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The family caregiver's discourse on the hospitalization of the elderly with Alzheimer's disease

O discurso do cuidador familiar sobre a hospitalização do idoso com doença de Alzheimer

El discurso del cuidador familiar sobre la hospitalización del anciano con enfermedad de Alzheimer

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ABSTRACT

Objective: To investigate the perception of the caregiver about the hospitalization of the elderly with Alzheimer disease. **Method:** This is a descriptive study, exploratory and qualitative in nature, performed with 11 family caregivers of elderly with Alzheimer disease. The data were collected from April to June 2013 through semi-structured interview. The data analysis was based on the Discourse of the Collective Subject **Results:** Two summary central ideas emerged: worsening of cognitive function in the elderly with Alzheimer disease during the process of hospitalization and the lack of qualification of the health staff to take care of an elderly with dementia. **Conclusion:** According to the results obtained, there is an urgent need for training and/or specialization of health professionals to attend the elderly with dementia and their families. The family is an integral part of the care given to the elderly, and it is critical to understand and see it as a complex social unit. **Descriptors:** Caregivers; Alzheimer Disease; Elderly; Hospitalization.

RESUMO

Objetivo: Conhecer a percepção do cuidador sobre a hospitalização do idoso com doença de Alzheimer. **Método:** Trata-se de um estudo descritivo, exploratório, de natureza qualitativa, realizado com 11 cuidadores familiares de idosos com doença de Alzheimer. Os dados foram coletados no período de abril a junho de 2013, por meio de entrevista semiestruturada. A análise dos dados foi pautada no discurso do sujeito coletivo (DSC). **Resultados:** Emergiram duas ideias centrais síntese: piora da função cognitiva do idoso com doença de Alzheimer durante o processo de hospitalização e o despreparo da equipe de saúde para cuidar de um idoso com demência. **Conclusão:** De acordo com os resultados obtidos, urge a necessidade de capacitação e/ou especialização dos profissionais de saúde para atender o idoso com demência

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e sua família. A família é parte integrante do cuidado a esse idoso, sendo fundamental compreendê-la e assisti-la como uma unidade social complexa.

Descritores: Cuidadores, Doença de Alzheimer, Idoso, Hospitalização.

RESUMEN

Objetivo: Investigar la percepción del cuidador acerca de la hospitalización de las personas mayores con la enfermedad de Alzheimer. **Método:** Este es un estudio descriptivo, exploratorio y de naturaleza cualitativa, realizado con 11 cuidadores familiares de ancianos con enfermedad de Alzheimer. Los datos fueron recolectados durante el periodo de abril a junio de 2013 a través de la entrevista semi-estructurada. El análisis de los datos se basa en el discurso de los sujetos colectivos. **Resultados:** Surgieron dos ideas centrales resumen: empeoramiento de la función cognoscitiva en los ancianos con enfermedad de Alzheimer durante el proceso de hospitalización y la falta de personal sanitario a cuidar de un anciano con demencia. **Conclusión:** De acuerdo a los resultados obtenidos, existe la urgente necesidad de formación y/o especialización de los profesionales de la salud para atender a los ancianos con demencia y sus familias. La familia es una parte integral de la atención que los ancianos, siendo fundamental para entenderla y verla como una unidad social compleja.

Descriptores: Cuidadores, Enfermedad de Alzheimer, Ancianos, Hospitalización.

INTRODUCTION

For the first time in human history, people aged 60 and over will exceed children under the age of 14, corresponding to 22.1% and 19.6% of the world's population, respectively.¹ Projections for Brazil indicate that in 2020 there will be a contingent of 29.8% of people aged 60 and over and 4.7 million over 80 years.²

With the change in the morbidity and mortality profile, chronic and/or chronic degenerative diseases became more evident. The increase in chronic diseases in the elderly population favors greater demand for health services, intensifying the use of these services and, in turn, demands more frequent gerontological nursing care at different levels of care.³

Among the health problems that most affect the elderly, the dementia syndromes are among the group of affections that have been having a strong impact on the family structure and society.⁴ Nearly 35.6 million people live with dementia and the number is expected to double to 65.7 million by 2030 and triple to 115.5 million by 2050. Alzheimer's Disease (AD) is the most common cause of dementia and possibly contribute to the increase of about 70% of the cases.⁵

AD is a progressive neurodegenerative disease manifested by cognitive and memory impairment, progressive impairment of daily living activities, and a variety of neuropsychiatric symptoms and behavioral changes. It usually develops slowly and continuously over a period of several years.⁶

With the progression of the disease, it is common for the elderly to need help, especially to perform their daily living activities (DLAs), and the presence of a caregiver is fundamental. The care given to these elderly can be made by lay caregivers, informal or non-professional, who, in our culture, most of the time is the family itself responsible for this care.⁷

In view of the increase in cases diagnosed with AD in the elderly, it is seen, at the same time, the ignorance of many families about the care of the elderly with this dementia.⁸ In

these cases, hospitalization can be a consequence because, with the evolution of AD, the individual is affected by disabilities and becomes dependent.

In this perspective, when the elderly with AD are hospitalized, in addition to specific and complex care, they will need to be accompanied and assisted by a caregiver, especially during the hospitalization process. In view of this context, the following question was raised: how does the caregiver perceive the hospitalization of the elderly with AD?

To answer this question, the purpose of this study is to know the caregiver's perception about the hospitalization of the elderly with Alzheimer's Disease.

METHOD

This is an exploratory-descriptive study of qualitative nature, carried out with 11 family caregivers of elderly people enrolled in a support group for the elderly with dementia of the Brazilian Association of Alzheimer's Disease and other similar diseases (ABRAZ-RJ). These associations support families in hazy and unfamiliar moments about the progression of the disease and its repercussions on the family structure.⁸

This support group usually meets weekly and is coordinated by a family caregiver. The members are mostly relatives of elderly people with dementia. In addition, there is the voluntary participation of health professionals who seek to help these caregivers with information and guidance pertinent to their demands.

For the subjects' participation, the following criteria were adopted: attending the ABRAZ-RJ support group and having experienced at least one hospitalization of the elderly with AD. Formal caregivers and those who only accompanied the elderly in a home environment were excluded.

Data collection took place from April to June 2013, and was started only after approval of this study in the Ethics and Research Committee of the Federal University of Rio de Janeiro / UFRJ - São Francisco de Assis School Hospital, under the opinion of No.: 230,038 and CAEE: 14342413.1.0000.5238. The Term of Free and Informed Consent (TFIC) was presented to the caregiver, who, according to his/her signature and consent, formalized his participation in the research.

The semi-structured interview was used as a data collection technique, which was based on the following aspects: (a) characterization data of the caregiver, (b) data pertinent to hospitalization of the elderly, such as: time of hospitalization and its main causes and, (c) perceptions of the caregiver about the hospitalization of the elderly with AD.

The interviews were recorded in audio format and then transcribed in full and analyzed. To ensure the anonymity of each participant, we chose to name D1, D2, D3 and so on, when their respective statements were revealed.

The analysis was based on the Discourse of the Collective Subject (DCS). The DCS is credited with condensing a synthesis discourse, in the perspective of the collective unity obtained through several collaborators, of its discursive manifestations.⁹

For the production of the DCS, four methodological figures are used: Key Expression (KE) formed by excerpts from the statements that reveal the essence of the content of the representations; Central Idea (CI) that is the linguistic expression that describes the sense present in the testimonies; Anchoring (AN) is a statement written in a positive way and that represent the basic idea that sustains the discourse, that is, it reveals the Social Representation of what is under focus. The DCS is the gathering of the speeches, written in the first person singular, that present central ideas or similar anchorages.¹⁰

The process for constructing the data itself was based on the following steps: selection of KE; grasp of the CI and construction of the DCS of each KE; identification of similar or complementary CIs, transcribing in full the terms used by the participant of the study, besides the concentration of the KEs referring to the CIs in a synthesis speech, thus constituting the DCS.¹¹

RESULTS AND DISCUSSION

The sample consisted of 11 family caregivers. There was predominance of the female gender, age group over 60 years old, with complete higher education and reported degree of kinship: spouse and/or daughter of the elderly with AD. Regarding the care time, these caregivers provided care for the elderly with AD, ranging from two years to more than six years. The hospitalization time of the elderly with AD, informed by the caregivers, was less than or equal to 30 days, being the main causes of hospitalization: pneumonia and urinary infection.

The interviews were organized in discourses, divided into two central ideas, which enabled a better understanding of the caregiver's perception regarding the hospitalization of the elderly with AD. The central ideas were: CI (1): worsening cognitive function of the elderly with AD during the hospitalization process; CI (2): the unpreparedness of the health team to care for a patient with dementia.

Central idea (1): worsening cognitive function of the elderly with AD during the hospitalization process

Because I think 100% of Alzheimer's symptoms are mental confusion, which affects one's cognition. So, one of the first signs and symptoms that I noticed in her was the mental confusion. Because I got home and she did not recognize me. It got worse, she was bewildered. She lost the notion of time and space in the cognitive aspect. She acknowledged me, but she lost track of where she was, was forgetting people. She also does not remember who stayed in the hospital, who operated and who were to visit her. [...] That's why I insisted in making her see me all the time, because in a strange place, no matter how sick the patient is, she feels more familiar that way. [...] It was a huge place and I still had to share the ward. She thought we were at my sister's house and I'd make her think that way all the time. I woke up in the middle of the night with the floor full of blood and my mother was not in the room. When I realize it, I was in the bathroom. She had severed the venous access, filled the ground with blood, the

vein was severed and she was washing the access place. This happened a lot because she was in a different place [...] She was more depressed. Although they give her sleep remedy, she is an Alzheimer's patient. As it has been a week, they lose track of time, of what happens, they get very lost, I think. (DCS: D3, D5, D6, D8, D10, D11)

The most characteristic and typical symptom initially found in AD are changes or difficulties related to memory. The memory most affected is that of recent events, preserving the memory of ancient facts. AD is characterized by a multiple cognitive decline that compromises memory and progressive loss of functional capacity.¹² Especially on impaired memory diagnosis in hospitalized elderly,¹³ there are some factors that favor the deficit of registration of factual information for the hospitalized elderly, such as: the process of disorientation, impairment of memory and cognitive functions.

As the disease progresses, it is likely that the elderly with AD will begin to have difficulty performing their daily activities. Therefore, the dependency is installed and, consequently, there is the need for a caregiver. In this context, there is still a probability that the elderly will become bedridden, requiring more complex care. With the restriction of mobility, many elderly people are susceptible to pneumonia and other infections, and frequent hospitalization. Therefore, it is of utmost importance the constant evaluation of the cognitive state of these elderly, considering that there is a direct influence of cognition with the physical mobility of the elderly.

From the report of the caregivers, it was possible to perceive that hospitalization impaired even more the cognitive function of the elderly with AD, leaving them confused, disoriented and stressed. The change in routine known by the elderly with dementia can be commonly associated with catastrophic reactions or behaviors in individuals with dementia.¹⁴ Complementing this discussion, it is also known that the elderly with cognitive impairment at an advanced stage of the disease, when hospitalized, due to the lack of environmental stimulation, tends to present an exacerbation of the disease, increasing, consequently, its degrees of dependence.¹⁵

Thus, hospitalization can have a great impact on the elderly, especially the elderly with AD. Individuals with dementia are more likely to be institutionalized.¹⁶ These individuals may be hospitalized for a primary cause, for example: due to a feeding deficit due to dysphagia or a secondary cause, to treat dysphagic-associated pneumonia.^{17,18} Findings revealed by the caregivers corroborate this assertion, since the main causes of hospitalization of the elderly with AD were pneumonia and urinary infection.

Contextualizing the care for the individual with dementia, the health sector urgently needs to meet the demands to respond to a plurality of needs and specificities, demographic changes, social conditions, epidemiological changes, focusing on the individual and collective human being.¹⁹ Elderly health care encompasses questions that go beyond medical practices, imposing a multifaceted view on the health professional, considering biopsychosocial, cultural and spiritual issues.

In the case of elderly people with dementia syndromes, this practice is no different. Professionals should be alert to

recognize and implement actions and/or health care based on a new approach to care for individuals with chronic degenerative diseases. This approach is characterized in the management of the health needs of individuals and their families and/or social support network. These needs are expressed through signs and symptoms, whether declared or not declared, but which are perceived, observed and analyzed by health professionals prepared and imbued with precautionary and non-curative health practices directed at people's quality of life and well-being.

Thus, the nurse must know and understand the daily life of the caregiver of the elderly with AD, rescuing life values, social conditions and ways of coping with problems.²⁰

For this, it is necessary to identify the health needs of the individual and/or population and changes in the models of care and management of work processes, focusing on the need of citizens and health production.²¹

In this sense, the elderly with AD have specific care needs, require complex care, ranging from technical skills and applicability of scientific knowledge, as well as sensitivity of the health team to accommodate the caregiver of this elderly person, recognizing him as a protagonist of the care directed to the elderly with dementia. Specifically on the role of the caregiver in relation to the elderly with AD, we can cite, as an example, cognitive stimulation in the elderly with AD performed by the caregiver, monitored and supervised by a nursing program directed to the elderly and their caregivers.²² In this example, nursing can be perceived in response to a need of the elderly/caregiver binomial when implementing management strategies related to the cognitive response of the elderly with AD.

Considering that AD is a progressive and progressive neurodegenerative disease, the orientations or educational actions in health directed to the caregiver are the key pieces for the health care of the elderly in process of dementia, because when the doubts, insecurities and fears of the caregivers are healed, they feel safe and welcomed in the care process and, automatically, this is reflected in the promotion of care for elderly with dementia. Thus, hospitalization or institutionalization of the elderly with AD can become a more distant reality, reducing the risks inherent to the hospitalization process itself and recurrent hospitalizations, such as for infectious causes and/or other comorbidities.

Central Idea (2): the unpreparedness of the health team to care for a patient with dementia.

Soon they began to hold my mother [...] as it is said - they are not aware of the disease, so they began to give anxiolytics so that she would keep sleeping [...] and I had already warned that it could not be given. She almost had a low blood glucose problem, almost got into a coma. It was very serious ... they want to take care of the patient, want him to obey as if he were a normal person and he will not obey you ... I asked her to leave because I automatically sent her doctor to take her from the ITC, because she had nothing [...] The longer the patient with Alzheimer's stays inside [the hospital], the worse. (DCS: D1, D2, D4, D6, D7, D9, D11)

Hospitalization can be considered a risk factor for death among the elderly, as it can cause adverse events such as infections, social isolation and the occurrence of iatrogenies. Elderly patients are especially exposed to iatrogenic events. This is because, in many circumstances, they are treated like any other adult patient, disregarding the uniqueness of senescence and senility.^{23,24}

Iatrogenesis is understood as any pathogenic alteration caused by medical practice. It is essential to avoid iatrogenesis in the elderly due to their more pronounced vulnerability to drug-related adverse reactions, non-drug interventions due to senescence, the risk of polyopathy and polypharmacy, as well as disabilities.²⁵

It is observed that the prevalence of iatrogenias in the elderly is very high, since they have their peculiarities, being more susceptible to errors. Once this "iatrogenic cascade" has begun, the elderly end up being hospitalized for longer, not for the underlying disease, but for the consequences of inadequate care.²⁶

The findings presented in this study point to the specific needs of hospitalized AD patients and their caregivers. Most elderly people have different needs compared to other groups, because their organic condition makes them more susceptible to any episode of illness, especially elderly people who already have a chronic-degenerative disease, such as AD. Therefore, these elderly, when hospitalized, should have a differentiated and specialized care mainly by the nursing professionals, since these professionals are the ones who stay longer "bedside" with the elderly patient.

Although studies^{1,5} point to the increasing life expectancy, as to projections related to the increase in dementia, in care of health practice, one also sees a small number of human resources and health-care spaces, be it hospital or non-hospital spaces, that meet the demand and, above all, the real health needs of the elderly and their family and/or social support network. It is worth mentioning that, according to the National Agency for Health Research Priorities,²⁷ in sub-agenda 6, which deals with the Health of the Elderly, it is a priority to periodically evaluate the quality of care for the elderly in the hospital and asylum system of UHS and supplementary health. It should also be noted that this same Agency still proposes the evaluation of programs and strategies for guidance to families and caregivers responsible for elderly dependents.

For this reason, training human resources in health, creating and expanding spaces for elderly people, especially for the elderly in the process of dementia, is of the utmost importance, being a requirement "almost astonishing", given the world and Brazilian reality presented and represented by the demographic profile and epidemiological characteristics of the elderly population and their care demands.

Regarding the training of human resources to assist the elderly person, one of the guidelines of the National Policy on Elderly Health²⁸ is indicated, which points to the training and continuing education of health professionals of the UHS in the health area of the elderly, in addition to supporting the development of studies and research in this area. However, in nursing care practice, it can be observed that most nurses

do not seek specialization in specific areas, such as geriatrics or gerontology, which constitutes a great barrier in the care process for the elderly, especially those elderly with AD.¹⁸

The nurse can help the caregiver during the hospitalization process of the elderly for a better quality of care in and outside home, from health education integrated with a multidisciplinary team, providing support and assistance for the care to be performed by them. The nurse must have a holistic view of the situation, observing the individual as a whole, considering, in addition to its diseases, its biopsychosocial context.²⁹

Therefore, it is necessary that the nurse seeks strategies to welcome and support the family and the elderly with AD throughout the hospitalization period, as well as care approaches that satisfy orientations directed to the discharge of this elderly person. The nurse should educate the family about AD changes, taking into account the need for changes in family dynamics that are likely to occur.

In view of the above, assisting the elderly, especially the demented elderly and their family, requires commitment, knowledge and participation of professionals trained and able to intervene in the family, supporting the needs imbricated in the care of those persons.⁹ It is important to highlight the complexity of care for the elderly with dementia, since the family caregiver, for the most part, does not have the necessary knowledge to assume and perform certain functions and care, because they require the technical competence of health professionals, especially nursing care.³⁰

Undoubtedly, health care for the elderly with chronic diseases requires an extended period of treatment and follow-up, since the elderly with AD requires nurses and their staff to approach the family in the planning of care actions. There is a demand for clarification and guidance from the family or social support network for the elderly with AD, on: the clinical state of the disease, its evolution, stages or phases of its presentation, behavioral changes and possible management techniques, therapeutic possibilities (pharmacological and non-pharmacological), referenced sites for medical care and dispensing of specific drugs, associations or groups of help to caregivers of elderly people with dementia, as well as legal aspects involving AD.³

Thus, it is of the utmost importance for contemporary nursing to rethink the care of demented elderly and their family caregivers. As previously pointed out, the nursing team is the one, among other health professionals, that stays longer with the patient "bedside", especially when it comes to hospital care. Given the above, the training of mid-level nursing professionals is also fundamental. Certainly, these professionals, when well trained, can contribute to the better identification of problems and/or demands of these caregivers, favoring the development of the care planning traced by the nurse.

It is also added that there is an urgent need for participation, involvement, mobilization of health professionals, in what concerns to AD, because, through reports and experiences, people who experience the difficult but brilliant task of being a caregiver, the task was to uncover each day a unique "new differentiator", based on the needs brought not only by caregivers, but also those observed by the nurses.³¹

In this sense, it is fundamental to point out that care for the individual with dementia requires from the health team, in particular the nursing team, ethical commitment, development of emotional and technical skills, and empathy in the development of the caring process.

As a limitation in the accomplishment of this study, it is pointed out that it was developed in only one support group for elderly caregivers with AD and other associated dementias (Abraz_rj). Therefore, the results obtained cannot be considered for the total population of elderly people with AD and their respective caregivers. Generalizations about the caregivers' perception about the hospitalization of the elderly with AD do not fit all. Based on the data collected, it is recommended that the nurse, especially the one who provides hospital care, seek training, specializing and updating on the health of the elderly person, family and their social support network, recognizing the increase population expectancy, major associated comorbidities and, mainly, their demands and/or health needs.

CONCLUSION

According to the results obtained, there is an urgent need for training and / or specialization of health professionals to attend the elderly clientele, particularly the elderly with dementia and their family. The family is an integral part of the care process for the demented elderly, and it is therefore essential to understand and to see it as a complex social unit that has its own needs.

The AD daily demands that this unit reorganize itself structurally and internally, in order to deal with the demands and changes brought about by the dementia process. With this, the nursing team must be instrumented to meet the needs of the pair elderly and caregiver, especially when the needs exceed the home environment and extend to the hospital territory, since the sudden change of environment and routine, caused by hospitalization, can provoke significant changes to the elderly, such as worsening of the cognition of the elderly with AD. In addition, hospitalization can be an overload factor for the caregiver, since he/she needs to (re) organize his/her personal, social and family life to accompany the elderly in the hospital environment, a factor that may contribute to physical and emotional stress. In this sense, the findings of this study may contribute to the strengthening of initiatives, proposals or actions of health to the elderly, specifically, with regard to the permanent education of health professionals and the periodic evaluation of the care to this clientele next to the hospital system, strengthening, in turn, the Health Policies directed to this population.

The hospitalization of the demented elderly can be considered a challenging factor for the health team, since there is a need to manage problems that involve the bio-psycho-socio-cultural and spiritual dimensions. Therefore, it is suggested that these professionals approach collective spaces of discussion and information about the person with dementia, such as study groups, discussion groups, forums and support groups for caregivers and the elderly in the dementia process. These spaces can act as "labs" of real stories,

needs and demands, as well as spaces where the exercise of citizenship and solidarity can be shared with people who experience care for an elderly person with dementia.

Finally, it should be pointed out that the care provided to the elderly with AD during hospitalization are specific and complex and impose on all professionals involved ethical commitment, empathy and knowledge, aiming at a dignified care, free of iatrogenies and prioritizing a reduced permanence time of the elderly in the hospital environment and, consequently, of their caregiver.

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