

Quality of Life of Elderly with Alzheimer's Disease: a Comparative Study Between the Patient's and the Caregiver's Report¹

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This paper aimed to compare the reports of patients and caregivers about how they perceive quality of life (QoL) in general and each of its dimensions in elderly with Alzheimer's Disease (AD). The participants were elderly diagnosed with AD (n=53) attended by the Exceptional Medication Program in a city in the interior of Sao Paulo; and their respective family caregivers. The QoL measures were obtained through the Quality of Life Assessment Scale on Alzheimer's Disease. The results showed statistically significant differences in the "memory" ($p < 0.05$) and "you in general" ($p < 0.005$) dimensions. Regarding the final score, the average in the patient's version was 29.32 points (sd=6.27), against 28.33 points (sd=5.58) in the family version, $p > 0.100$. Although the relative and patient reports were not identical, the results pointed to a high level of consistency among information.

Descriptors: Quality of Life; Alzheimer Disease; Dementia; Caregivers; Aged.

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Qualidade de vida do idoso com doença de alzheimer: estudo comparativo do relato do paciente e do cuidador

Este estudo teve como objetivo comparar o relato do paciente e do respectivo cuidador familiar sobre a percepção geral e de cada dimensão de qualidade de vida (QV) do idoso com doença de Alzheimer (DA). Os participantes foram idosos diagnosticados com DA (n=53), atendidos pelo Programa do Medicamento Excepcional de uma cidade do interior paulista, e seus respectivos cuidadores familiares. As medidas de QV foram obtidas por meio da Escala de Avaliação da Qualidade de Vida na Doença de Alzheimer. Os resultados mostraram que apenas as dimensões "memória" ($p<0,05$) e "você em geral" ($p<0,005$) apresentaram disparidades estatisticamente significantes. Quanto ao escore final, a média na versão do paciente foi de 29,32 pontos ($dp=6,27$) e na versão do familiar foi de 28,33 pontos ($dp=5,58$), $p>0,100$. Embora os relatos do familiar e paciente não sejam idênticos, os resultados apontaram elevada consistência entre as informações.

Descritores: Qualidade de Vida; Doença de Alzheimer; Demência; Cuidadores; Idoso.

Calidad de vida del anciano con enfermedad de Alzheimer: estudio comparativo de los relatos del paciente y del cuidador

Este estudio tuvo como objetivo comparar los relatos del paciente y el del respectivo cuidador familiar sobre la percepción general y de cada dimensión de calidad de vida (CV) del anciano con enfermedad de Alzheimer (EA). Los participantes fueron ancianos diagnosticados con EA (n=53), atendidos por el Programa del Medicamento Excepcional de una ciudad del interior del estado de Sao Paulo, y sus respectivos cuidadores familiares. Las medidas de CV fueron obtenidas por medio de la Escala de Evaluación de Calidad de Vida en la Enfermedad de Alzheimer. Los resultados mostraron que apenas las dimensiones "memoria" ($p<0,05$) y "usted en general" ($p<0,005$) presentaron disparidades estadísticamente significativas. En cuanto al puntaje final, el promedio en la versión del paciente fue de 29,32 puntos ($de=6,27$) y en la versión del familiar fue de 28,33 puntos ($de=5,58$), $p>0,100$. A pesar de que los relatos del familiar y del paciente no son idénticos, los resultados apuntaron una elevada consistencia entre las informaciones.

Descriptores: Calidad de Vida; Enfermedad de Alzheimer; Demencia; Cuidadores; Anciano.

Introduction

The most disseminated and well-known definition of quality of life (QoL) nowadays is that by the World Health Organization⁽¹⁾ (WHO), which describes it as an individual's perception of his position in life, in the context of the culture and value systems he lives in and with regard to his objectives, expectations, standards and concerns. This definition includes six main domains: (1) physical health, (2) psychological state, (3) levels of independence, (4) social relation, (5) environmental characteristics and (6) spiritual beliefs⁽¹⁾.

Quality of life (QoL) is an eminently human perception that includes different meanings, influenced

by multiple factors that are not limited by time, socioeconomic, cultural and health conditions⁽²⁾. Despite the lack of a consensus meaning, researchers⁽³⁾ agree about the QoL construct, characterized as: (a) multidimensional, related to the fact that life covers multiple dimensions, such as the social, mental, material, physical, cultural, economic, among others; (b) dynamic, given its inconstant characteristic in time and space; (c) subjective, determined by the importance and perception of the individual meaning attributed to inter and intraindividual experiences.

As QoL is defined as a subjective perception, there is great controversy about the choice of whom should answer an instrument aimed at assessing the QoL of patients with Alzheimer's disease. In literature, the type of respondent is related to the degree of severity of the dementia, that is, assessment instruments directed at patients with light or moderate cognitive impairment use the reports of patients, caregivers or both while, in severe cases, information is provided by the caregiver only.

In a search carried out in MEDLINE/PubMed in 2007, using different combinations of the following keywords: "instrument", "measure", "scale", "quality of life" and "dementia", 11 specific instruments were found to assess QoL in dementia. These are: (1) QUALIDEM⁽⁴⁾, (2) Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP)⁽⁵⁾, (3) DEMQOL⁽⁶⁾, (4) Quality of Life Assessment Scale on Alzheimer's Disease (QoL-AD)⁽⁷⁻⁸⁾, (5) The Cornell-Brown Scale for Quality of Life in Dementia (CBS)⁽⁹⁾, (6) Dementia Care Mapping (DCM)⁽¹⁰⁾, (7) Quality of Life Assessment Schedule in Dementia (QOLAS)⁽¹¹⁾, (8) The Quality of Life in Late-Stage Dementia Scale (QUALID)⁽¹²⁾, (9) Dementia Quality of Life Instrument (DQoL)⁽¹³⁾, (10) Activity and Affect Indicators of Quality of Life⁽¹⁴⁾.

Among these, the psychometric properties for severe cases of dementia had been studied for the QUALIDEM⁽⁴⁾, PWB-CIP⁽⁵⁾, DEMQOL⁽⁶⁾, DCM⁽¹⁰⁾, QUALID⁽¹²⁾ and the Activity and Affect Indicators of Quality of Life⁽¹⁴⁾ only, and all of these only used the caregiver's report. The patient's report was considered in the DEMQOL⁽⁶⁾, QdV-DA⁽⁷⁻⁸⁾, CBS⁽⁹⁾, QOLAS⁽¹¹⁾ and DQoL⁽¹³⁾ only, which indicated adequate reliability and validity in assessment by patients with initial-stage dementia^(7,9,11,13). Although loss of discernment and conscience are common in dementia, some researchers believe this loss can be independent of the perception of well-being and emotional states themselves⁽¹³⁾.

In view of the issue about who would be the ideal subject to answer about the QoL of demented patients, this research aimed to compare the reports of patients and their respective family caregivers about the perception of elderly patients with AD's QoL in general and in each dimension.

Method

Study design

An exploratory and descriptive cross-sectional study was carried out with a non-probabilistic sample.

Study place and period

This research was carried out in São Carlos, a medium-sized city in the center of São Paulo State which, with an estimated population of approximately 218 thousand inhabitants in 2007, according to the Brazilian Institute of Geography and Statistics (IBGE), 12% of whom were 60 years or older. This percentage was higher than the national average of 8.6%⁽¹⁵⁾. Data were collected during nine months, starting in August 2006 and extending until April 2007.

Sample

Participants in this research were 106 subjects, divided in two groups: (a) group of elderly with AD (G_{DA}) ($n=53$)* and (b) group of family caregivers of G_{DA} (G_{CUID}) ($n=53$). The criteria for inclusion in the G_{DA} were: being 60 years of age or older, with a medical diagnosis of light or moderate AD according to DSM-IV criteria and objective assessments – Mini-Mental State Examination and CDR Scale⁽¹⁶⁾, being attended by the Exceptional Medication Program (EMP) in the city, receiving pharmacological treatment with an acetylcholinesterase inhibitor, made available by the EMP for three months or more, not presenting severe language disorders. With the help of the city's Health Secretariat, all possible G_{DA} components were surveyed and, within this group, the order was drafted in which they would be invited to participate in the research. Some of the subjects drafted ($n=26$) could not be part of the sample because they refused, were not located, had died, changed address or did not comply with the inclusion criteria. The G_{CUID} was constituted by the G_{DA} members' respective family caregivers.

Instruments

The following instruments were used:

(a) *Sociodemographic characterization form of elderly with AD and family caregiver*: aimed to collect personal and sociodemographic data on the elderly and relative; (b) *Brazil criterion economic questionnaire*⁽¹⁷⁾: used to assess the socioeconomic level, through the family's purchasing power, based on the number of durable consumption goods owned, instruction level of family head and some other factors, such as the presence of a domestic aid. This scale divides the population into seven social classes (A1, A2, B1, B2, C, D e E); (c) *quality of life assessment scale on Alzheimer's disease*^(8,18): instrument adapted, translated and validated for the

*This n represents 35.1% in the total number of all possible components of G_{DA} ($n=148$).

Brazilian culture to assess the QoL of caregivers and elderly with AD. Three versions: one for the patient to assess his/her own QoL (PQoL-AD), another for the caregiver to assess the patient (CQoL-AD) and yet another for the caregiver to assess his/her own quality of life (COQoL-AD). In this study, two versions were used: the PQoL-AD and the COCoL-AD. The participants scored the thirteen dimensions (physical health, willingness, mood, housing, memory, family, marriage, friends, you in general, ability to do tasks, money and life in general) of the scale, ranging from 1 (bad) to 4 (excellent). Although there are other instruments to assess QoL in dementia cases, as mentioned in the introduction, the choice of this instrument was justified because it is the only one that has been translated, adapted and validated for the Brazilian culture^(8,18).

Data collection procedure

After the study was approved by the Research Ethics Committee at São Carlos Federal University (UFSCar) and the Municipal Health Secretariat had agreed with the use of its files to locate elderly patients diagnosed with AD, attended by the Exceptional medication Program, the search for possible participants started. The first 53 patient-relative pairs who agreed to participate and complied with the inclusion criteria constituted the study groups. Data for each individual were collected at their respective homes and considered according to the answers obtained on the instruments without other people's intervention, although these could be present at the moment of the interview, as some elderly with AD did not feel at ease without their caregivers.

Data analysis

All collected data were inserted in a database in Statistical Program for Social Sciences (SPSS) software, version 10.0, for Windows, for statistical analyses: (a) descriptive to characterize the subjects' profile and QoL; (b) Student's t-test to compare total QoL scores on each version and (c) Wilcoxon's non-parametrical test for paired samples in order to identify perception differences in each QoL dimension between the elderly's own version and that of the family caregiver. Statistical significance was set at 5% ($p < 0.05$).

Ethical aspects

All participants were informed about the research objectives and consulted about their availability to participate in the research, with the guaranteed secrecy of individual information. As some participants were in special conditions, third-party consent was also requested. Interviews only started after the free and informed consent term had been signed. None of the subjects were exposed to questions that would cause discomfort or humiliation. No type of physical damage was observed that was caused by the use of the instruments proposed in this research. The participants were guaranteed the right to interrupt their participation without any need for justification at any time.

Results

Sociodemographic profile of family caregivers and elderly with Alzheimer's disease

The sample of elderly with AD in this research included 36 women (68%) and 17 men (32%), with a mean age of 77.36 years (± 7.36 , $x_{\min} = 60$, $x_{\max} = 96$). As to the instruction level, 80% ($n = 42$) had at most finished basic education.

Family caregivers were also predominantly female (68%, $n = 36$), illiterate or without secondary education (60%, $n = 32$), and the group's mean age range was 63.81 years (± 13.41 , $x_{\min} = 37$, $x_{\max} = 89$). As to the degree of parenthood, 53% ($n = 28$) were partners and 43% ($n = 23$) were children, as well as one daughter-in-law (2%) and a sister (2%).

As the caregivers were relatives who lives at the same address as the patients, data related to socioeconomic status, as measured by the Brazil criterion economic questionnaire⁽¹⁷⁾, were identical and their distribution follows the national average in Brazil and Greater São Paulo, provided by the Brazilian Association of Research Companies⁽¹⁷⁾, with a slight tendency towards better conditions among the study subjects.

Quality of life of elderly with AD, according to the patients' and the family caregivers' reports

Frequencies and percentages on the QoL-AD with respect to the elderly with AD and the family caregiver's report about the patient are shown in Table 1.

Table 1 – Perception frequency among elderly with AD and their family caregivers about each dimension of the patient's QoL (number and percentage). São Carlos, SP, 2006

Version	Perception/score							
	Bad/1		Regular/2		Good/3		Excellent/4	
	Elderly n (%)	Caregiver n (%)	Elderly n (%)	Caregiver n (%)	Elderly n (%)	Caregiver n (%)	Elderly n (%)	Caregiver n (%)
Physical health	11 (21)	15 (28)	26 (49)	22 (42)	14 (26)	16 (30)	2 (4)	0 (0)
Willingness	21 (40)	21 (40)	17 (32)	17 (32)	14 (26)	14 (26)	1 (2)	1 (2)
Mood	13 (25)	16 (30)	16 (30)	19 (36)	23 (43)	16 (30)	1 (2)	2 (4)
Housing	0 (0)	0 (0)	11 (21)	9 (17)	41 (77)	40 (75)	1 (2)	4 (8)
Memory	27 (51)	36 (68)	18 (34)	13 (25)	8 (15)	3 (6)	0 (0)	1 (2)
Family	1 (2)	1 (2)	4 (8)	3 (6)	42 (79)	39 (74)	6 (11)	10 (19)
Marriage	0 (0)	1 (2)	5 (9)	3 (6)	35 (66)	35 (66)	13 (25)	14 (26)
Friends	11 (21)	10 (19)	11 (21)	13 (25)	28 (53)	24 (45)	3 (6)	6 (11)
You in general	7 (13)	12 (23)	19 (36)	27 (51)	26 (49)	14 (26)	1 (2)	0 (0)
Tasks	23 (43)	28 (53)	12 (23)	7 (13)	17 (32)	16 (30)	1 (2)	2 (4)
Leisure	27 (51)	32 (60)	11 (21)	9 (17)	15 (28)	11 (21)	0 (0)	1 (2)
Money	19 (36)	18 (34)	30 (57)	32 (60)	4 (8)	3 (6)	0 (0)	0 (0)
Life in general	9 (17)	10 (19%)	27 (51)	27 (51)	17 (32)	16 (30)	0 (0)	0 (0)

The results of the comparative statistical analyses of each QoL dimension for patients with AD, in their own version and that of their family caregivers, using Wilcoxon's test, are shown in Table 2, in increasing order of convergence, so as to highlight the most significant data.

Table 2 – Results, in increasing order of convergence, of comparative statistical analyses in each QoL dimension of patients with AD, in their own version and that of their family caregivers, using the Wilcoxon test. São Carlos, SP, 2006

QoL dimensions	Z	p
You in general	-3.04	0.002**
Memory	-2.13	0.033*
Housing	-1.51	0.132 ^{ns}
Leisure	-1.44	0.151 ^{ns}
Mood	-1.37	0.169 ^{ns}
Physical health	-1.28	0.201 ^{ns}
Family	-1.15	0.251 ^{ns}
Tasks	-0.74	0.462 ^{ns}
Friends	-0.55	0.585 ^{ns}
Life in general	-0.47	0.637 ^{ns}
Marriage (relationship)	-0.24	0.808 ^{ns}
Willingness	0	1.000 ^{ns}
Money	0	1.000 ^{ns}

ns=not significant.

*p<0.05.

**p<0.005.

As for the patient's final score, the mean score in the patient's own version was 29.32 points (± 6.27 ,

$x_{\min}=16$, $x_{\max}=42$), against 28.33 points (± 5.58 , $x_{\min}=19$, $x_{\max}=39$) in the relative's version, with $t(104) = 0.850$, $p > 0.100$. Figure 1 shows the distribution of the number of subjects according to the final QoL scores in each version.

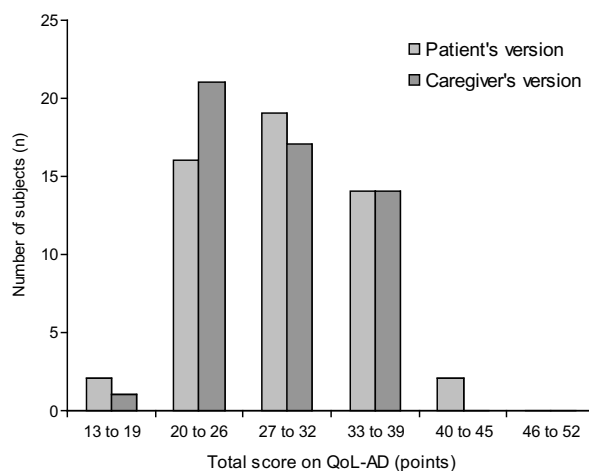


Figure 1 – Distribution of number of elderly with AD, according to final QoL scores in patients' and family caregivers' versions. São Carlos, SP, 2006

When isolating positive (good and excellent) from negative perceptions (bad and regular) with regard to the elderly's QoL, both versions can provide a general picture of the differences found (figure2).

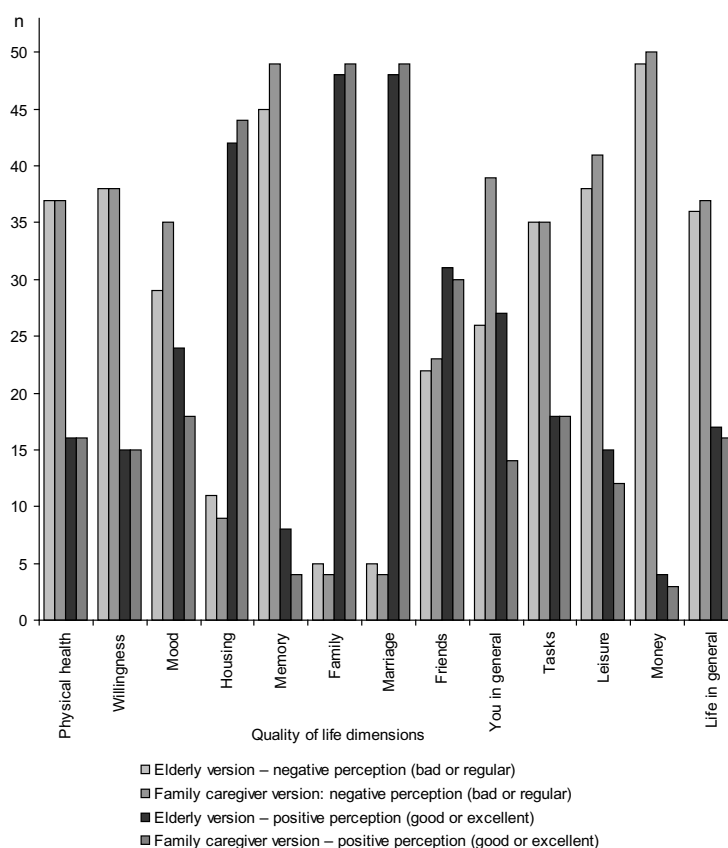


Figure 2 – Distribution of positive and negative perceptions on each dimension of elderly's QoL, according to their own perception and that of their family caregivers. São Carlos, SP, 2006

Discussion

Based on the results, a consistency ranking between patients' and caregivers' reports can be appointed. As for statistically diverging results, greater disagreement is found in the you in general than in the memory domain. On the other hand, domains without significant differences displayed strong consistencies, which were, in increasing order: housing, leisure, mood, physical health, family, ability to perform tasks, friends, life in general and marriage (or closer relation). Willingness and money showed perfect consistency. However, with respect to the latter, the small sample size and difficulties to interview patients and caregivers separately (as described in the data collection procedure) should be noted.

As for positive and negative perceptions, caregivers tended to overestimate dimensions like family, marriage and housing, as they were family members who lived in the same house and considered themselves as good to their elderly family members. Physical health, willingness and ability to perform tasks were identical in the two versions, which reveals relatives' good

sensitivity with regard to these dimensions. Caregivers tend to underestimate the remainder.

The findings support observations described in literature about the possible association between these trends and the damage caused by judgment and criticism, with alter the patient's perception or the relative's reference standards⁽⁸⁾. Another source of influence is due to the fact that common sense presupposes that a person with a degenerative disease will have a bad QoL⁽⁸⁾.

Conclusions

The results of this research indicate a direct connection with practice, as current pharmacological treatments for AD only contribute to a discrete improvement or the stabilization of symptoms⁽¹⁹⁻²⁰⁾. Consequently, surveying data about the patient's QoL helps to assess the global success of the intervention. As behavioral disorders and mood oscillations are frequent symptoms among patients, professionals cannot count on patients' cooperation all the time. Sometimes, misunderstandings can come up due to the sporadic

episodes that affect patients during consultations or in unfamiliar institutional environments, and this excerpt can impair the disease's treatment. In this case, the reliability of the relative's report, as indicated in this research, is convenient.

Hence, similar future research would be interesting,

carried out in other realities, using other QoL assessment instruments in cases of dementia, as well as research correlating the consistency of reports with variables like gender, dependence level of the elderly with AD, proximity of family relationship and contact time between patient and caregivers.

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