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RESEARCH

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EVALUATION OF STIGMA IN ACCESS TO THE PSYCHOSOCIAL CARE CENTER

*Avaliação do estigma no acesso ao centro de atenção psicossocial**Evaluación del estigma en el acceso al centro de atención psicossocial***Adriane Domingues Eslabão¹** **Leandro Barbosa de Pinho²** **Elitiele Ortiz dos Santos³** 

ABSTRACT

Objective: to evaluate the relationship between stigma and access to the Psychosocial Care Center. **Method:** qualitative evaluation study, case study type, guided by the Fourth Generation Evaluation. Ten users, ten family and nine workers participated in the research. Semi-structured interviews, document analysis and records in field diaries, carried out in 2019, were used for data collection. For data analysis, the Constant Comparative Method was used. **Results:** the experience of stigma by people in psychological distress hinders their relationships in society and access to care at the Psychosocial Care Center and other network services. With the use of an innovative evaluation, the participants problematized the issue of stigma and brought contributions to the confrontation. **Conclusion:** it is necessary to combat stigma in mental health and make human relationships more empathetic and respectful, ensuring better income distribution, access to quality health and education.

DESCRIPTORS: Mental health; Psychiatric nursing; Nursing; Social stigma; Health services accessibility.

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RESUMO

Objetivo: avaliar as relações do estigma com o acesso ao Centro de Atenção Psicossocial. **Método:** estudo de avaliação qualitativa, tipo estudo de caso, guiado pela Avaliação de Quarta Geração. Participaram da pesquisa dez usuários, dez familiares e nove trabalhadores, para coleta de dados utilizou-se a entrevista semiestruturada, análise documental e registros em diários de campo, realizados em 2019. Para a análise dos dados utilizou-se o Método Comparativo Constante. **Resultados:** a vivência do estigma por pessoas em sofrimento psíquico dificulta as suas relações em sociedade e o acesso aos cuidados no Centro de Atenção Psicossocial e em outros serviços da rede. Com o uso de uma avaliação inovadora os participantes problematizaram a questão do estigma e trouxeram contribuições para o enfrentamento. **Conclusão:** é preciso combater o estigma em saúde mental e tornar as relações humanas mais empáticas e respeitadas, garantindo melhores distribuições de renda, acesso a saúde e educação de qualidade.

DESCRITORES: Saúde mental; Enfermagem psiquiátrica; Enfermagem; Estigma social; Acesso aos serviços de saúde.

RESUMEN

Objetivos: evaluar la relación entre el estigma y el acceso al Centro de Atención Psicossocial. **Método:** estudio de evaluación cualitativa, tipo estudio de caso, guiado por la Evaluación de Cuarta Generación. En la investigación participaron diez usuarios, diez familiares y nueve trabajadores, para la recolección de datos se utilizaron entrevistas semiestructuradas, análisis de documentos y registros en diarios de campo, realizados en 2019. Para el análisis de datos se utilizó el Método Comparativo Constante. **Resultados:** la vivencia del estigma por parte de las personas en sufrimiento psíquico dificulta sus relaciones en la sociedad y el acceso a la atención en el Centro de Atención Psicossocial y otros servicios de la red. Con el uso de una evaluación innovadora, los participantes problematizaron el tema del estigma y trajeron contribuciones para la confrontación. **Conclusión:** es necesario combatir el estigma en salud mental y hacer más empáticas y respetuosas las relaciones humanas, asegurando una mejor distribución del ingreso, acceso a salud y educación de calidad.

DESCRIPTORES: Salud mental; Enfermería psiquiátrica; Enfermería; Estigma social; Accesibilidad a los servicios de salud.

INTRODUCTION

The Comprehensive Mental Health Action Plan 2013-2030 aims to prevent mental disorders and guarantee human rights through access to the best health care, with full participation in society, access to work and freedom from discrimination and stigmatization.¹ In Brazil, the services of the Psychosocial Care Network, especially the Psychosocial Care Center (CAPS), play a strategic role in combating stigma, guaranteeing access and mental health care, with a view to defending the human rights of people suffering from mental illness.

The CAPS is a specialized service, based in the territory and open to the community, serving the population spontaneously and those referred by the Health Care and Intersectoral Network services. This service provides care for people with more severe and persistent mental disorders and more intensive rehabilitation.² CAPS combat stigma, but run the risk of producing and prioritizing traditional protocols focused on psychopharmacological medicalization, psychiatric consultations and restrictions on activities within the institution.³

The term stigma is directly related to a deeply derogatory attribute, established by society, by the social environment, which can lead to great discredit of the person who receives this attribute.⁴ Stigma has a direct relationship with social transformations, with the norms and values by which the individual can be "rejected" or "accepted" depending on the socio-cultural demands established. These demands can result in the exclusion and marginalization (real and/or symbolic) of individuals.⁵

In one study, it was identified that the term stigma is strongly associated with exclusion, isolation, discrimination and prejudice, as a mark carried by the person, a barrier to their life, a negative characterization that can lead to illness and death.⁶ Stigma in mental health, including that which exists in health services and treatment providers, produces important barriers to accessing quality care, leading to delays and abandonment of therapy, as many users do not seek care services, fearing being labeled.⁷⁻⁸

In this way, reducing stigma and discrimination in relation to mental health is an important and increasingly relevant focus for public policies in the fields of health, work and research. In addition, the reality of health services points to overload, multiple demands, funding restrictions for training and help for teams to carry out anti-stigma actions in mental health.⁷ Therefore, this article aims to evaluate the relationship between stigma and access to the Psychosocial Care Center.

METHOD

This evaluation study has a qualitative approach and is a case study, using the assumptions of Fourth Generation Evaluation, which has a participatory research dimension that has made it possible to produce knowledge on complex aspects brought up during the data collection stage. Fourth Generation Evaluation is an innovative, constructivist rese-

arch method that takes into account the claims, concerns and issues that are important to interest groups.⁹

This evaluation uses a hermeneutic-dialectic process. It is hermeneutic because of its interpretative character and dialectic because it brings in different points of view to build more elaborate consensus among those involved. The hermeneutic-dialectic process seeks to achieve consensus when possible, or to clarify points of disagreement, enabling an agenda for negotiation.⁹

Data collection took place during the first half of 2019 in a type I CAPS in a municipality with approximately 25,000 inhabitants in the interior of the state of Rio Grande do Sul. The research participants were nine workers, whose inclusion criterion was having a relationship with the service for at least three months. The exclusion criterion was being on vacation and/or sick leave, so one professional did not take part in the interview collection stage.

Ten of the service users took part. The inclusion criteria were attending CAPS at the time of data collection and having good communication skills. With regard to family members, ten people took part and the inclusion criteria were people who accompanied or had already accompanied a family member undergoing treatment at the CAPS, not necessarily linked to the users who agreed to take part in the research.

Documentary analysis was used to collect the data - a technique that allows us to search for and identify precise data in the documents selected to make up the study.¹⁰ Participant observation is a fundamental technique for evaluating the context studied, and is essential for the researcher to be accepted in the research environment.¹¹ During the period of participant observation, 118 hours were spent recording in field diaries. Semi-structured interviews were conducted using the dialectical hermeneutic circle and the Constant Comparative Method of data analysis.⁹

The interviews were conducted using the Hermeneutic-Dialectic Circle technique, based on the choice of an emblematic person from each interest group, called respondent 1 (R1), to whom an interview script was applied with open questions about the functioning of the service and their impressions about access to mental health care. This interview was analyzed in its entirety to identify some important themes related to the research objectives and some initial constructs. These are called construct 1 (C1) and were systematized and saved to be asked of respondent 2 (R2).⁹

R2 was asked the same questions as the original script, plus the themes from construction 1 (C1). R2's reflections became more sophisticated than the original ones, giving rise to construct 2 (C2). For R3, the original study questions were applied, plus the C1 and C2 constructs. Thus, at the end of the data collection with R10 or R09, in the case of the workers, we would have an increasingly elaborate and refined material, with the original questions of the circle and also some unfolded questions that emerged from the application of the device in each interview.⁹

Once the interviews were completed, all the material was gathered and a negotiation stage was carried out. In other words, a stage of "validation" of the empirical material, all the material was organized and returned to each interest group, so that the participants could recognize each other, rework their questions and criticize their positions. At this point, the participants had the chance to give their opinion, modify or affirm their credibility.

The data collection and analysis process took place in parallel, one guiding the other, based on the Constant Comparative Method. In the data analysis, the themes were re-grouped, giving rise to units of meaning and the formation of the thematic category which resulted in the following central themes of the research: Organization of the service, Ambience, Network management and Relationship between the service and society. From the latter emerged the theme of stigma, which is the subject of this study.

To guarantee the anonymity of the participants, the interviewees were identified with the following letters: F for family members, U for service users and P for workers, together with the number corresponding to the order of the interview. The data came from the Users' Negotiation Group (GNU), the Family Negotiation Group (GNF) and the Professionals' Negotiation Group (GNP).

This study presents the results of a doctoral thesis defended at the Postgraduate Program of the Federal University of Rio Grande do Sul.

The research is in accordance with the principles of National Health Council Resolution (CNS) No. 510/2016 and was approved by the Research Ethics Committee (CEP) of the Federal University of Rio Grande do Sul, under opinion number 3.115.068, CAAE: 04070818.0.0000.5347, on January 17, 2019. All participants in the study signed the Free and Informed Consent Form.

RESULTS

The participants in the survey identified that prejudice is present in the person who experiences it, in the family and in society, and is aggravated by situations of poverty and the population's low level of knowledge.

We go to the (health) center, if we're going to get an appointment to see the general practitioner, for something else, they call us... they say "here comes the crazy one, here comes the CAPS crazy one". And here (CAPS) there is no longer this prejudice. Then I get very sad about it, because I think, why is there such a difference between normal people and us? I say we're almost the same as them, we just have a problem. [...] So to get on the bus, even on the bus there's prejudice. (U2)

I think people are prejudiced, "[...] in fact, people aren't just prejudiced against mental illness [...]" There is prejudice. There's prejudice against mental illness, there's prejudice

against people, who even turn their backs because others are laughing because you have HIV.

There's a lot of prejudice. "[...] he didn't say it, but I saw it. Because I was always with him, so you can tell. People are very prejudiced [...]. Because his own family doesn't accept it, his own family thinks it's silly." (F6)

A lot, especially in a place with very little education, with huge poverty, the less education you have, the greater the prejudice. (P7)

Stigma and prejudice in mental health cause barriers to accessing services in the area and receiving care from specialized professionals, since there is an understanding that only the CAPS or the hospital should be the place of treatment for the "crazy/ill":

And mainly because there's this stigma that "sick people, crazy people, go there", so it's not for me and then they end up looking for the hospital, a path without logic. (P6)

People actually think that the CAPS is a place for crazy people "[...] it makes it difficult for people to go and look, not just for the CAPS itself, but to see a psychologist, a psychiatrist, it's kind of scary for them [...]" (P8).

Everywhere I go, at the doctor's I don't even say that I go to CAPS, because if I say that I go to CAPS, it seems that if I say I'm in pain here, he'll say "Oh, it'll pass, just take a little something and it'll pass". (GNU)

Sometimes people come here having been ill for many years and it's the first time they've sought care because of this stigma. I'm very shocked [...]. Not just in relation to the CAPS, even with the psychologist. (GNP)

For family members, the role and care offered by CAPS needs to be publicized more in other services in the network and in society - to raise awareness among the population:

One thing that I think would be really important is to work on raising awareness outside of there, a bit more, because people see CAPS as a monster, like "I'm not going there because only people who are like this, who are like that, go there". Spreading the word about what it is, how welcoming it is, that it's not a punishment, a strict place, that it's a place to be welcomed. (F7)

Like everything else, there's always prejudice, but it's really nice to talk about it more, to make people understand, because sometimes people say something they don't even know, "look, that guy's crazy", just by seeing someone come into CAPS like that. (F9)

So publicizing this service (CAPS) as an open, free service that takes care of people is very important, because mental disorders, whether it's depression, schizophrenia or bipolar disorder, are all associated with that historical stigma of a psychiatric hospital that you're crazy, dangerous, stay away. Psychiatric hospitals did this for many years, even with people who didn't have any mental disorders [...]. The media should

publicize this nationwide, this model, freedom, this model of care with respect, people's individuality, uniqueness. (GNF)

Thus, for the participants, the cultural issue related to prejudice should be worked on among professionals, through extra CAPS activities such as outings, trips and events that seek to raise awareness among the population:

It's related to the cultural issue in the municipality, which has a lot to do with prejudice in the community. I think this is an aspect that has improved significantly, thanks to the actions developed by the municipality, by professionals, not necessarily by management. (F1)

Yes, it's very important (to publicize CAPS in order to reduce prejudice). Neighborhood associations would be an important point for the local community and for sharing with others [...], getting them out of CAPS is important, they travel, they go on trips, they see the places. And the issue of prejudice, which people still look at in a very distorted way. (F10)

There will be a team meeting today, but with the aim of "organizing a schedule of activities for 2019" [...]. On July 27, an event will be held in the town parish with the aim of combating prejudice in mental health. (DC)

DISCUSSION

Prejudice resides in society's social imaginary, a construct that makes it difficult for the person, the family and the health services to provide care, comfort and movement around the territory for those experiencing psychological suffering. Internalized stigma is another challenge, as is the fact that we place the stigma on the "other", but it doesn't always "come from outside", because often the family itself reproduces it, as F6 pointed out.

The view of mental disorder varies between the perception of society, the family and the user's conception of themselves, which can be stigmatizing, leading to a loss of identity for the individual who starts to recognize themselves and be recognized by the internalized stigma. Stigmatization and internalized stigma experienced by people with mental disorders lead to illness, negative feelings of sadness, a sense of incompetence and disruptions in life.¹²

Another study identified the perceptions of family members and workers in a community treatment team in relation to the experiences of stigma and discrimination experienced by people living with mental illness. It pointed to the existence of stigma and discrimination linked to appearance and behavior, fear of being shunned in social relationships, impairment in key areas of life and weaknesses in dealing with discrimination.¹³

Stigma in mental health is cultural and the result of a society that describes a pattern of "so-called normal" human beings playing traditional roles in the family, at work and in society, without the right to experience and/or live with a mental disorder. Therefore, fighting stigma is part of mental health care, the search for citizenship and human rights.

In the social imaginary, it is also believed that a person who experiences mental suffering will manifest it forever, even if they receive adequate care. What's more, for some people, the person experiencing mental suffering is responsible for their condition, and phrases such as "it's cool", "it's a passing sadness" are uttered by family and friends, which further delays the search for help.^{8,12,14}

Naturally, the above diagnosis would lead us to plan goals for psychosocial interventions at a collective and community level; such as helping to make society more affectionate, with human beings who are more understanding and who can deal with the deep-rooted stigma of madness, of psychological suffering, given the evident demand for mental health care, a characteristic of today's society.¹⁵

It's important to consider that ignorance and poverty promote higher levels of prejudice, as P7 pointed out. It is therefore necessary to invest in the fight for a fairer society, with better conditions of access to quality education and social inclusion. Fighting stigma means fighting the great social ills and making the world a more humane, empathetic place, with respect for differences and a pleasure to live in.

With regard to access to mental health care, it was identified that users are afraid of suffering prejudice in a territorially-based service such as the CAPS, building flows that are directed towards closed spaces far from the community, such as the psychiatric hospital. Thus, contradictorily, the research points out that being a CAPS user and undergoing treatment with specialized professionals generates stigma, hindering access for those who need to be cared for.

Studies show that the difficulty in accessing mental health services is due to fear of stigma, society's judgments, shame and labels, among other things.⁴⁻⁶ When analyzing the life history of homeless people and people who use drugs, for example, it is possible to identify a lot of social suffering, exclusion and a failure to adapt to conventional systems - requiring health professionals to be more aware and open to providing care.¹⁶

In primary care, for example, there are multiple forms of stigma and barriers to accessing care in the service. Stigma in mental health and in relation to drug use and/or abuse is related to gender, class, age, race and even people's degree of distress - as users may consider social norms to be alienating, or even expect behaviors and expectations in health spaces that are not met.¹⁷

Diagnoses are important in clinical care, but they can also make it difficult for people with psychological distress to seek help from specialized mental health services, for fear of being "labeled".¹⁸ Thus, many people experience psychological distress and don't seek care because they don't know how to deal with this situation, making them invisible to many care spaces, such as family, health, education, work and society.

In this sense, care must be traced and built from the territory to the health, education and social assistance services, among others, and with the appreciation of everything that can be offered in the subjects' living spaces. Modernity demands a closer and continuous approach to the territory, filling the gaps created by

the modern world is urgent in mental health care. It is necessary to identify what the territory can offer, community groups, income-generating activities, socializing and meeting spaces.

From this perspective, for the participants in the survey, it is necessary to act strongly on the cultural issue in the municipality in relation to mental health, to raise awareness and publicize the work carried out by CAPS. The activities such as outings to public services, trips and social interaction provided by CAPS are identified as tools to reduce the processes of prejudice and lower the barriers to accessing mental health care.

In field diary records, the CAPS team organized an event to combat discrimination and prejudice in mental health. The municipality has Municipal Law No. 1,467 of July 15, 2011, which established a Municipal Day to Combat Discrimination and Prejudice in Mental Health. July 27 is dedicated to activities that can demystify misconceptions about specialized services and, above all, raise awareness and provide guidance to the population.

In order to combat stigma, it is necessary to create active strategies. In England, for example, official advertising to this end has been successful. Combating stigma can reduce the mortality of people with mental illness, avoiding neglect and inadequate care.¹⁹ And interventions centered on communication, training, education, meetings and anti-stigma campaigns are fundamental.¹⁷

Fighting stigma is an immense challenge, as it involves economic, political, historical and cultural processes that must transform the relationship between society and madness, which is still based on maintaining stereotypes that produce excluded individuals.²⁰ Thus, fighting stigma is directly linked to human rights such as access to quality education, housing, income and health, which can reduce the pain of people with mental suffering and reduce the stigma experienced by this group.

FINAL CONSIDERATIONS

The research showed that the experience of stigma creates barriers to access and affects not only users, but also professionals who work in mental health care and services that replace the asylum model, built to achieve social inclusion and break with segregating modes of care. The fight against stigma involves cultural issues, and it is necessary to invest in actions to publicize and raise awareness in society about mental health care and the fight for people's human rights.

Combating stigma in mental health involves the hard work of transforming society, making human relations more empathetic and respectful, ensuring better income distribution and access to quality education, which is what transforms stigmatizing thoughts and attitudes. Finally, the study has some limitations, such as the non-participation of professionals, family members and users from other components of the Psychosocial Care Network and the intersectoral network - given the impacts of stigma for people in psychological distress in all sectors of society.

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