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## RESEARCH ARTICLE

### UNDERSTANDING PAIN AND PSYCHIC SUFFERING OF CAREGIVERS AND PATIENTS WITH PARKINSON'S DISEASE

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#### ABSTRACT

**Background:** Parkinson's disease may affect individual's quality of life, once it interferes in their functional capacity. Caregivers can also have their quality of life compromised due to the difficulty of dealing with complex manifestations of the disease, so it might be possible they assume the position of a hidden patient, suffering from the overload of the function, which contribute for their illness. **Method:** Search in PubMed and Scielo databases, with a total of nine selected articles. **Results and Discussion:** Emotional, social, physical factors and personal characteristics might interfere in caregivers' quality of life. In addition, patients and family members may also have impaired quality of life. Thus, it is important for these professionals, subjects affected by Parkinson's disease and family members to participate in support groups is necessary in order to share feelings experienced in daily life. **Conclusion:** Therefore, it was possible to verify that caregivers also needs guidance and support to deal with the problems provided by caring for the others.

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## INTRODUCTION

Parkinson's disease (PD) is a universal, chronically progressive neurodegenerative disease that affects individuals of both sexes, regardless of race or social class. It predominates in people over 65 years of age, however the incidence can be early. The pathology is characterized by the degeneration of neurons that result in dopaminergic decrease in the ganglia at the base, thus producing several symptoms, mainly motor disorders. It should be noted that such pathology presents motor and non-motor symptoms. The main motor symptoms are: tremor at rest, stiffness, deficits in balance and gait, bradykinesia and reduction in the range of motion, and gait changes and loss of postural balance are common in parkinsonian patients 2.

With the progression of the disease, the individual may present non-motor symptoms, which include depression, sleep disorder, anxiety, lung dysfunction, mild changes in voice quality, intestinal constipation and hyposmia. These motor and non-motor disorders tend to diminish the quality of life (QL), as they generate physical, psychological and social impacts, thus compromising the person's independence and autonomy. Moreover, individuals with PD need constant assistance to perform their daily activities and instrumental activities of daily life. Thus, the need of the caregiver's performance that plays an important role in the treatment arises. The caregiver's function is directed to the care process related to the progressive course of the pathology, involving medication administration, care management, fall surveillance, among other actions that have the purpose of preserving the biopsychosocial well-being, however this professional tends to present difficulties in dealing with the clinical characteristics of the disease, because it emits a variety of signs and symptoms, which results in the overload of the daily assistance

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provided to the patient<sup>4,5</sup>. Another impasse faced by the caregiver refers to adjusting his routine with the services offered, since it can generate overload and affect the professional's quality of life, causing him to develop problems related to sleep disorder, sadness, emotional stress, fatigue and hypertension, since such symptoms are associated with the prognosis of his patient's disease<sup>5,7</sup>. In view of the caregivers' performance, it is important to direct attention to them, because they need guidance and assistance that can contribute to their QL and reflect positively on the care of the patient with PD<sup>5</sup>. Therefore, the present study will be a review of the caregivers' quality of life and how they assume the role of hidden patient during the care process of parkinsonian individuals.

## MÉTODODO

The present study is a systematic review of the literature, guided by the question: In what way does the caregiver assume the role of an occult patient during the process of caring for individuals with Parkinson's disease? The literature survey was carried out through the PubMed and Scielo database, having as temporal cutout the publication periods between 2010 and 2020, finding nine articles. The keywords used were: Parkinson's disease, quality of life, hidden patient, caregivers. On inclusion and exclusion criteria, it was through the reading of the abstract of the scientific articles, since it was taken into consideration to select studies that effectively punctuate the process of caring for the person with PD and the QL of the caregivers of parkinsonian patients. The listed articles were submitted to a careful analysis for the development of this content.

## RESULTS

This systematic review was performed through the selection of nine scientific articles, according to the above mentioned criteria. These studies were extracted from the PubMed and Scielo platforms. Data stratification was made difficult by the reduced availability of studies that describe the caregiver's perception in the care process of Parkinson's patients.

## DISCUSSION

The caregiver's performance is more and more present in the daily life, considering that there is a prevalence of chronic diseases in our society, among them Parkinson's disease, making the presence of this professional essential. It is worth mentioning that the profile of most of the caregivers are female, in the age of fifty, generally assumed by people who have a bond with the person with PD, being family members who play the role of caregiver, mainly by their spouse<sup>4,8</sup>. Thus, it was possible to notice that the act of caring requires individualized assistance and excessive responsibility, which can trigger anxiety and concern, since caring for a parkinsonian patient generates a challenging situation due to the fact of dealing daily with the range of signs and symptoms and increased demand for care, i.e., implementation of full-time care and uncertainties that encompass the life of the patient being cared for and consequently the life of the caregiver<sup>4</sup>. In this context, during the caring process, the caregiver needs to make constant adjustments in his personal and professional life, which can cause damages to his physical

and mental health, being common, to develop a series of psychiatric symptoms, such as depression<sup>5,9</sup>. Moreover, the higher the professional's age, the greater the impact in relation to the decrease of his functions<sup>5</sup>. Another point to be highlighted is the emotional factor, being that the male sex presents a negative perception in this aspect, because historically it can be said that women are more involved with the act of caring for the other, while for men this is a complex task that can reflect on the emotional ambit<sup>5</sup>. The act of caring is a function that generates physical and emotional wear and tear for the caregivers, because it goes beyond physical care, causing suffering and making these professionals become hidden patients<sup>4,8</sup>. Therefore, their insertion in support groups contributes to the exchange of experiences and feelings experienced during their care practice, tends to minimize anxiety and stress caused by work, allows the development of skills, knowledge of PD and strengthening of the bond with the patient<sup>4</sup>. Such factors mentioned above can add to the professional's QL and facilitate the patient's and caregiver's daily life.

Information	Title	Autors	years
Pubmed	Assessment of overload in outpatient caregivers of patients with Parkinson's disease and their risk factors	Benavides Olga, Alburquerque Daniela, Cuevas P.C	2013
Scielo	Double task in Parkinson's disease: a systematic review of randomized clinical trials	Chaves P.M, Marinho M.S, Tarabal T.O	2014
Pubmed	Family caregivers: what do they need? An integrative review	Fernandes C. S, Angelo Margareth	2016
Scielo	The perspective of the caregiver of the person with Parkinson's: integrative revision	Ferreira D.P.C, Coriolano M.G.W.S, Lins C. C. S.A	2017
Scielo	Quality of life of Parkinson's patients and their caregivers	Filippin N.T. et al	2014
Pubmed	Impact of support for people with advanced Parkinson's disease on quality of life and burden on caregivers	Modugno Nicola et al	2020
Scielo	Adaptation of family caregivers of elderly people with Parkinson's disease: transition process	Nunes Simony Fabíola Lopes et al	2019
Scielo	Being a caregiver for someone with Parkinson's disease: situations experienced	Padovani Camila et al	2016
Pubmed	Psychiatric symptoms in patients and caregivers with Parkinson's disease	Saadat, Pavam et al	2020

It is convenient to point out that studies evaluate the caregivers' QL by means of a Quality of Life Assessment Questionnaire (SF-36), which is an instrument composed of 36 items, scored from 0 to 100, the lower the score means that the health condition requires special attention<sup>5</sup>. It is also necessary to emphasize that support groups, for instance, therapeutic groups, are also fundamental for patients affected by PD and their families, since they need to verbalize their anguishes and share feelings generated with the prognosis of the pathology<sup>4</sup>.

In this perspective, family members may present several feelings, such as fear, guilt, sadness, among others, which go through the suffering of dealing with the family member affected by PD, and the limitations imposed by the pathology reflect in all those involved in the care process and the feelings are intensifying as the disease progresses, mainly regarding the physical and mental limitations of the subject with PD, influencing the adequacy of the life of the patient, family member and caregiver<sup>8</sup>.

## CONCLUSION

The caregiver and the patient with PD jointly suffer impacts associated with QL. The quality of life of the caregiver interferes in emotional, social and physical factors, as well as in personal characteristics, such as age, gender and schooling<sup>4</sup>. In addition, the caregiver is in charge of doing all the activities that the patient cannot perform, presents an affective bond, latent responsibility and frustration, which can result in lifestyle limitations and consequently lead to illness<sup>4,5</sup>. Thus, the participation of this professional in support groups may contribute to the development of strategies to cope with the problems caused by the act of caring, since the support directed to the caregiver assists in the management of PD and allows the caregiver to have a deep knowledge about the disease and its prognosis<sup>4,5</sup>. It is also necessary to add that the caregiver needs breaks in the performance of his functions in order to improve his QL, having time to invest in self-care, rest and above all reduce the stress generated by the performance of his activities<sup>4</sup>. According to the literature, it can be said that the health system needs to act in an integrated way, that is, to act in an interdisciplinary way to contribute to the well-being of the individual with Parkinson's disease and its caregiver, because the assistance services should offer an integrated approach, which allows the knowledge of available services for specialized care and understanding of the health-disease process by the caregiver<sup>4</sup>.

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