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Idosos com doença de alzheimer: como vivem e percebem a atenção na estratégia saúde da família

Elderly with alzheimer's disease: how they live and notice the attention in the health strategy of the family

Ancianos con la enfermedad de alzheimer: cómo vivir y como darse cuenta de atención en la estrategia salud de la familia

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ABSTRACT

Objective: Understand how seniors live with Alzheimer's and their perceptions about the actions of the health strategy of the family (FHS). **Methods:** Exploratory and descriptive study, conducted with ten seniors who agreed to give information. Two forms were used for the evaluation, the index of Katz and the Mini Mental State Examination. Approved by the Research Ethics Committee of the grape with the opinion n° 608,721. **Results:** The elderly were mostly female, married and illiterate. Had cognitive impairment and some were independent in practice of daily life activities. There are weaknesses in the adaptation of households, but they notice the efforts of their relatives in the space adjustment. The elderly demonstrated satisfaction regarding the attention on ESF. **Conclusion:** Infer the importance of improving the condition of life, independence and autonomy of the elderly.

Descriptors: Aged, Alzheimer Disease, Health Care.

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RESUMO

Objetivo: Compreender como vivem os idosos com Alzheimer e as suas percepções sobre as ações da Estratégia Saúde da Família (ESF). **Métodos:** Estudo exploratório-descriptivo realizado com dez idosos que concordaram em dar informações. Utilizou-se dois formulários para a avaliação, o Índice de Katz e Mini Exame do Estado Mental. Aprovado pelo Comitê de Ética em Pesquisa da UVA com o parecer nº 608.721. **Resultados:** Os idosos eram, em sua maioria, do sexo feminino, casados e analfabetos. Apresentavam comprometimento cognitivo e alguns eram independentes na prática das atividades da vida diária. Existem fragilidades na adaptação dos domicílios, porém percebem-se esforços dos familiares no ajuste do espaço. Os idosos demonstraram relativa satisfação quanto à atenção dispensada na ESF. **Conclusão:** Infere-se a importância de um cuidado que potencialize a melhoria da condição de vida, independência e autonomia do idoso.

Descritores: Idoso, Doença de Alzheimer, Atenção à Saúde.

RESUMEN

Objetivo: Comprender cómo viven los ancianos Alzheimer y sus percepciones sobre las acciones de la Estrategia de Salud de la Familia (ESF). **Métodos:** Estudio exploratorio descriptivo, realizado con diez ancianos que accedió a dar información. Utiliza dos formas para la evaluación, el Índice de Katz y el Mini Examen del Estado Mental. Aprobado en Comité de Ética con la opinión nº 608.721. **Resultados:** Los ancianos eran en su mayoría mujeres, casadas y analfabetos. Tenían deterioro cognitivo y eran independientes en la práctica de actividades diarias. Existen deficiencias en la adaptación de los hogares, pero se da cuenta de los esfuerzos de los familiares en el ajuste de espacio. Los ancianos demostraron satisfacción con respecto a la atención en ESF. **Conclusión:** Inferir la importancia de un cuidado esa influencia para mejorar las condiciones de vida, la independencia y autonomía de las personas mayores.

Descritores: Anciano, Enfermedad de Alzheimer, Atención a la Salud.

INTRODUCTION

Aging can be understood as a natural process of gradual reduction in the functional reserve of individuals, which, under normal conditions, does not usually cause any problems. However, given overload conditions, as the examples of diseases, accidents, and emotional stress, it can cause a pathological condition requiring assistance.¹

Health services do not seem to follow epidemiological changes in the recent decades, in which there is a significant increase in the population over 60 years old. Attention aimed at this population group is flawed, making aging a synonymous of disease and disability, and often disregards the relevant care and the ability to perform basic and instrumental activities of daily living, with a reductionist view that ignores the healthy aging phenomenon.

The health system response is usually fragmented, both in terms of completeness and continuity of care, which makes the provision of comprehensive care, aimed at promotion, prevention, treatment and rehabilitation of the elderly difficult.² In this logic, Brazil needs more effective policies to assist the elderly, as well as ideal training of human resources to assist them.³

Thus, Brazil is rapidly moving to a more aged demographic profile, in which chronic diseases occupy a prominent place, implying the need for adjustments of social policies, particularly those geared to meet the growing demands in the areas of health, welfare and social assistance.⁴

The incidence and prevalence of chronic diseases have grown significantly in the elderly, and among these, dementia stands out as an important cause of morbidity and mortality, composing the sixth group of the most important diseases in relation to the impact on functionality and elderly mortality.⁵

Studies indicate that populational aging process has been accompanied by a decline in some cognitive abilities, thus increasing the occurrence of psychiatric disorders, including dementia and depression, which stand out as the most common mental disorders in the elderly. In older age groups, the prevalence of dementia increases, becoming alarming, since elderly people with dementia may be considered vulnerable.⁶⁻⁷

The most common and prevalent form of dementia in the elderly is Alzheimer's disease (AD), understood as a neurodegenerative, progressive and irreversible disease of insidious onset, characterized by progressive loss of memory and other cognitive functions, that impair the patient at activities of daily life and in their social and occupational performances.⁸⁻⁹

The aim of this study was to understand how seniors with Alzheimer's are living and their perceptions of the actions of the Family Health Strategy (ESF), which accompanies them. This study supports its importance in the high incidence of Alzheimer's disease, which is the most common cause of degenerative dementia, affecting approximately 4.6 million people worldwide each year,¹⁰ representing therefore a major public health problem.

METHODS

This study is classified as exploratory and descriptive, which seeks to provide greater familiarity with the problem in order to make it more explicit or build hypotheses associated with the description of certain population's characteristics.¹¹

A study performed with 10 elderly patients with AD, from February 2013 to May 2014, identified at a macro area of a city in the North of Ceará. This macro area comprises six Family Health Centers (CSF), and this choice is justified by the fact that it is the one with a greater number of elderly.

We used the following inclusion criteria: to present availability and acceptance to participate in the study, from the Term of free and informed Consent, and have cognitive ability to respond verbally to questions to be carried out, with the help of family members or caregivers, regardless of beliefs, origins, socioeconomic or educational status.

After the identification of the subjects, households visits were scheduled, making it possible to carry out an extensive direct observation through the use of a questionnaire structured in three parts: characteristics of the patient,

household characteristics and actions offered by the ESF. It is emphasized that this information explored in the questionnaire directed the organization and analysis of data.

We used the Katz Index¹² and the Mini Mental State Examination,¹³ in order to evaluate the functional capacity of the elderly, with emphasis on the performance of activities of daily living, and cognitive ability. The Mini Mental State Examination (MMSE) was designed to be a clinical evaluation practice of changing the cognitive status in geriatric patients.¹³ The score can range from 0 to 30 points, and is composed of questions grouped into seven categories, with respective high scores: time orientation (5 points), placement orientation (5 points), three-word record (3 points), attention and calculation (5 points), recall of three words (3 points), language (8 points) and visual constructive capacity (1 point).¹⁴ As for the Katz Index, it is characterized as an assessment of independence or functional dependence of patients to perform the bathing activities, clothing, personal hygiene, continence, mobilization and feeding.¹²

The study complied with the ethical principles established by the National Health Council Resolution nº 466/12, and was approved by the Research Ethics Committee of the State University of Vale do Acaraú under the Opinion nº 608,721.

RESULTS AND DISCUSSION

The presentation of the results of this study begins with the characterization of the subjects, in order to trace the profile of the elderly, and support interrelations with the findings. The study included 10 elderly, six female and four male; one belonged to the age group between 60-69 years, four between 70-79 years, four between 80-89 years and one between 90-99 years; seven were in the married condition and three in the widower.

About education, prevailed the elderly who could not read and write. The farmer professions, dairy and tailor were mentioned, but the majority (n = 5) was considered of the home and has not exercised any profession previously.

Only one research participant practices physical activity often, an aspect that affects the active aging, since physical activity may represent an important non-pharmacological contribution to mitigate the rate of cognitive and motor decline facing disease progression.¹⁵

All individuals use medications on a daily basis, whether for the treatment of Alzheimer's disease or other pathologies, as diabetes mellitus, psychological disorders, labyrinthitis and hypertension.

When asked about living with Alzheimer's disease, the answers appointed the difficulty to walk alone, to feed, perform daily activities and even the coping capacity of problems/needs. Alzheimer's disease is a progressive neurodegenerative disorder that causes dementia, compromising the independence and autonomy of patients over their slow evolution, which directly affects the way of life of the elderly.¹⁶

It is necessary to understand specific features of living with Alzheimer's disease. Thus, we proceed to discuss the results that address the elderly in their major life scenarios, which should be supportive for coping with the disease in the home and within ESF.

Characteristics of the household

Due to cognitive changes related to Alzheimer's, special care should be aimed at seniors' homes. Otherwise, the home can be configured a potential space for accidents. So, care to people living with Alzheimer's should also involve planning and adjustments to the residences.

The physical environment where they live should be adapted to maintain maximum autonomy and minimal dependence possible. For this, it is important to use strategies that contribute to the household and has a positive influence on the elderly's quality of life.¹⁷

It is crucial to know the households in order to determine the risk factors for the occurrence of falls, which may result in health problems of the elderly, interfering thus in the ability to perform their daily activities. According to studies, individuals living with Alzheimer's are at increased risk of falls, especially when associated with cognitive decline.¹⁸

Thus, an observation of the main rooms of the homes of the elderly was conducted in order to describe the home and identify the risk factors. Regarding the elderly room, it appears that this environment is an integral part of all households in the study, presenting as major risk factors: the slippery floors (n = 6), low illumination (n = 6), space inappropriate to ambulate (n = 2), obstacle in the displacement of the bed to the door (n = 1) and steps in the room (n = 1).

The bathroom used by the elderly, present in all households, show the following: absence of support bars (n = 10), slippery floors (n = 6), low light (n = 7), steps in the bathroom (n = 1) always wet (n = 3) and no non-slip mat in shower (n = 10).

Analyzing the corridor, present in just four residences, can be seen as major risk factors: the lack of grab bars in homes with corridors (n = 4), slippery floors (n = 2), low light in the environment (n = 3) and furniture on the space (n = 1).

Regarding the living room evaluation, present in eight households, is presented as alarming factors for the risk of falls: the slippery floors (n = 4), presence of steps (n = 4), low light (n = 3), coffee table (n = 1) and no non-slip feature carpet (n = 2).

As for the kitchen, existing in the households of the ten seniors, were identified as major risk factors the space: inadequate to ambulate (n = 7), there is very low cabinets (n = 6), high cabinets (n = 4), slippery floors (n = 3), steps in the kitchen (n = 4), and low light (n = 5).

The backyard is present in six households, and presents the risk factors: the presence of steps or unevenness in the environment, as well as plant or tree roots (n = 4), broken or damaged floor (n = 1), obstacles (garbage, rubbish, cans) (n = 2) and pets (n = 2).

The external sidewalk at home, existing in all homes of the elderly, presents risks: the presence of steps or unevenness on the environment (n = 7), uneven surface (n = 3), broken sidewalk or damaged (n = 3), obstacles (garbage, debris, bags, cans) (n = 4), narrow pavement (n = 5), steep slopes (n = 3) and uneven surface (n = 3).

Based on the results presented so far in the study, home falls are often caused during everyday activities such as go up and down the stairs, go to the bathroom or work in the kitchen. This suggests how important it is to check the functional capacity of homes in the elderly as the dependency for the performance of activities of daily living of the elderly tends to increase about 5% at 60, to around 50% between 90 years or more.¹⁹

Cognitive and functional abilities of the elderly

Alzheimer's disease affects the functional capacity, the level of independence and autonomy of the elderly. Interest in the functional capacity of the elderly with Alzheimer's has intensified, as the knowledge is needed, both to better understand the evolution of the disease and the definition of early diagnosis and to identify the degree of dependence to determine the care that will be held.²⁰

Pursuant to the Mini Mental State Examination in cognitive assessment of the elderly, we obtained the following information: in time orientation, two of the respondents correctly answered for the day identification; none for the day of the month; one for month; one for year; eight for the approximate time of day; as to where, they all knew properly to report a specific location, where they were, neighborhood or nearby street and city; and eight were able to identify correctly the state. In the immediate memory, eight have achieved maximum points, and none was without repeating a word. In the topic attention and calculation, only an elderly resolved the calculations correctly. In evocation, only one got the top score, and six did not receive any score. With regard to the assessment of language, nine named objects correctly, seven repeated the phrase nine obeyed the command, two read and obeyed the phrase "close your eyes", two wrote a sentence and none could copy the design. In the interim, Table 1 shows the distribution of the elderly according to the total score achieved by applying the MMSE.

Table 1 - Distribution of elderly people with Alzheimer's disease according to the scores achieved in the Mini-Mental State Examination - Sobral/CE, 2014

| Scores achieved in the Mini-Mental State Examination | N |
|--|---|
| score 11 | 1 |
| score 12 | 2 |
| score 14 | 3 |
| score 18 | 1 |
| score 20 | 2 |
| score 22 | 1 |

It appears that there was considerable variation in the score, and being the elderly with impaired cognitive function, some in higher and others lower intensity.

Studies suggest that education contributes substantially on developing cognitive tests. One perceives a significant difference to assess cognitive performance through the MMSE, emphasizing the need to establish cutoff points for different educational time. The level of education is one of the main factors influencing the performance of subjects, being of great importance in determining the final scores.²¹

Table 2 shows the distribution of scores performed by the elderly on MMSE compared to schooling.

Table 2 - Distribution of education and MMSE score of the elderly with Alzheimer's Disease - Sobral/CE, 2014

| MMSE Score Associated to Education | N |
|------------------------------------|----|
| Unable to read/write | |
| score 11 | 01 |
| Escore 12 | 02 |
| score 14 | 03 |
| score 18 | 01 |
| Literate | |
| score 20 | 02 |
| score 22 | 01 |

It was found a slight relationship between schooling and performance on the MMSE. However, it is believed that, in larger samples, this relationship may occur more significantly. Respondents who could not read or write had the lowest scores, comprising between 11 and 18. The literate, however, had scores between 20 and 22. The low level of schooling interferes with the autonomy, independence and hence the functional capacity of the elderly.²²

Based on the Katz Index, we investigated the functional capacity of the elderly, by evaluation of the activities of daily living (ADLs). This instrument uses the following dependence of degree classification: A - Independent to eat, be continent, mobilize, using the toilet, dressing and bathing; B - Independent to perform all these functions except one; C - Independent to perform all functions except for bathing and another function; D - Independent to perform all functions except for bathing, dressing and another function; E - Independent to perform all functions except bathing, dressing, using the toilet; F - Independent to perform all functions except bathing, dressing, using the toilet, mobilize and another function; G - Dependent to perform six functions and; Other - dependent to perform at least two functions, but can not be classified in C, D, E and F.¹² In Table 3 are the results of applying the Katz index in the elderly in this study, distributed by the degree of dependence.

Table 3 – Assessment of functional ability in elderly patients with Alzheimers upon Katz index by sex. Sobral/CE, 2014

| Katz Index | Female | Male | Total |
|------------|--------|------|-------|
| A | 03 | 03 | 06 |
| B | 01 | - | 01 |
| C | - | - | - |
| D | - | - | - |
| E | 01 | 01 | 02 |
| F | - | - | - |
| G | - | - | - |
| Other | 01 | - | 01 |
| Total | 06 | 04 | 10 |

The results show a predominance in group A, six elderly considered independent for the performance of ADLs. Among those with some dependence, one was in the group B, two in group E and one in another. It was not possible to associate the functional capacity to sex, since no significant difference between the results was shown by male and female elderly.

As to the assessment of the degree of dependence, it was found that most of the elderly remained with preserved functional capacity, with relative autonomy to carry out their activities without supervision of the caregiver. As to the bathroom items, clothing and personal hygiene, it was found that only three elderly have dependency. Therefore, based on the analysis of the Katz Index, it could be concluded that the act of eating was the role that older people played with greater independence (n = 10), as of the bath activities (n = 7), personal hygiene and clothing (n = 7), mobility (n = 9) and incontinence (n = 9) are the ones that showed elderly people with some degree of dependence.

The study results allow a closer relationship between age and functional capacity, justified by the fact that the greatest impairment in performing daily activities manifest in elderly patients with older age, making these more dependent.

It is essential to evaluate the functional capacity by the nursing and multidisciplinary team, as well as the diagnosis, since it relates to the impact of a disabling disease or condition of the individual and the impact on their quality of life and their families, and, thus, impact to the health care system as a whole.²³

Thus, it is considered relevant the monitoring of health professionals within the ESF, the elderly living with dementias, in order to guide caregivers and family members about the disease characteristics, as well as joint strategies to promote autonomy and independence.

Elderly perception about the care offered by the ESF

It is necessary to devote special attention to the elderly, as the healthy aging process involves promoting care, prevention, education, intervention. For this, the involvement and qualification of primary care is necessary

with multidisciplinary and interdisciplinary approach to integration in the family.⁹

Table 4 shows the strategies used by professionals working in the ESF for the care of the elderly with Alzheimer's and family, understanding that these are subject to the consequences of the disease.

Table 4 – Care strategies aimed at the elderly with Alzheimer's and the professionals involved. Sobral/CE, 2014

| Strategy used by the health team | | Nº of elderly |
|---|------------------------|---------------|
| Support group | Attend | 0 |
| | Do not attend | 10 |
| Home visits from ACS | Receives visit | 10 |
| | Do not receive visit | 0 |
| Number of home visits of other professionals in a month | Does not receive | 02 |
| | One visit | 03 |
| | Two visits | 02 |
| | More than three visits | 03 |
| Higher level health professional who conducts home visits | Nurse | 06 |
| | Doctor | 07 |
| | Psychologist | 01 |
| | Nutritionist | 02 |
| | Physiotherapist | 04 |
| | Social worker | 03 |
| | Pharmaceutical | 01 |
| | Occupational Therapist | 03 |

With the analysis of Table 3, it appears that all the elderly (n = 10) do not attend support groups in CSE, increasing a warning sign for professionals as for good practices for health maintenance. These Support Groups are configured as an alternative for the elderly to seek improvements in physical and mental conditions, through leisure and exercise, and the development of other occupational and recreational activities that provide improved quality of life.²⁴

The home visit is configured as a different opportunity for care, a rich time, which establishes the movement of relations, including qualified listening, the bond and the welcoming, favoring the family groups or communities to be better able to become more independent in their own health production.²⁵

It is emphasized here the importance of conducting home visits to the elderly with Alzheimer's in multidisciplinary approach, with trained professionals on the condition of offering care and meeting the demands of this group, as well as allowing the development and adaptation to daily life activities, generating greater autonomy and independence.²⁶

As regards to the distribution of actions related to dispensing of drugs. Some respondents receive medicines monthly in CSF Pharmacy Diabetes Mellitus and Hypertension and others receive medicines in other health services for the Alzheimer's disease. In all cases, family members, be their spouse, children or even grandchildren, were responsible for the administration of drugs, six of them take drugs in CSF pharmacy of residing neighborhood, five take drugs in other health services.

As for orientation that have or receive on the correct use of medicines, six received guidance from a health professional, being explained the time, the right way, the effects of drugs and the warning signs, and the effects of Alzheimer's disease to older people themselves, when possible, and to family members.

For this, a bulletin board can be used with all medications that must be taken, and arranged through symbols (understandable by the elderly) indicating the time of day to be administered, and the characteristics of the drugs.

Among the elderly of the study is noteworthy that only three perform pharmacological treatment for Alzheimer's disease. This signals weakness in the care provided, since the drug is configured in structuring strategy for treatment. Another aspect that draws attention is the lack of non-pharmacological strategies against Alzheimer's, shown in Table 4 which shows the Support Group as the one mentioned by the subjects.

Pharmacological strategies and psychosocial interventions for patients and their families comprehend the treatment for Alzheimer's disease. With regard to pharmacological treatment, many psychoactive substances have been proposed for the preservation or restoration of cognition, behavior and functional skills. However, the effects of drugs are limited to the delay in the natural course of the disease, allowing only a temporary improvement in the functional status of the patient.²⁷

When asked if a professional had explained the disease, the majority (n = 8) stated that had received a number of guidelines, and cited some professional categories, such as community health workers, nurses and doctors. Only two patients mentioned that they were diagnosed and received medical guidelines for private consultations, with all others exclusively assisted by the ESF.

In this light, it is signaled that the ESF contributes to the care of elderly patients with Alzheimer, addressing aspects of prevention of diseases resulting from senility, and health promotion through a multidisciplinary team. It is noted also that the provision of basic health services of public holding prevailed in 80% of the elderly in this study, which suggests the evolution of the coverage of the Family Health Program in Brazil and the provision of treatment for diseases specific as Alzheimer.²⁸

The ESF in addition to providing preventive care, provides the elderly a privileged space for a comprehensive health care, the possibility of a relationship between

professionals, community and home care which enables a performance in context of the reality experienced by the elderly within family.²⁹

In dealing with the perception of the subjects of the study on the CSF's care, the majority (n = 6) stated attending and use the CSF drugs, but say they attend only when presenting a health problem/need. Of those who said they did not attend, 2 identified as reasons unwillingness to walk to the CSF and 2 reported having health insurance, using only some of the ESF services such as vaccines, drugs and home visits.

About care in the CSF, most seniors indicated as being good (n = 5) and the others were divided between regular (n = 4) and bad (n = 1). The results demonstrate a certain satisfaction of the elderly, especially with home visits from community health workers and other health professionals, but they needed a more continuous and effective monitoring. Data for negative qualifications are due to delays in care for the elderly in CSF, not solving the problems and the lack of guidance on the care process.

So, one should raise awareness of the importance of comprehensive care, considering all the circumstances and needs of older people living with Alzheimer's and their families by making available adequate access to the ESF services, pharmacological treatment or nonpharmacological, an open listening and monitoring of qualified staff, thereby providing quality care.

CONCLUSIONS

Health care of the elderly is configured as a priority area of primary health care in Brazil. However, research indicates for adjustments and improvements to be carried out to appropriate care to this population group.

Early in the collection, great difficulty was faced in the search for data and information about people living with Alzheimer's in the city. Initially, there was the search for a record in the pharmacy of special drugs, but such registration did not have customer data information, so that they could be identified per household. Given this fact, we were directed to another service, where the address information was also impossible, since it would be necessary to seek information in paper records, which would only be possible through a number of protocol provided by the above-mentioned service, not having a computerized system for registration of these customers.

The way to find the subjects was therefore through the CSF information, so difficulties were also found, as the absence of specific record and lack of team members as clients with Alzheimer's, besides the difficulty of some professionals to conduct visits with the researcher.

In this context, we emphasize the importance of an updated register of older people living with Alzheimer's, being made available from the pharmacy of special drugs, which is carried out at dispensing drugs to the family health centers, facilitating monitoring the elderly and their families.

In addition to the fulfillment of the instruments, it was important to note the difficulties faced by the family and the client living with Alzheimer's. Families have proved receptive to the study and clients have collaborated satisfactorily. The insertion in the elderly home provided greater knowledge of the reality which is that client and his family, making it possible for an approach that allowed to draw inferences as to risk factors in the environment, family relationships, and questions, problems and strategies of coping. The good receptivity of respondents suggests that home visits carried out by health professionals to this population group are configured as an important tool for promoting health and preventing disease and injury, since they live with a degenerative disease, that interferes with the ability to perform daily activities, as well as social relationships, requiring continuous and full monitoring.

The subjects presented impaired cognitive ability, but as the functional capacity, most of carries out its activities without the help of family members or caregivers. It was noted that households are not adapted to prevent accidents, but also noticed a commitment of family members and caregivers to provide conditions conducive to the quality of life of the elderly.

Respondents users showed relative satisfaction with the attention given in the ESF. However, signaled as a limiting factor the presence of a community health agent during the interview and may have influenced the responses to matters related to the compliance of the ESF.

Thus, it is inferred as being essential for more effective and continuous monitoring of the multidisciplinary team of the ESF for the elderly with Alzheimer's disease and their caregivers, providing guidance and information necessary for the care of this population group and enhancing the improvement of condition life, independence and autonomy of this elderly.

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