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Alzheimer's disease influence on the perception of quality of life from the elderly people*

INFLUÊNCIA DA DOENÇA DE ALZHEIMER NA PERCEPÇÃO DE QUALIDADE DE VIDA DO IDOSO

INFLUENCIA DE LA ENFERMEDAD DE ALZHEIMER EN LA PERCEPCIÓN DE CALIDAD DE VIDA DEL ANCIANO

Keika Inouye[1], Elisete Silva Pedrazzani[2], Sofia Cristina Iost Pavarini[3]

ABSTRACT

This study aims to compare the general perception and each dimension of the quality of life (QoL) of an elderly group with Alzheimer's Disease (AD) (n=53) to those of a similar group regarding the socio-demographic variables (n=53). The QoL measures were obtained through an Assessment Scale of the Quality of life in Alzheimer's Disease, and the data were typed into a database in the program Statistical Program for Social Sciences for the execution of the statistical analysis (descriptive, Student's t-test, Mann-Whitney and Chi-Square). Results showed that all dimensions of QoL measured by the instrument were statistically inferior in the group of elderly with AD. Regarding the total scores of QoL, the mean was 40.18 points for elderly without AD and 29.32 for elderly with AD, $t(104) = 9.449$, $p<0.001$. These results indicate that older people with AD present inferior levels of QoL, which suggests that AD has a negative influence in their perception of quality of life.

KEY WORDS

Aged.
Alzheimer disease.
Dementia.
Quality of life.

RESUMO

Este estudo tem por objetivo comparar a percepção geral e de cada dimensão de qualidade de vida (QV) de um grupo de idosos com Doença de Alzheimer (DA) (n=53) com as de um grupo semelhante quanto às variáveis sociodemográficas (n=53). As medidas de QV foram obtidas por meio da Escala de Avaliação da Qualidade de Vida na Doença de Alzheimer, e os dados foram digitados em um banco de dados no programa Statistical Program for Social Sciences, para a realização de análises estatísticas (descritivas, teste-t de Student, Mann-Whitney e Qui-Quadrado). Os resultados revelaram que todas as dimensões de QV medidas pelo instrumento eram estatisticamente inferiores no grupo de idosos com DA. Quanto aos escores totais de QV, a média obtida foi de 40,18 pontos para idosos sem DA e de 29,32 para idosos com DA, $t(104) = 9,449$, $p<0,001$. Estes resultados apontam que idosos com DA apresentam medidas de QV inferiores, sugerindo que a DA influencia negativamente na sua percepção da qualidade de vida.

DESCRITORES

Idoso.
Doença de Alzheimer.
Demência.
Qualidade de vida.

RESUMEN

Este estudio tuvo como objetivo comparar la percepción general y de cada dimensión de calidad de vida (CV) de un grupo de ancianos con Enfermedad de Alzheimer (EA) (n=53) con grupo semejante en cuanto a sus variables sociodemográficas (n=53). Las medidas de CV fueron obtenidas a través de la Escala de Evaluación de Calidad de Vida en la Enfermedad de Alzheimer, los datos fueron procesados como base de datos utilizándose el programa Statistical Program for Social Sciences, para la realización de análisis estadísticos (descriptivos, tests-t de Student, Mann-Whitney y Qui Cuadrado). Los resultados revelaron que todas las dimensiones de CV medidas por el instrumento eran estadísticamente inferiores en el grupo de ancianos con EA. Respecto de los puntajes totales de CV, la media obtenida fue de 40,18 puntos para ancianos sin EA y de 29,32 para ancianos con DA, $t(104) = 9,449$, $p < 0,001$. Estos resultados determinan que los ancianos con EA presentan puntajes de CV inferiores, sugiriendo que la EA influencia negativamente en su percepción.

DESCRIPTORES

Anciano.
Enfermedad de Alzheimer.
Demencia.
Calidad de vida.

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INTRODUCTION

According to criteria provided in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR)[1], Alzheimer's Disease (AD) is a type of senile dementia, with progressive and irreversible cognitive decline and multiple cognitive deficits, one of which is in memory, sufficiently intense to cause an impact on Activities of Daily Living (ADLs), excluding other diseases that could explain the observed symptoms[1]. In the disease's initial stages, elderly individuals tend to get easily confused and forget recent facts. As the disease progresses, the patient begins to have difficulty performing simple tasks such as using household items, dressing, hygiene and eating. In the final stage, the individual presents severe language disorders and becomes bedridden. In each of these successive stages, a gradual loss of autonomy and consequent dependency on caregivers' supervision is observed[2].

In epidemiological terms, AD is the most common type of dementia and accounts for about 56% of the total number of cases and its prevalence affects about 5% of individuals older than 65 years of age and 20% of those older than 80 years of age[2]. Although the progress of medical practices leads to more efficient interventions, the current pharmacological treatment for elderly individuals with AD mainly aims to slow the evolution of symptoms, improving the patients' cognitive status, reducing psychological problems and optimizing their autonomy to perform ADLs. All these combine to produce a discreet improvement in or stabilization of autonomy, though it is important to evaluate to what extent a given intervention improves the well-being and Quality of Life (QoL) of individuals undergoing treatment[3-4].

The cognitive deficit caused by AD elicits feelings of powerlessness, helplessness, weakness and a lack of hope for the future. The degenerative morbid processes accelerate psychological and functional decay, compromising QoL.

The most disseminated and widely known current definition of QoL is that provided by the WHO: *an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standard and concerns*. This definition includes six main domains: (1) physical health; (2) psychological state; (3) levels of independence; (4) social relationships; (5) environmental features; and (6) spiritual standards[5].

QoL is simultaneously an individual and collective notion, a product of culture defined by a society. It results from the combination of degrees of satisfaction that accrue from family, love, social, occupational, environmental and existential life. In generic terms, the distance from an individual's expectations and reality determines QoL; the less the distance, the better[6].

The principles of aging with QoL describe the pro-active elderly individual, who defines his/her objectives and struggle to achieve them, gathering resources useful in adapting to changes and actively involved in maintaining his/her well-being. This model derives from satisfaction with life to models based on concepts of independence, control, social and cognitive competences[7].

The cognitive deficit caused by AD elicits feelings of powerlessness, helplessness, weakness and a lack of hope for the future. The degenerative morbid processes accelerate psychological and functional decay, compromising QoL. Lack of memory hampers bringing people into one's affective, social and family relationships. Without remembering facts, places and people, the elderly individual has difficulty interacting with his/her environment, loses autonomy in self-care, planning and performing tasks that permit psycho-social adaptation and taking responsibility for his/her actions[8].

There are few national scientific studies specifically addressing QoL for AD taking into account its breadth and multi-dimensionality[9-11]. Scientific material addressing the QoL of elderly individuals with AD mainly focus on cognitive functions and ADLs, however, QoL comprises other dimensions such as health, energy, mood, housing, memory, family, marriage, friends, the ability to perform tasks, leisure, money and life as a whole[10-11]. In this context, the perception of patients is relevant because the pharmacological approach is only symptomatic and is inefficient in containing the progressive degenerative characteristic of the disease[12].

The importance of evaluating the perception of elderly individuals with AD concerning their QoL refers us to the quantitative-qualitative duality of pharmacological treatment. As relevant as prolonging the life of a patient and slightly minimize his/her cognitive symptoms is the need to know how this patient feels in relation to his/her expectations, standards and concerns. Despite the progression of symptoms, it is believed that individuals are less affected by clinical aspects and what really plays a role in patients' QoL are psychological components, available psycho-educational resources and knowledge to deal with the disease[13]. This relatively recent finding is supported by the increased number of publications addressing QoL in dementia in the PubMed database, especially from the 1990s on[14].

OBJECTIVES

In its broadened perspective, increased life expectancy needs to be accompanied by improved, or at least, a maintained QoL[15]. Hence, this study compared the general perception of each dimension of the QoL of a group of elderly individuals with AD in relation to a group of elderly individuals without AD. The groups were matched in relation to socio-demographic variables aiming to quantify the influence of AD in the elderly individuals' perception of QoL.

METHOD

Setting – This study was carried out in São Carlos, a mid-sized city located in the central region of the state of São Paulo, Brazil, which according to the Brazilian Institute of Geography and Statistics (IBGE), had around 218,000 inhabitants in 2008, 12% of which were 60 years old or older[16].

Participants – With the help of the City Health Department, we sought out all the elderly individuals with AD (n=148), potential participants who were invited to participate in the study according to a randomly selected order. The first ones to be invited and who consented to participate in the study, composed the Group of elderly individuals with AD (G_{AD}) (n=53): people 60 years old or older, diagnosed with mild or moderate AD according to the current Brazilian legal criteria (DSM-IV criteria and objective cognitive evaluations, Mini-Mental State Examination and Clinical Dementia Rating (CDR) Scale)[17], participating in the Exceptional Medicine Program (EMP), undergoing pharmacological treatment with one of the acetylcholinesterase inhibitors provided by the EMP, with an average of 3.47 years under pharmacological treatment (sd=2.70, $x_{mín}$=0.5, x_{max}=16), with no severe language disorders. The Control group of elderly individuals without AD (G_{WAD}) (n=53) was composed of people with age, gender and locale of residence matching that of the G_{AD}.

Instruments - (a) Participants' Characterization Form: the form addressed the participants' socio-demographic data (name, age, schooling, medication, duration of treatment) and information concerning daily and social activities such as: physical activities, religious groups, clubs for seniors, art workshops, memory workshops, psychological treatment, physiotherapy, and university programs for senior citizens. Questions addressing family composition, professional activities, leisure and/or hobbies were also included. (b) Questionnaire Critério Brasil [Brazilian Criteria for Economic Classification]: the questionnaire was used to evaluate the participants' socio-economic level through family purchasing power. This scale divides the population into seven social classes (A1, A1, A2, B1, B2, C, D and E)[18]. (c) Quality of Life in Alzheimer's Disease Scale – patient's version (PQoL-AD): Instrument adapted, translated and validated for Brazilian culture to evaluate the QoL of elderly people with AD. The scale's thirteen dimensions (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 the participants through the attribution of grades from 1 (poor) to 4 (excellent)[10-11]. This instrument was chosen because it was validated in the same format for elderly individuals with AD and for their caregivers, who do not necessarily have health problems or are older than 60 years of age, thus appropriate to evaluate any person[11]. Therefore, we ensure the reliability of the data obtained in both groups, assuring the possibility of comparisons.

Procedure of data collection and analysis: After the City Health Department (CHD) authorized the study to be carried out with individuals that received medication from the EMP and the Research Ethics Committee at the Federal University of São Carlos (UFSCar) approved the project (protocol n° 221/2006), a search was carried out of the CHD files to identify potential participants. Those who consented to participate in the study, met the inclusion criteria and signed a free and informed consent form composed the G_{AD}. We also asked for the consent of those responsible for the individuals in this group. Data on each individual was collected in their residences and considered according to the answers obtained in the instruments without the intervention of others, though caregivers were allowed to be present at the time of the interview, since some elderly individuals with AD would not be comfortable without the presence of their caregivers. The individuals composing the G_{AD} suggested potential individuals to participate in the G_{WAD} group. All data collected were stored in a database in the Statistical Program for Social Sciences (SPSS), version 10.0 for Windows to for statistical analysis: (a) descriptive analysis to characterize the groups' profiles; (b) Students' t test and Pearson's Chi-square to test the matching of the groups; (c) Students' t test to compare total QoL scores; (d) Mann-Whitney to identify differences in the perception of QoL between the group of elderly individuals with AD and the group of elderly individuals without AD.

RESULTS

Socio-demographic profile of the sample of elderly individuals with AD (G_{AD})

Of the 53 G_{AD} participants, 68% were women (n=36) and 32% were men (n=17). The group's average age was 77.36 years old (*sd*=7.36, $x_{mín}$=60, x_{max}=96); the women were 78.86 years old, on average (*sd*=7.65, $x_{mín}$=60, x_{max}=96) and men were 74.18 years old (sd=5.67, $x_{mín}$=64, x_{max}=83).

In terms of schooling, 30 (57%) were illiterate or had not completed primary school; 12 (23%) had completed primary school or had incomplete secondary school; two (4%) had concluded secondary school or incomplete high school, three (6%) had completed high school or incomplete college; and six (11%) had a bachelor's degree. It is noteworthy that men had higher levels of education compared to women and all those with a bachelor's degree were men.

Data concerning socio-economic status, obtained through the *Critério Brazil*[18] questionnaire, revealed that 8% (n=4) of the participants belonged to class A2; 15% (n=8) to B1; 15% (n=8) to B2; 38% (n=20) to C; 23% (n=12) to D; and 2% (n=1) to Class E.

In relation to family composition, 2% (n=1) of the sample was composed of singles without children; there was one men and one women separated with children (n=2), 34% (n=18) were widowed with children and the majority of them, 60% (n=32), were married with children. In regard to the variables of gender and marital status, 16 men and 16

women had a partner and only women were either single or widowed.

In relation to the participants' occupations, most of them, 62% (n=33) had once had a paid job but were no longer working; 8% (n=4) never had a paid job and 30% (n=16) still helped in some household chores.

In relation to participation in activities they considered to optimize their QoL, 38 individuals (72%) reported they had no access to such activities, seven (13%) performed some directed exercise with the help of a physiotherapist or occupational therapist, four (8%) participated in memory workshops, two (4%) participated in university programs for senior citizens, and only one (2%) attended psychological treatment and another (n=1) attended a religious group.

Socio-demographic profile of the sample of elderly individuals without AD (G_{WAD})

Because the G_{WAD} was the control group, its gender composition was identical to the G_{AD} (68% of the participants were women and 32% were men). The group's average age was 76.08 years old (sd=6.91, $x_{mín}$=55, $x_{máx}$=93): women were 77.47 (*sd*=7.35, $x_{mín}$=55, $x_{máx}$=93) and men were 73.12 years old (sd=4.83, $x_{mín}$=61, $x_{máx}$=81).

A predominant tendency concerning illiteracy was presented by G_{WAD} individuals. 68% (n=36) of the group's participants were illiterate or had not completed primary school; 15% (n=8) had completed primary school or not completed secondary school; 6% (n=3) had completed secondary school or not completed high school; 2% (n=1) completed high school but not college; and 9% (n=5) had a bachelor's degree.

Economic status obtained according to the Critério Brazil questionnaire[18] revealed that 2% (n=1) of the participants belonged to Class A1; 15% (n=8) to B1; 15% (n=8) to B2; 38% (n=20) to C; 23% (n=12) to D; and 2% (n=1) to Class E.

The most common family composition among G_{WAD} individuals was *married with children* (49%, n=26), followed by 'widowed with children' (40%, n=21). All singles (8%, n=4) and separated with children (4%, n=2) were women.

Some variables that differentiate this group were:

- Work: 21% of the individuals had a paid job (n=11);
- Activities: 53% (n=28) participated in a religious group; 13% (n=7) had hobbies such as reading, traveling, crochet and crafts; and 49% (n=26) practiced some physical activity at least once a week; 40% (n=21) walked.

Testing whether the matching of G_{DA} and G_{WAD} is balanced according to socio-demographic variables

The groups G_{DA} and G_{WAD} did not differ statistically in terms of age t (104)=0.925, $p > 0.500$, gender, $\chi^2(1) = 0.0$, $p \geq 1.000$, or educational level, $\chi^2(4) = 2.636$, $p > 0.500$. The variable *socio-economic status* was significantly different between the groups $\chi^2(6) = 13.901$, $p < 0.500$, which reinforced our initial hypothesis since the control group (not experiencing AD) presented higher general scores of QoL and lower average monthly income.

Comparative evaluation between each dimension and the G_{DA} and G_{WAD} total score of QoL

The results of the evaluation of each dimension of QoL obtained through the PQoL-AD are presented in frequency and percentage for each group in Table 1.

The significance of the comparative statistical analyzes of the perception of each dimension of QoL obtained in the PQoL-AD of G_{AD} and G_{WAD} are presented in Table 2.

Table 1 - Distribution of frequencies of the perceptions of the groups G_{AD} and G_{WAD} concerning QoL (in numbers and percentage) - São Carlos, SP, Brazil - 2006/2007

QoL Dimensions	PERCEPTION / GRADE							
	POOR / 1		REGULAR / 2		GOOD / 3		EXCELLENT / 4	
VERSION	G_{AD}	G_{WAD}	G_{AD}	G_{WAD}	G_{AD}	G_{WAD}	G_{AD}	G_{WAD}
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
1. Physical Health	11 (21%)	4 (8%)	26 (49%)	19 (36%)	14 (26%)	18 (34%)	2 (4%)	12 (23%)
2. Energy	21 (40%)	2 (4%)	17 (32%)	7 (13%)	14 (26%)	29 (55%)	1 (2%)	15 (28%)
3. Mood	13 (25%)	0 (0%)	16 (30%)	4 (8%)	23 (43%)	31 (58%)	1 (2%)	18 (34%)
4. Living Situation	0 (0%)	1 (2%)	11 (21%)	3 (6%)	41 (77%)	41 (77%)	1 (2%)	8 (15%)
5. Memory	27 (51%)	1 (2%)	18 (34%)	7 (13%)	8 (15%)	12 (23%)	0 (0%)	33 (62%)
6. Family	1 (2%)	0 (0%)	4 (8%)	1 (2%)	42 (79%)	24 (45%)	6 (11%)	28 (53%)
7. Marriage	0 (0%)	0 (0%)	5 (9%)	0 (0%)	35 (66%)	21 (40%)	13 (25%)	32 (60%)
8. Friends	11 (21%)	0 (0%)	11 (21%)	0 (0%)	28 (53%)	28 (53%)	3 (6%)	25 (47%)
9. Self as a whole	7 (13%)	0 (0%)	19 (36%)	6 (11%)	26 (49%)	31 (58%)	1 (2%)	16 (30%)
10. Chores	23 (43%)	3 (6%)	12 (23%)	2 (4%)	17 (32%)	35 (66%)	1 (2%)	13 (25%)
11. Fun	27 (51%)	3 (6%)	11 (21%)	4 (8%)	15 (28%)	34 (64%)	0 (0%)	12 (23%)
12. Money	19 (36%)	7 (13%)	30 (57%)	38 (72%)	4 (8%)	6 (11%)	0 (0%)	2 (4%)
13. Life as a whole	9 (17%)	0 (0%)	27 (51%)	13 (25%)	17 (32%)	35 (66%)	0 (0%)	5 (9%)

Table 2 - Results of the comparative statistical analysis of the perception of each dimension of QoL obtained in the PQoL-AD of G_{AD} and G_{WAD} through the Mann-Whitney test - São Carlos, SP, Brazil - 2006/2007

DIMENSIONS OF QoL	Z	p
1. Physical health	-3.277	0.001***
2. Energy	-6.070	0.000***
3. Mood	-6.019	0.000***
4. Living situation	-2.797	0.005**
5. Memory	-7.843	0.000***
6. Family	-4.618	0.000***
7. Marriage (relationship)	-3.988	0.000***
8. Friends	-6.172	0.000***
9. Self as a whole	-5.166	0.000***
10. Ability to do chores around the house	-6.075	0.000***
11. Ability to do things for fun	-6.413	0.000***
12. Money	-2.725	0.006*
13. Life as a whole	-4.935	0.000***

* p<0,01; ** p≤0,005; *** p≤0,001.

We observed that all the dimensions of QoL of the G_{AD} were significantly lower than those of the $G_{WAD.}$ Regarding the total scores of QoL, the average was 40.18 points for the elderly individuals without AD and 29.32 points for those with AD t (104) = 9.449, p<0.001. Figure 1 shows the distribution of the number of G_{AD} and G_{WAD} individuals according to total scores obtained in the PQoL-AD; it is worth noting that G_{AD} display to lower scores (to the left).

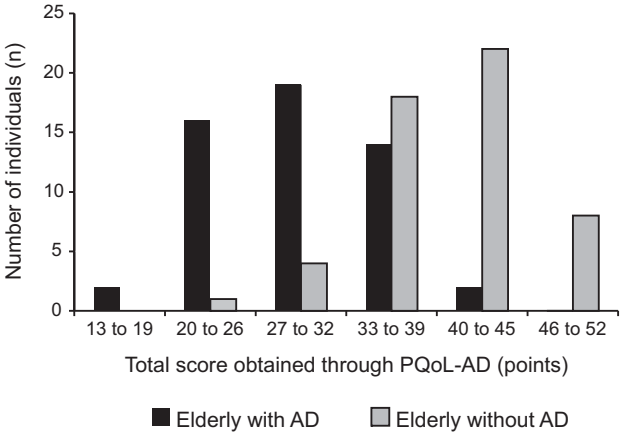

Figure 1 - Distribution of the number of individuals in the groups of elderly individuals with and without AD according to the final scores obtained through the PQoL-AD - São Carlos, SP, Brazil - 2006/2007

When positive perceptions (good and excellent) were isolated from the negative perceptions (poor and regular), the G_{AD} individuals revealed more satisfaction in family social relationships. *Marriage or closed relationship* and *family* were the highest-evaluated QoL dimensions: 91% (n=48) of the elderly individuals with AD considered them *good* or *excellent*. According to the ranking, the third highest-evaluated item was *living situation*, a variable related to the family environment and which was positively perceived by 79% (n=42) of the individuals.

However, the perceptions indicating the greatest dissatisfaction among G_{AD} individuals were financial situation (*money*) in which 49 participants (92%) judged theirs as poor or regular, regardless of their income, followed by *memory* (85%, n=45), *energy* (72%, n=38) and availability of *leisure* activities (72%, n=38) (Figure 2).

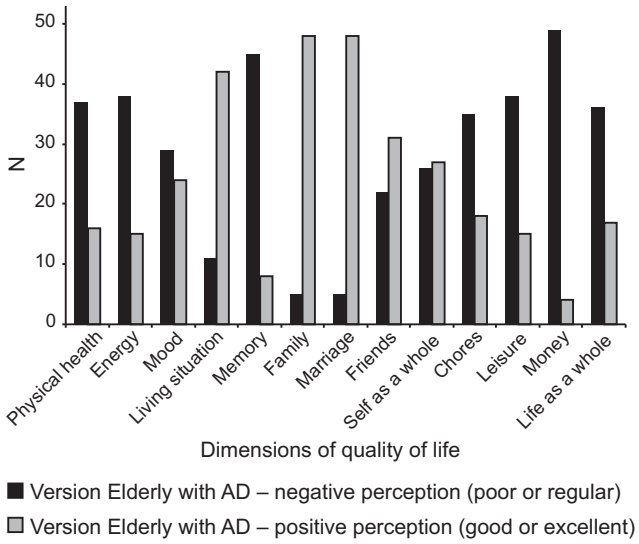

Figure 2 - Distribution of positive and negative perceptions of each dimension of QoL according to the perception of elderly individuals with AD - São Carlos, SP, Brazil - 2006/2007

Coincidentally, even though in different proportions, the three QoL dimensions most highly ranked by the elderly without AD were *marriage or closed relationship*, *friends* and *family*, the most significant dissatisfaction also referred to the financial situation (Figure 3).

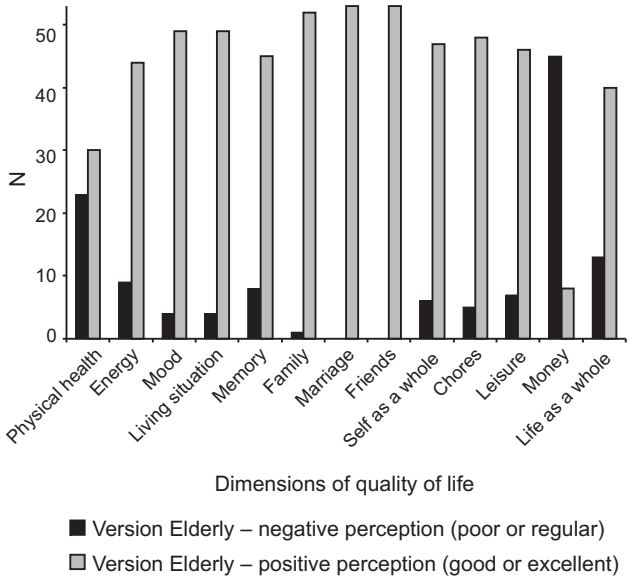

Figure 3 - Distribution of the positive and negative perceptions of each dimension of QoL according to the perception of elderly individuals without AD - São Carlos, SP, Brazil – 2006/2007

DISCUSSION

Since chronic-degenerative diseases and mental disorders are influenced by population aging, which increases conditions favorable to dementia, already frequent among elderly people, more common in the population[19], discussions about QoL are essential to appropriate care to patients and even reduce public expenditure on care. Evaluation of QoL has been the focus of many studies in the health field, which shows the importance this variable has acquired as a measure with which to evaluate to what extent a treatment is successful in terms of well-being and satisfaction with life.

This study corroborates many studies that point to the predominance of the female sex in the population with AD[20]. Similar to studies that characterize elderly individuals without AD, the socio-demographic profile of people with Alzheimer was predominantly female, married with children, illiterate or with incomplete primary school, originated from Classes "C" or "D" [21]. When compared to the group without AD, individuals with the disease were significantly less active, performing no physical exercise whatsoever, demanding non-pharmacological strategies to cope with the disease and access to alternative services such as occupational therapy, physiotherapy and psychological treatments.

Acknowledging that this study was an one-time experience carried out in a city in the interior of São Paulo, where there is no specialized center for treating AD, we believe that similar studies conducted in other settings and also studies correlating patients' QoL according to their level of cognitive impairment with associated psychological problems, and to caregivers' and environmental characteristics, would be interesting. The results of these correlations would enable one to better address and plan non-pharmacological strategies to meet the real needs of elderly individuals with AD.

This study's methodological design does not allow us to attribute causality, however, or even allow stating that AD is accountable for the lower QoL scores obtained or that the more active lifestyle of the group without AD increased their QoL. These findings show that people with AD live in adverse conditions with hindered access to empowering resources, while their quantified levels of QoL are below the average of elderly individuals without AD.

Since the family environment and interpersonal relationships were valued by the participants of this study regardless of the group to which they belonged, encouraging and fostering partnerships between families and professionals is important for elderly individuals' well-being. Through a joint effort, we can devise preventive measures and interventions that ensure aging is seen as an achievement through the re-signification of negative values associated with dementia and old age.

Although various authors stress QoL is a subjective construct influenced by multiple factors that are not limited by time, socio-economic or cultural conditions[9-11], the results revealed that the mental health issue is a factor limiting individuals' well-being. Therefore we agree with the argument of some authors who state there is a *universal culture* in which some elements are common to any human being to psychologically feel well (or bad), be in a good (or bad) physical condition, and feel (or not feel) socially integrated and functionally competent[22].

CONCLUSION

This study's findings show that elderly individuals with AD report lower QoL measurements, suggesting that AD negatively influences their perception. Hence, public policies should enable the availability of strategies related to education, physical exercise, cognitive rehabilitation, social and artistic activities from the perspective of care related to the dimensions of QoL negatively perceived by this population. Managers and health professionals should be attentive to consider the concept of health from the perspective of well-being, acknowledging that people with AD need other types of support besides simple access to hospitalization, consultation and medication.

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