Research Article
Artigo de Pesquisa
Artículo de Investigación

DOI: http://dx.doi.org/10.12957/reuerj.2019.26923

Family relationships of people with mental health problems: processes of social exclusion and inclusion

Relacionamentos familiares de pessoas com transtornos mentais: processos de exclusão e inclusão social

Relaciones familiares de personas con trastornos mentales: procesos de exclusión e inclusión social

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ABSTRACT
Objectives: to identify and to analyze the processes of social exclusion and inclusion that happen in the family of the person with mental disorder. **Method:** qualitative approach was used as a research methodology. Subjects of this investigation were 17 users of a Psychosocial Care Center, in the city of São Paulo, Brazil, in addition to 12 people from their social networks. For data collection, semi-structured interviews were realizes and, for data analysis, it was the discourse analysis technique. **Results:** social exclusion of users of a Psychosocial Care Center in the family can occur due to social disruption and distance, or in a more subtle way. However, to the extent that users are valued and find a role in the family, relationships of exchange and mutual help are established. **Conclusion:** relationships are developed in a dialectical process, going through conflicts and situations of reciprocity, with the family being the main social inclusion network of these people.
Descriptors: Mental health; family relations; interpersonal relations; social participation.

RESUMO
Objetivos: identificar e analisar os processos de exclusão e inclusão social que acontecem na família da pessoa com transtorno mental. **Método:** utilizou-se a abordagem qualitativa como metodologia de pesquisa. Os sujeitos desta investigação foram 17 usuários de um Centro de Atenção Psicossocial, da cidade de São Paulo, e 12 pessoas de sua rede social. Para a coleta de dados foram realizadas entrevistas semiestruturadas e, para apuração dos dados, foi utilizada a análise do discurso. **Resultados:** identificou-se que a exclusão social dos usuários na família pode ocorrer pela ruptura e distanciamento ou de uma maneira mais sutil. Porém, na medida em que os usuários são valorizados e encontraram um papel na família, se estabelecem relações de troca e de ajuda mútua. **Conclusão:** os relacionamentos se constroem em um processo dialético, passando por conflitos e situações de reciprocidade.
Descritores: Saúde mental; relações familiares; relações interpessoais; participação social.

RESUMEN
Objetivos: identificar y analizar los procesos de exclusión e inclusión social que ocurren en la familia de la persona con trastorno mental. **Método:** se utilizó el enfoque cualitativo como metodología de investigación. Las personas de esta investigación fueron 17 usuarios de un Centro de Atención Psicosocial, en la ciudad de São Paulo, Brasil, además de 12 personas de sus redes sociales. Para la recopilación de datos, se realizaron entrevistas semiestructuradas y, para el análisis de datos, fue la técnica de análisis del discurso. **Resultados:** la exclusión social de los usuarios de un Centro de Atención Psicosocial en la familia puede ocurrir debido a la interrupción social y la distancia, o de una manera más sutil. Sin embargo, en la medida en que los usuarios sean valorados y encuentren un papel en la familia, se establecen relaciones de intercambio y ayuda mutua. **Conclusión:** las relaciones se desarrollan en un proceso dialéctico, pasando por conflictos y situaciones de reciprocidad, siendo la familia la principal red de inclusión social de estas personas.
Descriptores: Salud mental; relaciones familiares; relaciones interpersonales; participación social.

INTRODUCTION

Family relationships are the main form of social bonding for people with mental health problems, and they are, in general, the individuals that users of Psychosocial Care Centers (Centros de Atenção Psicossocial, CAPS) can count on, forming the primary sociability network.

The family is part of the micro-variables in the user's context, influencing their possibilities of social participation. The relationship between family members and users influences the psychosocial rehabilitation process, family members can provide support for users to build their daily life in the community, or they can cause a sense of helplessness and loneliness.

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Received: Jan 16th 2017 – Accepted: Nov 12th 2019

DOI: http://dx.doi.org/10.12957/reuerj.2019.26923

This article aims to assist in the reflective process on the family role in the mentally disordered person's social exclusion and inclusion process, in the context of Psychiatric Reform, which are essential aspects for the nursing care promotion in the mental health field. Thus, the objectives of this study were to identify and analyze the processes of social exclusion/inclusion that take place from the family nucleus.

LITERATURE REVIEW

In the model centered on the psychiatric hospital, with prolonged hospitalizations and frequent readmissions, there is a greater chance of relationships with family members and other people in the social network becoming fragile, resulting in the isolation of people with mental problems[1-6].

However, with the changes that have occurred since the Psychiatric Reform, there has been a reduction in psychiatric beds, with users being referred to decentralized and community-based mental health services, redirecting the health care provision from a central service to a wide range of health equipment [2-7]. Thus, the families of people with mental problems have been faced with a new treatment form that is no longer centered on admission to a psychiatric hospital[8].

These transformations in mental health care have led to an increase in the commitment demands of the mental problem person's families, significantly altering the path of their participation in the care process. Family members have become key partners in the care of users[9,10], as they can contribute to their sense of security and support[11,12], as well as making it possible to provide care in contexts less stigmatizing than the psychiatric hospital[11-14].

However, family members are still in the process of developing a "way of perceiving the person who experiences this illness as an integral, multifaceted, historical human being inserted into the world of daily life"[15:52]. For relatives, it has not been a very simple process to adhere to the treatment perspectives advocated by the psychosocial paradigm[14]. In this way, inserting the family in the treatment of the people with mental problems tends to reduce hospitalizations, ease conflicts and improve the quality of life of everyone at home[(9-11)].

In this process, it is important for families to be heard, to share their experiences, their anxieties, and their victories, and to reflect on their relationship with the family member who has fallen ill and on their strategies for dealing with the disease[6], with the aim of reducing the overload[16-21]. Therefore, investing in the family network also encompasses the subject's social network, favoring psychosocial rehabilitation and the expansion of affective and material exchange spaces.

METHODOLOGY

The qualitative approach was used as the research methodology. The subjects of this investigation were people with mental problems, users of the São Paulo's western region CAPS II, who were living in the community and facing the challenge of social inclusion and building a meaningful life, and people from their social network.

The CAPS director was asked to perform a characterization of the service and identify practices that aim to promote social inclusion. Among the users who participated in these actions were those: enrolled in the institution for at least one year; conscious, oriented in space and time, without moderate or severe cognitive deficit; who agreed and were willing to participate in the research, and who were present on the data collection days. To preserve the participants' anonymity, they were identified using the letter U for the user and the letter R for users' social network individuals

Each user interviewed was also asked to indicate a person from their social network to participate in the survey, excluding the CAPS technical team (family members, people from institutions such as hostels and churches were indicated, and 1 of the interviewed indicated a neighbor). These people made it possible to report on the social inclusion of users in the community's vision. The selection criterion was the user's agreement to participate in the interview with the indicated person as well as their interest and consent. A total of 29 interviews were conducted, 17 with users and 12 with people from their social network.

For data collection, semi-structured interviews were conducted with CAPS users and people who are part of their social network. The semi-structured interview uses closed and open-ended questions and offers freedom for the interviewee to discuss the proposed topic.

CAPS, the study scenario, was informed about the objectives, purposes and methodological procedures of it and agreed to the development of the research on the place. The project was also approved by the Ethics and Research Committee of the Municipal Health Secretariat, which authorized the development of the research (Opinion No 143/08). The interviewees signed an informed consent form, authorizing the use of the data collected in the aforementioned survey, and confidentiality was guaranteed regarding their identities.

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The Discourse Analysis was used to determine the data, which considers that the discourses are related to the society's culture, reproducing what a social group has to say. Men identify with what they say and in the process, they build themselves as subjects[22]. Discourses must be thought out from the historical and social processes that constitute it. The historical-social place in which the enunciating subjects of a given discourse find themselves involves the context and the situation in which they are and intervenes in the discourse production.

After data collection, the interviews were transcribed in full, constituting a text for analysis. From the repetitive reading of the text, the authors got used to the data, questioning and writing down interesting data for the analysis. The data analysis work occurs from spoken sentences, delimiting and establishing a correspondence between the sentences' fragments; in this process, patterns, analytical topics, and discursive qualities were identified. An initial analysis was carried out in the process of writing, reading, and analysis. The analysis was examined with colleagues from the research group, and after their considerations, the final analysis was conducted[23,24].

The empirical category Family: processes of social exclusion/inclusion was identified. Thus, this article deals with this empirical category with the focus on the social support offered by the family.

RESULTS

Family: processes of social exclusion

It is common in any family for conflict and tension to occur, as it is in the families of people with mental problems. However, when family conflicts become exacerbated and more difficult to resolve, there is a greater possibility for the social exclusion of the person with mental problem to occur.

One of the forms of social exclusion experienced by people with mental problems is the estrangement of family members, who withdraw from social contact with the user, abandoning the relationship. In this way, family members are no longer a reference for the user, a person they can count on or maintain an affective exchange relationship with. Distancing may occur with a decreasingly frequency of meetings with the person with mental problem, with each more spaced contacts, as reported below.

> *The father is a more distant figure. He's not a person who participates in his life. (R13)*

Another form of family distancing may occur due to the superficiality of contact, which is consistent with the ideology of user's prejudice and devaluation, as exemplified by people in their social network. This relationship form is also a form of social context reproduction, of a society with little solidarity, where people can value their work more, for example, than their social relations' network.

> *And with other people, with my sister, for example, he has a superficial coexistence. Because he has more contact with me. With the cousins it's just 'Hi, is it all good, how are you?', and that's it. (R8)*

Faced with the difficulties of relationships and the lack of understanding about how to deal with a person with a mental problem, often the family's distancing from the user occurs explicitly, in the form of a rupture.

> *The other son I have. When M. started showing up with this disease, he simply moved away from home and got very far from the family, even disappeared. (R4)*
>
> *So it's difficult, living with the siblings is complicated, they do not get along. He [user] prefers to stay in this situation [living in a hostel] rather than living with his siblings. (R8)*

Another difficulty the family faces is the overload they suffer due to the presence of a person with mental problem. Family members feel overwhelmed in every way: physical, financial, time demand, and the emotional overload of those who live their daily lives with the person and invest their efforts in trying to help them develop.

> *[About relationship with the user] I am tired, I am getting beyond the stress. Because he is a person who sucks me all energy out. (R15)*
>
> *Because with or without money, you have to hold his bar. I cannot abandon him. (R7)*

The forms of social exclusion of people with mental problems in the family can occur objectively, by the rupture, distancing and lack of support, or subjectively, by how the relationship is built, in a contact permeated by feelings of fear, tiredness, overprotection, and overload. Thus, the family shows that it often needs help from health professionals to promote the user's social inclusion.

Furthermore, it is important not to blame the family for their way of relating to the person with a mental problem, but to understand the complexity of mental health care and the central role that family members play in this process.

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Family: social inclusion processes

On the other hand, it was also possible to identify several advances regarding the possibilities of social inclusion that occur from the family nucleus. Despite the conflicts faced in day-to-day relationships, family members have shown their potential in helping and establishing exchange relationships with users.

The reception of the family is one of the important aspects of the social inclusion of the person with mental problem because when they are welcomed they can feel that they belong to a social group, breaking the isolation that is one of the paths that leads to social exclusion.

> *It's because I have a welcoming family, because if I did not have a family, a real family, which is the main thing you have... If I did not have a family like that, maybe I would be crazy already. (U10)*

Another important aspect regarding family members is that they help users to face prejudice. They have the potential to lend their contractual power to the user and to provide support for the user to circulate in society and establish links not only with the family. If family members can break the prejudice about mental health problems in their relationship with users, this new way of dealing with the person begins to appear in society, serving as a model. The family nucleus can be a starting point for users to face prejudice against mental health problems and build their way towards social inclusion.

> *And together with my husband, I was able to show my face and show my son to the world. That he was ill but no different from the others. That he could be at any place. (R4)*

It has also been identified that one of the supports offered by relatives is the financial one. In the context where most people with mental problems experience a reality of financial disadvantage, family members often need to help users so that they have access to the minimum material conditions.

Although the literature emphasizes the overload of the family that needs to help financially the member with a mental problem, on the other hand, in the present work the speeches also point out the positive side of this help from relatives, which is a form of social support and user's inclusion in the family nucleus.

> *[About material help] Usually, it is my physician nephew. And also my sister. (U10)*
>
> *My sister always helps me a lot. Sometimes, she buys what is needed. (U11)*

The relationship with family members has also been pointed out as important in helping people with mental problem to move around the city. Family members offer company to the users so they can attend different social spaces, fundamental support that helps people with mental problems to interact and participate in social environments, helping in the social inclusion process of this population.

> *I go out with my mom anyway... we go to the church and come to CAPS. (U13)*
>
> *I talk to her [aunt], or go out with her. We went to the beach one day, I traveled with her. (U8)*

Also, the user's treatment at the CAPS helps family members to build their relationship with the people with mental problems, as they receive guidance from the technical team and share with the institution responsibilities which relieve the family burden. The fact that users do not have the day focused solely on the family, but have other options for activities and social contacts is a factor that helps the relationship with family members at times when they are together.

> *And it gives a relief to the family too, because everybody gets very stressed out when the person stays all day, there must be a little break, you know. (R15)*
>
> *It got better a little bit[the relationship with the family] as the psychologist has been orienting her. (U6)*

In this context where users gain more autonomy, are valued and empowered, they may find a social role in the family nucleus, a social function that belongs to them, a comfortable place in the family dynamic. If the person with a mental problem is not seen as incapable, they have the opportunity to find a new identity in the family, not just the identity of an ill person who needs care.

> *So in this [the house] construction, I included R. a lot. And I got used to having R. like this with me, his opinions are so good. Look, I did not imagine. It was one of the most beautiful things that ever happened to me. (R12)*
>
> *I often have to go on a trip, and he proposes to stay in the house and take care of the dogs. So he likes to help. So he feels useful, so I think it makes him happy, he feels important. (R8)*

It must be stressed that one of the main questions about family relationships is how this relationship is made, and it is clear that often the user will need help and care from their family members and the availability of families to help them is a positive aspect. However, one must be careful that this relationship does not take away from the user value and contractual power, that they are not seen with pity and as someone who should only be careful.

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DISCUSSION

Mental health problem is a phenomenon little understood and accepted and often feared by relatives[8], who report difficulties brought by living with the individual with mental problem. They reflect on the lack of time, the lack of specific knowledge about the mental health problem, the difficulty in dealing with the crisis and the changes in family dynamics after the illness situation, which converges with the scientific literature on the subject [8-21].

The relatives report feelings regarding the overload that the caregiver's role gives them, and at the same time, they show affection for the ill relative. They report attitudes that range from availability for the reception to extremely tiredness due to excessive demands from the person with mental problem, characterizing the overload widely discussed by several authors[16-21; 25].

In this dialectic process of social exclusion and inclusion, family members may also find it rewarding to care for the person with mental problem by seeing them improving and establish themselves in the community, thus, family members and users can develop a comfortable, supportive and loving relationship[26], promoting, then, psychosocial rehabilitation.

The relationship with family members is something established over time, built from the coexistence in daily life. The subject's history is intertwined with their social network people's history, with various moments in which the presence of family members was marked positively or negatively.

Everyday life is the family life's arena, where family members connect from the activities of daily life[27]. The family constitution, as the subject's particular social network, also makes social organization possible, since it is from the family that the housing nucleus is formed, that child education is structured, and often that public health services are offered.

To the extent that users are valued and have found a role in the family, relationships with family members become exchange and mutual help relationships, breaking with the dynamics of the caregiver and the one to be cared for. The user and their family support each other and can share life's problems. The person with mental problems ceases to be a constant burden for the family member, building relationships beneficial to both the user and the people in their family, breaking the cycle of isolation and segregation.

Social inclusion means going from being a person who only receives, a charity case, to becoming an active member of society, who can contribute with others[27]. In this scenario, the person with mental problem becomes a citizen with the right to social participation in the city where they live with family and friends[4].

However, families often need organized social support to be able to articulate internal resources to deal with situations related to mental health proplem[28,29]. In this context, the greater the number of hours together with the users, the greater the level of overload perceived by the caregivers. When users leave home and attend a daily attention program that helps them deal with day-to-day problems and improve their autonomy and social skills[29], family members feel less overwhelmed[16-21]. In this way, nurses and other health service professionals should be attentive to promoting approaches that follow the aforementioned logic, in addition to offering therapeutic listening[30] to family members in order to contribute to reducing the daily burden.

Thus, nurses and service teams must be prepared to have not only the ill person as the object of the work but, due to the paradigmatic change that has occurred in the mental health area, the attention focus must be broadened, including the family as a central element in mental health care[15;30].

CONCLUSION

Family members are imbued with the values of common sense, historically built, that put the person with a mental problem in a place of devaluation and disability. With the onset of illness these common sense values influence family relationships.

However, despite the difficulties in the relationship with family members, the family was also pointed out as the main social support network for this population. There is a contradiction in relation to the family which, while it may exclude, also represents one of the main supports for the person with mental problem in their social inclusion process.

In the health care of people with mental problems, it is necessary to help them so that they can increase their contractual power in all the places where they circulate, starting with the family nucleus itself. It is possible that by transforming the forms of relationship with people with mental problems, a change in the form of social inclusion consistent with the current process of psychiatric reform will be achieved.

DOI: http://dx.doi.org/10.12957/reuerj.2019.26923

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