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FAMILY CAREGIVERS' PERSPECTIVES ABOUT THE CARE OF THE ELDERLY PERSON WITH PARKINSON

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ABSTRACT

Objective: To assess the caregivers' perspectives about the care of the elderly person with Parkinson's disease. **Methodology:** It is an exploratory study, of descriptive character with a qualitative approach held by the Snowball technique, collected in the residences of the 12 family members of the elderly people with Parkinson disease. Two instruments were used: a sociodemographic and economic questionnaire and a semi-structured interview guide. The information's examination was carried out using the Thematic Content Analysis technique of Laurenci Bardin. **Results:** The study participants were all female, with ages ranging from 30 to 40 years old and they were homemakers. Four categories arose from the data assessed: activities' overload and the impacts of it on the care of the elderly person with Parkinson's disease; Financial impacts that were a result of the care to the elderly person with Parkinson's Disease; Unpreparedness of the caregivers regarding the care of the elderly with Parkinson's disease; and Emotional aspects coming from interaction with the elderly people with Parkinson's disease. **Conclusion:** The study exhibited for most of participants the activities' overload, the financial impacts, the lack of preparation to take care of the elderly, in addition to experiencing mixed feelings concerning the assistance care which are situations lived by the family caregivers.

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INTRODUCTION

The population aging has been happening in a quick and gradual way worldwide. Nowadays, for the first time in history, most people can reach longevity (World Health Organization, 2015). This process of demographic transition in the Brazilian society is a reflection of the association of numerous factors including decreases in birth and fertility rates, and the increase of life expectancy (Miranda et al., 2018). It is a fact that population aging is deeply connected to

the health-disease process, since the age advance can lead to the elderly people weaknesses. Among these are the Chronic Non-communicable Diseases, in which the Parkinson's Disease (PD) is comprised (Gomes et al., 2014). Staying only behind the Alzheimer's, PD remains in the second place with respect to the most common neurodegenerative illnesses in the world. Therefore, the number of subjects with this disease has significance because of the great social economic and demographic impacts that it conveys (Santos, 2015; Silva et al., 2015). PD is an idiopathic, progressive, slow and chronic illness of the central nervous system (CNS), marked by the dopamine producer neurons degeneration and cell death, a neurotransmitter associated to movement control. The neurons'

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death essentially affects the motor coordination of the subject affected, decreasing this way their functional capacity (Barreto and Femoseli 2017). Functional ability is determined as the susceptibility that the subject has to perform daily life activities (DLA), these activities are settled by the own subject for their self-preservation and survival, without needing another person's support (Souza *et al.*, 2014). The elderly person with PD does not have the physical conditions to execute their daily life and work tasks. With this, emerges the figure of the caregiver to help the elderly person in the execution of these activities, this person is frequently a member of the family of the elderly person with PD (Silva *et al.*, 2014; Filippin *et al.*, 2014; Gutierrez and Fernandes, 2017). Nevertheless, there are numerous challenges faced, as this process encompasses attention, precaution, caution, dedication and the adaptation necessity by the caregiver's part to a life and routine in accordance to the elderly's person reality (Filippin *et al.*, 2014). This way, the study has as goal to examine the perspectives of the family caregivers regarding the care of the elderly person with Parkinson, in a city in the interior of Bahia.

MATERIALS AND METHODS

It is an exploratory study, of descriptive character with a qualitative approach, performed with twelve family members that are the caregivers of elderly patients with PD, the participants are residents in the city of Vitória da Conquista-Bahia and they agreed to contribute to the study by signing the term of Informed Consent Term (ICF). For the research's accomplishment was used the "Snowball" technique, also known as Snowball methodology, which is described as a non-probabilistic sample form with an intentional or convenience selection, taking into consideration the study's specific group characteristics. This technique uses reference chains, a kind of network, that being the search for the initial study's participants that have the suggested profile for the research, called seeds, which point to other research interest participants of their own social network until the proposed goal, is reached. The sampling frame hit a saturation point when there was no new signs or the new signs did not bring relevant data to the research (Vinuto, 2014; Baldin and Munhoz, 2011). Two instruments were used for data collection: a) demographic and economic, comprised of questions related to the characterization of the participants, such as: sex, age, marital status, schooling, profession, individual and family income, religion and color; b) semi-structured interview, drafted by researchers to comprehend the family's perspective concerning the care of the elderly person with Parkinson's disease. The issues raised contained questions such as: how is it for you to live with a family member diagnosed with Parkinson's disease? What are the complications that you deal with on the daily care of the elderly person with Parkinson's disease? After finding out about the Parkinson's diagnose of your family member, was there a growth on the activities that had to be performed for him/her? Taking care of an elderly family member with DP caused any emotional impact in your life. After the elderly person was diagnosed with DP were there any changes to the economical aspects of the family?

The interviews happened in the elderly people homes, at a beforehand arranged time with the respondents. The stories were recorded on audio with the participants' knowledge and consent. The information analysis was held through the statements transcription by the researchers, following in an

exact way the respondents' report. It was used the Thematic content analysis technique (Bardin, 2015). To accomplish the assessment through this technique, it was performed a pre analysis, the exploration of the material and the treatment of the outcomes, and this comprises the codification and inference (Bardin, 2015). Following the principles of Resolutions 466/201214 and 510/201615 of the Ministry of Health, there were adopted all the fundamental ethical aspects, "taking into consideration the human dignity respect and an adequate special protection to the participants in scientific research with human beings." There was no participants' discrimination or exposure to unnecessary risks. The participants were instructed about the research's nature, just as its objectives, methods, expected benefits, potential hazards and the distress it can cause. The participants' names were changed to ensure anonymity and confidentiality. They were identified with the letters Family caregiver (FC) followed by a number sequence, for example: FC. 01.

RESULTS AND DISCUSSION

From the data obtained, all the participants were characterized by female subjects (n=12). The reason for the female prevalence in care is linked to the historical society roots, once women and men historically had really different social roles, with the woman being assigned for the care issue and the man with the role of providing for the family institution (Ferreira *et al.*, 2017). Regarding the age group, (n = 6) were aged between 30 and 40 years. Those aged ≥ 61 years were the second that more prevailed (n = 3). Concerning the marital status, there was an equal division, with (n = 6) married and (n = 6) single. The fact of being married carries with it two features, the negative one being associated with the accumulation of the activities carried out, and the positive as far as the partner represents a support figure (Fuhrmann *et al.*, 2018). Regarding the schooling, it was verified a higher frequency of participants with complete high school level (n = 5). Another study indicated that schooling affects the quality of the elderly person care, because knowledge sponsors better care (Gutierrez *et al.*, 2017). Concerning the profession, (n = 3) are homemakers, (n = 3) are teachers and (n = 6) have different professions. 8 of the caregivers have individual income of 1 to 5 minimum wages and (n = 11) with the same amount as family income. The color (n = 6) is considered brown "parda", followed by the white (n = 4) and black (n = 2) colors. The Catholic religion was the predominant among the participants with (n = 6), followed by the evangelical (n = 5) and spiritist (n = 1). The semi-structured interview enable us to know the family perspective regarding the care of the elderly person with Parkinson's disease. After the analysis and categorization it was possible to make the division into four categories:

Categories

Category 1 - Activities overload and its impacts on the elderly person with Parkinson's disease.

Category 2 - Financial impacts regarding the care of elderly person with Parkinson disease.

Category 3 - Caregivers' lack of preparation on the assistance of the elderly person with Parkinson's disease.

Category 4 - Emotional aspects that come from the interaction with the elderly person with Parkinson's disease.

Category 1 – Activities overload and its impacts on the elderly person with Parkinson's disease

DP is an illness that primarily impairs the motor coordination of the subjected affected, bringing with it numerous challenges. The movements difficulties, comprising tremors, rigidity, tardiness and postural instability, affect most of the time, independence and makes the diseases' holder to lose his/her freedom. What occurs is a limitation on his/her autonomy and self-care, becoming essential the assistance of a caregiver (Ferreira *et al.*, 2017). The caregiver who many times composes the family environment of the elderly with Parkinson (Gutierrez and Fernandes, 2017), to the extent that the care directed to the dependent elderly people, happens traditionally in the family scope (Souza *et al.*, 2015). Just as with the elderly people, the family caregivers may suffer lifestyle impacts taking them to a physical and emotional overload, having in mind that depending on the disease's stage, there is a need for ongoing follow-up (Souza *et al.*, 2014; Ferreira *et al.*, 2017; Lino *et al.*, 2016). The care assistance for the dependent elderly people during a long period of time causes changes in the caregivers' family and social lives (Fuhrmann *et al.*, 2015).

This situation is showed in the following speeches:

Everything is hard, because with Parkinson he broke two arms and stayed without the movements becoming dependent of me for everything, for taking a shower, getting up from bed in the morning, to serve his lunch. Out of nowhere, he is feeling well and then soon he gets worse (FC. 02).

There has to be a lot of patience, because the difficulties are numerous. The limitations ask a lot of us, a lot of effort. On my father's case he is at an advanced stage being totally dependent, as if he were a baby. I had to give up a lot of things to look after him all the time (FC. 03).

In the beginning, there wasn't any problem because he could walk, he took his shower by himself but then when he was bedridden things changed, sometimes we even have to feed him, as there was no way he could eat by himself. (FC. 06).

For the majority of the study's participants, the dependence developed by the elderly is one of the factors that complicates their quality of life. The necessity to adopt a dedication routine nearly exclusive to this elderly person is many times exhausting and stressful (Gutierrez and Fernandes, 2017). The physical exhaustion and the decrease of the caregivers' health status frequent, leading to the development of new diseases or the intensification of the preexisting ones (Fuhrmann *et al.*, 2015).

The following speeches, display this reality:

I have a skin problem, psoriasis and everything makes the symptoms to get worse, yesterday when I saw the condition he was, I arrived home devastated (FC. 05).

It disturbs my emotional and physical state a lot, I had to take medicine to sleep and I always have to be going to the doctor to check everything I feel (FC. 06).

The facts showed support to the ones that were spotted by Ferreira *et al.* 2017 in their study, where he found that the process of taking care of a person with Parkinson's disease may result in consequences for the subject responsible for the

care whether they are physical or emotional. Consequently, the caregiver requires special attention aiming to increase his quality of life, performing an adjustment to his healthy routine and reducing the harms that this process may cause.

Category 2 - Financial impacts regarding the care of elderly person with Parkinson disease

The financial burden is one of the highlighted aspects in the speeches described by the study's participants. This happens because of a large demand for care and the complete commitment to the elderly person with Parkinson's disease, generating an impact on the family environment. Furthermore, this comes from the fact that many caregivers need to stop their professional activities to look after the sick relative, producing as negative implication the loss of family direct income (Souza *et al.*, 2014; Ferreira *et al.*, 2017). Another fact that has interference with the finances context are the expenses from the illness itself, because a part of the family income is aimed at the treatment's costs and in the effort to provide a better quality of life to the elderly people (Lourenço *et al.*, 2015). This assertive was endorsed by Bovolenta *et al.* 2016 in their study, which stated that PD is the second long-term neurodegenerative disease with increased prevalence in the world as well as the one with highest expenses. The following lines evidence this reality:

I'm the youngest daughter, I had to give up on my job so I could take care, because my other sisters work and didn't have time (FC. 02).

One difficulty is the lack of money, of income, because I wish for here to be a house with a better structure for him. The greatest difficulty that I have is this, because the trend is to get worse (FC. 03).

This year I stopped working, but before I had to work and even to help to take care of him and after it there was no way I had to stop working to be with him full time (FC. 04).

There is medicine, diaper, to pay a person to be here 24 hours, because we can't. Sometimes the money is just enough, it's only to survive. We have to leave something behind and reunite everybody because the money isn't enough (FC. 06).

To live with chronic degenerative diseases like PD requires a comprehension of the elderly people and their family members, because with the limitations imposed by the illness in their daily life makes them go through social, emotional and economic changes (Miranda *et al.*, 2017). This ratifies the outcomes found in the present study.

Category 3- Caregivers' lack of preparation on the assistance of the elderly person with Parkinson's disease

This subcategory exposed a central difficulty of the caregivers concerning the caring process, being illustrated that most of the family caregivers are not prepared to provide this assistance. As verified in a study performed in the metropolitan region of Porto Alegre (RS) with elderly caregivers who looked for a Day Home with a guidance objective, for the elderly people assistance or professional caregiver training, it was noticed that even the caregivers who worked in the area for years, as professionals or not, did not have the training to support this function (Gutierrez and

Fernandes, 2017). Lino *et al.* 2016 in their study concerning the overload prevalence and the linked factors to the caregivers of dependent elderly people, in a poor region of Rio de Janeiro, Brazil, had identified what was after strengthened by Gutierrez *et al.* 2017 that there is evidence regarding the caregivers' little knowledge about the medical problems and the necessary care that the elderly people need.

This fact is clear on some participants' speeches:

We don't have experience, we've never taken care of someone, we've never done it and now we had to learn to take care of him, but it is with difficulties (FC. 04).

Our family is very close, we like him a lot, but we aren't able to take care of him as he deserves, without being aware of what he can and can't (FC. 05).

As noticed in the above speeches, taking care of a dependent elderly person is frequently hard and challenging, this happens because the lack of preparation directly intertwines with the suitable care assistance as the qualified caregiver makes care more effective, besides making the possible emotional symptoms that the lack of preparation may cause to be minimized or extinct. That said, it is indispensable that caregivers are trained and enlightened about the diseases' evolution just as the precautions that each stage demand so that they can even with challenges, be more prepared to look after the elderly with Parkinson (Kucmanski *et al.*, 2016). In spite of the challenges found about following up and looking after an elderly person with Parkinson disease, some caregivers can feel secure and confident. In this study, five of the twelve respondents stated not having difficulties regarding care, and they consider normal the activities they execute. It is supposed that this outcome is linked to the fact that the elderly people that are monitored by these caregivers are in the early stage of the disease, which does not involve intense amount of work and follow-up.

Category 4- Emotional aspects that come from the interaction with the elderly person with Parkinson's disease

In line with Souza *et al.* 2016, from the moment the family comes across with the news that in their family they have a dependent elderly, there occurs a process of initial fears accompanied by instability until one of the family member to place themselves and begin to develop the caregivers' role. Because it is a new fact that is presented in a sudden manner, this family member can go through countless emotions. Although depending of the individuality, these feelings may frequently be mixed, with positive emotions like the satisfaction in taking care of a loved one, affection and love, to negative emotions generated by the activities' overload, uncertainty and distress (Gutierrez and Fernandes, 2017; Reis *et al.*, 2017). Among the negative signs perceived, tension, sadness, anxiety, anguish, stress, concern, are continuously stated by the one who experience this reality. These symptoms are most frequently linked to the degree of dependence displayed by the individual receiving the care (Lino *et al.*, 2016). In this study, five of the respondents stated not to suffer any emotional impact regarding the interaction with the elderly person with PD. By contrast, some caregivers stated various feelings that confirm the findings of Lino *et al.* 2016 and Gutierrez *et al.* 2017 as shown below:

I lose sleep, I have insomnia, I have stress, I have body aches, I am anxious, I am worried about their future all of this, it tears me apart (FC. 01).

When you see the person you love in pain, at a stage that you're not able to solve. Because I like to solve things, I try in all forms, but when I realize that I can't I lose my balance, I'm worried because I don't know what to do (FC. 12).

The fact of seeing a person that was super active suddenly stop their movements and becomes dependent of another person makes us feel shaken. However, we never demonstrate it to her. It is difficult, but with love, we achieve everything (FC. 08).

Lino *et al.* 2016 in their study state that independent of the more or less favored socioeconomical conditions the mere fact of being a caregiver entails threats to their health. This way, it is needed a different perspective on the part of the health professionals and the health managers to provide affective, emotional, material, informational and social interaction supports, with the intention to relieve the burden that the caregiver carries, and as a positive result to enhance the conditions of care that the dependent elderly person gets.

Conclusion

Based on this study, it was possible to comprehend the family caregiver perspectives regarding the care of the elderly people with PD in a city in the interior of Bahia. It becomes clear that the care of the elderly person with PD brings significant impacts on the life of the family caregiver. Among these, the overload linked to the dependence settled by the elderly person with PD requires the caregiver an ongoing provision of care. Furthermore, they also need to renounce their activities and adjust themselves to a routine focused only at the ill family member, what frequently produces exhaustion and a consequent reduction in their quality of life. Financial impacts were also highlighted, since the caregivers endure the need to leave their work activities or because they are unable to pay a professional to fulfill the caregivers' position to take care of the elderly, or because they do not trust someone to do this job, consequently what happens is a reduction of the individual and family income. Another equally significant factor to consider on this issue are the treatments' costs and the attempt to provide a better quality of life to the elderly person. It was noticed that while taking care of an elderly person with PD the family caregiver experience various difficulties. The lack of preparation is another factor that was highlighted on the participants' speech once the deficiency of knowing how to act regarding the symptoms of PD will directly influence on the quality of assistance provided. That way, it is indispensable that the family caregivers are aware about the disease, just as the appropriate way to perform the care. Besides facing physical disorders, emotional dilemmas are also a part of the caregivers' routine. The feelings displayed are unclear, coming from self-satisfaction and affection that care offers to the distress these circumstances impose. This way, the attention and assistance to the caregiver's emotional state should be a principle of health professionals who monitor the elderly person with DP. Although it has been found a diversity of articles addressing this topic, this study limitation was the fact that the studies were centered only on the caregivers' characterization and profile, unlike this one that looked for analyzing the caregivers perspectives regarding the care, from

a more subjective view. This way, it is recommended that more research are performed to this end, since when intensifying the vision towards the caregivers' quality of life it reflects directly to the quality care assistance to the elderly person with Parkinson's disease.

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