IMPACT BY CARE GUIDELINES AND PERCEPTION OF THE QUALITY OF LIFE IN CAREGIVERS OF THE ELDERLY

ABSTRACT

Objective: to analyze burden and the quality of life of caregivers for the elderly with dementia, guided by health professionals. Method: exploratory and inferential study with a quantitative approach, conducted with 37 caregivers, from August to November 2011, using the WHOQOL-Bref and Caregiver Burden Scale, after approval by the Research Ethics Committee, CAAE 0065.0.135.000-11. Results: most (21/56.75%) of the caregivers received some guidance on care; of these 17 (46.00%) had no or minimal burden. The perception of quality of life showed overall average score of 73.50 (sd = 4.25), and the Physical and Psychological Domains had higher scores (73.97; sd = 4.25 and 70.00; sd = 4.30) and Social (57.43; sd = 20.75), the lowest score. There was a significant correlation between the guidance received and the Psychological and Social Dimensions. Conclusion: it was found that the guidance received by caregivers influenced their positive perception of quality of life.

Descritores: Stress; Caregivers; Frail Elderly; Dementia; Quality of Life.

RESUMO

Objetivo: analisar sobrecarga e qualidade de vida de cuidadores de idosos com síndromes demenciais, orientados por profissionais da saúde. Método: estudo exploratório e inferencial, com abordagem quantitativa, realizado com 37 cuidadores, de agosto a novembro de 2011, utilizando a escala Whoqol-Bref e a Caregiver Burden Scale, após aprovação do Comitê de Ética e Pesquisa, CAAE 0065.0.135.000-11. Resultados: a maioria (21/56,75%) dos cuidadores recebeu alguma orientação sobre o cuidado; destes 17 (46,00%) apresentaram ausência ou sobrecarga mínima. A percepção da Qualidade de Vida geral apresentou escore médio de 73,50 (dp=4,25), sendo que os Domínios Físico e Psicológico apresentaram maiores escores (73,97; dp=4,25 e 70,00; dp=4,30) e o Social (57,43; dp=20,75), o escore mais baixo. Houve correlação significativa entre orientações recebidas e as dimensões Psicológica e Social. Conclusão: constatou-se que a orientação recebida pelos cuidadores influenciou a percepção positiva da qualidade de vida neste. Descritores: Estresse; Cuidadores; Idoso fragilizado; Demência; Qualidade de Vida.
INTRODUCTION

Dementia is a syndrome characterized by a progressive decline in cognitive and global function in the absence of an acute impairment of consciousness, and that is significant enough to interfere with the social activities and daily life of the individual.1

Estimates show that the number of cases of dementia in Latin America should increase at 393% until the year 2040. In Brazil, the problem affects about one million people.2 Among the various etiologies involved in the development of dementia syndromes, is Alzheimer’s disease (AD) which corresponds to approximately 60% of the cases, being the most prevalent in the third age, and the vascular dementias that are the second most common cause of dementia.

Given the care needs of the dementia syndrome patient, arises the caregiver’s role.3 The task is assigned to take care of a person who may or not be a member of the family, receives payment, whether professional or not, and that takes care of the dependent elderly in their daily activities such as personal hygiene, feeding, medication routine among others.4

The care provided to the elderly by the caregiver at home (primary caregiver) is a trend supported by public policies to assist the elderly population and contributes to the reduction of costs of hospital care.5 However, assuming the responsibility of assisting the elderly dependent is a stressful and exhaustive task, especially for the family caregiver due to affective involvement and the change of a relationship of reciprocity to dependence on the performance of daily activities.6

The care of a dementia patient generates physical and psychic burdens that negatively impact the quality of life of caregivers leading to physical, emotional and social problems.7 The emotional burden of caregiver is generated by countless situations and can be identified in two types: the objective and the subjective. The objective is to be the disruption arising from changes in finance, in the exercise of roles in overseeing the patient and in personal relationships. Since the subjective relates to feelings such as overhead, loss of control and helplessness.8

The literature shows the questioning of the extent to which the dependence of the patient with dementia syndrome have an impact on the Quality of Life (QOL) of people involved in the care process and the possible factors and aggravating the situation.9

According to the Quality of Life group of the World Health Organization (WHO), the term Quality of Life (QOL) is defined as “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, standards and concerns”.10 This concept is linked to several factors, such as the state of health, leisure, spirituality, social and family relationships, the longevity, the economic situation and the professional achievement.

It is a complex and multidimensional phenomenon, the QOL construct is composed of objective and subjective aspects that can be positive or not within the context analyzed. The QOL reflects, therefore, the perceptions that people have about the opportunities to meet their needs, whether or not they are satisfied and fulfilled at that time of life, regardless of their social or economic status.11

The physical and psychological health of caregivers can be strongly influenced by the behavior and demand of care. Thus, the difficult process of caring for elderly people with dementia syndromes, coupled with the increased responsibilities that this function promotes, can lead to fatigue, overload and stress of these caregivers and may negatively impact on their QOL perception.12

Studies conducted in the past few decades indicate that the isolation felt by primary caregivers, can be minimized by means of the social network (friends, family); in the exchange of experiences between caregivers through support groups and the provision of formal guidance, emotional and psychological support performed by health professionals.13

In Brazil, the assistance and education to elderly caregivers, may be effected:

- by the public health system, primarily the Basic Health Units (BHU) and teams of the Family Health Strategy (FHS) seeking allow universal and continuous access to the system, reaffirming the guiding principles of the Brazilian Health System;

- by formal non-profit organizations, such as the ABRAZ (Brazilian Association of Alzheimer’s disease);

- by religious organizations.

- by care units linked to higher education institutions (HEIs), outpatient clinics, hospitals and clinics.

The FHS is characterized by a reorientation of the health care model that aims to meet the individual and the family full and
continuously promoting prevention, protection and recovery of health through the registration and linking of users of health system.\textsuperscript{15}

According to the Brazilian Health Ministry, each team of FHS should offer assistance to a maximum 4,000 inhabitants and have weekly working hours to 30 hours, and are the responsibility of the public authorities municipal ensure the deployment of the teams and the fulfillment of its guidelines. \textsuperscript{15} Teams of FHS are able to resolve 85\% of all health problems in their community preventing diseases, avoiding unnecessary hospital admissions and promoting the quality of life of the population. The FHS also plays an important role in identifying the needs of home caregiver and can provide basic guidelines to assist them. \textsuperscript{15,16}

Within the framework of the civil society, health professionals and family members of persons with (Alzheimer’s Disease) founded the ABRAZ (Brazilian Association of Alzheimer’s disease) in 1991, in the state of Sao Paulo, Brazil. The ABRAZ offers information and guidance to family members and caregivers through meetings of support groups clarifying on the progression and treatment of the disease, the everyday aspects of care and how to deal with the burden, in addition to promoting individual guidance to caregivers and their families. Currently the ABRAZ counts with 21 Regional and 51 sub-regional in the Brazilian states, in addition to maintaining an open channel with the interested public through telephone and over the internet. \textsuperscript{17}

In turn, the HEIs that make up health professionals and that keeps care to this population, also have a relevant role in coaching of caregivers with strategies to cope with the stress and consequent improvement in their perception of the quality of life. Their performance occurs in clinics and hospitals school which in addition to the patients and their families, provide awareness of the professionals involved and the training of the students regarding the syndrome and its impact on quality of life.

To understand the perception of the quality of life of caregivers and the factors that are directly involved in their daily lives is essential to plan comprehensive actions in health that addressing solutions to minimize the harmful effects of the burden of care experienced by them. \textsuperscript{9}

The relevance of the theme is justified due to the significant increase in the number of elderly patients with chronic-degenerative diseases, among which stand out the dementia syndromes, the most prevalent was the Alzheimer’s disease and the increase in the number of caregivers also elderly. \textsuperscript{14}

This study aims at analyzing burden and quality of life of caregivers of elderly with dementia syndromes, guided by health professionals.

\section*{METHOD}

Exploratory, cross-sectional study with inferential quantitative approach conducted with 37 caregivers of patients with AD, registered in the School Health Unit (USE) of the Federal University of Sao Carlos (UFSCar), the FHS Jardim Sao Carlos and the Alzheimer’s Association (Abraz) Sao Carlos section, in the city of Sao Carlos, Sao Paulo.

After the authorization of the coordinators of the units, the project was submitted for evaluation by the Committee for Ethics in Research with Human Beings of the Federal University of Sao Carlos and approved by the Opinion no. 318/2011 case no 23112.001161/2011-00, CAAE 0065.0.135.000-11.

In this phase was carried out survey in the registries of the units to identify elderly with dementia and their caregivers. Thirty seven caregivers of registered patients with AD were identified. After the pre-selection was held contact with them by phone (for those caregivers who did not attend for more than six months in the unit where they were registered) or in person during care units and carried out the invitation to participate.

The participants, being informed about their goals and strategies for data collection, signed an Informed Consent Form (ICF) authorizing the collection that was carried out at home with the permission of the resident, in the period between August and November 2011 and with the following inclusion criteria: caregivers over the age of 18 and literate; family caregivers of elderly patients with dementia syndrome and who agreed to participate in the study. It is noteworthy that the ethical principles in researches were respected.

To identify the caregiver burden was utilized the Caregiver Burden Scale (CBS), Likert type instrument, adapted and validated in Portuguese. \textsuperscript{18}

The scale consists of 22 items, divided into five dimensions, namely: General Tension, Isolation, Disappointment, Emotional Involvement and Environment. It can be self-administered and obtaining an overall score and for each dimension. The questions are graded from 0 (zero) to 4 (four), in which the respondent must mark the response that...

The analysis of the score is performed from the arithmetic mean of the values obtained (overall score of the instrument varies from 0 to 88) in each of the dimensions. The score of each dimension is obtained by arithmetic mean of the values corresponding to the questions of each dimension, being that the higher the score, the higher the degree of difficulty faced by caregivers in the corresponding item.

The Quality of Life (QOL) perception was assessed by the WHOQOL-BREF prepared by the Research Group on Quality of Life the World Health Organization (WHO), validated in Portuguese by Dr. Marcelo Pio de Almeida Fleck, in 1998, with support from the WHO. 10

It is a Likert type instrument, with an ordinal response of 05 positions, indicating the frequency with which the respondent felt, or feel about their QOL over the past two weeks: (1) nothing; (2) very little; (3) average; (4) alot; (5) completely. It is composed of 26 questions, two questions are general and others are relevant to the subjective evaluation of the individual in relation to the aspects that interfere in their lives.

Because it is a multidimensional concept, this measurement instrument covers four areas, namely: physical, psychological, social relationships and environment. The scores must be carried out using the SPSS statistical program in accordance with the syntax itself. 10

In order to check the degree of dependence of the elderly was used the Index of Katz modified by The Hartford Institute for Geriatric Nursing (1998). 18

This instrument aims to measure the degree of independence of the elderly in performing basic activities of daily living hierarchically related, namely: eating, bathing, dressing, grooming, mobilize themselves and maintain control over their eliminations. For each activity the dependence of the elderly in achieving is evaluated and assigned an (01) independence point is present, give a minimum score of zero (very dependent) and maximum six (06) points (independent).

The study had as dependent variables: the perception of QOL and burden level and as independent variables: gender, marital status, level of education, degree of kinship, if received orientation to the care (nominal); age, time in which exercise the care and elderly dependence (ordinal).

To assess the reliability of the instruments (WHOQOL-BREF-bref and CBS) submitted to analysis Cronbach's Alpha. The correlation analysis between variables were performed with Confi dence Intervals (CI) of 95%. In all inferential analysis, the P-Value was calculated associated with the null hypothesis (Ho) adopted in each test. In this study, the entire difference whose P-Value < 0.05 was considered statistically significant.

The data received statistical, descriptive and inferential treatment with the descriptive analysis. The inferential analysis was performed by Pearson’s Correlation Coefficient (r) , to check associations between the means of the scores and quantitative variables numeric; the Coefficient of ordinal correlation Spearman’s correlation test was used to assess the existence of dependence between the ordinal variables of the study and the Mann Whitney U-Test to assess the significance of the differences between the dichotomized variables.

RESULTS

The biosocial data of the study population (N = 37) demonstrated that the majority of caregivers were female (28 -75,67%), married (21 -56.75%), daughters (27 -73,00%), in the age group between 40-59 years (16 -43,00%), retired (15 -40,54%), had concluded highschool (18 -49,00%), were main caregiver between 3 to 8 years (20 -54,00%) and received some kind of orientation for caring (21 -56.75%).

The instruments used were good reliability, being that for the WHOQOL-BREF, the alpha general was α=0.77. The values of alpha for the other domains, namely, Physical, Psychological, Social, and Environment were α = 0.686; α=0.733, α=0.639 and α=0.583, respectively.

In assessing the overall perception of quality of life, the average was 73.50, and the physical and psychological domains had the highest scores and the social field, the lowest value with 57.43 (Table 1).
In this study, health professionals who offered guidance to caregivers performed their activities in Abraz Section São Carlos, in the School Health Unit (USE) of the Federal University of São Carlos and the Jardim São Carlos Family Health Strategy team. The Abraz has a medical professional specializing in psychiatry and geriatrics, one physiotherapist and an occupational therapist; the USE has a program for the Elderly act in which psychologists, physicians, occupational therapists and faculty members of the Gerontology course with training in nursing and social care.

Whereas the formal guidelines for the care provided by health professionals, it was found that eight (08) caregivers participated in the meetings of ABRAZ; the areas where obtained higher scores were Physical (Average = 66,07) and Environment (Average= 63.28).

Eight (08) caregivers were enrolled in the USE and regularly attended the support group; the areas of most scored were Physical (Average = 67.41) and Psychological (Average = 66.66). The other caregivers (05 - five) received specific guidelines in teams of ESF, in Basic Health Units and Center of Medical Specialties and also obtained higher scores in the Physical and Psychological areas (Table 2).

There was no statistical correlation with the average overall score or in areas with the place or professional, which offered guidance.

The CBS presented alpha of 0.820 and the degree of general overhead for the majority (17 - 46.00%) of the caregivers was “no” or “minimal burden”, with a mean score of 23.70 (sd = 12.75); 14 (38.00%) caregivers presented a burden of “mild” to “moderate”. The analysis of the dimensions of the CBS, it was found that the dimension General Tension presented the highest score (11.51; sd =7.05) and the Emotional involvement, the lowest with 1.81 (sd = 2.27) (Table 3).

The five caregivers coaching by nurses had higher overall CBS scores (32.00, sd = 10.34). The degree of dependence, measured by Katz, it was observed that 16 (46.00%) of the elderly were independent, and 12 (33.00%) very dependent in relation to the caregiver.

There was a moderate, negative and statistically significant correlation between WHOQOL-BREF and CBS scores indicating that when CBS increase decrease the scores of WHOQOL-BREF (r = -0432, p = 0.008), and statistically significant correlation between the Psychological dimension with age up to 30 years (r= 12.92; p= 0.001) and guidance for health professionals (r= 6.82; p= 0.03); the dimension Environment with age up to 30 years (r= 9.56; p= 0.041) and the Social

| Table 1. Distribution of scores for the domains of WHOQOL-BREF, São Carlos, 2011. |
|---------------------------------|----------------|------------------|------------------|
| Dimensions of the WHOQOL-BREF   | Average (sd)   |                  |
| General QOL                     | 75.30 (1.69)   |                  |
| Physical                        | 67.47 (14.98)  |                  |
| Psychological                   | 62.04 (18.02)  |                  |
| Social                          | 57.43 (20.75)  |                  |
| Environmental                   | 60.98 (12.68)  |                  |

| Table 2. Areas of WhoQol-Bref with highest score among caregivers who received guidance for the care and professionals that performed them. São Carlos, 2011. |
|---------------------------------|---------------|----------------|-----------------|
| Category                        | Professional  | N   | Woqol domain | Average (sd) | Minimum | Maximum |                  |
| Nurse                           | 5             | Physical | 65.00 (13.45) | 42.86        | 78.57   |
| Nurse and Psychologist          | 4             | Psychological | 75.00 (10.75) | 62.50        | 87.50   |
| Psychologist                    | 3             | Physical | 65.47 (5.45)  | 60.71        | 71.43   |
| Physiotherapist                 | 2             | Psychological | 62.50 (11.78) | 54.17        | 70.83   |
| Doctor                          | 7             | Physical | 61.79 (31.66) | 4.00         | 92.86   |

| Table 3. Distribution of scores for the CBS dimensions. São Carlos, 2011. |
|-----------------|----------------|---------------|
| CBS Dimensions  | Average (sd)   |               |
| General Tension | 11.51 (7.05)   |               |
| Isolation       | 2.72 (2.86)    |               |
| Deception       | 5.45 (3.73)    |               |
| Emotional       | 1.81 (2.27)    |               |
| Environment     | 2.51 (1.99)    |               |
In this study the caregivers is in line with others researches: the majority are female, married, and daughters with 40 to 50 years of age.4,6,9,13,19,20,22

Today's society the majority of women carries cumulative tasks, ranging from care with the family and with the home, education of children, professional activity, and are more susceptible to stress than men.4,24

In the evaluation of the general perception of the quality of life the average was 73.50 (sd= 1.69), and the physical and psychological domains showed higher scores, with 73.97 (sd= 4.25) and 70.00 (sd= 4.30) respectively, and the social domain, the lowest value with 57.43 (sd= 20.75) (Table 1).

A study to assess the QOL of caregivers of dependent people attended by teams of FHS and their relationship with social support, found overall score of 54.6 (sd = 21.4), with the best scores in the physical (66.7 - sd = 17.8) and Social (60.9 - sd = 13.6). The same study indicated that caregivers who reported receiving informal support showed better scores in the Social dimension, with statistical significance and worse scores in the physical domain.19

Studies show that the caregiver who has a partner or spouse has higher scores in the assessment of perceived quality of life. This suggests that a stable relationship is a factor contributing to strengthening the support social.4,22 In this study, although the most of the population is married, the social domain was the one that had the lowest mean (57.43, sd = 20.75).

Others factors that affect the positive perception of the quality of life of caregivers are the presence of social network, good physical and mental health and spiritual well-being.25-6 Studies indicated that biosocial factors such as advanced age, female gender, low education level and not having companion are related to low levels of QOL.27-29 In this study, the majority caregivers were female, between 40 and 50 years, with high school and married, corroborates the good perception of QOL. It may be inferred, therefore, that the age, the higher level of schooling and the stable affective relationship have influenced the positive perception of QOL. In addition to these aspects, it should be considered the result of the analysis of the Katz indicating that 43% of the elderly are independent, a condition that may have contributed to a better perception on the quality of life of caregivers.

Caregivers attended at ABRAZ had higher scores on the Physical (66.07) and Environment (63.28) domains. This finding may be related to the types of activities carried out by this organization, the intense participation of family members and caregivers in support groups exposing their difficulties in daily care, finding creative solutions to reduce physical burden and socializing.

Physical and Psychological domains received the highest scores among caregivers who received professional guidelines. The guidance received by health professionals showed positive correlation with the Psychological and Social dimensions, i.e. those caregivers who received guidelines for care obtained better perception of QOL in these dimensions. From this finding, it can be inferred that the guidelines received influenced the perception of quality of life in these dimensions for the caregivers, empowering them to take care of themselves. Some studies have analyzed the impact on QOL of caregivers undergoing therapy and support with health professionals identifying better perception of quality of life in those caregivers were instructed to modify the care with the elderly with sections of occupational therapy at home.30

It is essential that caregivers of elderly people receive in their homes visits of health professionals to assist to the elderly and their family, guiding the caregiver for caring.5 There was no statistical correlation with the average overall score or in areas with local or professional who offered guidance. However, it appears that the highest score in the Psychological domain (75.00; SD= 10.75) refers to the caregivers who received guidance from both professionals, nurse and psychologist, emphasizing the importance of multidisciplinary care.

Women up to 30 years of age showed a positive correlation with the Psychological dimension (r= 12.92; p = 0.001) and Environment (r= 9.56; p= 0.041), indicating that younger caregivers perceive these dimensions as positive for the assessment of QOL. The Social dimension has obtained the lowest score (57.43; SD= 20.75) in order to

Impacto das orientações para o cuidado e percepção...
meet other studies that indicated that the care leads to detachment of socialising. The degree of general burden, assessed by CBS, for the majority 17 (46,00%) of caregivers was “absent” or “minimal burden”, with an average score of 23.70 (sd=12.75). It has been assumed that the high percentage of elderly independent could have influenced the values of burden level (CBS), but the test of correlation resulted in nullity, although data in the literature suggest that the smaller the dependence of the elderly reduces the level of stress of this caregiver.4,5,7,21

The analysis of the CBS dimensions, it was found that the General Tension dimension presented the highest score (11.51; sd=7.05) and the Emotional involvement, the lowest with 1.81 (sd=2.27) (Table 3). This result can be explained by the affiliation between the caregiver and elderly, which reinforces the culture of the family taking care of parents in old age and the changing role affecting the emotional level. Such data will meet the indicated in other studies, in which the dimension Emotional Involvement has the highest score. A study of spouse caregivers of disabled persons AD, this dimension was positively associated with the degree of relationship, being the most affected are spouses.8

The burden for this population can be explained by the roles played by the spouses, which accumulate domestic activities with care and often have worn marital relations, which does not occur with frequency in children relationships, feeling the caregiver in “obligation” to take care of their parents, and therefore better accepting this care relationship.

In the analysis of the perception of burden, the caregivers in the age group of 51 - 60 years had a higher average score with 26.43% and positive correlation with the general CBS (r=12.19; p=0.015) indicating feel overburdened with the task of caring. In this age group, the caregiver is entered in the third age and experiencing the physiological decline of the aging process with the physical, emotional, psychological and social impact in this phase of life. Associated with these issues, it is assumed that the elderly care, which in this study are the parents, are at a more advanced age, requiring a greater demand for care. Thus, the perception of burden will be greater.

There was no statistical correlation between educational level and CBS scores. In a study performed with the primary caregivers of patients with rheumatoid arthritis using the same instrument found that lower level of formal education was associated with higher scores in the CBS.18 In other study with caregivers of elderly patients found the highest degree of formal education was associated with the greatest negative impact in the CBS.8

Impacto das orientações para o cuidado e percepção de...
realization of a broader interventionist action aimed at preventing disease and promoting health and well-being of the caregiver.

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Impacto das orientações para o cuidado e percepção...