


DETERMINING FACTORS IN THE SITUATIONAL TRANSITION OF FAMILY MEMBERS WHO CARE OF ELDERLY PEOPLE WITH PARKINSON'S DISEASE

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ABSTRACT

Objective: to investigate the facilitator and inhibitory factors in the transition of elderly caregivers with Parkinson's disease.

Method: a qualitative, exploratory and descriptive study, based on the family transition nursing theory developed with 20 elderly caregivers of elderly people with Parkinson's disease, enrolled in the *Associação Parkinson de Santa Catarina*, from March to August 2015. To analyze and interpret the data, we used the thematic analysis of content proposed by Bardin, with the help of the ATLAS.ti software for data organization.

Results: some factors were identified and considered as facilitators for the process of transition from the familiar to the exercise of the role of caregiver, such as: previous experiences as caregiver; spirituality and religiosity; family support network and health services. Other factors were identified as inhibiting factors for transition: emotional and physical health conditions; advanced age; personal life activities/commitments; family financial burden; and inadequate family support. It was observed that most family caregivers reported having previous experience in caring, having advanced age, and being able to care for the elderly with the disease. However, he considers his condition of emotional and physical health insufficient, resulting in overload. Lack of access to health services and family and financial support make it difficult to provide care.

Conclusion: nurses should seek strategies to direct attention to facilitating factors in the family context in order to help the family to achieve well-being and healthy transition to the role of caregiver.

DESCRIPTORS: Parkinson's disease. Elderly health. Family. Caregivers. Nursing.

HOW CITED: Nunes SFL, Alvarez AM, Costa MFBNA, Valcarenghi RV. Determining factors in the situational transition of family members who care of elderly people with Parkinson's disease. *Texto Contexto Enferm* [Internet]. 2019 [cited YEAR MONTH DAY]; 28: e20170438. Available from: <http://dx.doi.org/10.1590/1980-265X-TCE-2017-0438>

FATORES DETERMINANTES NA TRANSIÇÃO SITUACIONAL DE FAMILIARES CUIDADORES DE IDOSOS COM DOENÇA DE PARKINSON

RESUMO

Objetivo: investigar os fatores facilitadores e inibidores na transição situacional de familiares cuidadores de idosos com doença de Parkinson.

Método: estudo qualitativo, exploratório e descritivo, com base na teoria de enfermagem de transição familiar desenvolvido com 20 familiares cuidadores de idosos com doença de Parkinson, cadastrados na Associação Parkinson de Santa Catarina, entre os meses de março a agosto de 2015. Para analisar e interpretar os dados, utilizou-se a análise temática de conteúdo proposta por Bardin, com auxílio do *software* ATLAS.ti para organização dos dados.

Resultados: alguns fatores foram identificados e considerados como facilitadores para o processo de transição do familiar para o exercício do papel de cuidador, tais como: experiências anteriores como cuidador; espiritualidade e religiosidade; rede de apoio familiar e dos serviços de saúde. Outros fatores foram identificados como condicionantes inibidores para transição: condições de saúde emocional e física; idade avançada; atividades/compromissos da vida pessoal; sobrecarga financeira familiar; e suporte familiar insuficiente. Observou-se que a maioria dos cuidadores familiares refere ter tido experiência prévia em cuidar, possuir idade avançada, e ser portador de habilidades para cuidar do idoso com a doença. No entanto, considera sua condição de saúde emocional e física insuficiente, tendo como consequência a sobrecarga. A falta de acesso aos serviços de saúde e apoio familiar e financeiro dificultam a prestação do cuidado.

Conclusão: os enfermeiros devem buscar estratégias para direcionar a atenção aos fatores facilitadores no contexto familiar objetivando auxiliar os familiares a alcançarem o bem-estar e a transição saudável para o papel de cuidador.

DESCRITORES: Doença de Parkinson. Saúde do idoso. Família. Cuidadores. Enfermagem.

FACTORES DETERMINANTES EN LA TRANSICIÓN SITUACIONAL DE FAMILIARES CUIDADORES DE ANCIANOS CON ENFERMEDAD DE PARKINSON

RESUMEN

Objetivo: investigar los factores facilitadores e inhibidores en la transición situacional de familiares cuidadores de ancianos con enfermedad de Parkinson.

Método: estudio cualitativo, exploratorio y descriptivo, con base en la teoría de enfermería de transición familiar desarrollado con 20 familiares cuidadores de ancianos con enfermedad de Parkinson, registrados en la *Associação Parkinson de Santa Catarina*, entre los meses de marzo a agosto de 2015. Para analizar e interpretar los datos, se utilizó el análisis temático de contenido propuesto por Bardin, con ayuda del *software* ATLAS.ti para la organización de los datos.

Resultados: algunos factores fueron identificados y considerados como facilitadores para el proceso de transición del familiar para el ejercicio del papel de cuidador, como: experiencias anteriores como cuidador; espiritualidad y religiosidad; red de apoyo familiar y de servicios de salud. Otros factores fueron identificados como condicionantes inhibidores para la transición: condiciones de salud emocional y física; edad avanzada; actividades/compromisos de la vida personal; sobrecarga financiera familiar; y apoyo familiar insuficiente. Se observó que la mayoría de los cuidadores familiares dicen haber tenido experiencia previa en cuidar, poseer edad avanzada, y ser portador de habilidades para cuidar del anciano con la enfermedad. Sin embargo, considera su condición de salud emocional y física insuficiente, teniendo como consecuencia la sobrecarga. La falta de acceso a los servicios de salud y apoyo familiar y financiero dificultan la prestación del cuidado.

Conclusión: los enfermeros deben buscar estrategias para dirigir la atención a los factores facilitadores en el contexto familiar, con el objetivo de ayudar a los familiares a alcanzar el bienestar y la transición sana para el papel de cuidador.

DESCRIPTORES: Enfermedad de Parkinson. Salud del anciano. Familia. Cuidadores. Enfermería.

INTRODUCTION

Parkinson's disease (PD) is the most common motor neurodegenerative disease and the second disorder most prevalent in the elderly.¹⁻² The clinic of the PD represents an integration of four main components: motor symptoms; cognitive alterations; behavioral and neuropsychiatric disorders; and the symptoms related to dysfunctions in the nervous system autonomous.² The progression of these clinical alterations, associated with the irreversibility of the disease, has a considerable impact on the life not only of those who have the disease, but also of their relatives, who need to overcome the functional disabilities and dependencies that arise with the progression of the disease.³

This impact on the life of the family, especially the caregiver, is associated with the demand for care and occurs because, as the PD evolves, physical limitations increase, causing successive lack of autonomy and the need for the person to be helped in their care. activities of daily living and participation in social life.⁴⁻⁵ The care given to the dependent elderly person becomes increasingly complex as the family perceives itself submerged in feelings that are difficult to manage, de-structuring the emotional systems and causing deprivations and modifications in the lifestyle to understand the new needs arising from overload and of the time spent caring for his relative affected by the disease.⁶

The relative is a reference to affection and attention to the person with dependency.⁷ Thus, the caregiver family needs to adapt to the demands generated after the diagnosis, since becoming a caregiver is not something planned or chosen⁸ and depends on aspects such as: characteristics of the evolution of the disease; existence and functioning of the family network; the abilities of the family member chosen for the role of caring and their position within the family.⁹

In addition, the family member, when assuming the role of caregiver, needs time and effort to adequately manage the changes caused by the disease and confrontations with various daily challenges, in order to live a healthy transition to this new role.^{7,10}

As a way to help support family caregivers, nurses, as professionals of the health team, need to ensure the effective maintenance of the partnership, since these are essential to ensure the continuation of essential care for the person with a chronic illness.¹⁰ Therefore, they should understand family interactions with the disease and identify the functioning of the family network, distinguishing the needs of the family members themselves, in order to guide the orientations and strategies that will alleviate the discomforts caused by living with the changes generated by the disease.⁹ This is because, often, these family members may not or may not know they need help and guidance for self-care.¹¹

Since PD refers to a disease that causes an unexpected crisis in the family, generating changes in the routine of the members, especially in the life of the family member responsible for the care role, it is necessary to evaluate the effect of the supplementation of roles in these clients who have experienced transitions from the caring experience.

Drawing on the supplementation of roles in a transitional situation through the conceptual framework for nursing practice in Transition Theory,¹² the focus of our attention will be the situational transition. This is the most directly involved in the experience of family caregivers of elderly people with PD, since the limitation and/or dependency experienced by the person with PD causes a process of adaptation, changes of roles and changes in the family context. The theory defines a situational transition as one that includes the events that lead to changes or redefinition of the person's roles, that is, the transition that determines the change of roles.¹²

Considering the changes that have occurred in the family life towards the uniformity of the role of caregiver, it is indispensable to identify the main needs demonstrated by this, especially in the performance of activities related to care, so that a correct diagnosis of the family can be performed, facilitating the entire transition process.¹⁰

Therefore, the present study aimed at investigating the facilitating and inhibitory determinants in the of elderly caregivers with Parkinson's disease.

METHOD

Descriptive and exploratory study of a qualitative approach, using the theory of situational transitions¹² to understand the family caregivers of elderly people with PD.

The study site was the Parkinson's Association of Santa Catarina (*Associação de Parkinson de Santa Catarina - APASC*), a private non-profit civil entity located in the city of Florianópolis, covering the State of Santa Catarina. It aims to bring together people with PD and assure them of support and assistance, as well as develop and support actions, collect and disseminate information on therapeutic research to improve the quality of life of people with the disease and that of their relatives and caregivers.¹³

At the time of data collection, there were approximately 100 people with PD who were enrolled and actively participated in APASC. Participants in the study were 20 family caregivers of people with PD who were enrolled in APASC who, through an intentional sample, met the following inclusion criteria: being the primary caregiver responsible for partial or full day care for a minimum period of six months in the home context; reside in Greater Florianópolis; and be 18 years of age or older.

Data collection took place between March and August 2015, through a semi-structured interview, previously scheduled, performed at the participants' home and recorded after consent. The interview script was composed of guiding questions to explore the changes occurred in family relationships after the diagnosis of PD; and factors that have caused them, in order to better understand how the process of transition to the caregiver role occurs. For example: Tell me of the feelings that came to you when you learned about the diagnosis of PD in your relative; were you ever aware that you were in the process of becoming a carer? Tell me about it; among other issues. Closing of the collection obeyed the criterion of data saturation.

The analysis and interpretation of the textual data occurred concomitantly to the collection, using the thematic content analysis,¹⁴ associated with the Archivfuer Technik software, *Lebenswelt und Alltagssprachetext interpretation - Qualitative Research and Solutionsversion 7.5.2 (ATLAS.ti)*, a tool that helps the researcher to organize, record and follow up the records, collaborating for the methodological rigor of the study.¹⁵

The terms commonly used in the thematic analysis of content are indicators and categories,¹⁴ which in this study will be treated as codes and families, respectively, according to ATLAS.ti.

And so, they will allow the recognition of two families, the first one being called facilitative resources in the exercise of the role of caregiver, composed of three subcategories, and the second one designated as Inhibitory resource to perform the role of caregiver, composed of five subcategories.

To ensure confidentiality and preserve identity, participants were identified from the letter F, meaning familiar, and by the increasing number of the respective interview conducted (Example: F1, F2, F3, ...).

In the study, the national precepts indicated for research with human beings were assured, in accordance with Resolution No. 466/12 of the National Health Council, of the Ministry of Health,¹⁶ and the Free and Informed Consent Form is delivered in two copies.

RESULTS

Among the family members interviewed, 16 family caregivers were female, 11 had a bond to be the spouse of the elderly with PD, 11 reported being retired; and the age was 37 to 85 years. The level of schooling of the participants varied between a fundamental study (eight) and a higher level

(eight). As for religious affiliation, 15 participants claimed to be Catholics, four Spiritists (follow the doctrine of French Allan Kardec), two evangelicals, and only one reported not believing in God or any other superior idea. In addition, 14 participants reported daily care of the elderly.

This information related to the data of the family members of the study contributed to the analysis and discussion of the data, as well as to understanding the phenomenon of the determinants of the situational transition of relatives of elderly with PD; still, they are based on the theoretical framework of transitions¹² by stating that beliefs and cultural attitudes, socio-economic status and preparation and knowledge of those involved in the process of becoming caregiver may facilitate or inhibit the transition healthily. The following is a description of the main families along with subcategories.

Facilitating factors in the performance of the caregiver role

The factors facilitating the transition process to the role of caregiver were: managing care through previous experiences as a caregiver; spirituality and religiosity in facing the transition process; and the formal network and access to health services.

Previous experiences as caregivers provide skills that can facilitate the process in performing the new role, especially in the progression and evolution of the disease.

[...] I tried to take care of a brother of mine, for a while, who lost the movements of the belly button down. He's in the chair, sitting, and I've seen the scene of everyone chatting, everyone saying he was okay, when I turn around, I see bedsores that fit a whole orange inside. Then they brought him to Florianópolis, and I stayed with him for two months. So a person to take care of sick is not easy, must understand, see the person! When I went to take care of my wife, who had a worsening and stayed in the wheelchair, I remembered my brother, because I did not want her to have those bedsores (F1).

One aspect of this study is that some relatives had experiences as a health professional, reporting that such training provided the necessary knowledge to care for the elderly with PD.

[...] I worked for a few years as a nursing technician, so it helps. Helps a lot. (F13).

The reports show that spirituality and religiosity collaborate to encourage the family, motivating feelings of hope or acceptance of the condition established by the disease. It has been observed that believing in something helps to cope with the disease and renews the hopeful expectation in hope of the condition, believing that the suffering caused by the disease is part of life and in the positive perspective of living with the disease.

[...] I think having a religion, believing in a greater force helps a lot in how to see the changes. Sometimes I'm a little distressed, I'm a little nervous, then I say: "Jesus, I need you." It looks like it's here at home, there's a Christ up there and there's a Divine Holy Spirit. So I'm with Him always by my side, so you have nothing to complain about. Thank God (F6).

In addition to the personal attributes of the caregiver, it is important to identify the resources available in the community, as well as the support of family, neighbors and friends. Having a formal social support network with health services that are effective in assisting the elderly with PD reflects on the satisfaction of family caregivers.

[...] The good thing about this place is that it has this health center, and that's very good. Because we used to live in another neighborhood that had not been put in the neighborhood, but here is a marvel [...] even though she has a health plan and cannot walk, the professionals at the clinic are always coming. The geriatrician comes, the doctor comes. Wow, very good, very good (F8).

The analysis of the testimonies reveals that having an organized association and group to share the same experience, carrying out specific activities and interventions in the maintenance and rehabilitation of the disease is essential in improving the self-esteem of the elderly person with PD and, consequently, in the satisfaction of the family caregiver when perceiving improvement of their relative.

[...] everything changed when they gave the referral to that Parkinson's association there, did not they? Because to my daughter there is a marvel, it's a wonderful thing. And I realize that since she started to go, she's happier (F3).

[...] I think she went into the group, as she calls it... the help group [...], did very well because, there, she met people who had the same disease (F5).

Other evidence is the participation of health professionals in the group meetings, promoting the confidence and safety of family caregivers.

[...] the teachers, the nurses, the doctors, the staff are always present, so that's very well done there (F4).

Inhibitor factors to perform the role of caregiver

Some personal factors have been identified that hamper the performance and consequent adaptation of the relative to play the role of caregiver, among them: emotional and physical health conditions; advanced age; personal life activities/commitments; family financial burden; and inadequate family support.

As the disease progresses, the elderly with PD may need more assistance, requiring more of the familiar caregiver.

[...] there are times when it starts with complaints of pain, it's complicated. Sometimes we want to have lunch with her, do some company, but we cannot. We must get the plate and leave, because it's a lot of complaint. But it was not like this before, because now we have a lot of time in this situation, taking care of it. Then we get the nervous system well shaken (F14).

Psychological counseling is something that family members feel need during the transition process, to support and understand the repercussions of the disease in the family context. Another factor that may compromise family involvement in care activities is their physical condition.

[...] I miss a psychological support, but I say that the psychological situation is very serious, because when you have in the family someone with a problem, you also end up having some problem with the person (F5).

The results of the study identified which is increasingly common elderly caring for another elderly in the home context. Of the 20 participants, 14 were over 60 years of age, which creates personal concern about the present and future execution of care.

[...] I cannot do everything either because I'm 85 (F3).

The advanced age of the family caregiver may also give rise to a sense of apprehension about the future, both in terms of the ability to provide care and possible institutionalization.

[...] I have already thought at the time that we, or even myself, also be weakened: we will have to go home to rest. I already thought that. I already told her that. Because, there, you have several nurses, you have a cook, if you need a doctor, you call, the doctor already serves several people depending on the clinic, and you form a group there (F1).

Often, personal routine compromises the transition process of the family member, since the obligation to reconcile daily commitments with activities related to the monitoring of the elderly with PD becomes a challenge. Work life affects the participation of the family member in the accompanying care actions.

[...] I try to follow her to the fullest, but I also have a lot of activity, right? [...] I have a very busy life, mainly because of the service hours, and I cannot always go out to accompany her (F10).

The high costs associated with chronic illness can lead to family financial stress. Lack of access to medications, supplements, specific tests and consultations generate financial expenses that cause changes in the family budget and can be a difficult factor for the transition process of family caregivers.

[...] it's all right yet. But even so, we must hold on with spending a little more to be able to handle paying everything, because we know that the burden of a house is very [...] water, electricity and telephone, and more and more (F3).

Most of the family members of this study take care of the elderly who are partial or totally dependent to perform basic activities of daily living, which contributes to the overload of the familiar caregiver. It was also observed the existence of lack of support from other relatives for the care of the elderly with PD.

[...] who could help me was my husband, even because it is her son [elderly with PD], but he is very nervous and I calmer, because I am more accustomed, but he is very apprehensive, well stressed. When she does not eat, he is already nervous, thoughtful; when she does not take the medicine, he wants to fight, she does not understand [...] it goes there and begins to speak altered with it, but no use, no use (F11).

DISCUSSION

The transition process can be influenced by facilitating or inhibiting factors, referring to the person and the social and community context in which it is inserted.¹⁷ The identification of these factors will help the nurse to understand the conditions that can help the individual to walk towards well-being and those that will put him at risk of experiencing a difficult transition.^{12,17}

An integrative literature review aimed at determining the main needs expressed by the family caregiver in the care of the dependent person, in the light of the Theory of Transitions, found that, for family caregivers, the mastery of knowledge is the most important need, since the satisfaction of this allows them the best perception of the whole situation experienced, as well as the relevance of their new role.¹⁰

Previous preparation to play a new role promotes the transition process and having experiences with earlier transitions makes it possible to develop conditions to face an unfavorable event, to provide maturity, stability, and personal growth.¹⁸

Previous experiences as a volunteer caregiver make it easier to adapt to the new role; however, nurses must analyze and clarify that the transition process is unique and treated as a new condition, requiring definition or redefinition of the roles in which the individual is involved, even if the characters have similar characteristics.¹⁹

Other aspects relevant to the caregiver refer to cultural beliefs and attitudes attributed to events, considered determinants in the transition process, which can have a facilitating or difficult role in the consolidation of a healthy transition.¹²

In a cross-sectional study carried out with 122 elderly caregivers of elderly people with dementia, in order to analyze the combined effect of spirituality and self-efficacy in the stress process when

caring for a family member, he indicated that spirituality and self-reliance have been associated with higher levels well-being of caregivers; and that the greater the combination of the two factors, the lower the risk of depression and the overload of family caregivers.²⁰

In a study of stress coping theory, we examined the effects of spirituality and religion on depression in 209 family caregivers responsible for caring for people with neurodegenerative disease. It was observed that belief and religiosity were configured as a strategy to minimize negative feelings²¹ The results of some studies imply that religious involvement can play an important role as a strategy for coping with stress and isolation of the caregiver, with direct effects on family caregiver depression.²¹⁻²²

Nursing professionals should consider spiritual well-being in the satisfaction and behaviors adopted in life, when evaluating families that experience a chronic situation. This is because belief in a higher being and prayer are evolutionary characteristics of the human being that help him to survive, act as a coercive force in positive personal behavior and as a member of society, facilitating the coping of unexpected circumstances that illness can bring to the family.²³

The existence of a formal and active social support network is necessary and can cooperate in solving the problems experienced by family caregivers.^{6,24}

In the international context,²⁵⁻²⁸ the difficulty in accessing services was a barrier pointed out by the family member to provide care for people with PD, especially in the case of limited availability and lack of insurance coverage for services. The need to improve access to services for patients and, in this way, increase efforts to promote the well-being of the caregiver is emphasized.²⁵

The study²⁵ has also identified that collaboration of specialized clinics and community support groups with ongoing research on caregiver needs can be strategies to develop individualized caregiver offerings for caregivers and to help them overcome barriers related to caregiving activities.

The efficient and qualified performance of the nurses and other professionals of the health teams make it possible to modify the epidemiological, emotional and social profile of the community, proactively collaborating for the implementation of the health service.²⁴

In research aimed at understanding the formal and informal social support used by family caregivers of the elderly, it was verified that the family, through internal agreements, establishes a dynamic of relaying the care of daily activities and manages to transform the stressful situation resulting from care.²⁴

Work done by researchers from Oregon/United States University of Health and Health²⁶ compared young spouses of the elderly who present distinct stages of disease development and revealed several important differences. Of note is the finding that young spouses were more likely to be working, caring for children and therefore reported more pressure for lack of personal resources than older spouses.²⁶

The speeches referred to the concern of the spouse, in old age, not being able to take care of itself and, consequently, not able to perform care. Some authors^{7,11} consider it important that nurses use strategies such as the application of problem-solving therapy, which customizes family care and streamlines mediation with the social support network, helping caregivers to seek help from other family members.

In the testimonies, it is observed that the years of care execution can lead to the emotional stress of the family member, making difficult the passage through the transition. Similar results were found in a study on the determinants of the burden and quality of life in Brazilian caregivers of patients with PD. It has been identified that mood disorders, burden and changes in the sleep of caregivers of people with PD are associated with the behavioral symptoms present in the person with PD and the time of care.²⁷

National study with caregivers of elderly dependents revealed that one of the main needs of this group is the psychological help and support networks. Stress coping strategies can help you cope adequately with the demands.²²

Research conducted in the UK with members of the Parkinson's Association showed that, to reduce the activity impact to care for and tension of the caregiver should be taken to health of the patient with PD and the family caregiver.²⁸

Due to the incorporation of a new role, the health professional should evaluate how the family members adapt to their functions in the new situation, and not focus this evaluation on the family caregiver. This assessment should include the evolution of family roles, the impact on family functioning and the family's belief that their needs need to be modified,¹¹ so that there is no overloading of the familiar caregiver and thus the transition process evolves in a healthy way.

Similar reports were found in research with caregivers of people with Parkinson's, in which participants also reported having needs for different services, especially neurology, physiotherapy and pharmacy.²⁵

At the international level, the financial burden with treatment is also present, making treatment a challenge. The costs of some antiparkinsonian medicines are considered the main causes of financial burden with the disease, despite insurance coverage with the prescribed drugs.²⁹

The meanings brought into the accounts warn that not all members have skills to care for the elderly with PD, overloading the activity to only one relative. Similar data were also found in a reflexive essay in the national context about the family as caregiver, identifying that although there are family rearrangements for care in the chronic situation, it is common to the responsibility of caring for a single person, who does not rely on the help of others to perform the tasks.³⁰

Nursing, because it has ample space to work with families, has the responsibility of evaluating the family configuration and checking the limits of its members, guiding them, enabling them to care and supporting families in the arrangement of the home environment and in family relationships, so that there is adequate rotation and distribution by abilities regarding the attributions of care.²⁴

The integration between the family system, the social network and nursing care is established as an important strategy to deal with the different events imposed during the experience with a chronic illness.²⁴ In this way, looking at the conditions provides a response to health professionals about the use of personal and existing resources in the community, in order to help family caregivers develop self-management skills for the care of their relative with PD.

It is important to emphasize that, because it is a study carried out in a local association, specific for people with Parkinson's disease, with culture and regional behaviors, this study may not portray the reality of other places that do not have a structured service network and civil society organizations. Thus, new studies on conditioners are essential in this thematic area, in order to clarify possible gaps in care for the family member who plays the role of caregiver for the elderly with neurodegenerative diseases.

Although this study focuses on relatives of elderly people with PD, it provides elements by understanding participants' expectations and experiences, to reflect on how nurses can develop strategies which may be useful for family caregivers of people with other chronic neurodegenerative diseases in the home context. Thus, the conditioning factors addressed in this research can help nurses to motivate the family caregiver in transition towards well-being and to minimize the risks of complex experience of the process.

CONCLUSION

The results of the study make it possible to conclude that using a specific theoretical framework can support the conception of nurses and the family member in the identification of stressful events and

the perception of how internal and external personal supports can provide benefits or disadvantages in the process of transition from family to the role of caregiver. Empowering this conception entails nursing interventions focused on helping to reorganize and adapt to the new situation.

The present study also points to the importance of identifying the facilitating and hindering factors that are present in the life of the family caregiver and that can lead them towards well-being, towards healthy transition, or the risk of experiencing a difficult transition.

In this sense, not only the nurses, but all health professionals who accompany relatives of elderly people with PD should focus their attention on the constraints present in the family context. This practice of evaluating the family context will promote the elaboration of interventions aimed at enhancing the facilitating conditions, so that they stand out from the existing inhibiting factors, in order to help the family to achieve a healthy transition.

REFERENCES

1. Gazewood JD, Richards DR, Clebak K. Parkinson disease: an update. *Am Fam Physician*. [Internet]. 2013 Feb 15 [cited 2017 May 30]; 87(4):267-73. Available from: <http://www.aafp.org/afp/2013/0215/p267.pdf>
2. Beitz JM. Parkinson's disease: a review. *Front Biosci (Schol Ed)*. [Internet]. 2014 [cited 2017 May 30]; 1(6):65-74. Available from: <https://www.bioscience.org/2014/v6s/af/S415/fulltext.htm>
3. Navarro-Peternella FM, Marcon SS. Quality of life of a person with Parkinson's disease and the relationship between the time of evolution and the severity of the disease. *Rev Latino-Am Enfermagem* [Internet]. 2012 [cited 2017 May 30]; 20(2):384-91. Available from: <http://dx.doi.org/10.1590/S0104-11692012000200023>
4. Simpson J, McMillan H, Leroi I, Murray CD. Experiences of apathy in people with Parkinson's disease: a qualitative exploration. *Disabil Rehabil* [Internet]. 2015 [cited 2017 May 30]; 37(7):611-9. Available from: <http://dx.doi.org/10.3109/09638288.2014.939771>
5. Faller JW, Silva Barreto M, Ganassin GS, Marcon SS. Sobrecarga e mudanças no cotidiano de cuidadores familiares de paciente com doença crônica. *Cienc Cuid Saude*. [Internet]. 2012 [cited 2017 May 30]; 11(1):181-9. Available from: <https://dx.doi.org/10.4025/ciencucuidsaude.v11i1.18876>
6. Anjos KF, Boery RNSO, Pereira R, Pedreira LC, Vilela ABA, Santos VC, Rosa DOS. Associação entre apoio social e qualidade de vida de cuidadores familiares de idosos dependentes. *Ciênc Saúde Coletiva* [Internet]. 2015 [cited 2017 Oct 10]; 20(5):1321-30. Available from: <http://dx.doi.org/10.1590/1413-81232015205.14192014>
7. Ferre-Grau C, Casado MS, Cid-Buera D, Lleixà-Fortuño M, Monteso-Curto P, Berenguer-Poblet M. Caring for family caregivers: An analysis of a family-centered intervention. *Rev Esc Enferm USP* [Internet]. 2014 [cited 2017 May 30]; 48(spe):87-94. Available from: <http://dx.doi.org/10.1590/S0080-623420140000600013>
8. Vidigal FC, Ferrari RFR, Rodrigues DMMR, Marcon SS, Baldissera VDA, Carreira L. Satisfaction in caring for older adults with Alzheimer's: perceptions of the family caregivers. *Cogitare Enferm* [Internet]. 2014 [cited 2017 May 30]; 19(4):268-75. Available from: <http://revistas.ufpr.br/cogitare/article/download/36739/23950>
9. Manoel MF, Teston EF, Waidman MAP, Decesaro MN, Marcon SS. As relações familiares e o nível de sobrecarga do cuidador familiar. *Esc Anna Nery* [Internet]. 2013 [cited 2017 May 30]; 17(2):346-53. Available from: <https://dx.doi.org/10.1590/S1414-81452013000200020>
10. Melo RMC, Rua MS, Santos CSVB. Necessidades do cuidador familiar no cuidado à pessoa dependente: uma revisão integrativa da literatura. *Rev Enf Ref* [Internet]. 2014 [cited 2017 May 30]; 3(2):143-51. Available from: <https://dx.doi.org/10.12707/RIV14003>

11. Diaz LJR, Cruz DALM, Silva RCG. Content validation of nursing outcomes in relation to family caregivers: content validation by Brazilian and Colombian experts. *Texto Contexto Enferm* [Internet]. 2017[cited 2017 Oct 11]; 26(2):e4820015. Available from: <https://dx.doi.org/10.1590/0104-07072017004820015>
12. Meleis AI, Sawyer LM, Im EO, Hilfinger Messias DK, Schumacher K. Experiencing transitions: an emerging middle-range theory. *ANS Adv Nurs Sci* [Internet]. 2000 [cited 2017 May 30]; 23(1):12-28. Available from: <http://dx.doi.org/10.1097/00012272-200009000-00006>
13. Associação Parkinson Santa Catarina - APASC. Estatuto da Associação Parkinson Santa Catarina. Outubro de 2007 [cited 2017 May 30]. Available from: <http://www.parkinson-sc.com.br/index.php?idx=2&fn=ZXN0YXR1dG8ucGhw>
14. Bardin L. Análise de conteúdo. São Paulo, (SP): Edições 70; 2011.
15. Yin RK. Pesquisa qualitativa do início ao fim. Porto Alegre (RS): Penso; 2016.
16. Ministério da Saúde (BR), Conselho Nacional de Saúde, Comissão Nacional de Ética em Pesquisa. Resolução n 466 de 12 de dezembro de 2012: diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Brasília (DF): MS; 2012. [cited 2017 Mar 06]. Available from: <http://conselho.saude.gov.br/resolucoes/2012/reso466.pdf>
17. Schumacher KL, Meleis AI. Transitions: A central concept in nursing. *Image J Nurs Sch* [Internet]. 1994 [cited 2015 Apr 20]; 26(2):119-27. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/8063317>
18. Chick N, Meleis AI. Transitions: A nursing concern. In: Meleis AI. *Transitions Theory: Middle range and situation-specific theories in research and nursing practice*. New York: Springer Publishing Company; 2010. p.24-37.
19. Meleis AI. *Theoretical nursing: development and progress*. 5ª ed. Philadelphia (US): Wolters Kluwer/ Lippincott Williams & Wilkins; 2012.
20. Lopez J, Romero-Moreno R, Marquez-González M, Losada A. Spirituality and self-efficacy in dementia family caregiving: trust in God and in yourself. *Int Psychogeriatr* [Internet]. 2012 Dec [cited 2017 Mar 06]; 24(12):1943-52. Available from: <http://dx.doi.org/10.1017/S1041610212001287>
21. Sun F, Hodge DR. Latino Alzheimer's disease caregivers and depression: using the stress coping model to examine the effects of spirituality and religion. *J Appl Gerontol* [Internet]. 2014 [cited 2017 Mar 06]; 33(3):291-315. Available from: <http://dx.doi.org/10.1177/0733464812444462>
22. Pinto FNFR, Barham EJ. Habilidades sociais e estratégias de enfrentamento de estresse: relação com indicadores de bem-estar psicológico em cuidadores de idosos de alta dependência. *Rev Bras Geriatr Gerontol* [Internet]. 2014 [cited 2017 Mar 06]; 17(3):525-539. Available from: <https://dx.doi.org/10.1590/1809-9823.2014.13043>
23. Rivas Castro A, Romero Cárdenas Á, Vásquez Munive M, Canova Barrios C. Bienestar espiritual de adultos mayores con enfermedades crónicas de la ciudad de Santa Marta, Colombia. *Cult Cuid Enferm* [Internet]. 2013 [cited 2017 Mar 06]; 10(1):17-26. Available from: <https://doi.org/10.18041/1794-5232/cultrua.2013v10n1.2097>
24. Theed R, Eccles F, Simpson J. Experiences of caring for a family member with Parkinson's disease: a meta-synthesis. *Aging Ment Health* [Internet]. 2017 [cited 2017 Oct 09]; 21(10):1007-16. Available from: <http://dx.doi.org/10.1080/13607863.2016.1247414>
25. Lageman SK, Mickens MN, Cash TV. Caregiver-identified needs and barriers to care in Parkinson's disease. *Geriatr Nurs*. [Internet]. 2015 [cited 2017 Mar 06]; 36(3):197-201. Available from: <http://dx.doi.org/10.1016/j.gerinurse.2015.01.002>

26. Abendroth M. Development and initial validation of a Parkinson's disease caregiver strain risk screen. *J Nurs Meas* [Internet]. 2015[cited 2017 Mar 06]; 23(1):4. Available from <https://doi.org/10.1891/1061-3749.23.1.4>
27. Carod-Artal FJ, Mesquita HM, Ziolkowski S, Martinez-Martin P. Burden and health-related quality of life among caregivers of Brazilian Parkinson's disease patients. *Parkinsonism Relat Disord* [Internet]. 2013 [cited 2017 Mar 06]; 19(11):943-8. Available from: <http://dx.doi.org/10.1016/j.parkreldis.2013.06.005>
28. Drutyte G, Forjaz MJ, Rodriguez-Blazquez C, Martinez-Martin P, Breen KC. What impacts on the stress symptoms of Parkinson's carers? Results from the Parkinson's UK Members' Survey. *Disabil Rehabil* [Internet]. 2014[cited 2017 Mar 06]; 36(3):199-204. Available from: <http://dx.doi.org/10.3109/09638288.2013.782363>
29. Shin JY, Habermann B, Pretzer-Aboff I. Challenges and strategies of medication adherence in Parkinson's disease: A qualitative study. *Geriatr Nurs* [Internet]. 2015 [cited 2017 Mar 06]; 36(3):192-6. Available from: <http://dx.doi.org/10.1016/j.gerinurse.2015.01.003>
30. Bellato R, Araújo LFS, Dolina JV, Musquim CA, Corrêa GHLST. The family experience of care in chronic situation. *Rev Esc Enferm USP* [Internet]. 2016 [cited 2017 Oct 11]; 50(spe):81-8. Available from: <http://dx.doi.org/10.1590/S0080-623420160000300012>

NOTES

ORIGIN OF THE ARTICLE

Article extracted from the dissertation - The transition from the relative of elderly people with Parkinson's disease to the role of caregiver, presented to the *Programa de Pós-Graduação em Enfermagem, Universidade Federal de Santa Catarina*, in 2015.

CONTRIBUTION OF AUTHORITY

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ETHICS COMMITTEE IN RESEARCH

Approved by the Research Ethics Committee of the State Secretariat of Health of Santa Catarina under favorable opinion No.1,002,947/2015, Certificate of Presentation for Ethical Appreciation (CAAE): 42370314.7.0000.0115.

CONFLICT OF INTEREST

There is no conflict of interest.

HISTORICAL

Received: June 12, 2017.

Approved: November 08, 2017.

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