



Necessity of Support for Caregivers of a Person with Alzheimer's Disease

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General Note

 Article is recommended to print as color digital version in recycled paper.

ABSTRACT

Objective: To identify the strategies adopted by family caregivers of a person with Alzheimer's disease. **Material and methods:** Systematic review of the literature, using the keywords "Support", "Caregiver", "Alzheimer's" and "Nursing Interventions"; using the PICO method. Between 2008/2015 ten electronic databases were selected, including for analysis of 8 articles. **Results:** Show that caregivers suffer physical and emotional changes, arising from excessive work associated with the process of care, enhanced by the non-acceptance of the diagnosis, the need to overcome obstacles, manage conflicts and plan for the future; what determines the importance of support to maintain their quality of life. **Conclusion:** Faced to the intense need to readjust felt by caregivers, it is the responsibility of the health professionals to present alternatives resources, in order to achieve goals of care, increasing the patient's bond with the caregiver.

Keywords: Support, Caregiver, Alzheimer's Patient and Nursing Interventions

1. INTRODUCTION

Alzheimer's disease (AD) is a neurodegenerative process, progressive^(1,2), related to the age and of unknown etiology. It is characterized by the deterioration of intellectual skills previously acquired that interfere in occupational or social activity daily⁽³⁾. The clinical picture of AD is characterized by behavioral and cognitive changes, including the appointment of memory, thinking and reasoning. The most obvious early symptom of the disease is the commitment of recent memory⁽¹⁾, being his descendant character evolution.

Dementia is the clinical expression of various pathologies, including the DA, which is the most prevalent, accounting for 50 to 70% of cases. Both the impact and the prevalence of dementia increases almost exponentially with age, doubling approximately every 5 years^(4,5,6). The global impact of dementia has been increasing dramatically in recent decades. In 2005 the estimative was about 7.5/1000 of people a year in 2012 estimative points to 7.7/1000 people per year, which translates into about 1 new case every 4 seconds⁽⁷⁾. The prevalence of dementia over 60 years of age varies between 5-7%, being higher in the countries of Latin America (8.5%) and being lower in Africa (2-4%)⁽⁸⁾. In 2004 the dementias constituted the sixth leading cause of death in most developed countries and it was considered the fifth most common cause of death in 2006⁽⁹⁾.

The severity level is divided into three stages: mild, moderate and severe. In each one of the stages referred it can be observed a gradual loss of autonomy and the consequent increase of the need for care and supervision of caregivers⁽¹⁰⁾. The incidence of this disease increases with age, and affects approximately 4% of people aged between 65 and 75 years, 10% of which are between 75 and 85 years and 17% of all the people with more than 85 years^(11, 12).

It is possible to assume that a chronic illness, such as AD, can bring inconvenience, both for the holder and for informal caregivers. Playing this role can generate changes and excessive work, as well as stress, interfering with the routine of everyday life of the caregiver. In the final stage of the disease, the patient needs total aid, making it difficult to coexist and demanding family and/or caregiver's time, knowledge and understanding of the disease⁽¹³⁾.

Nursing care must serve as a model to be followed by these relatives, friends and other caregivers, because humanization should be present in all activities, with a look of understanding and respect for the sick. Approximately 80% of the care provided to patients with AD, is provided by family members⁽¹⁴⁾. In this way the team who work with the patient such as nurses, family and other health professionals should seek a result in improving the ability of self-care, increasing self-esteem and motivating the patient in order to learn and improve the Art of Caring⁽¹⁵⁾.

It is also the responsibility for health professionals to share with family members and informal caregivers some guidance and clarification on the basis of their technical competence, without losing the tenderness, to minimize the fear of being a caregiver and the patient's bond with his family. This attitude will provide greater comfort and tranquility for the person who receives help, because the greater the degree of empathy, the better will be the response of a patient with neurological sequelae. The caregiver is the support of the sick person and thus their safety and tranquility will depend on the understanding that the caregiver transmits^(3,15).

2. MATERIALS AND METHODS

A systematic review of the literature is one of the methods of research used in the practice of evidence-based and its purpose is to gather and summarize results of research on a given topic in a systematic and orderly manner, contributing to the knowledge of the theme^(16,17). The method used was based on PICO strategy (acronym for patient, intervention, comparison and outcomes). This way it

maximizes the inclusion of relevant information in different databases, focusing on the research object and avoiding unnecessary lookups⁽¹⁸⁾.

Observing with rigor all steps required in the usage of this method, the time interval between March and July of 2016, a protocol was developed for the identification of studies of interest to this work and that consisted of a research on the search engines: Ebsco and B-ONline, and on the following databases: CINAHL Plus, PubMed/ MEDLINE, LILACS, Scielo, Web of Science, ScienceDirect, Cengage Learning, Academia Search Complete, Psychology and Behavioral Sciences Collection, John Wiley & Sons, SportDiscus, The Joanna Briggs Institute, U.S. National Library of Medicine, Directory of Open Access Journals, Springer Science & Business Media and Repository of Scientific Open Access of Portugal.

For the identification of relevant studies a search strategy was used, using the following descriptors Quality of Life AND Caregiver AND Alzheimer Patient AND of Nursing Interventions. After meeting all these protocol assumptions, some articles, that did not meet the requirements, were phased out, developing methodically a reductive process.

3. RESULTS

It was selected for the study eight articles that follow in Table 1.

Table 1 Description of selected studies and main results of investigations

| Study | Author(s)/ Year | Main Results |
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| S1: "Family dynamics in face of Alzheimer's in one of its members" | Barbara Alana Vizzachi, Celina Daspett, Maria Goreti da Silva Cruz, Ana Lúcia de Moraes Horta; 2015. ⁽¹⁹⁾ | -Three categories Emerged: the effects of Alzheimer's on family dynamics; the development process of Alzheimer's disease and the adaptation strategies in relation to the disease. -It was possible to verify that there are several demonstrations of negative impact of Alzheimer's disease in the family, as well as in the patient. -In this adaptation process is very important to maintain mutual aid, the mobilization of resources to enable the memories of the past and appeal whenever indicated to the spirituality and faith. -It was possible to conclude that, before counseling is essential to have an understanding of the structure and family dynamics. |
| S2: "Conhecimento e intervenção do cuidador na Doença de Alzheimer: uma revisão da literatura"/ "Knowledge and intervention of the caregiver in Alzheimer's disease: a review of the literature" | Cinthy Dolores Santos Maia Leite, Terce Liana Mota de Menezes, Érica Verônica de Vasconcelos Lyra, Cláudia Marina Tavares de Araújo; 2014. ⁽²⁰⁾ | -The articles selected for review were divided into three categories: knowledge about the functional and cognitive decline of a patient with Alzheimer's, understanding the psychological and behavioral symptoms of dementia and knowledge of language impairment. -In most studies, it was found that the guidance as to what is the disease and its evolution can interfere in the way the caregiver schedules and performs the care. -It was possible to conclude that it is necessary the creation of opportunities for caregivers who are part of the family and professionals to better understand the patient and consequently the possibilities of healthcare interventions (safe and effective). -Refers to be fundamental to implementation of psycho educative programs, able to provide information and practical guidance to caregivers, to improve support for caregivers for patients with Alzheimer's disease. |
| S3: "As dificuldades vivenciadas pelo cuidador do paciente portador de | Gleice Helen Silva Bárbara, Fátima Kelle Bonfim, Clecilene Gomes Carvalho, Sérgio Ricardo Magalhães; | -This study it intended to identify the difficulties experienced by the caregiver of the sick person with Alzheimer's disease; in order to preserve their health and to prevent possible diseases that the overload can cause. |

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| Alzheimer"/ "The difficulties experienced by the caregiver of a patient with Alzheimer's disease" | 2013. ⁽²¹⁾ | <p>-It was concluded that there are various difficulties experienced by the caregiver, including the physical, emotional, economic and social deprivation.</p> <p>-It has been found that it is of great importance the continuously monetarization of the caregiver, in order to prepare them for the changes that will occur in their lives, as a result of Alzheimer's disease.</p> <p>-It was validated that the attention to caregivers of patients with some kind of psycho frame is essential, as it is reflected in a better quality of life for the caregiver and consequently to the sick person.</p> |
| S4: "As Intervenções de Enfermagem que permitem a diminuição da sobrecarga do Cuidador Informal de cuidados à pessoa com demência"/ "The nursing intervention that allows the reduction of the burden of an informal caregivers who cares for a person with dementia" | Dulce Vargas; 2012. ⁽²²⁾ | <p>-Nurses are able to prevent and detect early overload of informal caregiver of people with dementia, having at their disposal numerous evaluation instruments.</p> <p>-It was concluded that the early evaluation, helps nurses to plan/select the appropriate interventions, based on the evidence to prevent and reduce the burden of the caregiver, suggesting the use of Calgary Models and the Intervention in the Family.</p> |
| S5: "Cuidadores Informais de Doentes de Alzheimer: Sobrecarga Física, Emocional e Social e Psicopatologia"/ "Informal Caregivers of Alzheimer's Patients: physical, social, emotional and psychopathology overload" | María de Fátima da Cunha Pereira; 2011. ⁽²³⁾ | <p>-The results suggest that informal caregivers present considerable levels of physical, emotional and social overload.</p> <p>-In relation to the psychopathological profile the higher values are found at the level of depression, followed by the somatization, obsessive symptoms and anxiety.</p> <p>-It turns out that the biggest excessive work is associated with worse mental health. The socio-demographic variables, of context and clinics are directly related with the significant differences in physical, emotional, social excessive work and to the psychopathological profile.</p> <p>- It is concluded that the caregivers expect of nursing professionals more information about the disease and its evolution so that they can better deal with the disease situation in their family. Also appeal to the need of being replaced temporarily in the performance of its functions.</p> |
| S6: "Nursing interventions to assist in decreasing stress in caregivers of Alzheimer's patients" | K. Skinner; 2009. ⁽²⁴⁾ | <p>-Although Alzheimer's disease affects mostly people who are beyond 65 years, it can also affect younger people.</p> <p>-There are many factors promoters of stress involved in the care of a person affected by Alzheimer's disease: loneliness, depression, dealing with unpredictable behavior, lack of knowledge with regards to care, patient safety and take care of basic needs are often challenging for caregivers.</p> <p>-Nursing interventions should include: encouraging caregivers to learn more about the disease and understand what is available in the community such as Social Support, as well as legal issues and financial understanding.</p> |

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| S7: "Cuidadores familiares de pessoas portadoras de Doença de Alzheimer: revisão da literatura"/ "Family caregivers of people with Alzheimer's disease: review of the literature" | Katiele dos Santos Almeida, Marinês Tambara Leite, Leila Mariza Hildebrandt; 2009. ⁽²⁵⁾ | <p>-There has been the presence of physical and mental stress among caregivers in the lives of families; however they are influenced by factors such as: motivation, knowledge and skills by the family who provide care.</p> <p>-It was concluded that there are repercussions in the lives of caregivers, with physical and mental overload.</p> <p>-It was concluded in the same way that health professionals should direct their gaze and assume the responsibility to promote a qualified assistance to an elderly dependent care and their families.</p> |
| S8: "Patient Safety and Quality: An Evidence-Based Handbook for Nurses" | Susan C. Reinhard, Barbara Given, Nirvana Huhtala Petlick, Ann Bemis; 2008. ⁽²⁶⁾ | <p>-It was concluded that family caregivers are essential partners in care plan for people with chronic diseases.</p> <p>-The nurse must be concerned with various issues that affect patient safety and the quality of care as the dependence of the caregiver.</p> <p>-It is very important to promote communication and support to the caregiver in order to develop the empowerment, fosters patient safety.</p> <p>-Interventions and earlier studies have shown improvement in the results when the nurses are involved in partnership with the caregiver.</p> <p>-It is crucial to encourage nurses to help caregivers to become more confident and competent in the delivery of health care.</p> |

4. DISCUSSION

According to the articles we can see that the informal caregivers of patients with Alzheimer's disease are the target of physical, economic, emotional and social changes and there is an excessive burden during the care process of patients with Alzheimer's disease^(23,27,28). There are so many factors promoters of stress involved in the care of a person with Alzheimer's disease, such as loneliness, depression, dealing with unpredictable behavior, lack of knowledge in relation to the care of the patient and control of a patient's safety, are often challenges for caregivers. These facts corroborate with all studies, although with special emphasis on studies S1, S3, S5, S6 S7 and S8; but for the patient it is positive the attendance by informal caregivers⁽²⁹⁾. The Alzheimer's patient caregiver is the main element in the treatment of the disease assuming social importance, in order to maintain the basic needs of the patient, being the one who guides the patient. As a result, this difficult task turns out to have direct effects on the quality of life of who cares, causing in the long term the loss of emotional stability prejudicating their health⁽³⁰⁾. This psychological impact that caregivers might suffer is usually because this caregiver is not prepared to take all the care and the responsibilities demanded of him or her. They need to be properly prepared, requiring further support to evince this care; these facts are evidenced in studies S1, S2, S5 and S7.

In the sociocultural context today, the family continues to play a fundamental role and to be the basic unit in which we develop and socialize. It is in the family that every individual seeks the support necessary to overcome moments of crisis that arise throughout their lives. The disease, in particular a disabling disease such as Alzheimer's, requires a huge readjustment, with frequent implications on family dynamics³¹ as reveal studies S1, S2, S5, S7 and S8. When a family is confronted with the disease of one of its members, all elements will suffer from anxiety and stress. The onset of the disease is a change to the family system, because it implies a process of readjustment of the structure, roles, communication patterns and affective relations of family members. The outstart of a chronic illness such as Alzheimer's disease, into a family completely changes the family dynamics. The loss of functional capacity observed in the elderly with chronic degenerative disease, involves reorganization of the family nucleus in order to redefine roles and responsibilities, in addition to disarticulate the family dynamics and destabilize the interpersonal relations experienced in their everyday lives⁽³¹⁾. These facts are mentioned in all the studies surveyed.

In order to support these families each element of the team of multidisciplinary health is essential to meet the needs of the family caregiver, having as objective a holistic and health care incorporated^(32,33), as referred in all studies of this research. The nurse is, without doubt, one of the pillars of the team, it has as competence to promote the process of readaptation, educate, and help

better manage internal and external resources not only of the individual patient, but also the family and the community. In the face of Alzheimer's disease, the nurse is an active element, since it is related to the variables that affect the response of the individual to the factors of stress^(32,33), and these facts run counter to that in studies S4, S5, S6, S7 and S8. It is of great importance to support the caregiver with the aim of preparing them for the changes that are occurring in their lives as a result of Alzheimer's disease. Nursing interventions should include: encouraging caregivers to learn more about the disease and understanding what is available within the community such as social support and understanding financial and legal issues^(32,33). In this way, the human interaction of the nurse with the client/system never runs out, especially in this delicate task of nursing who cares for an Alzheimer's disease patient.

5. CONCLUSION

After analyzing the studies mentioned, it was possible to recognize that the care for patients with Alzheimer's disease has a negative and significant impact in the physical and emotional well-being of informal caregivers. The resilient behavior is essential for overcoming the disease by the patient's family. Instead of facing a chronic disease as a battle, it may be more appropriate to recognize the influence of a patient condition and accept what is beyond control, in order to be able to live with it. Faced with the intense overload experienced by informal caregivers is important to find alternatives, since these are often full time caregivers looking after patients, who often, give up definitely of their objectives.

The Nurse should take care and be present together with the patient/family/caregivers, stimulating the patient and involving the family for the care, promoting physical security in order to reduce anxiety and agitation. It is very important to convey specific knowledge about the skills of healthcare for the elderly so as to help the person with Alzheimer's disease and their caregivers by supporting them so they could maintain the highest levels of health. The Act of Caring is a continuous attitude of work and involvement that requires a lot of professionals who must take an ethical conduct with a willful character, always striving to enhance the knowledge and mobilize skills to better qualify their intervention of care.

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