

PALLIATIVE CARE IN ELDERLY PEOPLE WITH PARKINSON'S DISEASE

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Abstract: INTRODUCTION: Parkinson's disease (PD) is a neurological disorder triggered by the degeneration of dopaminergic neurons in the substantia nigra. It presents with motor disorders, such as bradykinesia, tremor and rigidity, and non-motor disorders, such as cognitive and mood changes, in addition to increasing the risk of heart and lung diseases. Cognitive dysfunction and mood disorders contributed to the emergence of disability and social isolation, causing a decrease in quality of life. Palliative care focuses on alleviating suffering through the management of physical, psychosocial and spiritual issues, with the help of trained professionals. To establish end-of-life care actions, the wishes of the patient, their family members and caregivers must be respected. **OBJECTIVE:** To analyze aspects of palliative care in elderly people with PD. **METHOD:** Integrative review of articles found in the LILACS, SciELO and PubMed databases, using the keywords "Palliative care", "Palliative Care" and "Parkinson's Disease". **RESULTS:** The selected articles converge on the need for palliative care in patients with PD, as a way to improve quality of life. Another fundamental factor highlighted was the treatment of the individual as an integral being, through multidisciplinary assistance. Associated with this, individualized care plans are recommended, as well as promoting access to quality information. **CONCLUSION:** Palliative care in PD promotes improved quality of life for both the patient, their caregiver and their family. Furthermore, as it is not possible to standardize the progression of the disease, individualized care planning is necessary. Finally, it is essential to make the patient and family aware of the pathology and its progression, so that palliative care can begin as soon as possible, allowing the patient, in addition to having relief from suffering, to express their wishes and preferences.

Keywords: Parkinson's disease; Process

INTRODUCTION

Parkinson's disease (PD) represents a neurological disorder caused by the deterioration of dopaminergic neurons located in the substantia nigra, with the ventrolateral layer being the area most affected by this degeneration. Therefore, the manifestation of motor disorders, such as bradykinesia, tremor and rigidity, is common. These problems can significantly impact not only the physical, but also the psychological sphere of the individual, manifesting themselves through non-motor symptoms, such as cognitive dysfunction and mood disorders. Those

Challenges can contribute to the emergence of functional limitations, social isolation and reduced quality of life (FERREIRA et al, 2017).

Living daily with PD, in essence, often constitutes a challenge, as postural instability, motor difficulties and other symptomatic indications can compromise functional capacity, as well as the patient's independence and autonomy (FERREIRA et al. al, 2017). Furthermore, it is important to note that PD was categorized as the 14th leading cause of death, being associated with conditions such as cancer, heart failure and lung diseases. Therefore, it is essential to employ approaches that aim to mitigate suffering, addressing the physical, psychosocial and spiritual dimensions, such as Palliative Care (KLUGER et al, 2018). Therefore, a multidisciplinary approach is essential for the management of patients with PD, often involving the figure of a caregiver, who may or may not maintain family ties with the patient.

In this context, the National Palliative Care Council developed a specific guideline aimed at people affected by PD, which recommends the development of an advanced care plan, aimed at promoting autonomy and respect for the wishes of the patient, their family and

caregivers, in line with the recommendations of the National Health Service (NHS) (KLUGER et al, 2018; MACCHI et al, 2019). It is worth highlighting that it is also extremely important to consider the well-being of the caregiver when planning palliative care interventions, as this factor directly impacts the dynamics of the relationship established with the patient (MACCHI et al, 2019). Therefore, the scope of this article is to analyze the elements that encompass palliative care for elderly people affected by Parkinson's Disease.

METHODOLOGY

An integrative review was carried out, covering the critical analysis of 12 scientific documents located in the LILACS, SciELO and PubMed databases. The scope of this review was to investigate the intersection between "Palliative Care," "Palliative Care" and "Parkinson's Disease" as primary keywords. Among the initial set of 12 selected articles, we proceeded with the exclusion of 7 of them due to the lack of appropriate methodologies that met the established scientific rigor criteria. The remaining 5 articles were included in the scope of this study, considering that they presented methodologies with relevance and scientific substance. A detailed list of these articles can be found in Table 1, below: (Table 1).

DISCUSSION

Parkinson's Disease (PD) entails a series of consequences that considerably affect both individuals affected by the disease and their families. This pathology causes emotional and social impacts, the magnitude of which cannot be underestimated. A notorious link is established between PD and depression, a condition that frequently manifests itself in PD patients, further worsening their health condition. Furthermore, socialization disorders are palpable, compromising verbal and visual communication, resulting in

difficulties for the patient to express their basic needs. This difficulty in communication extends to the circle of caregivers and family members, exacerbating the challenges of understanding and assistance (HUDSON, et al, 2005).

It is pertinent to note that there is a paucity of investment in palliative care aimed at patients with PD. This population of individuals is rarely considered a priority group for support from palliative care specialists, mainly due to the perception that PD does not generally result in a terminal outcome (HUDSON, et al, 2005). However, it is essential to understand that the provision of palliative care must not be anchored in the diagnosis of the disease, but rather in the assessment of the individual needs of each patient. The practical application of this principle, however, is a complex task. This arises from the fact that neurodegenerative diseases, such as PD, often exhibit a less predictable progression compared to malignant diseases, which makes predicting prognosis and identifying the final stage of life challenging (WALKER et al, 2013).

Furthermore, given the complex nature of PD, it is crucial that health professionals and social workers are adequately prepared to facilitate access to quality information, responding in an enlightening manner to the concerns of patients and their families, thus minimizing related anguish. The prognosis of the disease (FERREIRA et al, 2017). However, it is important to highlight that many family members of patients with PD are often unaware of the availability of specific palliative care services for this condition. As a result, few PD patients and their families have documented conversations with doctors about their wishes for end-of-life care. The lack of appropriate access to these services is due to a variety of factors, including the physical and cognitive decline that many PD patients face. Around half of patients who die are described

AUTHOR/YEAR OF ARTICLE	TITLE	TYPE OF STUDY OBJECTIVES	RESULTS
Dharah Puck Cordeiro Ferreira Maria das Graças Wanderley de Sales Coriolano Carla Cabral dos Santos Accioly Lins	The perspective of the caregiver of a person with Parkinson's: integrative review	Descriptive integrative review Analyze scientific productions regarding the process of caring for people with Parkinson's Disease (PD), based on the caregiver's perspective.	a) The process of caring of the person with PD; b) The positive and negative aspects associated with the process of caring for people with PD; c) Support for the caregiver of the person with PD: What can be done for them?
Zachary A. Macchi, Claire E. Koljack, Janis M. Miyasaki, Maya Katz, Nick Galifianakis, Lindsay P. Prizer, Stefan H. Sillau, Benzi M. Kluger.	Patient and caregiver characteristics associated with caregiver burden in Parkinson's disease: a palliative care approach	Cross-sectional study Assess the characteristics of the patient and caregiver, including spirituality and mourning, which affect mental overload caregiver in a population with Parkinson's disease with moderate to high palliative care needs.	A total of 175 patients (70.9% male; mean age 70.7 ± 8.1 years; mean disease duration 117.2 ± 82.6 months), and 175 caregivers (73.1% female; age mean 66.1 ± 11.1 years). spiritual well-being of patient (Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing Scale - faith subscale, r2 = 0.024, P = 0.0380), patient's health-related quality of life (Parkinson's Disease Questionnaire - 39, r2= 0,161, P<0.0001), caregiver depression (Hospital Anxiety and Depression Scale - Depression, r2 = 0.062, P = 0.0014), caregiver anxiety (Hospital Anxiety and Depression Scale, r2 = 0.077, P = 0.0002), and the perspective of caregiver on the patient's quality of life (Quality of life in Alzheimer's Disease. Caregiver perspective, r2 = 0.088, P < 0.0001) contributed significantly to the interview Zarit Scale score.
Kluger BM, Shattuck J, Berk J, Sebring K, Jones W, Brunetti F, Fairmont I, Bowles DW, Sillau S, Bekelman DB Peter L Hudson, Christine Toye, Linda J Kristjanson,	Defining Palliative Care Needs in Parkinson's Disease Would people with Parkinson's Disease benefit from palliative care?	Observational cross-sectional study To determine the prevalence of clinically significant symptomatic, psychosocial and spiritual problems in PD and understand their impact on health-related quality of life. Descriptive qualitative study Describe the experience of Parkinson's Disease and consider the relevance of palliative care for this population.	Potential palliative care needs, including high symptom burden and grief, were common in patients with Parkinson's disease and contributed to condition-related quality of life even when controlling for depression and motor severity. Across all domains investigated, patients with Parkinson's disease had similar or higher levels of palliative care needs than patients with advanced cancer. Five themes were developed from data analysis: (1) emotional impact of the diagnosis; (2) stay connected; (3) lasting financial difficulties; (4) managing physical challenges; and (5) find help for advanced stages.
Walker RW, Churm D, Dewhurst F, Samuel M, Ramsell A, Lawrie C, Hill J, Threapleton CJ, Wood B, Gray WK	Palliative care in people with idiopathic Parkinson's disease who die in hospital	Qualitative study Investigate whether palliative care guidelines are followed for people with Parkinson's disease who die in hospital.	For the 236 patients identified, the average age at death was 82.8 years. Of these patients, 110 (46.6%) died in hospital, 56 (23.7%) at home, 59 (25.0%) in a nursing home and for 11 patients (4.7%) the place of death was not recorded. For those who died in hospital, only three patients, and seven patients' relatives, had a recorded discussion with a clinician about their preferred place of death and only 15 (13.6%) were referred to a specialist palliative care team. 46 patients (41.8%) were placed on the Liverpool Care Pathway.

Table 1 Table produced by the authors.

as being unable to make any decision in the last month of their lives, with 68% of them experiencing communication difficulties and 47% experiencing mental confusion, which makes it practically impossible to determine their preferences and desires (WALKER et al, 2013).

It is important to highlight that the symptoms, both physical and mental, of PD vary significantly between patients. Therefore, assistance and care must be highly individualized, adapted to the specific needs and realities of each individual (KLUGER et al, 2018). In this context, palliative care emerges as an absolute priority in the treatment of PD, extending not only to the patient themselves, but also to their caregivers and family members. Given the highly debilitating nature of the disease, it is essential that caregivers are prepared, both physically and emotionally, to face the challenges that arise (ZACHARY et al, 2020). It is essential to ensure the well-being of the caregiver through a comprehensive approach to care services for those affected by PD, aiming to improve their ability to care and mitigate the physical, emotional and social burden. (MACCHI et al, 2019)

Additionally, it is important to consider that PD also has substantial financial implications. As the disease progresses, the associated costs increase, especially when the patient becomes completely dependent.

A sensitive and effective approach to palliative care for PD must encompass the provision of psychological support to deal with feelings of loss and apprehension about the future. This support can be fundamental in helping both the patient and their caregivers face the emotional challenges of the disease. Furthermore, training of specialists and

caregivers is essential to provide the best possible palliative care, adapted to the specific needs of each patient (HUDSON, et al, 2005).

CONCLUSION

Palliative care in the context of Parkinson's Disease (PD) represents a necessary approach aimed at improving the quality of life of both the patient affected by the disease and their caregivers and family members. This approach aims to mitigate the suffering faced throughout the progression of the disease and covers a wide range of dimensions, including the physical, psychosocial and spiritual spheres. It is essential that palliative measures extend to all individuals directly involved in the care of patients with PD, notably caregivers, as during the period of care, a significant emotional bond is established. The well-being of these caregivers plays a direct and substantial role in the quality of care provided to the patient.

Due to the degenerative nature of PD, it is not feasible to establish a uniform progression of the disease. Therefore, it is essential to formulate a highly individualized care plan, adapted to the specific needs of each patient. This involves thoroughly assessing the state and demands of each person affected by PD, in order to develop effective and appropriate assistance strategies.

Finally, it is extremely important to offer enlightening guidance to both the patient and their family about PD, as well as the progressive decline that it imposes, not only in the physical, but also cognitive and psychological spheres. Establishing this dialogue early is essential, as it allows the patient to express their desires and preferences, thus contributing to achieving assistance that is more aligned with their needs, desires and preferences.

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