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Caregivers of elderly and excessive tension associated to care: evidence of the Sabe Study

Cuidadores de idosos e tensão excessiva associada ao cuidado: evidências do Estudo SABE

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ABSTRACT: ***Introduction:*** Multiple illness and injury classes can cause a functional disability of the elderly, or the right to seek help from another person. Caregiving can be generated without the caregiver functions, leading to burden. ***Objective:*** to describe the sociodemographic and care profile of caregivers of the elderly and to analyze the factors associated with excessive stress regarding care. ***Method:*** This is a cross-sectional study, part of the SABE (Health, well-being and aging) Study, carried out in the city of São Paulo in 2010, with 362 caregivers. The excessive stress associated with care was evaluated by the Zarit Scale, and the load was found to be less than 24 points and the presence of burden was considered, with scores ≥ 24 points. Hierarchical Logistic Regression was used to analyze the factors associated with the stress of family caregivers. ***Results:*** Most of the caregivers were family members (91.5%), being female (75.4%), mean age 53.9 years (SD ± 15.5), married (65.3%), lived in the same household with the elderly (68.2%). One-third of them presented burden, which was associated with age (OR = 1.04, p = 0.001), family dysfunction (OR = 5.60, p = 0.000), continuous care (OR = 78, p = 0.030). ***Conclusions:*** The data reveal the need to maintain their needs and support to caregivers, especially their relatives and their sources of life and their debts.

Keywords: Aged. Family. Caregivers.

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**in memoriam.*
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RESUMO: ***Introdução:*** A presença de múltiplas doenças e agravos crônicos pode ocasionar a incapacidade funcional do idoso, o qual poderá requerer a necessidade de ajuda de outra pessoa. A prestação de cuidados diários e ininterruptos pode gerar no cuidador situações estressoras, levando-o a sobrecarga. ***Objetivo:*** Descrever o perfil sociodemográfico e assistencial dos cuidadores de idosos e analisar os fatores associados à tensão excessiva associada ao cuidado. ***Métodos:*** Trata-se de um estudo transversal, parte do Estudo Saúde, Bem-Estar e Envelhecimento (SABE), realizado no município de São Paulo, no ano de 2010, com 362 cuidadores. A tensão excessiva associada ao cuidado foi avaliada pela escala de Zarit, e considerou-se ausência de sobrecarga pontuação inferior a 24 pontos e presença de sobrecarga os escores ≥ 24 pontos. Utilizou-se regressão de logística hierárquica para analisar os fatores associados à tensão dos cuidadores familiares. ***Resultados:*** A maioria dos cuidadores era familiar (91,5%), do sexo feminino (75,4%), com média de idade de 53,9 anos (desvio padrão — DP ± 15,5), casado (65,3%), residente no mesmo domicílio do idoso (68,2%). Um terço deles apresentou sobrecarga de cuidado, que foi associado à idade (*odds ratio* — OR = 1,04; p = 0,001), ao relato de disfunção familiar (OR = 5,60; p = 0,000) e à prestação de cuidado contínuo (OR = 2,78; p = 0,030). ***Conclusão:*** Os dados revelam a necessidade de políticas públicas que incluam as necessidades e o suporte aos cuidadores, em especial, os familiares, a fim de melhorar sua qualidade de vida e a sua prestação de cuidados às pessoas idosas.

Palavras-chave: Idoso. Família. Cuidadores.

INTRODUCTION

The increase in life expectancy has been accompanied by an increase in the prevalence of diseases and noncommunicable chronic diseases with a direct impact on social and health policies, since there is also a progressive increase in people with functional limitations due to such diseases with a constant need for care[1]. Caring for someone is complex because it involves a series of changes and adaptations both of the caregiver and of the one being taken care of. Studies on elderly caregivers identify their profile historically as familiar, female, spouse or daughter, aged between 50 and 55 years[2-7].

The family caregiver, most of the time, has to take on such a function almost suddenly, and is generally not prepared, either psychologically or technically, for the performance of his new role. Very often, either by a family agreement or by exclusive lack of options, a family member is "elected" as an ideal, natural, necessary, desirable or possible caregiver, even if this person does not know, has not been consulted or is not that person's choice.

This creates personal, family, and even professional conflicts if they perform other day-to-day job functions. Such circumstances can create a state of prolonged stress, leading the caregiver to ignore their own needs and neglect self-care, resulting in illness or even premature death. On the other hand, evidence suggests that carers' burden may ultimately lead to neglect of the person being taken care of[8,9].

Therefore, it is necessary to be clear about the conditions triggering the burden of the caregivers in order to allow the adequate therapeutic planning that involves the elderly,

caregiver and family, thus enabling the prevention of health problems and the improvement in the quality of life of all involved.

Thus, the objectives of the present study were to describe the sociodemographic and care profile of caregivers of the elderly and to analyze the factors associated with excessive stress regarding care.

METHODS

A cross-sectional study using the database of the Health, Welfare and Aging Study (*Estudo Saúde, Bem -estar e Envelhecimento* – SABE), referring to cohorts A, B and C of the year 2010. The sample consisted of 362 caregivers, family members or not (domestic servant, paid caregiver or other non-family figures), living in the city of São Paulo (SP), who were characterized as to age, gender, schooling, marital status, family relationship with the elderly, frequency of care and residence or not with the person cared for.

The excessive stress associated with care was only verified among family caregivers (n = 331); hence the 31 non-family caregivers being excluded from the analysis of the factors associated with this tension. For this evaluation, the Zarit Burden Interview (ZBI)[10] scale was adapted and validated in Brazil[11]. This scale evaluates the informal caregiver's burden in relation to different domains: health, social life, economic situation, mood and type of relationship with the elderly person. It is composed of 22 items, each 1 categorized from 0 (never) to 4 (always) points, making a total of 88 points that reflect the level of tension (burden) of the caregiver. The higher the score, the greater the identified burden. There is no established cut-off point for the Brazilian population that has been validated; therefore, tertiles have been used for classification.

Initially, the normal distribution of the burden variable, which was not detected ($p = 0.000$), was tested by the Kolmogorov-Smirnov test. Then, the burden among family caregivers was divided into tertiles:

- 1st tertile: < 12 points;
- 2nd tertile: between 12 and 23 points;
- 3rd tertile: ≥ 24 points.

Excessive stress associated with care (burden) was considered for the caregivers classified in the third tertile. First and second tertiles were grouped because they did not present statistical differences, being classified as absence of excessive tension.

We investigated the association between excessive tension of the caregivers and the following characteristics:

- sociodemographic: gender, age (continuous), marital status (married, widower, separated, single) and degree of kinship with the elderly (spouse, child, grandchild, sibling, son/daughter-in-law or other relative);

- health conditions of the elderly: difficulty in carrying out basic activities of daily living (ADL) (eating, bathing, dressing, walking a room, getting up and sitting in bed, going to the bathroom) and instrumental activities of daily living (IADL) (taking care of one's own money, using means of transportation, buying food, placing a phone call and taking one's own medication), depressive symptoms, cognitive decline, number of diseases, referred diseases (hypertension, diabetes, osteoporosis, chronic obstructive pulmonary disease, cardiovascular disease, stroke and osteoporosis) and number of medications (none, only one and more than one). The presence of depressive symptoms was evaluated by the brief geriatric depression scale, with cutoff values above five[12]. It was established as endowed with cognitive decline the elderly that presented values < 13 points in the mental state mini exam[13];
- variables related to the care and relationship of the caregiver with the elderly: family functionality, time in the caregiver role (< 1 year, 1 to 5 years, ≥ 5 years), place of residence (same household, nearby household and distant household), impact of the activity on work/study, time spent on care (full-time, once a day, alternate days and whenever needed), and whether or not to receive help from another caregiver.

The family functionality was evaluated by family APGAR (adaptability, partnership, growth, affection and resolve), validated in Brazil by Duarte[14]. This is a screening test composed of the five predominant domains in family relationships — adaptation, companionship, development, affectivity and resolving ability —, that assess the degree of satisfaction of the family member in question and the behavior of their family towards each one of them, expressed in numerical form, ranging from 0 (never) to 4 (always). Scores from 0 to 8 classify the family as having high family dysfunction; 9 to 12, moderate family dysfunction; and from 13 to 20, good family functionality[14].

The analysis was performed in Stata version 11.0. Logistic regression was used to analyze the association of carers burden with explanatory variables. The magnitude of the association was estimated by the simple and adjusted *odds ratio* (OR), at a significance level of 5%. The hierarchical analysis was used, following a distal-proximal direction, starting with the sociodemographic characteristics of the caregiver (block 1), followed by variables related to the elderly's health conditions (block 2) and then variables related to care and to the relationship between the caregiver and the elderly (block 3) (Figure 1).

The variables that obtained $p < 0.20$ in the univariate analysis were included in their respective blocks for modeling. From this, they were being conjugated, constructing two more models (block 1 + 2 and block 1 + 2 + 3). A variable was maintained in the model of its respective block when it presented $p \leq 0.05$ or when there were changes in adjusted OR greater than 10% in the variables of the previous block. The variables of the block already tested were kept and lost significance when a new variable of another block was included.

The SABE Study of 2000 was submitted and approved by the National Commission for Ethics in Research (*Comissão Nacional de Ética em Pesquisa* – CONEP) (opinion No. 315/99).

The waves from 2006 and 2010 were submitted and approved by the Research Ethics Committee (*Comitê de Ética em Pesquisa* – COEP) of the Public Health College of the University of São Paulo (opinions No. 83/06 and No. 2.044 / 10, respectively).

RESULTS

Of the 362 caregivers evaluated, 91.5% were family members and 8.5% were nonfamiliar. Among non-family caregivers, the majority were female (92.2%), with a mean age of 50.7 years (SD ± 12.7) and married (44.4%). Among the family caregivers, 53.6% were sons/daughters, 28.9%, spouses, 4.0%, siblings, 3.7%, grandchildren, 3.4%, sons-in-law or daughters-in-law and 6.4%, other relatives. Regarding the time dedicated to care, 34.4% reported

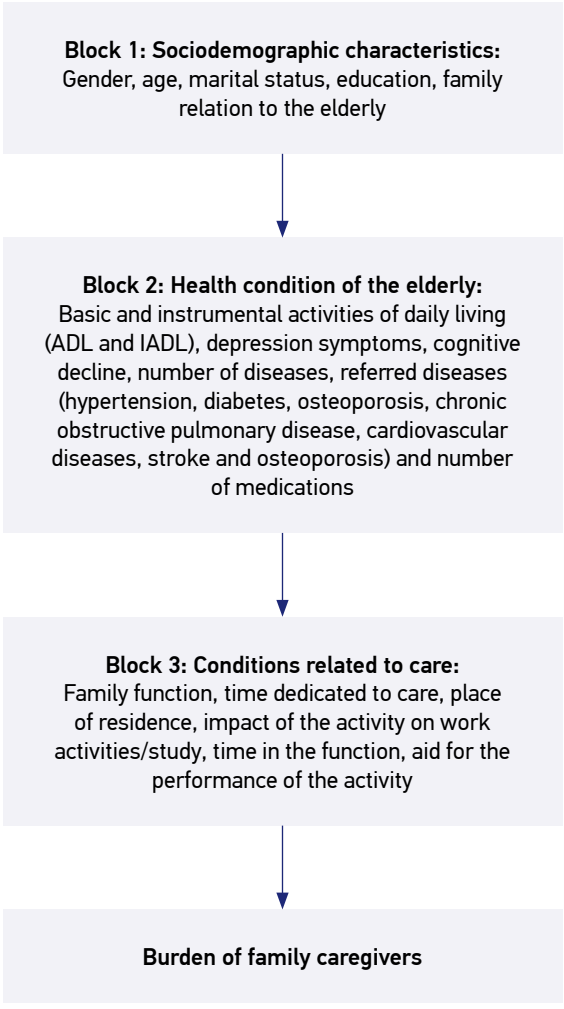

Figure 1. Hierarchical analysis blocks.

Table 1. Distribution (%) of caregivers according to sociodemographic and care characteristics, and type of caregiver. Municipality of São Paulo, 2010 (n = 362).

Characteristics	Family (n = 331)	Non-family (n = 31)	p-value
Gender			
Male	24.6	2.8	0.043*
Female	75.4	92.2	
Age (Mean ± SD)	53.9 ± 15.5	50.7 ± 12.7	0.280
Age in categoriess (years)			
< 60	61.0	75.7	0.162
≥ 60	39.0	24.3	
Marital status			
Single	21.1	14.6	0.004*
Married	65.3	44.4	
Separated	8.3	28.9	
Widowed	5.3	12.1	
Education			
No	7.1	8.0	0.881
Yes	92.9	92.0	
Geographical distance from the elderly			
Same household	68.2	21.3	0.000*
Nearby household	27.4	46.2	
Distant household	4.4	32.5	
Frequency of help			
Whenever necessary	41.9	53.1	0.574
Once a week/alternate days	2.0	1.3	
Once a day	21.7	13.1	
Full-time	34.4	32.5	
How long has been taking care of the elderly (years)			
Less than 1 year	11.3	34.1	0.014*
1 to 5	30.7	30.4	
More than 5	58.0	35.5	
Having assistance in providing care			
Yes	36.1	51.1	0.248
No	63.9	48.9	
Total	91.5	8.5	

Source: SABE Study (2010). *Values lower than 0.05.

Table 2. Distribution (%) of family caregivers according to excessive stress associated with care and socio-demographic and care characteristics. Municipality of São Paulo, 2010 (n = 321*).

Variables	Excessive stress associated with care		OR	p-value
	No	Yes		
Gender				
Male	77.6	22.4	1.00	0.062
Female	64.0	36.0	1.95	
Age (Mean ± SD)	51.9±	58.6	1.03	0.001**
Marital status				
Married	67.5	32.5	1.00	
Single	72.5	24.5	0.67	0.241
Separated	53.1	46.9	1.83	0.233
Widowed	50.6	49.4	2.02	0.129
Family relation to the elderly				
Spouse	59.1	40.9	1.82	
Son/daughter	69.7	30.3	1.14	0.709
Other family member	72.5	27.5	1.00	0.118
Geographic distance fromt he elderly				
Same household	61.3	38.7	1.00	
Nearby household	80.2	19.8	0.39	0.005**
Distant household	76.6	23.4	0.48	0.299
Frequency of help				
Whenever necessary	80.2	19.8	1.00	
Alternate days	68.1	31.9	1.89	0.622
More than once a day	69.2	30.8	1.80	0.139
Full-time	50.5	49.5	3.98	0.000**
Stopped working				
No	69.3	30.7	1.00	0.144
Yes	58.6	41.4	1.59	
How long has been taking care of the elderly (years)				
Less than 1 year	58.0	42.0	1.00	
1 to 5	67.8	32.2	0.65	0.322
More than 5	66.6	33.4	0.69	0.348
Having the help of someone				
No	64.3	35.7	1.00	0.310
Yes	68.9	31.1	0.78	
Family dysfunction				
No	73.2	26.8	1.00	
Yes	38.7	61.3	4.31	0.000**
Total	69.6	30.4		

*Ten family caregivers did not respond to the Zarit scale. **Values lower than 0.05. Source: SABE Study (2010).

care at all times and 41.9% when necessary. Some of them (19.7%) reported having left their work activities to take on the role of caregiver (Table 1).

Differences between family and non-family caregivers were observed in the marital state, in the place of residence and in the time of exercise in the caring role. It was noted that most family caregivers reported being married, living with the elderly and exercising the function for more than five years (Table 1).

In the assessment of excessive stress associated with care, 30.4% of the caregivers, that is, almost a third of them, presented scores higher than 24 points, thus creating a higher burden (Table 2).

In the univariate analysis, it was observed that the tension levels were associated with the increase of the age. Not living in the same household as the elderly is a protective factor of the burden, when compared to those who lived in the same household. Referring to the exercise of the function as continuous is associated with greater burden in relation to those who assisted according to the need of the elderly, which, in a way, expresses the tension involved in the performance of the function, which is so intense that becomes immeasurable. The identification of the family as dysfunctional by the caregiver increased four times the chance of having tension associated with care (Table 2).

Caring for more dependent elderly significantly increases the chance for the burden of caregivers: 2.84 for ADL and 22.5 for IADL. The same can be observed among elderly with cognitive decline (OR = 1.98, p = 0.10) and encephalic vascular accident (OR = 2.07, p = 0.009) (Table 3).

In the multiple analysis, the characteristics associated with the excessive stress of family caregivers were age (OR = 1.04, p = 0.001), family dysfunction (OR = 5.60, p = 0.000) and continuous care (OR = 2.78, p = 0.030), adjusted for the caregiver's gender, difficulty in performing ADL, presence of cognitive decline and encephalic vascular accident in the elderly (Table 4).

DISCUSSION

In the most recent study, it can be observed that, even today, that there is a predominance of married women with an average age of over 50 years among caregivers of family and non-family elderly, corroborating other findings[3,4,7,8,15-17]. Historically, women have taken on the role of caring for their most needy family members, initially because such a role is seen as more feminine, then because they had not yet been in the labor Market[18,19].

Although the social panorama has been drastically modified and, today, it is impossible to imagine the labor market without the contribution of women, protective legislative measures to working daughters/wives have not been adopted in the same way as for working mothers, which contributes significantly to the elevation of blood pressure levels.

Daughters take care of elderly parents even if there are male children in the family. These, sometimes, take care of material help or external tasks, such as transporting the elderly to other environments (consultations, examinations etc.)[20].

This reality and the changes in family arrangements[21] contribute to the increase in the proportion of male caregivers (25%). This data is superior to those found by Gonçalves et al.[22] (15.7%) and Vilela et al.[23] (12.5%), similar to Fuhrmann et al.[3] and lower than those found by Gonçalves et al.[24] (40.2%), Caregiving USA 50 +[25] (40.0%), and Gratão et al.[4] (33.8%).

Table 3. Distribution (%) of the elderly according to health conditions and excessive stress associated with care. Municipality of São Paulo, 2010 (n = 321).

Variables	Excessive stress associated with care		OR	p-value
	No	Yes		
Difficulties in ADL				
None	73.3	26.7	1.00	
One or two	75.1	24.9	0.91	0.768
Three or more	49.1	50.9	2.84	0.001*
Difficulties in IADL				
None	97.3	2.7	1.00	
One or two	76.3	23.7	11.10	0.045*
Three or more	61.4	38.6	22.51	0.006*
Clinical conditions				
Hypertension	68.6	31.4	0.76	0.397
Diabetes	66.6	33.4	1.03	0.890
Chronic obstructive pulmonar disease	62.4	37.6	1.26	0.608
Heart disease	61.9	38.1	1.41	0.213
Stroke	54.2	45.8	2.07	0.009*
Osteoarticular disease	67.9	32.1	0.96	0.902
Osteoporosis	72.7	27.3	0.70	0.163
Multimorbidity	66.0	34.0	1.24	0.495
Polypharmacy	64.9	35.1	1.36	0.298
Cognitive decline	57.3	42.7	1.98	0.010*
Depression	64.7	35.3	1.79	0.077
Total	69.6	30.4		

ADL: basic activities of daily living; IADL: instrumental activities of daily living. *Values lower than 0.05. Source: SABE Study (2010).

This change is a challenge for health professionals, especially nurses, who should broaden their gaze to the "caretaker man" and review their associated stereotypes of caring as a feminine function. It is necessary and possible to encourage them to take on this family task, such as those who have decided to take care of their wives, bravely opposing social and cultural values and embarking on the task of caring, classified as eminently feminine[24].

The presence of middle-aged caregivers is also a challenge, since their functional reserve may be compromised and may impact, at some point, the best performance of their functions, compromising the quality of care provided to more dependent elderly. In addition, they may neglect their own care, thus accumulating the risk of developing physical and emotional illnesses that may compromise their health and negatively reflect on caretaking[5,8,21].

A study developed with 1,087 family caregivers (≥ 50 years old) revealed that they expressed a desire to receive information about how to keep their loved ones safe at home (43%) and how to manage their own stress levels (42%)[25]. Some studies[17,26,27] pointed out that caregivers need professional support and a space to share their doubts and desires, reinforcing the need to implement public policies aimed at the health care of the caregiver, as well as actions to instrumentalize families for the effective assistance to their more dependent elderly relatives.

Most caregivers (75%) lived with the elderly, which, on the one hand, may facilitate the performance of care activities and, on the other hand, contribute to the unfavorable economic conditions of families[24]. Many caregivers are unemployed and survive in a situation of living with the elderly, also living on the income of the latter while providing care[1].

Families are still the primary caregivers of the elderly due to cultural issues and the shortage of long-term care services[28]. They are responsible for social, functional, economic,

Table 4. Factors regarding excessive stress associated with care in family caregivers of the elderly. Hierarchical multiple logistic regression models. Municipality of São Paulo, 2010 (n = 321).

Variables	$OR_{adjusted}$*	95%CI	p-value
Age of the caregiver (continuous)	1.04	1.02 - 1.06	0001**
Family dysfunction			
No	1.00		0.000**
Yes	5.60	2.33 - 13.45	
Frequency of care			
Whenever necessary	1.00		
Alternate days	1.41	0.55 - 3.62	0.467
More than once a day	1.65	0.20 - 13.10	0.630
Full-time	2.78	1.11 - 7.00	0.030**

CI: confidence interval. *Model adjusted for difficulty in the basic activities of daily living, cognitive decline, stroke and gender of the caregiver. **Values lower than 0.05. Source: SABE Study (2010).

material and affective support. This assistance takes forms of help in household chores, cleanliness and other activities of daily living, company, affective support in normal and crisis times, transport and accompany to different places, medication care and help in case of illness[29].

In 2015, in the United States, the Caregiving report was developed, showing that six out of ten caregivers of individuals (≥ 50 years old) assist them in at least one ADL, mainly transferring them from bed to chair (45%), and collaborate (78%), on average, to carrying out four to seven IADL, such as commuting (78%), purchases (76%) or household chores (72%)[25].

The functions attributed to the caregiver involve the performance of practical activities of daily living that aim to assist the physically or cognitively engaged elderly[26]. Such tasks are often developed without adequate guidance or support, as they involve changes in routines and time spent in care, and can significantly affect their quality of life.

The act of caring can be an important stressor and, when associated with the chronic nature of the situation, may have a negative repercussion on the stress levels of caregivers[30]. In the present study, it was noted that most of them were engaged all the time or at least once a day. Some authors have identified that caregivers spend a considerable amount of time and effort to take responsibility for caring and found that more than half of them spend an average of four to five hours/day care for the elderly[31]. The different conditions of care found, due to their not being the most adequate ones, can have as consequences the increase of the tension levels (burden).

Dominguez-Sosa et al.[32] carried out a study with caregivers of beneficiaries of the Mexican Institute of Social Security and found a prevalence of burden (mild/intense) of 15%, half of what was observed in this study (30.4%). Such difference may be associated with the classification adopted.

Caregivers with higher levels of tension associated with care limit their social relationships, moving away from affective and professional relationships, reducing their social network and opportunities for socializing and leisure[7].

In view of the above, Pearlin et al.[33] proposed a model to explain the process of caring for the well-being of family caregivers. This model comprises four explanatory domains:

1. background and context of stress, which include social and economic characteristics of the caregiver;
2. stressors, composed of primary ones, directly related to the provision of care, such as cognitive and behavioral status, problems and extent of dependence of the care recipient; and secondary ones, which arise from the primary and are of a more subjective nature, such as family conflict, and self-esteem;
3. stress mediators: coping and social support are the main ones that can explain the variability in the responses to stressors among caregivers;
4. results or manifestations of stress: physical and mental well-being of the caregiver.

In this study, it was observed that the factors associated with excessive stress included the domain of stressors (report of family dysfunction and provision of continuous care).

The adoption of measures that aid family support could contribute to the elderly's permanence in their home, thus avoiding institutionalization[34].

The association of family dysfunction and excessive stress associated with care may be justified by the inability of family members to adapt to the needs and crises, not by mobilizing resources or even their participation in the care of the elderly[24,35]. Good family functionality, on the other hand, can ensure that the elderly, even if dependents, continue to live in community, along with their families.

The results found are challenging, as they question the organization of formal support services and the interaction between professionals, family caregivers and network interventions. The impact of the caring task can be mitigated by sharing, not only within the existing social support network, but also through other support networks such as support or psychoeducational groups[36].

CONCLUSION

It is concluded that caregivers are mostly family members, females, daughters, residents of the same household as the elderly and responsible for daily care. Some of them were burdened, which is associated with the frequency of care and the functional and cognitive conditions of the elderly.

Considering this, health professionals should guide caregivers with the demands of care due to the mental and functional condition of the elderly to reduce the burden and therefore the weight and stress, and increase the quality of life of caregivers and their sick relatives.

The findings point to the need for public policies that include the needs and support of caregivers, especially the relatives of the elderly, in order to improve the quality of life of family caregivers and the quality of care provided to the elderly.

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