

## THE INITIAL PHASE OF THE PROCESS OF LIVING WITH PARKINSON'S DISEASE

### A FASE INICIAL DO PROCESSO DA VIVÊNCIA COM A DOENÇA DE PARKINSON

### LA ETAPA INICIAL DEL PROCESO DE VIVENCIA CON LA ENFERMEDAD DE PARKINSON

Rafaela Vivian Valcarenghi<sup>1</sup>, Angela Maria Alvarez<sup>2</sup>, Simony Fabíola Lopes Nunes<sup>3</sup>,  
Andrelise Viana Rosa Tomasi<sup>4</sup>, Josiane Steil Siewert<sup>5</sup>, Rafaela Baptista<sup>6</sup>

#### ABSTRACT

**Objectives:** To know the experience of the person with Parkinson's disease from the appearance of the signs and symptoms to the confirmation of the diagnosis. **Methods:** Qualitative research, using the methodological framework of Data Based Theory. Participants of the in-depth interview were 30 people with Parkinson's disease, enrolled in the Santa Catarina Parkinson's Association, and later five people with the disease validated the results. The collection took place from September 2013 to April 2014. **Results:** There emerged three categories: Realizing that something is changing in their capacities, Going to physician offices, and Dealing with the impact of the disease. **Conclusion:** It was possible to know the experience of people with the disease in its initial phase, showing important aspects in the understanding of this process, and from that understanding reflect on care practices to this specific group, incorporating qualified assistance to these users of the services Cheers.

**Keywords:** Parkinson's disease. Chronic disease. Nursing. Diagnosis. Qualitative research.

---

<sup>1</sup> RN. Doctorate in Nursing at UFSC. Professor at Centro Universitário Estácio de Santa Catarina. São José/SC.

<sup>2</sup> RN. Doctorate in Nursing at UFSC. Professor at UFSC. Florianópolis/SC.

<sup>3</sup> RN. Doctorate student in Nursing at UFSC. Professor at UFMA. Imperatriz/MA.

<sup>4</sup> Physiotherapist. Doctorate student in Nursing at UFSC. Florianópolis/SC.

<sup>5</sup> RN. Doctorate in Nursing at UFSC. Professor at IFSC. Joinville/SC.

<sup>6</sup> RN. Master's degree in Nursing at UFSC. Nursing Assistant at HU/UFSC. Joinville/SC.

## RESUMO

**Objetivos:** Conhecer a vivência da pessoa com doença de Parkinson desde o surgimento dos sinais e sintomas até a confirmação do diagnóstico. **Métodos:** Pesquisa qualitativa, utilizando o referencial metodológico da Teoria Fundamentada nos Dados. Participaram da entrevista em profundidade 30 pessoas com doença de Parkinson, cadastradas na Associação Parkinson Santa Catarina, e, posteriormente, cinco pessoas com a doença validaram os resultados. A coleta ocorreu entre setembro de 2013 e abril de 2014. **Resultados:** Emergiram três categorias: Percebendo que algo está mudando em suas capacidades, Percorrendo os consultórios médicos, e Lidando com o impacto da doença. **Conclusão:** Foi possível conhecer a vivência das pessoas com a doença em sua fase inicial, mostrando aspectos importantes na compreensão deste processo, e a partir de tal entendimento refletir sobre práticas de cuidados a esse grupo específico, incorporando assistência qualificada a esses usuários dos serviços de saúde.

**Descritores:** Doença de Parkinson. Doença crônica. Enfermagem. Cuidados de Enfermagem. Diagnóstico.

## RESUMEN

**Objetivos:** Conocer la vivencia de la persona con enfermedad de Parkinson desde el surgimiento de los signos y síntomas hasta la confirmación del diagnóstico. **Métodos:** Investigación cualitativa, utilizando el referencial metodológico de la Teoría Fundamentada en los Datos. En la entrevista en profundidad, 30 personas con enfermedad de Parkinson, registradas en la Asociación Parkinson Santa Catarina, y posteriormente cinco personas con la enfermedad validaron los resultados. La recolección ocurrió entre septiembre de 2013 y abril de 2014. **Resultados:** emergieron tres categorías: Percibiendo que algo está cambiando en sus capacidades, Recorrer los consultorios médicos, y Lidando con el impacto de la enfermedad. **Conclusión:** Fue posible conocer la vivencia de las personas con la enfermedad en su fase inicial, mostrando aspectos importantes en la comprensión de este proceso, ya partir de tal entendimiento reflexionar sobre prácticas de cuidados a ese grupo específico, incorporando asistencia calificada a esos usuarios de los servicios de salud.

**Descriptores:** Enfermedad de Parkinson; Enfermedad crónica; Enfermería; Atención de Enfermería; Diagnóstico.

## INTRODUCTION

Chronic Non-communicable Diseases (DCNTs) are the leading causes of death in the world and have generated loss of quality of life with a high degree of limitation in work and leisure activities. Despite the rapid growth of DCNTs, their impact can be reversed through health

promotion interventions to reduce risk factors, as well as improved health care, early detection and timely treatment.<sup>1</sup>

Care for people in chronic situations is challenging for the nurse, they require different knowledge and skills.<sup>2</sup> In this sense, one of the DCNTs that deserves attention from health professionals and public policies is Parkinson's Disease (PD), which most commonly affects

people over 50 years of age and its incidence and prevalence tend to increase with the advancement of age. Because it is a neurological disease associated with the *Lewy* bodies and loss of dopaminergic neurons in the substantia nigra, its main signs are bradycinesia, rigidity, rest tremor and postural instability.<sup>3</sup>

Living daily with motor difficulties generates great stress, since many daily activities require the execution of different tasks simultaneously.<sup>4</sup> Thus, it is relevant that nurses have knowledge about living with such condition, in order to elaborate appropriate interventions to better coexist with the disease.

This study aims at: To know the experience of the person with Parkinson's disease from the appearance of the signs and symptoms until the confirmation of the diagnosis.

## **METHOD**

This is qualitative research, which had the Data Based Theory (PDT) as a Methodological Reference. TFD focuses on the knowledge of perception, meaning or the way people define events or the reality and how they act in relation to their beliefs.<sup>5</sup>

Thirty people with PD enrolled in the Santa Catarina Parkinson's Association

(APASC) participated in the study. The precepts of the theoretical saturation of the data were respected, performing in-depth interviews with three sample groups, according to the time of diagnosis of the disease: Sample group 1 (time of diagnosis of PD up to 5 years: 14 participants); Sample group 2 (time of diagnosis of PD from 5 years to 10 years: 7 participants) and Sample group 3 (time of diagnosis of PD over 10 years: 9 participants). As regards the age of participants, it ranged from 44 to 83 years old. The inclusion criteria in the research were: to have PD diagnosis; preserved cognitive condition, according to the Short Mental State Examination (MEEM) score.

The validators of the results were five people who did not participate in the first phase of the study, ranging in age from 41 to 75 years old, and time to diagnosis of PD between two and 18 years.

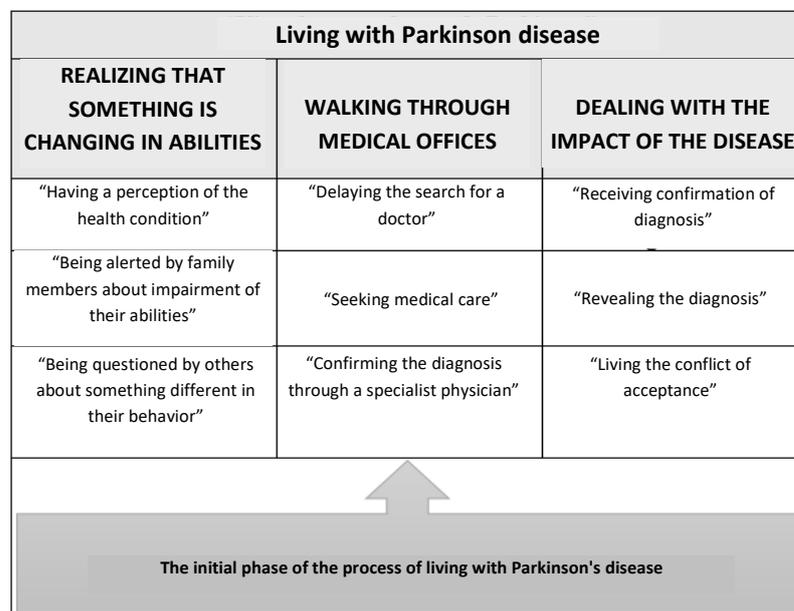
Data collection took place from September 2013 to April 2014. The interviews were recorded in mp3 and then transcribed for later analysis and coding according to the techniques established by the TFD: open coding (data are separated, examined and compared); (categories are related and defined their subcategories to generate precise and complete explanations about the phenomena) and selective coding (integrates and refines the categories).<sup>5</sup>

The research was approved by the Research Ethics Committee with Human Beings of the Federal University of Santa Catarina (UFSC), under favorable opinion number 329.662, CAAE: 14244513.9.0000.0121. Authorization was granted by APASC coordination to invite registered persons. Participants signed the Informed Consent Form (ICF). All phases of this research were based on Resolution 466/12 of the National Health Council.<sup>6</sup> Participants were identified with the letter “P” followed by Arabic numerals.

## RESULTS

Data analysis of the 30 participants allowed the revelation of the central phenomenon: “Living with Parkinson's disease” and unveiled the categories and subcategories that make up the initial phase of the disease, from the appearance of signs and symptoms to confirmation of the diagnosis, as shown in Figure 1:

**Figure 1** – Model “Living with Parkinson's disease: The initial phase of the process of living with Parkinson's disease.” Florianópolis, Santa Catarina, Brazil. 2015.



Source: authors, 2015.

Realizing that something is changing in abilities

This *category* portrays how the person begins to perceive that something is changing in their living, or in their health

condition. This perception precedes the diagnosis of the disease and has a varied period until the demand for health services.

At this stage, sensations are shared with family members or close associates regarding changes in what individuals and the community consider to be outside normalcy. The perception that something is changing in health can be revealed in many ways, as the subcategories show:

The subcategory “Having a perception of the health condition” is evidenced by the main signs identified by people with PD, especially when performing daily activities:

*[...] he had difficulty wiping his face, lifting objects, writing, he had a hard time writing [...]* (P15)

*[...] I began to feel a lot of fatigue, and after that fatigue I had a loss of smell. Difficulty writing, for example, a three was practically zero, could not make that curve... the size of the letter was reducing [...]* (P18)

The perception that the movements are different, presenting tremor or rigidity, leads the person to experience diversified feelings. Some of them believed that such signs and symptoms would be transient, but when they began to persist, they felt the need to discover what was happening.

The subcategory “Being alerted by family members about impairment of their abilities” portrays the warning by family

members that something was different with their health status. It is an important moment, because some had even felt something strange and now were obtaining the confirmation made by the relatives. On the other hand, in other situations it is the family member who first observes that the person is having some type of alteration:

*[...] people began to realize, when I was walking on the beach, when I moved... the problem of walking, I did not lift the right side of the arm, the arm did not follow the movement [...]* (P18)

*My son said: “Mom, you're shaking, stop it!”, then I looked at my arm and said, That's true, but I do not see it. So that was the first moment I realized* (P12)

The subcategory “Being asked by others about something different in behavior” shows that other people, such as friends, co-workers and strangers, also notice changes:

*[...] other people who were not attached to me, even strangers, asked if I had a problem with my arm, and I thought: there's something wrong, there are strange people noticing* (P25)

One can see a watershed for the person who starts with signs and symptoms still in their productive phase. As the disease progresses, co-workers begin to perceive difficulties in performing tasks.

*[...] I spoke to my boss and he said: "I already knew that for a long time!", because I had the symptom... I moved with the foot, just like if I had been accelerating a car... [...] This is Parkinson, I did not want to talk to you, I wanted you to find out." ...my boss [...] (P15)*

*[...] the cognitive part began to present problems, to forget the recent things, and one day, in a speech, I totally lost, I turned my focus... (P18)*

People notice the changes, meaning that signs of PD begin to be shared with others. Such changes become even more significant to the person as they are transmitted to society.

#### Walking through medical offices

This category follows the perception that something is changing in the state of health. Some believe it to be something related to the previous illness condition, others believe it may be PD. The ideas related to possible diagnoses cause the search for health services, especially by the medical professional. This moment is characterized as an itinerary used by people. These are referred from one doctor to another and to health services. The following subcategories are described:

The subcategory "Delaying the search for a doctor" demonstrates how people, even realizing their condition, are slow to seek support in health services.

They think it may be due to another health problem or seek services only when they perceive evidence of the condition. Seeking the doctor is an expected and shared behavior among people, even if they resist at first:

*[...] I thought that this small tremor that started after a few months could be a side effect of these injections (which I did for the pains in the arm), and soon I did not go to the doctor [...] (P16)*

*[...] I saw that there was something wrong, and I did nothing until I went to the doctor (P5)*

The care by the medical professional is the one initially sought, as revealed in the subcategory "Seeking medical care". People report the search for a doctor with whom they have performed earlier treatment, someone they trust, to investigate these symptoms.

The search for medical experts occurs due to the thought of possible other diagnoses, in the hope that when seeking the medical professional their problems are quickly resolved, however anguish is observed in the testimonies, when they realize that the solutions or clarifications do not take place immediately:

*[...] I went to a geriatrician because I had not been to a doctor for some time, I went to checkup, to see what it was, whether it was a lack of vitamin, or something that was not well, and he had some tests*

*done and then diagnosed at the second appointment that it was Parkinson's (P16)*

*I made several inroads to doctors, I went first with my general practitioner, who looked and the first thing that came to mind: "Oh, it's Parkinson's, but at your age"... he asked me to do some tests, then he said, "Maybe it's an essential tremor." And after a few months, he referred me to a neurologist (P12)*

Many physicians, through clinical examination and/or complementary examinations, suggest such a diagnosis and refer them to neurologists for confirmation and treatment.

The sub-category "Confirming the diagnosis through a specialist physician" revealed that searching for the neurologist occurs in two ways, through referral by another doctor, who after routine examinations identifies the possible diagnosis, or suggestion of others for immediate search by the neurologist.

Confirmation of diagnosis by neurologists is as follows:

*I was treating rheumatism, but always taking medications but with no effect, then one day the doctor said: "Your walking is not from someone with rheumatism, for me it's a neurological disease." She sent me to a neurologist, in 1997, and since then I treat myself. The neurologist soon diagnosed" (P28)*

From the neurologist the confirmation of the diagnosis occurs and

can have a great impact on the life of this person and his family. The specific treatment for PD begins, and the moment arises for the individual to internalize the condition and to reveal to the family and other people of his or her life.

#### Dealing with the impact of the disease

After the search for medical services, conducting routine exams and medical specialists, we have the confirmation of the diagnosis of the disease. Through the participants' testimonies, it may be noted that receiving confirmation of PD is very marked, there are several feelings involved, and these make it difficult to reveal the condition to other people. In addition, there is the conflict in accepting the new health condition.

The first impact when receiving the diagnosis is to visualize a limitation condition associated with the disease characteristics, revealed by the sub-category "Receiving confirmation of diagnosis". Due to the common sense of what PD is, it causes the person to imagine himself in conditions of disability and limitations. Through the speeches it is possible to describe the loaded visualization of impressions on preconceived images of a future with the disease and its incapacities:

*The diagnosis is terrible, quite complicated, even being almost sure he had Parkinson's, but when one really knows it, he loses ground. (P18)*

Many people report feelings of fear regarding the characteristics of the disease and have a very great impact when they receive the diagnosis:

*...] I had the impression that I was going to be dependent, that someone would have to take care of me, I was desperate because, for those who do everything by themselves, they self-determine, then I was terrified, it was terrible for me (P16)*

*I was afraid because I did not know this disease, I saw the people tremble so much, the people who had this disease, well weakened like that. I said: Oh, my God, what now? And me? I was terrified (P2)*

On the other hand, some participants were able to overcome the initial impact of the diagnosis and visualize their new health condition with a resilient attitude.

*[...] I am very optimistic, I have already taken to the good side (P17)*

*[...] I looked at it normally, it did not look like a burden, I knew that I would have limits and that it was a progressive disease [...]. (P19)*

The subcategory “Revealing the diagnosis” describes how people, after diagnosis, deal with the revelation to other

people of their conviviality. According to the reports, taking over the disease and revealing its condition to family members and others can compete for a certain amount of empowerment.

The following are the testimonies of how the disease was revealed:

*[...] I do not just talk about the disease. I think that it is better for me, I do not go on to other illness problems (P22)*

*[...] when someone asks, I say it, I am not ashamed to say that I have the disease, there are people who hide it, who do not like to say, but I do not hide it from anyone (P23)*

*[...] I spent four months without telling my children, I did not even have the courage to tell, and there were so many things I had to say that I had this health problem, but it was very difficult (P16)*

It has also been identified that disclosure to other people means wanting to take over as someone who continues to live normally, despite illness. When dealing with the disease, the person tries to share his problem with the community and family, socializing information and seeking acceptance of the other members of his social group.

The subcategory “Living the conflict of acceptance” shows the meanings of assuming all the possibilities that disease carries. The person tries to delay this internalization as much as a

form of resistance. Acceptance of health condition varies among individuals in the same way as the acceptance period. Many take time to accept that they have the disease, others accept it a little more quietly, and others still perceive acceptance as an imposition.

We identify the conflicts that occur until the acceptance of the new health condition:

*[...] it is very difficult to accept, because we doubt it, the medication was difficult to hit, I'm still shaky, so I'm always in doubt, is it really it? The medication is not working, why? I'm in this phase (P6)*

*There are days I accept, there are days I do not accept (P10)*

Coexistence with DCNT encompasses acceptance and the social, cultural, and people's experiences. Accepting is something imposed, because, the person has no choice, since it is a chronic condition. PD conditions people to have to cope with such a situation, and acceptance influences how each person understands and experiences day to day with the disease. In the reports we can see the feeling of imposition against the condition of chronicity and acceptance:

*I'm trying to accept it, because there's no alternative, there's no other way, and I'm trying to*

*figure out what is the best way to live with this situation (P16)*

*It's hard to accept that someone has Parkinson's, and I, too, did not want to accept, I did not. I know it's not a terminal illness, but I know it's a difficult disease to deal with (P13)*

The person, when discovering the disease, goes through a process of conflicts and times when he accepts the condition, at other times he does not accept the disease.

This conflict lasts for a certain period, and over time the disease is overcome, the person realizes that although he has a disease that can be limiting to the activities, he can live with it:

*Over time, one learns to live with the disease, with the difficulties (P16)*

*[...] it was very bad, but not today, today I have already gained more morale (P5)*

The way the situation is faced makes you live better:

*To live with the disease first is to accept the condition, I think one does not need to question: why me? And those who do not accept, I usually realize that some who do not accept, suffer more (P18)*

*From the moment I learned about the disease, I did everything to be able to win, and thanks to my effort, I was successful (P27)*

Through acceptance of the disease it is possible for people to share positive attitudes and responses. People who accommodate themselves, going through a process of positive adjustment find more acceptance of the group and feel healthier.

## DISCUSSION

The meaning perceived by the different signs and symptoms is likely to be influenced by the extent to which they interfere with the particular aspects of life, some of which will be specific to each individual, especially occupational and leisure activities.<sup>7</sup> This implies being alert to the signs and symptoms and to the appropriate diagnosis to start the treatment.<sup>8</sup>

The presence of signs and symptoms resulting from a chronic disease can act as a driving force to family members to focus intensively on caring for the person in such condition<sup>9</sup>, either in the attempt to be attentive to the aggravation of perceived changes, or in the support and stimulation.

The category “Being questioned by others about something different in their behavior” shows that before the search for medical services, people had previously presented some sign and symptom that indicated some body disorder.<sup>10</sup>

Preventing the search for medical services can be compared to the survey data on the time between onset of symptoms and treatment, where the authors identified as the main causes reported for delay in seeking medical care: “finding that the symptoms did not indicate any disease” in 38.7% of the cases; “cost for moving to a health unit” by 16.1%; “difficulty in getting care” in 14.6%; “lack of available time to look for a health unit” in 12.6%; and “think they would improve spontaneously” by 11.6%.<sup>11</sup> Such data show the need to be shared with society in general guidelines on PD so that other people with the same signs and symptoms are encouraged to seek health services for research as well as health services should be prepared to make the diagnosis and treatment.

In a research with people who used a center for PD, the authors discuss the optimization of comprehensive care for people with PD and the need for careful and periodic verification of treatment.<sup>12</sup>

The impact of the diagnosis is the first moment of difficulty and that requires a positive overcoming for good conviviality with the disease. There is also a lack of information regarding the diagnosis, both by the professional and the community, thus delaying the start of treatment.<sup>10</sup> It is very difficult to receive the diagnosis because it affects the

physical, emotional, mental and social aspects of their lives and of their relatives.<sup>13</sup>

Feelings about diagnosis are important for nurses to assist people with PD and their families through counseling, support, symptom management and care planning.<sup>14</sup>

Dialogues and interactions that promote the diagnosis should be stimulated by health professionals, reinforcing the coping and empowering of people to combat the prejudices and stigmas of the disease.

In this sense, it is understood the importance of the health multiprofessional team in establishing a bond, through the effective communication between the individual with PD and his or her family caregiver.<sup>15</sup>

Some denials of the disease, a relevant aspect in the process of living with PD. Acceptance is considered an internal process in which the person recognizes himself and assumes his reality. The acceptance process is mainly influenced by the “way of looking” of people, that is, there are people who deny the disease or have more difficulty accepting than those who know and have a positive look at the situation.<sup>16</sup>

## CONCLUSION

It was possible to know how the experience with PD occurs from the initial phase, from the first signs and symptoms to the acceptance of the condition. The person may notice some change, as well as family members, friends, co-workers may notice some change. After this perception, an itinerary begins in search of medical professionals for investigation, which can be postponed, but ends up in the search for various specialties, until confirmation by the neurologist doctor.

Regarding the limitations, in this study the participants in this study were self-selected and, although representative of the general population of people with PD in Brazil, their perceptions may not reflect the general population of people with PD who experience the disease in other cultural contexts, however, the detailed understanding of these participants and the alignment with the findings of other studies add to the body of knowledge in this field.

The study provides relevant information that may influence the way of caring for people with PD. And, it has as contributions the knowledge of the experience with PD, so that nurses are aware not only of the motor characteristics of the disease, but also of the feelings and needs of each person. Nursing plays a key role in linking and assisting the person

with PD and his family through activities that promote health through healthy living.

## REFERENCES

1. Ministério da Saúde. Brasil. Plano de ações estratégicas para o enfrentamento das doenças crônicas não transmissíveis (DCNT) no Brasil: 2011-2022. Departamento de Análise de Situação de Saúde. – Brasília: Ministério da Saúde, 2011, 148 p.
2. Furtado LG, Nóbrega MML. Model of care in chronic disease: inclusion of a theory of nursing. Texto contexto - enferm. [Internet]. 2013 Dez [cited 2017 May 26]; 22(4): 1197-1204. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-07072013000400039](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072013000400039)
3. Kalia L. Parkinson's disease. The Lancet. 2015; 386 (9996): 896-912.
4. Terra MB, Rosa PC, Torrecilha LA, Costa BT, Ferraz HB, Santos SMS. Impacto da doença de Parkinson na performance do equilíbrio em diferentes demandas atencionais. Fisioter. Pesqui. [Internet]. 2016 Dec [cited 2017 May 26]; 23(4):410-415. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1809-29502016000400410&lng=pt&nrm=iso](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1809-29502016000400410&lng=pt&nrm=iso)
5. Strauss, A, Corbin J. Pesquisa qualitativa: técnicas e procedimentos para o desenvolvimento de teoria fundamentada. 2ª ed. Porto Alegre (RS): Artmed, 2008.
6. Brasil. Resolução nº 466/2012. Dispõe sobre as diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Brasília: Conselho Nacional de Saúde; 2012.
7. Reddy P, Martinez-Martin P, Brown RG, Chaudhuri KR, Lin JP, Selway R, et al. Perceptions of symptoms and expectations of advanced therapy for Parkinson's disease: *preliminary report of a Patient-Reported Outcome tool for Advanced Parkinson's disease (PRO-APD)*. *Health and Quality of Life Outcomes*. [Internet]. 2014 [cited 2016 Dec 26]; 12(11):1-10. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3906878/>
8. Ju YS, Habermann B. Nursing Research in Parkinson's Disease From 2006 to 2015 A Systematic Review. *Clinical Nursing Research*. 2017 Apr; 26(2):142-156.
9. Chen T, Thomas C, Habermann B, Berger S, Tickle-Degnen L. Through the Eyes of the Care Partner: Daily Experiences Living With a Person With Parkinson's Disease. *American Journal of Occupational Therapy*, 2016; 70(4\_Supplement\_1).
10. Sorrell J. Living with Parkinson's Disease. *J Psychosoc Nurs Ment Health Serv* [Internet]. 2017 Apr [cited 2017 May 26]; 55(4):15-18. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/28407154>
11. Maior ML, Guerra RL, Cailleaux-Cezar M, Golub JE, Conde MB. Tempo entre o início dos sintomas e o tratamento de tuberculose pulmonar em um município com elevada incidência da doença. *J. bras. pneumol.* [Internet]. 2012 [cited 2016 Dec 26]; 38(2): 202-209. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1806-37132012000200009&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1806-37132012000200009&lng=en).
12. Kessler D, Liddy C. Self-management support programs for persons with Parkinson's disease: An integrative review. *Patient Educ Couns* [Internet]. 2017 Apr [cited 2017 May 20]; S0738-3991(17): 30244-6. Available from: [http://www.pec-journal.com/article/S0738-3991\(17\)30244-6/fulltext](http://www.pec-journal.com/article/S0738-3991(17)30244-6/fulltext)
13. Soleimani M, Bastani F, Negarandeh R, Greysen R. Perceptions of people living with Parkinson's disease: a qualitative study in Iran. *Br J Community Nurs* [Internet]. 2016 Apr [cited 2017 May 26]; 21(4):188-195. Available from: <http://www.magonlinelibrary.com/doi/full/10.12968/bjcn.2016.21.4.188>
14. Galvão TLA, Oliveira KKD, Maia CAAS, Miranda FAN. Assistência à pessoa com Parkinson no âmbito da

- estratégia saúde da família. Rev Pesqui Cuid Fundam. [Internet]. Dec 2016 [cited 26 may 2017]; 8(4):5101-07 Available from:  
[http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/4448/pdf\\_1](http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/4448/pdf_1)
15. Ferreira DPC, Coriolano MGWS, Lins CCSA. Knowledge as a tool to promote care of the elderly with Parkinson's disease. Rev. enferm. UFPE on line[Internet]. 2016 Dec [cited 2017 May 26]; 10(12):4628-4636. Available from:  
<http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/viewArticle/9830>
16. Zaragoza SA, Senosiain GJM, Riverol FM, Anaut BS, Díaz SCA, Ursúa MÊS, et al. Elementos clave en el proceso de convivencia con la enfermedad de Parkinson de pacientes y familiares cuidadores. An Sis Sanit Navar. [Internet]. Apr 2014 [cited 26 may 2017]; 37(1):69-80. Available from:  
[http://scielo.isciii.es/scielo.php?script=sci\\_arttext&pid=S1137-66272014000100008&lng=es](http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1137-66272014000100008&lng=es)

RECEIVED: 07/12/18

APPROVED: 12/03/19

PUBLISHED: 07/19