Main difficulties found by caregivers of patients with Alzheimer’s disease

PRINCIPAL DIFICULTADES ENCONTRADAS PELOS CUIDADORES DE PACIENTES COM A DOENÇA DE ALZHEIMER

Patrícia Costa dos Santos da Silva¹, Fábio de Souza Terra², Jenifer Imaculada Coelho³, Tayara Cristina Reis⁴, Vanessa Morais Novais Martins⁵

ABSTRACT

Objective: to identify the main difficulties found by caregivers of patients with Alzheimer’s disease. Method: this is a descriptive and epidemiologic study, with a cross-sectional cohort and quantitative approach, carried out with 12 caregivers of Alzheimer’s disease patients. Two semi-structured forms were used for data collection. The data were analyzed and organized in tables through the software Microsoft Word. This research was approved by the Research Ethics Committee of Universidade José do Rosário Vellano, under the Protocol 207/2010. Results: 50% reported difficulty for diagnosing the disease; 75% reported lack of knowledge on the disease; 25% reported being unprepared to face the problem; 41.6% had difficulty for performing daily care activities, such as bath, feeding, and hygiene; 25% had difficulty in occupational activities and 41.6% in ambulation. The disease and aggressive behavior were the issues referred to by caregivers as those of greatest need for clarification. Most caregivers reported fatigue, sadness, and depression and that the care provided prevented her/him from pursuing leisure activities. The association of these variables was statistically significant (p = 0.045). Conclusion: the guidelines and recommendations by health professionals help guide strategies for the improvement and maintenance of the biopsychosocial balance both of the person with the disease and her/his caregiver.

Descriptors: Alzheimer disease; caregivers; health of the elderly; old age assistance.

RESUMO

Objetivo: identificar as principais dificuldades encontradas pelos cuidadores de pacientes com a doença de Alzheimer. Método: trata-se de estudo descritivo e epidemiológico, de corte transversal e abordagem quantitativa, realizado com 12 cuidadores desses pacientes com doença de Alzheimer. Para a coleta de dados foram utilizados dois formulários semiestruturados. Os dados foram analisados e organizados em tabelas utilizando o programa Microsoft Word. Esta pesquisa foi aprovada pelo Comitê de Ética em Pesquisa da Universidade José do Rosário Vellano, sob o Protocolo n. 207/2010. Resultados: 50% relataram dificuldade em diagnosticar a doença; 75% relataram déficit de conhecimento sobre a doença; 25% referiram estar despreparados para encarar o problema; 41.6% tiveram dificuldade em realizar as atividades de cuidado diário, como banho, alimentação e higiene; 25% apresentaram dificuldade nas atividades ocupacionais e 41.6% na ambulação. A doença e o comportamento agressivo foram os assuntos referidos pelos cuidadores como de maior necessidade de esclarecimento. A maioria dos cuidadores referiu sentir cansaço, tristeza e depressão e que o cuidado prestado o impidiu de realizar atividades de lazer. A associação dessas variáveis foi estatisticamente significativa (p = 0.045). Conclusão: as orientações e esclarecimentos dos profissionais de saúde ajudam a direcionar estratégias para a melhora e a manutenção do equilíbrio biopsicosocial tanto do portador como de seu cuidador.

Descriptors: doença de Alzheimer; cuidadores; saúde do idoso; assistência a idosos.

RESUMEN

Objetivo: identificar las principales dificultades encontradas por los cuidadores de pacientes con la enfermedad de Alzheimer. Método: se trata de un estudio descriptivo y epidemiológico, de corte transversal y abordaje cuantitativo, realizado con 12 cuidadores de pacientes con la enfermedad de Alzheimer. Para la recogida de datos fueron utilizados dos formularios semi-estructurados. Los datos fueron analizados y organizados en tablas por medio del programa Microsoft Word. Esta investigación fue aprobada por el Comité de Ética en Investigación de la Universidad José do Rosário Vellano, bajo el Protocolo 207/2010. Resultados: 50% reportaron dificultad para diagnosticar la enfermedad; 75% reportaron déficit de conocimiento acerca de la enfermedad; 25% reportaron no estar preparados para hacer frente al problema; 41.6% tuvieron dificultad para desempeñar las actividades de atención diaria, como baño, alimentación e higiene; 25% presentaron dificultad en las actividades ocupacionales y 41.6% en la ambulación. La enfermedad y el comportamiento agresivo fueron los asuntos referidos por los cuidadores como de mayor necesidad de aclaración. La mayoría de los cuidadores informaron sentir fatiga, tristeza y depresión y que la atención ofrecida lo impidió de realizar actividades de ocio. La asociación de esas variables fue estadísticamente significativa (p = 0.045). Conclusión: las orientaciones y las aclaraciones de los profesionales de salud ayudan a encaminar estrategias para la mejora y el mantenimiento del equilibrio biopsicosocial tanto del portador como de su cuidador.

Descriptors: enfermedad de Alzheimer; cuidadores; salud del anciano; asistencia a los ancianos.

¹Nurse. Ph.D student at the Ribeirão Preto College of Nursing of Universidade de Sao Paulo (EERP/USP). Professor at Universidade José do Rosário Vellano (UNIFENAS). Alfenas (MG), Brazil. E-mail: patriciacostadasilva@hotmail.com; ²Nurse. Ph.D in Sciences obtained from EERP/USP. Adjunct professor at the Nursing School of Universidade Federal de Alfenas (UNIFAL). Alfenas (MG), Brazil. E-mail: fabiosouterra@yahoo.com.br; ³Nursing student at Universidade José do Rosário Vellano (UNIFENAS). Alfenas (MG), Brazil. E-mail: tayara.reis@hotmail.com; ⁴Nurse. Graduated from Universidade José do Rosário Vellano (UNIFENAS). Alfenas (MG), Brazil. E-mail: vanessa.morasis@live.com.br
INTRODUCTION

With population aging, dementia represents an important public health problem, which is increasing in prevalence and complexity, especially in developing countries. In Brazil, the prevalence of dementia has reached 7.1% of people aged > 65 years, and, among these patients, 54.1% were diagnosed with Alzheimer’s disease (AD). This disability brings on a progressive functional decline and a gradual loss of autonomy, which, as a consequence, leads to a total dependence on other people.2

This way, family, essential at any given stage of life, plays a relevant role during transient or permanent periods of decreased physical and/or psychic aptitude; i.e., periods of lesser ability, in varied degrees, limited capacity for self-care.3

Within this context, AD can cause disaggregation and dissolution of financial, personal, and emotional relations, being, many times, considered a familial and social disease. Thus, family assistance has an extreme importance and relevance for the success of treatment. Through information, reflection, guidance, discussion, and counseling, the meetings aim at providing a better management of emerging conflicts or even the prevention of predicted ones. These interventions facilitate the identification and fulfillment of the needs of the patient and her/his family members and caregivers, besides favoring the creation of more effective and satisfactory strategies for working with this patient.2

In the family environment, caring for elderly people brings on duties that can favor both negative and positive factors; however, the literature stress the negative responses which influence the caring process, once one longs for the intervention to address these gaps, aiming at the prevention of health problems to family caregivers and maintaining the quality of life they expect to have.4

The assistance and support to the patients’ families are part of the nursing assistance for patients with dementia. The difficulty of caring for a patient with cognitive deficits in a physical, emotional, and socioeconomic basis can be immense, therefore, families should be assisted in the planning of care activities and encouraged to participate in support groups. It is worth stressing that counseling can provide an invaluable contribution to the families of patients with AD..5

OBJECTIVE

To identify the main difficulties found by family members and caregivers of patients with AD.

METHOD

This is a descriptive and epidemiologic study, with a cross-sectional cohort and a quantitative approach. It was carried out at the home of AD patients who are assisted in an outpatient unit of secondary health care of a town in the southern state of Minas Gerais, Brazil.

The study population consisted of fourteen caregivers from both sexes. The inclusion criteria were: caring for an AD patient; being assisted at the service concerned; living in the town of Alfenas, Minas Gerais, Brazil; and agreeing to participate in the study.

The sample, with a non-probabilistic design, consisted of twelve caregivers, and 2 subjects were excluded because they did not meet the inclusion criteria or did not agree to participate in the study.

All participants were informed on the research and they were asked to sign the Free and Informed Consent Term, according to Resolution 196/96, from the Brazilian National Council of Research, which concerns researches involving human beings. The subjects were informed on the right of privacy, confidentiality, and anonymity of information and that the results obtained shall be divulged. The authorization from the people in charge of the outpatient unit of secondary health care was also asked, and the information with regard to the AD patients was obtained there.

A semi-structured form containing 8 questions on sociodemographic aspects, as well as health-related information, was used for data collection. A semi-structured form containing 10 questions related to the patient’s care, knowledge on the disease, and issues with a higher need for clarification was used to identify the main difficulties found by the AD patients’ caregivers. The instruments were filled in by the researchers as an interview, without interference in the answers. This interview, which had been previously scheduled, was held at the home of AD patients, in order to avoid interference in the daily activities.

The data were analyzed in a quantitative and descriptive manner and organized into tables through the software Microsoft Word, to provide a better characterization of
caring for patients with Alzheimer disease, with the display of absolute and percentage values.

To verify the association between the practice of a leisure activity and the presence of symptoms such as tiredness, sadness, and depression, data were entered into the Software R and underwent statistical analysis through the application of Fisher’s exact test, considering the 5% (p < 0.05) significance level.

The research project was submitted to assessment by the Research Ethics Committee of Universidade Jose do Rosario Vellano (UNIFENAS), and it was approved under the Opinion 207/2010. The data collection was carried out between October and November 2010.

Table 1. Characterization of caregivers of patients with AD, Alfenas-MG, 2011 (n = 12)

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td>100.0</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 - 39</td>
<td>04</td>
<td>33.3</td>
</tr>
<tr>
<td>40 - 59</td>
<td>04</td>
<td>33.3</td>
</tr>
<tr>
<td>60 - 79</td>
<td>04</td>
<td>33.4</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>06</td>
<td>50.0</td>
</tr>
<tr>
<td>Single</td>
<td>04</td>
<td>33.4</td>
</tr>
<tr>
<td>Widower</td>
<td>01</td>
<td>8.3</td>
</tr>
<tr>
<td>Divorced</td>
<td>01</td>
<td>8.3</td>
</tr>
<tr>
<td>Schooling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete primary education</td>
<td>03</td>
<td>25.0</td>
</tr>
<tr>
<td>Complete primary education</td>
<td>04</td>
<td>33.3</td>
</tr>
<tr>
<td>Complete secondary education</td>
<td>03</td>
<td>25.0</td>
</tr>
<tr>
<td>Incomplete higher education</td>
<td>01</td>
<td>8.3</td>
</tr>
<tr>
<td>Complete higher education</td>
<td>01</td>
<td>8.3</td>
</tr>
<tr>
<td>Chronic diseases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>06</td>
<td>50.0</td>
</tr>
<tr>
<td>No</td>
<td>06</td>
<td>50.0</td>
</tr>
</tbody>
</table>

Most participants, 33.3%, have complete primary education (Table 1).

Regarding family income, 3 caregivers (25%) earn up to a minimum wage, 8 (66.6%) earn from 1 to 3 and only 1 (8.35%) earns more than 3 minimum wages.

In Table 2 one observes that 6 (50%) caregivers have some chronic disease and there was a predominance of arterial hypertension, with 4 caregivers (33.3%) presenting this disease and 3 (25%) presenting musculoskeletal problems.

Table 2. Distribution of carriers of patients with AD who have some chronic disease, Alfenas-MG, 2011 (n = 12)

<table>
<thead>
<tr>
<th>Chronic diseases</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arterial hypertension</td>
<td>04</td>
<td>33.3</td>
</tr>
<tr>
<td>Depression</td>
<td>01</td>
<td>8.3</td>
</tr>
<tr>
<td>Musculoskeletal problem</td>
<td>03</td>
<td>25.0</td>
</tr>
<tr>
<td>Thyroid dysfunction</td>
<td>01</td>
<td>8.3</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>02</td>
<td>16.8</td>
</tr>
</tbody>
</table>

*There was more than one answer for each respondent.

Among the medicines used by caregivers one highlights the anti-hypertension medicines, with 4 (33.3%) users; 2 (16.7%) used medication for treating the musculoskeletal dysfunction; 2 (16.7%) used medication for treating diabetes, and 1 (8.3%) used thyroid hormones. In this variable there was more than one answer for each respondent.

Regarding the degree of kinship between the caregiver and the AD patient, 6 (50%) are daughters; 3 (25%), wives; 2 (16.7%) aren’t relatives, but hired caregivers, and 1 (8.3%) is a sister.

It’s possible to observe that 7 (58.3%) houses had to undergo modifications after the patient became sick and 11 (91.6%) lived in a house of their own. Among the modifications needed, 3 (25%) reported that the AD patient

**RESULTS**

The data of this study revealed that, with regard to gender and age group (Table 1), there was a complete predominance of female individuals (100%) and these caregivers were equally distributed among the age groups.

Regarding marital status (Table 1), most female caregivers are married (50%).

It was found that, with regard to profession, 1 (8.3%) is retired, 8 (66.8%) are housewives, 1 (8.3%) works as nursing technician, 1 (8.3%) works as caregiver, and 1 (8.3%) is a student.
had to move to another room, 3 (25%) said that they had to adopt safety measures in staircases, bathrooms, and bedrooms, and 8 (66.6%) purchased new furniture and equipment, such as airbed, shower bath chair, and wheelchair.

When asked whether it was difficult to obtain the AD diagnosis, 6 (50%) said yes and the same proportion, 6 (50%), said no. With regard to the difficulties found by the caregiver and her family for dealing with AD, 10 (83.3%) said that they haven’t enough knowledge on the disease; 3 (25%) indicated lack of training to face the problem; 1 (8.3%) pointed out acceptance among family members; and 1 (8.3%) referred to the social life. In this item there was more than one answer for each respondent.

In this study, 5 (41.6%) of caregivers had difficulty for performing daily care activities such as bath, feeding, and hygiene; 5 (41.6%) reported difficulty for assisting with ambulation; 3 (25%) reported difficulty for performing occupational activities with AD patients.

Regarding the issues with a higher need for clarification in the perception of caregivers, 7 (58.3%) need information on AD and its phases; 3 (25%) reported to need clarification on aggressiveness; 1 (8.3%) needs information and guidance on how caring for an AD patient; 1 (8.3%) mentioned needing guidance with regard to the performance of hygiene; and 1 (8.3%) reported she needed no clarification.

Concerning the assistance and information on AD on the part of the health care professionals who assisted the patient and caregiver, 5 (41.7%) reported that they were informed on the disease and its evolution; 3 (25%) reported to be partially informed, they had to ask and look for information in order to be assisted; 1 (8.3%) reported to be poorly informed; and 3 (25%) said that they had no information on the part of the health care professionals. One highlights that, among those who received information from the professionals, 7 (58.3%) said to receive it from the physician; 5 (41.6%) from the nurse; and 2 (16.7%) from the psychologist. In this item there was more than one answer for each respondent.

It was found that, among the caregivers, 10 (83.3%) reported that the care provided to the AD patient hinders the performance of leisure activities. With regard to the caregivers who present symptoms such as tiredness, sadness, and depression, 9 (75%) mentioned presenting these symptoms. Associating the presence of these symptoms to the practice of leisure activities, it was found that there was a statistically significant difference (p = 0.045) (Table 3), that is, the caregivers who presented these symptoms reported that the care activities hinder them from performing leisure activities.

Table 3. Association between the practice of leisure activities and the presence of symptoms such as tiredness, sadness, and depression. Alfenas-MG, 2011 (n = 12)

<table>
<thead>
<tr>
<th>Presence of symptoms such as tiredness, sadness, and depression*</th>
<th>The care provided hinders the practice of leisure activities</th>
<th>Total (n = 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>%</td>
</tr>
<tr>
<td>Yes</td>
<td>09</td>
<td>75.0</td>
</tr>
<tr>
<td>No</td>
<td>01</td>
<td>8.3</td>
</tr>
</tbody>
</table>

Total (n = 12)

*Application of Fisher’s exact test, value p = 0.045.

**DISCUSSION**

This study showed a complete prevalence of female caregivers, in the age group from 40 to 79 years, indicating a reality of the Brazilian culture, i.e., the woman has the skill to care, provide the needed support in the many situations faced by the family, most of the times caring is a duty of a daughter or wife.6–7 It was verified that among these female caregivers there were elderly people, some presenting chronic diseases and having no favorable health conditions to care for an AD patient in an effective manner. In this situation, one can realize that we have elderly people caring for elderly people with a high demand of needs to be fulfilled. One stresses that the predominance of female caregivers with a 50-year mean age are also characteristics frequently found in many Brazilian and international studies.6–9

In this research, it was observed that most caregivers interviewed are housewives and have a monthly income lower than three minimum wages, leading to money-related difficulties for providing care, once, due to the function of elderly person caregiver, these individuals end up leaving their jobs.10

Although in different proportions and considering the differences between age groups, this study observed that most caregivers present a low education level. This
profile is in accordance with the data from IBGE\(^1\): in 2009, the average schooling in Brazil was 7.1 years of study regarding people \(\geq 25\) years, which represents an education level below the conclusion of primary education.

Regarding the presence of chronic diseases in the caregivers under study, it was found that 50\% have a chronic disease, and arterial hypertension (AH) was the most reported one. Within this context, one highlights that arterial hypertension presents a direct and linear relation to age, the prevalence of AH is \(> 60\%\) in the age group \(> 65\) years, and, as most caregivers is \(> 40\) years, this could justify the data found.\(^1\)

Considering the use of medicines, one highlights the anti-hypertension ones. This finding is confirmed by the preceding information, and AH is the most reported disease among the population under study.

Concerning the houses, it was observed that, in this study, seven of them underwent modifications after the AD patient became sick, with emphasis on the interviewed caregivers who lived in a house of their own, something which facilitated the adaptations needed. The fact that the elderly people who participated in this study live in an urban area at a small town may have contributed to the purchasing of a house of their own. The ownership of a house is one of the indicators taken into consideration in the dimension “safety of ownership” and, in this case, 73.1\% of the Brazilian houses located at an urban area are said to be owner-occupied houses.\(^5\)

It was verified that, often, practical changes occur in the life of the caregiver, such as the adaptation of the physical environment, turning it difficult to maintain the elderly person in a certain bedroom, something which required changes, including the installation of stair rails to prevent falls (especially in the bathroom) and the removal of furniture and carpets, keeping the environment clean and with plenty of natural light, so that the dependent elderly person can walk freely.\(^1\)

This study shows that there is a need for clarification on the disease and its phases, always considering the sociocultural and economic context of those for whom the information is provided, so that the identification of the disease can be carried out more easily by the family members of the elderly person. Programs for permanent training and education directed towards the health care professionals who work in the primary attention of the Unique Health System (SUS), in the field of health of the elderly, should be developed in an ever accelerating rhythm.\(^14\)

The difficulties found by the caregiver in the performance of daily care activities, such as bath, feeding, hygiene, assistance in ambulation, and the performance of occupational activities, along with the lack of information from the professionals, the need for clarification with regard to the disease, its phases, and the difficulty for dealing with the psychiatric and behavioral manifestations produce physical, mental, and emotional distress.\(^13\)

Regarding the presence of assistance or guidance on the disease and its evolution from the health care professionals, 5 caregivers said to have received this kind of help. Although only one caregiver says to have no need for clarification on AD, the physician, the nurse, and the psychologist were the professionals reported as those who provide such information. Comparing this result to the data obtained in a study approaching the coping conditions of families caring for elderly patients with AD, where 9 caregivers said they do not receive assistance or guidance from professionals in the health centers and 5 reported to receive it. Out of these 5 caregivers, 4 mentioned receiving help from the support group and 1 from physicians.\(^13\)

The family member who cares for an AD patient often assumes the duties and responsibilities alone, and many family members end up helping occasionally.\(^15\) It was verified in this study that most caregivers indicate that the care provided hinders the performance of leisure activities, and only caregivers mentioned that the care activities do not hinder leisure. One stresses that only 1 of these caregivers, who is not a family member, that is, she is a hired caregiver, who has off work days to rest, however, when the caregiver is a family member her identity as the main caregiver is built day by day, coping with the routine of care activities and the reflection triggered by these tasks, leading her to assume the condition of caregiver, and then it ends up to establish a dependence relation to the weakened elderly person.\(^15\)

One should highlight, in this study, that 83.3\% of caregivers reported to present symptoms such as tiredness, sadness, and depression. A huge research corpus documents the adverse effects of prolonged stress along with the care for a family member with AD or an associated dementia. These effects include a higher risk for depression\(^16\)\(^-\)\(^-\)\(^17\), anxiety, physical morbidity\(^17\), mortality\(^18\)\(^-\)\(^19\), and obesity.\(^20\) There is also an increase in the levels of hormones responsible for stress\(^21\)\(^-\)\(^22\),
decreased immune function, the healing process becomes slower, and cases of hypertension and coronary heart disease occur.

The research presented a connection between depression, frequently experienced by the AD patients’ caregivers, and an increased incidence of emergency assistance. When associating the practice of a leisure activity to the presence of symptoms such as tiredness, sadness, and depression, it was found a statistically significant difference (p = 0.045), something which shows that these findings are consistent with the “self-reports” of health problems and decreased welfare of caregivers, turning them vulnerable and leading their functional ability to be constantly at risk, that is, perhaps they will also need to be cared for. Therefore, this situation should encourage the health care professionals to commit themselves to the creation of strategies aiming at the planning and implementation of an individualized assistance to the elderly person and her/his caregiver.

CONCLUSION

Having the data obtained in this study as a basis, one may identify the existence of a knowledge deficit on the disease and a lack of training to face the problem. Daily care activities, such as bath, feeding, and hygiene, and ambulation were indicated by the caregivers as the main difficulties found, and they wanted to have a better guidance on the way of providing these care activities.

One believes that the development of this research, as a panorama of the main difficulties faced by the caregivers of patients with AD, had an crucial importance, especially with regard to Nursing, once it evidences the need for establishing a relationship between the health professionals and the caregivers, considering that most caregivers indicated a lack of enough information on the disease and its evolution, besides reporting the need for clarification with regard to the disease and its phases, as well as tips to cope with the patient’s aggressiveness.

One highlights that most caregivers said to experience tiredness, sadness, and depression and that the care provided hinders her/him to pursue leisure activities, showing the need for a dignified reception by the formal services, something which can collaborate to prevent the family members from feeling so lonely, so that they can acquire the knowledge and ability needed to meet the demand of care activities.

It is worth stressing the main limitation of this research, i.e., the small number of AD patients in the town where the study was carried out. But this fact does not decrease the value and significance of this paper to the scientific field, once it can provide the health services with information, leading them to change their way of treating AD patients and their caregivers, especially with regard to the active participation of the nursing team.

Thus, new assessments on the coping conditions of caring families become a must, through the development of intervention clinic studies which assist such families, especially with the application of other research methods. The explanations and clarifications provided by the health professionals help to drive strategies for the improvement and maintenance of the caregiver’s biopsychosocial balance.

In this setting, one highlights the nursing professional’s role as a member of the multiprofessional staff and advisor of family members who tackle with the problem, providing them with support and confidence, which will be important both for the AD patient and all the family members, contributing, this way, to lead them to have a better quality of life.

REFERENCES


Main difficulties found by caregivers of patients...

