

EVALUATION OF QUALITY OF LIFE OF INFORMAL CAREGIVERS OF ELDERLY PATIENTS WITH ALZHEIMER'S DISEASE

AVALIAÇÃO DA QUALIDADE DE VIDA DE CUIDADORES INFORMAIS DE IDOSOS PORTADORES DA DOENÇA DE ALZHEIMER

EVALUACIÓN DE LA CALIDAD DE VIDA DE LOS PACIENTES ANCIANOS CON LOS CUIDADORES INFORMALES DE LA ENFERMEDAD DE ALZHEIMER

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ABSTRACT

This study aims to clarify the quality of life of informal caregivers of elderly patients with Alzheimer's disease and to investigate possible differences in biopsychosocial aspects that affect the quality of life of these caregivers. This research is quantitative in nature. The sample consisted of 50 informal caregivers, being 25 adults and 25 elderly. Data collection used the following instruments: WHOQOL-BREF, Geriatric Depression Scale, Depression Screening Scale and Anxiety Scale. Results for the WHOQOL-Brief showed scores higher than 60 on a scale from 0 to 100 in all areas, but only in the environment area presented a statistically significant difference between the two groups. Less than half of the participants obtained scores for depression and most of them had average degree of anxiety. These results may support work aimed at improving the quality of life of informal caregivers of the elderly.

Keywords: Aged; Alzheimer's Disease; Caregivers; Quality of Life.

RESUMO

O presente estudo objetivou conhecer a qualidade de vida de cuidadores informais de idosos portadores da doença de Alzheimer e verificar se existe diferença nos aspectos biopsicossociais que interferem na qualidade de vida desses cuidadores. Esta pesquisa é de caráter quantitativo. A amostra constituiu-se de 50 cuidadores informais, sendo 25 adultos e 25 idosos. Para a coleta de dados utilizaram-se os seguintes instrumentos: WHOQOL-Breve, Escala de Depressão Geriátrica e Escala de Rastreamento de Depressão e Escala de Ansiedade. Resultados referentes ao WHOQOL-Breve apresentaram pontuação superior a 60, em uma escala de zero a 100, em todos os domínios, porém, apenas no domínio do meio ambiente houve diferença estatisticamente significativa entre os dois grupos estudados. Constatou-se que a maioria dos participantes apresentou grau médio de ansiedade, mas menos da metade obteve pontuação para depressão. Tais resultados poderão subsidiar trabalhos que visem à melhoria da qualidade de vida de cuidadores informais de idosos.

Palavras-chave: Idoso; Doença de Alzheimer; Cuidador; Qualidade de Vida.

RESUMEN

El estudio tuvo como objetivo conocer la calidad de vida de los cuidadores informales de pacientes ancianos con enfermedad de Alzheimer, y para comprobar si existen diferencias en los aspectos biopsicosociales que afectan a la calidad de vida de los cuidadores. Esta investigación es de carácter cuantitativo. La muestra estuvo constituida por 50 cuidadores informales, con 25 adultos y 25 ancianos. Para recoger datos que hemos utilizado los siguientes instrumentos: WHOQOL-Breve, Escala de Depresión Geriátrica, la Escala de Depresión de selección y la Escala de Ansiedad. Los resultados para el WHOQOL-Breve tuvo una puntuación de 60 en una escala de 0 a 100 en todas las áreas, pero sólo en el ámbito del medio ambiente se observaron diferencias significativas entre los dos grupos. Se encontró que menos de la mitad de los participantes obtuvieron puntuaciones para la depresión y la mayoría de ellos tenían un grado medio de la ansiedad. Estos resultados podrían subsidiar los trabajos para mejorar la calidad de vida de los cuidadores informales de personas mayores.

Palabras clave: Anciano, Enfermedad de Alzheimer, Cuidadores, Calidad de Vida.

INTRODUCTION

The gradual increase in the elderly population demonstrates that Brazil is in a population aging process, and currently, there are about 20 million people over 60 years old.¹

In the aging process, there is a significant effect of old age in addition to certain health problems that can cause some degree of dependence in the elderly. Among these health events, Alzheimer's disease (AD) stands out – a chronic, progressive and degenerative disease.

Data from a report by Alzheimer's Disease International estimates that 35.6 million people worldwide may live with dementia in 2010, and it also projects that this number will almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.²

Alzheimer's disease, a type of dementia, compromises the elderly's health as a whole, resulting in dependence upon others to perform daily life activities and requires the presence of caregivers to help with this disability.

Modern family units are smaller, however the number of elderly members tends to increase, making the caregiver's role more difficult, since the probability of sharing or switching the caregiver position may decrease, due to a lack of other family members available for this activity.³ We also noticed the rise of aged people who take on the role of elderly caregivers.⁴

The overwhelming task of caring is often repetitive, continuous and, many times, a solitary and unrestful activity, which can affect the psychological life of the caregiver, with physical consequences that may lead to emotional and social isolation.⁵ Caregivers also are likely to develop anxiety, which is characterized by worry, irritability, fatigue, insomnia, tachycardia, among other symptoms, due to the great responsibility that the task of taking care of another person can bring.⁶

In this approach, individuals who suffer from an anxiety disorder constantly worry, which will interfere in the quality of sleep, attention span and concentration, besides expressing somatic symptoms caused by excitation of the autonomic nervous system.⁷ Therefore, it is important to identify signs of chronic anxiety in order to implement treatment and minimize the consequences of the disorder, thus interfering positively in their care.

Depression can also occur, and it is characterized as a mood disorder, in which a person has persistent and pervasive feelings of sadness, changes in appetite, sleep disturbances, loss of energy, lack of concentration, feeling of guilt, hopelessness, and thoughts of death and suicide. And also, biological influence (genetics), situational (unexpected death of a family member) and stressful factors are significant triggers to the development of depression.⁷

Frequently, depression and anxiety go together.⁸ Thus, the stress caused by the continuous task of caring for the AD patient can affect the health and quality of life of the caregiver, also interfering with the quality of care provided.

The major difficulties of defining quality of life come from the notion of self-perception of the individual, i.e., it consists of unequal meanings for different people on diverse occasions, or even, distinctive meanings for the same person, depending on his or her state of mind or mood.

The World Health Organization (WHO), since the early 1990s, has emphasized that measures of quality of life are of particular importance in the evaluation of health, considering both individual and social perspectives.⁹

The WHOQOL group¹⁰ defined quality of life as a person's perspective regarding their position in life, social environment that they live in, as well as their expectations, goals, habits and anxieties.

In the healthcare area, quality of life can be assessed through objective and subjective parameters, based on biological, clinical and epidemiological nature, and evaluations of individuals and groups, respectively, considering internal parameters, which relate to standards and social expectations of welfare.¹¹

The Brazilian reality is still incipient to the awareness related to quality of life of informal caregivers, since they express some discontent. So, the task of caregiving may affect quality of life of the caregiver. Being important to conduct research, investigations and studies attempt to update knowledge and provide information about life conditions of the caregiver. This information can be turned into a source of support to the management of public policy and, consequently, contribute to improving quality of life of the caregiver and individual receiving care and, furthermore, promote the quality of the provided care.

This study aimed at finding out the quality of life of the informal caregivers of the elderly with Alzheimer's disease; identifying biopsychosocial aspects that affect quality of life of these caregivers and verifying differences in biopsychosocial aspects between adults and the elderly.

PATIENTS AND METHODS

It is a descriptive, transversal and field study of quantitative approach.

The research project was approved by the Ethics in Research Committee of the School of Nursing, University of São Paulo. To ensure participants' rights, the items of the Resolution CNS 196/96 were fully respected. All participants signed the Informed Consent.

The study was conducted with informal caregivers of elderly people with AD, associates and/or participants in support groups of the Brazilian Association of Alzheimer's (ABRAz) in the metropolitan region of São Paulo.

The data collection instrument was self-applied, the first part being composed of questions related to identification

data and sociodemographic characteristics of the participant. There were also the following instruments: Depression Screening Scale CES-D – applied in the adult sample, establishing 15 as cutoff;¹² Geriatric Depression Scale GDS-15 – used in the elderly sample, considering grade six as presence of depressive symptoms¹³; State-Trait Anxiety Inventory STAI¹⁴ – the following categorization was used: 20 to 40 points (low anxiety), 40 to 60 points (average anxiety), 60 to 80 points (high anxiety)¹⁵⁻¹⁷; and the WHOQOL-BREF to measure quality of life.¹⁸

Information obtained by applying the instruments was subjected to statistical-descriptive analysis. Through these, data were obtained relating to frequency, central tendency, dispersion and correlation, from which other statistical treatments were planned, involving comparison of subjects by sociodemographic criteria and, also, by criteria emerged from analysis of data collection instruments' results. To achieve the proposed objectives, the theoretical parameters, which governed the construction of the instruments used, were respected.

The EpiData® program was used to create the database. For statistical analysis, the program *Software Statistic Package for Social Science* (SPSS), version 13 was utilized. The significance level for statistical tests was 5% ($p < 0.05$).

RESULTS

A total of 50 informal caregivers of the elderly with AD comprised the sample. The participants were divided in two groups, 25 adult caregivers (20-59 years) and 25 elderly caregivers (60-87 years). The demographic profile of the participants is presented in Table 1.

The mean age of the 50 caregivers was 58.98 years (standard deviation 13.48), with a minimum age of 20 years and maximum of 87 years, and, among the adults, the largest number of individuals was aged between 51 and 59 years (44%). Most of the elderly were aged between 71 and 79 years (52%).

Regarding gender, 82% were women, being 42% daughters and 22% were wives. It was also found that 98% of caregivers were family members. Considering education, 46% of the participants had college degree and 28% had only a high school diploma. About family income, 24% of the individuals reported an income greater than 10 minimum wages.

Table 2 establishes relationship between presence or absence of the caregiver and some disease.

It was observed that 62% of caregivers reported having some type of disease.

Table 3 presents results from use of GDS-15 and CES-D scales to detect depressive symptoms in elderly and adults, respectively.

In the GDS-15 scale, an average of 3.56 was obtained, with scores that can range from zero to 15. In the CES-D scale, the

average was 17.52. Both scales had high Cronbach's alpha scores – 0.806 for GDS-15 and 0.786 for CES-D. These results indicate good internal consistency of the instruments for this sample.

This study used the State-Trait Anxiety Inventory (STAI) to assess the degree of anxiety in caregivers. Data is shown in Tables 4 and 5.

In Table 4, it was found that 80% of adults and 100% of elderly had scores between 40 and 60, indicating an average trait anxiety.

In Table 5, it was observed that 72% of adults and 80% of elderly had scores between 40 and 60, indicating average state anxiety.

Table 6 shows the results of WHOQOL-BREF, according to each domain from the 50 participants.

The WHOQOL-BREF score can range from zero to 100, with high index scores presenting good quality of life. The highest average was found in the physical domain – 69.45, and the lower in the environment domain – 62.88.

It was also noticed that all domains had high Cronbach's alpha, which represents a good internal consistence of the instruments in all four domains.

Comparison of average scores of WHOQOL-BREF between the two groups is presented in Table 7.

The domain environment obtained the lower average (58.38) among domains.

The evaluation of quality of life reported by adult and elderly caregivers from WHOQOL-BREF indicated that 30 (60%) individuals stated having good quality of life, and only one participant (2%) stated having very bad quality of life.

Regarding the evaluation answered by the participants front of health satisfaction, it was found that 56% of caregivers were satisfied with their health status, and 18% were unsatisfied – with the largest number of unsatisfied individuals in the adult caregivers group.

DISCUSSION

Sociodemographic data found in this study corroborate statements of other authors that report a majority of individuals who perform the role of caregivers within the family as being female and usually are daughters and wives.¹⁹⁻²¹

Regarding caregivers, the Bambuí project identified that the social support network was mainly centered in the family and, in case of diseases; usually the children had the key role of caring, making decisions, scheduling appointments and paying bills.²²

Among diseases reported by the participants, the highlights were: hypertension, thyroid diseases, osteoporosis and diabetes. The prevalence of these diseases was higher in the elderly group. It is noted that 32.3% of caregivers reported having more than one disease. Several Brazilian studies also found similar data.^{20, 22-26}

Table 1 - Caregivers sociodemographic profile, São Paulo, 2008

Variables	Age group 1 (age < or = 59)		Age group 2 (age > or = 60)		Total	
	n=25	%	n=25	%	n=50	%
Age (Average=58,98; SD=13,48)						
20<x≤30	2	4,0	0	0,0	2	4,0
30<x≤40	3	6,0	0	0,0	3	6,0
40<x≤50	9	18,0	0	0,0	9	18,0
50<x≤60	11	22,0	0	0,0	11	22,0
60<x≤70	0	0,0	12	24,0	12	24,0
70<x≤80	0	0,0	13	26,0	13	26,0
Gender						
Female	19	76,0	22	88,0	41	82,0
Male	6	24,0	3	12,0	9	18,0
Education						
Incomplete primary education	3	12,0	7	28,0	10	20,0
Complete primary education	1	4,0	2	8,0	3	6,0
High school diploma	7	28,0	7	28,0	14	28,0
College degree	14	56,0	9	36,0	23	46,0
Income						
> 1 a 2 minimum wages	0	0,0	1	4,0	1	2,0
> 2 a 3 minimum wages	4	16,0	1	4,0	5	10,0
> 3 a 4 minimum wages	2	8,0	4	16,0	6	12,0
> 4 a 5 minimum wages	3	12,0	2	8,0	5	10,0
> 5 a 10 minimum wages	3	12,0	3	12,0	6	12,0
More than 10 minimum wages	5	20,0	7	28,0	12	24,0
Not informed	8	32,0	7	28,0	15	30,0
Marital status						
Single	11	44,0	4	16,0	15	30,0
Married	10	40,0	20	80,0	30	60,0
Widower	1	4,0	0	0,0	1	2,0
Other	3	12,0	1	4,0	4	8,0
Family relationship or bond						
Daughter	16	64,0	5	20,0	21	42,0
Wife	1	4,0	10	40,0	11	22,0
Sister	0	0,0	5	20,0	5	10,0
Son	5	20,0	0	0,0	5	10,0
Husband	0	0,0	3	12,0	3	6,0
Daughter-in-law	1	4,0	2	8,0	3	6,0
Friend	1	4,0	0	0,0	1	2,0
Granddaughter	1	4,0	0	0,0	1	2,0

Table 2 - Identification of people with diseases. São Paulo, 2008

Variables	Age group 1 (age < or = 59)		Age group 2 (age > or = 60)		Total		p-value
	n=25	%	n=25	%	n=50	%	
Do you have some disease?							
Yes	12	48,0	19	76,0	31	62,0	0,079 ^a
No	13	52,0	6	24,0	19	38,0	

^a Chi-square test.

Table 3 - Scores of scales that track depressive symptoms among caregivers. São Paulo, 2008

Scales of Depression	N = 50	Average	Standard Deviation	Median	Minimum	Maximum	Cronbach's alpha
GDS-15	25	3,56	3,03	3,00	0,00	10,00	0,806
CES-D	25	17,52	8,76	19,00	0,00	35,00	0,786

Table 4 - Caregiver's scores in Scale Trait. São Paulo, 2008

Scale STAI T	Age group 1 (age < or = 59)		Age group 2 (age > or = 60)		Total	
	n=25	%	n=25	%	n=50	%
Scores from 20 to 40	2	8	0	0	2	4
Scores from 40 to 60	20	80	25	100	45	90
Scored from 60 to 80	3	12	0	0	3	6

Table 5 - Caregivers scores in Scale State. São Paulo, 2008

Scale STAI S	Age group 1 (age < or = 59)		Age group 2 (age > or = 60)		Total	
	n=25	%	n=25	%	n=50	%
Scores from 20 to 40	7	28	5	20	12	24
Scores from 40 to 60	18	72	20	80	38	76

Table 6 - WHOQOL-BREF scores obtained from all caregivers. São Paulo, 2008

Domains	Average	Standard Deviation	Median	Minimum	Maximum	Cronbach's alpha
Physical	69,45	14,22	69,65	35,71	96,43	0,735
Psychological	66,75	15,46	68,75	29,17	100,00	0,806
Social Relationships	64,58	21,03	70,83	25,00	100,00	0,721
Environment	62,88	13,52	65,63	28,13	90,63	0,717

Table 7 - Comparison of WHOQOL-BREF average scores between the two groups. São Paulo, 2008

Domains	Group 1 (age < or = 59) Average and Standard Deviation		Group 2 (age > or = 60) Average and Standard Deviation		p-value
	Average	Standard Deviation	Average	Standard Deviation	
Physical	68,00	12,77	70,90	15,66	0,476 ^e
Psychological	63,33	16,49	70,17	13,85	0,119 ^e
Social relationships	59,67	22,78	69,50	18,27	0,099 ^e
Environment	58,38	11,04	67,38	14,47	0,017 ^e

^e Student's t-test.

Adding all individuals who scored for depressive symptoms, regardless of scale, they were present in 42% of caregivers. These findings corroborate the results of other studies about depression in caregivers.^{8,19, 22,27,28}

On the scales of state-trait anxiety, it was found that most adults and all elderly indicated an average trait of anxiety, and most adults and elderly people showed an average state of anxiety.

Behavioral disturbances of patients with dementia have a negative impact on the lives of their caregivers, causing susceptibility to the development of depressive and anxiety states.^{8,29,30}

It is known that individuals with anxiety also have constant worry.⁷ Therefore, it is inferred that caregivers can manifest anxiety due to continuous preoccupation with the dependent elderly and with the care provided. In addition to worry, there may be the workload of the caregiver related to domestic activities and care provided to the elderly.

The domain environment of WHOQOL-BREF, which obtained low scores in this study, refers to physical safety and protection, home environment, financial resources, health and social cares, opportunities for acquiring new information and skills, participation and opportunities of recreation/leisure, physical environment (pollution/noise/traffic/climate) and transportation.³¹

A study conducted with 20 non-professional caregivers of patients with Alzheimer's disease, showed an average score of 55.4 for physical domain; 46.5 for psychological domain; 47.5 for social relationships domain; and 54.5 for the environment domain.³² Correlating these data with this study's findings, it was observed that the caregivers in the present study had higher scores, which may indicate better quality of life.

It is known that, despite some caregivers affirming to be satisfied with their quality of life, they lack leisure activities.^{33,34}

The increase in free time, especially in old age, usually comes from the release of work and caring for children, activities that tend to be significantly less intense in this stage of life. However, for caregivers the workload increases due to obligations of care provided to demented elderly, thus hampering leisure time.

Although 62% of the caregivers in this study cited having some type of disease and 70% of them mentioned using medications, in general they are satisfied with their health.

Research conducted with caregivers of frail elderly revealed that 33% of caregivers reported having good health. However, it is known that health problems may interfere with assessment of quality of life, as this is of subjective character.³⁵

It was observed that in both the present study and in Gonçalves *et al*³⁵ research, the perception of quality of life was positive, and in this study, the majority of caregivers (adults and elderly) rated their quality of life as good, without major differences between age groups. It was also verified that both the

perception of caregivers and the scores found in the domains indicate good quality of life.

The care provided to elderly people with AD by their caregivers requires knowledge, enhanced skills and emotional strategies, as it is linked to the individual subjectivity field of the one who takes care and the own subjectivity of care/caring.³⁶

From the results in this study, it becomes relevant the importance of working together with elderly caregivers, in a global way, concerning their physical, mental and social needs, in order to ensure better quality of life and combat isolation and social stigma, that the arduous task of caring can cause these individuals.

CONCLUSION

The analysis of results showed that the majority of caregivers present an average degree of anxiety and less than half have scores for depressive symptoms. The lowest score refers to the environment domain of the WHOQOL-BREF, and this dissatisfaction is due to lack of participation in leisure activities.

It is believed that these results will incentivize scholars in the field of Gerontology to act in the perspective of macro management related to public policies as well as in the micro-management related to comprehensive care provided to the elderly and their caregivers, in order to improve the quality of life of informal caregivers of elderly.

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