

Quality of life of caregivers of octogenarians: a study using the WHOQOL-BREF

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Quality of life of caregivers of octogenarians: a study using the WHOQOL-BREF

Objective. To evaluate the quality of life of octogenarians and to identify the domains related to quality of life and health.

Methodology. A cross-sectional, quantitative study conducted in 2010 in the Family Health Units of Campina Grande/PB, Brazil. The study sample consisted of 52 subjects that met the eligibility criteria of: 18 years or older, being a lay caregiver of octogenarians, and having no apparent cognitive problem. A questionnaire containing a sociodemographic section and the WHOQOL-BREF that is composed of two questions about the perceptions of quality of life and health, and 24 on the physical, psychological, social relationships and environmental domains.

Results. The Cronbach's alpha was 0.72, attesting to the reliability of the instrument used. The domain scores were: environmental (59.43), psychological (59.01), social relationships (46.77) and physical (43.86), whose values indicate dissatisfaction of subjects with regard to aspects related to quality of life. The environmental domain was correlated with quality of life and the physical domain with perceptions of health; the daily safety and pain aspects had the highest correlations with quality of life.

Conclusion. The perception of the caregivers regarding quality of life was not good. The environmental and physical domains had the highest correlations with quality of life and health.

Key words: nursing; aged, 80 and over; quality of life; caregivers.

Calidad de vida de los cuidadores de octogenarios: un estudio utilizando el Whoqol-Bref

Objetivo. Evaluar la calidad de vida de los cuidadores de octogenarios e identificar los dominios relacionados con la calidad de vida y la salud. **Metodología.** Investigación de tipo transversal,

realizada en 2011 en las Unidades de Salud de la Familia de Campina Grande/PB, Brasil. La muestra estuvo compuesta por 52 personas que cumplieron los criterios de elegibilidad: edad \geq 18 años, ser cuidador informal de octogenarios y no presentar problemas cognitivos aparentes. Se aplicó un formulario sobre datos sociodemográficos y el instrumento Whoqol-bref, el cual contiene dos preguntas sobre la percepción de la calidad de vida y de la salud y de 24 referentes a los dominios físico, psicológico, relaciones sociales y ambiental. **Resultados.** El alfa de Cronbach total fue 0.72, mostrando la alta confiabilidad del instrumento utilizado. Los dominios obtuvieron los siguientes puntajes: ambiental (59.4), psicológico (59.0), aspectos sociales (46.8) y físico (43.8), cuyos valores indican la insatisfacción de los cuidadores en los aspectos relacionados con la calidad de vida. Se encontraron correlaciones con significancia estadística entre el dominio ambiental y la calidad, y entre el dominio físico y la salud, teniendo los ítems de seguridad diaria y dolor las mayores correlaciones con la calidad de vida y salud. **Conclusión.** La percepción de los cuidadores de octogenarios sobre su calidad de vida no es satisfactoria. Enfermería debe preparar a estas personas para que puedan cumplir con su función de cuidar al octogenario y, a la vez, para que puedan disponer de tiempo para cuidar de sí mismos.

Palabras clave: enfermería; anciano de 80 o más años; calidad de vida; cuidadores.

A qualidade de vida dos cuidadores de octogenários: um estudo com o Whoqol-Bref

Objetivo. Avaliar a qualidade de vida dos cuidadores de octogenários e identificar os domínios correlacionados com a qualidade de vida e saúde. **Metodologia.** Pesquisa transversal, quantitativa, realizada em 2011, nas Unidades de Saúde da Família de Campina Grande/PB. A amostra compôs-se de 52 sujeitos que atenderam aos critérios de elegibilidade: idade \geq 18 anos, ser cuidador informal de octogenários e não apresentar problema cognitivo aparente. Aplicaram-se um formulário sobre dados sócio-demográficos e o questionário Whoqol-bref, composto de duas questões referentes à percepção da qualidade de vida e da saúde e 24 referentes aos domínios: físico, psicológico, relações sociais e ambiental. **Resultados.** O Alfa de Cronbach total foi 0.72, atestando a confiabilidade do instrumento utilizado. Os domínios obtiveram os seguintes escores: ambiental (59.43), psicológico (59.01), aspectos sociais (46.77) e físico (43.86), cujos valores indicam a insatisfação dos sujeitos no tocante às facetas relacionadas com a qualidade de vida. O domínio ambiental possui maior correlação com a qualidade de vida e o domínio físico com a saúde, tendo as facetas segurança diária e dor as maiores correlações com a qualidade de vida e saúde. **Conclusão.** A percepção dos cuidadores de octogenários sobre sua qualidade de vida não é satisfatória. Os domínios mais relacionados com a qualidade de vida e a saúde são, respectivamente, Ambiental e Físico.

Palavras chave: enfermagem; idoso de 80 anos ou mais; qualidade de vida; cuidadores.

Introduction

Due to a higher incentive from several countries, preventive actions have greatly affected epidemiological indicators, such as mortality and fertility, which have reduced systematically. This scenario, while reflecting improving global health, resulted in a significant increase in the number of elderly who have shown greater longevity.¹ In 2010, the population of Brazil, specifically, had

more than 11% elderly people, defining it as a country in process of population aging.² Based on this growing trend, the projection for 2025 is for Brazil to occupy the sixth global position for the number of elderly.³ The number of people aged 80 years or older is greater than 1.6 million, something close to 12.8% of the elderly population, and 1.5% of the total population, with

an estimated increase to nine million in 2020 and about 14 million in 2040.

The increased prevalence of octogenarians generates significant implications for the state, as various sectors are affected, such as the economy and the health.³ Regarding this latter aspect, an increased incidence of chronic degenerative diseases can be verified.^{4,5} In this case, functional disability can impair the independence and autonomy of these people, a condition that compromises the health, quality of life and often, demands permanent care.^{6,7} Caregivers are integrated into the context of this study, as individuals responsible for the implementation of home care for octogenarians, both within and outside the family context, in order to meet their needs. In some cases, when family members have resources, the caregivers are nursing professionals.. However, most of them are family members without the necessary qualifications for these activities.⁸ Therefore; caregivers face difficulties in performing their duties, because along with common professional unpreparedness, they do not have someone with whom they can share responsibilities. Thus, they have a difficult task, characterized for being repetitive, endless and often combined with other domestic and professional activities; resulting in exhaustion, social isolation, disregard for their hygiene, sadness, occurrence of diseases such as depression, and impairment of leisure activities.^{9,10}

This study assumes that the activities performed by the octogenarians' caregivers can negatively impact their quality of life. Its relevance is based on the inclusion of issues relating to the elderly on the international agenda, since this population group has grown substantially across countries, as well as the potential of this research to contribute to the improvement of the practice of nurses working in the gerontology, and with the development of actions and public policies designed for this area. The objective was to evaluate the quality of life of caregivers of octogenarians, and to identify the most related domains to health and quality of life.

Methodology

This was a cross-sectional survey with a quantitative approach, conducted in 2010, in the Family Health Units (FHU-USF) of Campina Grande / PB, Brazil. The population consisted of 5831 caregivers of octogenarians who were registered in the USF of Campina Grande during the period of February and March of 2010. The sample was calculated using the formula: $n = N \cdot Z^2 \cdot P(1-P) / (N-1) \cdot e^2 + Z^2 \cdot (1-P)$ where: n = sample value; N = population value; Z = confidence interval (1.96); P = prevalence (1.5);⁴ e = tolerated error (0.05), with a probabilistic $n = 52$. The sampling process occurred by conglomerate, considering each one USF as a conglomerate. The units and the participants were randomly and proportionally selected, considering the six health districts existing in the city.

The eligibility criteria of the subjects were age greater than 18 years, providing care for an octogenarian as an informal caregiver, and not presenting any apparent cognitive problem that could compromise the completion of the research instruments. The approach strategy for data collection was home visits, in which the researcher was accompanied by community healthcare agents. At this time, two instruments were administered: a form with questions concerning sociodemographic data, and the WHOQOL-BREF questionnaire.

The WHOQOL-BREF consists of 26 questions, of which two related to the perception of quality of life (QOL) and health, and 24 referred to four domains and their respective aspects of life: physical domain (dependence on medication and treatment, energy and fatigue, sleep and rest, activities of daily living, work capacity, pain and discomfort); psychological domain (thinking, learning, self-esteem, body image and appearance, negative and positive feelings, spirituality and personal beliefs, memory and concentration); Social relationships domain (social support, personal relationships and sex life); and environmental domain (home environment, financial resources, physical environment

-pollution, climate and traffic, health and social care, opportunities to acquire new information and skills, leisure, transportation, safety and protection).¹¹

The answers to the WHOQOL-BREF questions were given using a Likert scale. In each domain, the questions received a score from 1 to 5 according to the answers: not at all (1) not much (2), moderately (3), a great deal (4) and completely (5). The overall score followed an increasing scale on the perception of quality of life, ranging from 0 to 100 points.¹¹ At first, a spreadsheet with the data collected, was keyed by two independent data entry personnel to avoid possible errors, and was subsequently analyzed with the aid of the Statistical Program for the Social Sciences (SPSS) for Windows, version 17.0. The analysis of information related to socio-demographic data and domain score was performed using descriptive statistics. The internal reliability of the WHOQOL-BREF was obtained by the Cronbach's alpha test. Next, eight models of logistic regression were performed to verify the correlation between domains and QOL and health: (physical₁, psychological₂, social relationships₃, environmental₄, and QoL) and (physical₁, psychological₂, social relationships₃, environmental₄, and health). For implementing of the models, QOL and health were considered to be dependent variables, with the ways of life as independent, with statistical significance set at 0.05.

The project was submitted to the Research Ethics Committee (REC) of the Higher Education and Development Center (CESED), CAAE in 0490.0.133.000-08. Data collection began only after the approval was issued. All the criteria established by Resolution 196/96 of the National Health Council were respected. The subjects were informed about the study and signed the Terms of Free and Informed Consent, assuring privacy, confidentiality and decline in participation without any onus.¹²

Results

Sociodemographic profile: Among the 52 participants, 90.4% (n = 47) were female and 9.6% (n = 5) were male, indicating a ratio of 9.4 women for every man. The mean age of the group was 45.25 years (\pm 7.18; Xmin = 18 Xmax = 85). Regarding religious belief, 71.1% (n = 37) reported being Catholic, 23.1% (n = 12) evangelical, and 5.8% (n = 3) other beliefs. With respect to education, 67.3% (n = 35) reported less than ten years of study, while 32.7% (n = 17) had over ten years. Concerning marital status, 51.9% (n = 27) live with a partner, and 48.1% (n = 25) without a partner (single, widowed or divorced). About the financial conditions, 92.3% (n = 48) reported a monthly income of up to two minimum wages, and 7.7% (n = 4) earned more than two.

Reliability of the instrument: The WHOQOL-BREF instrument used in the research showed high internal consistency for this sample. The Cronbach's alpha of 0.72 demonstrated satisfactory reliability.

Scores of the domains: The scores of the domains that compose the WHOQOL-BREF were: environmental domain (59.43 points); psychological domain (59.01 points); social relationships domain (46.77 points); and, physical domain (43.86 points). The resulting overall score was 52.26 points; these values indicate dissatisfaction of the subjects regarding aspects related to quality of life.

Correlation of aspects with quality of life: As shown in Table 1, the logistic regression tests performed between the aspects of life of each domain - physical, psychological, social relationships and environmental - and the QOL variable showed that the environmental sphere was correlated ($p = 0.014$) to the detriment of other areas, which did not have statistically significant interference ($p > 0.05$).

Table 1. Statistical parameters resulting from logistic regression between the quality of life of caregivers of octogenarians and the physical, psychological, social relationships and environmental aspects of life. Campina Grande-PB, Brazil, 2011

Domains	Test score	Parameters	
		DF*	<i>p</i>
Environmental	19.166	8	0.014
Physical	7.171	7	0.411
Psychological	6.920	6	0.328
Social relationships	2.860	3	0.414

(*)degree of freedom

Among the aspects of life included as independent variables, within the environmental domain, the perception of daily safety showed significant correlation with QOL ($p = 0.001$). Other correlations with different aspects were not observed.

Correlation of aspects with health: After logistic regression with the health variable and aspects of life of each domain - physical, psychological, social relationships and environmental - with results shown in Table 2, the physical domain showed correlation with the perception of caregivers of octogenarians about health ($p = 0.019$).

Table 2. Statistical parameters resulting from logistic regression between the health of caregivers of octogenarians and the physical, psychological, social relationships and environmental aspects of life. Campina Grande-PB, Brazil, 2011

Domains	Test score	Parameters	
		DF	<i>p</i>
Environmental	16.770	7	0.019
Physical	12.105	8	0.147
Psychological	7.566	6	0.272
Social relationships	5.143	3	0.162

(*)degree of freedom

Among the aspects of life included as independent variables of the physical domain, the perception of pain was the one that had a significant correlation with health ($p = 0.001$). Other correlations with different aspects were not observed.

Life aspects of environmental and physical domains: Although the main objective of the WHOQOL-BREF is not to assess aspects of life in an isolated manner, it was decided to present such data relating to the domains that showed positive correlation with quality of life and health

of caregivers of octogenarians - environmental and physical; understanding that this information may suggest some possibilities for comprehension of the studied situation. Table 3, shows that money appears to be the aspect of the environmental domain with the greatest dissatisfaction among caregivers (96.2%).

Regarding the physical domain, shown in Table 4, medical treatment was the major source of unhappiness among caregivers of octogenarians (86.6%).

Table 3. Perception of 52 caregivers of octogenarians on the aspects of life in the environmental domain, and Cronbach's alpha for each item. Campina Grande-PB, Brazil, 2011

Aspects of environmental domain	n	%	Cronbach's alpha
Safety			
Satisfied	35	67.3	0.70
Dissatisfied	17	32.7	
Physical environment			
Satisfied	38	73.1	0.69
Dissatisfied	14	26.9	
Money			
Satisfied	02	3.8	0.65
Dissatisfied	50	96.2	
Information			
Satisfied	26	50	0.71
Dissatisfied	26	50	
Leisure			
Satisfied	12	23.1	0.68
Dissatisfied	40	76.9	
Housing			
Satisfied	43	82.8	0.61
Dissatisfied	09	17.2	
Health services			
Satisfied	40	77	0.69
Dissatisfied	12	23	
Transportation			
Satisfied	22	42.3	0.70
Dissatisfied	30	57.7	

Table 4. Perception of 52 caregivers of octogenarians on the aspects of life in the physical domain, and Cronbach's alpha for each item. Campina Grande-PB, Brazil, 2011

Aspects of physical domain	n	%	Cronbach's alpha
Pain			
Satisfied	13	24.9	0.69
Dissatisfied	39	75.1	
Medical treatment			
Satisfied	07	13.4	0.65
Dissatisfied	45	86.6	
Energy			
Satisfied	41	78.9	0.61
Dissatisfied	11	21.1	
Locomotion			
Satisfied	27	51.9	0.72
Dissatisfied	25	48.1	
Sleep			
Satisfied	19	36.5	0.70
Dissatisfied	33	63.5	
Daily activities			
Satisfied	12	23.1	0.71
Dissatisfied	40	76.9	
Job			
Satisfied	08	15.5	0.69
Dissatisfied	44	84.6	

Discussion

The sociodemographic profile found in the study pointed to a predominance of females in the caregiver function of octogenarians, with the presence of men not being excluded in this assignment, even if in low proportion. The literature justifies the majority presence of women as caregivers, because the difference between genders contributed to their difficulty in accessing education and professional training, involving them in domestic activities and care of relatives.⁹ Furthermore, the natural consequence of the phenomenon that led women to not seek professional qualification, when it is not the absence of employment, is informal activities with the smallest remuneration, explaining why this study found most caregivers had low levels

of education, less than ten years of study, earning more than two minimum salaries.

The mean age of the study participants, who were mostly women, was within an age group considered advanced. Such data are corroborated by other studies, which show, in addition to more women providing care for dependent older people, a mean age similar to our findings.^{13,14} With regard to QOL of caregivers, the environmental domain was correlated with the perception of daily safety. By analyzing the QOL of caregivers of elderly individuals with hearing impairments in light of the WHOQOL-BREF, a study conducted in the state of Rio Grande do Sul, in Brazil, found the environment and physical domains were the

most related and more closely involved with QOL of caregivers.¹⁵

Concerning the QOL and health of caregivers of octogenarians, the physical domain was correlated, with the perception of pain the highest. In a study involving these issues with dependent elderly, this correlation was identified, as well as the fact that the higher the degree of dependence of the elderly, the worse the QOL of the caregiver.¹⁶

The present study did not investigate the degree of dependence of elderly people; however, being octogenarians, a considerable degree of dependence is expected, which can interfere with the physical domain, especially pain, with the health of the caregiver. In addition, the broad correlation between these variables can suffer some influence of the physical effort required to provide care to the octogenarian. An investigation conducted with 126 caregivers of elderly in the Brazilian city of Campinas, state of São Paulo, found a correlation between the workload of caregivers and pain, and in addition, the dimension pain achieved the lowest mean score in the measurement of QOL of these subjects.¹⁷ The satisfaction of caregivers of octogenarians about aspects of life of physical and environmental domains was identified. For the environmental domain, a high degree of dissatisfaction with the financial aspects and leisure was found. Of these, the worst aspect of satisfaction was financial; which is corroborated by a study assessing the quality of perceptions of the elderly with dementia and their caregivers, which showed the financial situation as that with the worst perception by caregivers.¹⁸

The dissatisfaction of the caregivers with leisure was significant. This is primarily due to the workload from the act of caring, added to domestic responsibilities, such as childbearing, since, most women are historically responsible for these activities. Regarding the dissatisfaction identified with sleep and daily activities within the physical domain, this can be due to the workload of these caregivers, which has negative impacts on the daily routine. Other research indicates that, in

general, individuals with the function of caregiver are overloaded, as well as needing to meet other responsibilities assigned to them, impairing their own quality of life.¹⁷

In general, the caregivers of elderly patients are unhappy with aspects of life related primarily to the physical environment, financial resources, health services, transportation and items included in the environmental domain.¹⁹ This dissatisfaction affects these subjects, turning caring into an exhausting experience, worsening the QOL. Moreover, another factor that can interfere with the QOL of the caregivers is the lack of training to perform their duties. The peculiarities of caring surpass the capacity of families, resulting in the need for professional caregivers. However, caring for the elderly usually occurs at home, and is performed by a family member. Therefore, it is important to invest in the preparation of these people so that they can provide care with satisfactory quality.⁵

The training of the caregivers, sometimes involves the use of theoretical knowledge as a practical tool, and guidance to enable adapting them to home care; and it can be performed by nurses.⁵ Therefore, these professionals must be attentive to this reality, assuming the co-responsibility in caring for the elderly, especially in primary health care.²⁰ A properly prepared caregiver can acquire a positive impact on her QOL, as she is instructed in schedule management and efficient ways of planning, implementation and evaluation of care; providing her with time and willingness to care for herself and her private life.

The conclusion of this study is that the perception of caregivers of octogenarians about QOL is unsatisfactory, particularly with regard to environmental and physical aspects such as daily safety and pain, respectively. From this perspective, it is believed that activities related to the caregiver function can have a negative impact on the lives of those who take on these assignments.

The practical implication that this study presents is to indicate that the practice of nursing

professionals working in gerontology should be improved to meet the need for support for caregivers of octogenarians, seeking to improve their QOL and in turn, the care of elderly, since, as shown by the results of this study, caregivers are mostly nonprofessionals. The study also provides an important contribution to public health, as it addresses important epidemiological aspects for creating and improving health policies involving the caregiver / octogenarian binomial, as it allows a data corpus that can be used for development and testing of hypotheses for future studies. Finally, despite the important contributions of this research to the knowledge of the area, the study limitations are its cross-sectional design, small sample size and the majority proportion of female participants. Such research conditions can decrease the power of generalization of the results to other similar populations.

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