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Perceptions of people in psychological distress about restoring life trajectory

ABSTRACT | Objective: to identify the perceptions of people in psychological distress about experiencing the disease and restoring their life trajectory. Method: a descriptive, exploratory study with a qualitative approach, carried out with nine users registered in a Family Health team. A semi-structured interview was used as a data collection instrument. The testimonies were recorded, transcribed in full, categorized and discussed through Content Analysis. Results: the process of accepting psychological distress is a central component of recovery and is closely related to functioning, disease management and quality of life. Empowerment and coping mechanisms for restoring daily life were also evidenced, such as the search for religious support, family support and community support activities with support actions. Conclusion: being a person with psychological suffering is experiencing daily suffering, thus having several limitations to carry out your daily activities.

Keywords: Schizophrenia; Stress, psychological; Mental health; Returning state.

RESUMEN | Objetivo: identificar las percepciones de personas en sufrimiento psicológico sobre la vivencia de la enfermedad y el restablecimiento de la trayectoria vital. Método: estudio descriptivo-exploratorio, con abordaje cualitativo, realizado con nueve usuarios registrados en un equipo de Salud de la Familia. Se utilizó una entrevista semiestructurada como instrumento de recolección de datos. Los testimonios fueron registrados, transcritos íntegramente, categorizados y discutidos a través de Análisis de Contenido. Resultados: el proceso de aceptación de la angustia psicológica es un componente central de recuperación y está relacionado con el funcionamiento, el manejo de la enfermedad y la calidad de vida. Se evidenciaron mecanismos de empoderamiento y afrontamiento para restaurar la vida cotidiana, como la búsqueda de apoyo religioso, familiar y actividades de apoyo comunitario con acciones de apoyo. Conclusión: ser una persona con sufrimiento psicológico es vivir un sufrimiento diario, por lo que tiene varias limitaciones para realizar sus actividades diarias.

Palabras claves: Esquizofrenia; Estrés psicológico; Salud mental; Estado de retorno.

RESUMO | Objetivo: identificar as percepções de pessoas em sofrimento psíquico acerca da vivência da doença e do restabelecimento da trajetória de vida. Método: estudo descritivo, exploratório, com abordagem qualitativa, realizado com nove usuários cadastrados numa equipe de Saúde da Família. Utilizou-se uma entrevista semiestructurada como instrumento de coleta de dados. Os depoimentos foram gravados, transcritos na íntegra, categorizados e discutidos por meio de Análise de Conteúdo. Resultados: o processo de aceitação do sofrimento psíquico é um componente central da recuperação e encontra-se intimamente relacionada ao funcionamento, ao manejo da doença e à qualidade de vida. Também foi evidenciados mecanismos de empoderamento e enfrentamento para restabelecimento da vida cotidiana como a busca por apoio religioso, apoio familiar e as atividades de apoio comunitário com ações de suporte. Conclusão: ser portador de sofrimento psíquico é vivenciar um sofrimento diário, tendo assim várias limitações para realizar suas atividades cotidianas.

Palavras-chaves: Esquizofrenia; Estresse psicológico; Saúde Mental; Estado de retorno.

Cláudio Luís de Souza Santos

Nurse, Specialist in Mental Health at the Multiprofessional Residence of the State University of Montes Claros (UNIMONTES). Substitute Member of the Regional Nursing Council (COREN). Montes Claros (MG), Brazil
ORCID: 0000-0002-9127-6349

Patrick Leonardo Nogueira da Silva

Nurse, Master's Student at the Postgraduate Program in Primary Health Care at the State University of Montes Claros (PPGCPS / UNIMONTES). Montes Claros (MG), Brazil
ORCID: 0000-0003-2399-9526

Fábio Batista Miranda

Nurse, PhD student at the Postgraduate Program in Nursing and Biosciences at the Federal University of the State of Rio de Janeiro (PPGENFIBIO / UNIRIO). Rio de Janeiro (RJ), Brazil
ORCID: 0000-0003-0934-980X

Ana Patrícia Fonseca Coelho Galvão

Nurse, Master in Health and Environment, Professor in the Nursing Department at Ceuma University (UNICEUMA). São Luís (MA), Brazil
ORCID: 0000-0003-3376-5678

Valdira Vieira de Oliveira

Nurse, Master of Nursing, Professor of the Nursing Department at Faculdade Santo Agostinho (FASA). Montes Claros (MG), Brazil.
ORCID: 0000-0003-2020-2489

Carolina dos Reis Alves

Nurse, Master and Doctor in Health Sciences, Professor at the Nursing Department at Faculdade Santo Agostinho (FASA). Montes Claros (MG), Brazil.
ORCID: 0000-0003-2020-2489

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INTRODUCTION

In Brazil, the movements of the Brazilian Psychiatric Reform and the Anti-Asylum Fight are marked by the presence of users, family members and mental health workers, with an emphasis on the role of users for the reversion of the care model of the hospital-centered base, to introduce the care paradigm psychosocial support for health care and the achievement of rights. However, the construction of users' autonomy and their social insertion have made little progress; initiatives for inclusion in work, art and culture remain timid and localized. Services have made little progress in promoting users' autonomy towards leading their own lives independently, whether in

the family context or in the broader social group.⁽¹⁾

Due to mental health problems, this population group of people with psychological distress experiences significant losses in their daily lives, with the presence of strong stigma in society, impoverishment, job loss and social isolation, aggravated by the loss of a social role, loss of sense of self and the meaning of your own life.⁽²⁾ Faced with this scenario, a new movement emerges in mental health, a new paradigm, recovery, which is born on the initiative of the users themselves in search of their recovery, involving their autonomy and protagonism. The word recovery can be understood as recovery of psychic functions, physical and social aspects in everyday life in the family and in society, which involves strengthening social ties, including a citizenship project with guaranteed rights, responsibility combined with a social support network and an associative life in the community.⁽³⁾

That said, recovery goes beyond the cure of symptoms as a focus for the treatment of mental suffering, it is based on the restoration of hope, the recovery of life due to losses from the disease and the search for new meanings. It is an experience that depends essentially on the subjective condition, in which the subject with mental suffering can recognize himself as the inventor of his ways.^(3,4) This research is justified by the rich experience of user recovery processes, revealing possibilities to promote new life alternatives for the user and in the construction of new ways of dealing with their own psychological suffering.

Therefore, this article aims to identify the perceptions of people in psychological distress about the experience of the disease and the reestablishment of the life trajectory.

METHODS

Monograph article entitled "Restoring life: the recovery experience for the care of mental health users", presented to the Multiprofessional Residency Commission - COREMU of the State University of Montes Claros - UNIMONTES. Montes Claros (MG), Brazil, 2016.

This is a descriptive, exploratory study with a qualitative approach, conducted with nine users registered in the Family Health Strategy (Estratégia de Saúde da Família - ESF) in the Vila Anália neighborhood, located in the eastern region of the municipality of Montes Claros, Minas Gerais. The following inclusion criteria were adopted for participation in the study: (1) being 18 years or older; (2) not having speech-language limitations or restrictions (hearing and / or vocal deficiency), in view of the oral recording of the statements; (3) be a registered user, registered in the coverage area and assisted by the ESF.

A letter of introduction and an Institutional Consent Form (TCI) were sent to the Coordination of Primary Care (AB) of the Municipal Health Secretariat of the city of Montes Claros (SMS / MOC) for authorization of the study. The institution was duly advised on the research guidelines, with a science signature authorizing the research. Data collection was carried out in the second half of 2016, during the month of November, by the responsible researcher.

To capture and store the testimonies of the participants, a cell phone with an MP3 recorder was used. The end of the interview was determined through data saturation. The testimonies were transcribed in full, and analyzed through Content Analysis⁽⁵⁾, covering three phases: (1) pre-analysis, (2) exploration of the material and (3) treatment of the results, inference and interpretation.

After analyzing the interviews of the participants, the testimonies were structured according to three dimen-

sions (D), which are: (D1) Meaning of having psychological distress; (D2) Family, social interactions and professional experience; and (D3) Empowerment and recovery practices. In each dimension, categories (C) of analysis were established for this study, which are: (D1C1) "Real dimension of experienced suffering"; (D1C2) "Having psychological distress is having drug dependence"; (D2C1) "Satisfactory living", (D2C2) "Conflicting interactions", (D3C1) "Religious support", (D3C2) "Family support" and (D3C3) "Interactions in the community".

Participants were duly informed about the study guidelines and signed the Informed Consent Form (ICF) for voluntary participation in the research. The study participants' confidentiality and anonymity were guaranteed. The testimonies were identified by means of codes composed by the letter "E", and Arabic numbers from 1 to 9 (E1-E9).

The study followed the ethical precepts established by Resolution No. 510, of April 7th, 2016, of the National Health Council (CNS), which regulates the conduct of research involving human beings.⁽⁶⁾ The research project was assessed and approved by the Research Ethics Committee of the State University of Montes Claros (CEP UNIMONTES), through Plataforma Brasil, under substantiated opinion no. 1.792.195, Certificate of Presentation for Ethical Appreciation (CAAE) nº 60789316.0.0000.5146.

RESULTS AND DISCUSSION

D1 - Meaning of having mental suffering

D1C1 - Real dimension of the suffering experienced

The process of accepting psychological distress is a central component of recovery and is closely related to functioning, disease management and quality of life (QOL). That said, it is essential to identify the meaning of ha-

ving this type of suffering. In reading the interviews about the testimonies of the study participants, when questioned about the meaning of having psychological suffering, two categories emerged. For the interviewees, the meaning of having psychological suffering is considered to be experiencing daily suffering with several limitations to carry out daily activities.

Ah, it's bad, right, I can't go out to places, it gets bad, right [...] I feel sick, going out with people, it causes anxiety disorder. (E1)

It's bad, because sometimes we can't, you know, sometimes we want to go somewhere, a place like this where we can't stay, hear too much noise and can't. (E3)

Respondents highlight that their condition creates difficulties to socialize, given that some external factors generate anxiety disorder and can trigger crises, as highlighted by respondents E5 and E9:

Vixi, it's too bad, too bad. [...] you get very depressed. It's not ... There are times when it gives me a stir, it's bad. (E5)

Oh, it's not very good, we suffer more, I don't sleep well, there are times when I wake up in the early morning, I have to get up and go out on the street. (E9)

In this sense, the existential suffering is increasingly evident in the statements, which is corroborated by a study carried out with schizophrenic clients that evidenced hearing voices as a trigger for the isolation of the subject, making everyday life even more lonely.⁽⁷⁾ Another aspect that highlights the suffering experienced by them is the restrictions of family life making it difficult

for them to socialize externally, as well as the conflicts generated.

It is a great suffering that we have. There are days when crises happen [...], there are times when we are very anxious. It is like that, that bad thing in our minds, there are times that sometimes even our relatives [...] do not believe we have this problem [...], then we get depressed. It's such a thing. There are times when you [...] feel like running into the woods, as if the house doesn't fit you. Then when I go, [...] when I'm really bad, then I go to my sister's house, I go about 10 times, I just arrive [...] in the yard and go back. I can not. (E6)

Given this, it appears that the disease becomes a great suffering to the patient and the people around him. When we approach the aspects that lead the social life of patients with such diagnoses, we can see the constitution of a deep dissatisfaction, suffering and pain. Schizophrenia is known as one of the most serious and challenging psychiatric illnesses. It is defined as a complex clinical syndrome that comprises various psychopathological manifestations of: thinking, perception, emotion, movement and behavior.⁽⁸⁾

The aforementioned study corroborates the finding in the study highlighting that the trajectory of the psychotic client is full of much suffering, since living with the disease causes significant changes in life in which the onset of the disease marks the passage of what was considered normal and what happens to be considered sickly.⁽⁸⁾ Thus, a basically incurable suffering stands out, in view of the difficulties of effective treatment, the emotional lack of control that gets worse and worse; given that psychosis is not seen as a disease, in the classic sense of the term, however it is

a severe disorder of brain functioning.

D1C2 - Having psychological distress is having drug dependence

The study subjects attribute that drug addiction also generates psychological distress, since the use of psychoactive agents allows the maintenance of their basic human needs, activities of daily living (ADL) and establishment of social interactions as highlighted in the statements:

It's horrible, because if I depend on a medicine to sleep, [...] I have to depend on a medicine to sleep, and sometimes we don't even have the medicine, sometimes we don't even get the medicine, [...] I stay in bed, I don't sleep at all, if I don't take the medicine I don't sleep at all! I stay up all night [...]. So it's a very bad thing, [...] because [...] you have to sleep through medication, and except for the medication I take to sleep, I take depression medication [...], there are times that I feel bad even at home [...], but it is with the drugs that I control myself. (E8)

I take the medication [...] and ... I can't work anymore, I stay at home, and I can't do anything. (E7)

Considering that such problems have no cure, it is precisely at this stage that the person loses his control of an active and or productive social life. In the case of schizophrenics, they begin to experience difficulties in several areas such as work, studies, family life, among others. A study identified that respondents find it difficult to carry out daily actions, such as: walking on the street, working, talking, and despite improvement and control of the crisis is linked to the use of medication, there is a consensus among users that the crisis

may return and experiences such as hearing voices may persist despite the use of medication causing suffering. ⁽⁹⁾

D2 - Family, social interactions and professional experience

D2C1 - Satisfactory coexistence

Study participants show that despite the problem being a suffering, family, social and professional life was not affected, being considered as good and adequate.

They deal well [...], there is no problem with the other. [...] Inside the house, there it is right. [...] I also read, with my friends well, I have no enemy, just a friend, so there is no one, yes, there is no one who has malice "with" me, you see. (E7)

No, no ... But "living together" is good. [...] It's normal, normal... (E9)

It is noticed that, despite all the characteristics and difficulties, the treatment brings good results for those who follow it correctly. With this punctual process, one can follow his life normally or similar to any other individual, such as: studying, working, dating, getting married, having a family and social life. Adherence to treatment is not an easy task, as it includes, in addition to medications, frequent attendance by family members to various psychological sessions. ⁽⁸⁾

D2C2 - Conflicting interactions

Schizophrenia is a mental disorder that develops with severe impairment of the ability to interact socially in an appropriate and functional way. (10). Other subjects claim that some situations generate conflicting interactions with the family and society, due to the perception of a different world and an aggressive process that can emerge during the process of daily life as highlighted below:

No, I am retired. [...] here at home it's just me. [...] Vixi, I don't know, I do anything, I'm bursting. [...] I get nervous about anything. [...] no, if I see it like this, I talk. (E5)

[...] sometimes [...] inside the house [...], there are days when you're very aggressive, another time [...] you don't even want to talk to people, even with, even with the social [...] who sometimes [...] has that problem, the outsider doesn't understand you either [...]. When you're nervous like that, that thing, then I try, they do it to control me, but I can't control it. (E6)

It can be seen that participant E6 mentions that he seeks to use an anxiety and irritability control mechanism. In this context, a scientific study elucidates that when it comes to the context of mental health, it must take into account what is possible at that moment for the user, in search of their well-being, making room for him to identify possible ways out for the your suffering. ⁽¹¹⁾ With this, the family has a crucial role, being considered even as the main element in the care of patients, given that, regardless of their wishes, family members have to translate the world for their schizophrenic family member, consoling, helping, advising and guiding your relative and helping in the realization of all ADLs:

Is bad [...]. I stay at home, I have to give them both medication, controlled inside the house, I also take it, then there's no way, I have to help like that, sometimes just like taking a shower, shaving a beard, washing my hair, that he even if it doesn't wash, the other little one is the same, I keep helping. (E3)

In the same way that the patient suffers twice, due to the disease and prejudice, the family also suffers, with the disease, with discrimination and social misunderstanding in addition to the burden of care. In schizophrenia, the difficulty is linked to several factors such as disconnected speech, personal irritability, lack of concentration among other points. However, there are studies for improvement and training for those who have patients with such disorders, although at the same time it is precarious due to the lack of social and also personal interest, leading to a lack of motivation and apathy, which are well represented in the statements below.

Sometimes I don't even leave the house, I don't leave the house, I spend all the time indoors [...] I don't go to a neighbor's house, [...] my life is just inside the house [...]. (E8)

[...] there are times like that, inside the house, [...] you are very aggressive, there are days [...] you are very aggressive, another time [...] you don't even want to talk to people [...]. (E6)

Schizoaffective disorder is characterized by significant mood symptoms, psychosis and other symptoms of schizophrenia. It is distinguished from schizophrenia by the occurrence of one or more episodes of depressive or manic symptoms. ⁽¹²⁾ These behavioral changes cause suffering in the family, since the tasks never end, making the coexistence traumatic and the interviewees of another study report this interaction as a kind of cross, which mistreats, hurts, leaves marks caused by the monitoring closely in the process of getting sick. ⁽¹³⁾ Customers also identify everyone's difficulties and suffering:

It is a great suffering. [...] there are days when crises ha-

ppen [...], there are times when we get very [...] anxious. It is like that, that bad thing in our minds, there are times when sometimes even the relatives of us [...] do not believe that we have this problem [...], then we get depressed, it's something like that, there are times when [...] I want to run to the bush, then the house doesn't fit you, then when I go, sometimes like that, when I'm really bad, then I go to my sister's house I go about 10 times, I just arrive at the yard and [...] I go back, I can't. (E6)

Given the above, it is essential to promote the insertion of the user in the family and also in the community in search of their recovery, in this aspect the next dimension highlights the mechanisms of empowerment / recovery used by the participants in resuming their lives.

D3 - Empowerment and recovery practices

D3C1 – Religious support

The relationship between religion, religiosity, spirituality and mental health / illness has been a subject of great interest in the social, philosophical, neural, behavioral and health sciences. The fact of believing in something transcendental, has the meaning of a rope as if to take these people out of a bottomless pit. Scholars elucidate that religiosity interferes with health and mental disorders, being considered as a resource to help with the difficult coexistence with mental illness, helping in their understanding, since they attribute to God their responsibility, allowing them to better support coexistence with disease and its consequences. ⁽⁸⁾

[...] Caught with God [...], He helps. [...] I take medicine. (E1)

I take medicine, I drink tea, I also pray [...], I take it from God. [...] Catholic. [...] I will, I won't go much, but I will. (E3)

A study identified that the religious / spiritual experience results in life encouragement combined with the support of the social network of members of religious institutions; in which this religious / spiritual experience is understood as a tool to face the daily difficulties imposed by the limitations caused by delusions and hallucinations, resulting in comfort and hope for better days in your daily life. ⁽¹⁴⁾ Other studies question the real efficiency of religious treatment and or support to religion to achieve an improvement, or even a definitive cure, despite studies that prove the incurability of such disorders. ⁽¹⁵⁾ However, another author mentions that this psychological suffering, associated with the fact that it is a chronic disease with no possibility of cure, users find in religion a source of comfort and hope. ⁽⁸⁾

In a study that assessed the degree of religiosity and spirituality of 99 German psychiatrists concluded that the more religious they were, the more they considered religion and spirituality to be beneficial in understanding the disease and treating the patient, articulating conventional treatment with religious and spiritual support. ⁽¹⁶⁾ Another aspect that also influences the use of religion as a springboard for coping in which spirituality has always been linked to the family, many of the interviewees, despite the answer being related to something transcendental religious, many continued to report the importance of family to themselves. Which does not allow us to stop analyzing that spirituality has a value to be noticed in the family culture and that it is very important for these patients.

D3C2– Family Support

Our family is the most precious asset

we have. And that doesn't change for a schizophrenic or for people with big or small mental disorders. The basis or safe haven of health or disease is always found in family origins or roots. The family is made of bonds to last. It doesn't matter if it's a blood or a heart family. ⁽¹⁷⁾

Then they help, [...] then they go, do [...] something, help me [...], that they already know that sometimes I [...] don't sleep at night, sometimes I go without food, then they will see [...], then they help, everyone helps. [...] I can't complain because they see that I'm not doing well, then one makes lunch, one does something else, helps me a lot [...], but when I was [...] worse, then they didn't understand that sometimes I was nervous, then they didn't understand what it was, then they already understand more or less [...], then talk like this, [...] you have to take medicine, you will be calm, because these days you are very [...] nervous, [...] but thank God at home this is how it is. (E6)

At home, [...] who takes care of me the most is a girl of mine, [...] she is the one who takes care of me the most, has the most patience with me, [...] when I need a medicine it is she who do it, because the woman is not always quiet at home, she keeps working. So, who is at home is me and she lives nearby [...]. (E7)

Most studies indicate that, in relation to assistance, there is a need for new ways of family support and an expansion of the health network. Another aspect that deserves attention is the overload of family members who are often the only contact for social interaction of these subjects as described below:

Ah, do you mean to say, talk? [...] here at home we don't see anyone. [...] That's it, [...] Just us! (E1)

[...] then when my husband even understood me a little, the day I went to the doctor, I was very bad, then he said: she cannot be nervous, [...] her problem is very dangerous, that it can attack the heart, because when it gets too agitated it is very dangerous [...]. He didn't understand, so now that he could understand a little, there are times when I'm in those crises, then he keeps silent, then he starts ... [...] when I spoke, he started to be nervous because I was nervous, then we are already trying to [...] deal with this life, because then I have to control [...] to see if I can do it [...], every day I know that I have this problem that will not be solved [...], because the [...] medication, even taking it, is difficult. I know I have to see if I can live with the life I have [...]. (E8)

However, this close contact can generate a series of discontent of the patient towards his family, this fact probably occurs because of the excessive stress that occurs on both sides. It is worth emphasizing that despite the movements to reestablish the client in mental suffering through recovery, it is salutary that the political and social reintegration programs do not ignore the suffering and the needs of the family, which are enormous, since there are maladjusted, indifferent or even family structures hostile to the customer; in which empowerment must pass through healthy family structures since this individual suffers twice, due to illness and prejudice, the family also suffers twice, with the illness of the member and with social discrimination and misunderstanding.⁽¹⁸⁾

D3C3 – Social interactions in the community

Community support activities with support actions are intended to teach people the skills they need to live in community. Since all schizophrenics can experience times of violence among other unpleasant symptoms. However, this study observed that communication difficulties is one of the symptoms of schizophrenia, highlighted in the statements.

[...] live with her, but with a neighbor until, thanks to God, I have no problem, but that's why I don't like chatting with a neighbor, I don't leave home, there are times when I I don't want to leave the house. (E6)

Have patience [...]. Talk to me, and that's it. [...] The neighbors, those who know how to understand [...], now those who do not know do not understand, not many know. [...] (E7)

Communication is impaired due to the disconnected speeches and the lack of patience of those considered normal, causing difficulties in the dialogue where the dialogue becomes increasingly precarious and scarce, enhanced by prejudice, which causes the rupture of the restoration of communication between speaker and broadcaster.⁽¹⁷⁾ Another aspect perceived in the statements is the importance of performing distraction activities as described:

Ah, I try to distract myself. [...] I go out to see the boys playing there, I try to distract myself, I go out to see the game. (E9)

[...] women come every week, they come to measure my blood pressure, they come every week, every month they are here. [...] It's just medicine [...] [...] yeah, I consulted,

I consulted this week I went there. [...] yes, the doctor from here. [...] Uhum. (E4)

In society, the issue of prejudice and discrimination to which they are subjected stands out particularly, thus hampering the mechanisms of how to deal with crisis issues.

[...] live with her, but with a neighbor until, thanks to God, I have no problem, but that's why I'm not like that, stay like that, chatting with a neighbor, I don't leave the house, sometimes I don't I want to leave the house. (E6)

Another important aspect is the difficulty of establishing work activities, given that when assuming the disease, it is also assuming that there is no control over life, behavior, generating discredit before others, losing their citizenship and losing their rights as a person.⁽¹⁹⁾

I worked, you know, I used to, with, with ... I have to deal with it, just like me and my husband, right, so it's just the two of us, so I have to keep him, try to raise him, right, because he has Alzheimer's problems, and it has been said that there is no way, you know? So I don't, I always have to try to cheer him up so he won't fall, right, because if he falls, I'm even more nuts, in society I don't even go out, I won't explain why I don't even go out huh?! [...] I have, but there are few. (E8)

The family and society should have a role of facilitator of the interaction, acting as an escape valve for the convulsive crises of the so-called madmen, since a human being does not live isolated as much as he wants,

since the human essence turns to social interaction and effective efficient living. ⁽¹³⁾

CONCLUSION

This study sought to identify the perceptions of people in psychological distress about the experience of the disease and the reestablishment of the life trajectory. Thus, based on the data collected, it was observed that, for most of the study participants, being a person with psychological distress is experiencing daily suffering, thus having several limitations to carry out their daily activities. With that, it was possible to inquire that such a disease becomes a great suffering for

the patient and the people around him, because it is clear that, in view of the aspects that were addressed, a deep dissatisfaction, suffering and pain from the participants was noted. It can be seen that at this stage, for most interviewees, having psychological distress is losing control of a social or productive life, thus making it difficult in several areas, such as family life, work, and their social life. Also, as limitations of the study, it is worth noting the insufficient number of publications whose addresses the subject in psychological distress, as well as the families and caregivers who are intrinsically involved in the process.

It is worth mentioning that, despite these limitations, the study sub-

jects show several mechanisms of empowerment and coping to recover and face daily life, despite the adversities, such as the search for religious support believing in the divine being and helping to endure suffering; it also has family support and community support activities with support actions. Introducing the debate about being a person with psychological distress and how to reestablish life with empowerment enabling the guarantee of all rights and promoting their citizenship is a great challenge becoming it is necessary to carry out studies on the theme and targeting recovery as a state of recovery and restoration of psychological, physical and social functions. 🐦

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