

## Being caregiver of people with Parkinson's Disease: experienced situations

*Ser cuidador de pessoas com a Doença de Parkinson: situações vivenciadas*  
*Ser cuidador de personas con la enfermedad de Parkinson: situaciones vivenciadas*

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### ABSTRACT

**Objective:** To understand the experience of caring for a person with Parkinson's Disease. **Method:** We used the qualitative study and thematic analysis with family caregivers of people with Parkinson's Disease. **Results:** Three thematic categories were identified, being: *Feelings related to Parkinson's Disease; Changes in family daily routines; Caregiver strategies for self-care.* **Final considerations:** Family care has shown the need for health services to provide caregivers support, as they experience situations of overload in care that can contribute to their illness. The findings also allow nurses to see the need for differentiated care for caregivers that, by assisting them with their needs, favor the quality of life of the caregiver, reduce the possibility of illness, allowing a more efficient care to the entity with chronic illness.

**Descriptors:** Family; Caregivers; Parkinson's Disease; Family Caregiver; Nursing.

### RESUMO

**Objetivo:** Compreender a experiência de cuidar de uma pessoa com a Doença de Parkinson. **Método:** Utilizou-se o estudo qualitativo e a análise temática com cuidadores familiares de pessoas com a Doença de Parkinson. **Resultados:** Foram identificadas três categorias temáticas: *Sentimentos referentes à Doença de Parkinson; Mudanças nas rotinas diárias da família; e Estratégias do Cuidador para o cuidado de si.* **Considerações finais:** O cuidado do familiar mostrou a necessidade dos serviços de saúde em fornecer suporte aos cuidadores, visto que estes vivenciam situações de sobrecarga no cuidado, que podem contribuir para seu adoecimento. Os achados ainda possibilitam ao enfermeiro a visualização da necessidade de uma assistência diferenciada ao cuidador que, ao assisti-lo em suas necessidades, favorece a qualidade de vida do mesmo, reduz a possibilidade de adoecimento, permitindo um cuidado mais eficiente ao ente com doença crônica.

**Descritores:** Família; Cuidadores; Doença de Parkinson; Cuidador Familiar; Enfermagem.

### RESUMEN

**Objetivo:** Comprender la experiencia de cuidar de una persona con la enfermedad de Parkinson. **Método:** Se utilizó el estudio cualitativo y el análisis temático con cuidadores familiares de personas con la enfermedad de Parkinson. **Resultados:** Se identificaron tres categorías temáticas: *Sentimientos referentes a la enfermedad de Parkinson; Cambios en las rutinas diarias de la familia; y Estrategias del Cuidador para el cuidado de sí.* **Consideraciones finales:** El cuidado del familiar mostró la necesidad de los servicios de salud en proporcionar apoyo a los cuidadores, ya que éstos experimentan situaciones de sobrecarga en el cuidado, que pueden contribuir a su enfermedad. Los hallazgos aún posibilitan al enfermero la visualización de la necesidad de una asistencia diferenciada al cuidador que, al asistirlo en sus necesidades, favorece la calidad de vida del mismo, reduce la posibilidad de enfermedad, permitiendo un cuidado más eficiente al ente con enfermedad crónica.

**Descriptor:** Familia; Cuidadores; Enfermedad de Parkinson; Cuidador Familiar; Enfermería.

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## INTRODUCTION

In the last decades, the increase of life expectancy has caused an increase of chronic diseases, among them the Parkinson's Disease. Approximately 10 million people in the world live with this disease. Its incidence is associated with aging, and estimates show that it can occur more often around age 50. The male population has one and a half times more chance of developing this disease<sup>(1)</sup>.

Parkinson's Disease (PD) is a chronic-degenerative condition, responsible for voluntary and automatic movements, caused by dysfunction of the basal ganglia, and death of dopamine-producing cells<sup>(2)</sup>. The main signs are progressive motor disorders, such as resting tremor, bradykinesia, stiffness, changes in posture and gait, and dementia<sup>(3-4)</sup>. Drug treatment efficacy gradually decreases as the disease progresses, because dopamine production within the brain is increasingly disturbed by the progressive degeneration of dopaminergic terminals<sup>(3-4)</sup>. Stem cell therapy has been highlighted as a great promise in the treatment of Parkinson's Disease and other neurodegenerative diseases, but further research in this field is needed to be safe prior to its implementation in humans<sup>(4)</sup>. Given the current treatment resources and the progression of the disease, patients need more and more individualized care and attention in daily tasks, requiring home caregiver to assist them, as well as professional care<sup>(5)</sup>.

Informal care is usually undertaken by people who are related to the patient, and the motivation for care is related to an expression of caring, love, gratitude, or respect for the family member. However, when care is performed by a single caregiver, changes in their routine may occur. These changes, coupled with overload of care can trigger psychosomatic changes in these people<sup>(6-7)</sup>, and need to be considered by health professionals who assist the family.

Given this, the caregiver also needs support in order to be able to deal with the new routine, which includes care and nursing as a care science that has the capacity to offer support to this caregiver in all spheres, but, sometimes it limits its performance to attending specific situations related to the person affected by the disease and does not extrapolate its assistance to issues related to the caregiver<sup>(8)</sup>.

In this sense, the knowledge of experiences lived by caregivers in their care practice contributes to scientific knowledge and development of strategies for holistic care to this family.

## OBJECTIVE

To describe the experience of caregivers during the care of a relative with Parkinson's Disease.

## METHOD

### Ethical aspects

The research project was approved by the Research Ethics Committee of the *Universidade Estadual de Maringá*, taking into account the aspects contained in Resolution 466/2012 on research with human beings of the National Health Council (*Conselho Nacional de Saúde*). Participants, after receiving

favorable opinion to carry out the study, were clarified regarding the objectives, methodology proposed, and risks and benefits of the research. Prior to data collection, all participants signed the Informed Consent Form.

The anonymity of the participants was assured, replacing their name with the letter "C" of caregiver and by a number that corresponded to the interview's order.

### Theoretical-methodological framework and type of study

This is a descriptive, exploratory qualitative study, based on Minay's thematic or categorical analysis technique<sup>(9)</sup>.

### Methodological procedures

#### Study setting

The research was carried out at the *Associação Maringaense de Parkinson* (AMP) (freely translated as Maringá Association of Parkinson's), created in September 2004, which works mainly to defend social rights of people with Parkinson's Disease and to help their families, according to the needs of each family. It was organized by relatives of people with Parkinson's who met and began to meet to share their experiences during the Parkinson's care. The admission to the institution follows the only criterion of having a relative with a diagnosis of Parkinson's Disease.

At the institution, counseling activities are also carried out by volunteer professionals, who are invited to give lectures on some topic of interest to the group. Some of these professionals performed sporadic individual visits to the participants of the association.

#### Data source

Caregivers of people with Parkinson's Disease were interviewed. The inclusion criteria established for the study participants were: to be an informal caregiver of person affected by Parkinson's Disease, to participate in the meetings promoted by the *Associação Maringaense de Parkinson*. Persons excluded from the study who were only accompanying the person affected by the disease at that time.

#### Collection and data organization

Data collection was performed from May to July 2012, using semi-structured interviews with all the informal caregivers of people with Parkinson's Disease who participated in the Association, totaling ten participants. The data collection tool was composed of questions that addressed sociodemographic characterization of participants and triggering questions about the experience of caring for a family member affected by Parkinson's Disease. The tool was elaborated by researchers after literature review and survey of the most important points regarding informal care for people with chronic-degenerative diseases.

The interviews were carried out with the use of tape recorder, allowing the caregiver to speak willingly about performing care for the family entity. Some moments of incomprehension of information by the researcher were again questioned so that there was a total understanding of participants' speeches. The interviews were carried out at the informant's home, because there is the place where care takes place, avoiding possible constraints and providing a better link between researcher and respondent.

The researcher's impressions, obtained during the interview, were recorded in a field diary, and this information subsidized the speech analysis process.

### Data analysis

The interviews, after being recorded, were transcribed in full and the data and information obtained were treated according to Minayo's thematic or categorical analysis technique<sup>(9)</sup>. This analysis was performed in the following steps: 1) Comprehensive reading of the selected articles by the author, with the purpose of impregnating with the material. 2) Exploration of the material collected through interview with caregivers, that is, analysis itself. In this phase, excerpts of each text were extracted and classified according to similarity between them, identifying the core meaning pointed out by the text parts in each class; 3) Dialogue with the data belonging to the sense nuclei, to see if they expressed that information initially identified and/or if there was another core meaning present in the classes; analysis and grouping of core meaning in theme; 4) New dialogue with the data and regrouping of the text parts by themes found; 5) After the data grouping, a writing was done by theme, aiming to contain the core meaning of the texts. This essay was articulated with a bibliographical reference made by the authors of the study<sup>(9)</sup>. After analyzing and interpreting the data, the following categories emerged: *Feelings related to Parkinson's Disease; Changes in family daily routines; Caregiver strategies for self-care.*

## RESULTS

From ten participants in the study, eight were female, two were male, two were single and eight were married. The kinship relationship between caregiver and PD person, the spouse, then children and a brother ruled. The age range of caregivers in the study ranged from 30 to 45<sup>(3)</sup>, 46 and 60 years<sup>(6)</sup> and one older than 60 years.

The time of the disease diagnosis ranged from seven months to twenty years. Linked to the time of the diagnosis received by the ill person is the time caregivers perform care. Most of caregivers interviewed had been caring for less than 10 years and one reported that the relative of Parkinson's Disease was still independent, requiring no specific physical care.

### Feelings related to Parkinson's Disease

The feelings experienced by caregivers concerning the care of the patient with Parkinson's disease were varied and are associated with the moment of discovery of the disease, in the effectiveness of diagnosis, in the treatment and in the way of facing the disease. Some caregivers revealed that the feelings of family members of Parkinson's Disease also interfered with caregivers' feelings and, at other times, generated need for interventions. Faced with this, the relatives' feelings affected by the chronic condition, present in the reports, were also described in this category.

Caregivers referred that sadness and depression were the most present feelings of the sick relative. These feelings became apparent when the affected family member faced limitations

imposed by the disease, which also generated fear on the part of the caregiver and relatives in the face of the situation:

*After the diagnosis of the disease, he was very down, he cried, he was desperate ... the family was scared, we got scared... (C1)*

Shame was also present in one of the reports and led to the interference of the caregiver, so that this feeling did not rule and influence the family member living with the disease with other family members. It is observed that this feeling was manifested due to demonstration of symptoms of the disease for the other, even if this other one is a member of the family itself:

*There was a lunch one day when a niece came, and he was already trembling, so he said: - You don't call me to go and eat out, because I won't eat near them, I feel ashamed. Then I said, "No, you won't be embarrassed, you are relative, you are family, she likes you very much, you will sit down and eat! With great effort we took him out from there... (C2)*

Caregivers' feelings found in their speeches range from more superficial feelings to deeper feelings and suffering from worsening illness:

*At first, I didn't even know what that was, so I didn't feel discouraged, now one of my sisters who had read a lot about it, it seemed that she felt like the floor was falling out from under her, she was sad, very discouraged. (C8)*

The most superficial feelings, as revealed in the speech of this caregiver (C8), are related to ignorance of the disease and its possibility of aggravation, different from the sister feeling of the caregiver, which is also present in the statement above. Another caregiver also mentioned the following, upon learning that her relative had Parkinson's Disease:

*When he said that he couldn't move his leg [...] my biggest concern was that he had a stroke, but I didn't even care about Parkinson's ... when we scheduled an appointment, I arrived and asked the doctor and I thought he would say that was stroke, but when he said it was Parkinson's, "It's less worse", I said. Because with Parkinson's you can walk and with stroke you can't walk. (C2)*

It is observed in the speech that the caregiver was more afraid of the disease he already known and knew that caused physical limitations. Since Parkinson's Disease, as it was a disease that was not fully known until that moment, did not generate worries in the caregiver.

However, caregiver's feelings change when the disease progresses and causes greater dependence on the family member affected by Parkinson's. The caregiver (C8), who previously reported not having been discouraged by Parkinson's Disease, reports the following after the progression of the disease:

*Now, seeing her in pain is worse. Seeing her wanting to talk and not being able to give medicine and she chokes, these things are worse. (C8)*

Another caregiver has also reported:

*After we found out that he had dementia, then I think it was sad, because the disease doesn't really bother me ... we've gotten used to the medication routine, everything. Now what I feel most is when it starts to get in the way of everything, which we see is the neurological part. (C1)*

Sadness feelings due to physical and neurological aggravation of the familiar are revealed, which can exert a shocking effect both for this and for your caregiver.

### Changes in family daily routines

The progression of Parkinson's Disease triggered symptoms that led families to modify some activities to protect the family member of Parkinson's from accidents and health problems. These modifications required readjustments of the life of the sick relative and the caregiver. In this process, some situations were highlighted in the reports and highlighted in this category. Regarding the changes in the daily life of the caregiver, it is observed that these adjustments are more visible in situations in which the disease has already caused physical and mental limitations to the Parkinson's patient. On the other hand, in a family, the caregiver did not need to change their routine, because the disease did not generate limitations to the family member affected:

*I live my life normally, I didn't stop doing anything, I walk, including her. Sometimes I walk with her, when I want a more intense walk I go alone, I practice dancing, so I take my normal life, I didn't leave doing anything because of her. (C7)*

However, the fact that a person plays the role of home caregiver of a family member who is ill, even though he does not have a physical limitation, still generates an overload in the caregiver, related to his/her concern for well-being of the family with disease.

In other families, the changes reported by caregivers were more intense:

*Sometimes I have other things to do, I want to watch soap opera, but I have to help him. (C10)*

*I had a very independent life, I left, I had volunteer work in the church ... with time I was leaving, leaving and now I left everything, everything, I only go to church once a week. (C1)*

The limitations that are referred by caregivers are related to physical and mental disabilities. In some situations, the Parkinson's Disease patient needs to be helped and the presence of the caregiver is critical for an activity to happen:

*The other day he wanted to wear pants and he went in the wardrobe, took a shirt and was trying to dress by the sleeves ... Because of the issue of food I cannot leave him alone. (C1)*

*Also musical instrument that he loved, our breadwinner was music, he played clarinet, sax, flute, everything and now he cannot play. (C4)*

At other moments of the speeches of caregivers, we observe the concern that they have in relation to the changes derived from the disease, which leads the family member to have physical, emotional and neurological limitations:

*So, his food is what worries me the most, especially if he is alone, for him to heat a food, often if he leaves many minutes in the microwave, until the food burns. (C2)*

*It is characteristic of the parkinsonian picture, they have this situation of depression that has been installing and they isolate themselves. So we stay in watchful care.... (C7)*

This caregivers' concern about the disease can also generate an overload on caregivers, as it goes beyond physical care itself. It is an attention that must be constantly given to the family so that their physical and emotional health is not impaired.

### Caregiver strategies for self-care

Even with overload and concerns regarding care, it was observed in the reports, caregivers' strategies to carry out their own care. They perform physical activities such as walking, swimming, water aerobics; perform periodic examinations and seek activities for spiritual care. They emphasize that these activities help in the rest of the body and the mind.

Regarding physical care, six caregivers reported worrying and finding time for themselves in the care routine:

*I take one hour a day for me, that's when I go to walk in the woods ... and I run, I walk, I do those exercises ... I take an hour for me, otherwise my head can't stand ... this is very important for us too, to have some fresh air, and I come with another provision... (C1)*

Spiritual care has been referred by two caregivers, and is also highlighted by one of them as a way to reduce mental overload:

*I can still go to church because is near, so I leave him, then I go, because otherwise I would go crazy. (C5)*

*I leave it to go to Mass because I really like to go to Mass, I cannot leave this ... I don't have much problems with stress. (C2)*

In other excerpts, some caregivers highlight the concern and need for personal care and that this later reflects on the care provided to the family with Parkinson's disease:

*I have to take good care of myself not to get stressed or screwed, because things are rough. (C1)*

It is perceived that the physical and spiritual health of the caregiver is an essential factor for coping with the disease.

## DISCUSSION

Studies have shown that knowing the experiences lived by caregivers and the situations they face in their care routine contributes to scientific knowledge, with the development of nursing strategies for total care of this family, caregiver and care<sup>(10-12)</sup>.

Parkinson's Disease has affected more males than females, and the role of main caregiver is undertaken, most often by females<sup>(2,13)</sup>, which was also revealed by this study. Historically, the woman is the caregiver; usually resides in the same household and, in cases of illness in the family, takes care of her husband, parents and, in some cases, their children<sup>(2)</sup>. More often women leave employment to devote themselves to caring for a family entity<sup>(14)</sup>. However, in this study, the presence of two caregivers was also observed, revealing that it is possible and necessary to encourage men to assist in family care activities. Studies reveal the presence of men performing care tasks with special dedication, contrary to the traditional gender stereotype, which attributes to women care activities<sup>(13,15-16)</sup>.

Regarding the degree of the caregiver's relationship, the research shows that, in the first place, it is the spouse who most undertakes the role of primary caregiver<sup>(2,17)</sup>, as corroborated in this study. This fact happens not only because of affective proximity, but also because of responsibilities assumed in marriage and through obedience to sociocultural norms and standards<sup>(2,17)</sup>.

Seven of the ten caregivers interviewed were over the age of 45. Some studies report that, the greater the caregiver's age, the lower the impact of feelings regarding the disease and its diagnosis, and the lower is the existence of conflicts that may have negative effects on the organization of family nucleus. These factors can be attributed to the fact that, the greater the age, the greater the affective maturity and the more easily they can get involved in care activities<sup>(18-19)</sup>. However, authors also point out the need for alerting to possible destabilization of the dynamics of family relationships in situations in which the caregiver has an advanced age, because in these families, as in the others, financial difficulties and other conditions may occur that make it difficult to perform care (progression of chronic diseases, weakening and increased dependence on care) and which can create negative impacts on intra-family relationships<sup>(13)</sup>.

Because it is a slowly progressing degenerative disease that often causes physical and mental impairment, Parkinson's Disease causes changes not only to the carrier, but also to all family members involved. Family members' feelings affected by the disease generated, at times, concern in caregivers and, in others, the need for intervention so that the picture of feelings could be improved.

In some situations, the caregivers' feelings were more superficial, due to the lack of knowledge about the disease and its progression. These feelings became more intense when the family members began to develop physical and/or mental limitations. Compared with results of other researches carried out with family caregivers of people with chronic diseases, there were feelings of sadness, fear, loneliness, deprivation of freedom, fatigue, dissatisfaction with life due to the demands of care<sup>(7,13,18)</sup>.

Other studies also point out that many caregivers needed to restrict their activities by caring for a sick or elderly family member, and their daily schedule becomes increasingly restrictive because of the needs of the family member<sup>(17-18)</sup>. Emphasizes that it is common for caregivers to feel guilty about participating in some leisure activity because they do not want to experience something enjoyable without their relative with Parkinson's being able to participate<sup>(17)</sup>.

Regarding the changes in the caregiver daily life, the modifications of the routine of this caregiver were proportional to the dependency of the affected family member. However, even those family members who do not yet have physical dependence, the caregiver's concern for the family member's well-being was observed, and in some cases the caregiver was concerned with taking the sick family member to walk and supervised the personal cares. This concern with the familiar, however independent, also generates overhead to the caregiver. The overload of family caregivers can be defined as objective overload (costs generated by illness, disturbances in the family and professional routine, and frequency of care) and subjective (degree of discomfort felt by the caregiver)<sup>(20-21)</sup>. It can cause acute or chronic illness of the caregiver, making him/her as sick as the family member with chronic disease<sup>(22)</sup>. A study that aimed to identify the overload of the caregiver of children or adolescents with mental disorders observed that the interference that child or adolescent care brings to family relationships becomes more apparent as it hinders or prevents the performance of social activities and leisure, by the constant dedication to care, triggering tension and overload<sup>(16)</sup>. Another study comparing the overload between primary and secondary caregivers of elderly patients with Alzheimer's disease showed that the former had a greater overload, mainly in activities related to daily care. This is because major caregivers generally assume full or greater responsibility in care, devoting most of their time to care for the sick relative, while the secondary caregiver is limited to complementary activities, and to provide financial resources<sup>(22)</sup>.

Given this, it is necessary to evaluate the impact of the role of caregiver in families, which can provide important information to health professionals for the development of specific psychosocial and educational interventions to each involved in care, thus providing an aid family mental health<sup>(19,21-22)</sup>. Some psychoeducation programs have been carried out with caregivers of relatives of chronic diseases, aimed at helping to reduce the family tension generated by the overload of care. Throughout the care process, it is necessary information and support from the professionals to the family so that the latter can recognize the family demands and elaborate appropriate approaches within an integral rehabilitation framework of the being care<sup>(14)</sup>.

Interventions can also be elaborated by the nurse with the family, through a nursing consultation, in the health unit or in the home, and this, when performed with the family's needs, may assist in the elaboration of strategies to reduce the overload referring to care<sup>(19,23)</sup>.

Increasingly, caregivers are recognized to play a crucial role in complementing the support provided by health and social services<sup>(23)</sup>. Thus, it is emphasized the importance of these services in providing support to caregivers and helping to minimize the burden of caring for someone with a long-term neurological disease<sup>(24)</sup>.

On the other hand, even with changing the routine of some caregivers, it has been observed that these have found a moment to perform self-care. They perform physical activities, religious activities, even more restricted than before and emphasize that this is a way to take care of themselves and to gain strength to maintain the care routine. This result is similar to that found

in other studies that found that effective coping with the care routine involves using strategies that include: obtaining strength from spiritual beliefs; to learn relaxation and stress reduction techniques so that the caregiver can maintain his/her social commitments, allowing his/her life not to undergo so many changes; to manage time better; make use of the available support services; to improve the quality of communication with the relative with Parkinson's, and to be psychologically prepared for the future when disease progresses<sup>(18,25)</sup>.

In this sense, in order to help with strategies used by caregivers to improve their quality of life and promote their health, counseling programs could also be proposed addressing themes such as the adaptation of the home environment to the needs of each individual; information on government programs in the country to obtain financial assistance for the person with special needs; caregiver and dependent person health care; counseling on the abilities and difficulties of the person with special needs, as well as existing community mechanisms and programs that offer opportunities to acquire new information and skills; counseling regarding participation in leisure activities and availability of public transport adequate to the needs of the user; and counseling on the rights of people with special needs<sup>(26)</sup>.

#### Study limitations

The study presented some limitations regarding the reality of a municipality in Paraná State countryside, which makes it difficult to generalize the findings to other social contexts and raises the need for other researches that explore the theme in order to contemplate other aspects that did not appear in this study.

#### Contributions to the Nursing

The research also presents contributions to the Nursing area, making it possible for the nurse to see the need for a differentiated

caregiver. Assisting him/her in his/her needs favors the quality of life of the same, reduces the possibility of illness and, thus, allows a more efficient care to the entity with chronic illness.

#### FINAL CONSIDERATIONS

This study presented aspects of changing the family's routine that has a family member with Parkinson's Disease, in addition to the caregiver's concerns familiar with the well-being and individual needs of the sick person. It has also presented strategies that caregivers have to reduce their overload and carry out self-care.

Relatives who live with a person with Parkinson's Disease may present different feelings due to the situation experienced, such as loneliness, fear, guilt, sadness, among others, as well as causing physical and emotional distress to the family member who takes care of daily care. Daily changes of caregivers were greater when the disease progression occurred and, with this, it generated greater overload to them. This overload can cause the illness of the caregiver and, consequently, interfere with the quality of care offered. It is important to emphasize the need for feelings and this overload to be considered during professional care.

Some strategies to deal with physical and mental overload are being carried out by caregivers themselves, such as practicing physical activity and seeking spiritual support. But the family caregiver will often not be prepared for this role, needing the support of health professionals to care for themselves. The nurse, in turn, in knowing the care routine of family caregivers of people affected by chronic diseases, can include this knowledge in discussions with the health team, in order to plan effective actions that include and strengthen the whole family during the care.

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