ISSN: 2318-8413 DOI: 10.18554/refacs.v9i0.5669

REFACS

Occupational roles of a parent and primary caregiver of a person with schizophrenia

Papéis ocupacionais de um pai e cuidador principal de um portador de esquizofrenia

Roles ocupacionales de un padre y cuidador principal de una persona con esquizofrenia

Received: 23/03/2021
Approved: 19/07/2021
Published: 26/08/2021

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This is a qualitative case study, carried out in 2018 in a city in the interior of the state of Minas Gerais, in a Psychosocial Care Center for adults. It aimed to analyze the occupational roles of a family member who was the main caregiver of a child with schizophrenia. We used the Occupational Roles Identification List and semi-structured interviews for data collection and applied to thematic content analysis. There was an impact on the father's occupational roles when he became a caregiver, due to the emotional, social and financial burden experienced during the care process and by the bureaucracy of the public administration. The roles of caregiver, family member and hobby presented themselves as present and possible to follow in the future. Being a caregiver to a person with a mental illness has been shown to lead to the loss of several occupational roles.

Descriptors: Mental Health; Occupational Therapy; Caregivers.

Este é um estudo de caso qualitativo, realizado em 2018 numa cidade do interior mineiro, num Centro de Atenção Psicossocial para adultos, com o objetivo de analisar os papéis ocupacionais de um familiar, cuidador principal de um filho com esquizofrenia. Utilizou-se a Lista de Identificação de Papéis Ocupacionais e entrevista semiestruturada para coleta de dados e aplicada a análise de conteúdo temática. Observou-se impacto nos papéis ocupacionais do pai ao tornar-se cuidador, em razão da sobrecarga emocional, social e financeira vivenciada durante o processo de cuidado e pela burocracia da administração pública. Os papeis de cuidador, membro de família e passatempo se apresentaram como presentes e possíveis de seguirem no futuro. Ser cuidador de uma pessoa com transtorno mental mostrou acarretar a perda de vários papéis ocupacionais.

Descritores: Saúde Mental; Terapia Ocupacional; Cuidadores.

Este es un estudio de caso cualitativo, realizado en 2018 en una ciudad del interior de Minas Gerais, en un Centro de Atención Psicosocial para adultos, con el objetivo de analizar los roles ocupacionales de un familiar, cuidador principal de un niño con esquizofrenia. Se utilizó la Lista de Identificación de Roles Ocupacionales y la entrevista semiestructurada para la recogida de datos y se aplicó al análisis del contenido temático. Se observó el impacto en los roles ocupacionales del padre al convertirse en cuidador, debido a la sobrecarga emocional, social y financiera experimentada durante el proceso de cuidado y la burocracia de la administración pública. Los roles de cuidador, familiar y afición se presentaron como presentes y posibles de seguir en el futuro. Ser cuidador de una persona con trastorno mental demostró implicar la pérdida de varias funciones laborales.

Descriptores: Salud Mental; Terapia Ocupacional; Cuidadores.

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INTRODUCTION

According to the tenth edition of the International Classification of Diseases (ICD-10), mental disorders are classified as diseases associated with functional impairments of the individual, resulting, in most cases, in psychological, biological, genetic, social, chemical or physical disfunction[1]. Mental disorders can lead to changes in mood and thought that result in damage to the individual's overall performance in the biopsychosocial and spiritual spheres[1]. People with mental disorders need care to minimize suffering and improve quality of life, and for that, there are some services at different levels of health care and social assistance.

Brazilian public policies, after the Psychiatric Reform, started to advocate deinstitutionalization of mental health care and deconstruction of the asylum and its paradigms, replacing them with non-asylum and community-based services, promoting citizenship principles that enable the quality of life, from the construction of bonds and human interaction[2], welcoming and treating the subject, in services such as Psychosocial Care Centers (*Centro de Atenção Psicosocial* - CAPS), Therapeutic Residence Services (TRS) and Basic Health Units (*Unidade Básica de Saúde* - UBS), with aimed at sociocultural reintegration.

With the implementation of substitute care services for people with mental disorders provided by the deinstitutionalization of mental health, care in the psychosocial care network seeks to strengthen family and community bonds, encouraging the family to play a more effective and participative role in providing of care to the user[3]. However, this care strategy of the community model, which enables bonding and coexistence with the sick person, can have an impact on the lives of family members, due to the difficulties faced in the performance of care, the overload, the feeling of lack of assistance on the part of mental health services, and the concerns about the sick patients/relatives[4].

In Brazil, a family member is usually responsible for taking care of the people who are part of the family, especially those who require more attention. Such action can cause changes in routine, restrictions in social and professional life, in addition to losses in the financial sphere due to abandonment or reduced workload. This, therefore, can have a negative impact on the caregiver's physical, social and emotional health, generating anxiety, stress, personal disorder, decline in quality of life and financial burden[5], whether due to lack of time, unwillingness to abdicate the person receiving care, fatigue, performing excessive tasks and continuous supervision; which can also generate restriction of leisure activities, leading to social isolation[6].

This context may reflect difficulties in the performance of the caregiver's occupational roles. Occupational roles are the images that people have of themselves, as occupants of a position in social groups and as the executor of the obligations and expectations placed in these roles[7]. Thus, the objective of this work was to analyze the occupational roles of a family member, the main caregiver of a child with schizophrenia.

METHODS

This study, carried out in October 2018, is characterized as exploratory, with a qualitative approach, used when the theme involves the universe of human production, the meanings of human relationships from different points of view and their representations[8]. We opted for the development of a single case study, which represents an empirical investigation and a comprehensive method, which seeks to investigate a specific and delimited case[9].

The work was carried out in a Psychosocial Care Center (CAPS) in a municipality in the interior of the Minas Gerais state. This was the place where the adult with schizophrenia underwent treatment and where access to the participant was possible.

The research participant was a father, the primary caregiver of an adult with schizophrenia. He was selected because he is the main person responsible for this task and has followed his son's treatment for at least six months. The role of main caregiver was confirmed, as his wife had been sick for a few years and there was no one else to help him in this occupation.

Data collection took place in a reserved room at the CAPS, with the presence of only one researcher and the participant. The interview lasted an average of 40 minutes, and the Occupational Roles List[10] was applied. Sociodemographic issues and questions about the time the family member had been undergoing treatment at the CAPS were also raised; about the process of discovering the disease and starting treatment; about how he perceive the treatment nowadays; if anything changed in his day-to-day after the child's diagnosis and if he faced difficulties in this process.

The Occupational Roles Identification List[10] seeks to gather information about a person's occupational roles, and can be used for both clinical follow-up and research. Occupational roles consist of productive or leisure behaviors, which contribute to the personal identity of individuals, organize the use of time and enable the involvement of individuals in the social structure[10].

This assessment instrument has been validated for use in Brazil and can collect data on the individual's perception of their life; about occupational roles that they have already developed, that they are currently developing and intends to develop in the future, about satisfaction with these roles, as well as additional information about a person's ability to maintain the balance between roles[10].

Data from the List of Occupational Roles were registered in the instrument itself and the interview was recorded in digital media and later transcribed for analysis. There was a record of impressions about the respondent and the service in a field notebook, which were analyzed along with other data. The information collected by the two instruments was analyzed through content analysis[11].

First, we initially analyzed the data obtained from the Occupational Roles Identification List, raising the frequency of occupational roles performed over time (past and present) and which the participant intends to play. Then, the degree of importance that the participant attributed to each occupational role was verified.

Then, there was a pre-analysis of all the material collected through the interview, with a reading of the content of the participant's statements, checking the relevance and representativeness of the material in its entirety, to then carry out the exploration of the whole[11].

In the material exploration phase, the categorization of the material was carried out, based on the clipping of the registration units of the learned content. Next, the selected thematic units and semantic categorization were enumerated. Afterwards, the results obtained were interpreted through inference[11].

The respondent was informed about the proposal and stages of the investigation and then signed the free and informed consent form.

The study was submitted for evaluation by the Research Ethics Committee of the Universidade Federal do Triângulo Mineiro, having been approved under registration CAAE 93322518.1.0000.5154 of July 14, 2018.

RESULTS

The family member interviewed was named by the fictitious name of Inácio to preserve his identity. He was 60 years old, married, on leave from work (a farmer) due to back problems, had a family income of one minimum wage and lived in a city neighboring the institution where his son was undergoing treatment. Inácio has six daughters and four sons, the result of two marriages, and the CAPS user is the child of his second marriage.

To travel to the CAPS, the father and son used public transport and, due to the unavailability or delay of that transport to return, they used a private company vehicle, paying the costs themselves. Inácio mentioned that he faced difficulties due to the bureaucracy of the public administration, that it is very difficult to be a resident of one municipality and have to undergo treatment in another, that the treatment at the CAPS is good. He stated that transport was lacking and expensive, as he supported his family, bought medicine and also had to pay for transport, all with a minimum wage, which represented a financial burden.

Inácio mentioned that, due to the needs faced by his son, he assumed full responsibility for the care at home and in the follow-up of the treatment, and he reported difficulties faced both due to this care, and in relation to himself, as well as his age, as he feels tired, and the "*little study*" (he studied until the fourth year of elementary school) and "*it is a daily battle to follow and understand everything*".

In the past, Inácio developed all occupational roles presented by the Occupational Roles Identification List (student, worker, volunteer, caregiver, domestic work, friend, family member, religious, hobby), except for participating in organizations (Table 1).

He played the roles of: caregiver, family member and hobby; and, in the future, he intended to keep these same roles, in addition to being a volunteer. In relation to domestic work, he said he would do it if necessary; he would not return to the role of religious, although he had faith in God (Table 1).

Table 1. Occupational roles, father of person with schizophrenia (Part I). Uberaba, MG. 2018.

OCCUPATIONAL ROLES	PAST	PRESENT	FUTURE
Student	X		
Worker	X		
Volunteer	X		X
Caretaker	X	X	X
Domestic work	X		
Friend	X		
Family member	X	X	X
Religious	X		
Hobby	X	X	X

As for the importance of occupational roles, Inácio reports that he studied until the 5th grade of elementary school, but did not complete it and would like to return to school, but he imagined that he would not fulfill this dream. Work was the occupation that he attributed the most importance, but he was no longer able to perform this activity due to physical wear and tear and his back problem. He has already been a volunteer for seven years in the collegiate of a school and would like to do some activity like this in the future; he performed domestic work only at certain times, such as when his wife was in postpartum period or when he lived alone (Table 2).

He did not have a network of friendships, as he considered it a detail, he was afraid to share his life and be judged by these people, valuing more to the responsibilities of marriage. He considered it important to dedicate his time to his family, God and health professionals.

For Inácio, the occupational role of caregiver brought changes to his life in several aspects; however, despite the changes, he said that, in the future, in addition to the roles he currently plays, he would just like to be able to volunteer at some institution and return the good he has received.

Ignatius said that he has a huge belief in God. Currently, he does not follow a specific religion, but has "*a very great spirituality and perceives God in the small details of daily life, mainly connected to aspects of nature*". As for the hobby occupational role, he uses as a resource for his leisure time listening to music on the radio. This moment is important to him, because it helps him to organize himself in delicate moments, such as when he is desperate, tired and with negative thoughts.

Table 2. Occupational roles, father of person with schizophrenia (Part II) Uberaba, MG. 2018.

Occupational roles	No importance	Some importance	A lot of importance
Student		X	
Worker			X
Volunteer		X	
Caretaker			X
Domestic work	X		
Friend	X		
Family member			X
Religious			X
Hobby			X
Participant in Organizations			

Some resources are pointed out to deal with the issues that arise during the whole process of being a caregiver. Belief in a God helps to deal with emotional issues. In addition, the family promotes a support network, even if many family members have a poor health condition. So, he hoped that things would improve, having hope for the new days and how important today was for that tomorrow: "*While there is life, there is hope!*" and, highlighted the expectations in the long-term treatment, however, showed difficulty in accepting the illness, diagnosis and prognosis of the child:

He complains a lot, says: "Will I have to take medicines my whole life?" and I say: no young man, you are not going to live taking medicine all your life, take it according to the doctor's instructions, if God wants and you follow the medical advice, we will get out of this. I hope it can get better, while there is life, there is hope! You can't give up, the fight is big, but God is bigger! Without God I believe that I can't do anything, if God didn't give me this opportunity, I wouldn't be here today.

Being a caregiver became his main occupational role with the illness of his son, when he was already away from his work duties on the farm. In addition, he reports the entire process, which he called bureaucratic, for his son to undergo treatment in the neighboring city, because his hometown does not have a CAPS, and this took a lot of time and effort. The role of family member was mixed with that of caregiver, as there were other family members with poor health, such as the mother, who is unable to perform the same care with her child, nor is it possible to visit her.

Inácio made clear the burden he felt, as he had to take care of his youngest child, but after the CAPS user became ill, he began to dedicate himself almost exclusively to his care. He described the obstacles faced in the first occurrences of the child's outbreak, the difficulties in getting treatment in health services, highlighting the current existence of obstacles in transport.

He reported that he accompanies his son every day for treatment at the CAPS, because the transport offered by the municipality in which they live is available at certain times that do not meet the child's needs. The return, in turn, is by private transport.

At the same time, Inácio has noticed an improvement in his son's health status since he started treatment at the CAPS, so he does everything for him to attend the service:

Time is very short, he has to stay part-time at CAPS, but the ambulance arrives here at midday and doesn't pick us up, it picks us up late. They say that the ambulance has another emergency and it snowballs and I'll tell you, it's complicated.

The trajectory to get a place for treatment at the CAPS was highlighted, as there is no such service in the city of origin, complaining about the bureaucracy of the health system:

To get this place from him [at CAPS], *he was admitted to the sanatorium first. To the second Hospital Escola, which returned it to the back and then had problems with the police, then after he was referred and admitted by police order, then the city hall came with the envelopes from there to be admitted to here, look at you see the mess of our country. I know it's intercity.*

The discovery of the illness of his son, a CAPS user, took place when he started to miss work, in which he was once assiduous and respected; in addition, he ran away from home at night and he (the father) went out in search of him:

He jumped the wall and walked out any time of the morning, we were going to sleep and didn't know anything. He was registered at work for about 4 or 5 years and started to be absent, and continued like that... He was never absent and the company was suspicious because of that. That's it, that's it. It was more than a year.

He also reported the difficulty in dealing with the mental disorder, which transformed his routine into constant learning of patience and of leaving it to God's hands:

Nowadays it's calmer because the medicine helps. Now the assistance is better, the care is better, right. But what helps me is having patience, because nobody wants illness. The only thing is to be patient, take God's hand and don't give up.

Inácio says that his daily life is very hectic, mainly because he has to deal with all the issues related to his health and that of his son in the CAPS host city, and the fear of the onset of his son's crises.

He pointed out financial difficulty to promote a standard of care for the child, established in the therapeutic project by CAPS professionals. He showed concern, saying that he experiences a delicate health and financial situation, which could lead him, even if unintentionally, to neglect some aspect guided by the professionals:

His medicine cost 800 reais and I ear ed 1200 reais, then I ran into a nutritionist, going to the pharmacy was R$ 800.00, going tot the nutritionist was R$ 700.00 and the question I asked; I want a key answer from you, do you want him to eat and run out of medicine? Or do you want me to buy the medicine and starve?" Tough question that one... Or do you want me to steal so I do it all? The medicine was R$ 800.00, the nutritionist's food was R$ 700.00, it was R$ 1500.00 and I earned R$ 1200.00, so? So that's why I say, analyze things, what I told you a little real, a little cent, today you have to go after it.

DISCUSSION

The lack of adherence of family members of a person with a mental disorder to the services offered by the CAPS may be associated with lack of knowledge about the service and social participation as a means of inclusion and development of the subject's rights; and the emotional exhaustion of the family member facing the experience of caring for a person with a mental disorder, circumstances that justify the complexity of meeting the demand to accompany the user, and contributing to a reduction in the role of the family in the process of being a caregiver[12].

The case presented is of a male caregiver, different from the reality in which the role of main caregiver is usually assumed by a woman. Although men are currently contributing more to household chores, they are still minority in the task of caring, due to the influence of patriarchy on gender roles[13].

As for the difficulties pointed out by the participant in relation to age, due to the natural deterioration of health, older caregivers feel more difficult in performing this role, as they feel more overloaded and have more difficulties in performing daily activities, both for their own care, as for the care of the family member, who is also older and often more dependent[14].

The low level of education shown by the caregiver parent can increase the burden felt. With less education, caregivers may have lower income and lower quality of life, compared to people with better education, in addition to having difficulties in understanding the illness of the person being cared for, the guidance given by health professionals or even in reading prescriptions or medication package insert[15].

In relation to occupational roles, Occupational Therapy understands that, when they are performed satisfactorily, the occupation can lead to an improvement in self-esteem and self-confidence and, consequently, to happiness. Occupation is a basic human need that offers meaning in life. The way the occupation is performed can result in health, well-being and/or illness, and can calm or speed up the subject, through skills, movements and functions[16].

The participant brought the belief in God as a relief for the problems faced. Spirituality is a tool for coping, comfort and hope for better days in the face of daily difficulties in the existing difficulties for people with mental disorders who suffer from hallucinations and delusions in the face of the user's coexistence with their families, becoming an encouragement for life itself[17].

Another adversity highlighted by the participant was ensuring treatment at the CAPS and transportation to another municipality. Since 1999, there is an ordinance of the Ministry of Health that regulates Out-of-Home Treatment (OHT)[18] in the Unified Health System (SUS). Among the regulations, the ordinance provides for transport to the city of reference for treatments, when agreed by the municipalities and when they have tried all the appropriate means in the city of origin of the patient and when the patient's recovery is a possibility. In addition, Decree No. 46,434/14 ensures the right to a free place of two seats for people with disabilities with individual income at two minimum wages, being necessary to reserve the seat 12 hours in advance of the departure time of the vehicle at the starting point[19].

The family caregiver experiences difficulties when receiving the diagnosis of mental illness, presenting a possible initial disorganization; distressing feelings may arise, such as: guilt, fear, sadness and even anger. In this sense, the reorganization and priority of comprehensive care are encouraged by the expectation of cure, requiring intervention of professionals in relation to these emotions, clarifying their doubts, realizing the need for care of the family member as well as the user, so that feel comforted and strengthened to provide and offer emotional support[20].

The burden felt by caregivers with lower income is greater than by those who do not have financial problems[14]. Added to the burden required for care, financial stress can increase when the caregiver needs to leave their paid activities to provide care and, also, the person who requires care before also had an income, but the mental disorder makes it difficult for them to stay in the market of work.

CONCLUSION

With the introduction of substitute mental health care services, the family has become one of the main sources of psychosocial support, but being the main caregiver of a person with a mental disorder leads to the loss of most occupational roles.

Although the family member has to accompany the user to a medical appointment, there is no action aimed at family members on that day, a medical appointment occurs for several users, just a monthly family meeting. This exemplifies the need for more appropriate proposals for welcoming these family members for a better understanding of the diagnosis/prognosis, the demand related to suffering and the stigma of being a caregiver of a mental patient and the rights they have in the face of existing bureaucracies.

Psychosocial care seeks to intervene in the real process of deinstitutionalization so as not to reinforce the "walls" that inhabit them, a place of mutual support to minimize emotional, social, financial burden and possible negligence in treatment, and which, consequently, promotes the production of life to users and their families.

This study had the limitation of being a single case, but it possibly points out contexts in which other caregivers experience the same fact, and for this reason, research with bolder designs is suggested that can expand the understanding of the family caregiver for people with mental disorders, especially male caregivers.

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Associate Editor: Divanice Contim

CONTRIBUTIONS

Emmanuelle Cristina Silva Ribeiro contributed to the design; collection and analysis of data and writing of the manuscript. **Andrea Ruzzi Pereira** participated in the design of the project; data analysis and reviewing.

How to cite this article (Vancouver)
Ribeiro ECS, Ruzzi-Pereira A. Occupational roles of a parent and primary caregiver of a person with schizophrenia. REFACS [Internet]. 2021 [cited in *insert day, month and year of access*]; 9(Suppl. 2):852-860. Available from: *insert access link*. DOI: *insert DOI link*

How to cite this article (ABNT)
RIBEIRO, E. C. S.; RUZZI-PEREIRA, A. Occupational roles of a parent and primary caregiver of a person with schizophrenia. **REFACS**, Uberaba, MG, v. 9, Suppl. 2, p. 852-860, 2021. DOI: *insert DOI link.* Available from: *insert access link*. Access in: *insert day, month and year of access*.

How to cite this article (APA)
Ribeiro, E.C.S., & Ruzzi-Pereira, A. (2021). Occupational roles of a parent and primary caregiver of a person with schizophrenia. *REFACS*, *9*(Suppl. 2), 852-860. Retrieved in *insert day, month and year of access* from *insert access link*. DOI: *insert DOI link*.