

Original Article

PERCEPTION OF THE QUALITY OF LIFE OF CAREGIVERS OF OCTOGENARIANS

PERCEPÇÃO DA QUALIDADE DE VIDA DOS CUIDADORES DE OCTOGENÁRIOS
PERCEPCIÓN DE LA CALIDAD DE VIDA DE LOS CUIDADORES DE OCTOGENARIOS

Camila Alves Nogueira¹, Fabiana Paulino Alves², Alexsandro Silva Coura³, Caroline Evelin Nascimento Kluczynik Vieira⁴, Bertha Cruz Enders⁵, Inacia Sátiro Xavier de França⁶

The objective of the study was to investigate the perception that caregivers of octogenarians have regarding the quality of life and aspects of life that are more harmful to this quality. A cross-sectional, descriptive and quantitative study conducted in 2010 with 52 subjects of the Family Health Units in Campina Grande-PB, Brazil that responded a socio-demographic questionnaire and the WHOQOL-Bref. Data were analyzed with the SPSS. The total WHOQOL-bref score was 52.26 points. The aspects that were more jeopardized were: sex life (94.3%), feelings (67.4%), pain (65.5%) and leisure (53.8%); the least affected were: living quarters (82.8%), energy (78.9%), physical appearance (78.9%) and personal relationships (76.9%). The caregivers' perceptions regarding the quality of life are marked by dissatisfaction, thereby leading to the belief that the care activities can have a negative effect on their lives.

Descriptors: Aged, 80 and over; Quality of Life; Caregivers.

Objetivou-se investigar a percepção de cuidadores de octogenários em relação à qualidade de vida e aspectos de vida que mais prejudicam tal qualidade. Estudo transversal, descritivo, com abordagem quantitativa, realizado em 2010, nas Unidades de Saúde da Família de Campina Grande-PB, Brasil. Participaram 52 sujeitos, que responderam um questionário sociodemográfico e o WHOQOL-bref, sendo a análise efetuada pelo SPSS. O escore global do WHOQOL-bref foi de 52,26 pontos. Os aspectos mais comprometidos foram: vida sexual (94,3%), sentimentos (67,4%), dor (65,5%) e lazer (53,8%); e os menos comprometidos: moradia (82,8%), energia (78,9%), aparência física (78,9%) e relações pessoais (76,9%). A percepção dos cuidadores de octogenários com relação à qualidade de vida é marcada pela insatisfação, fornecendo subsídios para se acreditar que as atividades de cuidado podem repercutir negativamente na vida dos cuidadores.

Descritores: Idoso de 80 Anos ou mais; Qualidade de Vida; Cuidadores.

El objetivo fue investigar la percepción de cuidadores de octogenarios acerca de la calidad de vida y aspectos de la vida que más afectan esa calidad. Estudio transversal, descriptivo y cuantitativo, llevado a cabo en 2010 con 52 sujetos, en las unidades de salud de la familia de Campina Grande-PB, Brasil, que respondieron un cuestionario socio-demográfico y el WHOQOL-bref, siendo el análisis efectuado a través del SPSS. El escore total del WHOQOL-bref fue 52,26 pontos. Los aspectos mas comprometidos fueron: vida sexual (94,3%), sentimientos (67,4%), dolor (65,5%) y diversión (53,8%); los menos comprometidos fueron: vivienda (82,8%), energía (78,9%), apariencia física (78,9%) y relaciones personales (76,9%). La percepción de los cuidadores de octogenarios, acerca de la calidad de vida es marcada por la insatisfacción, lo que lleva a creer que las actividades del atención pueden repercutir negativamente en la vida de los cuidadores.

Descriptores: Anciano de 80 o más Años; Calidad de Vida; Cuidadores.

Corresponding Author: Alexsandro Silva Coura

Rua Doutor Sebastião Zuza de Matos, 4449, bl: 23, apt. 104, Condomínio Jardim Botânico, Neópolis, Natal, Rio Grande do Norte, Brasil. CEP: 59080-470. E-mail: alex@uepb.edu.br.

¹ Nurse. Health Management Specialist from the State University of Ceará (UECE). Brejo Santo, CE, Brasil. E-mail: camilanogueira24@hotmail.com.

Nurse. Master's degree student in Public Health at Universidade Estadual da Paraíba-UEPB. Campina Grande, Paraíba, Brasil. E-mail: fabiana@elogicasistemas.com.br.

³ Nurse. Doctorate student in Nursing at Universidade Federal do Rio Grande do Norte-UFRN. Natal, Rio Grande do Norte, Brasil. E-mail: alex@uepb.edu.br.

⁴ Nurse. Master's degree student in Nursing at Universidade Federal do Rio Grande do Norte-UFRN. Natal, Rio Grande do Norte, Brasil. E-mail: carolinekluczynik@gmail.com. ⁵ Nurse. Doctor. Professor of the Post-Graduation course in Nursing at Universidade Federal do Rio Grande do Norte-UFRN. Natal, Rio Grande do Norte, Brasil. E-mail: bertha@ufrnet.br.

⁶ Nurse. Doctor. Professor of the Post-Graduation course in Public Health at Universidade Estadual da Paraíba-UEPB. Campina Grande, Paraíba, Brasil. E-mail: inacia_satiro@hotmail.com.

INTRODUCTION

The increase of life expectancy in the world can be related to the improvement of the quality of life of people (QL), to the advancement in science, to the improvement and more access to the health services in Brazil, especially after the implantation of the Sistema Único de Saúde (SUS)⁽¹⁾ (Public Health Service). Because of that, the aging of population is a real perspective and needs reflection. There is also a need to reflect on the process of caretaking, once an adequate assistance can promote a better OL to people at this age range ⁽²⁾.

In this process, we point out that the growth of the elderly population (from 60 years old on), as well as the octogenarians (above 80 years old), bring alterations in the composition of age of the elderly. However, we observe that there is no difference in the caretaking of those people, who are considered as part of the same age range group, although the people who are 80 are usually more vulnerable ⁽³⁾.

In the case of the octagerians, the chronic non-transmissible diseases (CNTDs) are frequently found and they are directly related to a greater functional incapacity ⁽⁴⁾. These people need a permanent caregiver, depending on their degree of fragility. Caregivers are the ones who assume the responsibility of taking care, providing support or help in some of the person's needs, having as objective the improvement of health and QL ⁽⁵⁾.

In most countries this care is usually provided by female professionals, due to cultural matters, for example, in the past women did not work outside their homes. However today the women are more active in the market, so they have less time to take care of the elderly members in the family. Even so, in most cases, they are married women, and because of that, they take the responsibility of care together with the

household tasks, thus generating too much work and an overload on several aspects of their lives, contributing to their carelessness regarding the commitment with their own health and $QL^{(6)}$.

Regarding QL, we notice the perception of the caregiver regarding his role in life. This is a wide concept, which interrelates the outside world with the inside world ⁽⁷⁾. When this concept is applied to caregivers, some stressing effects are identified. This is observed because the gradual cognitive losses presented and even the changes of the personality of the elderly require a certain degree of common sense from the caregiver in order to have a satisfactory social relationship ⁽⁸⁾.

Facing this scenario, the Health Department, through the guidelines established by the National Health Policy for the Elderly (1999), aims to stimulate discussions and studies on aging with dependency, where the informal caregiver is included, an indispensable person for the care of the elderly, in order to stimulate the quality of this assistance⁽¹⁾.

Based on the assumption that the development of care activities to the octogenarians interfere in the QL of the caregivers ⁽⁸⁾, the objective of this study was to investigate the perception of caregivers of octogenarians regarding QL and aspects of life which jeopardize such quality.

This study is pertinent, once the health of the elderly is included in the Agenda Nacional de Prioridades de Pesquisas em Saúde ⁽⁹⁾ (Health Research Priorities). Besides that, it is understood that this investigation is important because of the difficulties faced by the caregivers responsible for the care of octogenarians in order to provide adequate assistance ⁽¹⁰⁾, due to the lack of qualified nursing professionals ⁽¹¹⁾; and the possibility

to contribute for the strengthening of public health policies for the elderly patients and their caregivers in order to improve the QL of those people.

METHODS

This is a cross-sectional study, descriptive, with quantitative approach, made in 2010, in 26 Family Health Units (FHU) in the County of Campina Grande/PB, Brazil.

Part of a probabilistic sample, obtained through sample calculation, considering a population of 2,332 people and prevalence of 1.5 % (12), 52 caregivers of octogenarians took part in the study. The technique of cluster sampling was used, considering each FHU in the county of Campina Grande. The participants were chosen from selected conglomerates, based on geographic principles, the division of this city in Paraiba in six sanitary districts, and considering the principal of proportionality. Some FHUs were chosen at random in each district until the number of samples wanted was obtained, being six units in district II, five in III, five in I, four in VI, three in IV and three in V. In each FHU the caregivers who participated in the research were also chosen in the same way, so that all of them would have the same probability of participating in the sampling.

The criteria of including adults who were taking care of people 80 years old or more were considered, adjoined in some selected FHU, being classified as informal caregivers. Those were criteria of exclusion in the research. The participants who presented apparent cognitive problems were excluded of the research.

The strategy to join the subjects of the research and the data collection was the home visit, followed by the Communitarian Health Agent (CHA) responsible for micro area. Two tools were used: Questionnaire I and the WHOQOL-bref. Questionnaire I was used for the

investigation of the demographic and socioeconomic variables.

The WHOQOL-bref is a questionnaire developed by the World Health Organizations (WHO), with 26 questions, or aspects of life which represent the facets of four domains: the physical domain, the psychological domain, domain of social relationships and the domains of environment. The answers were given in a scale of the Likert type (1, 2, 3, 4, 5) according to the perception of the participants regarding the facets: very dissatisfied (1), dissatisfied (2), neither dissatisfied nor satisfied (3), satisfied (4) and very satisfied (5). The final punctuation follows a crescent scale on the perception of QL which varies from 0 to 100 points, being 0 the indication of total dissatisfaction with the QL, and 100 of total satisfaction (13).

The data collected were implanted in an electronic data bank and analyzed through the program called Statistical Package for the Social Sciences (SPSS) for Windows version 17.0, and presented through tables. The descriptive statistics was used and the averages, standard deviations, and absolute and relative frequencies were calculated.

The Project was approved by the Research Ethics Committee (REC) of the Centro de Ensino Superior e Desenvolvimento (CESED), under CAAE no. 0346.0.000.405-10. The subjects were clarified regarding any question on the research and signed an Informed Consent Form (ICF), assuring them the rights of privacy, secrecy and decline in the participation.

RESULTS

Socio-Demographic Profile

47 women and five men participated in the study, with the proportion of 9.4 women to each man (Table 1). Among the 52 participants, the majority was

catholic (71.1%), without college education (98.1%), married (51.9%) and with income up to two minimum wages (92.3%). The average of the age of the

caregivers of the octogenarians was 45.25 years (±18.07; Xmin=18, Xmax=85).

Table 1 – Socio-demographic profile of the caregivers of the octogenarians. Campina Grande, PB, Brazil, 2010

Variables	No.	%
Sex		
Male	05	9.6
Female	47	90.4
Age Range		
13-30 years	12	23.1
31-50 years	22	42.3
61-85 years	18	34.6
Religion		
Catholic	37	71.1
Evangelic	12	23.1
Others	03	5.8
Schooling		
None	02	3.8
Grade School 1	13	25
Grade School 2	20	38.5
High School	16	30.8
University	01	1.9
Marital Status		
Single	18	34.6
Married	27	51.9
Widow (er)	03	5.8
Divorced	04	7.7
Family <i>per capita</i> income		
1 minimum wage [*]	29	55.8
2 minimum wages	19	36.5
3 minimum wages	04	7.7

Minimum wage = R\$: 510.00.

Physical and Psychological Domains

According to Table 2, the aspects of life which presented more impairment (very dissatisfied or dissatisfied) in the physical domain were: pain (65.5%), medical treatment (57.7%), work (55.8%) and daily activities (50%). On the other hand, the ones with less impairment (satisfied or very satisfied) were: energy (78.9%) and locomotion (51.9%). The average score of

punctuation in this domain was 43.86, indicating much dissatisfaction with several facets.

Regarding the psychological domain, there was a score of 59.01 points, showing moderate dissatisfaction with the facets of the domain. There was more impairment in the *feelings* aspect (67.4%). The aspects with less impairment were: physical appearance (78.8%), meaning of life (71.2%) and personal satisfaction (67.3%).

Table 2 – Distribution of the caregivers of octogenarians according to the perception regarding the aspects of life in the Physical and Psychological domains. Campina Grande, PB, Brazil, 2010

Domains Physical	VD*		\mathbf{D}^{\dagger}		ND-NS [‡]		S [§]		VS	
	No.	%	No.	%	No.	%	No.	%	No.	%
Pain	27	52	07	13.5	05	9.6	12	23	01	1.9
Medical Treatment	04	7.7	26	50	15	28.9	05	9.6	02	3.8
Energy	01	1.9	01	1.9	09	17.3	40	77	01	1.9
Locomotion	13	25	05	9.6	07	13.5	22	42.3	05	9.6
Sleep	07	13.5	09	17.3	17	32.7	14	26.9	05	9.6
Daily Activities	14	26.9	12	23.1	14	26.9	09	17.3	03	5.8
Work	15	28.8	14	27	15	28.8	05	9.6	03	5.9
Psychological										
Enjoying Life	06	11.5	09	17.3	15	28.8	20	38.6	02	3.8
Meaning of Life	0	0	01	1.9	14	26.9	34	65.4	03	5.8
Concentration	01	1.9	08	15.4	10	19.2	30	57.7	03	5.8
Physical Appearence	01	1.9	03	5.8	07	13.5	36	69.2	05	9.6
Personal Satisfaction	05	9.6	02	3.8	10	19.2	31	59.6	04	7.7
Feelings	15	28.8	20	38.6	02	3.8	03	5.8	12	23

^{*}VD = Very Dissatisfied; †D = Dissatisfied; †ND-NS = Neither Dissatisfied nor Satisfied; §S = Satisfied; ||VS = Very Satisfied.

Environmental and Social Relationships Domains

In table 3, there was more impairment in the social relationships domain regarding sexual life

(94.3%). On the other hand, there was less impairment in personal relationships (76.9%) and support from friends (76.9%). The score of punctuation of this

domain was 46.77, showing more dissatisfaction with its aspects.

Concerning the environmental domain the average punctuation obtained was 59.43, reflecting moderate dissatisfaction of the subjects under investigation regarding the facets related to the domain. The aspect with more impairment was leisure (53.8%), and the aspects with less impairment were: housing (82.8%) and health services (77%).

Table 3 - Distribution of the caregivers of octogenarians according to the perception regarding the aspects of life in the Social Relationships and Environmental domains. Campina Grande, PB, Brazil, 2010

Domains	V	VD*		D [†]		ND-NS [‡]		S§		VS	
Social Relationships	No.	%	No.	%	No.	%	No.	%	No.	%	
Personal relations	01	1.9	02	3.8	09	17.4	38	73.1	2	3.8	
Sexual Life	47	90.5	02	3.8	02	3.8	0	0	01	1.9	
Support from Friends	03	5.8	01	1.9	08	15.4	37	71.1	03	5.8	
Environmental											
Securitiy	01	1.9	0	0	16	30.8	35	67.3	0	0	
Physical Environment	01	1.9	09	17.3	04	7.7	34	65.4	04	7.7	
Money	0	0	03	5.8	47	90.4	02	3.8	0	0	
Information	01	1.9	04	7.7	21	40.4	24	46.2	02	3.8	
Leisure	14	26.9	14	26.9	12	23.1	10	19.3	02	3.8	
Housing	02	3.8	01	1.9	06	11.5	38	73.2	05	9.6	
Health Services	01	1.9	02	3.8	09	17.3	39	75.1	01	1.9	
Transportation	0	0	02	3.8	28	53.9	21	40.4	01	1.9	
Transportation	0	0	02	3.8	28	53.9	21	40.4		01	

^{*}VD = Very Dissatisfied; † D = Dissatisfied; *ND-NS = Neither Dissatisfied nor Satisfied; §S = Satisfied; | VS = Very Satisfied

Global Score

According to the figures obtained by the physical, psychological, social relationships and environmental

domains the global score of WHOQOL-bref for the sample analyzed was 52.26 points, indicating moderate dissatisfaction of the participants with their QL.

DISCUSSION

The predominance of the female sex and adults taking care of octogenarians are data confirmed by the literature ^(14,15). Other researches strengthen the presupposition that women, from their youth, are induced to watch over and take care of the family. This

question is a cultural one, once the women did not have any functions out of the house. Still today although they are more active in the working market, the woman is still the main caregiver of the elderly of the family. This overload of work results in carelessness with themselves, impairment of their health and in their $OL^{(6,15,16)}$.

Regarding the other socio demographic features, most of the caregivers declared to be catholic, having grade school or high school, married and earning up to two minimum wages. A study with caregivers of octogenarians made in Colombia, found statistic association between the perception of fatigue and the marital status, low income and low schooling. Because it was a cross-sectional analysis it was not possible to infer causality to the event, however, according to the authors, this situation is converted in a vicious circle which negatively affects both the caregiver and the person being taken care of, which induces to work overload and unfavorable socioeconomic conditions to reach adequate QL⁽¹⁵⁾.

Regarding QL, the results revealed that the physical domain had an average score of 43.86 points, which were more affected by the variables: pain, medical treatment, work and daily activities; and less affected by the variation of energy. Such conclusion is worrisome, for this domain deals with several important aspects in the routine of people. So, the improvement of the caregiver's QL needs to follow diverse strategies turned to the solution of specific problems regarding daily problems and the improvement in the social support. In this context it is important to point out that these strategies depend on formal and informal resources that the services and the community must offer to help him assist the basic needs of the elderly as well as providing more occasions for rest and personal care⁽¹⁷⁾.

Still regarding the physical domain, the low punctuation regarding pain is relevant once pains can impair the caregivers´ QL and therefore the quality of the cares rendered to the octogenarians. A study made

in São Paulo revealed, with statistic significance, that the female caregivers are more affected by pain than the male caregivers⁽¹⁶⁾, confirming the present study which shows mostly women providing homecare.

Regarding the psychological domain the score was 59.01 points, more committed to feelings, revealing, according to WHOQOL- bref suggestions, the occurrence of feelings such as bad humor, despair, anxiety and depression; and less committed to physical appearance and the meaning of life. These results revealed that taking care of the elderly at home can break out different feelings, many times negative ones. For example, activities which may seem simple to those who perform them became hard, causing emotional tiredness, characterized by depressing and anxious feelings. For this reason, many caregivers become patients, due to the overload of continuous and lonely activities without family recognition⁽¹⁸⁾.

Regarding the social relationships domain, which obtained score of 46.77, the aspect of more impairment was the sexual life. Another study revealed that there was meaningful relation between the satisfactory sexual activity and the increase of the average score of the social relationships domain. So, a better condition of this domain can reflect better sexual practice although this statement has the limitation of risk of bias of the reverse causality; it was also revealed that most of the interviewees (68.2%) reported to be neither satisfied nor dissatisfied with the current sexual life⁽¹⁹⁾.

On the other hand, in the present study, the aspect with less impairment in the social relationships domain was the support of the friends. In a similar way through a research performed in the capital of São Paulo, 47% reported to be satisfied or very satisfied with the support received from friends or relatives⁽¹⁹⁾. Such information confirms the importance of the net of

social relationships in the compensatory support, which must be stimulated, in order to grant a better QL to the caregiver and, indirectly, better care of the octogenarian.

Regarding the environmental domain, the average punctuation was 59.43. The most impaired aspect was leisure, and the aspects of less impairment were housing and health services, confirming the result of a study performed with the caregivers of elderly people in the city of São Paulo, which concluded that one of the biggest obstacles experienced is the impossibility of getting out of the house, especially to enjoy leisure activities period. In most of the cases there is no one who can substitute them with the responsibilities of care with the elderly. It was observed that, independently of the age variable, the activities of recreation are altered due to the activities of care, causing a sensation of lack of autonomy to manage their own lives, once they have to live according to the dependences of the elderly⁽¹⁶⁾.

In this context, the alteration in the routine of the caregivers, due to the need of following the octogenarians, is a factor which needs to be carefully observed by the nurses during the actions of health promotion in the families. A study made with 40 caregivers of elderly, in a program of home assistance of a federal university, it was noticed that the change in the routine of life to take care of them is related to the QL of the interviewed caregivers⁽¹⁶⁾. For this reason, it is important to developed programs which can minimize the negative affects of the activities of a caregiver on the QL once the caregivers who receive social support from professionals or from their own community have a larger probability of keeping their physical and psychic health preserved⁽²⁰⁾.

Therefore, the four domains analyzed presented low punctuations. The values obtained by the physical,

psychological, social relationships and environmental domains generated a global score of the WHOQOL-bref of 52.26 points, a figure that reveals that the participants of this study have an impaired QL especially in the physical and environmental domains. Similar results were shown in a revision study performed in a systematized way, in which the evaluation of the QL of the caregivers of elderly was negative. The same study emphasizes the need of having broader social and professional approach for the caregivers through the creation of a net of social support that involves the family, the community and the state, as well as the clarification regarding the aspects of the QL of caregivers to the nurses⁽⁷⁾.

Taking into consideration the increase of part of the Brazilian population above 80 years as well as the level of dependency linked to this condition, it is relevant to include the attention to the caregivers of octogenarians⁽¹⁸⁾ in the strategies of health and social policies.

Another relevant factor is that the health professional must pay attention to the planning of health care, taking into consideration the social economic conditions of the caregiver and the family as well as the early detection of vulnerabilities of the caregivers in order to have feasible training minimize difficulties and overload of activities of care. So, it is necessary to optimize the potential benefits for the mental and physical health of the caregiver, besides the maintenance and promotion of care to the octogenarian, once these caregivers are potential agents of promotion, protection and recovery of themselves and of the octogenarians⁽¹⁸⁾.

So, it is believed that, providing a better QL to the caregivers will bring better assistance to the octogenarians. A research made in a city of average size

revealed a positive relation between moderate and strong, and directly proportional to the QL of caregivers and octogenarians. Thus, we can presume that the QL of the caregiver interferes in the QL of the elderly⁽⁸⁾.

Regarding the limitations of the study, one of them is the small amount of samples, which makes difficult possible generalizations of the results for the population scope, as well as stronger statistical analyzes.

CONCLUSIONS

The results of the study show that the perception of the caregivers of octogenarians investigated regarding the QL is marked by dissatisfaction. The data obtained provide subsidy to believe that the activities of care may have a negative impact on the lives of caregivers of people who are 80 years old or more, once the domains of bigger negative influence for the QL were the Physical and Environmental domains. The aspects sexual life, feelings, pain and leisure were

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outstanding as having the biggest impairment of the domains. The ones with less impairment were: energy, physical appearance, personal relations and housing.

In this context, it is recommendable that the teams of the FHUs develop activities of prevention and promotion of health for the caregivers and for the octogenarians once the binomial elderly/caregiver must be considered in order to achieve more qualified assistance. Therefore, the actions must prioritize the attention of the familiar nucleus trying to minimize the vulnerability of the people who take care of elderly, regarding damages to their QL.

It is also suggested that the method used in the present study should be applied in other counties as well as investigations which try to verify associations between the socio demographic aspects and the QL of the caregivers of octogenarians and investigate possible correlations between the QL of caregivers and of octogenarians.

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