

## PERCEIVED QUALITY OF LIFE OF ELDERLY PATIENTS WITH DEMENTIA AND FAMILY CAREGIVERS: EVALUATION AND CORRELATION<sup>1</sup>

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Inouye K, Pedrazzani ES, Pavarini SCI, Toyoda CY. Perceived quality of life of elderly patients with dementia and family caregivers: evaluation and correlation. Rev Latino-am Enfermagem 2009 março-abril; 17(2):187-93.

*This study aimed to evaluate the perceived quality of life of elderly patients with dementia and their respective family caregivers and identify correlations between variables. Participants (n=106) were elderly patients with Alzheimer attended by the Exceptional Medication Program in a city in the interior of Sao Paulo, and their respective caregivers. Measures of quality of life were obtained through the Quality of Life Assessment Scale on Alzheimer's disease. Data were entered into a database in the Statistical Program for Social Sciences for descriptive analysis and Spearman's correlation. The total average score for patients and caregivers was 29.32 (sd=±6.27, x<sub>min</sub>=16, x<sub>max</sub>=42) and 38.83 points (sd=±5.62, x<sub>min</sub>=29, x<sub>max</sub>=49). The associated rho coefficient was (+)0.406 (p<0.005). This result indicates moderate correlation between quality of life of caregivers and elderly patients with dementia.*

**DESCRIPTORS:** dementia; Alzheimer disease; caregivers; quality of life

## PERCEPCIÓN DE LA CALIDAD DE VIDA DEL ANCIANO CON DEMENCIA Y LA DE SU CUIDADOR FAMILIAR: EVALUACIÓN Y CORRELACIÓN

*Este estudio tuvo como objetivo evaluar la percepción de calidad de vida del anciano con demencia y la su cuidador familiar y, también, identificar las correlaciones de esas variables. Los participantes (n=106) eran ancianos con enfermedad de Alzheimer, asistidos por el Programa del Medicamento Excepcional de un municipio del interior paulista, y sus respectivos cuidadores. Las medidas de calidad de vida fueron obtenidas por medio de la Escala de Evaluación de la Calidad de Vida en la Enfermedad de Alzheimer. Los datos fueron digitados en un banco de datos en el programa Statistical Program for Social Sciences, para realización de análisis descriptivo y de correlación de Spearman. El promedio de los puntajes totales para pacientes y cuidadores fueron, respectivamente, 29,32 (de=±6,27, x<sub>min</sub>=16, x<sub>max</sub>=42) y 38,83 (de=±5,62, x<sub>min</sub>=29, x<sub>max</sub>=49). El coeficiente ("rho") encontrado en esa asociación fue (+)0,406 (p<0,005), este resultado muestra una correlación moderada entre la percepción de calidad de vida del cuidador familiar y la del anciano con demencia.*

**DESCRIPTORES:** demencia; enfermedad de Alzheimer; cuidadores; calidad de vida

## PERCEPÇÃO DE QUALIDADE DE VIDA DO IDOSO COM DEMÊNCIA E SEU CUIDADOR FAMILIAR: AVALIAÇÃO E CORRELAÇÃO

*Este estudo teve como objetivo avaliar a percepção de qualidade de vida do idoso com demência e seu cuidador familiar e, também, identificar correlações dessas variáveis. Os participantes (n=106) eram idosos com doença de Alzheimer, assistidos pelo Programa do Medicamento Excepcional de um município do interior paulista, e seus respectivos cuidadores. As medidas de qualidade de vida foram obtidas por meio da Escala de Avaliação da Qualidade de Vida na Doença de Alzheimer. Os dados foram digitados em um banco de dados no programa Statistical Program for Social Sciences, para realização de análise descritiva e correlacional de Spearman. A média dos escores totais para pacientes e cuidadores foram, respectivamente, 29,32 (dp=±6,27, x<sub>min</sub>=16, x<sub>max</sub>=42) e 38,83 pontos (dp=±5,62, x<sub>min</sub>=29, x<sub>max</sub>=49). O coeficiente ("rho") encontrado nessa associação foi (+)0,406 (p<0,005), tal resultado aponta correlação moderada entre a percepção de qualidade de vida do cuidador familiar e do idoso com demência.*

**DESCRIPTORES:** demência; doença de Alzheimer; cuidadores; qualidade de vida

## INTRODUCTION

Population aging influences chronic-degenerative diseases and mental disorders, making dementia conditions, frequent among the elderly, more common in the population. Among these, Alzheimer's disease (AD) stands out, representing 50 to 60% of all cases and affecting approximately 10 to 20% of individuals older than 65 years<sup>(1)</sup>.

The Brazilian Ministry of Health's therapeutic strategy for AD has been focused on the optimization of the cholinergic function with administration of medication that inhibits the acetylcholinesterase enzyme (rivastigmine, galantamine and donepezil), which results in patients' stabilization or slight improvement of cognitive functions for a relatively short period<sup>(2)</sup>. It compromises not only the quality of life (QoL) of elderly patients but also that of people close to them. Thus, the family's social and emotional structure is shaken by the responsibility of providing physical, emotional and financial support that usually depend on a family member<sup>(3)</sup>.

In Brazil, informal care is delivered to about 80 to 90% of cases of assistance to the elderly<sup>(4)</sup>. In general, caregivers are women, usually wives or daughters who, even having a paid job, diminish their social and leisure activities to care for a close relative<sup>(5-6)</sup>.

Being a family caregiver, as opposed to a transitory event, is a situation that demands daily responsibility and transforms individuals' life. It demands time, energy, work, affection, effort and good will. Gradual cognitive losses, behavioral and emotional changes, and even changes in the patients' personality require great capacity to adapt with a view to living together satisfactorily<sup>(3)</sup>. Innumerable daily arrangements are necessary to meet progressive and irreversible patient demands<sup>(7)</sup>.

The great majority of informal caregivers does not have information and support necessary for care<sup>(3)</sup>. It becomes a risk factor for their physical, emotional, social and financial distress in the face of the progression of chronic diseases in elderly patients in Brazil<sup>(8)</sup>. Thus, research and information on the theme are crucial to base intervention programs and policies in the fields of health and social well being. Studies addressing to what extent AD affects QoL of people involved in the process and what the potential facilitators and aggravating factors are is considered a factor of increasing importance<sup>(9)</sup>.

In face of this new challenge, inherent to increased longevity, this study aimed to evaluate the perception of quality of life of elderly patients with dementia and their respective family caregivers and identify correlations between these variables. Hypotheses are herein presented.

- Null hypothesis (Ho):  $r = 0$  (there is no correlation between the perception of QoL of elderly patients with AD and perception of QoL of their respective family caregivers).

- Research hypothesis (He):  $r \neq 0$  (there is correlation between the perception of QoL of elderly patients with AD and that of their respective family caregivers).

## METHOD

### Study setting and time

This study was carried out in a medium-size city in the central region of São Paulo, Brazil. Its population, according to IBGE (Brazilian Institute of Geography and Statistics) estimates, was approximately 213,000 inhabitants in 2007, 12% of whom were 60 years or older. Because this percentage was higher than the national average (8.6%), higher incidence and prevalence of chronic-degenerative diseases related to aging, including dementia, are expected<sup>(10)</sup>. Data collection was carried out between August 2006 and April 2007.

### Participants

All potential participants (n=148) among elderly patients with AD were identified by consulting the files of the Municipal Secretary of Health and were randomly drawn to be invited to participate in the study. The first to agree composed the *Group of elderly patients with AD* ( $G_{AD}$ ) (n=53): people 60 years or older, diagnosed with AD, according to current Brazilian legal criteria<sup>(2)</sup>, attended by the municipal Exceptional Medication Program, in pharmacological treatment with acetylcholinesterase inhibitors available through the program for three months or more, without severe language disorders. The *Group of family caregivers* ( $G_{CARE}$ ) (n=53) was composed by the  $G_{DA}$ 's respective caregivers.

### Instruments

(a) *Sociodemographic characterization form of elderly patients with AD and respective family caregivers*: it aimed to collect personal and sociodemographic data of the elderly patients and family caregivers.

(b) *Questionnaire Criterio Brazil*: used to assess socioeconomic level based on family purchasing power, ownership of durable goods, level of education of the family head and some other factors, such as the availability of a maid. This scale adopts seven socioeconomic classes (A1, A2, B1, B2, C, D and E)<sup>(11)</sup>.

(c) *Quality of Life Assessment Scale on Alzheimer's disease (QoL-AD)*: this adapted instrument was translated and validated for the Brazilian culture to evaluate QoL of caregivers of elderly patients with AD<sup>(9,12)</sup>. Two versions were used: one for the patients themselves to evaluate their perception of QoL (PQoL-AD) and another for caregivers' self-evaluation (CQoL-AD). The 13 dimensions of the scale (physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money and life as a whole) were evaluated by participants through the attribution of scores that varied from "1" (bad) to "4" (excellent)<sup>(9)</sup>.

#### Procedure of data collection and analysis

Data of each individual were collected in their households and considered according to answers obtained in the instruments without anyone's interventions, though the presence of other people at the moment of the interview was allowed because some patients with AD would not feel comfortable in the absence of their caregivers. All collected data were inserted into a database in the Statistical Program for Social Sciences (SPSS) version 10.0 for Windows for statistical analysis. Descriptive statistical analyses were performed, aiming to characterize the profile of the sample of elderly people with AD and family caregivers according to gender, age, marital status, schooling, socioeconomic status, kinship degree and general perception of QoL. Spearman's correlations, based on the final scores obtained through QoL-AD (PQoL-AD and CQoL-AD), were performed to identify correlation between the perception of QoL of elderly patients and perception of QoL of family caregivers.

#### Ethical aspects

Data collection was initiated only after approval was obtained from the Research Ethics Committee at the Federal University of São Carlos and the Municipal Secretary of Health where elderly patients with AD were attended. Since some participants were in special conditions, agreement was asked from their legally responsible caregivers. After the free and informed consent term was signed, participants were submitted to the interviews. None of the participants were exposed to activities that caused any discomfort or humiliation. No physical harm was observed with the use of instruments or material proposed in this study. All participants were assured of their right to cease participation at any moment during data collection, without obligation to justify their decision.

## RESULTS

#### Sociodemographic profile of the sample of elderly patients with AD(G<sub>AD</sub>)

The sample of elderly patients with AD was predominantly female (68%, n=36), married, with children (60%, n=32), average age of 77.36 years ( $\pm 7.36$ ,  $x_{min}=60$ ,  $x_{max}=96$ ). In terms of schooling\*, 57% (n=30) were illiterate or had incomplete elementary school; 23% (n=12) had complete elementary school or incomplete middle school, 4% (n=2) had complete middle school or incomplete high school, 6% (n=3) had complete high school or incomplete higher education and 11% (n=6) had a bachelor's degree. It is worth mentioning that men had higher levels of education compared to women and all those with a bachelor's degree were male.

Data regarding socioeconomic status obtained through the *Criterio Brasil*<sup>(11)</sup> revealed that 8% (n=4) of the participants belonged to class A2; 15% (n=8) to class B1; 15% (n=8) to B2; 38% (n=20) to C; 23% (n=12) to D; and 2% (n=1) belonged to class E. This income distribution found in G<sub>AD</sub> corresponds to the national average and average of São Paulo according to the Brazilian Association of Marketing Research Companies<sup>(11)</sup>.

\* The nomenclature used in the questionnaire *Criterio Brasil* was not the officially adopted at the time. However, as this was familiar to the participants, since it had been adopted for many years and was the one used in the questionnaire, the researcher decided to keep it. Current Brazilian education comprises:  
- nursery education (< 6 years old)  
- primary school (6 to 14 years old) = elementary + middle school  
- secondary school (>14 years old) = high school

The average time of treatment of AD with medication inhibitor of acetylcholinesterase was 3.47 years ( $\pm 2.70$ ,  $x_{min}=0.5$ ,  $x_{max}=16$ ).

Sociodemographic profile of the sample of family caregivers of elderly with AD ( $G_{care}$ )

In 68% (n=36) of the studied cases, caregivers had the typical profile described in literature<sup>(3)</sup>: women, living in the same household, who were usually daughters (36%, n=19) or wives (28%, n=15) (Table 1). However, considerable participation of men (32%) was found. Thus, it is important to consider issues related to caregivers' gender at the moment of planning psychoeducational interventions.

Table 1 – Distribution of kinship degree of family caregivers according to gender

Kinship	n	%
Spouse		
Female	15	28.3
Male	13	24.5
Daughter or Son		
Female	19	35.9
Male	4	7.5
Daughter or son-in-law		
Female	1	1.9
Male	0	0
Siblings		
Female	1	1.9
Male	0	0
Total	53	100

The age range of this group was 63.81 years ( $\pm 13.41$ ,  $x_{min}=37$ ,  $x_{max}=89$ ). Of the 53 individuals, 34 (64%) were 60 years or older, which shows that seniors are taking care of elderly patients. Their average time as caregivers was 3.43 years ( $\pm 2.72$ ,  $x_{min}=0.5$ ,  $x_{max}=16$ ). This result is slightly lower than the  $G_{AD}$ 's time of pharmacological treatment of AD. In one of the cases, the caregiver was replaced over time. Since caregivers were relatives living in the same household as elderly patients with AD, data regarding socioeconomic status were identical due to the characteristics of the instrument measurement that evaluate the possession of durable goods in individuals' home<sup>(11)</sup>.

Family caregivers presented a low level of education, though slightly higher than the elderly group. In this case, a higher percentage of women presented complete high school or bachelor's degree (n=13, 24%). The general scenario was: 30% (n=16) were illiterate or had only finished elementary school, 30% (n=16) had complete elementary school or incomplete middle school; 6% (n=2) had complete middle school or incomplete high school, 15% (n=8) had complete high school or incomplete higher education and 19% (n=10) had a bachelor's degree.

Perception of QoL of elderly patients with AD and family caregivers

The results obtained through PQoL-AD and CQoL-AD are presented as frequencies and percentages in Tables 2 and 3.

Table 2 – Frequency distribution of perceived quality of life of elderly patients with Alzheimer's disease, measured through PQoL-AD (in number and percentage)

Dimensions of QoL	Perception of elderly with AD/score							
	Bad/1		Regular/2		Good/3		Excelent/4	
	n	%	n	%	n	%	n	%
1. Physical health	11	21	26	49	14	26	2	4
2. Energy	21	40	17	32	14	26	1	2
3. Mood	13	25	16	30	23	43	1	2
4. Living situation	0	0	11	21	41	77	1	2
5. Memory	27	51	18	34	8	15	0	0
6. Family	1	2	4	8	42	79	6	11
7. Marriage	0	0	5	9	35	66	13	25
8. Friends	11	21	11	21	28	53	3	6
9. Self as a whole	7	13	19	36	26	49	1	2
10. Ability to do chores around the house	23	43	12	23	17	32	1	2
11. Ability to do things for fun	27	51	11	21	15	28	0	0
12. Money	19	36	30	57	4	8	0	0
13. Life as a whole	9	17	27	51	17	32	0	0

Table 3 – Frequency distribution of perceived quality of life of family caregivers, measures through CQoL-AD (in number and percentage)

Dimensions of QoL	Perception of family caregiver/score							
	Bad/1		Regular/2		Good/3		Excelent/4	
	n	%	n	%	n	%	n	%
1. Physical health	2	4	20	38	23	43	8	15
2. Energy	0	0	11	21	30	57	12	23
3. Mood	1	2	10	19	30	57	12	23
4. Living situation	0	0	7	13	36	68	10	19
5. Memory	0	0	6	11	23	43	24	45
6. Family	0	0	0	0	30	57	23	43
7. Marriage	0	0	2	4	25	47	26	49
8. Friends	0	0	4	8	25	47	24	45
9. Self as a whole	0	0	11	21	29	55	13	25
10. Ability to do chores around the house	0	0	5	9	27	51	21	40
11. Ability to do things for fun	2	4	13	25	25	47	13	25
12. Money	11	21	35	66	7	13	0	0
13. Life as a whole	1	2	21	40	24	45	7	13

In isolating positive perceptions (good and excellent) from negative ones (bad and regular), we observe that  $G_{CARE}$  displayed a greater degree of satisfaction in social relationships. All caregivers (100%, n=53) considered their families good or excellent, 96% (n=51) considered they had close marriages or relationships and 92% (n=49) considered they had close friendships. However, perceptions of greater dissatisfaction were related to financial condition (money), which 46 participants (87%) rated as bad or regular, regardless of the social class they belonged to, followed by health (42%, n=22) and "life as a whole" (42%, n=22). Positive perceptions highlighted by elderly patients with AD were family (90%, n=48), marriage (90%, n=48) and living situation (79%, n=42), and negative perceptions were related to financial situation (93%, n=49), memory (85%, n=45), ability to do things for fun (72%, n=38) and energy (72%, n=38).

The distribution of total scores of QoL of elderly patients with AD and caregivers is presented in Figure 1. In general, the average of  $G_{AD}$  was 29.32 points ( $\pm 6.27$ ,  $x_{min}=16$ ,  $x_{max}=42$ ) and average of  $G_{CARE}$  of 38.83 points ( $\pm 5.62$ ,  $x_{min}=29$ ,  $x_{max}=49$ ).

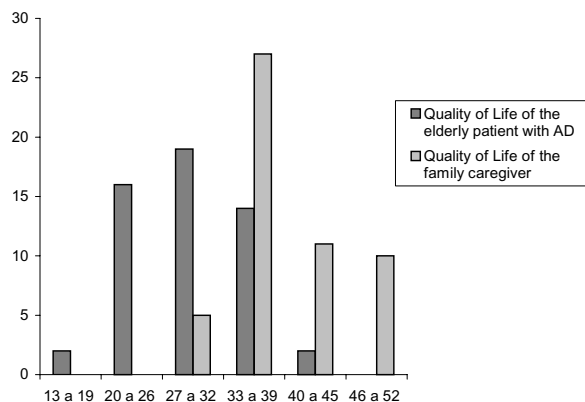


Figure 1 – Distribution of total scores of QoL of elderly patients with AD and caregivers

Correlation between the perception of QoL of elderly patients and family caregivers

Spearman's rho coefficient of linear correlation found for this association was +0.406 ( $p < 0.005$ ). The index shows a moderate<sup>(13)</sup> and directly proportional relation between these variables. Thus, since  $r \neq 0$ , the null hypothesis is rejected and we assume there is a relation between the general perception of QoL of family caregivers and elderly patients with AD. Figure 2 supports this statement.

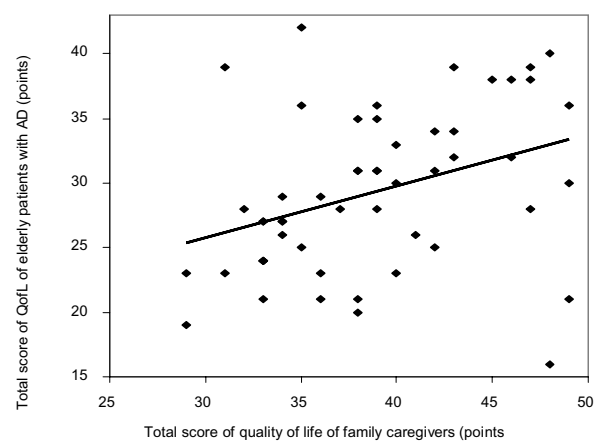


Figure 2 – Relation between the total QoL score of the family caregiver and the elderly with AD

## DISCUSSION

We perceive in the description of the caregivers' sociodemographic profile that, even though women are the majority, which is in accordance with several studies, the participation of men was considerable and cannot be ignored.

Another noteworthy fact was that seniors are taking care of the elderly. While this information is

not unprecedented, it should be considered by researchers and practitioners, as it is becoming more common with increasing longevity.

This study allowed the researchers to relate the perception of QoL of family caregivers and that of patients, as well as to evidence the valorization of both in interpersonal relations. Family and marriage were the dimensions both groups evaluated best, which lead to the reflection of how this information could be used to contribute to a better planning of health actions focused on comprehensive care delivery to this population.

## CONCLUSIONS

Positive perceptions and the main difficulties of caregivers and patients with Alzheimer appointed in this study can contribute to strengthen the care process with quality of life. Health promotion, in a broader perspective, should include people's well being, acknowledging the importance of social, economic, cultural and spiritual relations in a continuous process of education, growth, personal updating and fulfillment, so as to permit them to be active members of and contribute to society.

Insoluble and permanently stressing situations like chronic diseases require control and coping strategies<sup>(14)</sup>. The complex problem that involves living with a chronic patient compromises, in addition to the biological sphere of the affected person, different life styles of the family and social group<sup>(15-16)</sup>. It is important to consider the family both as a unit of care and a unit to be taken care of. Overwhelmed and exhausted caregivers have their

quality of life threatened due to stress generated by the responsibility of taking care, which oftentimes leads to feelings of powerlessness, health problems, tiredness and irritability<sup>(17)</sup>. The acknowledgment, in this study, that the general perception of QoL of the elderly patient is proportionally and directly related to the perception of the caregiver, leads to further investigation on this topic with a view to establishing new directions so that intervention programs are designed according to the main needs of both, emphasizing the preservation of positive aspects so as to value sharing, cooperation and help, which support balance amidst difficulties. Patients' and caregivers' education should be based on dimensions that involve interpersonal relationships valued by groups, strengthening principles of tolerance and respect between people, coping in the face of constant changes, which time and environment impose on patients' body, history, skills and capacities.

With increased life expectancy, becoming a caregiver will be increasingly more common, since the incidence of chronic diseases grows proportionally to aging. Research involving caregivers' QoL are as important as patients' QoL, because those with diminished QoL will possibly have less disposition and energy to provide the care people with dementia require. Discussions on the issue are essential, especially in the current society in which AD affects about 15 million of people worldwide<sup>(18)</sup>. In this perspective, psychoeducational interventions should also optimize quality of life through the promotion of knowledge and skills that encourage the less skilled, meeting their individual needs, so that everyone feels accepted, understood and respected in their different ways of being and living.

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