CARE OF THE ELDERLY WITH ALZHEIMER'S IN LONG-STAY INSTITUTIONS CUIDADOS PRESTADOS AO IDOSO COM ALZHEIMER EM INSTITUIÇÕES DE LONGA PERMANÊNCIA

EL CUIDADO A LOS ANCIANOS CON ALZHEIMER EN INSTITUCIONES DE LARGA ESTANCIA

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ABSTRACT

Objective: to analyze the care provided by caregivers for the elderly with Alzheimer's in Long-Stay Institution. **Method:** a qualitative study, descriptive-exploratory, conducted through interviews, with 14 professionals from an institution of long-stay, processed with the IraMuTeQ software. **Results:** there were obtained five semantic classes, namely: Class 2-The routine of care given by professionals of the institution; Class 1-The importance of the elderly care professionals with signs of the effects of Alzheimer's: difficulties of concentration and memory; Class 4-Memory lapses of the elderly with Alzheimer's disease; Class 5-The role of the professional in the full care to the elderly with Alzheimer's; Class 3-Absence of the family in the care for the elderly with Alzheimer's. **Conclusion:** the care is good, but negative points have been observed as idleness of the elderly, family, and absence of scientific-theoretical knowledge deficit on the part of some professionals. **Descriptors:** Elderly; Alzheimer's Disease; Caregiver; Family; Health Care; Nursing.

RESUMO

Objetivo: analisar o cuidado prestado pelos cuidadores aos idosos acometidos com Alzheimer em Instituição de Longa Permanência. **Método:** estudo qualitativo, descritivo-exploratório, por meio de entrevistas, com 14 profissionais de uma Instituição de Longa Permanência, processadas no software IraMuTeQ. **Resultados:** foram obtidas cinco classes semânticas, a saber: Classe 2 - A rotina dos cuidados prestados pelos profissionais da instituição; Classe 1 - A importância dos profissionais nos cuidados ao idoso com sinais das consequências do Alzheimer: dificuldades de concentração e memória; Classe 4 - Lapsos de memória dos idosos com a doença de Alzheimer; Classe 5 - O papel do profissional no cuidado integralizado ao idoso com Alzheimer; Classe 3 - Ausência da família nos cuidados ao Idoso com Alzheimer. **Conclusão:** o cuidado se encontra satisfatório, porém foram observados pontos negativos como ociosidade dos idosos, ausência familiar e déficit de conhecimento teórico-científico por parte de alguns profissionais. **Descritores:** Idoso; Doença de Alzheimer; Cuidador; Família; Atenção à Saúde; Enfermagem.

RESUMEN

Objetivo: analizar el cuidado proporcionado a los cuidadores de ancianos con Alzheimer de una institución de larga estancia. **Método:** estudio cualitativo, descriptivo exploratorio, a través de entrevistas, con 14 profesionales de una institución de larga permanencia, procesado en el software IraMuTeQ. **Resultados:** se obtuvieron cinco clases semánticas, a saber: Clase 2-La rutina de atención por profesionales de la institución; Clase 1-La importancia de los profesionales del cuidado a los ancianos con las muestras de los efectos de la enfermedad de Alzheimer: dificultades de concentración y memoria; Clase 4-Memoria decae de los ancianos con enfermedad de Alzheimer; 5-El rol de clase del profesional en el cuidado a los ancianos con Alzheimer; Clase 3-Ausencia de familia en los ancianos con cuidado de la enfermedad de Alzheimer. **Conclusión:** la atención es bastante buena, pero se han observado puntos negativos como la ociosidad de los ancianos, la familia y la ausencia de déficit de conocimiento científico teórico por parte de algunos profesionales. **Descriptores:** Ancianos; Enfermedad de Alzheimer; Cuidador; Familia; Atención a la Salud; Enfermería.

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INTRODUCTION

The aging process occurs naturally, progressive and irreversible in each individual, featuring the differently as it advances in years, from birth to death, and may be accentuated due to pathological factors and the style of life. The status of older persons regulating how elderly people aged 60 or more years of age.¹⁻²

The increase in longevity and population aging are realities experienced by several countries. However, the way and the speed at which these processes have been taking place depend on each society. While in most developed countries the process of population aging is in a more advanced stage, in those developing countries, including Brazil, this phenomenon occurs relatively in a recent period and accelerated³.

Projections for the years 2030 and 2050 confirm that the population of the elderly in Brazil will grow significantly, being the fall in fertility rate one of the reasons for this aging population⁴. As a result, considerable increase of aging-related diseases, chronic degenerative have been the most significant, causing dementia on the neurological system. Among these is Alzheimer's disease (AD), which affects about 50% to 60% of the elderly population.⁵

AD features initially insidious with progressive deterioration of neurological functions. The most prominent clinical impairment is in memory of episodic form and with obvious damage in the acquisition of new skills. Already in the intermediate stages, fluent aphasia, evidenced by the difficulty to name objects or choose the proper word to express an idea. Moreover, finally, in the terminal stages, there are striking changes in the default sleep-rest and behavioral changes such as irritability and aggression, psychotic symptoms, inability to walk, talk, and perform personal care.⁶

In this perspective, the demand for long-term care tends to increase around the world, generating public health problems. With that, the institutions of long permanence for the elderly (ILPIs), which are complex organizations, consist of mostly internal subsystems in the multidisciplinary team should take care of management and care processes global health of the elderly. These institutions may be governmental or non-governmental, and has residential character.⁷

The study was motivated before perception, during practical activities

curriculum, the need to provide adequate care by the professionals for patients affected by AD, to improve the quality of life of the elderly.

OBJECTIVE

- To analyze the care provided by caregivers for the elderly with Alzheimer's in Long-Stay Institution.

METHOD

A qualitative, descriptive-exploratory study in an institution of long-stay in the municipality of Teresina, Piauí, which was carried out in the period from August to October 2016, with the participation of 14 formal and/or informal caregivers. For inclusion in this study, caregivers should have at least six months experience in the institution. As a criterion of exclusion adopted those under 18 years of age.

It was used as data collection tool a semi-structured interview script; for such purposes, a voice recorder, in which information was stored and then transcribed and analyzed.

To support the analysis of the statements, we used the IRaMuTeQ software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*), developed in France by Pierre Ratinaud, in 2009, and beginning to use in Brazil in 2013. It allows various forms of statistical analysis on textual corpus and tables of individuals by words. To perform lexical analysis, the software identifies and reformats the text units, which become Initial Context units in Units of Elementary Context. And it made, so the research of vocabulary, with a reduction to words, based on their roots (stemming), being created a dictionary from the reduced forms and identified the active forms and additional⁸.

For the analysis of text, set the Hierarchical Classification Method, in which the texts were classified based on their respective vocabulary, and the set of them was divided by the frequency of reduced forms. From the matrix that crossed segments of texts and words (repeated tests X^2), there was applied the method of Descendant Hierarchical Classification, to get a stable and definitive classification^{9,10}. The analysis for this classification aimed to get classes of segments of text that, besides having presented vocabulary similar to each other, had different vocabulary of text segments of other classes. The relationship between the

classes was illustrated by means of a dendrogram.

The ethical aspects of this study are in line with the Resolution 466/2012, of the National Council of Health of Brazil. The research received opinion approved from the Research Ethics Committee, under the Opinion N 1,613,794, on 29th June 2016.

RESULTS

The participants were between the ages of 24 to 61 and were in their majority female, middle-level school, featuring a heterogeneous, with incomplete basic education to the technical training course. In relation to the length of service, there was the period from one to ten years of occupation in the house.

Textual data analysis by IRaMuTeQ allowed the separation of the corpus in five units of elementary contexts (UCE's), with 98 segments of texts, 784 distinct forms and 3294 occurrences of words in the text. The average frequency of the forms was 33.612245, generating distinct semantic classes, analysed by the Descendent Hierarchical Classification (CHD), with use of 70.41% of the corpus. The CHD considered the association of the classes from the fixed variables of the study: subject, age, schooling, occupation and time of service.

For the construction of the dendrogram (Figure 1) and for the subsequent analysis there were considered the words with frequency equal to or greater than the average frequency (i.e., greater than or equal to 3), with X^2 greater than or equal to 2.18 and significance p less than or equal to 0.0001. Each class was described by most significant words (more frequent) and by their respective associations with the class (Chi-square). For CHD, the analysis and discussion of classes followed the dendrogram with its partitions, and the reading was granted, from left to right.

Thus, the lexical analysis showed that the class 2 covers the routine of care provided by ILPI's professional. Class 1 discusses the importance of the elderly care professionals with signs of the effects of Alzheimer's: difficulties of concentration and memory,

class 4 for memory lapses of the elderly with Alzheimer's disease, class 5, which deals with the role of the professional in the full care to the elderly with Alzheimer's, and the class 3, which depicts the family's absence in the care for the elderly with Alzheimer's.

you need to take to the hospital, they are taken (Dept. 08).

Their routine is normal here, wake up in the morning, bathing, take coffee, all normal. Have the bedtime and waking up (Dept. 09).

Care are the baths, in the power supply has to put the spoon in hand and they take and take to the mouth, but some have to put in their mouth (Dept. 03).

We seek activities that not only take care of their physical, but also help in mind (Dept. 14).

Attention to the elderly is, intrinsically, related to the presence of the caregiver. This performs or help the elderly to develop their activities of daily living. At ILPI these actions are satisfactory for being carried out with a focus on encouraging the elderly in their autonomy and independence. Care to the patient, let flow his feelings and the desire to express his love through the care, concern, respect and concern, with the assistance of caring way, loving, tolerant and patient.¹

These feelings were perceived in the pros, both in the way they expressed during the interview, as in some moments that paid assistance, demonstrating total interest for the cause during the treatment and talk to the elderly and that, together it would come to these, the feeling of accomplishment. Thus, it is valid to point out that the professionals develop a fundamental role in patient care, because they stimulate and guide these patients about self-care with the quality standards of patient care and caregiver.

♦ **Class 1:** The importance of the elderly care professionals with signs of the effects of Alzheimer's: difficulties of concentration and memory.

This class consists of 15 UCEs (segments of text), which corresponds to 21.7% of the total corpus and is directly associated to the class five and four. The words that appear more frequent and meaningful of the text segments of this class are: remember, walk, go out, so care and among others, whose values of X^2 correspond respectively (18,74, 15,29, 15,29, 14,65, 12,28).

Through the speech of the professionals, it is understood that these have a little difficulty with the elderly through due to the memory factor, because these wanes so precipitated the minds of older people affected. As an example, in the psychic area there is the use of activities that exercise the mind and the body, such as food and hygiene, because much of the elderly no

longer makes these tasks by themselves, needing the full help of caregivers.

The problem is that sometimes we say things we do, and then have to repeat several times to remember, have to be constantly reminding, they still forget my name (Dept. 5).

We work with the part of memory, exercise their memory doing activity with all of them. Hi, I'm your caregiver, you don't remember, but they always say I don't know this, I don't know that, then we will talking with them slowly and everything on working (Dept. 9).

We sit down and talk, ask what they do, what they were like before their past. The care required here are resolved. (Dept. 12).

Here is one that makes ten times per second the same question in a matter of seconds he asks the same question again. The care that we caregivers we perform is to bring the possible improvement of them. (Dept. 11).

Take care of another person is not an easy activity. There are those that require physical exertion and emotional skills to deal with that. Such efforts are in fact perceived, so much so that in the cases of elderly people with advanced Alzheimer's there is total dependence of care to perform all activities. In some cases, it gives preference to caregivers men, due to the requirement of physical strength in activities such as locomotion.⁵

The importance of multidisciplinary team within the ILPIs is given for providing the elderly residents of the extended care, having as main requirement meet the functional changes caused by the disease, to determine the actions that can meet fully the needs of the elderly, as well as, serve them in a manner that respects the principles of autonomy. Still, it is of fundamental importance to family caregivers' support, showing the best way to overcome the impacts generated in the core of the family, providing integral care.¹¹⁻²

● **Class 4:** Memory lapses of the elderly with Alzheimer's disease

This class consists of 17 UCEs (segments of text), which corresponds to 24.6% of the total corpus and is directly associated to the class five. The most frequent and significant words that appear in the text of this class are: why, take, accept, no, to want, and among others, whose values of X^2 correspond respectively (27,52, 23,04, 16,49, 13,9, 12,19).

From the speeches of the professionals, it was possible to comprehend the deficiency in

the memory of older people affected by Alzheimer's at ILPI, in addition to demonstrate how important the attention, assistance, support and patience of the caregivers to deal with the daily memory lapses of these elderly. Through the interviews it was evidenced that the professionals are sometimes harassed by the public who visits ILPI and are unaware of the situation of the patient with Alzheimer's, because indeed, even though the elderly are taken care of by professionals, the same claim for visitors who do not receive satisfactory care, which according to the caretakers is not true.

Once called me and said, "Daughter I'm where? I don't know where I am? Daughter here anybody eat? I haven't eaten anything today! I skipped lunch. No snacks!" (Dept. 1).

It is because they are already losing their memory; they are no longer with the normal memory (Dept. 9).

They say they don't want (for the food), then we will talk, because sometimes they say "Oh I've taken!", but we know that is only the head of them, because they forget (Dept. 13).

Some say they have not taken bath and sometimes you have to repeat the procedure, even having already done. Often they talk to people who are visiting and they do not understand (Dept. 11).

In the episodes of deficit in the recent and remote memory impairment may be loss of concentration, inattention, as well as the loss of objects or moments of forgetfulness, like having lunch or showering, among other activities. Generally, Alzheimer's makes difficulty in facial recognition and/or of familiar places. With the evolution of the disease, memory tends to be increasingly deteriorated through the emergence of some symptoms, such as aphasia, apraxia, agnosia and visual and spacial changes that tend to progress. Being these episodes common in the AD, it is up to professionals understand and sensitize the families that are characteristic of AD.^{13,14}

Regarding the actions that are repeated occasions just to satisfy the patient, because as soon as their recent memories wanes, the caregivers are likely to feel overworked and stressed. Soon, should be aware that to take on the profession and the activities assigned to it, noting that the focus beyond physical care, mental care, also to take satisfaction and well-being to the elderly.¹⁵

Over time, due to the degenerative factor, the elderly with Alzheimer's lose gradually their cognitive function, and for

those who care, according to ABRAZ, get your autonomy may seem an assault, especially when there is resistance, and this time can make it difficult for both the caregiver and the receiving care.¹⁶

♦ Class 5: The role of the professional in the full care to the elderly with Alzheimer's

This class consists of 12 UCEs (segments of text), which represents 17.4% of total corpus and is directly associated to the class four. The most frequent and significant words that appear in the text of this class are: be, talk, forget, very, reach, and among others, whose values of X^2 correspond respectively (11,01, 10,49, 8,57, 7,17, 6,7).

In the speeches of the professionals, it is understandable that the assistance of carers when referring to practices, it is being employed with quality and performance. However, as for the scientific-theoretical knowledge about Alzheimer's and its stages, but also on other diseases that are common in the elderly, the same is minimal for part of the middle school professionals.

The ageing with AD the means to live larded by limitations and weaknesses that require the caregivers continuous learning and development of personal skills, as well as technical skills related to the acquisition of new knowledge and behaviors.¹⁶

Talk a lot about the past, but the present they forget fast. Are very dependent on us. When it comes to some bedridden is difficult in the hygiene, but that same (Dept. 2).

I think the assistance is good, because we have professionals accompanying them (Dept. 8).

Care that we have with them is at bath time, have the utmost care, get more attention, since there are more good memory (Dept. 9).

I did not know really what Alzheimer's is; there is a need for more information about the disease (Dept. 10).

For a proper assistance that meets the needs and preserve the integrity of the elderly are required acceptance, information, and flexibility on the part of caregivers, so that there is a satisfactory adaptation to the new condition of the hospitalized.¹⁷

As regards the knowledge for the right, it brings to the nurses that the way they are acting is the correct and the most appropriate; such a claim must also be emphasized for mid-level professionals, through continued education through

lectures, so that the same conduct integral care to the elderly with AD.¹⁸

They needed more knowledge and information on the disease on the part of caregivers and the professionals involved, with a view to creating more long-stay institutions for the elderly and the participation of these professionals in care offered to them.¹⁹

♦ **Class 3:** Lack of family care to the Elderly with Alzheimer's

This class consists of 12 UCEs (segments of text), which represents 17.4% of total corpus and is directly associated to the class one and two. The most frequent and significant words that appear in the text of this class are: family, lack, elderly, everything, well and among others, whose values of χ^2 correspond respectively (37,81, 20,17, 17,23, 6,7, 5,3).

In the testimony of the respondents, there is a notorious lack of family to the elderly with Alzheimer's of ILPI, which can lead to other problems such as illness, irritability, loss of appetite, insomnia, weight loss, and in more severe cases, depression. Another factor to be considered is the worsening of AD, due to the state of seclusion that they can be put. Since the absence of family ends up interfering with quality of treatment to the disease carrier.²⁰

We do everything to see the improvement of them, give a better life for them. If I had a family approach, it would be much better for an improvement of the elderly (Dept. 5).

The absence of family is very complicated, the lack of knowledge that some caregivers have with Alzheimer's. Yes we do everything we can to improve them, but the approach of the family becomes better for the improvement of the elderly (Dept. 6).

If I had more support from schools, college and especially the family, it would be much better for the well-being and mood of the elderly (Dept. 7).

Many are sad, sometimes appalled when the family takes visit, we feel them so the family is the basis of everything else we are in a good place, receiving the care, but without the family is bad. (Dept. 04).

When a patient is diagnosed with AD, generally, happen some changes in behavior, since all the family members are affected even in different degrees, what mostly happens to be the expulsion of some members, whether by shame, either don't understand the disease. The absence of family causes the elderly become a bitter individual

with life or no prospect of improvement, designing an unsatisfactory quality of life. In this sense, it is necessary that family members accept and understand the health problems of their loved one, because taking care of seniors with AD is an inherent and existential process.²¹

When an old man sees the family he becomes more comfortable, is happier (Dept. 10).
Good care of the family, you feel that warmth (Dept. 13).
He will progress according to the medication, if the family was treating early; it noted and was treating early, using the medication, so there won't be a complete loss of consciousness. That depends on a lot of that here, it is clear that the family has to follow, in order to make the medical monitoring (Dept. 13).

It is essential to encourage and develop intervention programs whose cornerstone is the family. Note that when there are family participation in care to these elderly people, they feel more willing and happy, which can slow down the effects of the Alzheimer's.²²

When the family is absent in elderly under assistance with Alzheimer's, he becomes more exposed to situations of significant morbidity in physical, social, psychic aspects; observing the actual importance of family participation by the elderly hospitalized. In this way, the professional nurse is the primary part for the integral care to elderly with dementia, because of his skill and competence to deal with the health of the elderly, with the caregiver and family, always aiming to the promotion of a better life quality for all.²³

This research presents some limitations. In view of the qualitative approach selected, the data collection was carried out in a single specific reality. It is recommended that the design of this study be reproduced in other Brazilian regions with different cultures, in order to increase understanding about the care provided by caregivers for the elderly with Alzheimer's in Long-Stay Institutions. Associated with this, it mentions the fact that the interviews took place in their own professional environment of the participants at the end of the work shift, which may have brought discomfort to that professionals could express themselves after one day of intense and continuous work at ILPI investigated.

CONCLUSION

It is concluded that the assistance performed by caregivers for the elderly with

Alzheimer's in Long-Stay Institutions, satisfactorily, given the need for this person that contains a degenerative and irreversible illness. Identified that through the organization of pre-established timetables, the professionals meet the entire demand of daily care for the elderly. In addition, some professionals have demonstrated theoretical and scientific ignorance about Alzheimer's, as well as on some other pathologies that affect older people.

The results of this study make it possible to provide subsidies for new reflections on the theme, collaborating as a scientific source for other related searches. Become necessary technical training and scientific strategies for professionals of the ILPIs, which can be accomplished through lectures on the subject and educational materials, so that there will be no just the practice of care, as well as scientific support, offering integral assistance to these elderly people.

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