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# Nurse's activities at the family health program when care of Parkinson's disease in Lagarto-SE

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**Abstract.** Parkinson's disease (PD) is a neurological disorder resulting from the degeneration of black brain cells, compromising the autonomous movements of the human body. The signs and symptoms triggered by PD have negative consequences for the patient and his family, bringing greater demand to the health services. Thus, it is the responsibility of the health team, including the nursing team, to provide support to these patients. Therefore, it was aimed to identify the performance of the nurse of the PSF of the city of Lagarto-SE in the care given to these patients. This is a descriptive and qualitative research. Participants were 10 nurses from 09 Basic Health Units. Data were obtained through a questionnaire related to nursing care provided to patients with PD and their relatives. The qualitative data analysis was performed according to the Bardin content analysis steps. It was possible to observe only two records of patients with PD. It was noted that some of the interviewees are aware of the care that should be provided to these patients and their relatives, but they identify important flaws. It was also identified possible difficulties faced in the care of patients with PD and suggestions from the participants to improve this care.

**Keywords:** Primary care, Nursing care, Parkinson's disease.

## Introduction

Parkinson's disease (PD) is an important neurodegenerative motor disease manifested by an extrapyramidal syndrome marked by tremor, stiffness, bradykinesia, akinesia and curved posture (SOUZA et al, 2011). PD predominates in males, beginning between 50 and 65 years old; however, in the hereditary forms, the symptoms usually begin in young adults, under 45 years old (MOREIRA, 2007).

The Brazilian Institute of Geography and Statistics (IBGE) reported that life expectancy increased, with a population growth of 21% over 65 years old, leading to a population estimate of around 200,000 individuals with PD (IBGE, 2016). Also, it is known that 10% of patients are less than 50 years old and 5% are under 40; and 36,000 new cases emerge each year in the country (SOUZA et al, 2011).

Primary health care is an important space for the population to enter health services since it allows the creation of a link between community and health team; In this sense, the Family Health Program (PSF) is a key strategy for the success of this goal. For the Ministry of Health, regarding the health of the elderly person, the National Program for the Elderly (PNAI), as well as other health policies advocate actions focused on the health of

this population aiming at the promotion of healthy aging, besides disease prevention (BRASIL, 2006).

In this sense, it is the responsibility of the health team to provide support to the patient with Parkinson's disease, contributing to the treatment that helps in the improvement of the symptoms of the diseases and the maintenance of independence and autonomy of the patient, promoting quality of life. In this context, the nursing profession occupies a strategic position to promote effective and modifying care for people with Parkinson's disease within the PSF to minimize the impact of these health problems on the life of the patient and the family.

Nurses have an important role in caring for patients with Parkinson's disease and should be assisted in their entirety, both psychologically and clinically; including all their basic care needs, focusing on the patient and their family.

Therefore, to describe the nurses' performance and their views on the care of patients with Parkinson's Disease, within the scope of the PSF, becomes very relevant, since it allows identifying the "strengths and weaknesses" of this action, allowing the subsequent qualification.

Thus, the purpose of this study was to identify the role of nurses in the Family Health

Program of the municipality of Lagarto-SE in the care provided to patients with Parkinson's disease (PD), knowing the care performed by nurses directed to these patients and their relatives; and the difficulties and facilities found by the nurses in the care directed to these patients.

## Methods

It was a descriptive research, in which the facts are "observed, registered, analyzed, classified and interpreted, without interference of the researcher" (RODRIGUES, 2007). Regarding the approach, the qualitative research was used, and the technical procedures were used, since the main characteristic is the collection of information directly from the nurses working in the Basic Health Units (UBS), to know the behavior of this group.

This study would initially be performed in the 16 UBSs of the municipality of Lagarto-SE and with 29 nurses; however, at the time of data collection, 10 nurses were dismissed and nine were on strike, resulting in 10 nurses from 09 UBS of the municipality. The 10 nurses accepted to participate in the research.

The data were obtained through a questionnaire filled out by the nurses of the Family Health Programs to investigate the performance and knowledge about nursing care performed by nurses to patients with PD. The questionnaire covered open questions related to nursing care provided to patients with PD and their families (Appendix B), as well as the facilities and difficulties faced in performing these care. Data were collected in January 2016.

The qualitative data analysis was performed according to the content analysis steps of Bardin (BARDIN, 2011). In the pre-analysis of the content, the data were read to promote further clarification; in the exploitation of the material, the records were codified, classified and categorized; and the treatment of the results, inference, and interpretation were made, from the categories obtained, with a descriptive analysis based on the literature on the subject.

## Ethical principles

This research was submitted to the Ethics Committee of the University Hospital of Aracajú, Federal University of Sergipe, and it was approved within ethical principles and current legislation.

## Results and discussion

The Census conducted in 2010 by IBGE shows that the elderly population in the municipality of Lagarto-SE represents approximately 10.38% of the total population, or 9,853 people (IBGE, 2016). Therefore, considering that the literature states that Parkinson's disease affects 3.3% of the elderly population (BRASIL, 2010), this municipality can present approximately 325 people with this disease.

However, in the nine UBSs investigated, only the registration of two patients with this

pathology in the respective areas of coverage was evidenced. The participants responded about this fact that:

*"Yes, only one patient, but she does not follow up at UBS, she does it with a private doctor." (E6)*

*"I have no patients with this pathology." (E5)*

*"I do not have these patients." (E7)*

*"Yes, a patient." (E10)*

Some possibilities to explain this low number of people with Parkinson's would be the difficulty of PD diagnosing, areas discovered by nurses, as well as the fact that not all the population is linked to the UBS.

Subsequent to the process of categorizing the data obtained in the research, it was possible to create five themes related to the knowledge of nurses about the care of the person with PD in basic care: Nursing care for patients with PD; Importance of family participation in the treatment of patients with PD; Care directed to the relatives of patients with PD; Difficulties and facilities in the care of patients with PD and Suggestions for improvement in the care of patients with PD.

### *Nursing care for patients with Parkinson's disease*

Nursing has an important role in the treatment of PD, requiring this professional to observe and evaluate how the disease affected the activities of daily living, functional capacities, responses to treatments and promote patient care, which allows for greater well-being and comfort (FEITOSA, 2011; KÜSTER et al, 2014; SOUZA et al, 2014). This knowledge is confirmed in the writing of one of the participating nurses:

*"As nurses, we need to promote the patient's quality of life. Then we look at how the disease has affected the activities of daily living and the patient's functional abilities and have mapped out a plan of care according to the stage of the disease." (E4)*

It should be emphasized that health professionals need to act in an integrated way, enabling multidisciplinary and multi-professional care, providing better recovery or minimizing damages to the patient (SOUZA et al, 2014, SAITO, 2011).

*"Requesting the support of the multi-professional team." (E9)*

*"Encouraging the search for a physiotherapist to help perform*

*exercises that make them more dependent.” (E6)*

*“Medical monitoring.” (E1)*

However, it is important to emphasize that within the multi-professional team, the nurse's contribution is strategic, continuous and relevant for the promotion of the health and quality of life of this population.

From the moment that the nurse guides the patient about his/her pathology, the patient acquires an understanding of his/her clinical condition, being able to reflect on the prescribed care, besides recognizing the benefits obtained by his/her adherence to the treatment (SOUZA; ALVES; PASSOS, 2010).

The lack of knowledge about PD by relatives generates inadequate behaviors (SOUZA; ALVES; PASSOS, 2010). In this sense, the nurse has an essential role in the education and clarification about the pathology both for the family and for the patient (SOUZA; ALVES; PASSOS, 2010; SOUZA et al., 2014). It was observed that some of the participants of the research are attentive about this:

*“Guiding the patient about the disease.” (E3)*

*“Providing guidance to the patient and caregivers for patient well-being”. (E5)*

Other nursing care includes: feeding orientation, use of thickeners and foods that minimize aspiration risks for the patient; advise on the need to perform daily exercises, with the purpose of strengthening the muscles, coordination, dexterity and reduce muscular rigidity; to encourage the patient to increase the intake of liquids and laxative foods and with a moderate amount of fiber, since constipation and urinary problems are clinical manifestations of the disease; to forward to the speech therapist, to instruct in the exercises that enable the improvement of voice and facilitate communication; to clarify the importance of the drug treatment, the time of the medications and dosage, among other care (FEITOSA, 2011; KÜSTER et al., 2014, SOUZA et al., 2014, SAITO, 2011, SOUZA, ALVES, PASSOS, 2010). Some of this care was cited by participants:

*“Defining daily exercise program; instructing the patient to improve swallowing. These are some guidelines that we can give to patients and family members. Improving nutritional needs; Controlling constipation and urinary problems.” (E4)*

*“Guidance on the importance of taking medication at the correct times.” (E6)*

Although none of the participants mentioned the issue of social isolation and depression, these are important factors to be addressed by nursing staff because of the negative consequences they may have on the patient and their family members. It is important to remember that it is the responsibility of all health professionals to seek to reduce the impact of the disease to the patient and the family (KÜSTER et al, 2014; SAITO, 2011).

Another issue not mentioned by the nurses was in relation to the Clinical Protocol and Therapeutic Guidelines for Parkinson's Disease. It is of paramount importance to guide patient care with PD, since it covers the whole national territory, establishing guidelines for diagnosis, treatment, dispensing and control of medications, monitoring, and registration of patients, at the state and municipal levels, regulating care access and organizing the reference network for this population. The same document also includes a clarification term that must be signed by the patient or his/her legal guardian so specific medications can be dispensed for patients with PD (BRASIL, 2010).

*Importance of family participation in the treatment of patients with Parkinson's disease*

When a person with a disability is at home, usually he/she does not have professional care, and in that case, a family member becomes the primary caregiver (SILVEIRA et al., 2011).

The family participation during the treatment and evolution of the PD of a family member is considered fundamental, both by the health professional and by the individual (SOUZA et al., 2010). The involvement of the family members in the care actions alleviates the limiting condition of the patient in his/her degenerative process (SOUZA et al., 2010; PETERNELLA & MARCON, 2010).

In this context, it is pertinent that the family participates in the entire process of illness and patient care, since it is possible to create bonds and provide a better quality of life (SOUZA et al., 2010; SOUZA et al., 2014; PETERNELLA & MARCON, 2010). This fact was well explained in the writing of one of the nurses:

*“Generally, family members will be the caregivers of the patient and they need to be part of the care plan to help patients in the best way possible.” (E4)*

It is indisputable that through the family, the individual can broaden their human relationships, so if they feel part of a family, it allows greater social participation. For the person with Parkinson's, the need for a suitable family environment is even more evident, since, from an affective family life, the patient increases his self-esteem and has a better coping of the challenges arising from the symptoms of the disease. The family support is fundamental for a better adaptation to the health condition, constituting the creation of a bond, important for a

better quality of life (SAITO, 2011; SOUZA et al., 2010; SOUZA et al., 2014).

*"They help in the evolution of this, as the PSF nurse does not have enough time to visit him daily, so the family has a fundamental role in care, support, and knowledge." (E8)*

*"Requesting relatives to the nursing consultation is a great allies of the care with these patients, for greater acceptance, organization, and adaptation to the difficulties. They are fundamental pieces to soften the symptoms, comfort, well-being of the patient, considering and respecting the individual needs." (E9)*

In these cases, the family plays an essential role, especially when there is adequate family interaction, together with commitment, involvement and the existence of an open dialogue, as it promotes better living conditions for both the patient and his family (SAITO, 2011; SOUZA et al., 2010; SOUZA et al., 2014; PETERNELLA & MARCON, 2010).

#### *Caring for relatives of patients with Parkinson's disease*

It is not only the patient's life that undergoes changes through a chronic illness, such as PD, because relatives also end up modifying their rhythm of life to support the patient, often causing a sense of dependence by the patient and bringing consequences for the health of the caregiver (SOUZA et al., 2014; PETERNELLA & MARCON, 2010).

With this new reality, from an unknown experience, orientation to the family becomes fundamental to explain the reality that the patient will experience, alleviating anxiety (SOUZA et al., 2010). Participants cited the importance of these guidelines in keeping with what is recommended:

*"It is extremely important to guide caregivers about the pathology in order to help the family deal better with the consequences, treatment of the disease." (E5)*

*"Speaking with the caregivers, showing the management with the patient, the phases of the disease; the necessary care and especially the importance of family interaction." (E2)*

The literature points out that the emotions provoked when the presence of a chronic disease, both for the bearer and the family, are similar, such as there are the negation, anger, and frustration due to the limitation imposed by the disease, depressive

symptoms, guilt, among others (PETERNELLA & MARCON, 2009).

The family experiences all the changes and feelings caused by the presence of a chronic illness in their environment. When it comes to PD, these difficulties are multiplied, because beyond its chronicity, it is a progressive neurodegenerative disease that compromises the physical, mental and social of the individual, generating dependencies and needs also experienced by the family (SAITO, 2011; PETERNELLA & MARCON, 2009).

It is necessary to evaluate and identify the characteristics and factors associated with the tension that the caregivers coexist, to create strategies for health promotion and social support for these people (PETERNELLA & MARCON, 2010). In this research, it was possible to observe that some nurses consider important the psychological support to the familiar:

*"Psychological support, insert them into therapeutic programs." (E5)*

*"Psychological support." (E9)*

It is important to highlight that nurses can perform specific actions aimed at strengthening and empowering family members of PD patients, to promote the well-being of the patient and his/her family.

#### *Difficulties and facilities in the care of patients with Parkinson's disease*

Because it is a chronic degenerative disease Parkinson's disease requires continuous attention by both the nurse and the tea. In this context, it is possible to observe that Brazilian basic health care services still encounter numerous barriers that prevent assistance from being provided with quality and resolution; implying greater complications for both the patient and the family.

The participants of this study cited some of these difficulties, as explained in the following statements:

*"Patients' access to specialized care. There is also difficulty in transportation for the staff to perform home care." (E1)*

*"Little time, lack of materials, accessibility." (E8)*

Therefore, they present difficulties not specifically related to the care of the person with PD, common in this type of service, related to the lack of material resources, high demand for care, and problems with the lack of transportation, hindering the active search and the periodic follow-up of the patients by the professional since often the patient cannot go to the unit, and they live in distant domiciles and/or in violent locations that expose the professional to risks.

The physical and cognitive limitations imposed on the person with PD have an impact on the health services, since they tend to generate a lot of demands on the team that treats them and accompanies them and, in turn, needs to be constantly improved to offer specialized and qualified care to the person. The patient and their family (SAITO, 2011).

It is recommended the adoption of strategies to improve the quality of life of patients, meeting the specificities of the patient, either in the manifestation of symptoms or in the complexity of factors that involve each case. Thus, the aim is to facilitate patient and family access to health services, deconstructing the image of the passive patient and reducing physical and bureaucratic barriers that may exist in these places (KÜSTER et al., 2014).

Besides the nursing work, the PD patient needs to be accompanied by other professionals such as speech therapist, physiotherapist, nutritionist, urologist, and psychologist, as well as neurologist and general practitioner (KÜSTER et al., 2014). It is relevant that this patient is accompanied by a multi-professional team, meeting the necessary demands. This was one of the difficulties cited by the nurses:

*"Follow up with trained professionals and multidisciplinary team." (E5)*

Nursing specifically provides care support, especially regarding the changes arising from somatic conditions, the condition of PD, and monitoring the effects resulting from the use of drugs. The lack of knowledge about these factors and strategies leads to a gap in care and the absence of effective actions that could avoid future problems for patients with PD and their family (KÜSTER et al., 2014). It is imperative that both the nurse and the team know about the pathology and all its aspects, so they can intervene in the changes that accompany them in the conviviality with Parkinson's Disease.

Regarding the facilities for the care of patients with PD, aspects that mainly highlight the nurse-patient-family relationship were placed:

*"The empathy and closeness of the team with the family and user." (E8)*

*"In my unit, there is only one patient with Parkinson's who is hypertensive, appearing regularly to "hyperdia" without much difficulty. The family accompanies and participates in the care, it is also accompanied by private doctor." (E10)*

The speeches lead to reflection on the importance of a good relationship between the nurse and the patient, effective participation of the family members, patients' access to services and efficient

follow-up by a multidisciplinary team, so the results are positive and facilitate the reach of the health goals.

#### *Suggestions for improvements in patient care with Parkinson's Disease*

When it comes to collective health, the confrontation of chronic conditions demands actions beyond the scope of management or services in isolation. One of the challenges in this context is to deconstruct the model of attention to acute conditions and events, empowering the subject so he knows how to prevent, understand and live with the chronic situation that presents itself, besides to citing the practice based on evidence and partnerships with the community as important tools to support the attention of this population (PETERNELLA & MARCON, 2010).

Health education is a transformative tool in basic care, signaled by participating nurses:

*"To perform educational groups for guidance in patient care." (E1)*

*"To act more in the orientation on the disease, and support to the bearers and relatives." (E6)*

Health education is very relevant for caring for Parkinson's disease patients. The PSF nurse should avoid mechanistic work, and focus on the individual needs of these patients, especially by providing guidelines and ensuring the effectiveness of this assistance.

It is often reported by the team that there is no time available, that there is a great demand for patients, preventing the execution of educational activities, both with patients and with relatives (VILLELA et al., 2009).

Chronic diseases, such as Parkinson's, are of greater concern because of their debilitating and limiting aspects, because of the wear and suffering of the affected person and the caregivers, as well as the lack of preventive care and health promotion, since a large part of the financial and human resources of the public services, according to demand, still prioritizes curative activities (BARROS; MAIA; PAGLIUCA, 2011).

Also, this need for specific knowledge about the disease and its care requires training of professionals, stimulation of the search for knowledge and discussions about this subject, as can be seen in the following statements:

*"Training for caregivers and professionals." (E5)*

*Performing continuing education." (E8)*

*"Actually, there is little talk of PD in carrier care." (E3)*

Once again, the question of the multidisciplinary team is emphasized as a suggestion in the care of patients with PD; showing a possible holistic and integral vision, looking for a service with quality according to the specificities of each one.

*"To have more complete teams." (E8)*

*"Presence of multidisciplinary team" (E10)*

It is noticed that attention to the person with Parkinson's has to be qualified. It is necessary to seek these patients, involving them in a multidisciplinary care with the participation of the family and the issues that involve nursing care need to go beyond genuinely technical tasks, because it becomes necessary to understand the totality of the human being that is being cared for with their limitations, needs, and particularities.

## Conclusion

This study sought to identify and understand nurses' performance with PD patients in the Family Health Programs of Lagarto-SE. The results evidenced that there is knowledge about only two patients with this pathology in the scope area of this study. Given this, it is noted that nursing care coverage to this people is still insufficient since there are many actions that need to be directed towards people with PD, being necessary that they be identified to make them primary care patients or that appropriate records of those already identified. With deficiency in the records, there may be patients who are not being adequately assisted, so it becomes very important to actively search for them.

Other data show that, even though there are few patients with PD, nurses have some knowledge about the care that should be directed to these patients and their families, which may favor the quality of care. However, the gap was identified on the knowledge about the Clinical Protocol and Therapeutic Guidelines for Parkinson's Disease, which guides the care of patients with PD.

There were also difficulties of the service in the care of patients with PD, for example, lack of material resources, lack of transportation, hindering the professional to have both the search and the periodic monitoring of this patient.

The research also identified suggestions for improvement to assist these patients, making it clear that the participants believe that health education and multidisciplinary work are important tools for health promotion and quality assurance.

The work was very relevant since it allowed identifying the potentialities and fragilities of this thematic, contributing for the later improvement of the service. It is considered necessary the development of quantitative studies both to analyze

the distribution of knowledge among nurses and to seek results that show the number of patients with PD in the city.

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