

## Quality of life among caregivers of elders with Alzheimer's disease\*

*Qualidade de vida de cuidadores de idosos com doença de Alzheimer*

*Calidad de vida de cuidadores de ancianos con enfermedad de Alzheimer*

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### ABSTRACT

**Objectives:** To evaluate quality of life among caregivers of elders with Alzheimer's disease and to examine the relationship between patients' quality of life score measured with the Katz Quality of Life Index and the relationship between the caregivers' quality of life measured with the SF-36 and depression score measured with the Beck Depression Inventory (BDI). **Methods:** This study was conducted in a geriatric clinic (Núcleo de Envelhecimento Cerebral) of the São Paulo Hospital of the Federal University of São Paulo. The sample consisted of 118 patients with Alzheimer's disease and their caregivers. Sociodemographic and comorbidity data and the Katz score of quality of life and the mini-mental status examination (MMSE) score of the patients with Alzheimer's disease were obtained through chart review. Data from caregivers comprised sociodemographic and comorbidity data and the SF-36 score of quality of life and the BDI score of depression. **Results:** SF-36 scores that were indicative of depression among caregivers were vitality (score = 56.8) and the scores on physical and emotional components were = 58.1, respectively. There was a significantly negative correlation between the caregivers' BDI score and the patients' Katz score, and between the caregivers' SF-36 and BDI scores. There was also a significantly positive correlation between the scores of the caregivers' SF-36 and the patients' Katz scores and between the patient's Katz and MMSE scores. **Conclusion:** The quality of life of caregivers of patients with Alzheimer's disease was compromised, which could influence the quality of care they provided to the patients. The quality of life of the caregivers got worse when the functional capacity of the elders with Alzheimer's disease was compromised.

**Keywords:** Caregivers; Alzheimer disease; Quality of life; Family nursing

### RESUMO

**Objetivo:** Avaliar a qualidade de vida de cuidadores de idosos com doença de Alzheimer e relacioná-la ao Índice de Katz dos pacientes e ao escore do Inventário de Depressão de Beck dos cuidadores. **Métodos:** O estudo foi desenvolvido no Núcleo de Envelhecimento Cerebral da Universidade Federal de São Paulo/ Hospital São Paulo. A amostra foi constituída, respectivamente, por 118 cuidadores e seus pacientes com doença de Alzheimer (DA). As informações coletadas nos prontuários dos pacientes foram sociodemográficas e mórbidas, Índice de Katz e Miniexame de estado mental (MEEM). Os dados do cuidador, obtidos por questionários, foram sociodemográficos e mórbidos, o SF-36 e o Inventário de Depressão de Beck (IDB). **Resultados:** Os escores mais comprometidos do SF-36 dos cuidadores foram: vitalidade (56,8) e os físicos e emocionais com 58,1, respectivamente. Houve correlação negativa entre o IDB do cuidador e o índice de Katz dos pacientes; entre o SF-36 e o IDB e as correlações positivas entre os escores do SF-36 e Índice de Katz e entre os domínios deste índice e os escores do MEEM. **Conclusão:** A qualidade de vida dos cuidadores de pacientes com DA mostrou-se alterada, podendo comprometer os cuidados por eles prestados e, evidenciou piora quando a capacidade funcional do idoso esteve mais comprometida.

**Descritores:** Cuidadores; Doença de Alzheimer; Qualidade de vida; Enfermagem familiar

### RESUMEN

**Objetivo:** Evaluar la calidad de vida de cuidadores de ancianos con enfermedad de Alzheimer y relacionarla al Índice de Katz de los pacientes y al escore del Inventario de Depresión de Beck de los cuidadores. **Métodos:** El estudio fue desarrollado en el Núcleo de Envejecimiento Cerebral de la Universidad Federal de Sao Paulo/ Hospital Sao Paulo. La muestra estuvo constituída, respectivamente, por 118 cuidadores y sus pacientes con enfermedad de Alzheimer (DA). Las informaciones recolectadas en las historias clínicas de los pacientes fueron sociodemográficas y mórbidas, Índice de Katz y Mini examen del estado mental (MEEM). Los datos del cuidador, obtenidos por cuestionarios, fueron el SF-36 y el Inventario de Depresión de Beck (IDB). **Resultados:** Los escores más comprometidos del SF-36 de los cuidadores fueron: vitalidad (56,8) y los físicos y emocionales con 58,1, respectivamente. Hubo correlación negativa entre el IDB del cuidador y el índice de Katz de los pacientes; entre el SF-36 y el IDB y las correlaciones positivas entre los escores del SF-36 e Índice de Katz y entre los dominios de este índice y los escores del MEEM. **Conclusión:** La calidad de vida de los cuidadores de pacientes con DA se mostró alterada, pudiendo comprometer los cuidados prestados por ellos y, evidenció desmejoramiento cuando la capacidad funcional del anciano estuvo más comprometida.

**Descriptores:** Cuidadores; Enfermedad de Alzheimer; Calidad de vida; Enfermería de la familia

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## INTRODUCTION

The World Health Organization (WHO) estimates that between 1950 and 2025, the number of elderly people in Brazil will increase 15-fold, whereas in other age groups it will be 5-fold. Brazil will be the sixth country in number of elderly, in 2025, with about 32 million people aged 60 or over<sup>(1)</sup>.

The *Pesquisa Nacional por Amostra de Domicílios* (National Household Sample Survey - PNAD), in 2001, mentions that one million and a half elderly people are in a fragile situation in the country. Fragile elderly are those over 75 or over 65 with some kind of functional impairment<sup>(2)</sup>.

Prevalence of chronic non-communicable diseases is higher among elderly and it is considered as one of the main causes for disability and dependence of these elderly. These limitations demand greater financial resources for rehabilitation, home care, and hospital stay for periods that are longer according to life expectancy and to worse health conditions<sup>(3)</sup>.

Concepts such as autonomy, dependence, and independence have been broadly discussed by health professionals working with the elderly. Functional decline that occurs over life, especially after 30-40 years old is influenced by several factors such as: physical and/or organic, by individual genetic formation, life habits, environment, educational and socioeconomic conditions, and family relations. Dependence and independence states, to a greater or lesser extent are present over life and they are not attributes of disabled, sick or elderly people<sup>(4)</sup>.

Alzheimer's disease (AD) is a dementia affecting the elderly and impairing their physical, mental, and social integrity, making them totally dependent on the most advanced stage of their disease and demanding increasingly complex care<sup>(5)</sup>.

Care demand resulting from AD and from health needs of the elderly influence the routine of caregivers and change their quality of life. To the WHO, quality of life (QOL) is the perception of individuals of their position in life, in the cultural context, and system of values they live in, and their perception concerning their goals, expectations, values and concerns<sup>(6)</sup>.

It is essential to know QOL of caregivers and the factors that influence it to plan full health actions with solutions to minimize the harmful effects of care overload experienced by them.

Thinking on the new Brazilian population profile, the ageing pattern, prevalence of non-communicable chronic diseases and the increasing need for care elderly people present, we decided to carry out a study to assess QOL of caregivers of elderly with AD and relate it with patients' Katz index and to caregivers score on Beck Depression Inventory.

## METHODS

The study was developed at *Núcleo de Envelhecimento Cerebral* (Brain Ageing Center - NUDEC) at Universidade Federal de São Paulo (UNIFESP), Hospital São Paulo. This institution is a reference center for the treatment and distribution of medication to people with AD.

Data collection occurred after the research project was approved by the Research Ethics Committee at UNIFESP (# 0940/07) and authorized by NUDEC to start the interviews that took place from March 2007 to April 2008.

The sample was formed by 118 caregivers from both genders, providing care for at least three months to their elderly patients with AD diagnosis.

Caregivers were selected after analysis of charts of patients with AD undergoing evaluation performed by neurologist and/or psychiatrist and/or geriatrician from NUDEC who met the clinical criteria of dementia secondary to AD and had Mini mental state examination (MMSE) scores from 12 to 24 those patients with more than four years of formal education, and score from 8 to 17 for patients with up to two years of study according to Regulation # 843, from October, 31<sup>st</sup>, 2002<sup>(7)</sup>.

Patients' information was collected through their charts and with caregivers. Data raised were sociodemographic; morbid and the ability to perform activities of daily living (ADL) through Katz index<sup>(8)</sup>.

For caregivers, questionnaires on sociodemographic data were applied; morbid, QOL through the generic SF-36 questionnaire (Medical Outcome Study 36 - item short-form health survey) translated and validated in Brazil<sup>(9)</sup> and Beck Depression Inventory (BDI) translated and validated in Brazil<sup>(10)</sup> to assess the presence or absence of depression and its level. SF-36 is a generic questionnaire formed by eight dimensions (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health), the score of each dimension ranges from 0 (worst possible) to 100 (best possible).

BDI has 21 items including symptoms and attitudes. Each question is formed by four alternatives describing traits characterizing the depressive picture. Answers range from 0 (absence of symptoms) to 3 (more severe depressive symptoms).

Katz index is related with ADL which demonstrate the ability of elderly for self care and being responsible for themselves at home. Each activity is assessed regarding dependence (or not) of the elderly to perform it. Score ranges from 0 to 18 and the lower the score, the lower the dependence.

## RESULTS

Sociodemographic characteristics of caregivers and

patients with AD are listed in Table 1. Mean age of patients was 79.6 years, 77.1% were women and most were widow/widowers or divorced. Caregivers were 57.4 years on average, most were females (85.6%) and married. Most caregivers were family members (80.3%), especially daughters, and 72.9% lived with the patient.

**Table 1-** Sociodemographic characteristics of caregivers and patients with Alzheimer's disease - UNIFESP/HSP - 03/2007 to 04/2008

Characteristics	Caregivers (n = 118)	Patients (n = 118)
Age (years)	57.4 (25-88)	79.6 (63-93)
Gender		
Female	101 (85.6%)	91 (77.1%)
Male	17 (14.4%)	27 (22.9%)
Skin Color		
White	104 (88.1%)	106 (89.8%)
Non-white	14 (11.8%)	12 (10.2%)
Marital Status		
Married	74 (64.3%)	45 (38.1%)
Single	22 (19.1%)	3 (2.5%)
other (widow/widower / divorced)	19 (16.5%)	70 (59.3%)
Occupation		
Employed	35 (29.7%)	0 (0.0%)
Self-employed	13 (11.0%)	1 (0.8%)
Unemployed	4 (3.4%)	1 (0.8%)
Housewife	28 (23.7%)	16 (13.6%)
Retired / pensioner	38 (32.2%)	100 (84.7%)
Schooling		
Illiterate/elementary school	12 (10.2%)	49 (41.5%)
Elementary school	31 (26.3%)	59 (50.0%)
High School	42 (35.6%)	4 (3.4%)
University	33 (28.0%)	6 (5.1%)
Monthly income (R\$)		
Individual	800 (0 – 5000)	418,5 (0 – 8000)
Family		1500 (0 – 25000)
Type of relationship		
Wife	21 (17.9%)	
Husband	13 (11.1%)	
Son/daughter	60 (51.3%)	
Other – relative, friend, employee	23 (19.6%)	

Values expressed as mean  $\pm$  SD, median (variation) or number (%).

**Table 2 –** Comorbidities and characteristics of patients with Alzheimer's disease (AD) and their caregivers - UNIFESP/HSP - 03/2007 to 04/2008

Patients (n = 118)	
Number of associated diseases	2 (0 -15)
Hypertension	69 (58.57%)
Visual deficit	48 (40.7%)
Deficit in movement	46 (39.0%)
Diabetes	35 (29.7%)
Katz index	5 (0 - 18)
Time (months) of AD diagnosis	44.4 $\pm$ 27.9
Mini Mental State Examination	16.0 $\pm$ 3.7
Caregivers (n = 118)	
Presented some kind of disease	114 (96.6%)
Saw a doctor at least once in the previous year	3.2 $\pm$ 3.1
Took some kind of medication	80 (67.8%)
Time (months) as caregiver	42.2 $\pm$ 33.4
Hours/week as a caregiver	107.7 $\pm$ 63.0
Lived with the patient	86 (72.9%)
Other people helped the caregiver	55 (46.6%)
Beck Depression Inventory	6 (0 - 29)

Values expressed as mean  $\pm$  SD, median (variation) or number (%).

**Table 3 –** Mean values of SF-36 scores of caregivers from the study, of caregivers of patients who with stroke; score of the regular Brazilian population, and the score of the regular population from other countries

SF-36	Study*	CBA**	Brazil***	United Kingdom***	France***
PF	82.9	67.0	83.0	86.2	91.3
RP	58.1	33.0	87.0	84.6	87.8
Bodily					
Pain	63.6	43.0	73.0	80.9	79.5
GH	71.1	44.0	75.0	72.0	76.7
VT	56.8	37.0	70.0	61.7	65.8
SF	63.6	51.0	84.0	88.4	83.9
RE	58.1	26.0	86.0	84.4	77.4
MH	60.3	42.0	73.0	75.1	69.3

SF-36 ("Medical Outcomes Study – 36 item Short- Form Survey"). PF= physical functioning, RP= role physical, GH= general health, VT=vitality, SF= social functioning, RE= role emotional, MH=mental health; \*\*Almeida MARP et al.(19); \*\*\*Diniz A. *Qualidade de vida de pacientes com HIV positivo e individuos com risco para infecção pelo HIV* (Quality of life of HIV positive patients and individuals at risk for HIV infection) [thesis]. São Paulo: Universidade Federal de São Paulo; 2007.

**Table 4 –** Linear analysis and multiple regressions of the variables correlating with dimensions of SF-36

SF-36	Hours/care week (p-value / R <sup>2</sup> )	Caregiver gender (p-value / R <sup>2</sup> )	Live with the patient (p-value / R <sup>2</sup> )	Total (p-value / R <sup>2</sup> )
Physical Functioning	0.003 / 7.4%	0.0142 / 5.1%	0.0025 / 7.6%	0.000 / 16.6%
Role Physical	0.001 / 9.2%			0.001 / 9.2%
Bodily Pain		0.0020 / 8.1%	0.0160 / 4.9%	0.000 / 14.6%
General Health			0.0010 / 8.4%	0.0010 / 8.4%
Vitality		0.0040 / 7.0%	0.0020 / 7.6%	0.000 / 16.7%
Social Functioning	0.0000 / 10.4%	0.0650 / 2.9%	0.0010 / 8.9%	0.000 / 17.1%
Role Emotional		0.0200 / 4.6%	0.0090 / 5.8%	0.000 / 13.1%
Mental Health		0.0230 / 4.4%	0.0000 / 11.3%	0.000 / 17.7%

**Note:** The center of the table presents values of the simple models. The total represents the multiple models; Spearman's Correlation (R); p value  $\leq$ 0.05.

Data from Table 2 show comorbidity and characteristics of patients with AD and their caregivers. Mean time with AD was 44.4 months, 46.6% received help from other people for care. Mean time as a caregiver was 42.2 months.

Data from Table 3 compared mean values of each domain from SF-36 of caregivers from this study with another survey performed with caregivers of patients with stroke (CVA), with the normal Brazilian population and that of European countries.

Data from Table 4 list the variables that correlate with dimensions from SF-36.

Data from Table 5 show negative and significant correlations between domains from SF-36 and Beck score and between SF-36 and Katz index.

**Table 5** – Correlation between domains from SF-36 and caregivers' Beck scores and Alzheimer's disease patients' Katz score - UNIFESP/HSP - 03/2007 to 04/2008

SF-36 (caregivers) n= 118		Beck (caregivers) n= 118	Katz (patients) n= 118
Physical Functioning	R	-0.54	0.07
	p-value	0.0000	0.4549
Role Physical	R	-0.32	-0.18
	p-value	0.0005	0.0555
Bodily Pain	R	-0.56	-0.23
	p-value	0.0000	0.0114
General Health	R	-0.50	-0.19
	p-value	0.0000	0.0351
Vitality	R	-0.66	-0.28
	p-value	0.0000	0.0019
Social Functioning	R	-0.51	-0.18
	p-value	0.0000	0.0575
Role Emotional	R	-0.41	-0.09
	p-value	0.0000	0.3188
Mental Health	R	-0.65	-0.22
	p-value	0.0000	0.0147

Spearman's Correlation (R); p-value  $\leq 0.05$ .

## DISCUSSION

In the present study we have observed that mean age of elderly with AD was 79.6 years; 77.1% were females; widow/widowers and divorced (59.3%). Mean time after AD diagnosis was 44.4 months, mean MMSE score was 16.0 and that of Activities of daily living was 5.7.

Studies with elderly confirmed a greater prevalence of women with AD. Author stresses that the same thing occurs in Brazil, suggesting that this greater prevalence may be due to a different mortality between the genders also in the Brazilian population<sup>(11-12)</sup>.

Every five years the prevalence of AD doubles among people aged between 65 and 85 years old, and

female gender is considered a risk factor for AD<sup>(13-14)</sup>.

In the literature, we have found also the predominance of female gender among caregivers of elderly with dementia and age ranged from 50 to 65<sup>(15)</sup>, similar to our findings.

Results from studies in our environment showed that most caregivers lived with the elderly, are married and perform care and household chores with too much work and overload in the following domains: social, physical, emotional, and spiritual, contributing to lack of self care and impairment of general health<sup>(16)</sup>.

Regarding time of care, hours in the week dedicated to care and kinship, our study present similar data to those of other studies<sup>(17)</sup> which showed that 55.2% of caregivers provided care for more than 4 years and most (55.2%) mentioned they dedicated 19 to 24 hours a day to the task.

Caregivers of patients with AD have greater chances of presenting psychiatric symptoms, health problems, greater frequency of family and work problems when compared to people at the same age who do not play this role<sup>(1)</sup>. Up to 60% of caregivers from patients with AD can develop physical and psychological disorders and the most commonly found are: hypertension, digestive and respiratory disorders; tendency to infections, depression, anxiety and insomnia<sup>(18)</sup>.

When SF-36 scores obtained in the population of the present study are compared to those of caregivers of CVA<sup>(19)</sup>, we check that all domains of caregivers from the present study were higher. However, when we compare scores of the Brazilian population to those from the English and French population, we see lower scores in the role physical and role emotional (58.1), mental health (60.3), bodily pain (63.6) and social functioning (63.6).

More hours of care per week, living with patients and being a female had a negative influence on caregivers QOL. Similar findings have been demonstrated by authors when they state that female caregivers suffer greater impact, possibly because of the different tasks performed by men and women. Women take up more exhausting activities such as patients' hygiene and managing household chores<sup>(20-21)</sup>.

In the present study, we have observed a positive correlation between caregivers' BDI scores and patients' Katz index. High depression indexes among caregivers of AD patients are present in the literature, affecting up to 30 to 55% of caregivers, who are two to three fold more likely to develop this disease than the rest of the population<sup>(22)</sup>.

Thus, the higher the MMSE, score the lower the dependence. A study carried out demonstrated important association between cognitive and functional decline in elderly with previous cognitive deficits and

lower scores at MMSE, showing progressive loss of the independence to perform ADL<sup>(23)</sup>.

The current study showed that the higher the score of caregivers' QOL, the lower the scores at Beck Depression Inventory and patients' Katz index, this result was similar to that of other study which refers that as dementia progresses, caregivers, in addition to get involved in instrumental activities of daily living, such as managing finances and medications, they also have more responsibility towards basic activities such as personal care tasks, bathing and feeding<sup>(24)</sup>.

One of the surveys carried out with caregivers indicates that taking care of dependent elderly has several adverse effects and there is an emotional impact experienced by family members taking care of people with mental illness or other age-related problems<sup>(25)</sup>. This emotional impact or overload has been defined as: "physical, psychological problems or emotional, social and financial problems presented by family members because they take care of sick elderly"<sup>(26)</sup>.

In another study, the author reports that caregivers present higher rates of depression and other psychiatric symptoms. They can present more health problems than people at the same age that are not caregivers. Additionally, they perform less social activities, have more

problems at work and present more frequently family problems because of the way they care for the relative. Some people present self erosion because of the way they submerge in the role of caregivers<sup>(27)</sup>.

## CONCLUSION

The results of the present study enabled to conclude that QOL of caregivers of elderly with AD assessed was impaired, the most affected SF-36 domains were: role physical and emotional (58.1), mental health (60.3) and bodily pain, and social functioning (63.6). Living with the patient, being a woman, and taking care of patients for many hours a week were variables that correlated with worse QOL of caregivers.

Greater functional impairment of elderly revealed higher caregivers' BDI scores, whereas lower MMSE scores demonstrated greater functional impairment of the elderly. QOL of caregivers was worse when functional capacity of the elderly was more impaired.

From the results, we understand that caregivers must be inserted in the AD patients' care plan since caregivers also present changes in several health aspects. Paying greater attention to caregivers provide them and AD patients with a better quality of life.

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