

**DIFFICULTIES IN THE CARE TO USERS WITH CHRONIC DISEASE: FAMILY
CAREGIVERS' REPORTS**

DIFICULDADES NO CUIDADO À USUÁRIOS QUE CONVIVEM COM PROCESSO CRÔNICO DE SAÚDE:
RELATO DOS CUIDADORES FAMILIARES

DIFICULTADES EN CUIDAR A LOS USUARIOS QUE CONVIVEN CON PROCESO CRÓNICO DE SALUD:
RELATO DE CUIDADORES FAMILIARES

Ana Clara Martins Santos Maia¹
Bárbara Vieira Oliveira e Silva²
Lívia Cozer Montenegro³
Adriano Marçal Pimenta⁴
Marcus Luciano de Oliveira Tavares⁵

ABSTRACT

Objective: To describe the difficulties experienced by the family caregiver in the process of caring for people who live with a chronic disease. **Methods:** Descriptive qualitative study carried out in a basic health unit in the city of Belo Horizonte. Inclusion criteria were being an informal family caregiver of persons older than 18 years classified as dependent according to the Barthel Index. Twenty-five interviews, intermediated by the community health workers of the basic health unit, were conducted with the caregivers, who were. **Results:** After analyzing the data collected, we identified that the difficulties of family caregivers are related to being able to reconcile their own routine activities with the needs of the dependent person and the overload generated by the dependence process, which is enhanced by the lack of other people to take turns in providing care. **Conclusion:** In order to provide care, family caregivers need information, psychological and financial assistance. In this context, the health system is flawed since it excludes caregivers' comprehensive care from public health policies. Nursing has a crucial role in this reality, since it has the necessary tools to bring the family caregiver closer to the health services, thus remedying the difficulties faced by them.

Descriptors: Nursing; Family Nursing; Chronic Disease; Primary Health Care; Caregivers; Home nursing.

¹Scholarship of Scientific Initiation. Nursing Academic by the School of Nursing of the Federal University of Minas Gerais (UFMG).E-mail: anac.maiams@gmail.com

²Nursing Academic by the School of Nursing of UFMG. E-mail: barbara.silva001@gmail.com

³Nurse. PhD in Nursing. Adjunct Professor, Department of Maternal and Child Nursing and Public Health, School of Nursing, UFMG.E-mail: liviacozermontenegro@gmail.com

⁴Nurse. PhD in Nursing. Associate Professor at the School of Nursing of UFMG. E-mail: adrianompimenta@gmail.com

⁵Nurse. Master in Nursing. Professor of the Nursing Department of Faculdade Pitágoras. E-mail: tavares_mlo@yahoo.com.br

Corresponding author: Lívia Cozer Montenegro. Address: Universidade Federal de Minas Gerais. Campus Saúde. Avenida Alfredo Balena, 190, Bairro Santa Efigênia. Cep 30130.100, Belo Horizonte, MG, Brasil.

RESUMO

Objetivo: Descrever as dificuldades vivenciadas pelo cuidador familiar no processo de cuidado à pessoas que convivem com um processo crônico de saúde. **Métodos:** Estudo descritivo, qualitativo, realizado em uma Unidade Básica de Saúde, na cidade de Belo Horizonte. Os critérios de inclusão no estudo foram: ser cuidador familiar informal de pessoas maiores de 18 anos, classificadas como dependentes segundo o Índice de Barthel. Foram realizadas 25 entrevistas com os cuidadores, intermediadas pelos Agentes de Saúde da Unidade Básica de Saúde. **Resultados:** Após análise dos dados coletados, foi identificado que as dificuldades dos cuidadores familiares estão relacionadas à: conseguir conciliar suas próprias atividades rotineiras com as necessidades do dependente e, a sobrecarga gerada pelo processo de dependência, que é aumentada pela falta de outras pessoas para revezar o cuidado. **Conclusão:** Para prestar o cuidado, os cuidadores familiares necessitam de informação, assistência psicológica e financeira. Neste âmbito, o sistema de saúde é falho, excluindo a saúde integral dos cuidadores das políticas públicas de saúde. A enfermagem tem papel fundamental nessa realidade, uma vez que possui os instrumentos necessários para aproximar o cuidador familiar dos serviços de saúde diminuindo, assim, as dificuldades enfrentadas pelo mesmo. **Descritores:** Enfermagem; Enfermagem Familiar; Doença Crônica; Atenção Primária à Saúde; Cuidadores; Assistência domiciliar.

RESUMEN

Objetivo: Describir las dificultades vivenciadas por el cuidador familiar en el proceso de cuidado de personas que conviven con un proceso crónico de salud. **Métodos:** Estudio descriptivo, cualitativo, realizado en una Unidad Básica de Salud, en la ciudad de Belo Horizonte. Los criterios de inclusión en el estudio fueron: ser cuidador familiar informal de personas mayores de 18 años, clasificadas como dependientes según el Índice de Barthel. Fueron llevadas a cabo 25 entrevistas con los cuidadores, intermediadas por los Agentes de Salud de la Unidad Básica de Salud. **Resultados:** Después del análisis de los datos recogidos, fue identificado que las dificultades de los cuidadores familiares están relacionadas a: conseguir conciliar sus propias actividades rutineras con las necesidades del dependiente y, la sobrecarga generada por el proceso de dependencia, que es aumentada por la falta de otras personas para revezar el cuidado. **Conclusión:** Para realizar el cuidado, los cuidadores familiares necesitan de información, asistencia psicológica y financiera. En este ámbito, el sistema de salud es fallo, excluyendo la salud integral de los cuidadores de las políticas públicas de salud. La enfermería tiene rol fundamental en esa realidad, una vez que posee los instrumentos necesarios para aproximar el cuidador familiar de los servicios de salud, sanando, así, las dificultades afrontadas por el mismo. **Descriptor:** Enfermería; Enfermería de la Familia; Enfermedad Crónica; Atención Primaria de Salud; Cuidadores; Atención Domiciliar de Salud.

INTRODUCTION

Chronic diseases are currently characterized by pathologies that are slow to develop, last for long periods and have long-term effects that are difficult to predict. At present, the pathologies that have repercussions on chronic diseases

are the main cause of mortality in Brazil⁽¹⁾.

As a consequence, there has been increase in the number of individuals with physical weakness and sequelae of incapacitating injuries caused by chronic diseases, such as blindness, amputations and paralysis, which, when combined, trigger multi-pathological users⁽²⁾.

The expressive number of individuals who present restrictions to perform their daily activities due to chronic diseases has pointed to the phenomenon of care dependence, demanding the implementation of continuous home care⁽³⁾.

Home care for individuals living with a chronic condition has usually been provided by someone who has a bond to the dependent person. The caregiver may be a friend or a neighbor, but it is more often represented by a family member. The family caregiver is the main responsible for providing or coordinating the resources required by the patient as well as ongoing care. Most of them do not have specific training for this activity and receive no remuneration for the service provided⁽⁴⁾.

In view of this, transformations occur in the dependent person and in the whole family, since they are exposed to a complex network of feelings produced by the uncertainties as to diseases, treatments and the possibility of aggravating the disability. Caregivers' need for support is not limited to support networks and financial support but there is also need of the support from friends and family that can guarantee the caregiver moments of conversations, reflections and appreciation for the work they do⁽⁵⁾.

Provision of care involves using health technologies according to individual needs throughout life in order to provide clear and objective actions to address the chronic process, improving the quality of life of these individuals, their caregivers and their families, thus promoting autonomy and reducing the severity of the disease⁽⁶⁾.

Despite the efforts of the Ministry of Health to organize guidelines for chronic disease care, define concepts and subsidize the organization of health care to address these diseases, the methods for the realization of comprehensive care are still insufficient to support families and offer assertive care actions to dependent individuals.

In an attempt to approach the needs of these individuals and families, the present study sought to describe the difficulties experienced by the family caregiver in the care of people living with a chronic disease.

METHODS

This is a descriptive study of a qualitative approach that allows an extended view of the experiences and subjective relations that involve the care provided in the home environment⁽⁷⁾.

The present study was based on the theoretical reference of family-centered care, since there is an understanding that the family is considered a crucial element in the care of its members⁽⁸⁾. This theory reveals the perspective of health professionals in listening to and respecting patient and family choices; the knowledge, values, beliefs and culture of these subjects converging towards the realization of comprehensive, participative and shared care⁽⁸⁾.

The study scenario was a Basic Health Unit (BHU) in the city of Belo Horizonte (MG). This BHU covers an area whose population is comprised of approximately 15,000 users. It has four Family Health Teams (FHTs) and was chosen as a scenario because it is 100% covered by the Family Health Strategy (FHS) and has a population with different levels of vulnerability.

The study subjects were family caregivers responsible for providing direct care to users dependent on an FHT belonging to the studied BHU. Initially, a meeting was held with Community Health Workers (CHWs) so that they could indicate users above 18 years that presented some degree of dependence on care and whose care was provided by persons who had no employment relationship.

After this first stage, the conditions of the indicated users were evaluated and some inclusion criteria were defined for the dependent users, namely being a person aged 18 years or older and classified as dependent through the Barthel Index (BI). The BI is an instrument validated in Brazil and considered one of the most used in the world to evaluate the individual's capacity for Activities of Daily Living (ADL). Through closed questions, this scale evaluates the individual's ability to perform ten tasks: feeding, bathing, dressing, grooming, evacuating, controlling urination, toilet use, transferring

from chair to bed, walking, going up and down stairs. Each task is assigned a score that, in the end, can vary from 0 to 100, the lowest scores being a high degree of dependence and the highest scores to a low degree of dependence or total independence⁽⁹⁾. The inclusion criteria for caregivers were being aged equal to or greater than 18 years and not receiving any payment for the care provided.

The data collection took place in the period from August to October 2016, in two stages. In the first, a mapping of the dependent users and their respective caregivers was carried out following the inclusion criteria already mentioned, comprising a total of 27 participants. In the second stage, visits were carried out by the CHW to the households of the 27 participants in which they could conduct an audio interview through a semi-structured script that addressed issues such as: "Do you have difficulties to perform some kind of care at home?". During the visits, the BI was also applied to assess the degree of dependence of the user.

The interviews were conducted with all caregivers of dependent individuals following Marconi's guidelines (2013)⁽¹⁰⁾, as a conversation between two people, the interviewer and the interviewee, with the purpose of acquiring important information regarding the understanding of the interviewee's perspectives and experiences. The interviews had an average duration of six minutes and were transcribed to enable the analysis of the data.

The study comprised a total of 27 participants, considering that two were excluded from the study because they were caregivers of independent individuals according to the BI, thus comprising a total of 25 participants.

The process of data analysis was constructed following the phases of content analysis, in the thematic modality, as proposed by Bardin⁽¹¹⁾, namely: phase 1 – *Pre-analysis*, carried out by means of successive floating readings of all material collected with the purpose of providing the approximation and interaction with the content to be analyzed; phase 2 – *Exploration of the material*, in which the exploration and treatment was carried out, followed by

the initial coding and categorization of the analyzed content. Subsequently, the initial categorization of the analyzed material formed a *corpus*, which could be submitted to phase 3 of *Treatment of Responses*. In this last phase, a process of classification and regrouping of elements that encompassed different variables and the same meaning was carried out, and this process resulted in the final categories that included the discourse of the research subjects, in the following dimensions: *Implications of family care in the caregiver's daily routine and aspects that hinder care provision*.

We decided to discuss the analysis approaches described above by revealing excerpts from the speeches of the caregivers, subjects of this study, who are identified with the codes adopted in the content analysis, represented by the letter I of interviewee, followed by the sequence number of the interview. In the same line of organization, the results were confronted and discussed based on the literature.

The research was approved by the Research Ethics Committee of the Federal University of Minas Gerais (UFMG) under registration No. 54550412.0.0000.5149 and authorized by the Municipal Health Department of Belo Horizonte. The study participants signed the Informed Consent Form (ICF) voluntarily, after the study proposal was clarified in all stages. Absolute secrecy of the information was guaranteed as well as the privacy and anonymity of the participants.

RESULTS

Characterization of study participants

Most of the participants in this study were aged between 18 and 59 years (55.4%), but there was a considerable number of elderly caregivers (44.6%). In relation to other characteristics, 78.4% were female, 52.5% were married, 75.4% had at least one child, 40.3% had incomplete elementary education and 72.7% had no paid work. Also, 35.2% did not have any individual source of income and, 41.7% reported being a dependent person's child. When questioned about their health situation, 64.7% of

caregivers reported having a chronic illness and 62.6% reported using continuous medications. Only 32.4% practiced physical activity, and 98.6% reported exclusively using the public health service.

Implications of family care in the caregiver's daily routine of and aspects that hinder care provision

The analysis of the collected data revealed that the caregivers presented difficulties in the care of dependent individuals who live with a chronic disease, especially when the implications of this care interfere in the daily routine of the caregiver. According to the participants, the family caregiver becomes overwhelmed to perform care to the dependent person and also to account for their own routine activities. Another difficulty is that the caregiver sees her/himself alone to meet the demands of the sick family member, needing adequate physical condition and means of transportation.

Regarding the implications of family care in the caregiver's daily routine, study participants stated that their routines were altered due to the difficulty of reconciling routine activities with care for the dependent person:

It is difficult, because I also have to work, I have to do my things, so it gets difficult. Once a week I have the help of my sister. I just got home, I am going to clean up here, do lunch, I cannot do everything; it is difficult (I2).

I have to take care of her and myself; this is very heavy. I make food for her; I have to wash her clothes. She puts on the clothes in a clumsy way and I have to tell her [...]. If it is getting cold she does not know that she has to put on warm clothes. I have to take care of her as if it was me (I5).

Participants clarified that the difficulties are mainly when it involves the need to leave the house and when they need to combine caregiver activities with work activities. The sum of activities, which generates physical and mental overload, was also a situation mentioned by the interviewees:

I need help, for sure, I do not think anyone can do it alone. Because you throw her to the side but here she comes, sometimes she has

defecated, needs to be changed, because if she comes, everything gets dirty. So it is difficult, it is needed two people, at least (I13).

Some things depending on her, yes, others no, because I also have to work, I have to do my things, so it gets difficult; we always have the help of my sister (I2).

In addition to these activities, the caregivers pointed out that there is a need to leave home to ensure the maintenance of the dependent's own health.

Get the medicines, everything, diaper, do the shopping, everything (I16).

The integrity of the dependent's health is important for the quality of life of the caregiver. One of the main difficulties reported by family caregivers with regard to basic care is the mobility of the dependent person. The patient's displacement is done without any help, either indoors or outdoors, and often the caregiver needs to exert intense force to move the dependent person:

If there is no one here to help me, I do it all on my own, but it is much heavier. So, to go downstairs with her I do it but I have to do push hard. But if it is just she and her, she does not stay without help (I22).

Taking a shower, she does it on her own. I just take her, put her in the chair and take her to the bathroom, [...] no problem. The only problem is the knee, she wore her knee in a way that she cannot move forward, it is difficult (I2).

There was this day when she fell ... [...] when I got there she was on the floor. I cannot do this alone, lifting her, because she is heavy. So I had to call my sister for help and we cannot lift her like this [...]. She crawled out of the bathroom to the room. As she was wet, she was slipping, so I dried her, she held the chair and we lifted her and we were able to take her to the room (I27).

The difficulty in transferring the dependent person produces negative consequences for the health of both. However, the dependent family member ends up being the most impaired, because they are often prevented from accessing health services and community

devices, being restricted to the home. Some even need public or private transportation vehicles to meet the needs of the dependent being:

There are things I used to do, for example, I used to walk with her in my arms everywhere. Now if I had to, it would be difficult to carry her [...]. I use to walk her to do physical therapy; I had no car at the time. Later I got a car, but until then I used to depend on other people's rides and it was difficult (I9).

An activity that presented difficulties to be performed due to physical efforts for the mobility of the dependent person was the bath. There are several factors that cause difficulties for the caregiver to perform the bath, of which the most commonly cited by the interviewees were the overweight of dependent beings and the difficulty to manipulate them.

Bathing him is very difficult, to be holding him. We have to hold him sited on the chair, to turn on the shower because he has difficulty holding on the handrail. He has difficulty; it is hard. We have to be more patient and attentive, because otherwise, you can't. Bath time is very difficult. (I1).

Her son helps me mainly to bathe because she is heavy and I cannot hold her by myself [...]. When I need to take her to the bathroom, I also call her son to help me, I cannot do it alone (I13).

From this perspective, the locomotion factors interfere in the accomplishment of the care, being able to cause difficulties for patient and caregiver, besides consequences on the physical health of the caregiver.

DISCUSSION

Many studies have focused on the difficulties of the family caregiver in the relationship with dependent users who have a chronic disease^(5,12-13). It is known that the care performed at home by the family is exhausting, burdensome and generates physical, mental and social illness^(5,12-13). The present study, however, advances in scientific knowledge by revealing in what aspects these difficulties appear during daily family care. For those who have not choose

providing care as a profession, taking over and being available to take care of a dependent person, even if it is their relative, is not an easy task. So, revealing these aspects is important for health services to create targeted strategies for what can actually compromise the quality of life of the family and the care to the dependent being due to a chronic condition.

The care of a person with chronic illness can be classified as a process full of difficulties that is faced by the patient's family and especially by a specific caregiver, who has his/her life and routine totally changed. For this reason, health services need to provide support to family caregivers, which, in addition to improving their well-being, ensures better care for the dependent person⁽¹²⁾.

The results of the present study revealed the following difficulties: the burden placed on the caregiver, the consequent lack of time to perform their routine activities, the difficulty in the patient's locomotion either inside or outside the home, difficulties in performing patients' bodily hygiene associated with their own mobility, and lack of knowledge of the techniques related to the care process.

Difficulties in carrying out basic care, such as bodily hygiene, may be affected by the lack of information on how such action should be performed, thus making it an arduous task. In fact, many caregivers are aware about the health problem that affected the family member, but not all have received guidance on the disease and routine care with the patient. Bodily hygiene activities performed by autonomous subjects seem to be part of their own nature, but as a caregiver, they need to have a minimum knowledge of ergonomic techniques, techniques to strengthen the subject's autonomy, to identify risk behaviors and situations, clinical and physical factors and they also need to want to be present in this caregiving action that takes patience, respect and trust. A study of caregivers of people who had suffered stroke in Taiwan in 2013 said that the greatest needs of caregivers are related precisely to the domain of information and the lack of support from health professionals, which justifies the need to provide

information on the progression and treatment of dependents' disease in a fast and clear way⁽¹³⁾.

Considering the paradigm of the family caregiver, there is, in the reality of care to the dependent person, the need to provide care and support to the caregiver, also. That is, someone who offers them protection and support, sharing their task and consequently facilitating their performance⁽¹⁴⁾. The data from this study showed that the first two groups of difficulties found justify this need. The burden placed on the caregiver and the consequent lack of time to perform routine activities are challenges also directly related to the lack of a second person with whom he or she can share the care. This obstacle leads to important consequences, such as the feeling of isolation and physical exhaustion, since caregivers cannot leave their loved ones alone or feel trapped by the patient's desire not to stay alone⁽¹⁵⁾.

Some Brazilian cities have already established programs that assign caregivers to the households with the objective of assisting and sharing interventions and follow-ups with the family caregivers so that they can better manage the daily activities of the dependent people. However, these are initiatives that, although benefiting many families, have extremely strict criteria, focused on elderly patients, without dimensioning the degree of dependence and the indicators of family vulnerability, with low evaluation of cases by the nurses of the family health teams or of the hospital, being individual programs, of little scope, that still do not compose an articulated support network.

Examples of this type of program are the Better at Home Program of the Federal Government and the Best Care Program, offered by the Municipal Health Department of Belo Horizonte, which provides a social caregiver at home. It is necessary to strengthen these programs in order to systematically meet families that are overloaded and often excluded from the possibility of offering greater comfort and care to the dependent being.

Although family care represents the possibility of the dependent user with a chronic condition to be closer to the family in an affective social relationship,

it is not always accompanied by the organization to maintain schedules in relation to medication, hygiene, food, leisure, among others. Most of the time, the family caregiver is held as the only responsible for the care and becomes deprived of social interaction, leading to risk for isolation, reinforcing care as a mandatory action of those who have or had a bond with the dependent patient⁽¹⁶⁾. Thus, the family caregiver becomes exhausted by the demand of health services, the need to take over transportation costs, use economic resources to guarantee the opportunity of health interventions or access essential medicines for treatments not always guaranteed by the public system.

Another difficulty pointed out by the subjects of this study concerns the locomotion of users dependent on care, both outside the home and inside the house. This challenge is not only related to movement facilitators, such as bath chairs, grab bars and motor vehicles, but with the use of the caregiver's physical strength, which in addition to causing damage to their physical integrity, evidences the need for another person to help them. In the search for a support network, the family finds itself isolated, since access to health services is often unfeasible due to the incompatibility of schedules, face-to-face assistance models, with little provision of information and communication technologies⁽¹⁷⁾.

The nurse, as a reference professional for the care of people and families, has the necessary tools to know the reality, bonds, relationships and family difficulties, recognizing how these factors can affect the care for the dependent person and the caregiver. Being in direct relationship with families makes it possible to create strategies for teaching and monitoring the health condition of the people involved in the care process, resulting in an improvement in people's quality of life.

FINAL CONSIDERATIONS

According to the results of the present study, the difficulties pointed out by the subjects appeared when the care began to interfere in the caregiver's daily

routine, overloading them in an integral way, especially when it involves the need to leave the house. Another obstacle in this relationship of care was pointed out when the caregiver sees him/herself alone with the demands of the individual in need of an adequate physical condition and means of locomotion, especially in what concerns the locomotion of the dependent person inside and outside the home. Inside home, the most arduous activity relates to bodily hygiene and outside home, with the means to transport the patient.

This study reaffirms that family caregivers need financial assistance, instrumental services and information to provide care, since the health system has not been a partner in the conduction, promotion, treatment and rehabilitation of users who live with chronic diseases, leaving their value of integrality as the sole responsibility of the family. Family

participation is essential for the sustainability of the public health system, especially in the current situation of early involvement with non-communicable chronic diseases, but it is necessary to include it in the care processes through actions of social promotion, health promotion and maintenance of emotional needs.

Despite the important results identified, this study has limitations. One of them is related to the fact that the investigation dealt with a local reality, which does not allow us to point out generalizations. In addition, another limitation of the study was the availability of health care staff to follow the visits and understand the importance of the family approach. However, considering the ethical aspects, these professionals were mediators between the researchers and the research subjects.

Acknowledgements: To the National Council for Scientific Development, to the Foundation for the Support of Research in Minas Gerais and to the Pro-Rectorry of Research of the Federal University of Minas Gerais.

Individual contribution of authors: Maia ACMS, Silva BVO and Montenegro LC participated in the design and writing of the project; analysis and interpretation of data; writing of the article and final approval of the version to be published. Pimenta AM and Tavares MLO participated in the relevant critical review of the intellectual content and final approval of the version to be published. All authors claim to be responsible for all aspects of the work, ensuring its accuracy and integrity.

Submitted: 22/02/2018

Accept in: 14/06/2018

REFERENCES

1. Malta DC, Silva MMA, Moura L, Moraes-Neto OL. A implantação do sistema de vigilância de doenças crônicas não transmissíveis no Brasil, 2003 a 2015: alcances e desafios. *Rev Bras Epidemiol.* 2017; 20(4): 661-75
2. Schmidt MI, Duncan BB, Silva GA, Menezes AM, Monteiro CA, Barreto SM, et al. Chronic non-communicable diseases in Brazil: burden and current challenges. *Lancet (British edition).* 2011; 377: 1949-61.
3. Canga A, Vivar CG, Naval C. Dependencia y familia cuidadora: reflexiones para un abordaje familiar. *Anales Sis San Navarra.* 2011; 34(3): 463-9.
4. Monteiro EA, Mazin SC, Dantas RAS. Questionário de avaliação da sobrecarga do cuidador informal: validação para o Brasil. *Rev Bras Enferm.* 2015; 68(3): 421-8.

5. Fernandes CS, Angelo M. Family caregivers: what do they need? An integrative review. *Rev Esc Enferm USP*. 2016; 50(4): 675-82.
6. Ministério da Saúde (BR), Secretaria de Atenção à Saúde, Departamento de Atenção Básica. Caderno de atenção domiciliar. Brasília: Ministério da Saúde; 2013.
7. Minayo MCS. O desafio do conhecimento. 11. ed. São Paulo: Hucitec; 2010.
8. Barreto MS, Arruda GO, Garcia-Vivar C, Marcon SS. Cuidado centrado na família em unidades emergenciais. *Esc Anna Nery*. 2017; 21(2): e20170042.
9. Minosso JSM, Amendola, Alvarenga MRM, Oliveira MAC. Validação, no Brasil, do Índice de Barthel em idosos atendidos em ambulatórios. *Acta Paul Enferm*. 2010; 23 (2): 218-23.
10. Marconi MA, Lakatos EM. Metodologia do trabalho científico. 7. ed. rev. e ampl. São Paulo: Atlas; 2013.
11. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2016.
12. Lethin C, Leino-Kilpi H, Roe B, Soto MM, Saks K, Stephan A, et al. Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study. *BMC Geriatr* 2016; 16(32).
13. Kuo LM, Huang HL, Huang HL, Liang J, Chiu YC, Chen ST, et al. A home-based training program improves taiwanese family caregivers' quality of life and decreases their risk for depression: a randomized controlled trial. *Int J Geriatr Psychiatry*. 2013; 28(5): 504-13.
14. Campos EP. Quem cuida do cuidador: uma proposta para os profissionais da saúde. 2. ed. Teresópolis: Unifeso; São Paulo: Pontocom; 2016.
15. Marchi JA, Carreira L, Sales C. Ser-cuidador de familiar com câncer e dependente: um olhar para a temporalidade. *Rev Eletr Enf*. 2015; 17(3): 1-9. DOI <http://dx.doi.org/10.5216/ree.v17i3.29276>
16. Plank A, Mazzoni V, Cavada L. Becoming a caregiver: new family carers experience during the transition from hospital to home. *J Clin Nurs*. 2012; 21(13-14): 2072-82.
17. Chaparro-Díaz L. Objectives of sustainable development and Non Transmissible Chronic Disease. *Rev Latino-Am Enfermagem* 2016; 24:e2717.