



CHALLENGES MET BY FAMILY CAREGIVERS OF ELDERLY WITH ALZHEIMER'S DISEASE ENROLED IN A SUPPORT GROUP

DESAFIOS DE CUIDADORES FAMILIARES DE IDOSOS COM DOENÇA DE ALZHEIMER INSERIDOS EM UM GRUPO DE APOIO

DESAFÍO DE CUIDADORES FAMILIARES DE ANCIANOS COM ENFERMEDAD DE ALZHEIMER INSERIDOS EN UN GRUPO DE APOYO

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ABSTRACT

Objective: to know the difficulties experienced by informal caregivers and their coping skills in the daily life of caring for elderly with Alzheimer's disease at home. **Method:** descriptive study with qualitative approach and content analysis. Data collection was carried out through interviews with nine family caregivers enrolled in a support group for elderly with Alzheimer's disease in the year 2012. **Results:** two categories emerged from the analysis of the interviews: Difficulties, fears or doubts and Caregiver coping strategies. **Conclusion:** the nurse should be included in these support groups because these represent spaces of intervention, awareness and sensitization with potential to unite people in order to provide a high quality and less traumatic home care for elderly with Alzheimer's disease. **Descriptors:** Alzheimer's Disease; Nursing; Caregivers; Elderly.

RESUMO

Objetivo: conhecer as dificuldades vivenciadas pelo cuidador informal e suas habilidades de enfrentamento no cotidiano de cuidar do idoso com doença de Alzheimer no domicílio. **Método:** estudo descritivo, com abordagem qualitativa e análise de conteúdo. A coleta de dados foi por entrevistas com nove familiares cuidadores inseridos em um grupo de apoio para idosos com doença de Alzheimer no ano de 2012. **Resultados:** a partir da análise das entrevistas, emergiram duas categorias: Dificuldades, medos ou dúvidas e Estratégias de superação do cuidador. **Conclusão:** o enfermeiro deve ser inserido nesses grupos de apoio, pois são espaços de intervenção, conscientização e sensibilização capazes de agrupar pessoas a fim de proporcionar um cuidado de qualidade e menos traumático ao idoso com doença de Alzheimer domiciliar. **Descritores:** Doença de Alzheimer; Enfermagem; Cuidadores; Idoso.

RESUMEN

Objetivo: conocer las dificultades vividas por el cuidador informal y sus habilidades de enfrentamiento en el cotidiano de cuidar al anciano con enfermedad de Alzheimer en su domicilio. **Método:** estudio descriptivo, con enfoque cualitativo y análisis de contenido. La recolección de datos fue por entrevistas con nueve familiares cuidadores inseridos en un grupo de apoyo para ancianos con enfermedad de Alzheimer en el año 2012. **Resultados:** a partir del análisis de las entrevistas, surgieron dos categorías: Dificultades, miedos o dudas y Estrategias de superación del cuidador. **Conclusión:** el enfermero debe ser inserido en esos grupos de apoyo, pues son espacios de intervención, conciencia y sensibilización capaces de agrupar personas a fin de proporcionar un cuidado de calidad y menos traumático al anciano con enfermedad de Alzheimer domiciliar. **Descriptores:** Enfermedad de Alzheimer; Enfermería; Cuidadores; Anciano.

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INTRODUCTION

The emergence of chronic degenerative diseases represents a deterioration of the natural aging process and dementias are among the particularly most debilitating of such diseases. These diseases gradually become a health problem as they undermine the everyday life of older people due to the neurodegeneration. Etiologically, there are more than fifty diseases associated with dementia, although the most common is Alzheimer's disease (AD). This condition causes strong impact on family structure and society and has the highest prevalence among all dementias, with rates around 50% to 70% of diagnosed cases in the United States in 2007. The increase of this prevalence is most evident in the elderly aged at 90 years or above, and the disease can affect about 37.4% of elderly.¹

Alzheimer's disease is manifested initially in an insidious manner with progressive deterioration of neurologic functions. The most prominent clinical damage occurs to the memory, episodically, and with obvious losses in the acquisition of new skills. Fluent aphasia can occur in intermediate stages, evidenced by difficulty in naming objects or choosing the right word to express an idea. Finally, terminal stages may include symptoms like pronounced changes in the sleep-wake cycle and behavioural changes such as irritability and aggression, psychotic symptoms, inability to walk, talk and perform personal care.²

Because of such cognitive difficulties incurred by the loss of ability to maintain daily activities by elderly with AD, the presence of a caregiver becomes fundamental. In this case, the care provided to these elderly may be performed by common people, informal or non-professional caregivers, and in our culture, the family itself is generally responsible for providing such care. It is also possible in some cases to pass the caregiver job to neighbours, godmothers/godfathers, co-workers, volunteers or hired companions such as attendants, nursing assistants and maids.³

In face of the increase of cases of Alzheimer's diagnoses and the lack of knowledge by many families on how take care of elderly affected by this disease, associations of support for elderly and their caregivers were created. These associations bolster families in difficult and unknown moments on the progression of the disease and its impact on the change of family structure. In this mainstay, the inversion of roles and the fact the elderly with Alzheimer's

disease forgets "the self and the us" represent, without a doubt, the inevitable path of the disease that brings more distress to caregivers. In this context, the nurse plays a crucial role in helping and counselling caregivers who often do not react in face of his/her own illness and, therefore, get ill together with the elderly.

Based in this context, the following questions emerged:

a) What are the difficulties experienced by informal caregivers while caring for an elderly with Alzheimer's disease?

b) What skills and/or resources the informal caregiver uses when experiencing difficulties in the daily caring for an elderly with Alzheimer's disease?

In order to answer these questions, the following objective was set:

- Get to know the difficulties experienced by informal caregivers and their coping skills in daily life caring for elderly with Alzheimer's disease enrolled in a support group for elderly patients with AD.

METHODOLOGY

Article drawn from the Undergraduate Course Conclusion Thesis << **Alzheimer's disease: nursing action before the resilience of caregivers in caring for the elderly** >> presented to the Anna Nery Nursing School, Health Sciences Center, Federal University of Rio de Janeiro/UFRJ. Rio de Janeiro (RJ), Brazil. 2012.

This was a descriptive study with qualitative approach. The subjects were enrolled in a support group for caregivers and family members of elderly patients with dementia which is part of the Association of Alzheimer's disease and other similar diseases (ABRAz- RJ). The sample consisted of nine informal caregivers of elderly with Alzheimer's disease who regularly attended ABRAz- RJ through the period of March - May 2012.

The support group chosen to carry out this research has meetings every week and is coordinated by a family caregiver and president of the ABRAz - RJ. Group members are mostly family caregivers. Health professionals who volunteer to help by offering information and relevant thematic lectures to answer the doubts of those attending the group also participated voluntarily in the study.

In order to be included in the study, subjects had to meet the following inclusion criteria: (a) accept and be available to participate in the survey; (b) be an informal caregiver of an elderly with Alzheimer's

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disease; (c) attend the ABRAZ-RJ support group. Exclusion criteria were: (a) be formal caregivers of elderly with Alzheimer's disease; (b) did not attend the ABRAZ-RJ support group.

Data collection was carried out only after approval by the Ethics and Research Committee of the Anna Nery Nursing School - EEN/UFRJ - Teaching Hospital São Francisco de Assis UFRJ, under consolidated opinion n° 5908/12 and CAAE: 00995012.3.0000.5238.

In order to implement field work, a semi-structured interview data collection technique was used and was guided by the following probing questions: a) What are the difficulties (fears, doubts) that you have when caring for an elderly with Alzheimer's disease?; b) What do you do when experiencing a difficult situation while caring for an elderly with Alzheimer's disease?

Interviews were recorded audio in MP3 format, then transcribed without eliminating the spontaneous character of the speeches. Data were analysed using the content analysis proposed by Bardin. The analysis was regulated by saturation of data collected and/or repetition of content emerged, in which the answers of respondents were grouped in a consistent and systematic manner in accordance with the objective set for the study.

RESULTS

The sample consisted of nine subjects, among them five were female and four were male. Two categories of analysis emerged from the questions addressed in the interview: *Difficulties, fears or doubts of caregivers caring for elderly with Alzheimer's disease; Caregiver coping strategies in the face of difficulties.*

♦ Difficulties, fears or doubts of caregivers caring for elderly with Alzheimer

This category gather the difficulties of caregivers in coping with problems related to: communication, aggressiveness and the evolution/stages of the disease itself. Regarding communication and aggressiveness, the interviewees voiced:

The biggest difficulty is communication because moments of lucidity are rare, when she understands something (...). (C.C)

My biggest fear, in fact, was his aggressiveness. (C.D)

The coping with the disease, for those who provide care, may be manifested in different ways and reveal issues involving: death, healing, disappointment, rejection, rejection,

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persuasion, learning, awareness and forgiveness. According to these issues, the interviewees noted:

The greatest difficulty is to convince, or persuade that elderly person with Alzheimer's, that he needs help. (C.G)

(...) The greatest difficulty, to start with, is the rejection and non-acceptance of the disease. After this, disappointment struck me, because I thought that this disease had a cure, and I believed that that situation was going to disappear. (C.H)

I would say that now, with all that I've learned in ABRAZ and with the caregiver course I did, and attending the support group, all this took away some of this idea of fear and dread. You become gradually more and more aware of what is happening and what will likely happen to that person. This way, you start to leave that feeling of guilt for what you did or what did not do. (...) At the beginning, what's more difficult is the acceptance of the disease. You understand that the person will slowly "disappear", it caused me fear. When you start studying and better understanding what's going on, everything gets better. (C.I)

♦ Caregiver coping strategies in the face of difficulties

It was observed that support is necessary in order to care for a person with dementia, especially with Alzheimer's disease. Accordingly, the following strategies of support in the care of individuals with AD were identified in the speeches of deponents: *Home Care* service, institutionalization, group support, and self-care.

Currently I have Home Care service. The professional goes to my house (...). This facilitated my life, very much, but I need to be coordinating everything. I talk to all professionals, reporting all problems she is experiencing. Also, I have a chart of my wife where I write, and also all caregivers and professionals responsible for the care, all put their observations there, every day. (C.A.)

For a long time I tried to do as much as possible, I even quit my job to be able to be with her as long as possible. I brought a caregiver to help me, but the situation was only getting worse, and even the doctor said her health was getting worse, due to her own lack of self-care. She was resistant, rejected to receive care. Even personal hygiene was complicated, she did not want help. Last year I had to put her in an institution. (...) Whenever I can, I try to be there with her. (C.E)

I'm looking for help here in the support group to try to find answers to my questions. For now, I have not lied to him. (C.F)

I did not quit my life, I have not quit living. I do travel, I have a young son to raise, and cannot live only to this care. And this is something I have learned here in the support group because, before that, I used to live exclusively to this care. (C.G)

(...) One cannot lose the desire to leave, go to the movies, to the theatre, be with other people. You cannot put yourself within a jail. If you do not have the full perspective that you are the main figure before that elderly, you will get sicker than him. You must take care of yourself to be able to take care of other person. (C.I)

DISCUSSION

The analysis of interviews about the difficulty of communication, aggressiveness in speech and physical aggression demonstrates that the findings refer to difficulties experienced by the majority of caregivers of Alzheimer patients. In this respect, similar findings were described in a study in which the authors realized that the knowledge of family caregivers about Alzheimer's disease is limited, and this may hamper the planning of care to the elderly and enhance the burden of the caregiver. Care is developed through a set of views and ways of feeling, imposed by family tradition. Such care is generally accepted uncritically, arising from common sense.⁴

Another important aspect that must be highlighted is the possibility of changing of behaviour. In this study, physical and verbal aggressiveness were present in the speech of respondents, and the feeling of fear when faced with these changes was highlighted. Changes in behaviour ranging from a progressive passivity to a marked hostility and aggressiveness may occur before cognitive difficulties⁵. Therefore, information given to caregivers should be focused in the deficit for carrying out the activities and behaviour as well as in the reference for care. Detection of problems in order to assist and guide the nursing care of the person with Alzheimer's disease is the first step to reduce barriers.⁶

Because this is a chronic degenerative disease, the caregiver of a patient with AD experiences situations that, in many cases, were unknown before diagnosis and now assumes responsibilities, tasks and skills that may become overwhelming. As a result, the caregiver may develop a set of physical, mental and socio-economic problems.⁷

The caregiver of an individual who suffers the process of dementia, in particular Alzheimer's disease, usually experiences situations where feelings such as fear of death, healing, disappointment, rejection, resistance, conceit, learning, awareness and forgiveness

are present. Thus, those feelings gradually turn into new values that modify the way of experiencing the bearer of AD and, therefore, bring forth the automatic reverberation of the caregiver inner references.

The unpredictable course of Alzheimer's disease can have an impact in the lives of caregivers. Losses occur in the life of the individual with Alzheimer's disease, incapacitating him or her to perform activities and making him or her increasingly dependent on a caregiver. The caregiver performs a solitary and anonymous activity in face of the diagnosis of Alzheimer's disease from the point that he or she receives the news, goes home and there, most of the time, learn to deal with this new condition. However, it is often the lack of preparation for the care what generates negative impacts on the life of the caregiver.⁸

Another important factor is the emergence of new identities, new roles, new situations experienced by elderly caregivers. Both, elderly and caregiver, seem to need to re-learn how to live in this new scenario⁹. So, caregivers interviewed in the present study showed to be, most of the time, overwhelmed by coping with the changes and difficulties incurred by Alzheimer's disease, and they used strategies to overcome and/or alleviate the daily situations of care. These strategies included, for example, search for support offered by Home Care Services, transfer the elderly to an institution and enrol into support/help groups.

Take daily care of an individual who is dependent may include the development of activities that require physical effort, to provide some aspects of the care, and also be aware of the implementation of certain procedures. It can be noticed that, over time, stressful features of the care activity arise, namely, the physical erosion and emotional stress of caregivers.¹⁰

Whereas care for elderly with AD is a multifaceted care and requires from those who take care the ability to perform domains and skills, the caregiver may need specialized and targeted guidance. In this sense, health professionals, especially nurses, are key elements in home care to the caregiver and to the person with Alzheimer's disease. In fact, one study found that the nurse is the key to a comprehensive care of elderly patients with dementia due to their ability to deal with the health of the elderly, with the caregiver and with the family, always aiming at the promotion of a dignified and high quality lifetime for everyone.¹¹

Give assistance to the individual with AD and their caregivers in the physical, personal and family aspect, therefore, may ease the burden

of the caregiver, promoting safety, information, guidance, individualized and personalized follow-up and, above all, welcoming the caregiver as subject and actor of the care. It is known that the physical and mental well-being of the person who lives daily with an Alzheimer patient is a weather predictor that the patient will remain at home, delaying a possible institutionalization.¹²

For these reasons, equip, support and promote actions or nursing interventions to caregivers of elderly with Alzheimer's disease is essential. In this understanding, support groups may be solidary spaces open for exchange of experiences and learning of caregivers as well as for the health team, especially nurses. It is about a "common place" where experiences can be shared and safety and reception is provided to participant, fostering, this way, the contact, approach and identification with each other.¹³

Therefore, it was observed that the group is a social support, because it underlies caregiver-care relationships, whose result consists in promoting the ability to cope with environmental stress in a moment of vulnerability. Thus, the caregiver should be sensitive and able to provide resources such as to enable to be welcomed¹⁴. In this regard, the support group is a place of discussion and sharing of experiences of unique moments with each elderly with AD.

The study found that support groups are spaces for important intervention, awareness and sensitization, complex and essential for caregivers and these are, therefore, an essential space for the promotion of educational and informative actions of nursing and of other fields of knowledge. Guidelines and care provided to patients with AD and to the family are still a recent perspective, lacking of studies and practical experiences.^{6,15}

CONCLUSION

Investigations about the daily routine of caring for the elderly with AD are essential to the understanding of care in different phases and/or stages of the disease. The presence of a relative as a caregiver of the elderly with Alzheimer's disease in the family environment represents a situation of potential conflict and driving of constant tensions, directly affecting the caregiver and the family dynamics.

Thereby, the assistance to elderly, and especially demented elderly and their families, requires commitment, knowledge and participation of trained and qualified professionals to intervene in the family, supporting the overlapping needs of the care

of those people. In view of these circumstances, knowledge of difficulties faced by caregivers and their coping skills can facilitate the implementation of proposed nursing actions. This would facilitate, ease or promote improvement in the quality of life of caregivers, even in the face of adversity and complications arising from the disease.

The work with and planning actions aimed at caregivers of people with dementia is a major challenge for health professionals. It is expected that the nurse has the technical competence and emotional and subjective ability in face of complications arising from this disease and, above all, in face of the doubts and fears that caregivers express while dealing with the elderly affected by this disease. Thus, care for the elderly with Alzheimer's disease requires solidarity in addition to information and knowledge.

Therefore, the present study contributes to the understanding that the care provided to elderly with Alzheimer's disease and their caregivers is a complex, specialized, multifaceted care, requiring from the nurse the ability to intervene on the real needs (doubts, fears and difficulties) brought by the caregiver. Furthermore, the caregiver must be recognized and considered a subject and social actor of the care given to elderly with Alzheimer's disease. This needs guidance, monitoring and planning of informative and educational actions. Finally, the health professional needs to enter into collective and specific spaces of discussion, as for example, informative and/or support groups to demented elderly caregivers in order to improve their knowledge and learning and provide interventions based on concrete demands and real care from the caregiver's perspective.

REFERENCES

1. Plassman BL, Langa KM, Fisher GG. 2007. Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology* [Internet]. 2007 [cited 2014 May 29];(1-2):125-132. Available from: http://sitemaker.umich.edu/klanga/files/plasman_adams_dementia_prev_neuroepi.pdf
2. Gallucci IJN, Tamalini MG, Forlenza OV. Diagnóstico Diferencial das demências. *Rev Psiquiatr Clín* [Internet]. 2005 [cited 2014 May 29];32(3):119-30. Available from: <http://www.scielo.br/pdf/rpc/v32n3/a04v32n3>.
3. Gonçalves. LHT, Alvarez AM, Santos SM. Os cuidadores leigos de pessoas idosas. In: Duarte YAO, Diogo MJD (Org). *Atendimento*

Oliveira JSC de, Ferreira AOM, Fonseca AM et al.

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Domiciliar: Um enfoque gerontológico. São Paulo: Atheneu; 2000.

4. Lenardt MH, Silva SC, Willig MH, Seima, MD. O idoso portador da doença de Alzheimer: o cuidado e o conhecimento do cuidador familiar. Rev Min Enferm [Internet]. 2010 July/Sept [cited 2014 June 19];14(3):301-7. Available from:

<http://www.reme.org.br/artigo/detalhes/120>

5. Saldick K, Wilcock G. The Increasing Burden of Alzheimer Disease. Alzheimer Disease and Associated Disorders [Internet]. 2003 [cited 2014 Jun 19];17(3):75-79. Available from:

<http://www.ncbi.nlm.nih.gov/pubmed/14512820>

6. Camacho ACLF, Coelho MJ. The importance of knowing the family on the special care to elderly with Alzheimer's disease. Rev enferm UFPE on line [Internet]. 2011 Sept [cited 2014 Jun 19];5(7):1605-12. Available from:

<http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/1689>

7. Perdomo M P. Las investigaciones dirigidas a los cuidadores de adultos mayores con enfermedad de Alzheimer. Rev haban cienc méd [Internet]. 2008 [cited 2014 June 19];7(3):1-7. Available from:

http://scielo.sld.cu/scielo.php?script=sci_arttext&pid=S1729-519X2008000300009.

8. Almeida KS, Leite MT, Hilderbrandt LM. Cuidadores familiares de pessoas portadoras de doença de Alzheimer: revisão de literatura. Rev Bras de Enferm [Internet]. 2009 [cited 2014 June 19];11(2):403-12. Available from: https://www.fen.ufg.br/fen_revista/v11/n2/pdf/v11n2a23.pdf.

9. Cattani RB, Girardon-Perlini NMO. Cuidar do idoso doente no domicílio na voz de cuidadores familiares. Rev Eletr Enf [Internet]. 2004 [cited 2014 June 19];6(2):254-71. Available from: <http://www.revistas.ufg.br/index.php/fen/article/view/812/929>

10. Pavarini SCI, Melo LC, Silva VM, Orlandi FS, Menciondo MSZ, Filizola CLA, et al. Cuidando de idosos com Alzheimer: a vivência de cuidadores familiares. Rev Eletr Enf [Internet]. 2008 [cited 2014 June 19];10(3):580-90. Available from: <http://www.fen.ufg.br/revista/v10/n3/v10n3a04.htm>.

11. Santana RS, Santos I, Caldas C P. Cuidando de idosos com demência: um estudo a partir da prática ambulatorial de enfermagem. Rev Bras de Enferm [Internet]. 2005 [cited 2014 June 19];58(1):44-8.

Available from:

http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672005000100008.

12. Bertolluci PH F, Okamoto I H. Manual de Consulta: doença de Alzheimer e outras demências. São Paulo: Lemos Editorial; 2003.

13. Fonseca AM, Soares E. O cuidador e os cuidados ao portador de doença de Alzheimer: contribuições à enfermagem. Rev Min Enferm [Internet]. 2008 [cited 2014 Jun 19];12(4):501-7. available from: 2008; <http://www.reme.org.br/artigo/detalhes/294>.

14. Campos EP. Quem cuida do cuidador: uma proposta para profissionais de saúde. 3rd ed. Rio de Janeiro: Vozes; 2007.

15. Valim MD, Damasceno DD, Abi-Acl LC, Garcia F, Fava SMCL. A doença de Alzheimer na visão do cuidador: um estudo de caso. Rev Eletr Enf [Internet]. 2010 [cited 2014 June 19];12(3):528-34. Available from: www.fen.ufg.br/fen_revista/v12/n3/v12n3a16.htm

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