



**OBJN**  
Online Brazilian Journal of Nursing

**ENGLISH**

Federal Fluminense University

**AURORA DE AFONSO COSTA**  
NURSING SCHOOL



Summary of theses  
and dissertations



## Care measures for older adults with Alzheimer's Disease: a descriptive-exploratory study

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### ABSTRACT

**Objectives:** to identify from the perspective of the nurse the care provided to older adults with Alzheimer's Disease and what the main challenge for its realization is.

**Method:** a descriptive-exploratory and qualitative study, conducted in August and September 2017, with 15 nurses working in the male and female medical clinic of a Teaching Hospital located in a municipality in the state of Paraíba. Data was collected through interviews and records in field notes, and were subjected to Content Analysis.

**Results:** four thematic categories emerged: Nurses' understanding of Alzheimer's Disease; Assistance to the older adult and the family; Lack of training; and Rejection of family members in the face of diagnosis. **Conclusion:** nurses have limited knowledge about the care of older adults with Alzheimer's Disease. This knowledge deficit can have consequences in the care of older adults with Alzheimer's Disease, as well as for their family members.

**Descriptors:** Older Adult; Family; Alzheimer's Disease; Knowledge; Nursing.

## INTRODUCTION

The significant increase in the life expectancy of Brazilians is due to scientific and technological advances and to the preventive actions that are expanding knowledge of the older adults, favoring reflection and improvement of the health conditions and, consequently, better quality of life<sup>(1)</sup>.

Given the multifactoriality involved in aging, this age group has generated great challenges and concerns for Brazilian public health due to the disposition of chronic conditions that accompany them, such as chronic degenerative diseases like Alzheimer's Disease.

Alzheimer's Disease (AD) is a progressive and chronic disorder characterized by the destruction of cholinergic neurons, being one of the leading causes of dementia in the world. Age is the most relevant risk factor in its development. It is characterized by an insidious and progressive decline of memory, language, gradual loss of functional capacity and autonomy, causing, over time, total dependency on other people. For being irreversible and presenting progressive deterioration, it can cause devastating effects in the family members, such as work overload and socioeconomic and psychological implications, as well as

intrafamily conflicts<sup>(2-3)</sup>. It is estimated that, globally, there are nearly 50 million people with dementia, with almost 10 million new cases each year<sup>(3)</sup>.

By understanding that AD causes dependence as it compromises the cognitive and motor functions and that there is an urgent need to know the phases of the degenerative process caused by the disease, as well as aiming at the acquisition of greater knowledge/information about how to perform the daily care tasks, it is perceived that Nursing actions need to be objective, preventive and effective.

When performing Nursing care for older adults with AD, nurses need to know and evaluate if there are limitations, because only in this way will they develop a specific care plan for the older adult, with a holistic and humanized view, applying the Systematization of Nursing Care.

These interventions performed by Nursing professionals have the objective of preserving the patient's capacity as much as possible and at achieving the best possible functional performance in each stage of the disease, always aiming at the physical and emotional well-being of the person with AD. Thus, it is necessary, whenever possible, to use care and educational actions focused on modifying unwanted situations and the environment itself<sup>(4)</sup>.

In this perspective, it is important that these professionals, throughout the assistance provided to the older adult with Alzheimer's Disease, can perform health promotion actions, with the objective of providing symptomatology control, greater safety, family interaction, comfort and better quality of life. In addition to that, there is a need for these professionals to understand the several aspects that involve the disease, such as its phases, the changes that the older adult develops during the disease process, the importance of family support and, mainly, knowing the life history, the way in which the family member faces the situation, in order to help families to live with the specificities imposed by AD, especially when external factors arise that, together, further harm the care relationship with the older adult<sup>(5)</sup>.

Nurses are the professionals responsible for the systematization of the care provided to the individuals. Thus, it becomes necessary to have clinical knowledge about the processes of life and aging, as well as about the main diseases that affect people in each age group. In 1994, the National Policy for the Older Adult (*Política Nacional do Idoso*, PNI) already referred to the need to include Gerontology and Geriatrics as curricular disciplines in higher education courses in the health area<sup>(6)</sup>. In 2006, the National Health Policy for the Older Adult (*Política*

*Nacional de Saúde da Pessoa Idosa*, PNSPI) was approved, which, in its guidelines, values permanent qualification in the area of health of the older adult, seeking to encourage the development of research and teaching on the aging process<sup>(7)</sup>.

Nurses' lack of knowledge about care in this aspect can culminate in serious harms to the life of the older adults, since cognitive and behavioral stimulation is essential for their rehabilitation and comfort<sup>(4)</sup>. Thus, the importance of determining the Nursing knowledge about Alzheimer's Disease and is perceived, mainly, how these professionals have been providing care to help the well-being of these individuals.

AD has repercussions on coping difficulties both for the older adults and for the family members and professionals, as lack of knowledge about the disease is a factor that can contribute to its severity, in addition to favoring the failure to perform due care. Therefore, it is fundamental that the nurses who work in care know this pathology, thus training themselves to develop effective measures that provide greater care, safety and comfort to the affected older adult<sup>(4)</sup>.

Thus, the study aimed at: identifying from the perspective of the nurse the care provided to older adults with Alzheimer's Disease and what the main challenge for its realization is.

## **METHOD**

This is a descriptive and exploratory study, with a qualitative approach. For this research, an interpretative approach was used seeking to understand how the nurses' knowledge about the care of the older adult with Alzheimer's Disease is presented.

This study comes from a Nursing Undergraduate Course Conclusion Paper. It was carried out in a Teaching Hospital in the municipality of João Pessoa, Paraíba, Brazil. The Institution has a structure formulated to meet the needs of patients, students and collaborators. It is a reference in medium- and high-complexity cardiovascular surgeries, and treats affiliated patients, private patients, and by the Unified Health System (*Sistema Único de Saúde, SUS*), from the entire metropolitan region of João Pessoa (PB). It has several services in different medical areas, such as general practice, cardiology, neurology, gynecology, proctology, urology, gastroenterology, head and neck surgery and intensive care, among others.

For data collection, 15 nurses were conveniently selected, due to the service having a covenant with the Higher Education Institution to which the researchers were related. To participate in the research, the pre-requisite established was that the subjects worked

only in the male and female medical clinic, for this being a long-permanence sector for most of the patients, thus providing the opportunity for the development of comprehensive care.

The construction of the instrument for data collection was based on the Manual of the Caregiver of the Person with Dementia<sup>(8)</sup>. The interviews were guided by a semi-structured script, whose questions contemplated socioeconomic characterization data and questions related to the professional practice towards older adults with Alzheimer's Disease. The research questions were led by the following questions: What do you understand about Alzheimer's Disease? What care do you provide to the older adults hospitalized with Alzheimer's Disease and their family members? Do you feel prepared to care for aged individuals with Alzheimer's Disease? What are your difficulties in assisting older adults with Alzheimer's Disease?

Data was collected in the months of September and August 2017, after approval by the Research Ethics Committee (*Comitê de Ética em Pesquisa, CEP*), under protocol No. 101/2017, CAAE: 71167517.9.0000.5179 and express authorization from the Teaching Hospital by the Internship, Research and Continuing Education Center (*Núcleo de Estágio, Pesquisa e Educação Continuada,*

NEPEC), through the same protocol and CAAE previously mentioned.

To start data collection, the researchers asked the hospital's management for a meeting with the nurses in the medical clinic sector, in order to present the study objectives, the data collection method and the Free and Informed Consent Form (FICF). Taking advantage of the meeting, the interviews were scheduled, respecting the service schedules, and establishing with the participants days and times for the meetings to take place.

The interviews with the 15 nurses were scheduled and carried out individually. The mean duration of each interview was 20 minutes. Although there was no time limitation for the answers, the effective scope of the answer to the research objective was adopted as interruption criterion. All the sessions were audio-recorded, with the respective record in field notes containing the researchers' impressions immediately after the entire observational part in each meeting.

Data was collected and transcribed by the researchers themselves, in order to facilitate the capture of details, such as pauses and intonations, for closer approximation with the study object. The 15 interviews totaled 05 hours.

The interview transcripts resulted in 169 text pages, combined with the 89 pages referring to the notes in the field diary. Each participant was assigned

an alphanumeric classification made up of the letter "E" and a number from 01 to 15, randomly assigned. Data production sought to guarantee the aspects that confer quality to qualitative research, namely: credibility, transferability and confirmability<sup>(9)</sup>.

To analyze the empirical data, the Content Analysis Technique proposed by Bardin<sup>(10)</sup> was adopted, which is organized based on a categorization process, classifying the constituent elements of a set, by differentiation and, subsequently, by grouping, with previously defined criteria. It was decided to adopt this technique because it is applicable to diversified speeches, aiming to obtain systematic and objective procedures for describing the contents of the messages, allowing inference of knowledge related to the conditions of production/reception of the messages.

Subsequently, the empirical material was subjected to a more in-depth study, guided by the objective and theoretical framework, aiming at the breakdown of the registration units, that is, the codification that corresponds to the transformation of the raw data of the text. This transformation, through textual clipping, classification and aggregation, made it possible to reach a representation of the content for formulating the categories. The statements that illustrate the categories

were coded by the alphanumeric classification, enabling data triangulation between the questions, categories and subcategories from the interpretation of the interviews on the Nursing care actions arising from knowledge on Alzheimer's Disease, as summarized in Chart 1.

**Chart 1** -Characterization on the nurses' understanding, care, professional training and difficulties to provide assistance to older adults with AD. João Pessoa (PB), Brazil, 2017.

| Questions   | Categories                                   | Subcategories              |
|---|--|----------------------------|
| What do you understand on Alzheimer's Disease? What are your difficulties in assisting older adults with Alzheimer's Disease? | Nurses' understanding on Alzheimer's Disease | Concept                    |
|   |  | Progression of the disease |
| What care do you provide to the older adults hospitalized with Alzheimer's Disease and their family members?                  | Assistance to the older adult and the family | Daily Care Measures        |
|   |  | Family participation       |
| Do you feel prepared to care for older adults with Alzheimer's Disease?   | Lack of training                             | Weaknesses                 |
| What are your difficulties in assisting older adults with Alzheimer's Disease?  | Family members' rejection of the diagnosis   | Non-acceptance             |

Source: Direct Research.

This study respected the ethical precepts of research with human beings, according to Resolution No. 466/2012 of the National Health Council<sup>(11)</sup>. All the

participants signed the Free and Informed Consent Form.

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## RESULTS

It was verified that the profile of the nurses who perform their duties in the medical clinic is that of young adults, where six (40%) are in the age group between 30 and 34 years old; 15 (100%) are female; seven (46%), single; and 13 (87%) have some graduate degree. Among the surveyed individuals, nine (60%) report having experience with older adults, and 14 (93%) feel able to care for older adults with Alzheimer's Disease.

After the identification stage of the socioeconomic and professional profile of the subjects, the structuring of the data triangulation between the questions, categories and subcategories was sought. To such end, after identifying the categories addressed from analyzing the content of the interviews, four thematic categories and six subcategories inherent to the care of older adults with Alzheimer's Disease and their weaknesses emerged, as described below.

### *Thematic Category 1 - Nurses' understanding on Alzheimer's Disease*

From the interviewees' statements, the subcategories listed as Concept and Progression of the Disease are observed, which are characterized by degenerative problems and chronicity of the disease, in

addition to the symptoms emerging during the disease process.

*It's the degeneration of the nerve cells, and it's affecting the whole organism [...]. (E5, E2, E8, E9)*

*Degenerative disease of the central nervous system that mainly affects older adults. (E6, E14)*

*There's no cure, but it can be treated [...]. (E7)*

*Alzheimer is, as far as I know, it's a disease that has no cure [...]. (E11)*

*It initially compromises the older adult's memory [...]. (E6)*

*Progressive disease that destroys memory and other brain functions [...]. (E7)*

*Alzheimer is a neurodegenerative disease that causes the decline of the cognitive functions [...]. (E12, E15)*

### *Thematic Category 2 - Lack of training*

Given this theme addressed by the nurses, the Weaknesses were defined as subcategory 2, having as main factor the need to improve knowledge about the content for the effective provision of care.

*We should participate in more training so that we can improve, because what we see in undergraduation is still very little. (E6)*

*[...] seek training [...] then I will be able to improve my assistance, I think that it's that, adopting the attitude of being*

*informed, of knowing, to be able to apply it in the practice. (E9)*

*[...] I could do a specialization in the area, do you understand? In the area to deepen more [...]. (E11)*

*Thematic Category 3 - Assistance to the older adult and the family*

The participants highlight the importance of Daily Care and Support for Family Participation for the care of the older adult with AD, having these as subcategories of this theme. For this, they are based on the limitations and individualized attention to the provision of adequate care, as well as on the motivation to the family member of the older adult.

*[...] his issue of food, the digestive part, whether he can eat by himself or not, we give this support to him, also the part of locomotion, the part of the bath [...]. (E7, E9)*

*Change of decubitus, care with food, with bronchoaspiration, depending on the Alzheimer degree, care with hygiene,*

## **DISCUSSION**

When conducting the interviews, it was evidenced from the first thematic category that nurses need to expand knowledge about AD, because they refer to it only as a degenerative problem of the central nervous system, which mainly

*care with the medication that is very important, which affects if you stop doing, care mainly with falls, risk of environments for them. (E13)*

*A lot of attention and mainly patience [...]. (E7)*

*[...] respecting all their questions, fears, disorientations and thus setting up some planning for the care of this older adult. (E8)*

*Psychological Treatment: therapy, support of the family members. (E5)*

*Stimulate a lot family dialog with him [...]. (E11)*

*Thematic Category 4 - Rejection of family members in the face of diagnosis*

Non-Acceptance of the diagnosis can be observed as subcategory 4, manifesting a situation of resistance on the part of the relatives of the older adult affected by AD.

*Resistance on the part of family members towards the disease, care and dependence. (E2, E10)*

affects older adults, and whose cognitive symptoms begin with memory disorders.

The Diagnostic and Statistical Manual of Mental Disorders – DSM-V<sup>(12)</sup> describes the importance of health professionals in knowing how to observe and assist this



demand, since the AD symptoms are insidious and progressive, compromising learning in addition to memory.

Given the scarcity of information about AD, as seen in category 2, the interviewees themselves assert the need for training to better develop care and promote comprehensive care in all the needs of the older adult. From this perspective, a research study<sup>(4,10,12)</sup> conducted points out the importance of health professionals improving their knowledge in order to develop educational and assistance strategies through evidence-based interventions.

It is known that nurses are the professionals responsible for coordinating and evaluating Nursing care<sup>(13)</sup>; however, the lack of harmony between technical-scientific knowledge and gerontological care is still perceived. This care-related inconsistency points to the need for the services to hold permanent education meetings, in order to qualify these professionals to assist the older adults in all their diseases, mainly the neurodegenerative ones<sup>(14)</sup>.

From the third thematic category, some of the Nursing care actions developed that were evoked by the interviewed nurses, based on the health needs and limitations of the older adults, were identified. The most mentioned were the following: attention to feeding, body

hygiene, change of decubitus from the perspective of the bedridden older adult, locomotion, attention to falls, and care measures to avoid bronchoaspiration.

Given the care measures mentioned above by the interviewees, the importance of executing them through interactive strategies is emphasized, so that the older adults, when conscious and oriented, perceive the interaction and zeal of these professionals towards them, thus feeling safe and well taken care of. In case they do not have their cognitive capacity at a satisfactory level, the researchers believe that interactivity in actions transmits love, comfort, respect and safety<sup>(15)</sup>. In addition to that, it promotes (re)guidance of the family members so that they can learn to develop more expanded care when returning home.

The guidelines around family home care collaborate to reducing the rejection of family members towards AD. As reported by the interviewees during category 4, there is still family resistance to the diagnosis as a barrier to maintaining care and providing adequate assistance to the older adult. Corroborating the findings, a research study reveals the need for Nursing to attribute technical information to the family members on the progress and care for the older adult with Alzheimer's Disease<sup>(16)</sup>.

In addition to that, it is up to the Nursing professionals to include in their care routine for the older adult with AD the development of Nursing diagnoses and interventions for the patient and caregiver; to promote cognitive improvement in the older adult; to assist and stimulate self-care; to stimulate verbal communication and memory; and to perform therapeutic workshops, among so many other actions<sup>(17)</sup>.

Also in the third category, support for family participation contributes for them to know how to face and feel motivated given co-living with the AD phases. Therefore, the importance is perceived of stimulating therapeutic communication with the family to establish the link between family, patient and the health professional. This type of communication contributes to the expression of affection, especially for those who need to be shown affection<sup>(18)</sup>.

After all, families that have older adults with AD experience a significant change in family dynamics, due to the daily routine with direct care that involves everything from personal hygiene and the environment to the search to rehabilitate the older adult's functional and cognitive capacity, actions that are difficult to be performed when disease progression starts<sup>(19)</sup>.

This therapeutic aid allows the family to reduce the burden, facing the challenges

posed by the work routine and by the care attributed to the specificities of the disease. In this sense, the nurse's support, as previously mentioned, will allow the family members to understand the physiological and behavioral changes that involve the older adult with Alzheimer's Disease<sup>(19,20)</sup>.

From thematic category 4, we observe the quotes by participants *E2* and *E10* on the rejection on the part of the family members, who resist taking care of the older adult and even accepting the disease. Such factors are associated with significant changes and to the restructuring of the entire routine that involves family caregivers, in most cases triggering emotional overload, decreased quality of life, and family imbalance. Therefore, we emphasize the importance of providing guidelines to these family members so that they can better co-live with the older adult affected by Alzheimer's Disease. Otherwise, rejection can be fatal to the patient's life, representing an imminent risk<sup>(16)</sup>.

Strategies such as holding meetings with the family members to discuss the current situation of the older adults and their diagnosis; suggesting the division of activities with other family members; and proposing the hiring of professionals, formal caregivers - when the necessary financial conditions exist -, can positively

interfere in the care of the older adults with AD, also avoiding family burden<sup>(20)</sup>.

The importance of the Nursing professionals as to how to manage the older adult with AD and to establish goals to improve quality of life and health requires from these subjects the expansion of their scientific and technical

knowledge, the construction of an affective bond to offer comprehensive care, and an increase in the relational and communicational capacity to institute interventions, aiming to aid communication between all those who are part of the daily life of this older adult<sup>(4)</sup>.

### **STUDY LIMITATIONS**

The study limitations relate to the sample size, as it only covers nurses from the medical clinic, and the fact that data collection was conducted at the interviewees' workplace, leading to losses in terms of the time needed to answer the interview, due to the professionals' concern to return to the service.

### **CONCLUSION**

The changes resulting from aging are followed with great difficulty by the family members and by the health professionals, since many do not know how to face the disease process and, mainly, perform the necessary care actions required by AD, causing immense obstacles for nurses to work together with family members in the performance of their duties, among which guidance on the disease and the care that involves hygiene, nutrition, functional and cognitive stimulation stand out.

The objectives of the study were achieved insofar as the nurses' knowledge about AD and care for the affected older adult was verified. The need was identified for the nurses to expand their knowledge on AD; otherwise, there can be serious consequences in assisting older adults with Alzheimer's Disease, as well as for the family members.

As the care manager, the nurse needs to be scientifically based for the development of technical skills. Therefore, it is suggested that these professionals invest in training to improve and share their knowledge and, consequently, guide the caregivers and family members on the adequate techniques for the prognosis of patients with AD.

Based on the results, new research studies are suggested in relation to the theme, so that public and private educational institutions, as well as

managers from the municipal, state and federal spheres, promote courses that train all the health professionals who work in Primary, Secondary and Tertiary Health Care Services, especially those in Nursing, for they spend more time with

the patient. After all, the nurses' restricted knowledge is a condition that allows for inadequate care to the older adult with Alzheimer's Disease.

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5. Suellen Duarte de Oliveira Matos took part in approving the final version of the manuscript.

6. Adriana Lira Rufino de Lucena took part in approving the final version of the manuscript.

Received: 10/12/2020  
Revised: 11/19/2020  
Approved: 01/26/2021