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ORIGINAL ARTICLE

KNOWLEDGE AS A TOOL TO PROMOTE CARE OF THE ELDERLY WITH PARKINSON'S

O CONHECIMENTO COMO FERRAMENTA DE PROMOÇÃO DO CUIDAR DO IDOSO COM PARKINSON

CONOCIMIENTO COMO UNA HERRAMIENTA PARA PROMOVER EL CUIDADO DE LOS ANCIANOS CON ENFERMEDAD DE PARKINSON

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ABSTRACT

Objective: to identify available resources and information on the disease for the elderly with Parkinson's disease caregiver. ***Method:*** a descriptive study, with a qualitative approach, carried out in a Pro-Parkinson Extension Program, in the city of Recife (PE), Brazil, with 20 caregivers of elderly people with Parkinson's Disease. The data collected was submitted to the Content Analysis Technique in the Categorical Analysis modality. ***Results:*** three thematic categories emerged: (1) Sociodemographic profile of elderly caregivers with Parkinson's; (2) Sociodemographic and clinical profile of the elderly with Parkinson's disease and (3) Information as a promoter of quality in care. ***Conclusion:*** access to knowledge can be definitive when it comes to the health-disease process of Parkinson's Disease, in which the health professional appears as a facilitator. ***Descriptors:*** Knowledge; Caregivers; Parkinson Disease; Aged.

RESUMO

Objetivo: identificar os meios disponíveis e as informações sobre a doença para o cuidador familiar do idoso com Parkinson. ***Método:*** estudo descritivo, com abordagem qualitativa, realizado em um Programa de Extensão Pró-Parkinson, na cidade de Recife (PE), Brasil, com 20 cuidadores familiares de idosos com Doença de Parkinson. Os dados coletados foram submetidos à Técnica de Análise de Conteúdo na modalidade Análise categorial. ***Resultados:*** emergiram três categorias temáticas: (1) Perfil sociodemográfico dos cuidadores familiares de idosos com Parkinson; (2) Perfil sociodemográfico e clínico dos idosos com Parkinson e (3) A informação como promotora da qualidade no cuidado. ***Conclusão:*** o acesso ao conhecimento pode ser definidor quando se trata do processo saúde-doença da Doença de Parkinson, no qual o profissional de saúde surge como um facilitador. ***Descritores:*** Conhecimento; Cuidadores; Doença de Parkinson; Idoso.

RESUMEN

Objetivo: identificar los medios disponibles y las informaciones acerca de la enfermedad al cuidador familiar del anciano con enfermedad de Parkinson. ***Método:*** estudio descriptivo con enfoque cualitativo, realizado en un Programa de Extensión Pró-Parkinson, en la ciudad de Recife (PE), Brasil con 20 cuidadores familiares de personas mayores con enfermedad de Parkinson. Los datos recogidos fueron sometidos a la técnica de análisis de contenido en modo de análisis categorial. ***Resultados:*** tres temas emergieron: (1) perfil sociodemográfico de los cuidadores familiares de personas mayores con enfermedad de Parkinson; (2) perfil socio-demográfico y clínico de las personas mayores con enfermedad de Parkinson; y (3) la información como un promotora de la calidad en la atención. ***Conclusión:*** el acceso al conocimiento puede ser el definidor cuando se trata del proceso salud-enfermedad de Parkinson, en la que el profesional de la salud surge como un facilitador. ***Descriptores:*** Conocimiento; Cuidadores; Enfermedad de Parkinson; Anciano.

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INTRODUCTION

The caregiver of the elderly can be considered as a new professional category in Brazil that has been widely discussed in the elaboration of policies and in the events focused in the area of gerontology and geriatrics.[1]

The caregiver's profession has been regulated through legislation directed to these individuals, such as Bill No. 4702/122, in order to accentuate the aging process, which results in the increase of people who need help in their daily lives. [3]

The association of aging with the increase of non-communicable chronic diseases, such as Parkinson's disease (PD), a neurodegenerative disease characterized by the presence of frequent motor disorders, contributes to an increasing need for a caregiver .[4] In addition, the increase in the prevalence of PD in the world with advancing age (all per 100,000): 60 to 69 years, with 428; 70 to 79 years, with 1087; And 80 years or older, with 1903, with the exception of the age group between 65 and 74 years, with 425.5

Despite the professionalization of care for the elderly, the presence of family caregivers is evident, so the family environment continues to perpetuate care within itself as a way to overcome economic, social and psychological barriers. Thus, informal home care accounts for approximately 80% of the care of the elderly who can not perform the Daily Life Activities (ADLs) in the member countries of the Organization for Economic Cooperation and Development, which are the main form of care in the world .[6]

Starting from the premise that the family caregiver carries out direct care for the elderly with Parkinson's, some questions arise in the family nucleus about the knowledge about care and self-care, since this ends up being the proper place to acquire it. In addition, it is essential to gather information on the needs of the population, since this contributes to ensuring the surveillance of the health-disease process.[7]

Thus, the objective of the study was: to identify the information and its available means for the caregiver of the elderly with Parkinson's.

METHOD

The article was prepared from the Master's Dissertation in Gerontology << Perceptions of the elderly with Parkinson's disease caregiver in relation to the care process >>, presented to the Graduate Program in Gerontology of the Federal University of Pernambuco/UFPE. Recife (PE), Brazil. 2016.

A descriptive study with a qualitative approach was carried out in the Pro-Parkinson Extension Program, a reference in Pernambuco in the multidisciplinary care of individuals with PD, located in the city of Recife/PE, under the approval of the Research Ethics Committee of the University Federal of Pernambuco, under the CAAE: 46834815.2.0000.5208.

The sample was obtained in a random and convenient, according to the agenda of the day of service, among 20 (twenty) caregivers of the elderly with PD. In order to guarantee anonymity, codenames, more precisely stone names, were used to replace the names of the respondents.

Data collection was performed between September and December 2015 and was divided into three moments. In the first, it was verified the agenda of the day of care, whether or not the elderly were accompanied by their respective family caregivers and the PD stage. In the second moment, the caregivers performed the Mental State Mini-Exam. And, after that moment, the semistructured questionnaire was applied with questions regarding the caring process.

The analysis of data on the semi-structured questionnaire about the sociodemographic profile of the elderly with Parkinson's caregivers and the socio-demographic and clinical profile of the elderly with Parkinson's were transcribed in a worksheet of the Microsoft Excel® application, with the purpose of organizing and facilitating the analysis.

As for the data of the semi-structured script with the family caregivers of elderly people with Parkinson's, Content Analysis allowed for the emergence of categories where it was possible to discover the nuclei of meaning that composes the communication after reading the statements that were aggregated, through the following steps: a) pre-analysis; B) exploitation of the material and c) treatment of results.[8]

RESULTS AND DISCUSSION

Three thematic categories emerged after the Content Analysis: (1) Sociodemographic profile of elderly with Parkinson's caregivers; (2) Sociodemographic and clinical profile of the elderly with Parkinson's disease and (3) Information as a promoter of quality in care.

♦ Socio-demographic profile of family caregivers of elderly people with Parkinson's disease

According to table 1, a predominance of the female sex in the accomplishment of the activities related to the care was observed, being this a common practice due to the historical context that associates the woman to the role of carer par excellence, mainly, in the long term care.[9-10]

Table 1. Socio-demographic profile of family caregivers of elderly people with Parkinson's disease. Recife (PE), Brazil, 2016. n= 20.

Variables	n	%
Gender		
Male	06	30
Female	14	70
Age group		
20 - 29 years	01	05
30 - 39 years	02	10
40 - 49 years	05	25
50 - 59 years	04	20
60 - 79 years	08	40
Color		
White	06	30
Black	03	15
Brown	11	55
Yellow	-	-
Marital Status		
Single	02	10
Married	18	90
Widow	-	-
Divorced	-	-
Consensual Union	-	-
Degree of kinship		
Spouse	08	40
Child	09	45
Sibling	02	10
Grandchild	01	05
Profession		
House wife	08	40
Others	12	60
Education		
Illiterate	-	-
Unitl 4th grade	01	05
5th a 8th grade	05	25
Complete middle school	02	10
Complete highschool	07	35
Complete higher education	05	25
Income		
Class A	01	05
Class B1	03	15
Class B2	06	30
Class C1	04	20
Class C2	04	20
Class DE	02	10

*Other professions: farmer, nurse attendant, culinarian, construction master, driver, mason, teacher, commercial representative, public servant, laboratory technician and veterinarian. ** Class A: R $ 11,037.00, Class B1: R $ 6,006.00, Class B2: R $ 3,188, Class C1: R $ 1,865, Class C2: R $ 1,277, Class DE: R $ 895.

The feminization of care was built historically. Although currently undergoing some changes, it is still present in the family contexto,[9] influencing even the choice of the family caregiver, as can be seen in the following report:

> *[...] and he is still a boy, so you can not tell much.* (Magnetite)
>
> *[...] the woman has to take care of, do some things, it's natural.* (Andaluzita)

As a result of the insertion of women in the labor market and some changes in the family configuration, it is difficult to predict who will care for the elderly in the future, considering that the woman stops assuming only the activities related to the home to fit into a new context and social roles.[6, 11-2]

Regarding the age group, it was possible to observe the presence of a new phenomenon that has been consolidating, which is the increase of the elderly caring for the elderly.[13] In this study, the family caregivers of elderly people with Parkinson's were elderly, aged 60 to 79 years (40%). This is corroborated by other researches: in Singapore, with emphasis on the age group of caregivers of people with

Parkinson's over 61 years (38%), and in Northern Ireland, older than 55 Years (81%).

The need for the presence of a caregiver is not restricted to the elderly with Parkinson's. In general, with increasing longevity and chronic diseases, there is an increase in the number of elderly people who need assistance.[16] Emphasizing that there are some characteristics that can contribute to a better caring performance, as can be observed in the following statements:

> *You have to be patient with them.* (Goldstone)
>
> *You have to be careful, you have to be an accountant.* (Citrine)
>
> *Caring means attention.* (Emerald)
>
> *[...] to be permanently in the presence of someone responsible, not only responsible, but also sensitive, caring to understand this process ...* (Citrine)

In relation to the degree of kinship two categories were: children - (45%) and spouses - (40%). Thus, in the case of the profession, caregivers were housewives (40%). With regard to schooling, most caregivers had a high school diploma (35%) and a class B2 (30%).

♦ Sociodemographic and clinical profile of the elderly with Parkinson's disease

According to table 2, the sample was homogeneous between genders, and had a higher prevalence among individuals aged between 71 and 75 years (30%). Regarding the PD stage, Stage II (30%) was highlighted.

Table 2. Sociodemographic and clinical profile of the elderly with Parkinson's. Recife (PE), Brazil, 2016. N = 20.

Variables	n	%
Gender		
Male	10	50
Female	10	50
Age Group		
60 - 65 years	05	25
66 - 70 years	03	15
71 - 75 years	06	30
76 - 80 years	04	20
over 80 years	02	10
Staging Scale by Hoehn & Yahr		
Stage I	04	20
Stage II	06	30
Stage III	05	25
Stage IV	05	25
Time of Parkinson’s disease		
Up to 1 year	02	10
From 2 to 4 years	05	25
From 5 to 7 years	05	25
From 8 to 10 years	03	15
Over 10 years	05	25

With regard to the time of living with PD, it can be observed that the following periods of time predominated: two to four years, five to seven years and over ten years. Each of them reached 25% of the sample. Considering the three together, they resulted in 75% of the total.

Family caregivers reported the presence of the four classic signs for the diagnosis of Parkinson's.[4] It was observed in the speech below how motor symptoms, such as bradykinesia and freezing, can contribute to a change in routine.

> *[...] the last time he stopped driving was because he crashed, it was on the avenue. Dangerous, because he is endangering his life and that of others.* (Quartz)

The positioning of the disease varies in each individual, being guided by the prognosis of PD, confronting the elderly with PD and their caregivers to create coping strategies.[17] When the health-disease process is optimistically viewed, there is a tendency for improvement The clinical outcomes of PD, acceptance of treatment, quality of life and lower costs.[18] Thus, this posture will not result in a cure, but will allow the individual to glimpse other horizons and seek new alternatives to ameliorate their signs and symptoms.

> *Now she's [...] optimistic. In her head, she only thinks that one day healing will happen. The doctor tells her that this helps a lot [...] because she is optimistic, does not surrender.* (Emerald)

On the other hand, pessimism, due to the instability of the disease and the absence of cure, may contribute to worsening the prognosis of the elderly with Parkinson's disease.[17]

> *She settled herself. She gave herself too much. Even going out for a walk is a big difficulty. She was a very active person, smart, but after Parkinson's she has a lot of spinal crisis.* (Onyx)

Parkinson's can interfere with interpersonal relationships, since the elderly's own ignorance of the disease, their family caregivers and all the people who are part of their social cycle, causes shyness, insecurity, shame, decrease self-esteem and social isolation.[19]

> *[...] I think that this social side loses a lot. Mommy does not want to leave the house anymore, she does not want to go to the mall after she has gone awry at her friends' meeting [...] because sometimes out of nowhere she starts shaking. Then she is ashamed. Thinking that she is a burden ... begins to isolate itself a lot.* (Magnetite)
>
> *[...] After she got this way she feels ashamed, I guess.* (Celestita)
>
> Not to notice his problem, he avoids, does not like much conversation. (Andaluzita)

It is important to minimize the changes resulting from the existence of PD, in addition to maintaining interpersonal relationships with friends, but to maintain the family bond[14] and try to change the routine, so as not to restrict the elderly to their home.

> *The two were very active on walks, an alternative that we seek is a weekend to take them to walk, to take them from home, to understand that life goes beyond that space, not to lose this will for life [...] At the right moment [...] I take to visit the family, the nature, the beach. So that breaks this routine of them to be in the house [...] to keep the family bond present, so that they feel welcomed by the family and surrounded by love, affection, understanding. But unfortunately, within our economic system, you do not have the availability you would like to have.* (Citrine)

Despite the support provided by the family, this does not negate the need for the elderly with Parkinson's to maintain their extra-family relationships. The maintenance of these provides the creation of new tasks and activities, when their own potentialities are valued.[17] The following discourse does not disregard family support, but reaffirms the importance of the social cycle.

> *This is support that is valid. Because I'm a daughter, but she needs to talk to people her age. It's different because it's her friends.* (Magnetite)

Independence and autonomy should be encouraged and maintained during the process of human aging, with the aim of guaranteeing the quality of life of the subject.[20] Nonetheless, in PD it is possible to encourage the elderly every day to make their personal decisions, as well as to perform their DLAs, as can be seen below:

> *[...] we encourage them to always move, to try to preserve the autonomy they have always had.* (Citrine)
>
> *She does her thing only [...] The day she needs it is going to be death of her.* (Magnetite)
>
> *Inside the bus, even for him to climb, he has to be holding him [...] He cannot. [...] you cannot do everything for him, you have to also guide him so he can do it, otherwise he will be dependent on you for everything.* (Quartz)
>
> *Do not let. I do not let him, I ask him, because I cannot say: I do not let! Because he also knows what he is doing, he has his own wills. And I always want him to have his own free will because it helps a lot the person who has Parkinson's [...]* (Amber)
>
> *For certain things she prefers to do and sometimes I let her because it is better for her to always do things.* (Emerald)

It is a challenge to face the reality of an incurable disease that causes instability.[17] The elderly with Parkinson's themselves perceive the changes that exist due to the presence of this pathology, which can lead to a difficulty in accepting their own present life condition, as evidenced in the speech below:

> *Because it's so complicated with Mom in that sense of caring, because she cannot bear to be a burden, if she does she is mortified.* (Magnetite)

It is important to know the non-driving symptoms of PD, such as depression and anxiety, in order to face them adequately.[19] It is worth noting that the association of depression with gait deficits can compromise the elderly's health with Parkinson's, for a negative prognosis, being considered as an important risk factor for death in the elderly.[21]

> *The person who is going to take care of him has to take care of love, so he does not go into depression. What kills people in a disease is not the disease itself, that it is suffering, but the depression that it will enter is what will end more with it [...]* (Alexandrite)

Caregivers find some ways to avoid the signs and symptoms of depression. Thus, the family is an essential stimulus in coping with this disease in the elderly with Parkinson's disease.[19]

> *[...] I try to include him sometimes in walks with the children so he does not isolate himself so much. Because he, knowing that he has always had an active life and suddenly gave a total turn in his life, makes him feel a little depressed [...]* (Quartz)

On the other hand, the negative prognosis and presence of signs and symptoms so evident, there is still room for hope of

improvement in the prognosis, resulting in acceptance and adaptation to the health-disease process.[17]

> *The doctor gave the medication and he took it. He did not stop taking it, he continued to improve and improve.* (Amber)
>
> *[...] she still has not become a difficult person to take care of, I can say, but if I ever get there, I hope the medicine advances and I get there to have a cure or at least permanent control.* (Emerald)

♦ Information as a promoter of quality in care

Knowledge about PD is indispensable to guarantee the quality of life of the elderly with Parkinson's, as well as their respective family caregivers.[19] However, the insertion of the family caregiver during the PD health-disease process allows him to construct his knowledge about this pathology.

> *[...] it is degenerative, it gradually takes away the mobility of the person.* (Alexandrite)
>
> *[...] Parkinson does not kill anyone.* (Topaz)
>
> *There is surgery, but not everyone can do it, because it will depend a lot on the patient and the degree of Parkinson's that the patient presents [...]* (Quartz)

The need to improve caregiver support through the provision of quality information on disease management can lead to better health care solutions for the elderly with Parkinson's disease.[14] Thus, the means of access to quality care information can arise in several ways, as explained in figure 1.

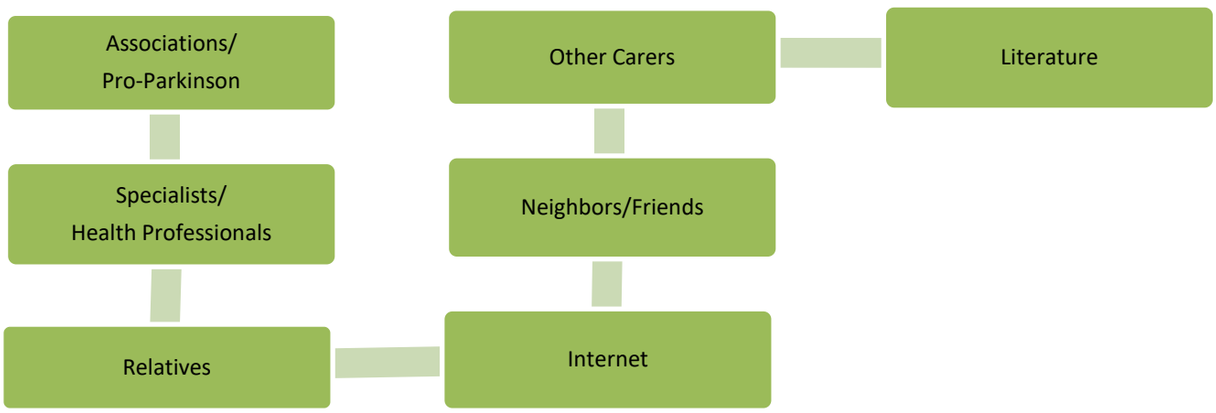

Figure 1. Means of access to information on caring for family caregivers. Recife (PE), Brazil, 2016.

A European study found data similar to this study regarding the sources of information available on the types of treatment and how to manage PD, the main ones being: the associations directed to Parkinson's (64.1%); the Internet (62.4%) and friends (62.4%).[22] This data reveals the important significance of the role of associations and the Internet, which reflects on the quality of content provided by this media.

Thus, the lack of information about PD by family caregivers can lead to the emergence of several questions, since some have never heard of the disease or, when one has knowledge, it is small.[23] This lack of information Can be observed in the statements below:

> *[...] I've heard of this disease. Now, tell me one thing: This disease comes from what? Comes how? How did this disease come about? [...]* (Rubi)
>
> *[...] generally, we will only understand after the illness is in a loved one of the family [...]* (Jaspe)

It is evident that, despite follow-up, doubts can arise that cause uncertainties about how PD appears, develops and what its signs and symptoms are. In order to address the existing gaps, it is necessary to create therapeutic training programs that would enable people affected by PD to have access to awareness raising, information, learning and quality monitoring.[19]

The training of family caregivers of elderly people with PD improves their quality of life and the elderly who receives care.[19] In addition, some caregivers report the interest and need for courses for family caregivers, since the family can not afford the costs of a formal caregiver.

> *I also think that the absence of a training course [...] the family or a family member may have access to more information, techniques or be aware of what has emerged from more recent formation, more interesting to deal with this situation of Parkinson. [...] when you know how she developed the disease, she [...] understands*

the patient's situation better. I think you're more sensitive. [...] Knowing is fundamental. (Citrine)

You will take care of a person, without guidance as a caregiver, get lost. Will not do. It will not act. (Emerald)

Others develop strategies to seek more accurate information to guide care of elderly with Parkinson's in order to improve the care provided, and may even act to prevent possible injuries, since family caregivers need informational support.[24]

I am very attentive and what was not passed on to me I seek. I'm afraid he'll fall and have the worst consequences of the fall. (Tourmaline)

[...] knowing the severity of the disease, will do something so it does not evolve so fast. (Amethyst)

The person takes more care, does not let him make moves that rises him to get hurt, to fall. (Galena)

The multiprofessional health team must be able to act in the promotion of health and prevention of diseases directed to the elderly population with PD. At first, it is ideal for the team to build a bond, as this individual and his/her family caregiver will better understand the explanations, be able to solve their doubts and expose their fears.[19]

It's been four years since we did acupuncture there [...] He is very dear there, we are very dear there, it looks like a family. (Amber)

Generally, I try to eliminate them with a specialist, in the case the neurologist, geriatrician too, because they are elderly [...] I try to see what literature has to orient and in the internet access, these are the tools I I use (Citrine)

All this is a whole, it is the people who help us. (Topaz)

Conceptions of care are present in every society and are built on specific practices and knowledge,[25] favored by the exchange of knowledge among elderly caregivers with Parkinson's through individual experiences that can be influenced by cultural aspects. Therapeutic groups, which are generally facilitated by health professionals, contribute to this construction through mutual support.[14]

I only have one neighbor, who talks a lot. Her husband has also passed away [...] the same problem that she has her husband had too. [...] (Goldstone)

[...] someone who has more knowledge than I do, when we come to the consultation, there are more people, who care more and more. (Tourmaline)

CONCLUSION

Access to knowledge can be definitive when it comes to the health-disease process of PD. In this access, the health professional that makes up the multiprofessional team emerges as a facilitator.

It is necessary that family caregivers have access to quality information that allows them to perform care with excellence and promptness, as this results in better care solutions and in the improvement of the quality of life of the family caregiver and the elderly with Parkinson's who receives the care.

Thus, there is a growing need for courses designed for family caregivers of elderly people with Parkinson's, as they need support to carry care, as well as spaces for discussion and exchange of experiences, through the creation of of therapeutic groups for family caregivers.

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