

ALZHEIMER'S DISEASE AND THE CHALLENGES OF NURSING CARE TOWARDS ELDERLY PEOPLE AND THEIR FAMILY CAREGIVERS

Alzheimer e os desafios dos cuidados de enfermagem ao idoso e ao seu cuidador familiar

Alzheimer y los desafíos de los cuidados de enfermería al anciano ya su cuidador familiar

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ABSTRACT

Objective: This study meant to analyze the main challenges and the care provided by nursing teams during the process of caring for elderly people bearing Alzheimer's disease and their family caregivers. **Methods:** It is an integrative literature review that was performed through article searching in the Scientific Electronic Library Online (SciELO) and the *Literatura Latino-americana e do Caribe em Ciências da Saúde (LILACS)* [Latin-American and Caribbean Literature in Health Sciences]. There were obtained 783 studies, of which only 13 met the inclusion criteria. **Results:** Care strategies associated to Alzheimer-related forms of behavior were proposed, namely, forgetfulness, denial of bathing, and the acceptance of the disease by the family. The lack of training and knowledge by some nursing professionals was evidenced as a challenging element vis-à-vis the relationship with elderly people and their family caregivers. **Conclusion:** It is important that public policies pursue to guarantee caring practices for elderly people bearing Alzheimer's disease, approaching the real needs experienced by such population, as well as family caregivers and health professionals.

Descriptors: Alzheimer's disease, Caregivers, Family, Nursing care.

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RESUMO

Objetivo: Analisar os principais desafios e cuidados despendidos pela equipe de enfermagem durante o processo de cuidar de idosos que vivem com Alzheimer e ao seu cuidador familiar. **Métodos:** Trata-se de uma Revisão Integrativa desenvolvida a partir da busca de artigos nas bases *Scientific Eletronic Library Online* e Literatura Latino-Americana em Ciências da Saúde. Obtiveram-se 783 estudos, dos quais apenas 13 atendiam aos critérios de inclusão. **Resultados:** Foram propostas estratégias de cuidados referentes a formas de agir relacionadas ao Alzheimer. Entre elas o esquecimento, negação do banho, aceitação da doença pela família. A falta de capacitação e conhecimento por parte de alguns profissionais da enfermagem foram evidenciados como elemento dificultador na relação com o idoso e seu familiar cuidador. **Conclusão:** É importante que as políticas públicas possam garantir a assistência ao idoso com Alzheimer, aproximando-se das reais necessidades vivenciadas pelos idosos, cuidadores familiares e profissionais da saúde.

Descritores: Doença de Alzheimer, Cuidadores, Família, Cuidados de Enfermagem.

RESUMEN

Objetivo: Analizar los principales desafíos y cuidados que el equipo de enfermería durante el proceso de cuidar a los ancianos que viven con Alzheimer y su cuidador familiar. **Métodos:** Se trata de una Revisión Integrativa desarrollada a partir de la búsqueda de artículos en las bases *Scientific Eletronic Library Online* y Literatura Latinoamericana en Ciencias de la Salud. Se obtuvieron 783 estudios, de los cuales sólo atendían a los criterios de inclusión. **Resultados:** Se han propuesto estrategias de atención a las formas de actuar relacionadas con el Alzheimer, entre ellas el olvido, la negación del baño, la aceptación de la enfermedad por parte de la familia. La falta de capacitación y conocimiento por parte de algunos profesionales de la enfermería fueron evidenciados como elemento dificultador en la relación con el anciano y su familiar cuidador. **Conclusión:** Es importante que las políticas públicas puedan garantizar la asistencia al anciano con Alzheimer, aproximándose a las reales necesidades vivenciadas por los ancianos, cuidadores familiares y profesionales de la salud.

Descriptores: Enfermedad de Alzheimer, cuidadores, la familia, Cuidados de Enfermería.

INTRODUCTION

The number of elderly people has doubled in the last 20 years, and in ten years it grew (55%), from 2001 to 2011, making up a representation of (12%) of the Brazilian population. The elderly population in Brazil are people over 60 years old and in 2013 totaled around 23.5 million people. Given this fact, the *Instituto Brasileiro de Geografia e Estatística* (IBGE) [Brazilian Institute of Geography and Statistics], infers that by 2050 there will be 66.5 million elderly people in Brazil, corresponding to an increase of (29.3%).¹

The significant reduction in the fertility rate, associated with a sharp drop in the infant mortality rate and the increase in life expectancy are the main determinants of this accelerated demographic transition in Brazil. As a result, Brazil is moving rapidly towards an older demographic profile, characterized by an epidemiological age transition, where chronic-degenerative diseases occupy a prominent

place.²

Bearing the aforesaid in mind, Alzheimer's Disease (AD) is a type of dementia, which commonly affects the elderly. It is a chronic syndrome that can be caused by a series of progressive diseases that affect memory, thinking, behavior and the ability to perform daily activities and self-care.³

The World Alzheimer Report estimated that 35.6 million people worldwide would live with dementia in 2010, predicting that this number will almost double every 20 years, reaching 65.7 million in 2030 and 115.4 million in 2050. This evolution is due to a large number of people bearing dementia in low and middle-income countries per capita. Thus, the numbers are worrying, since it affects the elderly population worldwide, requiring greater attention in the monitoring and care of this disease.³

The family is of fundamental importance concerning the process of providing care to the elderly person bearing Alzheimer's disease. This disease affects not only the elderly population but also their families and especially the family caregivers, as the degree of complexity of care increases. Family members may be insecure and look for help, so that they can properly conduct this responsibility. Generally, families with less purchasing power hold one of their members responsible for exercising the role of caregiver. There are two types of caregivers, the primary and the secondary. The primary caregiver is one who has all or most of the responsibility for the care of the sick elderly. Secondary caregivers would be family members, volunteers, and occupational ones, who provide complementary activities.⁴

In this framework, family caregivers undergo changes in their daily lives. This deserves support and appreciation from health professionals and other family members, in an attempt to reduce the vulnerability to which both are being attributed. It is important to note that this care process has an overload in physical and emotional terms, as many do not have other family members to perform or share the care. Thus, several areas of the life of this family caregiver can be affected, such as: social relationships, affective and professional areas, in addition to physical and mental health. It is this wear and tear that often causes family caregivers to renounce or postpone their own life projects.⁵

Considering such data, the nursing team must pursue to develop care strategies, both for people bearing Alzheimer's disease and for their family caregivers, ensuring all necessary support.⁵

The National Health Policy for the Elderly introduced by the Ordinance No. 2,528 from October 19th, 2006, aims to recover, maintain and promote the autonomy and independence of the elderly, directing collective and individual health measures to this end, in line with the principles and guidelines of the *Sistema Único de Saúde* (SUS) [Brazilian Unified Health System]. This policy is the target of all Brazilian citizens being 60 years old or more.⁶

Promoting the health of the elderly person includes the following guidelines: active and healthy aging; comprehensive health care for the elderly; encouraging intersectoral actions, aiming at comprehensive care; provision of resources capable of ensuring quality health care; encouraging participation and strengthening social control; training and continuing education of health professionals; dissemination and information to health professionals, managers and users of the SUS; promotion of national and international cooperation on health care experiences; support for the development of studies and research in this area.⁶

Therefore, it is essential to qualify the nursing team, given the real needs of elderly people living with Alzheimer's disease and their family caregivers, since the network of health services lacks specialized professional attention to serving this audience.^{7,8}

Hence, the study had as its general objective: to analyze the main challenges and the care provided by nursing teams during the process of caring for elderly people bearing Alzheimer's disease and their family caregivers.

METHODS

The integrative literature review was the method adopted here, having a descriptive and exploratory approach. The present method was chosen because it fits the scope of the study, which pursues to synthesize the main results of studies already published on a given theme, in an orderly and systematized way that allows general conclusions about a particular area of knowledge.⁹

In order to prepare this review, six steps were taken: identification of the problem; elaboration of the guiding question; establishment of inclusion and exclusion criteria; scientific data collection; selection and categorization of articles; assessment, interpretation, and synthesis of results.¹⁰

Therefore, the study had as a guiding question: What are the care practices and challenges experienced by the nursing team during the process of caring for elderly people bearing Alzheimer's disease and their family caregivers?

Data collection was guided by crossing the following descriptors: Alzheimer's disease, Caregivers, Family, Nursing and Nursing Care, all registered according to the Health Sciences Descriptors. Data collection took place from February to April 2018. The online databases were used as follows: Scientific Electronic Library Online (SciELO) and the *Literatura Latino-americana e do Caribe em Ciências da Saúde (LILACS)* [Latin-American and Caribbean Literature in Health Sciences].

The selection was made using the inclusion and exclusion criteria using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Diagram,¹¹ as shown in **Figure 1**. The inclusion criteria were as follows: abstracts and full texts available in the electronic

databases of health literature, free of charge in Portuguese and/or English indexed in national and international journals, published between the months of January 2007 and March 2018, which met the guiding question and the objectives of the present study. The exclusion criteria were as follows: articles that did not have full access and with paid access, outside the time limit, or that were in the format of reflection, editorials, literature review, theses, and dissertations.

For the analysis development, the work identification phase was initially carried out, where 253 were found in SciELO and 530 in LILACS. For the pre-selection phase, the abstracts of the articles were read in order to refine the sample, by excluding duplication, time limit and title, resulting in 38 in SciELO and 90 in LILACS. In the eligibility phase, the articles were thoroughly read, and those that did not meet the guiding question were excluded, totaling 6 in SciELO and 7 in LILACS. Ultimately, a total of 13 articles were included.

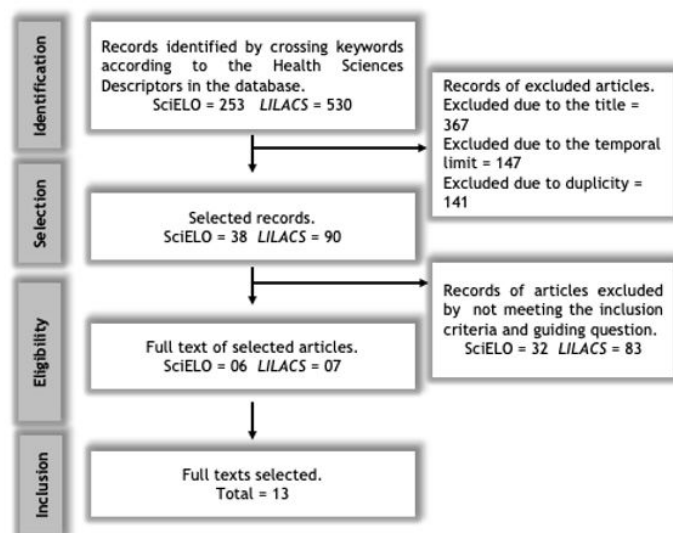


Figure 1: Flowchart representing the phases of identification, selection, eligibility and inclusion of articles in the integrative literature review through the PRISMA. Brasília city, Federal District, Brazil, 2018.

Source: It is originated from this research according to the PRISMA model.

Taking into consideration such sample and aiming for a better understanding and interpretation of the data, the articles were systematically categorized, resulting in the following empirical categories: positive and negative consequences faced by the family caregiver of the elderly person bearing Alzheimer's disease; nursing care for elderly people bearing Alzheimer's disease and their family caregivers; and, the challenges of public health policy concerning elderly care.

RESULTS AND DISCUSSION

The data presented in **Table 1**, were filtered through

the Prism Diagram (Figure 1). Thus, the LILACS database had the highest percentage of publications selected with (53.84%), followed by SciELO with (46.16%). In Table 1, data on the characterization of the studies are presented according to: authors, publication year, journals, objectives, methods, results and main conclusions. The analysis shows that there is a greater number of publications in 2015, corresponding to (23%), followed by the years 2011, 2012, 2014 and 2016 making a total of (15.38%) for each year, of (7.69%) in 2008 and (7.69%) in 2013.

It was found that nine studies, about (69%), correspond to journals in the nursing area, and (31%) correspond to the area of public health. With regard to the objectives (73.8%) of the selected articles, they pursue to describe, analyze and identify how the care for people living with Alzheimer's disease and their family caregivers is managed, (23%) highlight the care strategies and knowledge of nurses regarding the care provided to the elderly person, (15.38%) report how families provide this care.

Concerning the methodological approach, about (69.2%) are descriptive studies with a qualitative approach, (15.38%) correspond to cross-sectional and descriptive studies with a quantitative approach and (15.38%) are exploratory studies with both quantitative and qualitative approaches.

The results highlight that (30.76%) sought to describe nursing care and nurses' knowledge in the process of caring for elderly people bearing Alzheimer's disease and their families. A description of the care provided by the family caregiver and how this activity is perceived by the caregiver was found in (76.92%) of the analyzed articles. In (7.69%) of the analyzed data, it states the need for improvement within permanent or continuing education, for part of the nursing team, due to little knowledge to carry out the orientations in face of the specificities of Alzheimer's disease in the elderly's routine and your family caregiver.

For (15%) of the studies, it is important to address this matter in the political framework, as there is a dissociation from policy and practice, given the unmet needs of elderly people bearing Alzheimer's disease, their family caregivers and nursing teams.

Table 1: Characterization of the selected studies according to the authors, publication year, journal, objective, methods, results and main conclusions. Brasilia city, Federal District, Brazil, 2018.

| Author, year and journal | Objective | Methods | Results | Main Conclusions |
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| Freitas ICC, et al. 2008. Rev bras Enferm. | To describe and analyze living with Alzheimer's patients from the family caregiver's perspective. | Qualitative study. | Caregivers manifest the need for time to adapt to the physical and emotional demands of the new activity as a family caregiver. The limitations manifested by the elderly bearing Alzheimer's disease were, as follows: the inability to perform daily activities. When providing care, the family member experiences a stressful and exhausting routine, | It is possible to know part of the daily life of people who experience the practice of care as a family member. In this field, there are feelings manifested by the difficulties of the practice itself and by emotional |

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| | | | and exhausting routine, because the care is provided unilaterally. | emotional exhaustion, which are generated by the exclusive responsibility of only one member of the family as a caregiver. |
| Poltroniere S, Cecchetto FH, Souza EN. 2011. Rev. Gaúcha Enferm. (Online). | To unveil the knowledge of nurses in clinical inpatient units regarding the Alzheimer's Disease (AD) and the care demand by patients and family members. | Descriptive study with a qualitative approach. | There is evidence of the fragility regarding the knowledge about Alzheimer's disease and its phases, drug therapy and specific nursing care in the hospital setting. This lack of knowledge is a complicating element, given the nurse's approach with the client's family. The functions of guiding and educating were the main ways identified for the performance of the nursing role with the family of the elderly bearing Alzheimer's disease. | Nurses in the inpatient unit have limited knowledge about the topic. They are shown as secondary players in the caring process, when they should be more autonomous when providing care and attention to the family of elderly people bearing Alzheimer's disease. |
| Mattos CMZ, et al. 2011. Estud. Interdiscipl. Envelhec. | To apply the nursing process in elderly people bearing Alzheimer's disease who are participating in the UNICRUZ project. | Qualitative study. | Among nursing diagnoses, the following can be highlighted: anxiety, aspiration risk, activity intolerance, a deficit in self-care regarding food and hygiene, ineffective family control. For the family, elderly people bearing Alzheimer's disease are forgotten by society in the face of the National Policy for the Elderly, which emphasizes their social participation and active participation in society. It is clear that nursing diagnoses and their goals alleviate or meet the needs of the family and elderly people bearing Alzheimer's disease. Such intentions and care are related to nursing prescriptions, which were formulated individually for each clinical case, helping the family in providing care and social insertion. | The nursing process was applied to care for elderly people bearing Alzheimer's disease, which made it possible to clearly know the client's health status, and also to describe the points of nursing intervention through the diagnosis and prescriptions of such professional area. |
| Ramos JLC, Menezes MR. 2012. Rev Rene. | To ponder upon the care provided to elderly people bearing Alzheimer's disease based on oral reports from family caregivers, based on the Madeleine Leininger's Theory of Diversity and Universality of Cultural Care. | Qualitative study. | Most caregivers are women (95%), this group is formed mostly by daughters, with an average age of 53 years old. The findings prove how women are still seen as the main providers of family care, especially for elderly members. There is an increasing number of elderly people who care for other elderly people. The care actions are full of daily tasks for elderly people bearing Alzheimer's disease. The caregiver encourages the elderly person to perform self-care, such as dressing, which is a delicate moment that requires tolerance. | The importance of the nurse's performance is addressed in the study. This professional acts as a mediator between the elderly, family and health team. It is important to strengthen the care provided towards family caregivers of elderly people bearing Alzheimer's disease, in the field of assistance and public health policies. |
| Oliveira APP, Caldana RHL. 2012. Saude soc. | To investigate the repercussions of care in the life of the family caregiver of elderly people bearing Alzheimer's disease, as they understand that the family of the sick elderly person should not be considered only as a care unit, but also as a unit to be cared for. | Epistemological study with a qualitative approach. | Most caregivers are women, with family bonds, such as daughters or granddaughters. Social privation is a current reality in the lives of family caregivers, who manifest feelings of loneliness, isolation, fear, depression, anxiety, and sadness, which have an impact on their personal and professional routine. Caregivers see care as a form of retribution for the care that their country or grandparents have given throughout their lives. | The caregiver experiences several reactions to the activity of caring for the loved one, such as satisfaction, as well as moments of impatience, for not being able to manage care practices in a timely manner. The findings point to the deconstruction of exclusively negative meanings that involve the act of caring for the elderly person bearing Alzheimer's disease. |

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| Santos CF, Gutierrez BAO. 2013. Rev Min Enferm. | To know the quality of life of informal caregivers of elderly people bearing Alzheimer's disease, furthermore, checking if there is a difference in the biopsychosocial aspects that interfere in the quality of life of those caregivers. | Descriptive and cross-sectional study with a quantitative approach. | In this study (82%) of the caregivers were women and (62%) had some pre-existing disease, (98%) were family members, including daughters and wives. The study identified work overload, anxiety and depression as aspects that interfere in the life of family caregivers of elderly people bearing Alzheimer's disease, but the quality of life is still present in most participants. It is important to underline the importance of the nurses' approach towards family caregivers of elderly people bearing Alzheimer's disease, as they contribute to the familiarization with care practices, seeking to ensure an improvement in the quality of life of the elderly and also the caregiver. | Most caregivers have an average degree of anxiety and less than half have scores for depressive symptoms. Dissatisfaction is manifested by the absence of leisure. The study is important for the management of public policies in comprehensive health care for elderly people and their caregivers. | | | | this scenario, the family caregiver starts to live according to the elderly person, which forces them to quit their jobs. | practically limited to a family member who becomes a reference in daily activities, then generating effort overload. |
| Cruz TJP. et al. 2015. Rev. Bras. Enferm. | To know the influence of cognitive stimulation at home, which is performed by the caregiver of the elderly person bearing Alzheimer's disease. | Case study with a qualitative approach. | | | | | Most caregivers were female, over 50 years old, and daughters. The results obtained show that all elderly people bearing Alzheimer's disease have a cognitive improvement after the introduction of cognitive stimulation activity, according to the Mini-Mental State Examination (MMSE) test. Concerning the Katz scale, which assesses basic activities of daily living, about 60% of the elderly people remained independent and 40 dependents of performing daily activities at home. It was observed that during the stimulation, the elderly person showed a decrease in the level of dependence. Considering the Lawton scale, which aims to identify the level of functional condition, the majority of the elderly people remained dependent. In the Clock-Drawing Test, the level of education did not influence the cognitive impairment of elderly people. In this study, the improvements in cognitive status were due to the performance of stimuli, performed by family caregivers, three days a week. The research identified that negative feelings such as sadness, helplessness and mood changes were experienced by family caregivers, due to the lack of security and preparation for providing care. There is a prominent interest by caregivers in obtaining information about the disease. | According to the findings, elderly people and caregivers who participated in the research could benefit from the implementation of cognitive stimulation, as it contributed to improving the understanding of caregivers in relation to the importance of continuing the activity started in therapeutic workshops. | |
| Bagne BM, Gasparino RC. 2014. Rev enferm UERJ. | To assess the quality of life of the caregiver of the Alzheimer's patient and its relationship with the level of functional independence of the patient. | Descriptive and cross-sectional study with a quantitative approach. | Considering the total number of elderly people bearing Alzheimer's disease, 7 (10.6%) were classified as completely independent and 5 (7.6%) were totally dependent, and the others obtained some type of assistance in daily tasks. Caregivers had an average age of 55 years old, where most of them were female. Families with higher incomes had a better quality of life. The lack of professional activity in the marketplace due to care provision is a stressful factor, as one has to dedicate himself to the elderly person bearing Alzheimer's disease. | No significant relationship was found between the assessment of the family caregiver's quality of life and its relationship with the measure of functional independence of the patient. | | | | | |
| Vidigal FC. et al. 2014. Cogitare Enferm. | To understand the conditions of satisfaction of family caregivers of elderly people bearing Alzheimer's disease in the municipality of Umuarama, Paraná State. | Descriptive-exploratory study with a qualitative approach. | All caregivers were female, with an average age of 50 years old, where most of them were daughters of elderly people bearing Alzheimer's disease. It was evident that the family caregiver develops technical skills, as a way of learning to provide care to their relative with Alzheimer's disease. Family caregivers reported pleasure in being able to provide well-being to their loved ones, highlighting bathing as the care that most gave them joy. Resilience strengthened by faith is felt in the lives of caregivers, especially concerning satisfaction and the emotional bond with the person being cared for. In this framework, nursing professionals provide guidance about the care that must be performed by family members, given the understanding of Alzheimer's disease within the family, which will tend to cause changes in the family routine. Such nursing actions allow the caregiver to recognize the need for attention, affection and love for the sick elderly.] | The reality of this framework is seen as satisfactory, as the family caregivers feel satisfaction in returning the necessary care to the elderly. Belief pierces strength through faith. Nursing plays a fundamental role in this scenario, due to the guidance and assistance provided to the family caregiver and the whole family as well. | | | | | |
| Mendes CFI, Santos ALS. 2016. Saude soc. | To analyze the social representations of family caregivers of elderly people bearing Alzheimer's disease about the care practices. | Empirical and exploratory study with both qualitative and quantitative approaches. | | | | | The age group of caregivers was mostly around 60 years old or more. This shows that there are elderly people taking care of other elderly people. About (52%) of the caregivers express negative expressions, such as "prison" and "losing control of their own lives", due to the care provided to the elderly person bearing Alzheimer's disease. In (38%) of the family caregivers, there is an expression of gratitude and retribution for the care received early in life by the elderly affected by Alzheimer's disease. | It was found that the representations of family caregivers of elderly people bearing Alzheimer's disease are demonstrated with a feeling of loss of freedom, moral responsibility, giving back care and the inversion of roles. So, they are often unprepared to provide such care practices. | |
| Ilha S. et al. 2016. Esc Anna Nery. | To know the difficulties experienced by family caregivers of elderly people bearing Alzheimer's disease and to develop strategies that meet the difficulties experienced in the caring process. | Descriptive-exploratory study with a qualitative approach. | | | | | In regard to family caregivers, the majority were female, being wives or daughters. It was evidenced that the acceptance of Alzheimer's disease becomes something that is difficult for the family to understand, as well as the need of performing body hygiene for the elderly person, precisely because they express resistance, claiming that they have already performed such self-care. Moreover, the denial and acceptance of drug treatment, which generates | Considering the difficulties presented by the family caregiver, some strategies were indicated, such as: holding meetings with the family to expose the situation, making collective decisions about the disease, so that it can be accepted; when denying bathing, there are pleasurable | |
| Pizolotto, ALZ. et al. 2015. Espaço saude (Online). | To analyze how the family is organized to provide care to the elderly person bearing Alzheimer's disease at home. | Descriptive study with a qualitative approach. | The study shows that the role of caring is assumed almost exclusively by a family member, in a continuous activity. There is a need for special attention by the healthcare team towards the caregiver, who reports dedicating all his time to providing care to the elderly person bearing Alzheimer's disease. Nonetheless, the care practices are | There are adjustments in the routine and in the family environment due to the dependence of the elderly person who bears Alzheimer's disease. Nonetheless, the care practices are | | | | | |

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| | | | <p>aggressiveness. Nursing professionals have developed strategies related to forgetting the way home, such as: preventing the elderly person from leaving the house without knowing where he is going; going along without him realizing the reason; trying to identify him with a badge on his clothes, with full name, address, and telephone, in addition to informing neighbors about the disease.</p> | <p>strategies that encourage the elderly person bearing Alzheimer's disease to perform personal hygiene; in regard to aggressiveness, it is possible to try not to take it personally and never fight back. Nursing becomes an important profession in these care actions, due to the strategies and accessible language that is easy to understand by clients.</p> |
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Source: Original research.

Note: The journals' names were kept as in their original language.

Positive and negative consequences faced by the family caregiver of the elderly person bearing Alzheimer's disease

Considering the total of studies analyzed, (61.5%) cited that the female sex predominates as the main agent to provide care to the elderly person bearing Alzheimer's disease, being daughters or wives as the main family relationships, with an average age of 50 years old or more.¹²⁻⁹

Among the main consequences related to the activity of the family caregiver, there were found the negative feelings, due to the difficulty and the wear and tear faced daily while providing care, where only one family member is the main caregiver, presented in (69%) of the studies.

The literature points out that the changes that cause Alzheimer's disease in the elderly population affect family members at different levels, being associated with the difficulty in measuring the changes that the stages of the disease bring to their daily lives, as in the care to be performed. These changes generate sadness, fear, and anxiety on the part of the family, which later adapts and regains balance to deal with anxiety and anguish, but there is an increase in overload caused by the worsening of the disease and the absence of help from another family members.²⁰

In this framework, it is important to know the daily lives of people who live with a family member affected by Alzheimer's disease, as it will provide an understanding of the emotions, difficulties, emotional exhaustion, which are generated due to living with the sick family.²¹

This wear and tear tend to generate negativity in the feelings of the caregiver, as they have to quit their jobs, deprive themselves of leisure activities, by the withdrawal of their friends, decreasing their quality of life.¹⁹

When the family caregiver does not feel supported by the other family members, he will manifest discomfort and feeling of loneliness. Hence, it is necessary to pay attention to the caregiver who is in the particular situation of caring

alone for an elderly person and dependent member, due to their own illness.^{19,22}

The literature shows that there are positive elements, such as satisfaction with the performance of care due to the feeling of retribution that the family caregiver expresses in front of the loved one. This relationship of affection is built by the well-being that the family caregiver can provide to the elderly person bearing Alzheimer's disease, with the bath being highlighted as the main form of care that most guarantees their satisfaction. It is important to highlight that the activity performed by the family caregiver, when developed daily with less than five hours, guarantee them less work overload and a positive feeling about the act of caring.¹²⁻⁶

Nursing care for elderly people bearing Alzheimer's disease and their family caregivers

The nursing approach during the process of caring for elderly people bearing Alzheimer's disease and their family caregivers was observed in (30.7%) of the analyzed studies. Nevertheless, the data show a limited knowledge on the part of nurses who work in inpatient units. Limited knowledge about Alzheimer's disease was observed, being manifested by the professionals themselves in the face of activities that involve the family caregiver's own management and understanding of the disease. This unpreparedness is related to little knowledge about Alzheimer's disease and its phases, in addition to drug therapy and specific nursing care for sick elderly people.⁵

It is from the needs expressed by the family caregiver, that health professionals and the entire nursing team, should think of this subject as a being who also needs care.²³

Given the aforementioned, one of the responsibilities to be performed by nursing team is related to the guidance to family caregivers, about the understanding of Alzheimer's disease in their families and the adverse conditions that the disease tends to generate in the family routine. Such nursing actions help the family caregiver to recognize the need for attention, affection, and love, expressed by the sick elderly.¹⁶ That is why it is important for nurses and the entire nursing team to work with primary and secondary caregivers in an integrated manner, meeting their physical, mental and social needs.¹⁴

Other research points to the development of nursing diagnoses and strategies, such as: a survey of nursing diagnoses, the establishment of goals and care that can meet the needs of elderly people and their family caregivers. These actions seek to promote the cognitive improvement of elderly people bearing Alzheimer's disease, while promoting care strategies for family caregivers, in a way that facilitates care and reduces the exhausting feelings brought about by this responsibility.²⁴

Such goals and care practices are related to nursing prescription, with measures to promote healthy eating, assist and encourage self-care, improve verbal communication,

cognition and memory through games, readings and playful activities. Such measures must be specifically formulated by nursing, for each elderly person, which will assist the family in care and social insertion. These actions were only carried out through the development of the nursing process, which pursues to raise and describe important points for the care of elderly people bearing Alzheimer's disease, which allows listing several interventions due to nursing prescriptions.²⁴

Studies point towards the importance of cognitive stimulation in therapeutic workshops carried out by nurses, along with the application of mental status assessment tests, which has been guaranteeing improvements in the cognitive status of elderly people bearing Alzheimer's disease.

Cognitive stimuli must be developed through the identification of figures, objects, calendar, clock, relationship with people, recognition of the environment, stimulus to manual activities (knitting, crochet, sewing, and embroidery), leisure activities (sports, games, walking, dancing)) and/or intellectuals (reading books, newspapers, and magazines). The tests that can be applied, according to the literature, are the Mini-Mental State Examination, Katz Scale, Lawton Scale, Clock-Drawing Test, and Verbal Fluency Test.¹⁷

The tests were performed before and during cognitive stimulation. The Mini-Mental State Examination (MMSE) test was the one with the most positive results, where all the elderly people increased their scores, identifying that the stimulations achieved results in improving cognition. In this stimulating process, caregivers should be encouraged to participate, as such therapeutic workshops help the family member to understand the relevance of continuing activities.¹⁷

The following show the strategies and actions promoted by nursing, in view of the readjustment and understanding of the development of Alzheimer's disease in the family core: the acceptance of the disease by the family, through the development of meetings with the family to expose the situation, making collective decisions about the disease; related to the denial of bathing or general hygiene, it is possible to try to find pleasurable means that stimulate the person bearing Alzheimer's disease, such as games where there are scores and prizes; aggressiveness should not be considered as a personal thing, so you should not fight back; having patience with acts of forgetfulness, trying not to contradict the elderly; trying to identify the elderly person using a badge, with information, such as name, address and telephone number; as for financial autonomy, it is important that the elderly people have control of part of their earnings, so that they do not feel stolen or inferior; trying to monitor the elderly person daily during drug treatment, aiming to avoid either errors or loss of medication.²³

These strategies are aimed at the main difficulties referred to and experienced by the group of family

caregivers. They were built collectively and participatively, which favored the interrelation between caregivers and nursing professionals, due to the accessible and easily understood language.²³

The challenges of public health policy concerning elderly care

In the Statute of the Elderly, the following legal frameworks are guaranteed, such as rights for the elderly person, in accordance with Art. 15, comprehensive health care for the elderly is ensured through the SUS, guaranteeing universal and equal access, jointly articulated and continuous actions and services for the prevention, promotion, protection, and recovery of health, including special attention to diseases that preferentially affect the elderly.²⁵

It is incumbent upon the public power, as addressed in the § 2nd, to provide the elderly person, free of charge: medicines, especially those for continued use, as well as prostheses, orthoses and other resources related to treatment, habilitation or rehabilitation. Where health institutions must meet the minimum criteria for meeting the needs of the elderly, promoting the training and qualification of professionals, as well as guidance to family caregivers and self-help groups in accordance with Art. 18 of the Elderly Statute.²⁵

These standards partially meet the needs of the elderly person in general, as they are processed in a way that is separate from the reality experienced by elderly people, their families and their caregivers. Making it ineffective in view of the needs expressed by the subjects involved in the caring process towards elderly people bearing Alzheimer's disease.

It is important to point out that the existence of laws and protocols for health care for the elderly, by itself, will not guarantee facing the various challenges related to the care of this public. Considering this statement, the literature supports the construction of public policies that seek to approach the needs experienced by care professionals and family members in the caring process for elderly people bearing Alzheimer's disease. These strategies must consider the social, economic and cultural factors that involve the exercise of care. Still looking for ways to also assist the family caregiver.^{13,14}

It is fundamental to have continuous and efficient attention to the health and well-being of the elderly population. It is relevant to plan strategies in view of the different phases, the disabilities manifested by Alzheimer's disease and the way the family caregiver sees this path. Such actions must be based on comprehensive, adequate, qualitative and humanized care in health care networks.⁶

CONCLUSIONS

Nursing care pursues to develop methods that assist in the caring process for elderly people bearing Alzheimer's disease. These actions tend to facilitate, when the family caregiver's practice is well developed, through goals and guidelines related to each stage of the Alzheimer's disease.

In this process, the family caregiver expresses positive and negative feelings. Positivism occurs through the understanding and acceptance of the loved one's illness, which generates feelings of satisfaction in being able to repay the care one day received by the elderly person. The negative elements are related to wear, anxiety, sadness, social and professional isolation that family caregivers manifest, when they become the only subject who provides care.

Given this framework, nursing professionals have a big responsibility, so they must identify positive and negative feelings for caregivers, aiming to set goals and nursing care practices so that the family caregiver does not feel helpless. For this, it is necessary that the entire nursing team and other health professionals pursue to participate in the processes of permanent or continuing education regarding the health care of elderly people bearing Alzheimer's disease and their family caregivers, in view of the acceptance, understanding, and dynamics of caring practices related to the disease.

It is important that public policies pursue to guarantee caring practices for elderly people bearing Alzheimer's disease, approaching the real needs experienced by such population, as well as family caregivers and health professionals.

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