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BURDEN AND QUALITY OF LIFE OF INFORMAL CAREGIVERS OF ELDERLY PEOPLE WITH CHRONIC DISEASES

SOBRECARGA E QUALIDADE DE VIDA DOS CUIDADORES INFORMAIS DE PESSOAS IDOSAS COM DOENÇAS CRÔNICAS

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ABSTRACT: The objective was to evaluate the burden and quality of life of caregivers of older adults with chronic diseases. This was a cross-sectional study that used the Zarit Burden Interview Scale and the WHOQOL-Bref. A total of 299 caregivers participated, predominantly women, over 40 years old, without a partner, with low educational level, income of one minimum wage, having a family bond with the older person, and providing care for more than one year. Caregiver burden was classified as moderate to severe, and quality of life scores ranged from 59.4 to 70.8. There was a significant negative correlation between burden and the Social Relationships domain ($r = -0.234$; $p < 0.001$), Physical domain ($r = -0.465$; $p < 0.001$), Psychological domain ($r = -0.538$; $p < 0.001$), and Environment domain ($r = -0.379$; $p < 0.001$). It is concluded that the caregiver role generates substantial burden, which negatively impacts quality of life.

KEYWORDS: Aged. Caregivers. Chronic Disease. Stress Psychological.

RESUMO: O objetivo foi avaliar sobrecarga e qualidade de vida de cuidadores de pessoas idosas doentes crônicos. Trata-se de um estudo transversal que utilizou a Escala Zarit Burden Interview e WHOQOL-Bref. Participaram 299 cuidadores (mulheres, acima de 40 anos, sem companheiro, com pouca escolaridade, renda de um salário-mínimo, com vínculo com a pessoa idosa e tempo de cuidado maior de um ano). Sobrecarga foi moderada e intensa; qualidade de vida 59,4 a 70,8. Correlação entre sobrecarga e domínio Relações Sociais (r:-0,234; p<0,001); Físico (r:-0,465; p<0,001), Psicológico (r:-0,538; p<0,001) e Meio Ambiente (r:-0,379; p<0,001). Conclui-se que o papel de cuidador é gerador de sobrecarga impactando na qualidade de vida.

PALAVRAS-CHAVE: Cuidadores. Doença Crônica. Estresse Psicológico. Pessoa Idosa.

INTRODUCTION

The world is going through a singular and irreversible demographic transition period, which culminates in a process of population aging. As a result, one in nine people around the globe are 60 years old or older. As fertility decreases, the older population came to comprise 22% of the global population about two billion.[1-2] In Brazil, in 2022, there were nearly 32 million 60-year-old or older people, representing 15.6% of the Brazilian population. This represents a 56% increase when compared to 2010, and Brazil is still not among the ten countries with the highest longevity.[2]

This context is a challenge for public policies and especially for the health model, as it should lead to active aging through actions to provide autonomy to individuals[3,4]. Countries such as Canada, the United States, Australia and the Netherlands have been studying long-term care proposals about how to assist the older population in their territory, considering the debility and vulnerability of this population. It is essential to replace curative models with an integral approach, targeted at monitoring functional capacity in a context of non-communicable chronic diseases.[3]

A decrease in functional capacity means that a caregiver is necessary, who can be formal (receiving monetary compensation) or informal (with no monetary compensation, such as relatives and other close persons).[5-9] Nonetheless, those who provide care are not always prepared to do so and deal with the tensions and efforts that it requires.[7] A caregiver is deprived of many things in their life, as this role requires dedication and sacrifice, impacting personal and professional activities and, potentially, compromising their mental health, which can lead to physical, emotional, social, and financial burdens.[7,10,11]

Therefore, by discovering what it means for the relative of a chronic patient to be a caregiver, including their experiences with overload and the changes in their routine and quality of life, we can understand them better, uncovering signs to help the development of strategies to develop interventions for informal caregivers of older people. Considering the above, this study aimed to describe the sociodemographic and economic profile of informal caregivers of older people, evaluating their quality of life, and correlating this data.

METHODOLOGY

Cross-sectional, descriptive, correlational study with informal caregivers who were the support persons of older patients with chronic diseases during hospitalizations. This study was carried out in a tertiary hospital in the Northwest of São Paulo, a specialized center that served as a reference for 102 cities of the 15th Regional Health Department (RHD) of the state of São Paulo, from the second semester of 2018 until the end of the first semester of 2019.

The population of this study was formed by informal caregivers of older people with chronic diseases, who were their support persons during hospitalization. This study used convenience sampling, selecting informal caregivers of 60-year-old or older people diagnosed with chronic diseases. We included participants regardless of gender, as long as they were 18 years old or older, had the ability to communicate, and agreed to participate in the research by signing a consent form. Our sample did not include formal caregivers, caregivers who received monetary compensation, informal caregivers of older people hospitalized using private or corporate health insurances, nor any caregiver who did not want to participate in the study. Three instruments were used for data collection: a survey elaborated by the researchers, including sociodemographic variables (sex, age, family connection, income, educational level) of both the caregiver and the older person receiving care; clinical variables of the older person (level of dependency, comorbidities); and the Brazilian version of the Zarit Burden Interview (ZBI) a scale developed by Zarit & Zarit, and validated by Scazufca[8]; in addition to the brief version of the World Health Organization (WHO) quality of life measuring instrument (WHOQOL-Bref)[13]. The ZBI includes 22 questions about health, social and personal life, financial situation, emotional well-being, and interpersonal relationships. It evaluates how care activities impact the lives of the caregivers of people with physical and mental disabilities[8,9]. ZBI responses are given in Likert scales, with scores that vary from 22 to 88, and the higher the score, the higher the burden of the caregiver. Results from 0 to 20 indicate no burden; from 21 to 40, mild to moderate burden; from 41 to 60, moderate to severe burden; and from 61 to 88, intense burden.[12,13]

The WHOQOL-BREF has 26 questions, 2 of which are general — one relating to life, another to health —, while the other 24 are related to four domains and their respective facets[24,25]:

Domain I: physical health, including the facets: pain and discomfort; energy and fatigue; sleep and rest; activities of daily living; dependence on medication or treatments; work capacity.

Domain II: psychological, including the facets: positive feelings; thinking, learning, memory and concentration; self-esteem; body image and appearance; negative feelings; spirituality, religion, and personal beliefs.

Domain III: social relationships, with the facets: personal relationships, social support, sex life.

Domain IV: environment, with the facets: physical safety and security; home environment; financial resource; health and social care (availability and quality, opportunity to acquire new information and skills, participation); recreation and leisure; physical environment (pollution, noise, traffic, climate, transport).

Data collection was conducted in an interview with the caregivers, using the electronic records of the elders to complement data regarding their sociodemographic and economic characteristics, as well as their comorbidities and dependency level.

The t-test was used to check for associations between the total mean score of the ZBI Scale and the sociodemographic and economic variables of caregivers in two categories. Regarding the association between the mean total score of the ZBI Scale and the sociodemographic and economic variables of caregivers with three or more categories, we used the ANOVA analysis of variance. Finally, the association between the total ZBI Scale (quantitative variable) and the score of the WHOQOL-BREF domains was analyzed using Pearson's correlation coefficient (r), which can vary from -1 to 1. A negative or positive result indicates, respectively, whether the relationship is negative or positive; the value of the r coefficient shows the strength of the relationship between variables. The relationship is considered weak when r is from 0.10 to 0.30, moderate when r is from 0.40 to 0.60, and strong when r is from 0.70 to 1.[13] This study considered a significance level of 5% ($p \leq 0.05$).

This study was approved by the Research Ethics Committee of the Faculdade de Medicina de São José do Rio Preto (FAMERP), under CAAE 61391416.6.0000.5415 and Opinion No. 1.849.114.

RESULTS

The sample consisted of 299 seniors. Results regarding their sociodemographic profile, dependency level, and comorbidities are presented in Table 1. The presence of men (50.5%) and women (49.5%) was balanced. Most participants were over 70 (79.2%) and had incomplete elementary school (59.5%). In most cases, their degree of dependency was III or IV (55.5%). The most common comorbidities were systemic arterial hypertension (SAH), which affected 79.6% of the sample, while 31.4% had diabetes melllitus (DM) and 27.1% had both.

Table 1. Characterization of seniors, according to sociodemographic aspects, dependency level, and comorbidities.

Variables (n=299)		N	%
Sex	Male	151	50.5
	Female	148	49.5
Age group	60 to 69	62	20.8
	70 to 79	111	37.1
	80 or older	126	42.1
Educational level	Illiterate	82	27.4
	Incomplete elementary school	178	59.5
	Complete elementary school and incomplete high school	16	5.3
	Complete high school and incomplete higher education	5	1.7
	Complete higher education	2	0.7
	Not informed	16	5.4
Dependency level	Level I and II	133	44.5
	Level III and IV	166	55.5
Comorbidities	Arterial hypertension	238	79.6
	Diabetes mellitus	94	31.4
	Arterial hypertension and diabetes mellitus	81	27.1
	Neurological impairment	29	9.7
	Heart and kidney disease	42	14.0
	Respiratory disease	15	5.0
	Other	20	0.7

Table 2 shows the results of the sociodemographic and economic characterization of the caregivers, as well as results related to the care provided. Most were women (77.9%), 40 or older (79.9%), with no partner (50.8%), incomplete or complete elementary education (61.6%). 78.6% did not have a job and 60.5% earned up to one minimum wage. Most were family to the elder being cared for (88.6%); 51.2% lived with them; 51.8% had provided care to them for 12 months or more.

Table 2. Sociodemographic, economic, and care-related characteristics of the informal caregivers.

Variables (n=299)		N	%
Sex	Male	66	22.1
	Female	233	77.9
Age group	18 to 39	59	19.7
	40 to 59	142	47.5
	60 or older	97	32.4
	Not informed	1	0.4
Marital status	Has a partner	147	49.2
	W/o partner	152	50.8
Educational level	Incomplete elementary school	124	41.5
	Complete elementary school and incomplete high school	60	20.1
	Complete high school and incomplete higher education	90	30.1
	Complete higher education	22	7.3
	Not informed	3	1.0
Has a job	Yes	64	21.4
	No	235	78.6
Income	Up to one minimum wage	181	60.5
	More than 1 minimum wage	86	28.8
	Not informed	32	10.7
Family relationship with the elderly person	Yes	264	88.3
	No	9	3.0
	Not informed	26	8.7

Variables (n=299)		N	%
Lives with the elder	Yes	153	51.2
	No	139	46.5
	Not informed	7	2.3
Time caring for the elder	Up to 12 months	136	45.5
	12 months or longer	155	51.8
	Not informed	8	2.7

Table 3 shows the distribution of the levels of care and the burden of caregivers, according to sociodemographic and economic variables of the caregivers and the older adults. The overload has four facets: nonexistent, mild, moderate, and intense. In all variables analyzed, most caregivers had no burden (61.2%). 30.1% presented mild burden; 8.0%, moderate burden; and 0.7%, intense burden. Mild and moderate burdens were more common in female informal caregivers (32.1%), those who have a family relation with the older person (37.1%), 40-year-old or older caregivers (34.5%), those without partners (22.7%), with an income up to one minimum wage (26.1%), incomplete elementary school (16.4%), and those who do not have a job(28.4%). This was also observed in caregivers who have been provided care for longer than 12 months (24.4%) and those who live with the older person (23.4%). There are no significant differences in burden in regard to gender. Nevertheless, 23.4% of those who cared for older adults above 70 presented with mild overload. Additionally, the higher the educational level of the older person, the lower the burden of the caregiver.

The caregivers of older people with higher dependency levels show mild and moderate scores more often (26.7%). The burden had a statistically significant relation with neurological impairment and other comorbidities (psychiatric disease, hypothyroidism, dyslipidemia, neoplasms). Heart and kidney disease showed p=0.077, quite close to the significant value considered for this analysis (p≤0.05). The more limiting the comorbidity, the more burdened the caregivers. Although the SAH is the most common comorbidity, it is not the one that burdens most caregivers (34.1%). Mild and moderate burdens were more common in caregivers of people with respiratory disease (66.6%), neurological impairment (62.0%), heart and kidney disease (52.3%), other (50.0%), DM and SAH (35.8%), and DM (33.0%).

Table 3. Caregiver burden, according to the sociodemographic and economic variables of caregivers and older adults.

Variables (n=299)		Overload			
		Nonexistent	Mild	Moderate	Intense
		n (%)	n (%)	n (%)	n (%)
Sex of the caregiver (p-value=0.111)*	Male	48 (16.0)	16 (5.3)	2 (0.7)	-
	Female	135 (45.1)	74 (24.7)	22 (7.3)	2 (0.7)
Family relations with the older adult (p-value=0.612)*	Yes	151 (50.5)	88 (29.4)	23 (7.7)	2 (0.7)
	No	7 (2.3)	2 (0.7)	-	-
Age group of the caregiver (p-value=0.115)**	18 to 39	48 (16.0)	9 (3.0)	2 (0.7)	-
	40 to 59	77(25.7)	50 (16.7)	14 (4.7)	-
	60 or older	57 (19.1)	31 (10.4)	8 (2.7)	1 (0.3)
Caregiver marital status (p-value=0.041)*	Has a partner	101 (33.8)	37 (12.4)	9 (3.0)	-
	W/o partner	82 (27.4)	53 (17.7)	15 (5.0)	2 (0.7)
Caregiver income (p-value=0.142)**	Up to one minimum wage	101 (33.8)	60 (20.1)	18 (6.0)	2 (0.7)
	More than 1 minimum wage	56 (18.7)	25 (8.4)	5 (1.7)	-
Educational level (p-value=0.205)**	Incomplete elementary school	73 (24.4)	37 (12.4)	12 (4.0)	2 (0.7)
	Complete ES and incomplete HS	30 (10.0)	23 (7.7)	7 (2.3)	-
	Complete HS and incomplete ES	59 (19.7)	26 (8.7)	5 (1.7)	-
	Complete higher education	18 (6.0)	4 (1.3)	-	-
Caregiver has a job (p-value=0.019)*	Yes	33 (11.0)	22 (7.3)	7 (2.3)	2 (0.7)
	No	150 (50.2)	68 (22.7)	17 (5.7)	-
Time caring for the older adult	Até 11 meses e 29 dias	97 (32.4)	33 (11.0)	5 (1.7)	1 (0.3)
	12 months or more	81 (27.1)	54 (18.1)	19 (6.3)	1 (0.3)

	Variables (n=299)	Overload			
		Nonexistent	Mild	Moderate	Intense
		n (%)	n (%)	n (%)	n (%)
(p-value=0.004)*					
Lives with the older adult (p-value=0.002)*	Yes	82 (27.4)	50 (16.7)	20 (6.7)	1 (0.3)
	No	98 (32.8)	37 (12.4)	3 (1.0)	1 (0.3)
Sex of the older adult (p-value=0.936)*	Male	90 (30.1)	48 (16.1)	12(4.0)	1 (0.3)
	Female	93 (31.1)	42 (14.0)	12 (4.0)	1 (0.3)
Age group of the older adult (p-value=0.415)**	60 to 69	36 (12.0)	20 (6.7)	6 (2.0)	-
	70 to 79	67 (22.4)	32 (10.7)	12 (4.0)	-
	80 or older	80 (26.7)	38 (12.7)	6 (2.0)	2 (0.7)
Educational level of the older adult (p-value=0.228)**	Illiterate	40 (13.4)	30 (10.0)	11 (3.7)	1 (0.3)
	Incomplete elementary school	117 (39.1)	49 (16.7)	11 (3.7)	1 (0.3)
	Complete ES and incomplete HS	8 (2.7)	8 (2.7)	-	-
	Complete ES and incomplete HS	2 (0.7)	3 (1.0)	-	-
	Complete higher education	2 (0.7)	-	-	-
Dependency level of the older adult (p-value=0.001)*	Level I and II	98 (32.8)	29 (9.7)	5 (1.7)	1 (0.3)
	Level III and IV	85 (28.4)	61 (20.4)	19 (6.3)	1 (0.3)
Comorbidities	Arterial hypertension *P-value=0.464* (n=238)*	149 (49.8)	68 (22.7)	20 (6.7)	1 (0.3)
	Diabetes mellitus *P-value=0.129* (n=94)*	63 (21.1)	28 (9.4)	3 (1.0)	-
	SAH+DM *P-value=0.303* (n=81)*	52 (17.4)	26 (8.7)	3 (1.0)	-
	Neurological impairment *P-value=0.004* (n=29)*	10 (3.3)	13 (4.3)	5 (1.7)	1 (0.3)
	Heart and kidney disease *P-value=0.077* (n=42)*	19 (6.3)	17 (5.7)	5 (1.7)	1 (0.3)
	Respiratory disease *P-value=0.077* (n=15)*	5 (1.7)	9 (3.0)	1 (0.3)	-
	Other *P-value=0.033* (n=20)*	9 (3.0)	9 (3.0)	1 (0.3)	1 (0.3)

Cronbach's alpha coefficient: 0,840. *t-test. ** Anova.

Table 4 shows the results of the general QoL evaluation of the caregivers, according to the frequency of responses, mean scores, and their respective standard deviations for each general question about quality of life. The mean score was regular in both questions. It was found that 62.2% of caregivers believe their QoL is good or very good, while 36.4% see it as not good nor bad. 58.1% feel satisfied with their health and 39.1% are indifferent or dissatisfied.

Table 4. Frequency of the responses of caregivers of older adults and mean scores in general quality of life questions. (n=299).

Question	Possible responses	n	%
How would you rate your quality of life?	1-very bad	4	1.3
	2-ruim	16	5.4
	3-neither bad nor good	93	31.1
	4 -good	154	51.5
	5-very good	32	10.7
	Mean Score (±SD) *	3.7 (±0.79)**	
How satisfied are you with your health?	1 - very dissatisfied	8	2.7
	2- dissatisfied	43	14.4
	3-neither satisfied nor dissatisfied	74	24.7
	4-satisfied	140	46.8
	5-very satisfied	34	11.4
	Mean Score (±SD) *	3.5 (±0.96)**	

*SD: Standard Deviation. **A mean score between 3 and 3.9 is classified as regular.

According to Table 5, the mean scores of all domains were statistically significant. The mean scores for the Whoqol-Bref domains varied from 59.38 to 70.83. The highest score was in the Psychological domain, which includes the facets positive feelings; thinking, learning, memory and concentration; self-esteem; body image and appearance; negative feelings; spirituality, religion, and personal beliefs. This shows good resilience on the part of the caregivers.

The lowest scores were in the domain Environment, whose facets are physical safety and security; home environment; financial resource; health and social care (availability and quality, opportunity to acquire new information and skills, participation); recreation and leisure; physical environment (pollution, noise, traffic, climate, transport). This shows that some factors related to the environment where the caregiver lives are compromised.

Table 5. Mean scores for the Whoqol-Bref domains, according to the evaluation of the caregivers of older adults (n=299).

Whoqol-Bref Domains	Cronbach's alpha	Md	Mean ± SD	CI (95%)	P-value (t test)
Physical	0.833	67.9	65.7±19.0	63.5 – 67.9	<0.001
Psychological	0.748	70.8	68.5±15.9	66.7 – 70.3	
Social relationships	0.717	66.7	64.2±22.4	65.4 – 66.7	
Environment	0.695	59.4	59.0±13.8	57.4 – 60.6	

Md: median. SD: standard deviation. CI (95%): confidence interval of 95%.

Burden and quality of life presented a negative correlation. There was a weak correlation between the burden and the Social Relationships domain (r: -0.234; p=0.000), as well as a moderate correlation between burden and the Physical (r: -0.465; p=0.000), Psychological (r: -0.538; p=0.000) and Environment (r: -0.379; p=0.000) domains, as shown in Table 6.

Table 6. Correlations between overload and quality of life for caregivers of older people. (n=299).

Whoqol-Bref domains	Overload	P-value
Physical	-0.465*	<0.001
Psychological	-0.538*	<0.001
Social relationships	-0.234*	<0.001
Environment	-0.379*	<0.001

* % significant correlation (p≤0.001).

Regarding the facets of the Whoqol-Bref domains, caregivers showed poor results regarding Positive Feelings (47.37); Financial Resources (45.97); and Recreation and Leisure opportunities (32.86). Furthermore, we found that the scores from the facets Energy and Fatigue (58.70); Sleep and Rest (56.86); Thinking, Learning, Memory and Concentration (60.00); Sexual Activity (58.15); New Information and Skills (58.03); Physical Environment (54.61); and Self-assessment of quality of life (64.34) were very close to their minimum threshold (50.0), indicating that these aspects of the quality of life of the caregivers are also compromised (Figure 1).

DISCUSSION

This study found that the profile of caregivers of older people with chronic disease is mostly comprised by women, over 40 years old, with no partner, and incomplete elementary school. Most of them live with the older person and have a family relationship with them, having been responsible for their care for more than 12 months. The overload was greater in caregivers of people aged 70+, due to the greater degree of dependency caused by their age and the presence of comorbidities. These results show that the work of the caregiver causes overload and stress, which directly interfere in their quality of life, compromising factors such as positive feelings, recreation and leisure, energy and fatigue, sleep and rest, not to mention their capacity of concentration and sexual practices.

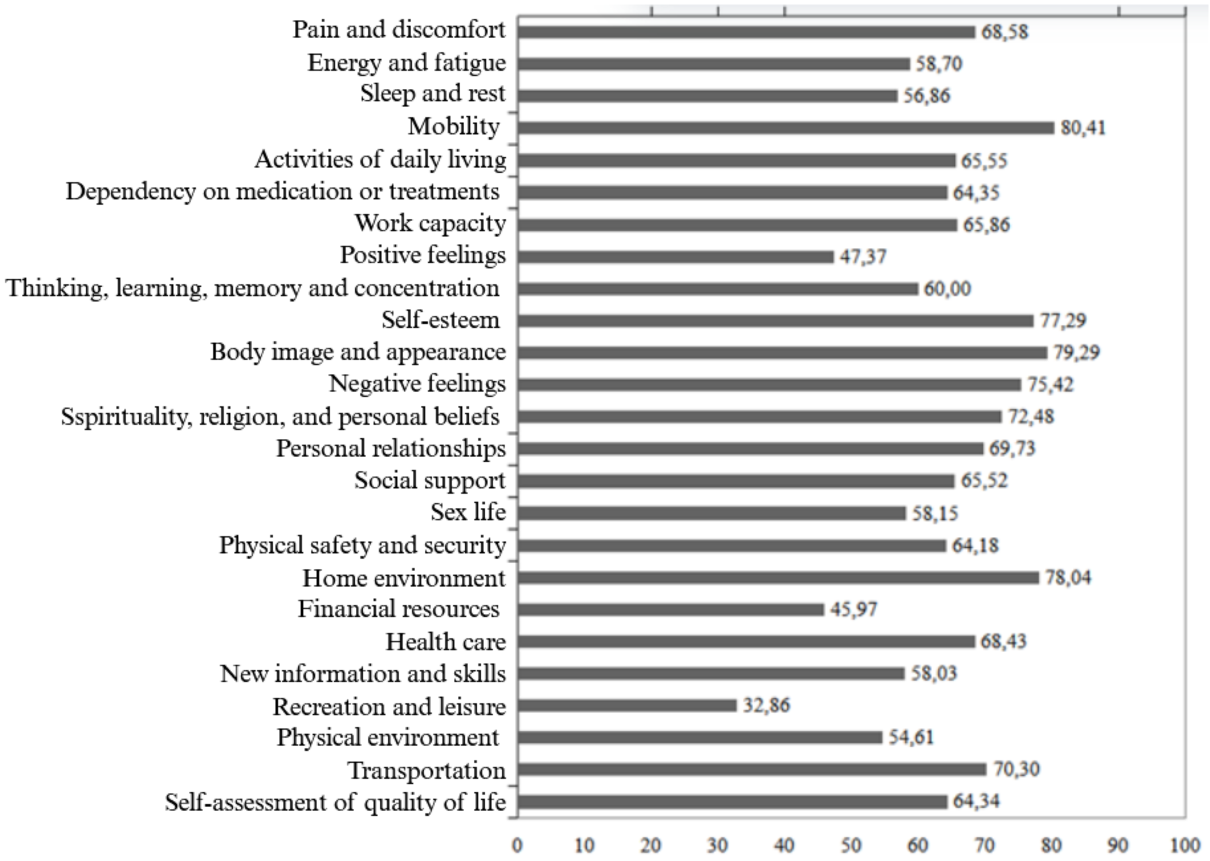

Figure 1. Mean scores for the facets of the Whoqol-Bref domains, according to the evaluation of caregivers of older adults. (n=299). Source: authors.

The analysis of the sociodemographic situation of the older adults hospitalized was similar to that of other studies.[14,15] The results may be related to the sharp growth of the population over 70, the greater longevity of women and high number of widows, and the greater exposure of men to health risk factors.[14] With regard to education, these disparities are common in Brazil, given that access to education was difficult in the past, in addition to the fact that studying was not a priority.[14,16] It is worth noting that the educational level is associated to cognitive development, which, in turn, is associated to one's ability to manage their self-care.[14,15] Furthermore, it is important to keep in mind that culture, educational level, age, and self-care capacity are factors that determine and condition health, interfering with one's understanding of aspects inherent to health, such as managing drugs, exercise, adequate diets, and others. Additionally, the aging process itself has negative impacts on one's functional capacity. [18]

The higher the age, the lower the functional capacity, and, consequently, the greater the dependency on other people's care.[19] Population aging must be watched closely, since it increases the incidence and prevalence of chronic-degenerative diseases. As a result, caregivers become increasingly needed to attend and understand the needs of this population. [15,28]

Currently, the caregiver for older individuals is increasingly common and necessary. The task of caring is very complex, long-lasting, and requires the caregiver not only to provide care, but also to be patient and dedicated, changing their personal and family routine and dealing with challenges and difficulties. Furthermore, these caregivers are not prepared to perform this role or lack the necessary information about how to do it. They often need to do other activities besides providing care, be they domestic or professional. As a result, the informal caregiver becomes physically and emotionally exhausted, leading to physical and emotional burdens that have an impact on their quality of life.[20,21]

The care is often provided by women, which become the main responsible for providing care to the older adults, as corroborated by other studies.[28,22,20,14] In this regard, there are sociocultural and historical relationships according to which the responsibility to provide care to the family is essentially female,[14,20] seeing as even when they are children, girls are educated to care for their family in the future.[23] Despite the growing insertion of women in the job market, when care must be provided to the family, the woman is the one who is under pressure to take responsibility for such care, which helps increase the levels of tension caused by the act of caring.[22,23]

In addition to the issue of gender, some studies show that most caregivers are aged 40+, have incomplete elementary school, mostly do not have a job, earn up to one minimum wage, and have a partner — results that differ from those found here.[14,21,22,24-28] The older age that is common among caregivers is a challenge, seeing as, due to the fact that caregivers are nearly as old as the people they care for, they have themselves levels of impairment to their functional capacity caused by the aging process and their own chronic diseases, which may interfere in the quality of the care provided and in their own care. Thus, their impaired health and their burden compromise their quality of life.[22,27]

Another factor that has an impact on burden is the educational level of the caregivers, given that those with higher educational levels suffer less or even do not suffer with burdens.[17,18] As discussed above, of the caregiver has more knowledge, they understand the disease better, which can facilitate the use of procedures and technologies when providing care, avoiding their prolonged exposure to stress. Lower educational levels and income are important indicators of social vulnerability, and can indicate the lack of individual, family, and social resources to meet the needs of people. In this context, they can interfere in the ability to receive and transmit information, and in the performance of activities associated with caring for the older adult and for themselves.[26] Active aging requires policies based on changes of habits and lifestyles, promoting health and preventing disease.[4]

In Brazil, the number of older adults who depend on others have grown in proportion to population aging, and health services are insufficient to attend the needs of this population.[27,28] The family, usually in the form of a daughter or wife, takes on this role.[24-24] In the family context there is a relationship of closeness and affection between the caregiver and the older person, which can be a positive influence for the caregiver to start this task and adapt to it. Nonetheless, the same affection bond means that the caregiver will often not let their difficulties show or even provide care because they feel obliged by social values and that they have no choice — a situation that usually affects only one family member. This causes a burden and physical and mental strains, especially in caregivers who are married, have the same educational levels, family bonds, and in cases where the person receiving care has arterial hypertension.[26]

Another important element that can burden a caregiver of older people is living with the individual they care for. In addition to the family factors mentioned above, this requires them to spend most of their day providing care, treating their own needs as secondary, seeing as they lack the time to exercise or enjoy moments of leisure. Thus, their physical and mental health becomes compromised, leading to chronic disease, depression, and other issues. This is made worse when they provide care for more than 12 months. [29,30]

In addition to the factors associated with the burden that were already mentioned, comorbidities and the level of dependency of the person receiving care can also increase the burden of caregivers. In this context, the burden is related to physical and emotional strain, often harming the family structure, leading to social isolation and the loss of identity on the part of the caregiver, who must receive support.[14]

As for their quality of life, the results of this study suggest that caregivers evaluate their QoL as good, feeling satisfied with it. In most domains and facets analyzed, the classification was regular — the same result found in literature. [15,28,38] The domain with the best evaluation was the psychological, with most caregivers showing good resilience. In this domain, body image and appearance were the facets with the best evaluation, while positive feelings received the worst. The factors that influence the QoL of the family caregiver are: stress; depression; poor sleep quality; type of dementia and neuropsychiatric symptoms; support, social support, and access to health services; leisure; pre-existing health problems; interventions that are funded to train caregivers; and spirituality.[28]

When the QoL of caregivers is impaired, this can lead to consequences both for the care that must be provided and for the health of the people who are providing care. In the current context of population aging, caregivers feel they have no support, ability, or are too exhausted to play this role, which may lead them to develop illnesses.[28] This situation has an impact on primary health care, especially in regard to integral care. This does not affect only the older person who is receiving care, but also the caregiver, whose demands related to their own health lead to burden. Policies to promote the health of this population significantly affect their QoL and, as a result, reduce their burden, as they feel supported by the health teams.[31]

The main limitations of this study are its cross-sectional design, which prevents us from establishing cause-and-effect relationships; and the fact that it only included professionals from one municipality, not allowing its results to be generalized. However, the study reveals important aspects of the relationship of these professionals with their work, especially seeing as their main role is associated with the practice of health care.

Another limitation of this study was finding a significant number of interviewees, given that many factors made data collection more difficult, including the frequent turnover of support persons and the time necessary for the interviews, as participants answered the questions in an environment where there was a lot of noise and many health workers coming to provide bedside care. Nevertheless, the caregivers received the researcher well and naturally.

This study provided a thorough diagnosis about the quality of life and burden of caregivers of older individuals, giving significant contributions to the formulation of public policies to promote active aging. This analysis may give support for primary health services to identify more precisely the needs of this audience and invest on actions to better the physical and mental health of caregivers of older people. These initiatives can include creating more humane environments and improving support networks, in order to improve conditions of life and the well-being of this vulnerable population.

CONCLUSION

This study found that females are the main responsible for caring for older adults with whom they have family relationships. They are predominantly aged 40+, with no partner, incomplete elementary school, and live and have an affection bond with the older person, having cared for them for more than 12 months. Their burden levels, considering the many sociodemographic and economic characteristics of both caregivers and the older people they care for, suggest that the quality of life of the caregiver is affected the most. Burden levels were classified as mild and moderate, especially when caring for adults who are especially old, due to the presence of severe comorbidites and a higher level of dependency.

Thus, we can state that the role of the caregiver is directly tied to the increase in burden and stress, which substantially affects the quality of their lives. This is especially true regarding Positive Feelings, Financial Resources, Recreation and Leisure, Energy and Fatigue, Sleep and Rest. It also affects cognitive functions, such as Thinking, Memory and Concentration, and even Sexual Activity.

Considering the growing number of family caregivers, it is essential to understand the characteristics, context, and health needs of this group. The health system, especially in regard to the management of services, is dealing with a new and urgent challenge: the implementation of public policies and health actions to support these caregivers, in order to reduce their burden and improve their quality of life. This study provides an important foundation for reflections that seek to preserve the physical and mental health of caregivers and provide better health care to their families, especially in the care of older adults.

REFERENCES

1. Rudnicka E, Napierała P, Podfigurna A, Męczekalski B, Smolarczyk R, Grymowicz M. The World Health Organization (WHO) approach to healthy ageing. Maturitas. 2020; 139:6–11. http://dx.doi.org/10.1016/j.maturitas.2020.05.018.
2. Maia LC, Colares T de FB, Moraes EN de, Costa S de M, Caldeira AP. Robust older adults in primary care: factors associated with successful aging. Rev Saúde Pública. 2020;54:35. http://dx.doi.org/10.11606/s1518-8787.2020054001735
3. Placideli N, Bocchi S. Modelos de atenção integral para idosos no mundo: revisão da literatura. Physis. 2021;31(3):e310326. http://dx.doi.org/10.1590/S0103-73312021310326
4. China DL, Frank IM, Silva JB da, Almeida EB de, Silva TBL da. Envelhecimento Ativo e Fatores Associados. Kairós-Gerontologia. 2021;24:141-56. https://doi.org/10.23925/2176-901X.2021v24i0p141-156
5. Santos KS, Ramos DA, Gonçalves JR. Análise da Política Nacional de Saúde do Idoso: uma revisão de literatura. Rev JRG Estud Acadêmicos. 2020;3(7):591-611. http://dx.doi.org/10.5281/zenodo.4281496.
6. Souza ANM, Martins DD, Medeiros GN, Alves RJ, Carlos BE. A Gente Fica Doente Também: Percepção do Cuidador Familiar sobre o seu Adoecimento. Gerais Rev Interinst Psicol. 2020;13(1):1-20. http://dx.doi.org/10.36298/gerais2020130106.
7. Lima EEP. Cuidador de Idosos. 1ª ed. São Paulo: SENAC São Paulo; 2018. 256 p. ISBN: 9788539623853.
8. Scazufca M. Brazilian version of the Burden Interview scale for the assessment of burden of care in carers of people with mental illnesses. Rev Bras Psiquiatr. 2002;2424(11):12–712. http://dx.doi.org/10.1590/S1516-44462002000100006
9. Bandeira M, Calzavara MGP, Castro I. Estudo de validade da escala de sobrecarga de familiares cuidadores de pacientes psiquiátricos. J Bras Psiquiatr [Internet]. 2008;57(2):98-104. http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0047-20852008000200003&lng=pt&tlng=pt http://dx.doi.org/10.1590/S0047-20852008000200003.
10. Dadalto EV, Cavalcante FG. O lugar do cuidador familiar de idosos com doença de Alzheimer: uma revisão de literatura no Brasil e Estados Unidos. Cien Saude Colet. 2021;26(1):147-57. http://dx.doi.org/10.1590/1413-81232020261.38482020.
11. Rocha MIF, Silva WWSV, Teixeira KSS, Silva Filho FAS. Dificuldades enfrentadas pelo cuidador do idoso com doença de Alzheimer: uma revisão integrativa. Rev Sustinere. 2022;10(2):573-90. http://dx.doi.org/10.12957/sustinere.2022.62570.
12. Rodríguez-González AM, Rodríguez-Míguez E, Clavería A. Determinants of caregiving burden among informal caregivers of adult care recipients with chronic illness. J Clin Nurs. 2021;30:1335-46. http://dx.doi.org/10.1111/jocn.15683.
13. Goes M, Lopes M, Maroco J, Oliveira H, Fonseca C. Psychometric properties of the WHOQOL-BREF(PT) in a sample of elderly citizens. Health and Quality of Life Outcomes. 2021;19(1):146-146. http://dx.doi.org/10.1186/S12955-021-01783-Z
14. Kobayasi DY, Rodrigues RAP, Fhon JRS, Silva LM, Souza AC, Chayamiti EMPC. Sobrecarga, rede de apoio social e estresse emocional do cuidador do idoso. Av Enferm. 2019;37(2):140-8. http://dx.doi.org/10.15446/av.enferm.v37n2.73044.

15. Albuquerque FKO, Farias APEC, Montenegro CS, Lima NKF, Gerbasi HCLM. Qualidade de vida em cuidadores de idosos: uma revisão integrativa: Quality of life of caregivers of the elderly: an integrative review. Rev Enferm Atual In Derme. 2019;87(25). http://dx.doi.org/10.31011/reaid-2019-v.87-n.25-art.189.
16. Borba AKOT, Arruda IKG, Marques APO, Leal MCC, Diniz AS. Conhecimento sobre o diabetes e atitude para o autocuidado de idosos na atenção primária à saúde. Cien Saude Colet. 2019 Jan;24(1):125-36. http://dx.doi.org/10.1590/1413-81232018241.35052016.
17. Jaime R, Sakurai H, Otakeguchi K, Orihara S, Hirose D, Sato T, Hirao K, Kanetaka H, Hanyu H, Shimizu S. Long-term effects of caregivers' education on depressive symptoms and sense of burden in caregivers of patients with dementia. Psychogeriatrics. 2023. https://doi.org/10.1111/psyg.12986.
18. Chevrier B, Untas A, Dorard G. Young adult caregivers in higher education: a study of prevalence in France. Journal of Further and Higher Education. 2023;47(5):699–710 https://doi.org/10.1080/0309877X.2023.2190878
19. Chien SC, Chang YH, Yen CM, Onthoni DD, Wu IC, Hsu CC, Chiou HY, Chung RH. Exploring concepts and trends in informal caregiver burden: systematic review using citation network and content analysis. Aging Clin Exp Res. 2023;35(12):2873-2885. https://doi.org/10.1007/s40520-023-02582-w.
20. Lin CC, Marques IVP, Silva GC, Silva EQ, Colombari AV, Nascimento Junior JRA. Quality of life, stress, coping and burden of caregivers of older people with Alzheimer's. Fisioter mov. 2024;37:e37132. https://doi.org/10.1590/fm.2024.37132
21. Martins LBF, Moura CRB, Carvalho AFM, Coelho NPMF, Feitosa MCP, Macêdo JLC. Estudo comparativo sobre qualidade de vida, sobrecarga e sintomas musculoesqueléticos em cuidadores de idosos. REAS.2020;12(3):e2933 https://doi.org/10.25248/reas.e2933.2020.
22. Nunes DP, Brito TRP, Duarte YAO, Lebrão ML. Cuidadores de idosos e tensão excessiva associada ao cuidado: evidências do Estudo SABE. Rev Bras Epidemiol. 2018;21. https://doi.org/10.1590/1980-549720180020.supl.2.
23. Isaac L, Ferreira CR, Ximenes VS. Cuidar de idosos: um assunto de mulher? Estud Interdiscip Psicol. 2018;9(1):108–25. https://doi.org/10.5433/2236-6407.2018v9n1p108.
24. Afonso RM, Tomáz T, Brandão D, Ribeiro Ó. Cuidadores de idosos centenários na região da Beira Interior (Portugal). Análise Psicológica [Internet]. 7 de junho de 2019;37(2):147–60. https://doi.org/10.14417/ap.1482.
25. Mendes PN, Figueiredo MLF, Santos AMR, Fernandes MA, Fonseca RSB. Sobrecargas física, emocional e social dos cuidadores informais de idosos. Acta Paul Enferm. 2019;32(1):87–94. https://doi.org/10.1590/1982-0194201900012.
26. Jesus ITM, Orlandi AAS, Zazzetta MS. Burden, profile and care: caregivers of socially vulnerable elderly persons. Rev Bras Geriatr Gerontol. 2018 Mar;21(2):194–204. https://doi.org/10.1590/1981-22562018021.170155.
27. Aires M, Fuhrmann AC, Mocellin D, Pizzol FLFD, Sponchiado LF, Marchezan CR, et al. Burden of informal caregivers of dependent elderlies in the community in small cities. Rev Gaúcha Enferm. 2020;41(spe). https://doi.org/10.1590/1983-1447.2020.20190156.
28. Rocha-Balcázar J, García-Peña C, Figueroa-Solano L, Castellanos-Perilla N, Cortes-Sarmiento DS, Pérez-Zepeda M. Caregiver burden in caregivers of hospitalized older adults and its associated factors. Geriatr Gerontol Aging. 2018; 12:196-201. https://doi.org/10.5327/Z2447-211520181800054.
29. Pereira Gomes N, Chaves Pedreira L, Gomes Neto M, Morais da Conceição M, dos Santos Sampaio R, Farias Amorim R. Caregivers for older people and the working conditions associated with care. Saúde e Pesquisa. 2024;17(1). https://doi.org/10.17765/2176-9206. 2024v17n1.e12239 .
30. Silva RAE, Silva CN, Braga PP, Friedrich DBC, Cavalcante RB, Castro EAB. Management of home care by family caregivers to elderly after hospital discharge. Rev Bras Enferm. 2020;73:e20200474. https://doi.org/10.1590/0034-7167-2020-0474
31. Lacerda MA, Silva LLT, Oliveira F, Coelho KR. O cuidado com o idoso fragilizado e a Estratégia Saúde da Família: perspectivas do cuidador informal familiar. Rev baiana enferm. 2021;35:e43127. https://doi.org/10.18471/rbe.v35.43127