



Revista Brasileira de Fisioterapia

ISSN: 1413-3555

rbfisio@ufscar.br

Associação Brasileira de Pesquisa e Pós-
Graduação em Fisioterapia
Brasil

Reis, Luciana A.; Santos, Kleyton T.; Reis, Luana A.; Gomes, Nardilene P.
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Revista Brasileira de Fisioterapia, vol. 17, núm. 2, marzo-abril, 2013, pp. 146-151
Associação Brasileira de Pesquisa e Pós-Graduação em Fisioterapia
São Carlos, Brasil

Available in: <http://www.redalyc.org/articulo.oa?id=235026389012>

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Quality of life and associated factors for caregivers of functionally impaired elderly people

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ABSTRACT | Background: Lifestyle changes, factors inherent to the caregiver's family and social environment, and physical and mental aspects determine a caregiver's quality of life (QOL). **Objective:** To evaluate the QOL and associated factors for caregivers of functionally impaired elderly people. **Method:** This was a cross-sectional study that analyzed data from a home-based care survey. The study sites were the homes of elderly people enrolled in Family Health Centers (Unidades de Saúde da Família) in Jequié, Bahia, Brazil. The sample consisted of 40 caregivers of functionally impaired elderly people. The instrument consisted of demographic data, health status, the Perceived Family Support Inventory, the Social Support Satisfaction Scale, and the World Health Organization Quality of Life Assessment (WHOQOL-BREF). The data were analyzed using a descriptive analysis and the chi-squared test at a 5% significance level, performed in SPSS version 15.0. **Results:** An association was found between the WHOQOL-BREF physical domain and the presence of sequelae ($p=0.006$), affective-cognitive inconsistency ($p=0.009$), and being the primary caregiver ($p=0.002$). The psychological domain showed an association with the presence of sequelae ($p=0.006$), the environment domain with the presence of diseases ($p<0.001$) and being the primary caregiver ($p=0.033$), and the social relations domain with the presence of diseases ($p<0.001$). **Conclusion:** The presence of sequelae or diseases, affective-cognitive inconsistency, and being the primary caregiver were related to decreases in their QOL.

Keywords: aging; quality of life; activities of daily living; physical therapy; rehabilitation; movement.

HOW TO CITE THIS ARTICLE

ReisLA, SantosKT, ReisLA, GomesNP. Quality of life and associated factors of caregivers for the elderly with impaired functional capacity. *Braz J Phys Ther.* 2013 Mar-Apr; 17(2):146-151. <http://dx.doi.org/10.1590/S1413-35552012005000078>

● Introduction

The Brazilian population is aging, and even though conditions and public health policies are far from being the most adequate and affordable, aging is no longer a privilege of the few¹. The aging process, when accompanied by health problems, often functionally impairs the elderly, making them increasingly dependent on others to perform activities such as dressing, feeding, and bathing themselves, as well as administering medications and other tasks, and these obligations are borne by third parties².

The caregiver's role is to be responsible for the care of and full attention to the elderly. However, tasks are assigned to the caregiver that, in most cases, are not accompanied by appropriate instructions. This obstacle directly affects their quality of life (QOL), including health problems ranging from mental to physical overload and body pain³. The load endured by the caregiver makes this person deserving of as much attention as the elderly who are under their care.

The disabled elderly person's caregiver is usually a family member who devotes much of his or her time and effort to their care. That lifestyle change, together with factors inherent to the family and social environment, as much the caregiver's as the elderly person's, and physical and mental aspects, combine to determine the caregiver's QOL⁴. Caregivers of elderly are often under-skilled because their training courses are still focused on concepts and theories from a biological perspective. Therefore, the implementation of measures focusing on the caregiver is critical to prepare them adequately by teaching them appropriate practices, which would benefit the lives of those who provide care and those who receive the care⁵.

Given the above and considering that the caregivers' lack of preparation is difficult to resolve in the short term, the caregivers' lifestyle, QOL status, and physical and mental aspects must be

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Received: 05/22/2012 Revised: 10/04/2012 Accepted: 11/21/2012

known^{6,7} so that we can understand the factors that affect their health status. This knowledge would enable rehabilitation science professionals to adopt preventive and curative multidisciplinary healthcare measures based on those data. The aim of this study is to evaluate the QOL and associated factors for the caregivers of functionally impaired elderly people to help plan and adopt multidisciplinary measures for improving the caregivers' QOL.

● Method

This was a cross-sectional study that analyzed data from a home-based care survey, termed "Relationship between family caregivers' training and the quality of care provided to functionally impaired elderly people" ("Relação entre capacitação dos cuidadores familiares e a qualidade da assistência prestada ao idoso com comprometimento da capacidade funcional"). The study sites were the homes of the elderly enrolled in the Family Healthcare Centers (Unidades de Saúde da Família) within the area included in the Jequiezinho neighborhood, in the municipality of Jequié, located in the southwest region of the state of Bahia, Brazil. According to the Brazilian Institute of Geography and Statistics census, in 2000, there were 147,202 inhabitants in the municipality of Jequié, with 71,899 men and 75,305 women; 14,085 of these inhabitants (9.6%) are over 60 years of age.

The sample of the present study consisted of 40 caregivers of functionally impaired elderly people. This research study was approved by the Ethics Committee for Human Research, Southwest Bahia State University (Comitê de Ética em Pesquisa com Seres Humanos, da Universidade Estadual do Sudoeste da Bahia) (Opinion No. 189/2008). All study subjects freely signed the informed consent form.

The study instrument consisted of sociodemographic data (gender, age group, education, marital status, relationship to the patient, and status as the primary or non-primary caregiver) and health conditions (presence and type of health problems and sequelae, completion, and type of treatment). Family support was examined using the Perceived Family Support Inventory (PFSI)⁸, which assesses issues such as family adaptation, autonomy, and affective-cognitive consistency of the elderly living at home. Social support⁹ was assessed using the Social Support Satisfaction Scale (SSSS). QOL was evaluated using the World Health Organization Quality of Life Assessment (WHOQOL-BREF)¹⁰.

PFSI was validated for Brazil by Baptista (2005)⁸ and consists of 42 items, divided into three dimensions. Its first dimension is termed affective-cognitive consistency, which involves questions regarding the expression of affection between members, whether verbal or not, as well as concern, sympathy, care, consistency of behavior, and problem-solving skills. The second dimension is termed family adaptation, and it scores questions regarding negative feelings towards the family unit, including anger, isolation, exclusion, and lack of understanding, indicating the absence of adaptation in the group. The last dimension is autonomy, wherein relationships of trust, freedom, and privacy among members are evaluated.

SSSS⁹ is a self-report questionnaire validated for Brazil, which enables the assessment of satisfaction with social support through its four dimensions. The first dimension, satisfaction with friends, measures the satisfaction with friendships/friends and includes five items. The second, termed closeness, measures the perceived existence of close social support and consists of four items. The third factor, termed satisfaction with family, measures the satisfaction with the social support of the existing family and is comprised of three items. The fourth factor, termed social activities, measures the satisfaction with social activities the subject participates in and is comprised of three items.

The WHOQOL-BREF¹⁰ is a self-administered questionnaire validated for Brazil, comprising 24 items divided into six domains: sensory function; autonomy; death and dying; past, present, and future activities; social anticipation; and closeness. The sensory function domain evaluates the sensory functioning (sight, hearing, touch, smell, and taste) and the impact of losing those sensory abilities on QOL. The domain autonomy domain refers to the ability of the subject to live independently and make their own decisions. The past, present, and future activities domain describes the subject's satisfaction with their achievements in life and their desires. Social participation outlines the participation in daily activities, especially in the community. The death and dying domain relates to concerns, anxieties, and fears about death. Closeness assesses the ability to build personal and close relationships.

The functional capacity of the elderly was assessed using the Barthel Index (used for assessing the basic activities of daily living)¹⁰ and the Lawton Scale (used for assessing the instrumental activities of daily living)¹⁰. The application of these scales showed that all the elderly evaluated (100%) had difficulty in

performing one of the activities of daily living, 62.5% were rated mildly dependent in the basic activities, and 52.5% were rated partly dependent in terms of the instrumental activities.

The data were analyzed using the statistical software SPSS, version 15.0. We performed descriptive analyses to characterize the sociodemographic and health data, PFSI and SSSS dimensions, and QOL domains, and we used Pearson’s chi-squared test to assess the study variables associated with the caregivers’ QOL domains. The significance level was 5% ($p<0.05$).

● **Results**

Most caregivers evaluated were women (85%). Many lived with their spouse or partner (42.5%), had between 5 and 8 years of education (30%), had a paternal kinship with the elderly patient (47.5%), was the primary caregiver (80%), and had health problems (82.5%), the most frequent of which were hypertension associated with osteoporosis (17.5%), hypertension (12.5%), arthritis associated with migraine (10%), and hypertension associated with lower back pain (7.5%) (Table 1).

The QOL of caregivers of functionally impaired elderly people was most compromised in the physical (65.08 points) and environment WHOQOL-BREF domains (60.93 points) (Table 2).

Regarding the perception of family support, caregivers showed greater impairment in affective-cognitive consistency (31.13 points). The caregivers’ greatest impairment in SSSS was in satisfaction with friends (18.83 points), closeness (12.78 points), and social assistance (8 points) factors (Table 3).

The score of the WHOQOL-BREF Physical domain was significantly associated with the presence of sequelae ($p=0.006$), affective-cognitive consistency ($p=0.009$), and being the primary caregiver ($p=0.002$), as determined by Pearson’s chi-squared test. The psychological QOL domain was significantly associated with the presence of sequelae ($p=0.006$), the environment domain with the presence of disease ($p<0.001$) and being the primary caregiver ($p=0.033$), and the social relations domain with the presence of disease ($p<0.001$).

● **Discussion**

The present study shows that caring for the elderly is almost exclusively borne by women, corroborating the results of a study conducted in the municipality of São Paulo⁴. That finding is interlaced with cultural

factors and the conventionalities of society, wherein women have caregiver role and are linked to aspects of life and care¹¹, whereas Martins et al.¹² offered the simpler explanation that the female population predominates in most countries.

A rather worrying finding from the present study was that only 15% of the population had more than nine years of education. Such a low level of education is correlated with less access to information. This condition, combined with the lack of guidelines, not only compromises the health of the elderly being cared for but also the caregiver’s own health³. In

Table 1. Profile of caregivers of older adults with impaired functional capacity. Jequié, Bahia, Brazil, 2012.

Variable	n	%
Sex	34	85.0
Female		
Male	6	15.0
Marital status		
Single	13	32.5
Living with spouse or partner	17	42.5
Separated, legally separated, or divorced	10	25.0
Education		
Illiterate	11	27.5
Can read/write informally	6	15.0
1 to 4 years	5	12.5
5 to 8 years	12	30.0
9 to 12 years	4	10.0
13 or more years	2	5.0
Degree of kinship		
Son	19	47.5
Caregiver	4	10.0
Sister	4	10.0
Spouse	7	17.5
Niece	3	7.5
Granddaughter	2	5.0
Daughter-in-law	1	2.5
Primary caregiver		
Yes	32	80.0
No	6	15.0
Presence of health problems		
No	7	17.5
Yes	33	82.5
Total	40	100.0

Table 2. Scores on the domains of whoqol-bref. jequié, Bahia, Brazil, 2012.

Domain	n	Mean	Standard deviation	95% CI
Physical	40	65.08	15.67	60.08
Psychological	40	74.37	18.38	68.49
Social Relations	40	72.70	19.97	66.32
Environment	40	60.93	13.31	56.68

Table 3. Scores on the Perceived Family Support Inventory and the Social Support Satisfaction Scale dimensions. Jequié, Bahia, Brazil, 2012.

Dimension	n	Mean	Standard deviation	95% CI
Perceived Family Support Inventory				
Affective-Cognitive Consistency	40	31.13	7.88	28.6
Family Adaptation	40	4.25	3.69	3.06
Autonomy	40	14.9	1.42	14.44
Social Support Satisfaction Scale				
Satisfaction with Friends	40	18.33	4.87	17.26
Closeness	40	12.78	4.46	11.34
Satisfaction with Family	40	14.13	1.34	13.69
Social Support	40	8.00	3.4	6.91

another study, caregivers with less than eight years of education had lower scores of general health status⁴.

This study detected a high prevalence of health problems in caregivers. In a previous analysis of 40 caregivers of elderly people, the burden placed on them directly affected their QOL and health status, as they often suffered from hypertension and cardiovascular, musculoskeletal, and mental health problems^{13,14}. This association is quite worrisome, especially considering that these are the main pathologies related to morbidity and mortality in the general population.

The health risk is even greater considering that nearly all caregivers were related to the elderly patients in the present study population, that is, they were informal caregivers. Informal caregivers are exposed to a variety of stressors, including the burden of tasks and diseases resulting from the job demands and the characteristics of the elderly¹⁵. The caregivers' psychological involvement is also higher because they are related to the patients, and the deterioration of the health condition of their elderly charges results in the decline of their own health¹⁶.

The QOL assessment showed that the physical and environment domains were the most impaired, while the psychological was the least affected. This result is similar to previous findings in that it

identifies the physical domain as one of the most affected, especially with the presence of body aches, fatigue, and musculoskeletal problems^{2,14}, but differs from others that reported large-scale psychological impairment¹⁷.

In a study conducted in Portugal, when the elderly were asked to compare their current health status to that of five years prior, nearly half of the participants reported having worsened health¹⁴. Several factors contributed to that decline, including strenuous and repetitive activities, the burden of tasks, and the need to wake up at night. However, the greatest difficulty in most cases is the stubbornness and resistance of the elderly to perform some functions¹⁵.

Another factor that seems to affect the QOL of caregivers directly is that they start living the life of their elderly charges, reducing their social support network of friends and relatives given the lack of time and opportunity for recreation, work outside the home, and changes in the family routine¹⁸. This finding is supported by the results of the present study, wherein the main impairments in SSSS were in the satisfaction with friends and closeness domains.

A network of social support will mainly affect the improvement of the caregiver's emotional aspects, which, in turn, may affect all other areas. This support ranges from the demonstration of confidence to the

guidelines received by professionals¹⁸. Caregivers who maintain or receive some social support notably have better scores in the social relations domain¹⁹. Providing support to caregivers contributes to relief work and stress situations they are experiencing²⁰. Family also has a key role in QOL preservation, although family ties are not always sustained because of changes at the time the subject becomes the caregiver²⁰.

In this study, the presence of sequelae showed statistically significant effects on both the physical and psychological domains of WHOQOL-BREF, and the presence of disease showed statistically significant effects on the environment and social relations domains. Those findings are corroborated in the literature, which shows that caregivers who work overtime and experience wear and fatigue show anxiety, depression, and somatization¹⁶. Therefore, the relationship becomes bidirectional, with sequelae and diseases impairing the QOL domains and the low QOL affecting the disease involvement and generating sequelae.

Lower scores in the physical and environment domains were also related to the caregiver's status as primary caregiver. These caregivers dedicate themselves full-time to the elderly, often with no time remaining to take care of their own health²¹. One study found that the presence of pain and physical limitations was the main caregivers' complaint¹³. The adaptations made to the living space for the comfort of the elderly dependent are not always helpful adaptations to the caregiver's demands¹⁶. Activities requiring physical space are those that bring the greatest challenges for caregivers¹⁵.

A finding deserving of close attention is the relationship between the physical domain of QOL and the affective-cognitive consistency dimension of PFSI. Caregivers are constantly facing opposing feelings, including love and anger, attachment and abandonment, and patience and impatience. This change in behavior is aggravated by physical wear, and abuse of and violence towards the elderly often arise in such situations^{5,15,21}.

Considering the results found in this and other studies, the QOL of caregivers of elderly people is often quite compromised, especially in the physical domain and in the primary caregiver. The presence of sequelae and diseases is also noticeably related to the decrease in QOL aspects.

Thus, the need for improved monitoring of caregivers of the elderly Brazilian population is clear. This monitoring should be provided by a multidisciplinary team, especially including

a physical therapist, who would strive toward prevention, education, ergonomics, rehabilitation, adequate management practices for the needy elderly, and the emotional aspects of coexistence. These interventions will greatly improve the QOL and health not only of the caregiver but also of the person being cared for. Another interesting strategy is to encourage the formation of groups of informal caregivers, led by healthcare professionals with the aim of promoting knowledge, exchanging experiences, collaborating on work activities, and discussing the best strategies for caregiving⁶.

● Acknowledgements

We thank Bahia State Research Foundation (Fundação de Amparo a Pesquisa do Estado da Bahia, FAPESB).

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