QUALITY OF LIFE IN THE CONTENT OF FAMILY CAREGIVERS OF ELDERLY WITH ALZHEIMER: INTEGRATIVE REVIEW

A QUALIDADE DE VIDA NO CONTEXTO DO SER CUIDADOR FAMILIAR DO IDOSO COM ALZHEIMER: REVISÃO INTEGRATIVA

LA CALIDAD DE VIDA DEL CUIDADOR FAMILIAR DE ANCIANOS COM EL ALZHEIMER: VISIÓN INTEGRADORA

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ABSTRACT

Objective: analyzing publications about quality of life of family caregivers of patients with Alzheimer's disease. Method: an integrative review, in order to answer the following question << How is discussed in the scientific literature the quality of life of family caregivers of patients with Alzheimer's? >> The publications were collected at LILACS database and Virtual Library SciELO, between May and June 2012. It was performed an analysis by thematic categories, after summarizing and organizing information. Results: living with Alzheimer's disease influences negatively the quality of life of family caregivers. This fact, related to the daily life of the family caregiver who presents overload due to living with the disease at home. Conclusion: nurse intervention is necessary, planning and implementation of actions applicable to the reality of care, due to the negative impact on the caregiver's life, aiming to look for quality of life, individual and familiar. Descriptors: Caregivers; Alzheimer's disease; Elderly; Quality of Life.

RESUMO

Objetivo: analisar publicações sobre a qualidade de vida dos cuidadores familiares de idosos com a doença de Alzheimer. Método: revisão integrativa, com vista a responder a seguinte questão << Como é abordada na literatura científica a qualidade de vida dos cuidadores familiares de idosos com Alzheimer? >> As publicações foram coletadas na base de dados LILACS e na Biblioteca Virtual SciELO, entre maio e junho de 2012. A análise foi realizada por categorias temáticas, após a sumarização e organização das informações. Resultados: o convívio com a doença de Alzheimer influencia negativamente na qualidade de vida do cuidador familiar. Fato este, relacionado ao cotidiano do cuidador familiar, que apresenta-se com sobrecarga devido à vivência com a doença em seu domicílio. Conclusão: é necessário intervenção do enfermeiro, planejamento e implementação das ações aplicáveis a realidade do cuidado, decorrente da influência negativa na vida do cuidador, com o intuito de buscar qualidade de vida, individual e familiar. Descriptors: Cuidadores; Doença de Alzheimer; Idoso; Qualidade de Vida.

RESUMEN

Objetivo: analizar las publicaciones sobre la calidad de vida de los cuidadores familiares de pacientes con enfermedad de Alzheimer. Método: revisión integradora, con el fin de responder a la siguiente pregunta << Como se ha discutido la calidad de vida de los cuidadores familiares de pacientes con enfermedad de Alzheimer en la literatura científica? >> Las publicaciones fueron recogidas en la base de datos LILACS y en la Biblioteca Virtual SciELO, entre mayo y junio de 2012. El análisis se realizó por categorías temáticas, después de resumir y organizar la información. Resultados: viviendo con la enfermedad de Alzheimer influye negativamente en la calidad de vida de los cuidadores. Este hecho, relacionado con la vida cotidiana del cuidador familiar que se presenta con una sobrecarga debido al vivir con la enfermedad en su casa. Conclusión: la intervención del enfermero, la planificación e implementación de acciones aplicables a la realidad de la atención son necesarias debido al impacto negativo en la vida del cuidador, con el objetivo de buscar la calidad de vida, individual y familiar. Descriptors: Cuidadores; Enfermedad de Alzheimer; Ancianos; Calidad de Vida.

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INTRODUCTION

The population’s aging is a known fact on the world stage since the last century, due to the rapid growth of the elderly. Rather, this phenomenon was observed only in developed countries, but, over the years, there have been changes in the demographic profile of the population, observing the growth of the elderly also in developing countries, particularly Brazil, which, in 2025, will occupy the 6th place in the number of elderly people, with 32 million people aged 60 or older.1,4

It is due to this growth, that care is increasingly present, especially in the lives of dependent elderly and who takes care of them. Aging is characterized as a complex process of psychological and social nature in human development. It is a natural and irreversible process, where the endogenous deterioration of functional capacity of the organism,5 as a consequence of aging, occurs. There has been the emergence of typical pathologies of this process, especially dementias. These are syndromes characterized by a gradual decline in cognitive functions, behavior and personality changes and deterioration in the daily activities of the affected people.5

Recognizing that they are progressive and degenerative, dementias reflect the situation of dependency and loss of autonomy of the elderly, resulting in the need of assistance and care. Among the dementias, Alzheimer’s disease is the most common dementia in the elderly, accounting for between 50% and 70% of its total incidence.7 This is characterized by gradual memory loss. There are estimates that by 2025 there will be 34 million cases of the disease worldwide.5

In this context, the family of the elderly affected by Alzheimer’s has been faced with care, being characterized as perceiving the other in the way it is and as it turns out, their speech and gestures, their pains and limitations.9 With the emergence of this illness in the family, often a relative becomes the primary caregiver. Usually this is a close relative, closely linked to the person affected by Alzheimer’s. It sometimes chooses to exercise this function, it is sometimes chosen.

Care provided to the elderly with Alzheimer’s and other demands related to the daily lives of the difficult task of being a family caregiver ends up changing their quality of life. It is understood by quality of life the perception of human beings in relation to their experiences, knowledge and values in which they live.10

The majority of the studies related to caregivers of elderly brings the predominance of women as an important characteristic, being the caregiver role held largely by daughters followed by wives.7,11-13 This fact may be related to gender issues, because the caregiver role is associated with women since the earliest of times.

Given this assumption, the following question arises: How is addressed in the scientific literature the quality of life of family caregivers of patients with Alzheimer’s? Despite the importance of family caregivers in the Brazilian reality, there are few studies that seek to understanding the consequences of caring in the lives of family caregivers of seniors affected by Alzheimer’s disease. Thus, due to insufficient information in the context of public health actions, most family caregivers do not have sufficient support and resources to perform qualified care, which contributes to their physical, emotional and social stresses, affecting the caregiver’s quality of life.14-7

OBJECTIVE

- Analyzing publications about the quality of life of family caregivers of patients with Alzheimer’s disease.

METHOD

A descriptive study, type integrative literature review, since this allows summarizing the research already completed and to draw conclusions on a topic of interest, contributing to the deepening of knowledge and its subsequent aplicability.19 Soon, reflections that encourage future studies reinforces the need to include the research in everyday clinical practices based on evidences.

According to the type of the integrative review, at first was formulated following question: How is addressed in the scientific literature the quality of life of family caregivers of elders with Alzheimer’s? Then the following steps were taken: selection of thematic issues, establishment of criteria for the selection of the sample, representing the characteristics of the original research, data analysis, interpretation of results and presentation of the integrative review,19 having as an instrument of databases created by the authors by summarizing and organizing the information collected.

The literature survey was conducted on the basis of Latin American Literature data on Health Sciences (LILACS) and the Scientific...
Electronic Library Online (SciELO), during the months of May and June 2012.

Inclusion criteria were: articles that address the quality of life of family caregivers of patients with Alzheimer's disease; published in national journals in English since 2006 and available in its entirety.

There were excluded the articles that did not comport with the subject mentioned and also those which were not presented in Portuguese, due to the focus of this study is specifically Brazilian family caregivers, for the analysis of other items could generate biases in the results of this study.

This is justified by a study that compares the level of life satisfaction among Brazilian and Portuguese caregivers, in which most the Portuguese presented themselves satisfied with life, however most Brazilians had a lower level of satisfaction in living.11

To prepare the articles there was used the following descriptors: "caregivers", "elderly", "Alzheimer's disease", "quality of life". There were identified 226 articles without limitations of time, 33 complete, seven of which were included. We chose to conduct a second search using those first three terms "caregiver", "elderly", "Alzheimer's"; there were identified 25 articles, 16 in full, there were selected six. And only one article had already been selected in the first search. Therefore the sample totaled 12 items.

Of which seven papers were identified using a quantitative approach, two experienced qualitative approach, one systematic review, one of reporting experience and a case study. Therefore, it is noteworthy that before the reading of the selected studies was an analysis of various types of studies where the level 3 of evidence was the prevalence of 58.3%, with level 4 and 5 also presented with 16.6%.20

It was developed a form for data collection, completed for each article of the final study sample. The form allowed obtaining identification information and authors of the article; source location; objectives and characteristics of the study; theoretical and methodological consistency; Data analysis, results and discussion; conclusions and recommendations for nursing practice. The data researched articles were analyzed using descriptive statistics, according to their contents.

RESULTS

It was observed that any periodic got the highest number of publications on the subject proposal, each presenting a publication.

When analyzing the whole sample (251 articles), according to the criteria of inclusion and exclusion proposed, it was found that there are a small number of complete reports in Portuguese (eight articles) in relation to the quality of life of caregivers of seniors with Alzheimer's . Worrisome development since the Brazilian population is aging and increasingly it is the increase of diseases typical of this stage of life that cause dependence and limitations. Consequently, those elderly need the assistance of caregivers.

In this context are inserted the nurses, professionals who have the art of caring for others in essence, having the possibility to intervene based on identifying the needs of those who care and who care, thus contributing to improving the quality of life family and elderly caregiver who receives care.21

In identifying the location of sources for articles, six are from SciELO and six Lilacs database. The descriptors used by most authors were "Alzheimer's disease" (10 articles), followed by "caregivers" (nine studies), and thirdly "quality of life" present in four articles. Appeared other descriptors: "aged", "health promotion", "communication disorder", "elderly health", "geriatric", "nursing home", "physical activity", "aging", "family", "nursing ", "geriatric nursing. "

It was found that all items presented their goals clearly, allowing easy understanding of the reader. Proposal is understood to aim action to answer the question of the study.22

When analyzing the research designs in the study sample, we found that seven of the articles used the quantitative approach, two experienced qualitative approach, one systematic review, one of reporting experience and a case study.

It is noteworthy that, before the reading of the selected studies, there was an analysis of various types of studies where the level 3 of evidence had a prevalence of 58.3%, with level 4 and 5 are also presented with 16.6%.20

In studies that reported the problem to be investigated, there were no disagreements between the type of object and the selected method.

Among the articles, two presented a literature review of the problem and foundation for the remaining steps of the research process; six had completed five conclusions and all responded well to the proposed objectives.

To analyze the content of articles, two thematic categories were developed. There
were part of the first articles that focused on the aspects that impact negatively on the quality of life of caregivers.², ⁷, ¹¹-³, ²³ And the second category the articles that addressed the importance of the support and assistance of the nurse caregiver binomial/elderly affected by Alzheimer’s.², ¹², ³-⁴, ²⁴, ²⁷-⁹

♦ Aspects that interfere negatively on the quality of life of the family caregiver.

Caring for an elderly affected by Alzheimer generates emotional, psychological and financial strain to the family caregiver, due to the gradual loss of cognitive functions of elderly people affected, progressing to dependence. Generally this process alters the quality of life of the caregiver.²¹

Quality of life is the realization of the human being with regard to its position in life, according to culture, values, goals and expectations.³⁰ Some studies used a scale of Quality of Life in Alzheimer’s disease to identify factors that affect negatively the quality of life of the caregiver.¹², ²³, ²⁴ This scale is adapted for use in Brazil, in order to evaluate both instrument the quality of life of caregivers, the elderly affected by the disease.

The Quality of Life Scale assesses 13 items, which are: housing, family, marriage, friends, ability to perform activities, money, life in general, physical health, mood, memory, and overall its ability to do activity leisure. Its score ranges from 13 to 52 points, with the closest score of 52 considered better quality of life.

In one study, the scale showed as negative effects on quality of life of the caregiver the following aspects: physical health, mood, memory, yourself in general, the ability to do leisure activity.²³ In another study, the negative review referred to the ability of doing leisure activity.²⁴ In another article, the scale showed how negative effects on quality of life of the caregiver aspects: physical health, mood, mood, you generally able to leisure activity.²²

They all show as negative factor for the quality of life of caregivers, the ability to leisure activity.², ²³, ²⁴ This fact probably related to the daily life of the family caregiver, who has been limited and large overhead due to experience with Alzheimer’s disease at home.

As for the other negative aspects found in other studies there were revealed as limiting the quality of life of the caregiver burden, caregiver communication in the

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binomial/affected elderly and lack of physical activity.², ⁷, ¹¹, ¹³, ²⁵-⁹

There was unanimity among all the studies when concluding that living with Alzheimer’s disease negatively influences the quality of life of caregivers. Some of the articles that addressed quality of life showed that this related to the caregiver’s worse when the functional capacity of the elderly has become more committed.¹², ²³, ²⁴

The division of labor in care is extremely important, because if there is such a division, care for the elderly with Alzheimer’s becomes increasingly exhausting and stressful. In this context, emphasizes the need for the intervention of the nurse to guide families about the importance of the division of tasks, seeking the involvement of all in care.

♦ The importance of nurses’ support to the binomial caregiver/elder suffered by Alzheimer

Some studies emphasize the importance of planning and implementation of nursing interventions aimed at family caregivers, as it needs to feel good and supported to achieve quality care to the elderly with Alzheimer.², ¹², ³, ²⁴, ²⁹

The plan of care to patients with Alzheimer’s disease should be extended to the inclusion of the caregiver, because after this play its part, is subject to submit changes to your saude.¹² Other studies emphasize the importance of not only assist the elderly with Alzheimer’s but also their caregiver, seeking better quality of life for both.², ²⁴, ²⁹

Also emphasizes the necessity of creating groups where the nurse can guide caregivers of seniors with Alzheimer providing them with support, knowledge, skills applicable to their daily reality and adaptation mechanisms related to confronting difficulties in the care when elderly affected by the disease, thus contributing to the acquisition of a higher quality life, both individual and family.², ³, ¹², ²⁴, ²⁷-⁹

CONCLUSION

The quality of life of caregivers of seniors with Alzheimer’s undergo changes after this take on such a role due to emotional, psychological and financial exhaustion brought on by routine care to be provided to the elderly affected by the disease.

Living with Alzheimer’s disease negatively influences the quality of life of caregivers. In this context it is of utmost importance to professional intervention nurses and other family caregivers of older people affected by Alzheimer’s disease, planning and
implementing actions to provide guidance, support, support, knowledge, and skills applicable to their reality in elderly care affected by disease, in order to seek a better quality life, both individual and family.

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Submission: 2013/04/27
Accepted: 2014/07/05
Publishing: 2014/08/01

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