

Descriptions of the health-disease-care process in the perspective of users of a psychosocial care center

Descrições do processo saúde-doença-cuidado na perspectiva de usuários de um centro de atenção psicossocial

Descripciones del proceso de salud-enfermedad-atención en la perspectiva de los usuarios de un centro de atención psicossocial

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The research aimed to describe the health-disease-care process for users of a Psychological-social Care Center (CAPS). Five semi-structured interviews, recorded and transcribed in full, were carried out in the period of February and March of the year 2015. The results showed that the biomedical and biopsychosocial models emerged in the interviewees' speeches, especially when they talked about health, since the concept of disease was associated with suffering and social prejudice. The concept of care was meant as an act of responsibility of users, provided by the CAPS team and by medication. Based on these results, we propose a reflection on the mental health care practices anchored only in the biomedical model, which can produce, as in this study, users who have difficulty living in society with their disorders and who have drug therapy as a central element for their health care.

Descriptors: Mental health; Chronic disease; Mental health services.

A pesquisa teve como objetivo descrever o processo saúde-doença-cuidado para usuários de um Centro de Atenção Psicossocial (CAPS). Foram realizadas cinco entrevistas semiestruturadas, gravadas e transcritas na íntegra, no período de fevereiro e março do ano de 2015. Os resultados mostraram que os modelos biomédico e biopsicossocial emergiram no discurso dos entrevistados, principalmente ao falarem sobre saúde, já o conceito de doença foi associado a sofrimento e a preconceito social. O conceito de cuidado foi significado como um ato de responsabilidade próprio dos usuários, proporcionado pela equipe do CAPS e pela medicação. A partir desses resultados, propõe-se a reflexão sobre as práticas de cuidado em saúde mental ancoradas apenas no modelo biomédico, as quais podem produzir, como neste estudo, usuários que têm dificuldade de conviver socialmente com seus transtornos e que têm a terapia medicamentosa como um elemento central para o seu cuidado em saúde.

Descritores: Saúde mental; Doença crônica; Serviços de saúde mental.

La investigación tuvo como objetivo describir el proceso salud-enfermedad-cuidado para usuarios de un Centro de Atención Psicossocial (CAPS). Se realizaron cinco entrevistas semiestructuradas, grabadas y transcritas en su totalidad, en el período de febrero y marzo del año 2015. Los resultados mostraron que los modelos biomédico y biopsicossocial surgieron en el discurso de los entrevistados, principalmente al hablar sobre salud, ya el concepto de enfermedad fue asociado al sufrimiento y al prejuicio social. El concepto de cuidado fue significado como un acto de responsabilidad propio de los usuarios, proporcionado por el equipo del CAPS y por la medicación. A partir de estos resultados, se propone la reflexión sobre las prácticas de cuidado en salud mental ancladas sólo en el modelo biomédico, las cuales pueden producir, como en este estudio, usuarios que tienen dificultad para convivir socialmente con sus trastornos y que tienen la terapia medicamentosa como un elemento central para su cuidado en la salud.

Descriptores: Salud mental; Enfermedad crónica; Servicios de salud mental.

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INTRODUCTION

Defining a mental disorder is not an easy task¹. Psychic suffering is considered a human particularity that requires a care directed to each person singularly², since the search for a single cause that determines health and vulnerability reduces the possibilities of understanding individuals³.

Assistance to patients with mental disorders has gone through some important historical milestones both in the world and in Brazil. Among them, the Psychiatric Reform, which began in Brazil in the late 1970s, had the proposal to fight for the rights of psychiatric patients, seeking to produce a critique of the so-called psychiatric knowledge and the hospital-centered model for the care of patients with mental disorders. The National Mental Health Policy, as a result of the struggles of the Psychiatric Reform, proposes to change the models of lunatic asylum care by community practices that aim to promote the autonomy of people with mental disorders⁴.

In order to do so, the Centers for Psychosocial Care (CAPS) were created in Brazil, with the aim of providing daily care to people suffering from severe and persistent mental suffering and avoid hospital admissions. Thus, many were the achievements of the Psychiatric Reform in Brazil, among them, the training of primary care professionals to meet people with mental suffering and the reduction and closure of psychiatric hospitals⁵. Therefore, the trajectories of mental health care practices seem to traverse two major poles, starting from the values that support the biomedical model, based on the hegemony of psychiatric and hospital-centered knowledge, to the development of the values that support the biopsychosocial model of health care.

In the biomedical model, the body is seen regardless of the psychological, social and subjective processes of individuals, and the diseases are explained solely related to physiological causes. Therefore, health is closely linked to the absence of physical diseases and has, in the field of mental health, its focus on the medicalization of symptoms⁶,

whereas individuals are transformed into drug users and submitted to the process of biomedicalization of life⁷.

However, mental health treatment should go beyond the use of medication. It needs to seek solutions for care linked to the values of the biopsychosocial model, which emphasizes that health and disease are born from the interaction of biological, psychological and social factors⁸. For this reason, we can state that each individual signifies the concept of health and disease according to their historical, political and cultural conceptions⁹.

Mental health care, anchored in the biopsychosocial model, seeks to build a therapy focused on the life history of the suffering subject¹⁰ and on discussions about the dynamic process of experiencing health and disease, which can produce a more active subject in the construction of their own health promotion process¹¹.

This process, when built together with the teams, can also facilitate the planning of care actions anchored in comprehensiveness^{12,13}. In addition, the participation of family, community and health services can also produce care experiences in which users participate as protagonists of the mental health care provided to them^{14,15}.

However, despite the contributions of the Psychiatric Reform and the values of the biopsychosocial model for mental health care, people suffering from mental disorders do not emerge significantly as participants in studies, which may reaffirm the view that people with mental suffering are unable to participate in the construction of their treatments, thus reproducing the lunatic logic of care of individuals with mental disorders.

The present research aimed to listen and give voice to these individuals in order to report their conceptions about the concepts of health, disease and care, thus contributing to the appreciation of the autonomy of people with mental suffering, as well as to the understanding of people with mental disorders. Thus, this research aimed to describe the health-disease-care process for users of a Psychosocial Care Center (CAPS).

METHOD

This is a qualitative and descriptive study that integrates a larger project, aimed at understanding the process of health, disease and care for chronic patients, caregivers and health professionals.

Study participants were users of a CAPS, located in Goiás state, Brazil. Five visits to CAPS were carried out to collect the data. At each visit, a user was interviewed according to the indication of the professionals of the CAPS team.

After accepting to participate in the study, each interviewee received the Informed Consent Form (ICF). A time was set for them to read it and clarify any doubts. Subsequently, semi-structured interviews were conducted, based on a previously elaborated script, composed of sociodemographic data, such as age and questions about the meanings of the health-disease-care process.

The interviews were conducted in a room at the institution individually, only with the presence of a researcher and the interviewee, with an average duration of forty minutes. They were all recorded and later transcribed in full.

The analysis of the data was carried out initially through the exhaustive reading of the transcribed interviews, the organization of the speeches of the participants and their subdivision into the dimensions of health, disease and care, built with the purpose of understanding the meanings of the health-disease-care process.

In a second moment, the statements corresponding to each previously elaborated dimension were read with curiosity, understood as the genuine interest in the participants' speeches¹⁵, seeking support in the social-constructionist methodological perspective, that considers that the meanings are constructed bound to certain values that can dictate social rules and several possibilities on what can be the reality and that, in addition, understands that the interviews can be an instrument for the contextualization of a certain theme¹⁶.

Subsequently, the speeches were discussed according to studies that dealt with

the field of mental health care. The study took place in the first semester of 2015 and was approved by a Research Ethics Committee (opinion no. 120/13).

RESULTS

The participants of the present work received fictitious names for the preservation of their identities. Of the five interviewees, three were male (João, Pedro and Joaquim) and two were female (Maria and Joana). The average age of the interviewees at the time of the interviews was 54 years and all were retired.

As for the diagnoses, we surveyed what was written in the medical records and the self-report of each interviewed patient.

It was identified as follows: It was identified as follows: João (diagnosis in medical record: schizophrenia; self-reported diagnosis: depression), Pedro (diagnosis in medical record: schizophrenia; self-reported diagnosis: mental disorder), Joaquim (diagnosis in medical record: schizophrenia; self-reported diagnosis: schizophrenia), Maria (diagnosis in medical record: bipolar affective disorder; self-reported diagnosis: mental illness) and Joana (diagnosis in medical record: epilepsy; self-reported diagnosis: epilepsy).

Subsequently, we proceed to the analyses of the themes, previously subdivided into the dimensions health, disease and care.

Health

The representations of the interviewees related to the health dimension were associated with the body and the accomplishment of daily life activities:

Health means to be good with your body, hygiene, sleep well, eat well. (Pedro)

It means the person has... is, not perfect but ... not having crises as I used to have. You can work, can study, can have relationships with the people of the city, work. (Joaquim)

Health is a good thing because you have will to do all the chores. You can sweep the house, clean the backyard, wash clothes, take care of your grandchildren who arrive. (Maria).

Disease

In relation to the disease dimension, Joana, Pedro and Joaquim associate their disorders with something much larger than an illness:

I do not feel sick. (Joana)

I have good health... but I also feel some pangs because of the disease, in the lung, in the chest, in the back. (Pedro) ...my problem is that my mind is very worn out... because I have used my mind a lot and it has worn... you can think this is madness... but it may be a bit of schizophrenia... the doctor says that it is something that comes from my mind... schizophrenia is not that the person is crazy, it means the person has their own world... disease for me is when the person does not work, does not study, has troubles, crises. (Joaquim)

The interviews also allowed us to understand the perception of the interviewees about the first signs and symptoms of their psychic sufferings, demonstrating that initially there was an ignorance of the participants about their disorders:

I have had depression for a long time without treatment. One day my daughter told me she was going to take me to the doctor... in the consultation he asked me a few questions... he told my daughter that what was killing her father was the depression and prescribed medication to me until I came here. (João)

I stayed laid down for six months... it was in 1996 I kept talking, mom, many things will change, things will change from now on. (Pedro)

...since the lying-in, I was like this, with a poor mind... till this I have a poor mind, but then I take the medicine from the doctor and a home remedy and it gets better. (Maria) I used to feel pangs in the head... I used to lose my senses, fall on the floor, and now I am not like that anymore... because I cannot get angry. (Joana)

Given the interviewees' perceptions of disease, we can mention some negative meanings reported, such as the representation of a possible link between the disease and death:

I have seen people who are there talking and then die; my youngest sister she died, she went to bed healthy and at the time of waking up, she was dead. (Maria)

I think that if I had not been hospitalized I would have died because it was very strong the things I suffered, a lot of pressure on my head... I felt something very bad inside me, it seemed that I was dying and I could not. (Joaquim)

Another aspect reported by the interviewees regarding the disease dimension refers to the use of medication as the only form of treatment of mental disorder:

Carbolito is the strongest medicine, I use it a lot... the nurse gave me a bag of medicines for me to take... I do not go without medicine at all. (Maria)

I thought that I had no problem, that I did not need medicine and every time I left the hospital I would promise the doctor that I would take the medicine and I did not take it. Then, there was this time I suffered a lot in the hospital and I decided not to fail taking the medicine anymore. (Joaquim)

In this dimension, it is possible to perceive the way in which the interviewees experience the concept of disease, associating it with discriminatory events:

There are some neighbors who are afraid of me, who walk past me and keep looking at me... they think I am dangerous. (Joana)

There are people who look away from us... some people have a prejudice against us... (Joaquim)

The lines of Joana and Joaquim, previously presented, seem to explain the perception of John when affirming that:

I do not find another place that supports, that tolerates us like CAPS. (João)

The data also made it possible to perceive the great suffering of the participants because of their experiences of threats against themselves, with suicidal thoughts:

I feel much sadness and something that I should not. Everything comes to our heads... I have remorse of it... these thoughts of doing it against me, but I am going to take my life... I take a lot in prayer, Thank God. (João)

I wanted to commit suicide... but people say that those who from suicide lose their soul... the disease brings these negative thoughts. (Pedro)

I will tell you about the diseases I have for you to see how severe it is...insomnia, schizophrenia, OCD (Obsessive Compulsive Disorder - the one you check things out), thyroid disease (because of which I have overweight), cholesterol problem and mental problem. If I were a person who did not believe in God, I had already done something crazy. (Joaquim)

Care

The care dimension was associated by respondents with something that depends on their involvement in order for it to occur:

Care is responsibility. (Pedro)

It is avoiding many things that are not right for our body. (João)

Care is the person to treat us well... when we have some problem here, we should look for the psychologists, the psychiatrists, talk about the problems. (Joaquim)

Care was meant as something provided by the other, in this case, by the multidisciplinary team, but which is only possible if individually sought:

They take very good care of me because I take prescription drugs. (Pedro)

The CAPS team take good care of me. (Maria)

I feel happy... better than when I was with my mother because she wanted to destroy me, she did not want to take care of me, she used to give me more medicines wanting to kill me, little by little, wanting to drive me crazy. (Joana)

DISCUSSION

The identification of the diagnosis described in the medical record of each participant, as well as the diagnosis reported by the users of the research, was carried out considering the presupposition of the social constructionist research that one should not disregard everyday conversations, since they are important for the production of knowledge¹⁷.

When comparing the diagnosis of the medical record, we can see that, for most of the interviewees, the self-reported diagnosis seems to acquire meanings that are more intelligible to common sense, demonstrating an attempt to experience the mental suffering that is close to what is socially accepted and therefore more inclusive.

On the health dimension, we can perceive in Pedro a conception of health associated with biological factors, thus reproducing a mechanistic and dualistic view typical of the biomedical model, which neglects the social and psychological aspects of the individual.

However, Joaquim and Maria demonstrated an expanded view of health by associating it with daily activities, such as work and study, in agreement with the prerogatives of the biopsychosocial model⁸. Work constitutes for the human being a true sense of life, since it collaborates for the structuring of the personality and the identity of the individuals¹⁸. In addition, belonging to an activity can promote the social reintegration of people with mental suffering¹⁹. For this reason, unemployment can promote mental suffering².

Most workers find work as the only means of socializing outside family life²⁰. From this point, the absence of work can lead to changes in mental health.

In relation to the disease dimension, Pedro, Joana and Joaquim, by associating their disorders with something much more magnified than a disease, showed that mental suffering may not be central to an individual's life¹¹. On the other hand, Maria and Joaquim reaffirmed in their statements the relevance of the biomedical model and psychiatric supremacy for the treatment of their mental disorders. Psychiatry, in the name of safety,

legislates that life can be guaranteed when associated with medication²¹⁻²⁷.

As the hegemony of the psychopharmacological discourse grows as the most suitable for the care of mental disorders, more people are diagnosed as patients and more drugs are consumed²², which also seems to be reproduced, at least in part, by Maria and Joaquim, when reporting their relationship with drugs. Nevertheless, when inadequately prescribed, psychotropic drugs tend to reduce the autonomy of individuals with mental disorders²³.

Joana, Joaquim and João referred to discriminatory events in the experience of their disorders, reaffirming the fact that, in social conventions, cultural causes or values are attributed to psychological suffering, rather than biological and/or psychosocial factors²⁴. This fact contributes to the exclusion of people with mental disorders.

In addition, John also seemed to demonstrate that relationships are based on what one thinks about the people with whom one lives²⁵. Added to this, his speech, besides the lines of Joana and Joaquim, demonstrated the experience of being segregated due to mental suffering, reaffirming that the diagnosis of a mental disorder negatively affects the patient, causes irreversible damages²⁶; and, being discriminated against because of the use of psychiatric medications can be synonymous with being outside the standard of normality necessary for living in society²⁷.

In short, negative representations are associated with the experience of psychic suffering, both from the symptoms triggered by the disorders and from the (negative) social representations built for the psychic suffering, which promote isolation and loneliness for the participants.

Regarding the care dimension, the interviewees recognize that their involvement is necessary, which agrees with the prerogative that health care plans and actions depend on individuals' commitment¹² and may emerge associated with information and independence²⁸, demonstrating the search for Pedro, João and Joaquim for autonomy. The CAPS assistance was verbalized by Joaquim,

Maria and Joana as a resource for care, thus reaffirming the importance of the CAPS team as facilitator of the promotion of mental health care.

Joana's speech should also be highlighted, in reporting on her relationship with her mother, which corroborates the discussion about the difficulties of family relationships in patients with mental suffering. Family disagreements, verbal and physical assaults, and fights are factors that contribute to the imbalance of the person with mental disorder²⁴.

Taking into account that the family relationship can be the mainstay, both for the prevention of a crisis and for its maintenance, situations in which the relationship is negative may make it difficult to maintain the mental health of people with mental suffering. However, for the participants, unlike Joana's family, the CAPS emerged as an important ally in supporting the interviewees.

The interviewees emphasized their experiences demonstrating how they perceive themselves in relation to their health, very associated to the exercise of a current or past work activity, as well as the role that the mental disorder occupies in their relations, with numerous discriminatory situations.

Suicide appears linked to mental suffering. In view of this, the mental disorder has several negative repercussions on the life of the interviewees, but when reporting on their sufferings and their forms of care, anchored mainly in medication, this provided an understanding of the experiences of these users.

CONCLUSION

The study allowed identifying that the biomedical and biopsychosocial models participate in the construction of the discourses of the interviewed users.

Among the three concepts studied, the one that most triggered meanings in the participants' discourse was the concept of disease. In it, the users briefly reported how the diagnosis of the disease occurred, which made possible to understand their experience as a person with mental disorders.

Many of the users have meant their disorder as something burdened with suffering caused not only by the symptoms of intense psychic suffering but also related to social constructions that prioritize an excluding view in the way of perceiving people with mental disorders.

Through the statements of the users, it was also possible to understand the role that medication plays in the treatment of these individuals. They believe that the use of the medicines provides a satisfactory health care.

The primacy of the biomedical model for mental health care, which predominated in the discourse of the interviewees of this study, deserves to be questioned, since it seems to contribute to the participants' feeling of being prevented from a satisfactory social interaction and reaffirm the centrality of the drug therapy for the care of their mental disorders.

The interviewees meant the care process as an act of self-responsibility, which reaffirms the desire for autonomy, and also mentioned the CAPS multidisciplinary team as a crucial facilitator for the promotion of mental health care.

This study has as limitation the fact of interviewing only users indicated by CAPS workers. However, based on the lack of studies and the results found, further studies should be produced that seek to give voice to people with mental disorders, since they can be important protagonists in the construction of their own health, disease and care process.

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CONTRIBUTIONS

Fernanda Sousa Silva and **Cintia Bragheto Ferreira** participated in the conception, design, writing and critical review. **Yasmin Livia Queiroz Santos** participated in writing and critical review.

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