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ORIGINAL ARTICLE

THE INSTITUTIONALIZATION OF THE ELDERLY WITH ALZHEIMER AS A DIFFICULTY OF CONSEQUENCE IN THE TREATMENT OF THE ELDERLY A INSTITUCIONALIZAÇÃO DO IDOSO COM ALZHEIMER COMO CONSEQUÊNCIA DA DIFICULDADE NO TRATO COM O IDOSO LA INSTITUCIONALIZACIÓN DE LOS ANCIANOS CON ALZHEIMER COMO CONSECUENCIA DE LA DIFICULTAD EN EL TRATO CON LOS ANCIANOS

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ABSTRACT

Objective: to grasp how it was for the family to make the decision to institutionalize the elderly with Alzheimer's. **Method:** an exploratory and descriptive study of a qualitative approach, conducted with six family members of elderly residents in a long term care facility. Data was collected through semi-structured interviews and submitted to Content Analysis technique. **Results:** the analysis enabled the identification of two categories, in which it was noted that there were mood swings and aggression, resulting from the disease, representing risks to the family members, making hospitalization a hard decision and, often accompanied by guilt, but more than is the opportunity to add quality to the care provided, contributing to the tranquility of the family. **Conclusion:** living with an elderly person with Alzheimer's is not difficult and the decision to institutionalize is permeated by the desire to offer quality care to the elderly and security for the family. **Descriptors:** Family; Caregiver; Alzheimer's Disease; Institutionalized.

RESUMO

Objetivo: apreender como foi para família a decisão de institucionalizar o idoso com Alzheimer. **Método:** estudo exploratório e descritivo, de abordagem qualitativa, realizado junto a seis familiares de idosos residentes em uma instituição de longa permanência. Os dados foram coletados por meio de entrevista semiestruturada e submetidos à Técnica de Análise de Conteúdo. **Resultados:** a análise possibilitou a identificação de duas categorias nas quais se observaram que as alternâncias de humor e agressividade, decorrentes da evolução da doença, representavam riscos aos membros da família, tornando a internação uma decisão sofrida e, muitas vezes, acompanhada de culpa, mas que representa oportunidade de agregar qualidade aos cuidados prestados, contribuindo para a tranquilidade dos familiares. **Conclusão:** a convivência com um idoso com Alzheimer é difícil e a decisão de institucionalizar é permeada pelo desejo de oferecer um cuidado de qualidade ao idoso e segurança para a família. **Descritores:** Família; Cuidador; Doença de Alzheimer; Institucionalizado.

RESUMEN

Objetivo: capturar como ha sido para la familia la decisión de institucionalizar a las personas mayores con Alzheimer. **Método:** estudio exploratorio y descriptivo, con enfoque cualitativo, realizado con seis familiares de ancianos residentes en una institución de larga permanencia. Los datos fueron recogidos mediante la entrevista semiestructurada y sometidos a la técnica de Análisis de Contenido. **Resultados:** el análisis permitió la identificación de dos categorías, en el que señalaron que el estado de ánimo cambia y la agresividad resultante de la evolución de la enfermedad, representan riesgos para los miembros de la familia, tornando la internación una decisión sufrida, acompañada a menudo por la culpa, más que representa oportunidad para calidad total a la atención, contribuyendo a la tranquilidad de los familiares. **Conclusión:** vivir con un anciano con enfermedad de Alzheimer no es difícil y la decisión de institucionalizar está impregnada por el deseo de ofrecer atención de calidad a las personas mayores y seguridad a la familia. **Descriptores:** Familia; Cuidador; La Enfermedad de Alzheimer; Institucionalizada.

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INTRODUCTION

The reduction of fertility rates since the mid-1960s, combined with increased longevity, features rapid population aging present on the world stage. In Brazil, it is estimated that, by 2050, the percentage of people over 60 will be approximately 30% of the population, which represents a challenge to society.¹

The aging comprises a dynamic process characterized by morphological, physiological, biochemical and psychological changes, determined by the progressive loss of the individual's adaptability to the environment². Among the changes resulting from the aging process, there is the decline of cognitive function, characterized by dementia in the elderly. It should also be noted that the incidence and prevalence of dementia increases exponentially with age, doubling the involvement index every five years, from 60 years of life.¹

Although human neurons are functional throughout life, the mechanisms that preserve their functions and protect against neurodegeneration during aging are unknown³. Among neurodegenerative diseases there is the Alzheimer's disease a more common form of dementia among older people, in which there is cognitive decline, compared to a previous level of the individual, resulting in impairment of their social and functional⁴ functions.

The mild cognitive impairment, represented by episodes of amnesia, disturbances in language and characterized the initial stage of the disease, over time, is increased and accompanied by other signs and symptoms, such as behavioral changes. With the advance of the disease, there is a loss in performing basic activities of daily life of the elderly, making it dependent care and progressively incapable.⁴

In this context, conditions to increasing need for a caregiver to meet the needs, provide care and conduct activities that these individuals cannot achieve by themselves, the family is the main source care provider⁵. However, inexperience and lack of knowledge related to the disease, incorporated into the lack of preparation and family support, influence negatively the quality of life of the family, and the quality of patient care activities.

Although care needs to meet a demand, the family (especially one who assumes the role of caregiver) have difficulty accepting the changes caused by the disease, because of the relationship with the elderly before the

dementia process which, progressively, affects another way of being, although it retains the same physical appearance, well known by family members⁶.

Thus, the care given becomes very complex, because the family is perceived as involved in difficult feelings to handles that end up imposing the isolation of care activities, deeply handicapping emotional systems involved, contributing to hardship and changes in life style, so that the new needs of the sick members can be included.⁶

Although the person's stay in the family and community core is important for coping with the disease, over time the behavior, changes made by the elderly, for some time, can mark a period of transition and contribute to the emergence of conflicts in family and among the elderly and other family members.

With the progress of the disease, however, the elderly are increasingly isolated and, at the same time, they become increasingly dependent on care and attention. In this context, often the family is no longer able to deal with meeting these demands, which lead to searching for alternative care, such as, the institutionalization of the elderly.⁷

Considering the relevance of this theme, it is important to reflect on the reality experienced by the family. Given the above, this study aimed to understand that family only perceive the care for the elderly with Alzheimer's disease. Thus, it is believed that this process may assist in understanding the needs and difficulties experienced by families living with this disease, with a view to the care process to the elderly.

METHOD

An exploratory and descriptive study of qualitative approach, conducted with six family members of elderly patients with a diagnosis of Alzheimer's disease, living in a long private stay institution in the city of Maringa, Parana, Brazil.

The institution used as a study site works since 2005, has a capacity for 40 elderly, who may remain in the institution only in the daytime, or fulltime. During the data collection, 16 elderly people with Alzheimer's disease, attended the institution, of which 12, were full-time.

Study participants were selected intentionally, with the help of a nurse responsible for the institution, which indicated the elderly who received frequent visits from family and whose visitors wielded the role of primary caregivers before institutionalization. Nine elderly people met

these criteria, however three families failed to have availability of time to participate in the interview.

The initial contact was the invitation to participate and present the objective of the study was done by phone. Upon acceptance of the family participating in the study, the interview was scheduled for the same day to be held and visit the elderly in the institution.

Data was produced in the period of July and August 2015, through semi-structured interviews, consisting of questions of socio-demographic (family and elderly) and guiding. The interviews were closed when the data began to be repeated, and others contacted family members could not reconcile their time to do the interview.

The statements were recorded in digital media, fully transcribed, after being subjected to content analysis, thematic mode⁸, following the pre-established steps that included the pre-analysis, material exploration and processing of data. In the pre-analysis, we proceeded to the organization, transcription and separation of the empirical material, floating, reading the data set, with identification of relevant aspects, from the purpose of the study. In the exploration of the material, the classification and aggregation of data was made from a thorough reading process, identifying the commonalities and specifics, giving rise to the previous categories. Finally, the treatment of data, was the deepening of categories, through the articulation of empirical data with theoretical material, considering the research objectives and the emerging themes.

The study was conducted in accordance with the provisions of the National Health Council Resolution 466/12, after projecting approval by the Standing Committee on Ethics in Human Research of the State University of Maringa (Opinion No. 48743515.7 / 2015). All participants signed a informed consent form in duplicate and were identified with the letter E (respondent), accompanied by an Arabic number, corresponding to the interview realization of order, followed by the degree of kinship with the elderly.

RESULTS

The six family members participating in the study were all female, were aged between 37 and 73 years, four married and two unmarried. Regarding education, three had completed higher education and three, incomplete.

None of the interviewees had experience in caring for elderly relatives. The elderly

insertion initiative in a long-stay institution left the main caregiver, after episodes of death threats and attempts to escape, resulting from behavioral changes caused by the disease. The time between the decision and the execution of the elderly institutionalization ranged from fifteen days to two years.

The analysis of statements allowed the identification of two empirical categories: *"The clinical course of the disease as a challenge to care"* and *"The institutionalization of the elderly as an alternative to care."*

♦ The clinical course of the disease as a challenge to care

Changes in behavior displayed by the elderly, from the disease, can pose risks to family members, sometimes because of the fickleness of conduct of the elderly, or even the aggressive behavior that hinders care.

When the disease began to evolve [...] he had a crisis and wanted to put the house on fire. He was very nervous and aggressive, had to go to the psychiatric hospital and, from there, went straight to the nursing home, follow the doctor's statement. (E1, daughter-in-law)

At first he went 5 or 6 days without bathing, and when he did he was obliged, had to call my brother to help me hold him. But then started to become quite aggressive, getting upset, it seemed the world turned upside down. They were these episodes of aggression and agitation that began to endanger the family members, and people were realizing that he could not care more. (E2, daughter)

Sometimes, aggressive behavior is not only towards the closest people.

It reached a stage that we needed someone watching him all the time because he wanted to go out to the street [...] he hid iron in my mom's room and said he would kill those who put the car in front of his house and had several episodes where I have to hold him and take him inside not to do anything crazy. (E2 daughter)

Alongside the risks posed by changing behavior, we also noted it is the eminence of feelings of insecurity on the part of caregivers face of care actions that need to be performed.

Alzheimer's brought ignorance, insecurity and fear in the way of taking care of it, because I always imagined like this: a person who broke his leg and is bedridden, needs to be changed so many times in so many hours, be fed, so all, this has orientation. In Alzheimer, we do not have to do anything, we do not know what it is. This information that is on TV only shows the beginning of the disease ... because most

people think that having Alzheimer's is having only forgetfulness, but it has several stages ... it's difficult to care for this, disease you, never know if you're hitting or missing (crying). (E6, daughter)

The reports explicitly show that the decision to institutionalize the elderly is basically due to two desires: to provide a more appropriate elderly care and quality of life for themselves, which is identified on expression as "handmaid of care."

I had to make a decision to lock a time my father in the room the night for him to sleep. You become a slave to care and are followed by the fear of doing it wrong [...] Because caring for a family member with Alzheimer's, apart from you not knowing what to do, you do not give any comfort to the person perceives no manifestation and you do not know if you got it right, you are totally lost. (E6, daughter)

The reports also show the feeling of sadness experienced only in the absence of affection and care of elderly family members, and the lack of recognition as the care actions offered by the family.

Alzheimer's is a very thankless disease because the person will forget the family, will lose the family's affection, then, gradually, she begins to treat the family differently. At this point, you realize you have no value more for that person, and that makes us suffer and I think even more than those who are with the disease. (E2, daughter)

The saddest thing is, that over time, he did not recognize me more and did not realize when I was showing love and how much he was missing by not getting more part of my life [...] to understand what we are doing for them or wanting to receive them, or could talk, remember a beautiful fact that we spent together. For them, we no longer exists. (E3 niece)

Until the development of the disease, institutionalization also means a way to provide security to the life of the family.

My mother started to get depressed, lived scared, her eyes-popped for everything, because all the time she kept thinking what he was going to do ... she was afraid of him grabbing something and hitting her. Had once come to grab her by the neck and lead her to the gate of the house for her to open it for him [...] (E2, daughter)

Here we have confidence that he is being well attended. In our house maybe we cannot continue the same care he had before, when his wife was alive. I am calm that she is being well taken care of, that the attention of nurses, physical therapy, all care of the caregivers; we realize that they are very dedicated, know what they do

well and responsible. Everything I ask, they know how to respond [...]. (E3 niece)
Ahh yes, because here he's safe. Being careful. Day and night they give assistance. So it's a tranquility. I feel okay here. (E4, wife)

In contrast, two interviewees stressed the importance of family involvement forward to the evolution of the disease:

[...] Even when he is aggressive and wants to attack me, I'm stroking his hair, I'm kissing his forehead, I tell him I love him, that I miss him and he will be calmer, because he feels he has someone in the family caressing it. (E3 niece)

To take care of the elderly with this disease, the family must have patience and learn to understand that it is no good to want to change his behavior, but, accept. (E5, daughter)

♦ The institutionalization of the elderly as an alternative to care

For the respondents, the familiar insertion with Alzheimer's in a long stay institution represented by an opportunity to add quality care to the life of the elderly.

And here he has the right times for his meal, physiotherapy, sunbathing, bathing ... Here's more care than at home. more systematic care, here they have a regular time to be served and this is what causes an improvement in the patient. (E3 niece)

While they recognize the improved care after institutionalization and quality of life by not exercising more the care of the three, interviewed experience this decision permeated by feelings of guilt, rejection and helplessness.

[...] He came here (asylum) and I know that he is well maintained. But the rest, "I am free", I cannot feel. Sometimes, I feel guilty about him being here. It is difficult, since the day he got sick, my world is over, it is and nothing more... (crying). (E5, daughter)
He's here (asylum), even though I know that it is good it is, very painful, because in my mind he had, to be at home with me and my family. (E2, daughter)

My guilt was born on the day I had to leave him here. I feel that I abandoned my father threw my father out. My quality of life has improved greatly, but the sense of guilt with me, to not have managed and have failed my father. (E6, daughter)

Finally, one of the participants, which has an institutionalized husband and, previously, presented a feeling of tranquility to know that the spouse is well maintained, still expresses sadness at the absence of a longtime companion.

I lived with him, we went out. I was alone (crying). It was not good for me. Now I live with my animals (crying). [...] I am aware

that it has to be like this. I have to put it in my head which is the best for him and for me! (E4, wife)

DISCUSSION

Allied the physiological changes inherent to the aging process, which can generate elderly dependence to the perform basic activities, and neurodegenerative dementias such as Alzheimer's, can contribute to the reduction and eventual lack of autonomy of the elderly, which makes them dependent on increasingly complex care. This disease progresses and affects the elderly progressively, with varying degrees of commitment, losses and necessities.⁹

In this specific context of the elderly afflicted with Alzheimer's disease, the family caregiver needs, and tries to mitigate the vulnerability that both are exposed to, learn how to handle the different demands of care presented in accordance with the stage of progression of the disease.¹⁰ Sometimes, the process of adaptation and experiences of each new phase of the disease requires reorganization in the structure and family dynamics so that care can be permanent and continuous.

Thus, the physical and mental losses that occur in the elderly with the Alzheimer's disease cause adverse effects on the health of the caregiver, that who feel overwhelmed, being responsible for the whole patient care and daily monitoring the familiar worsening prognosis.¹¹ With time, they can develop psychological disorders, as noted in the speech E2 of the participant's daughter.

So with the gradual, degenerative, course of the constant problems of memory and patient behavior, it is required of the caregiver a great adaptability which tends to be increasing, and that is positively associated to the demanded overload.¹²

Because it is a chronic degenerative neurological disease, doubt and uncertainty regarding the realization of the quality of care actions are inherent, affecting aspects of personal, emotional, financial and social of patients and their family counterparts.¹⁰

It was noted in the reports, which in an aggressive behavior manifestation situation of the elderly with Alzheimer's, E6 - daughter adopted behaviors that made her think about the quality of care offered by it, as well as the internal conflict that made her think that she rejected her father. In reference to this, it identifies the need to support these families by the health service, to so that they become able to face the complications of the care process and the emotional impacts can be

minimized within the family of the sick elderly.¹³

A study in two hospitals in Rio Grande do Sul, he pointed out that dealing with family was one of the main difficulties in assisting the elderly with Alzheimer's, during hospitalization, and for this reason, they are often characterized as inconvenient in the care scenario¹⁰. This result shows that, on one side, the family is recognized as a priority link in patient care with Alzheimer's and, others, professionals are not prepared to see the family as a positive agent in this process.

Nursing professionals should work with families, be planning strategies to meet them or diagnosing the needs of the client/family, as the family, without a doubt serves, great importance in the care and support to the patient, even considering that the family dynamics can be subject to change arising from the disease process.¹⁴

Besides professional assistance regarding the care, psychological support is essential to the maintenance and promotion of the family caregiver's quality of life, especially the absence of manifestations of affection by the elderly. So part of the care demonstration of reciprocity, satisfaction, love and affection, leaving only the conduct of those who care, emphasizing the relationship patient / caregiver and obligation, not by a desire to take care of their loved ones.

The perception that family with AD is physically present but mentally absent, leads the sick person to not have the characteristics that made them be recognized as someone who has always been - the same happening with their role and function in the family.¹⁴

In this design, being familiar with Alzheimer elderly caregivers, triggers the experiences of different feelings as uncertainty about the most appropriate way to act in every situation. The fear of not knowing how to recognize symptoms of worsening of the, condition and hence, the need to seek expert help, concerned with aspects of general health, since often the elderly does not accept being fed regularly, and refuse to perform and / or receive care with personal hygiene. Impatience behavior "rebels", sorry to see the old isolating increasingly, among others. These feelings can influence the care and welfare of the elderly with AD.¹⁵

Although the progressive course of the disease may hinder care, contributing to the accumulation of additional responsibilities of increasing, the study pointed out the importance of the family to develop mechanisms that contribute to the care and

patience, for example, present in E3's niece's testimony and E5-daughter.

It is noteworthy that through the deponents that were observed that by discrediting the effectiveness of the care exercised in the family, caregivers envision the new institutionalization opportunity to add quality in elderly care with AD.

The caring role does not end with the institutionalization, since the family is involved in the bonding and the family care relationship. For this reason, it is necessary to get greater attention from health professionals regarding the family caregiver's quality of life, especially, considering the reduction of burden of this family, as it can still manifest by guilt or abandonment of his family.¹⁶

It is also, necessary, to awaken the health professionals to expand their look at the context of the people involved in the disease process in order to put the family, in care planning, thinking of assistance extended actions directed the family in order to promote improvements in coping and living with the disease. New health education actions need to be developed, aiming at integrated care to the patient and his family, as the realization of self-help groups and / or mutual aid, home visits, nursing visits, and from that, develop actions and interventions , to assist and enable the family to care and live with the disease.

CONCLUSION

Alzheimer's disease provides changes in the daily routine not only in the patient's life, but of all who are around them, especially those who are part of the family unit and performing the role of primary caregivers, therefore, also need to be envisioned as people in need of care.

The caregiver needs care, that is coordinated in interventions to improve their quality of life, as, to assume the role of caregiver, shall perform the often tedious duties, repetitive and exhausting, physically and mentally. There is need for interdisciplinary education programs and support for caregivers, assisting them in reducing the overhead associated with the care of patients with dementia, since the care of elderly patients with Alzheimer's disease is continuous, complex and long term, characteristics that favor the commitment to health of those who perform them.

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