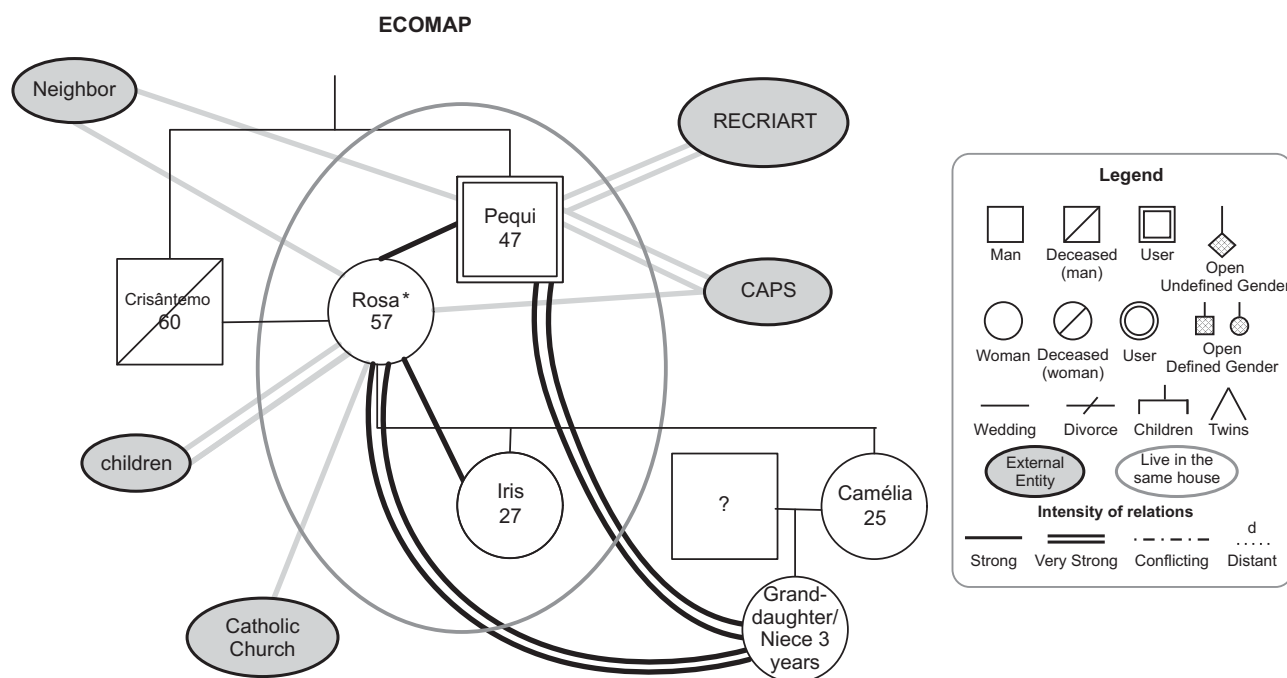


Figure 2 - Ecomap of Pequi Family

In Figure 1, it can be observed that Ter Rosa, 57 years old, is widow to Wil Crisântemo, who died at the age of 60. Wil Crisântemo is Pequi's brother, who had four other siblings: Dio Gerânio, 66 years old; Ana Acácia, who died at the age of 60 years; Dav Girassol, died at the age of 64 and Ali Azaléia, 60 years old. Wil Crisântemo and Ter Rosa have four children: Wi Cravo, 30 years old, married; Car Anis, 27 years old, married; Cam Iris, Car Anis' twin sister and, hence, 27 years old, single; and Ca Camélia, 25 years old, married, with a three-year old daughter. They have lived in the city for 25 years due to an employment proposal for the father. Pequi has been living with them for six years and, today, three people live at the house: Ter Rosa, Cam Iris and Pequi.

When Pequi's parents died, he was left alone at his parents' house in a city nearby. According to Ter Rosa's report, Dio Gerânio's sister-in-law was left in charge to take care of him, but treated him like a beggar. She also affirmed that he received financial support from the family, besides his salary. She tells that, one day, a neighbor called, saying that Pequi was being mistreated, had no more teeth and was dirty. The neighbors also affirmed that he screamed at night because he was hungry.

Ter Rosa reports: *He's no bother! I take care of him like a child. And I'm not his family.* She affirms that he was diagnosed with schizophrenia when he was 17 years old, that Pequi was hospitalized several times at a Psychiatric Hospital and that, after he came to live with her, he had never had any crisis.

The husband worked at an industry, in the graphical section. She was a seamstress, Pequi was a typographer

and Cam Íris worked in sales at a newspaper. The family's income corresponds to 4.81 minimum wages, she receives her husband's pension. Wil Crisântemo and Ter Rosa studied until the fourth grade of Primary Education. Pequi and Cam Íris finished Secondary Education.

As for the family's life context and the family's relation with the context, the family has its own home, in perfect hygiene and organization conditions, with eight rooms and an extra room being built for Pequi. Pequi already has a room at the house but, to guarantee his privacy and as he is the only smoker, they are making him a larger room in the back, with his own bathroom.

The relation with the neighbors is good: *They all like Pequi.* When the husband was ill, the neighbors offered to take care of Pequi, brought him food when she was at the hospital. The relation is also very good among family members. On Sundays, the children have lunch at Ter Rosa's house, the entire family meets. When people start to arrive, however, Pequi asks to have lunch first, gets his dessert plate and goes to his room to watch television. Ter Rosa affirms: *He does not like to eat with everyone.* Every day, she takes care of her three-year-old granddaughter in the morning. Pequi gets along well with the girl, as she loves to play with him. The only thing that bothers Ter Rosa is that he still insists on excluding himself. The entire family likes him, but he seems to feel intimidated by their presence. *Although things have improved a lot these days,* she affirms.

When Pequi does not go to Recriart, he comes back home earlier and goes to the room. In the morning, Ter Rosa takes care of her granddaughter and the house and,

in the afternoon, she sews a little. Sometimes her daughters visit her during the week. On Saturdays, she goes to mass in a Catholic Church and participates in rosaries in the neighborhood. She affirms that she would love to have Pequi participate in family meetings and have lunch together. She says he is very intelligent, that he talks well and knows what he is saying.

After getting to know the families' life context, the researchers attempted to identify how they could effectively act as protagonists in this inclusion process of users through work.

The families' perception – appointing the importance of work and routes for co-involvement

Data analysis on family members' perception in the process of their relatives' social inclusion through work, three thematic categories were apprehended: 1 – Assessing the user's participation – acknowledging the importance of work; 2 – Identifying difficulties and facilities in the family's and the user's participation; 3 – Identifying ways for the family to participate.

1 – Assessing the user's participation – acknowledging the importance of work

The family members acknowledged the importance of work for the users and perceive their interest in the activities carried out in the context of Recriart. They report perceiving that the users improved after their inclusion in the group. They also believe that work is relevant for users and, besides their small financial gain, they feel useful and valued, turning their work in the enterprise into a producer of existential sense. They also acknowledge improved self-esteem, as the group also constitutes a space that creates possibilities for new relationships, avoiding isolation at home.

I like him to participate, I think it's important! (Mar Alecrim, Family 2).

I think it's great this idea of work! Really great! (Ter Rosa, Family 20).

She improved a lot after she started there" (Jos Alfazema, Family 8).

He improved a lot after he started at the income generation... if it weren't for the generation, this time of day, he'd be walking around the house (Dol Amarilis, Family 11).

With the money she makes there, she buys her stuff (Anj Beladona, Family 18).

He's feeling more important. He said to my son that he's working! He said it distracts and that it's serious! (Ter Rosa, Family 20).

These reports reveal the importance all family members attribute to the users' inclusion process through work as a producer of existential sense and new relations. Besides creating existential senses, work can contribute in the structur-

ing of personality and identity, constituting a true sense of life as, in many situations, most time is spent working⁽¹⁶⁾.

Positive factors deriving from insertion in work, such as the valuation of human beings, recovery of self-esteem and significant changes in the relationship with relatives and friends were also evidenced in a research on the influence of work in CAPS users' lives⁽¹⁷⁾.

Thus, the emancipatory nature of the users' inclusion process through work is emphasized, although the emancipation generated in this process cannot be considered yet in its most radical sense; that is, of producing, besides changes in the living conditions of people inserted in the enterprise, the expansion of the social fields in which non-capitalist values and organization modes exist⁽⁷⁾.

2 - Identifying difficulties and facilities in the family's and the user's participation

This refers to positive and negative aspects the family members see with respect to the inclusion process through work. Facilities refer to the care the CAPS provides and the possibility of listening by professionals.

No, there's no difficulty at all, they facilitate everything [...] And, something else, talking with a professional is different. They are seeing everything, advising [...] (Fat Bonina, Family 14).

Regarding the difficulties, lack of knowledge on how to support the group is acknowledged, as well as family members' overload in care delivery to users, when these face difficulties to get integrated in the enterprise.

I don't know how to help. He seems like a big baby and I don't have time to take care. My life is targetless actually. I would like to have time for him. I would like him to be independent (Neu Campânula, Family 21).

Not having the medication is difficult. He fights, doesn't want to go, then, it's difficult (Ver Clematite, Family 3).

I think he doesn't like it because of the loaded bus... the difficulty is really the bus part... but he's afraid and says that he wants to go by car (Ela Ciclame, Family 13).

In interaction with the patients and in daily management, the family members suffer in psychological and material terms and in the organization of their own life⁽¹⁾. Coping and accepting are the main difficulties the relatives experience, who then start to suffer from transitory social disabilities and persistent disorders in couples' relationships⁽¹⁾. Currently, however, a consensus exists about acknowledging that the presence of social networks interferes in the maintenance and promotion of individuals' and families' quality of life⁽¹⁸⁾. Therefore, the importance of family intervention and families' co-involvement in rehabilitation projects, so that the family turns into the protagonist responsible for the treatment, organization and rehabilitation process of its relatives⁽¹⁾. In this sense, the need was identified for the support team to pay special attention to articulation with the service, so as to in-

volve the families under analysis with a view to strengthening the support team.

3 – Identifying ways for the family to participate

The third category presents how family members participate and are willing to continue participating in this process. The family's involvement can occur through meetings, help in manual work, sales and dissemination of the group, or also through prestige, encouragement and acknowledgment of users' productive capacity.

I do crochet, tapestry, I can help to finish off their things, right. To be prettier. If we talk we can see how to help, yes (Ver Clematite, Family 3).

I would like to go to meetings more, I went there once at the train station and I liked it a lot (Ver Clematite, Family 3).

During the other meeting I proposed my participation, including in sales. Offer in stores, to people I know, leave the products for them to get to know, right (Ros Cardo, Family 4).

... I think that going to the fair, disseminating [...] Like, in disseminating the people's work [...] The CAPS' work should be disseminated, like a testimony, that they help people not to go through that (Ger Bonina, Family 14).

I pay attention to what she does. I think that everything we do, if we have a big target, and the family supports it, we do it well (Ant Centáurea, Family 7).

During the fairs, you can take the family to grant them more prestige (Rod Glicínio, Family 5).

The family could help by encouraging! (Emi Gérbera, Family 6).

You acknowledge that they can do something. Nobody knew what to do with them. You value them" (Ger Bonina, Family 14).

The statements evidence the willingness/availability for co-involvement in the rehabilitation process of their family members. Among support forms, the importance of hav-

ing the family acknowledge users as subjects with skills is highlighted, granting them contractual power, broadening their autonomy, creating possibilities for participation in the social exchange process⁽¹⁹⁻²⁰⁾.

CONCLUSION

This research aimed to get to know the families of CAPS users who were members of a work and income generation group. Another group was to dialogue with the families to understand family members' perception about participating in this enterprise, in view of the importance of involving them in this process.

To get to know these perceptions, the methodological framework of the CFAM was used, which permitted not only knowledge on the families' structure and relations, but also the researchers' approximation with the families. It also enhanced knowledge on their feelings, conditions and difficulties, permitting a moment of listening, fundamental for these families' involvement process.

Among the questions raised, it was remarkable that, despite the overload they experienced, most families are willing to participate in this process, identifying several ways for co-involvement. Among support forms, the acknowledgement of people in psychic suffering as productive beings is highlighted, restoring their power to participate in social exchanges, as the true meaning given to psychosocial rehabilitation.

Although most families belong to poorer economic classes, besides the financial return, they acknowledge the importance of work as a space to create meanings, exchanges, new relations, and as a relevant factor to maintain their family members' quality of life. These evidences reinforce the importance of work as a factor of social emancipation, the meaning attributed to psychosocial rehabilitation as a process to reconstruct life, dreams and projects of patients with mental disorders and the complete exercise of citizenship.

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