

## Estratégias de Enfrentamento de Mulheres Cuidadoras de Pessoas com Esquizofrenia

Caregiver Women's Coping Strategies Toward Schizophrenia Bearing People

Las Estrategias de Afrontamiento de las Mujeres Cuidadores de las Personas con Esquizofrenia

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### ABSTRACT

**Objective:** The study's goal has been to know the coping strategies used by caregiver women toward patients bearing schizophrenia. **Methods:** It is a descriptive-exploratory study with a qualitative approach that was carried out in the general Psychosocial Care Center of Sobral city in Ceará State. The research had 15 caregiver women of patients bearing schizophrenia, and was performed from July 2015 to June 2016, based on interviews and after approval by the Research Ethics Committee from the *Universidade Estadual Vale do Acaraú*, under the CAAE 53208616.3.0000.5053. **Results:** The stress-triggering factors reported by the women were the following: physical and psychological exhaustion due to daily care with the schizophrenic patient; difficulty in dealing with the disease, their acceptance and fear of dying; and leaving the patient alone. The coping strategies presented by them were the following: seeking for spiritual and religious support; expression of feelings for stress relief; use of psychotropic medications; and participation of in-group activities. **Conclusion:** It is important that health care institutions can offer support to the caregiver.

**Descriptors:** Schizophrenia, Caregivers, Mental health.

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## RESUMO

**Objetivo:** Conhecer as estratégias de enfrentamento utilizadas por mulheres cuidadoras de pacientes com esquizofrenia. **Método:** Estudo de natureza exploratório-descritivo, com abordagem qualitativa, realizado no Centro de Atenção Psicossocial Geral de Sobral-CE, com 15 mulheres cuidadoras de pacientes com esquizofrenia, nos períodos de julho de 2015 a junho de 2016, a partir de entrevistas. **Resultados:** Os fatores desencadeantes de estresse relatados pelas mulheres foram: o desgaste físico e psicológico pelo cuidado diário com o portador de esquizofrenia; a dificuldade de lidar com a doença, sua aceitação e medo de morrer e; deixar o seu ente sozinho. As estratégias de enfrentamento apresentadas por elas foram: busca de apoio espiritual e religioso, expressão de sentimentos para alívio do estresse, uso de medicações psicotrópicas e participação em atividades grupais. **Conclusão:** É importante que as instituições de saúde, em especial aquelas que prestam cuidados à pessoa com transtorno mental, ofereçam apoio ao cuidador.

**Descritores:** Esquizofrenia, Cuidadores, Enfrentamento.

## RESUMEN

**Objetivo:** Conocer las estrategias de afrontamiento utilizadas por mujeres cuidadoras de los pacientes con esquizofrenia. **Método:** Estudio de carácter exploratorio descriptivo con enfoque cualitativo realizado Atención Sobral Centro Psicossocial con 15 mujeres cuidadoras de pacientes con esquizofrenia en el periodo de julio 2015 a junio 2016 a partir de entrevistas. **Resultados:** Los factores desencadenantes de estrés reportado por las mujeres fueron: estrés físico y psicológico para el cuidado diario del paciente con esquizofrenia; la dificultad de hacer frente a la enfermedad y su aceptación y; miedo a morir y dejar a la persona sola. Las estrategias de supervivencia por ellos estaban buscando apoyo espiritual y la expresión religiosa de los sentimientos para el alivio del estrés, uso de medicamentos psicotrópicos y la participación en actividades grupo. **Conclusión:** Es importante que las instituciones de salud, especialmente aquellos que atienden a las personas con trastorno mental apoyen al cuidador.

**Descriptor:** Esquizofrenia, Cuidadores, Confrontar.

## INTRODUCTION

Schizophrenia is a chronic and disabling mental disorder, being also one of the most serious and challenging, and significantly compromising the socialization potential of those affected. It is estimated to occur in 1% of the world's population.<sup>1</sup> It is one of the most relevant mental disorders in public health, receiving an estimable investment from the health system and causing great distress for the patient and his family, as it affects both the health of their such as those of their relatives and caregivers. Although with a low incidence, since it is a long-term disease, an estimated number of people with this disorder with varying degrees of impairment and needs are crowded together over the years.<sup>2</sup>

It must be understood that the concept of health has changed, and the ways of assisting these people have been differentiating over time, necessitating an integral view in view of their complexity.

Within this context stands out the Psychiatric Reform movement in Brazil, where there have been changes in public mental health policies, and mental health care

is no longer a hospital-centered, institutionalized and asylum-like model. Therapy that inserts the person with mental disorder into their family and social environment. Nevertheless, faced with this transition, the family becomes a protagonist in the caring process of people bearing schizophrenia.

The family is the basic unit that generates health.<sup>3</sup> The manifestation of mental illness in the family generates a great challenge to the balance of this unit. Many of the family members and caregivers are not prepared to care for these individuals with altered mental health status, which may be due to a lack of knowledge about the disorders, the resources in the community, lack of knowledge about how to act in a crisis situation, Warning signs, leading to an overload, both objective and subjective, the source of suffering, which can lead to mental illness.

Often times the woman assumes the role of caregiver. Culturally they are the caregivers, especially mothers in charge of caring for their family members when ill. This caregiver has also shown prominence in several care processes, including in people with mental disorders, since it is up to mothers, partners, sisters, aunts, or even grandmothers to assume this role of protagonist of care, even though they coexist with attitudes of risk on the part of the patient of mental disorder, as in cases of aggressions.

This centrality given to women as responsible for family care can have some consequences, such as undertaking heavy indeterminate and costly tasks in terms of health and quality of life, difficulty in accessing employment and professional development, social relations lack of availability of their own time, as well as economic issues.<sup>4</sup>

In the face of the difficulties experienced by the caregivers of people with mental disorders, they have to create coping strategies to deal with the problems of their daily lives.

Some of these strategies include the following: exercising a rewarding profession; developing more activities outside the home; belonging to the help group; trying to keep family life as close to normal; accepting the illness; distancing themselves emotionally from the illness and having religious beliefs that can reduce the burden of the caregivers and that are important to their quality of life and the people who need their care, including those with schizophrenia.<sup>5</sup>

There is a need to observe more carefully the caregiver, the risk factors to which she is exposed and the strategies used by her to face this situation.

Thus, conducting an investigation about which coping strategies are used by the caregivers of schizophrenia patients in the care of these individuals becomes essential for the insertion of these strategies among the health care professionals.

The study aims to contribute to the health of family members involved in this problem and its results may

help health professionals in the orientation of patients and caregivers, as well as the family, during the coping of the difficulties that these people experience in the care of the schizophrenic patient.

The study may also contribute to the academic environment in order to provide relevant information that can be used in the creation of instruments of cooperation in dealing with caregivers of people with mental disorders, so that these instruments can be useful in related services and with these health professionals on this issue. Therefore, the purpose of the present study was to know the coping strategies used by the caregivers of relatives bearing schizophrenia.

## METHODS

It is a descriptive-exploratory study with a qualitative approach. The study of exploratory and descriptive nature aims to provide greater familiarity with the problem, with a view to making it more explicit, as well as describing characteristics of a particular population or phenomenon.<sup>6</sup> A qualitative research deals with the sciences in a level of reality that cannot or should not be quantified, in other words, it works with the universe of meanings, motives, aspirations, beliefs, values and attitudes.<sup>7</sup>

The study was carried out in the general Psychosocial Care Center (PCC) of Sobral city, namely Francisco *Damião Ximenes*. This service develops a work with an interdisciplinary approach, in which there is the appreciation of the different knowledge and practices, aiming also at the elaboration of strategies and actions for the development of a critical, transformative practice, characterized mainly by humanized and quality attention, with a work aimed at promoting the exercise of citizenship and promoting the social inclusion of the assisted clientele.<sup>8</sup>

The study participants were fifteen women that are caregivers of patients bearing schizophrenia. As inclusion criteria, it was necessary for the women to be over 18 years old, having psychological conditions to respond to the interview, and being a family member of the person suffering from schizophrenia who have been attended for at least two years in the service. Another inclusion criterion was that they accepted to participate in the research by signing the Free and Informed Consent Term.

The study began in July 2015 and was completed in July 2016. Data were collected through interviews while the women attended their family member's consultation in the PCC.

The following questions were asked in the interviews in order to know the causes of the overload of caregivers: How is your daily care towards the person you take care of? What has changed in your life since your family member's diagnosis of schizophrenia? However, in order to gain insight into key coping strategies, the following questions were asked:

What do you do to address the specific responsibilities of the caring? Do you do any leisure activity?

The method of data analysis was the thematic content analysis, which consists in discovering the sense nuclei that compose a communication whose presence or frequency means something to the analytical objective aimed.<sup>7</sup> Thus, the analysis was divided in the three phases of the analysis thematic content. In the pre-analysis, the initial information was organized and systematized to create the categories, which include: "Between the care and the illness" and "Blocking the sun with a sieve: coping strategies". It should be noted that the profile of the caregivers who participated in the study was exposed. The women were coded by the letter W and the Arabic numeral following the interviews order, for instance: W1, W2... W15...

Afterward, the material exploration was carried out by the systematic analysis of the text according to the categories. Finally, the treatment of the results was performed, in which the categories were used as units of analysis, in a way that allowed to highlight the information obtained, being made later the inferences and interpretations provided in the theoretical framework or, suggesting other theoretical possibilities.

We also used a model with the main coping strategies presented in the study called the Toulousaine Coping Scale (TCS). This scale was created by a team of social psychology and health development at the Toulouse University in France and considers four types of coping strategies, as follows: control, social support, isolation and refusal, as well as positive and negative coping strategies.<sup>9</sup>

The study was carried out according to the Resolution No. 466/2012, highlighting the four basic references of bioethics: beneficence, non-maleficence, autonomy, justice and equity.<sup>10</sup> The Free and Informed Consent Term was also used, as well as the Informed Consent, aiming to document the commitment between the research participants and the researcher. The Legal Opinion No. 1.498.414 was issued by the Research Ethics Committee from *Universidade Estadual Vale do Acaraú*, under the CAAE 53208616.3.0000.5053.

## RESULTS AND DISCUSSIONS

### The caregivers profile

There were interviewed 15 caregivers of patients diagnosed with schizophrenia. Participants had family income ranging from one to three minimum wages. Their average age ranged from 45 to 70 years old. As for the educational level, incomplete elementary school predominated. In relation to the occupation, the majority revealed that it was domestic, being besides, only a retired teacher. Ten of the participants were from the municipality of *Sobral-Ceará*.

Regarding the family bond with the patient, nine of the interviewees were mothers; three sisters and three

were wives. With the new model of mental health care and de-hospitalization, the family has become an indispensable figure in caring for these patients, and women, because they are more present in their homes and because they are traditionally in charge of caring, have been pointed out as those who do the most care, especially mothers.<sup>11</sup>

The aforementioned information can influence the caregiver's overload process, since points such as the degree of relationship, frequency of caregivers and patients, and the personality of caregivers should be analyzed in order to understand the overload issue.<sup>12</sup>

### Between the care and the illness

Initially, when reporting on their daily care with the patient, all the participants stated that they had to perform various domestic care, in addition to caring for the family member in their daily lives. Among these tasks, the most cited were to prepare the family member's diet; perform your body hygiene, such as oral hygiene, hair, nail, bath; change clothes; as well as caring for household tasks such as cleaning the house and washing clothes. They also reported having to accompany them in medical consultations, support groups, emphasizing that these are, for the most part, quite dependent on their care. These responses were explained in the words of caregivers W1 and W2:

*I wake up, put him to brush his teeth, put his lunch, put it to watch television and I will take care of the household chores. Doing lunch, washing clothes, cleaning house, I have many jobs, because he pees on clothes, he is totally dependent on me and needs me to be controlling the food and the medication. I have to take care of my house, my husband, my children, I feel very tired, because all responsibility for my care is mine, I sleep too little. (W1)*

*He is dependent on me for everything; this causes a lot of fatigue, because I also have to take care of the house, the food, of my other daughters who work outside. My daughters work and they cannot help me, so it's all just me and it causes me a lot of tiredness. (W2)*

It is seen that the caregiver is responsible for various household tasks and for the care of the individual, assisting him in the execution of routine activities, such as food, hygiene care, medication administration, going to consultations, among others, and all this for generating physical and psychological fatigue. The caregiver starts to put their needs and wants in the background, which can generate additional responsibilities, stress, isolation and financial costs, becoming overwhelmed.<sup>13</sup>

The fear of death is another point highlighted by the interviewees, especially the older ones. There is concern

about the future of your family member after the death of the caregiver, which can be seen in the following speech:

*I ask God for strength, to take away my fatigue, to give me strength, to take away my worries, to protect him after my death, for this is my concern, who will take care of him when I am gone? (When speaking the caregiver gets emotional and cries), I have a lot of concern for the future, because when I die I fear that my son will be helpless, I always talk to the doctor who accompanies him here at the PCC. (W3)*

In a study carried out with relatives of patients with mental disorders at home, it was found that 72% of the participants reported being worried about the future, regarding the fact that they do not have anyone who can take care of the patient when they die.<sup>14</sup> Death was cited as a distressing factor and causes much suffering, as over the years, old age would not allow them to care for their relatives for a long time, and they feared that with their death they would become helpless, because they could not see anyone who would replace them with this care and knew that they could not live by themselves.

Another issue raised by caregivers was the difficulty they felt in caring for their relatives, reporting how difficult it is to care for people bearing schizophrenia. This can be attributed to symptoms in periods of aggravation that the disease brings, such as hallucinations, delusions, disorganized behavior and thinking, social blunting, as well as their behavior, which may be aggressive or attitudes considered strange for some people, including prejudices. The following statements present these feelings:

*It is very difficult to care of a person with this disease because they are difficult to deal with, they do not want to accept what we say. She even tried to kill herself. (W4)*

*I became a very sensitive person after his illness, I never accepted this condition in which he is, so when I go out with him, he shows the disorder with different behaviors, such as entering and leaving the church during the religious worship, that annoys me, because I do not want it noticed by people, they look different, and that causes a certain prejudgment. (W5)*

Mental disorder is still a phenomenon permeated with preconceptions and stigmata, difficult to deal with, and it is quite incomprehensible to society, either by the medical community or by other people involved.<sup>15</sup> It is found that there is difficulty in living with the patient with mental disorder, often due to aggressive attitudes, lack of affection, unpredictability and social isolation. The patient's behavior also creates a climate of tension in the family environment; the family is in a constant

state of alertness to perceive signs of aggression and to control their own behaviors, thus avoiding an unleashing of aggressive behavior.<sup>16</sup>

Another problem that can cause overload in the caregiver is the change in the life of the caregiver, since the illness of one of the family members can significantly affect the lives of other family members. The care that women give to their relatives bearing schizophrenia may interfere with their routines, life plan, and future dreams. The interviewees revealed that they left their life projects and their social life to fit the routine of their sick relatives, which can be evidenced in the following statements:

*I stopped working for a long time, because I had to take care of him, and that was necessary, because I liked to work and to have my money. (W7)*

*Before I could go out, work out, in a family home, today I cannot, my life is take care of him, changed everything, I have no friendship. I used to talk, to go to the bathroom, to go out with my friends, to go to church, but today I cannot do it. (W8)*

The implications of exercising care in the family context are difficult to measure, as the family often faces material and economic difficulties.<sup>17</sup> Added to these difficulties are the conflicts generated between the family members and the person with the disorder, who often do not find ways and means of coping, and realize that both their future plans (caregivers) and family members are affected by the disease and are compromised due to the severity of the mental illness.

In summary, it was possible to observe that the main stress factors of caregivers while taking care of the family member with schizophrenia were the excess of domestic care associated with family care, concerns and fears about the future, existing preconception towards schizophrenia and changes in their life routine.

### **Blocking the sun with a sieve: coping strategies**

By knowing the causes that may predispose to the illness of the women interviewed, it became necessary to know what coping strategies they used to confront the situation.

The coping of the stressful process is defined as cognitive and behavioral efforts undertaken to control the individual's responses to situations that are overburdening or exceeding their personal resources.<sup>18</sup>

Twelve of the interviewees pointed out religiosity as allied to the process, in other words, that they sought through prayer to alleviate their fears, stresses and thus be able to face the process of caring in a more relaxed way, as evidenced by the speeches of participants W2 and W5:

*The Lord is the one who strengthens me, my God that I serve and that is here always close to me, helping me to walk, if He gave me this son is because he knows that I can care. Before I was not a believer, it was this illness of my son that led me to seek God; today my faith and my religion help me to live. (W2)*

*I am very Catholic, I am of the church, I have a lot of confidence in God, and it is God who sustains me, I live my faith, and this has helped me to overcome these challenges, because it is not easy to see his son so grown, so dependent and disabled (W5)*

Religious people often have a greater capacity to cope with adverse life circumstances with the use of Religious/Spiritual Coping.

Religious/Spiritual Coping can be a device that encompasses strategies that provide a beneficial effect to the individual, such as seeking God's love/protection or greater connection with transcendental forces. It can be negative when it involves strategies that generate harmful consequences, for instance, redefining the stressor as divine punishment.<sup>19</sup>

Based on what has been presented, it is evident that religion and spirituality offer an effective means of coping strategy for caregivers, regardless of religious belief or its form of manifestation, as well as a place for effective faith, whether at home or in religious establishments.

Another coping strategy pointed out was the revelation of feelings to other people or to themselves through crying, sadness, happiness, among others:

*Sometimes I find myself very voluble, sometimes I cry, another time I'm happy, I have a little grandson in my house who also brings me a lot of joy. (W8)*

*I cry a lot, I am sad with the situation, because I have already suffered much suffering with him, early in the day he was hospitalized, not sleeping. (W9)*

Exposure of feelings as a coping strategy can improve stress, causing temporary relief, but often the exposure of these feelings shows a risk for future complications such as depression and abandonment of the patient being cared for. This can be corroborated with other studies that stress that the stress caused by the uninterrupted task of caring can affect the caregiver's health and quality of life, also interfering with the quality of the care provided.<sup>20</sup>

This condition must be perceived by the health professional who assists the patient with schizophrenia, given the complexity of dealing with mental health, the caregiver should perform full care of the patient-family binomial, that is, it should be promoted therapeutic possibilities that are capable of responding to health responses to the individual, family or community.

The use of medications was reported by nine women as coping strategy. Taking care of people with health problems can make a patient of the caregiver, and make them use daily medications,<sup>21</sup> as evidenced in the speeches:

*Today I use fluoxetine, I became a sad and distressed person; I cry a lot. (W10)*

*I also got sick of the nerves after this illness of my children; I take amitriptyline, and the nurse told me that who cares of people with this disease also needs medication. (W11)*

The use of psychotropic medications has become normal to women seeking to improve symptoms such as anxiety, insomnia and stress. They reported making use of these drugs, which they seek in their Basic Health Units. This evidences illness processes in the caregivers. The prescription of psychotropic drugs in the Family Health Strategy is associated with conditions such as: anxiety, difficulty sleeping, headache, mental fatigue, easy crying, discouragement and family problems.<sup>22</sup>

The women cited as a coping strategy their participation in the group activities of the Psychosocial Care Center (PCC). The support group technology is a resource that is being used by health professionals, as it helps them to alleviate feelings of solitude and social isolation, allowing for the exchange of experiences and reflection.<sup>23</sup>

In the meantime, the participation of some women in PCC group activities, together with the person bearing schizophrenia, allowed them to be distracted, and at the same time represented a leisure moment that diminished their stresses, as well as better knowledge of the process of illness of the person to whom he/she took care, thus providing a great entertainment therapy for both the caregiver and the schizophrenic patient.

Based on the results found and using the TCS, three types of coping strategies were identified, since the refusal item was not included in the responses of the women interviewed, according to Table 1.

**Table 1.** Principal coping strategies based on the Toulousaine's Coping Model.

	Control	Social Support	Isolation	Refuse
Coping Strategies	09 of the interviewees revealed use of psychotropic drugs for stress management	12 of the interviewees sought support through religiosity	03 das entrevistadas revelaram expor sentimentos por meio do choro	Não contemplou
Positive coping		(+) Seek for help with other people and groups		Did not contemplate
Negative coping	(-) Acceptance of the situation associated with the use of medicated product		(-) Escape and isolation	Did not contemplate

The coping strategies used by caregivers can be many, but without the support of health professionals and without proper information their repertoires are scarce, which can lead to illness.

The lack of knowledge of strategies can favor negative coping, leading to consequences and damages to their health, among them the use of non-prescription medicines or others, such as social isolation.

Through the response given to the stress factor, it will tend to the following respective poles: negative or positive, which directly influences the health-disease process.

## CONCLUSION

The results show the complexity of taking care of the person bearing schizophrenia. The difficulties experienced by these women presented an arduous routine, in which they have a duty to perform tasks ranging from daily activities to dealing with problematic behaviors, which sometimes cause discomfort, pain and anguish.

The main coping strategies practiced by the women were the search for support related to their religiosity, the disclosure of feelings to relieve stressors, such as crying, the use of psychotropic medications, to relieve symptoms of depression and sadness, and participation of in-group support activities.

It is essential that health institutions, especially those that provide care for the person with mental disorder, can offer support to the caregiver, with group activities and moments of

health education in order to sensitize the caregiver about his own care, helping him in positive strategies, thus contributing to improve their quality of life and well-being.

It was shown that health professionals can approach the caregivers with the objective of working coping strategies, focusing on either the caregiver's emotions or their problems. In the meantime, professionals can work on in-group activities, strengthening the subjects' self-esteem, as well as therapies along with the family, in order to strengthen the inclusion of other members in the care of the person bearing schizophrenia and, thus, reduce the burden of the caregivers.

The main limitation of the study was the limited number of participants. Another fact to be considered was that the research had to be performed in only one place, due to the fact that PCC is the referral service in the municipality regarding the diagnosis and treatment of patients bearing schizophrenia.

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