

**NURSING STUDENTS' PERCEPTION OF CAREGIVERS OF PEOPLE WITH  
SCHIZOPHRENIA****PERCEPÇÃO DE ACADÊMICOS DE ENFERMAGEM SOBRE OS CUIDADORES  
DE PESSOAS COM ESQUIZOFRENIA****PERCEPCIÓN DE LOS ESTUDIANTES DE ENFERMERÍA SOBRE LOS  
CUIDADORES DE PERSONAS CON ESQUIZOFRENIA**

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**ABSTRACT**

**Objective:** To find out how nursing students perceive the caregivers of people with schizophrenia. **Method:** A descriptive study with a qualitative approach, carried out at a public university with 79 nursing students. Data was collected using an electronic questionnaire, made available to participants via *Google Forms*, via *Whatsapp*®, organized into thematic categories and analyzed according to content analysis. **Results:** The following thematic categories emerged from the analysis: "Role of the caregiver of people with schizophrenia: what do I think about it?", "Challenges faced by the caregiver of people with schizophrenia in the view of nursing students", "Care networks and types of support for caregivers of people with schizophrenia" and "Caregivers of people with schizophrenia: are there discussions in undergraduate nursing courses?". **Conclusion:** Most nursing students are aware of the roles played by caregivers of people with schizophrenia.

**Descriptors:** Schizophrenia; Family caregiver; Nursing care; Students, Nursing.

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**RESUMO**

**Objetivo:** Conhecer a percepção de acadêmicos de Enfermagem sobre os cuidadores de pessoas com esquizofrenia. **Método:** Estudo descritivo, com abordagem qualitativa, realizado em uma universidade pública com 79 acadêmicos de Enfermagem. Os dados foram coletados por meio de um questionário eletrônico, disponibilizado aos participantes por meio do *Google Forms*, via *Whatsapp*®, organizados em categorias temáticas e analisados de acordo com a análise de conteúdo. **Resultados:** Mediante análise das falas emergiram as categorias temáticas: “Papel do cuidador de pessoas com esquizofrenia: O que penso sobre?”, “Desafios enfrentados pelo cuidador de pessoas com esquizofrenia na visão dos acadêmicos de enfermagem”, “Redes de atenção e tipos de suporte aos cuidadores de pessoas com esquizofrenia” e “Cuidadores de pessoas com esquizofrenia: há discussões na graduação em Enfermagem?”. **Conclusão:** A maioria dos acadêmicos de enfermagem conhecem as funções desenvolvidas pelo cuidador de pessoas com esquizofrenia.

**Descritores:** Esquizofrenia; Cuidador familiar; Assistência de enfermagem; Estudantes de enfermagem.

## RESUMEN

**Objetivo:** Conocer la percepción de los estudiantes de enfermería sobre los cuidadores de personas con esquizofrenia. **Método:** Estudio descriptivo con enfoque cualitativo, realizado en una universidad pública con 79 estudiantes de enfermería. Los datos se recogieron mediante un cuestionario electrónico, puesto a disposición de los participantes a través de *Google Forms*, vía *Whatsapp*®, organizado en categorías temáticas y analizado según análisis de contenido. **Resultados:** Del análisis surgieron las siguientes categorías temáticas: "Rol del cuidador de personas con esquizofrenia: ¿qué pienso al respecto?", "Desafíos que enfrenta el cuidador de personas con esquizofrenia en la visión de los estudiantes de enfermería", "Redes de atención y tipos de apoyo para cuidadores de personas con esquizofrenia" y "Cuidadores de personas con esquizofrenia: ¿hay discusiones en los cursos de pregrado de enfermería?". **Conclusión:** La mayoría de los estudiantes de enfermería son conscientes del papel que desempeñan los cuidadores de personas con esquizofrenia.

**Descriptor:** Esquizofrenia; Cuidador familiar; Cuidados de enfermería; Estudiantes de Enfermería

## INTRODUCTION

According to the World Health Organization (WHO), the concept of health is considered to be the complete physical, mental and social well-being of the individual, and is not characterized solely by the absence of disease.<sup>1</sup>

Historically, people with mental disorders were considered irrational individuals who posed a high risk to the population. Treatment took place in psychiatric hospitals or asylums, with

mistreatment and total isolation, causing greater suffering to the patient and their family. In view of this, family members, together with members of the health movement, sought better care for this population and the abolition of asylums, a movement called the Brazilian Psychiatric Reform.<sup>2</sup>

After the reform, the Psychosocial Care Center (CAPS) was created with the aim of improving patient treatment, psychosocial rehabilitation and providing

quality assistance to individuals with mental problems, in addition to encouraging social interaction, the performance of the role of citizen and autonomy.<sup>3</sup>

The WHO classifies the various types of mental disorders, such as depression, anxiety, panic disorder and schizophrenia.<sup>4</sup> Schizophrenia is characterized by changes in thinking, causing loss of memory, perception and strong emotional changes, which impair the performance of daily life activities. The disease develops in different ways, causing a strong biopsychosocial shock in the patient and overload to the caregiver.<sup>5-6</sup>

The burden on the caregiver can lead to serious types of psychopathological disorders that directly interfere with their lives, compromising the treatment and care of the person with a mental disorder. Often, the lack of knowledge and guidance on how to deal with the illness are some of the problems faced by the caregiver, causing their own mental illness, which requires attention and care for their health.<sup>7</sup>

Caregivers of people with schizophrenia face several situations during monitoring and care, since in addition to being the main person responsible for the schizophrenic patient, they are also, in most cases, those who carry out daily activities, such as preparing food, cleaning the home, accompanying people to appointments and

managing their finances, which leads to neglect of personal care, physical and psychological overload.<sup>8</sup>

Therefore, there is a need for assistance from care networks to provide services to caregivers, through health professionals who must offer support, knowledge, clarification of doubts and guidance.<sup>9</sup>

With regard to assistance to caregivers, nurses are responsible for offering comprehensive care and assisting them in a humanized manner, seeking to develop care for physical, social, mental and spiritual well-being, which requires training. From this, it becomes essential to focus on their training process during graduation so that they can overcome the biomedical and hospital-centric/asylum model.<sup>10-11</sup>

It can be said that care is centered, most of the time, on the person with schizophrenia, thus limiting qualified assistance to the caregiver. It is believed that this occurs due to failures in the implementation of content that makes up the curriculum in higher education institutions, which leads to the invisibility of classroom discussions about caregivers of people with schizophrenia.

Thus, the study is relevant to the academic community, since by identifying gaps in nursing students' knowledge about caregivers of people with schizophrenia,

higher education institutions can implement greater discussions and reflections not only about people with schizophrenia, but also about their caregivers.

There are few studies in the literature that address the perception of nursing students regarding the role of caregivers of people with schizophrenia, which justifies the present research. Thus, the study aimed to: understand the perception of nursing students about caregivers of people with schizophrenia.

## **METHOD**

This is a descriptive study, with a qualitative approach, carried out at a public university located in the South-Central region of the state of Ceará, in August 2020.

The study sample consisted of 79 nursing students regularly enrolled in the 7th to 10th semester of the bachelor's degree in Nursing. The inclusion criteria were: students who had already taken the Nursing course in the Mental Health Care Process and who had access to the internet to complete the questionnaire. Students who were unable to participate in the research were excluded, such as those with a medical certificate or maternity leave during the data collection period and who did not respond to the questionnaire after 15 days.

Data were collected through an electronic questionnaire, which contained three sections. The first section presented

the researcher's data, the research objectives, and the inclusion and exclusion criteria, which the students themselves had to apply to be eligible for participation, through the Free and Informed Consent Form (FICF), in which the participant had to select the box agreeing with the terms of the FICF to advance to the next section.

The second section consisted of sociodemographic information, such as age, gender, family income, and semester of undergraduate studies. In this section, the questions were objective and the participant was asked to select one option. The third section addressed subjective questions about what the students understood about the role of caregivers of people with schizophrenia, the main challenges faced by this population, the care networks offered to this population, and teaching about caregivers of people with schizophrenia in undergraduate courses.

This instrument was made available to participants through Google Forms, via WhatsApp®, to avoid direct contact with participants and, thus, mitigate the risk of transmission of COVID-19. These contacts were made available by the Nursing course coordinator, requested by the researcher, who communicated with a member of each class, explained the objectives of the research and requested that the questionnaire be sent to the other students, through the class's WhatsApp® group, as

well as requested that it be returned within 15 days.

It should be noted that the names of the participants were not mentioned in the construction of the text in order to preserve their identities, with codes being used to identify them, followed by the sequential number (ACADEMIC 1, ACADEMIC 2, ACADEMIC 3...).

The content analysis technique was adopted, a method that is divided into three phases: In the first phase, called pre-analysis, contact was made with the material obtained, through a skimming of the data. In the second phase, the organization of the base units took place, based on the points of convergence and divergence, with the purpose of synthesizing the content to categorize the data through thematic categories. Finally, the data were interpreted and then discussed with the scientific literature.<sup>12</sup>

The project was submitted and approved by the Research Ethics Committee (CEP) of the Regional University of Cariri (URCA), under CAAE number: 34097720.4.0000.5055 and opinion no. 4,195,391, approved on August 5, 2020. It is noteworthy that data collection was initiated after CEP approval. The research was developed in accordance with Resolution No. 466/2012 of the National Health Council (CNS), preserving ethics and respect for human beings.<sup>13</sup>

## RESULTS

Of the 79 students who participated in the study, their ages ranged from 18 to 28 years, with a prevalence of the age group of 21 to 23 years (n=59.5%), 62 (n=78.5%) were female and 17 (n=21.5%) were male. Regarding family income, the income of 1 to 2 minimum wages prevailed (n=34, 43%). Regarding the semester, the majority of the students interviewed were in the 10th period of the undergraduate Nursing course (n=31, 39.2%).

Through analysis of the speeches, the following thematic categories emerged, described below.

### **Role of caregivers for people with schizophrenia: What do I think about it?**

This category's main objective was to identify the knowledge of Nursing students regarding the person who plays the role of caregiver for a person with schizophrenia.

Participants responded that caregivers are essential in the treatment of people with schizophrenia, as they actively participate in their health-disease process.

*It is a role that requires a lot of responsibility and, above all, patience. During outbreaks, caution and an understanding of the disease are required in order to know how to act. In my opinion, caregivers should also receive psychological support, as their mental health is affected. (ACADEMIC 25)*

*The caregiver's role is to provide safety, correct medications, comfort and well-being to the schizophrenic. (ACADEMIC33)*

*It is a difficult role, which requires dedication, knowledge and patience. (ACADEMIC39)*

*Essential because through it, the client diagnosed with schizophrenia will be able to live fully, socially and adopt self-care measures. (ACADEMIC42)*

*It plays a fundamental role. Most care for people with mental disorders is full-time, especially when it is provided by the family, and in most cases it is provided by a first-degree relative, who often neglects their own needs to meet the needs of the person under care. (ACADEMIC 51)*

*The caregiver plays a fundamental role in the context of the mentally ill patient, as they need care to carry out activities of daily living, use medication and in crisis situations. (ACADEMIC 68)*

Other study participants did not have knowledge about the role of caregivers for people with schizophrenia.

*I don't know how to answer. (ACADEMIC4)*

*I don't have much knowledge about this performance. (ACADEMIC 8)*

*I don't know anything about the subject. (ACADEMIC 34)*

*I don't have much knowledge about this performance. (ACADEMIC47)*

*I've never heard of the topic. (ACADEMIC 79)*

### **Challenges faced by caregivers of people with schizophrenia from the perspective of nursing students**

This category allowed us to understand the perception of academics about the challenges faced by caregivers of people with schizophrenia. According to the participants, the affected mental health of caregivers is one of the main challenges faced, as they are mentally overloaded with

the responsibilities that fall to them in this role.

*Mental health, given the challenges they need to face. (ACADEMIC 15)*

*The psychological aspect, because often the family member, in addition to not knowing how to act, is afraid of the reactions presented. (ACADEMIC25)*

*I think mental health. A caregiver needs physical and mental health to provide care appropriately and with less risk to themselves. (ACADEMIC 43)*

*Emotional health is worn out. (ACADEMIC59)*

*Health as a whole, but especially psychological health. (ACADEMIC65)*

### **Care networks and types of support for caregivers of people with schizophrenia**

Regarding the academics' conception of assistance provided to caregivers of people with schizophrenia, most responded that this public does not have care networks and assistance is specifically aimed at people with schizophrenia.

*I believe there is no specific assistance. (ACADEMIC7)*

*There is no, since the assistance is intended only for the person receiving the care. (ACADEMIC 33)*

*No. Unfortunately, it is something that is not yet visible. (ACADEMIC 47)*

*I am not aware of any actions in this regard. (ACADEMIC 62)*

Regarding the types of support that could be offered to this audience, the academics suggested support groups, discussion groups and monitoring with specialized professionals.

*Support groups, UBS nursing assistance, home visits. (ACADEMIC10)*

*Support groups where they could talk and express their feelings and anxieties. (ACADEMIC 35)*

*Psychological monitoring and active listening to existing problems in the care that this person provides. (ACADEMIC43)*

*I believe that emotional support in CAPS, therapy at least once a week, conversation circles between these caregivers, some moments to relax and to learn more about the disorder to learn how to deal with them better. (ACADEMIC 54)*

*Support groups for caregivers. (ACADEMIC 68)*

### **Caregivers of people with schizophrenia: are there discussions in undergraduate Nursing courses?**

This category allowed us to know whether students had the opportunity to discuss caregivers of people with schizophrenia in their undergraduate nursing course at the institution where the study was conducted. Participants reported that teaching was focused only on providing care to people with schizophrenia and that care for caregivers was not addressed.

*No, we've never heard of it. (ACADEMIC 02)*

*No, on the occasions when the topic of schizophrenia was addressed, nothing was said about the family caregiver... only what the disease is, how it presents itself and the assistance to be provided was highlighted. (ACADEMIC16)*

*No, on the occasions when the topic of schizophrenia was addressed, nothing was said about the family caregiver... only what the disease is, how it presents itself and the assistance to be provided was highlighted. (ACADEMIC 57)*

*No, discussions are generally focused on the patient who has the pathology. (ACADEMIC63)*

## **DISCUSSION**

Most of the participants in the research were young people with an average age of 21 to 23 years. Nowadays, people enter college at a very young age, which is seen as something beneficial, as they will have the opportunity to practice their profession from an early age and contribute to society.<sup>14</sup> This is done through the offering of undergraduate courses in higher education institutions, providing the opportunity of new knowledge.<sup>15</sup>

Regarding gender, it is clear that there was a greater prevalence of women in the study. The female gender is still a prevalent number due to the prejudice that is still rooted in society that Nursing is a course for women due to the historical characteristics of the profession. Despite this, it is important to highlight a growing number of men in universities, as well as in the job market in this category.<sup>16-17</sup>

After analyzing the responses, it was possible to identify that some of the students have similar knowledge regarding the role of the caregiver, as the majority indicated that the caregiver is responsible for the main activities carried out during the patient's daily routine, such as administering medication, taking care of hygiene and attending appointments.

Schizophrenic patients may have functional implications and difficulties in carrying out their daily activities. In view of

this, the caregiver is the person responsible for carrying out activities such as administering medication at established times, personal hygiene, feeding and attending appointments at health services.<sup>18</sup>

While some of the students had knowledge about the role of caregivers, the other participants did not understand the main demands, due to a lack of training during their education, specific knowledge and skills. This created conflicts and difficulties for educational development and professional practice that affect the quality of mental health services.

People's prejudice towards mental disorders can often cause fear and apprehension among students and contribute to these future professionals engaging in inappropriate behavior as well as discriminatory practices that affect patient care.<sup>7</sup>

The mental health of caregivers, in the perception of study participants, is the most affected, since they are physically and emotionally overburdened by the responsibilities and activities they are given on a daily basis. In addition, several aspects are affected, such as economic, social, spiritual and emotional, as caregivers stop living their own reality to adapt to the life of the person under their care.

The caregiver, most often represented by the family figure, is the one who assumes the responsibility of caring for people with

schizophrenia. This role brings about various feelings, such as doubts, fear, anguish, despair and sadness, consequently causing the impairment of their mental health.<sup>19</sup>

When asked about the existence of care networks for this population, most participants reported a lack of support to meet the needs of this public, since most professionals focus on caring for patients affected by the disease. Moreover, as suggestions for help to meet the demands, the academics responded support groups, discussion groups and specialized monitoring, which would facilitate more effective care from the caregiver to the patient, thus making the caregiver's mental health visible.

Authors report in their study the lack of support for family members and caregivers of people with schizophrenia, since this public needs greater action from care networks and a comprehensive view due to the vulnerability of this population, ensuring adherence and inclusion in the services offered.<sup>20</sup>

According to the academics' point of view, teaching about caregivers of people with schizophrenia at the institution where the study was carried out presents gaps, as nursing care aimed at this public is not discussed in a complex way, which must be recognized and valued for its role in society, since they are overburdened people who



need care for their health, which leads to flaws since the training of these professionals and implies in the nursing care directed at these people.

The importance of in-depth knowledge on the subject is fundamental for the development of skills and competencies to provide qualified assistance to caregivers of people with schizophrenia.

This study was limited by the fact that it was carried out at a single university, which makes it necessary to understand the perception of nursing students from other institutions, since the results presented here cannot be generalized.

However, the results obtained in this research are valid and relevant for the construction of reflections on the subject. Thus, it is expected that this research can contribute to the realization of new studies on the knowledge and assistance offered to caregivers of people with schizophrenia and collaborate for the discussion of the subject in higher education institutions.

## CONCLUSION

The results showed that, although nursing students at the institution where the study was conducted reported the lack of discussions about caregivers of people with schizophrenia, the majority were aware of the functions performed by caregivers, the assistance that should be offered to this

population and their role in the social environment.

It is important to highlight the importance of nursing students being involved in scientific events and extracurricular internships that address topics that will contribute to their professional practice, seeking to expand their qualifications and not limit themselves to discussions offered in the classroom.

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