

From individual to collective: occupational profile of users of a Psychosocial Care Center*

Do individual ao coletivo: perfil ocupacional de usuários de um Centro de Atenção Psicossocial

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ABSTRACT: The occupations performed by individuals with mental disorders can inform us not only about the subjects' everyday lives, but also about how society has dealt with mental health problems. Thus, the objective of the present study is to know about the occupation of people with mental disorders in relation to the individuals' singularity, social network and their relationship with the social context. The study was performed by using the qualitative research methodology. Interviews were conducted with users of a Psychosocial Care Center II (CAPS), located in the city of São Paulo, and people from their social network. The semi-structured interviews were used as a means of investigation, and the data were analyzed using discourse analysis. It was noted that the occupations are key for the individuals to build their identity, and, while engaging in occupations, the users also build social networks. It was also observed that the everyday lives of people with mental disorders can be deeply and negatively affected by an unfavorable social context that offers neither support nor conditions for the individuals to engage in occupations that they consider significant. Thus, occupations comprise and build the thread that weaves the social inclusion and exclusion processes of this particular population.

KEYWORDS: Mental health; Occupational therapy; Social marginalization; Social support; Occupations.

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RESUMO: As ocupações realizadas pelas pessoas com transtorno mental podem nos informar não apenas sobre a vida cotidiana dos sujeitos, mas também sobre como a sociedade tem lidado com o transtorno mental. Assim, o objetivo do presente artigo é conhecer as ocupações das pessoas com transtornos mentais em relação à singularidade do sujeito, a sua rede social e na sua relação com o contexto social. A metodologia de pesquisa qualitativa foi escolhida para a realização da pesquisa em que foram entrevistados usuários de um Centro de Atenção Psicossocial II, da cidade de São Paulo, e pessoas de sua rede social. As entrevistas semiestruturadas foram utilizadas como um meio de investigação, e para a análise de dados foi utilizada a Análise de Discurso. Verificou-se que as ocupações são centrais para a construção da identidade dos sujeitos e que no processo de engajamento em ocupações os usuários também constroem redes sociais. Também se observou que as pessoas com transtornos mentais podem ter sua vida cotidiana profundamente e negativamente influenciada por um contexto social desfavorável, que não oferece suporte ou condições para que o sujeito se envolva em ocupações significativas. Assim, as ocupações constituem e constroem a trama que tece processos de inclusão e exclusão social desta população.

DESCRITORES: Saúde mental; Terapia ocupacional; Marginalização social; Apoio social; Ocupações.

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INTRODUCTION

The occupations are related to the individuality of the persons, who they are and how they live their everyday life, in its most intimate and singular aspect. The occupations also refer to the way the persons relate to the world. Therefore, occupations are an important element in the constitution of identity, social relationships and social participation.

In the international literature of Occupational Therapy, the construction of the concept of occupation says that the occupation is active, with purpose, significant, contextualized and it contributes to the construction and expression of identity¹. The occupations people choose to do reveal how their lives are and also offer us a look about their lifestyle and culture, and, over time, can evidence social changes².

People can show what they are and what their future projects are through what they do³. Besides, what people do composes and shapes the society where we live.

The experience of mental disorder can affect the way people get involved with occupations. They can face prejudice and lack of opportunities, what inhibit their participation in occupations.

The process of mental illness causes ruptures in the daily life; many times, "the social relationships and the daily activities change, or simply, no longer exist. So, mental disorder can be understood as impossibility and emptiness related to the loss of the daily life they had before"⁵ (p.1061). The occupations performed by the individuals can inform us about their daily life and the way society has dealt with mental disorder. Therefore, the aim of the current study is to get to know the occupations that people with mental disorder do related to the singularity of the individual, his/her social network and his/her relationship with the social context.

METHODOLOGY

A qualitative research was chosen to develop this study. Users from a Psychosocial Care Center (CAPS) II, in São Paulo city and people from their social network have been interviewed. The interviewees were indicated by the director of the service according to the following criteria: take part in social inclusion actions, be registered in CAPS for at least a year, give understanding answers to the questions presented, agree to participate in the research and be present on the day of data collection. Users indicated meaningful people from their social network to participate in the study, and the ones who agreed in taking part were

interviewed. Twenty-nine interviews were conducted: seventeen with users and twelve with people from their social network.

Total confidentiality in relation to users' personal information was assured, and they had to sign an Informed Consent form indicating their agreement to participate in the research. CAPS approved the development of the study and the research Project was approved by the Ethics in Research Committee of Municipal Department of Health (Ethics Approval n° 143/08). Semi-structured interviews were used as a means of investigation about that population's daily life, and they were made in person by the first author, at the interviewees', or at CAPS. To data analysis it was used the Discourse Analysis, which considers that not only language, text or speech can define discourse, but linguistics elements are needed to give it a material existence. Discourse is social; it does not only involve linguistic matters. Words, when they are said, are impregnated with social and ideological aspects⁶. In the process of data analysis, it was sought to learn about occupations of people with mental disorders, their way of doing while a unique individual, and also from the influence of their social context.

RESULTS

Among the users interviewed, 11 were in the intensive care and six in the semi-intensive care; 16 men and only 1 woman, what (according to CAPS informer) reflects the proportion of men and women attended in the intensive and semi-intensive care service. Only at the non-intensive care there is a greater proportion of women related to men

The age of the users ranged from 29 to 71 years old. All users had families, even though they were not always in touch with the members of their families. None of the users were included in the formal labor market, what confirms the difficulties found by that population to compete in the open labor market and be part of it. With regard to people from users' network, most of them were female (10), from 36 to 68 years old. All of them had a profession except for one of them who was a housewife.

The individuality of the person and his/her occupations

Illness promotes transformations in the person's daily life, where many of the occupations that were usual for the individual become difficult to be accomplished. This rupture can undermine his/her sense of identity, as indicated in the following excerpt from the users (u) and people from their social network (R).

R13: He had always been a very active person (before illness), participating, traveling, joining campaigns and church works.

U:17 (about a typical day after the beginning of the illness). I woke up, had breakfast, and stated complaining about life. I didn't know what to do, with my head full of problems..., I stayed in bed, watched a little TV, but most of the time I stayed in bed...

Changes in health or in life circumstances can change radically the capacity or desire to participate in some occupations, mainly the ones which are vital to the identity and to build a meaning of life.⁷ In the following examples, users report how they build their identities throughout their life history and how they valorize the fact of being someone able of doing things. Some of the users' occupation connect them to their past, making sense in their life history, helping them to build a continuity in their lives.

U1: My mom was a seamstress, so I took a course in industrial machine and sewing straight line; I like sewing, just like my mom. So, that's something that makes forget about my problems. For me, it is something very remarkable, even being simple.

U15: But, I already practiced yoga, if it hadn't been for the yoga, I wouldn't have lived; before coming to CAPS, I used to practice yoga, I have been practicing yoga for 40 years. I woke up and practiced yoga.

People from the users' social network can also notice that when the users are doing those activities, they seem to feel good. The accomplishment of the activities shows them that they are able of doing them, what helps them feel more confident. Occupations also help users find new roles in social life, more than the one of a sick person.

R7: He was very well at casa Lar (shelter) he used to do things. He called me and said: "Hi, today I in the kitchen, doing this". He told me everything enthusiastically. He was called to take part in the Council of elders. I think that, making him work and giving him an activity is very cool.

A main aspect in the process of identity constitution and the conduction of one's own life is the sensation of being able to do things. The perception of having abilities is important to improve confidence and increase the sensation of being powerful. The research participants expressed the feeling of being able when other people recognize their abilities and competence of doing things. Therefore, self-confidence is something built along the relationship with others, and it is related to the way other people's look influences the constitution of identity of the subject.

U6: (about life projects in another city) "My life there would be the same as it is here. But I would show my family that I am able to do things. I am able to work for others".

U1: I am either mending or sewing a button on a shirt

and I feel useful, then people notice and ask: "What did you do in those pants? What a different piece of clothes".

Occupation in individual's social network context

In the process of getting engaged in occupations, the individuals not only find what they want to do, but also get in contact with other people, building their networks. However, people with mental disorders experience the mental health stigma. It is even more complex for them to maintain life continuity, participating to the same occupations they used to do, because people around them can take them away from the shared occupations.

U9: (about a companion to hang out with), Lately, I am going neither out nor for a walk. I usually go by myself.

However, the participants' occupations help them meet people. When they are doing things, it is easier for them to make friends, or keep the ones they had before. The occupations they are used to do are associated to their social network at home, work place or any other ones, like the church.

U11: R has a TV set. The only thing is that a hardly watch it. I prefer listening to the radio. So, because of that, he seldom turns the TV on. He only watches the TV programs that he likes, and turns the radio on more frequently, because he knows I like listening to the radio, so he wants to share that with me.

Furthermore, the participation in occupations can be a signal of social inclusion, as one can be part of the community where they can use the possibilities offered by the context. The possibility of accomplishing occupations together with others demonstrates the opportunity of social belonging.

R15: (about social inclusion) So he has a social life and be part of a society. But it is not only this. He should have an activity where he could fit in a group.

Another positive aspect of social relationships is that the network can also facilitate the achievement of the work. The attempt to find a job for the users demonstrate a social network that offers support, that tries to increase the possibilities of the context to people with mental disorders and makes the environment less threatening for those users.

U9: And he (friend) said: "They are in need of a person in the stock to prepare the orders." And I had never worked before... Then, P. got me this job... It was my first job, it was pretty cool.

R13: But his brother-in-law, once, in order to help him, took him to do some work in his company. He has a construction engineering company and took him to do some office service.

In addition, at work, they can meet people, because most of the time people do not work alone; there are

teams, shared tasks and goals to be accomplished together. Work together is sharing part of life, with all good and bad aspects included. Working also means to be connected with other people.

U9: (about a relationship with a friend from work) "We used to meet at the company... I left home, walked down the street, stopped by at his house and went to company with him. Returning from work, we also met. It was cool."

U1: So, through this (sewing activity) we get close to people. As my mom was a seamstress, the neighbors took clothes to be made by her, and I took part in everything. That was a wide way of communicating to the neighbors and bringing a positive return.

Thus, users' occupations help them to keep in touch with others. It was also reported the importance of occupations in the constitution of family relationships, since an important way of building relationships is doing things together. In that case, the most important meaning of occupation is not what is done but the fact of doing things together; in this process a simple daily activity can become a very significant occupation.

U10: (about a companion for hang out) "I usually go shopping with my sister, to the supermarket and to the mall. We go to church as well".

U12: On Sundays, no matters what, I always visit my aunt. I visit my aunt and have some tea with her; she serves me something to eat and that's it. I talk to her and watch the game. I go there with my mom.

Sharing occupations is also a way of communicating feelings and emotions. When someone likes another one, and feels at easy with her/him, they will probably spend some time together, doing things together. Sharing occupations is a way of expressing the connection with the other person; it is an opportunity to show to that person that she is important and worthy.

R12: Now I can hardly hang out without R. It is impressive. We agree in everything, things that we want to do, where we are going to eat, in daily activities, you know. It's pleasant ... it is a pleasant company, that I have found out recently and it is pleasant.

Occupation in the social context

More than the individuality of the person and his/her relationships, occupations of people suffering from mental health problems are also related to the social context where they live. However, it was verified that people with mental health problems can have his /her life profoundly and negatively influenced by an unfavorable social context, that does not offer any support or conditions to the individual to get involved in meaningful occupations, as what happens to homeless.

U6: (about a typical day before attending CAPS) "I woke up in the morning, took a shower, brushed my teeth, I was living in the streets, but I always kept myself clean. Then, I wandered around the streets because I couldn't spend all day long at the shelter".

People suffering from mental health problems are placed outside society in many ways, having their possibilities of participations restricted.

Some people from the users' social network believe that they are not capable of having a job, and they are not able of doing the necessary tasks. This prejudice can restrict chances those people have to take part in productive occupations. In this way, getting a job is an extremely difficult area to people with mental disorders. They can notice the lack of opportunities and fight to develop themselves in a competitive context, which is unequal and offers few opportunities.

R3: "I think if he finds a job to work outside the home, in a company, as soon as he gets there, people won't want it. He can even fill out a form, but the people from the office will hire healthy workers, the good-looking ones, not somebody who has a problem".

U7: "I like working. But there is no job for me".

On the other hand, a person from one of the participant's network reported that social inclusion is the participation in meaningful occupations, without experiencing prejudice, in a favorable environment. From that point of view, social inclusion is able to make use of the possibilities offered by the social context, that is expressed in the occupations which one does, and in the way people live their own life. It can be said that a relevant aspect of social inclusion is to engage in occupations; a way of facilitating the process of social inclusion is to contribute to the increase of possibilities to participate in occupations.

R12: "Social inclusion, for me, is the participation of the person in any activity, without being excluded. Without having any difficulty in living day by day, that's what social inclusion is for me. It doesn't mean that the person doesn't have to work. It's not that. On the contrary, it is to have to work and can work, even though the person misses a leg, an arm, that is what I understand as social inclusion.

R15: (about social inclusion) "And to act on something, that comes first; it would be doing that the person really likes, that is very important".

However, CAPS and a Casa (the shelter) seem to be the only places where users can stay and take part in the occupations. The interviewees suggest that it is still difficult to engage themselves in occupations at the community, which restricts and complicates their possibilities to achieve a sense of accomplishment in life. That is a challenge faced by the users.

R17: "When there is an event at CAPs he takes part. But not, outside, only at CAPs".

In this context, it is difficult for people in mental distress to build a healthy daily living. Besides the burden of mental illness, the users must face an environment which does not offer them any support to rebuild their daily life, and promote social inclusion.

DISCUSSÃO

The beginning of the process of mental illness is frequently described as the disappearance of the person's sense of self, what, for many, it leads to the loss of previous identity, making difficult to maintain the same life projects⁸. People with mental health problems suggest that the inability to engage themselves in occupations the way they used to do before mental illness, means that they have to deal with changes related to the kind of person they consider being⁹. We are what we do and occupation is an essential part of self-formation. What people do is relevant for the construction of the sense of identity, which is related to all the occupations that really matter and because those occupations had been significant and fundamental during a certain period of time. So, a rupture in the daily occupations can affect the sense of identity⁷.

Typically, people understand the meaning of their lives taking into account occupations as part of the history of their lives, occupations people do add a sense of satisfaction about life. Besides, occupational choices allow people to maintain a satisfactory sense of identity¹¹.

. Yet, when a person does not feel able to do things, and does not trust their own abilities he/she will neither start a new occupation nor do something they used to. The fear of failure can inhibit the person's motivation, and paralyze their daily living.

If environment shows users that they are incapable, they will probably believe that they have neither capacity nor competence to do things, they may consider being worth less than others, or even that they cannot interact with other people. On the other hand, if people around express and value their capacity, that increases their self-confidence and triggers the process of construction of a positive identity.

In this way, occupations may help people with mental health problems to achieve the sensation that they are the same person they had been before the diagnosis⁹. Consequently, people with mental disorders can make associations between their identity and social roles, and they can look for occupations that support their identity¹².

As everyone else, people with mental disorders like

socializing and doing things with people from their social network¹³. Doing occupations in group is a bridge to be with others, occupations can bring people together¹⁴. One of the main motivations people with mental disorders find is to engage themselves in occupations in order to promote social contact¹².

The beginning of the process of mental illness can lead to the discontinuity of the occupations in which people get involved, and can have a series of negative consequences; one of them is isolation, which causes a reduction in their social network. As they have no occupations, people cannot meet others, what makes it difficult to make friends, because they are not invited to social occasions and they have no friends to take part in the occupation.

Occupations are significantly related to the viability of social integration¹⁵. There is a correlation between significant relationships and the improvement in mental health, as well as a correlation between the feeling of emptiness and the lack of significance because of the absence of relationships¹⁶.

An important result of taking part in occupations is the improvement of the social network¹⁵. In daily living, occupations frequently offer the context of interaction with others¹¹. When occupations are done in a social environment, they are frequently valued and they have a significant representation for the individual¹⁷.

The relationships of users with people around them reflect the way society accept them and include them, what brings consequences in how they perceive themselves being accepted and belonging to the social environment¹⁸.

Besides, people with mental health problems and with a competitive job activity are the ones who frequently have more regular contacts with several different people, as friends, partners or relatives¹⁹. In this context, work was seen as singular way to meet people. Work offers possibility of building a social network. Yuen e Fossey²⁰ also affirmed that work environment can offer priceless opportunities to reestablish a social network, especially for those who described some previous limited social interactions.

Another aspect mentioned was that occupations shared with family members facilitate people with mental disorders to have good relationships. Sharing occupations builds a sense of being together, sharing life. Users who perform occupations with their family members seem to show that their family offer them support, and that they will be present if the users need.

Besides, doing occupations together seems to promote exchanges among people, the sharing, reducing

the disparity that there is between the care givers and the care receivers, where a part of it is more competent than the other and because of this carries a burden. Doing things together can facilitate the establishment of mutual relationships.

The family members who offer a positive support to people with mental disorders help to reduce the risk of a limited participation in occupations²¹. More than that, family members tend to coordinate their agenda in order to do things together, for example, they can spend time together doing domestic chores or recreational activities²².

Therefore, in the architecture of our daily living, the coordination of occupations among members of social groups shapes everyday life²². People who live around the users affect the way they are going to feel socially included and how much they are going to be involved in the community²³.

However, society presents negative associations related to mental illness. The asylum-model which, during an extensive period of time, was preponderant in the history of psychiatry, used to stimulate that way of conceiving madness as something only negative when they both segregate people with mental disorders from social life and declare that these people are unfit for social interaction. This conception of treatment helped to shape the imaginary concerning people with mental disorders, that is, they must be dreaded and kept away⁵.

Thus, people with mental health problems tend to be excluded from all economic and social areas of life, from working to driving a car or having children²⁴. The discrimination occurs due to values created by society, which exclude and make people with mental health problems invisible to their community.

Occupational scientists conceive humans as occupational beings, and claim that society forms values, opportunities and resources to allow them to participate in occupation. Society has being planning communities, and increasing or decreasing opportunities to people take part in sport activities, attend school or build cars²⁵.

Therefore, one can notice that, as we do not live in a fair world in occupational terms, people with mental disorders can face restriction on their occupational possibilities and opportunities.

Occupational justice identifies some inequalities related to opportunities to participate in occupations. Occupation and participation are not a matter of the choice of an ideal lifestyle, they are a human right²⁶.

Occupational justice focuses on what people do concerning their relationships and living conditions. It implies that societies value differently the occupational

capacities and their various meanings. Occupational justice is the opportunity to get oneself involved in meaningful occupations²⁷. The construct of occupational justice is based on the concept that the individuals have the right to experience meaningful and enriching occupations, to develop themselves through important occupations to their health and social inclusion, to exercise their autonomy through the occupational choice, and to benefit from the privilege of participating in several occupations, without being excluded from citizenship and the participation in several occupations available in the community²⁸.

Both a fair community and nation in relation to occupations would be socially inclusive, in this case that would be guaranteed to everyone the right to participate in the occupations either they need or want to do in order to contribute with their individual or community lives²⁵.

However, people with mental disorders present more disadvantages to join the job market, and they are in risk of being caught by poverty and illness, becoming homeless or being arrested. Besides, many times, the mental health policies are not powerful enough to diminish the marginalization of people with mental disorders, what causes the growth of imprisonment and the decline of the possibility housing²⁴.

Notably, the prejudice towards people with mental disorders in working situations, for instance, is stated mainly by the employers who are only worried about the ability to do the work or the number of absences due to illness^{29,30}.

It is difficult for a person with mental disorder to find a job due to the obstacles in the labor market, the low level of education, financial limitations and lack of job security³¹. Furthermore, the disclosure of mental illness increases the possibility of the person to experience discrimination, and it can predispose employers and co-workers to have less confidence in the person's abilities, and they can even interpret problems as an evidence of the illness instead of a typical working situation³².

This fact suggests that users are identified in society primarily as mentally ill, and, in a lesser extend as worthy human beings³³. If the person does not have a job, there will also be a tendency to believe that he/she is worth less than others, what is also a prejudice. Having a job is an unwritten rule for social acceptance. It is important to remember that, starting from daily life in a micro level, a macro social context can be influenced. Many of social exclusion/inclusion processes occur during the development of daily living, in the smallest and subtlest occupations and daily relationships³⁴. In order to address the social exclusion issue, it is necessary to promote

changes for the people who face difficulties, so they will be able to recognize their potentialities and strengthen their abilities. Changes must occur in the community in order to remove barriers to participation²⁶.

CONCLUSIONS

The interviewees expressed that engagement in occupations is important for the reconstruction of the process of daily life; it also means to be socially included. In the social inclusion/exclusion process, what people do is a sign whether they are more included than excluded, and it can also constitute a way to increase the possibilities of social inclusion, when opportunities to occupational engagement are offered.

By getting involved in several occupations, people can deal with the demands of the environment; it is a way of expressing themselves, and finding a meaning in life, and adapting to the challenges imposed by reality.

In the process of building daily living after a mental illness, while building their identities, relating themselves with others around them in a social context, people with mental disorders strive to be able to lead their lives and live included in society.

Thus, occupations performed by people with mental disorders comprise and build the thread that weaves the social inclusion and exclusion processes of this particular population, starting from the unique aspects of the subject including both his/her social network and social context.

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