

**Burden of work in caregivers of frail elders living at home\****Sobrecarga de trabalho em cuidadores de idosos fragilizados que vivem no domicílio**Sobrecarga de trabajo en cuidadores de ancianos frágiles que viven en el domicilio***Renata Stackfleth<sup>1</sup>, Marina Aleixo Diniz<sup>2</sup>, Jack Roberto Silva Fhon<sup>3</sup>, Thais Ramos Pereira Vendruscolo<sup>4</sup>, Suzele Cristina Coelho Fabrício-Wehe<sup>5</sup>, Sueli Marques<sup>6</sup>, Rosalina Aparecida Partezani Rodrigues<sup>7</sup>****ABSTRACT**

**Objectives:** To assess the burden of caregivers of frail elders living at home; to characterize elderly that are considered frail and their caregivers; to assess the degree of dependency of the elderly according to the level of frailty and to correlate it with the burden of work of their caregivers. **Methods:** A transversal study with a sample of 60 caregivers and frail elderly who lived at home. Data collection was conducted in the home with frail elders and their caregivers. We used the sociodemographic profile of the elderly and the caregiver instruments, the *Edmonton Frail Scale*, the *Functional Independence Measure* for the elderly, and the *Zarit Burden Interview Scale* for the caregivers. Descriptive statistics and the Pearson test were employed for data analysis. **Results:** The majority of caregivers were female (75%), married (58.3%) and were children of the elderly (45%). Regarding the burden, 31.7% said they rarely felt burdened. However, a correlation was found between frailty and burden: the higher the level of frailty, the greater the caregiver burden. **Conclusion:** It was found that the majority of caregivers were female and the greater the degree of functional dependence, the greater the degree of frailty, which elevated the level of caregiver burden.

**Keywords:** Caregivers; Frail elderly; Geriatric nursing

**RESUMO**

**Objetivos:** Avaliar a sobrecarga dos cuidadores de idosos fragilizados que residem no domicílio; caracterizar os idosos que são considerados frágeis e seus cuidadores; avaliar o grau de dependência dos idosos de acordo com o nível de fragilidade e correlacioná-lo com a sobrecarga de trabalho dos seus cuidadores. **Métodos:** Estudo transversal com amostra de 60 cuidadores e de idosos frágeis, que viviam no domicílio. A coleta de dados realizada no domicílio com idosos frágeis e seus cuidadores. Utilizaram-se os instrumentos de perfil sociodemográfico do idoso e do cuidador, a Escala de Fragilidade de Edmonton, a Medida da Independência Funcional para os idosos e a *Escala Zarit Burden Interview*, para os cuidadores. Para a análise foram empregados a estatística descritiva e o teste de Pearson. **Resultados:** A maioria dos cuidadores era do sexo feminino (75%), casados (58,3%) e, 45% eram filhos. Quanto à sobrecarga, 31,7% responderam que raramente se sentiam sobrecarregados. Mas, houve correlação entre a fragilidade e a sobrecarga, ou seja, quanto maior o nível de fragilidade, maior a sobrecarga do cuidador. **Conclusão:** Evidenciou-se a maioria dos cuidadores do sexo feminino e quanto maior o grau de dependência funcional, maior o grau de fragilidade o que eleva o nível de sobrecarga do cuidador.

**Descritores:** Cuidadores; Idoso fragilizado; Enfermagem geriátrica

**RESUMEN**

**Objetivos:** Evaluar la sobrecarga de los cuidadores de ancianos frágiles que residen en el domicilio; caracterizar a los ancianos que son considerados frágiles y sus cuidadores; evaluar el grado de dependencia de los ancianos de acuerdo con el nivel de fragilidad y correlacionarlo con la sobrecarga de trabajo de sus cuidadores. **Métodos:** Estudio transversal realizado con una muestra de 60 cuidadores y de ancianos frágiles, que vivían en el domicilio. La recolección de los datos se realizó en el domicilio con ancianos frágiles y sus cuidadores. Se utilizaron los instrumentos de perfil sociodemográfico del anciano y del cuidador, la Escala de Fragilidad de Edmonton, la Medida de la Independencia Funcional para los ancianos y la *Escala Zarit Burden Interview*, para los cuidadores. Para el análisis fueron empleados la estadística descriptiva y el test de Pearson. **Resultados:** La mayoría de los cuidadores era del sexo femenino (75%), casados (58,3%) y, 45% eran hijos. En cuanto a la sobrecarga, 31,7% respondieron que raramente se sentían sobrecargados. Sin embargo, hubo correlación entre la fragilidad y la sobrecarga, o sea, cuanto mayor el nivel de fragilidad, mayor la sobrecarga del cuidador. **Conclusión:** Se evidenció que la mayoría de los cuidadores era del sexo femenino y cuanto mayor el grado de dependencia funcional, mayor el grado de fragilidad lo cual eleva el nivel de sobrecarga del cuidador.

**Descriptores:** Cuidadores; Anciano frágil; Enfermería geriátrica

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## INTRODUCTION

The aging of the population is a widespread global phenomenon. The intensity of growth of the “much older” population, considered to be 80 years and more, has risen progressively<sup>(1-3)</sup> and the increase in life expectancy may increase the incidence of non-communicable chronic diseases and incapacitating conditions in the elderly, with possible changes in physical, cognitive and emotional dependency, which can compromise their autonomy, and which generates greater demand for permanent care by the family caregiver group<sup>(4,6)</sup>.

The concept of fragility is not new, however, the recent systematization of information is, which enables an indication that an elderly person is fragile and vulnerable to the adverse effects of stressors of lower impact<sup>(7)</sup>.

Currently, there is no universally accepted model, which hinders a consensual definition, so groups use different concepts related to fragility<sup>(8)</sup>. What can be identified, among others, is a proposal developed by a Canadian group<sup>(7)</sup>, which was used in this study. The life history of the elderly may be related to fragility, since it presents biological, psychological and socioeconomic factors as mitigators of changes in this pathway<sup>(9)</sup>. Fragility has multidimensional, heterogeneous and unstable aspects that differ from incapacity (*disability*) or the natural aging process<sup>(10)</sup>. However, it may be associated with negative health outcomes such as functional decline and dependence<sup>(11)</sup>, which may lead the elderly to have need of a caregiver.

The term “dependency” is united with the fundamental concept of geriatric practice: “fragility” is defined as a vulnerability that the individual presents in relation to the challenges of the environment itself<sup>(6)</sup>.

In the home environment, the role of caregiver tends to be assumed by a single person, known as the “primary caregiver”, who assumes responsibility for the care without counting, in most cases, on the help of another family member or trained professionals<sup>(12,13)</sup>. The literature indicates that there is a greater involvement of women in this caregiving process<sup>(14)</sup>.

The experience of assuming the care of dependent elderly has been presented by family caregivers as a task that causes stress and exhaustion, due to emotional involvement and changes in the relationship that was formerly reciprocal, to a dependent relationship in which the caregiver, in order to develop activities related to the physical and psychosocial well-being of the elderly, places restrictions on her own life<sup>(15,16)</sup>.

The informal caregiver is exposed to a series of stressful situations, such as the burden of the tasks and the diseases that result from the work requirements and the characteristics of the elderly. Moreover, she

lacks information, and the physical, psychological and financial support needed to handle the daily care<sup>(16)</sup>.

In the exercise of roles, this change is anguishing, because of emotional involvement between the elderly and her family, the decrease in time for relationships with friends and neighbors, the solitude, the burden of the caregiving process, and the frustration at not being able to execute her own plans for her life; all of these are part of the disturbances that at any given time, can cause stress in the caregiver<sup>(17)</sup>.

Considering that the burden on caregivers of the frail elderly is of great social importance, given the absence of research with this population group, the proposal to conduct the present study offers scientific contributions and practical assistance to caregivers, in addition to knowing and discussing the definition of their role, their demands and needs. Furthermore, it offers a direction for assistance to these families, and construction and implementation of strategies to improve and reduce caregiver burden in caregivers of fragile elderly.

Thus, the question driving this study was: What is the burden of the caregivers of fragile elderly that are living in the community?

In view of the above, this research had as its general objective to evaluate the burden of caregivers of fragile elderly who resided at home. For that, we listed the following specific objectives: to characterize the elderly who are considered fragile and their caregivers; to evaluate the degree of dependency of the elderly, according to the level of fragility; and to correlate the level of fragility and caregiver burden of the caregivers of these frail elderly.

## METHODS

This was a cross-sectional study, conducted with elderly residents in the city of Ribeirão Preto – São Paulo. The sample was obtained by use of two-stage cluster sampling. For the first of these, we considered the census tract as the sampling unit, and for the second, the individuals greater than 60 years of age.

We decided upon a sample of 240 individuals, which guaranteed a maximum error of 6.3% with 95% probability. To arrive at the value of  $n = 240$ , we randomly selected 20 census tracts among the 650 that existed.

In the second stage, the streets were randomly selected from the drawn census tracts and blocks. The streets were traversed, starting with a randomly selected block, in a counterclockwise direction; households were visited until 12 seniors / sector who met our inclusion criteria were found.

Inclusion criteria were: age equal to or greater than 60 years; either gender; considered fragile, according to the fragility scale;<sup>(7)</sup> and, living at home with their caregivers.

In evaluating the 240 elderly, 153 (63.8%) were considered fragile, according to criteria established in the application of the *Edmonton Frail Scale* (EFS)<sup>(7)</sup>, of which only 60 elderly (39.2%) had a caregiver, which allowed for a sample of 60 caregivers for the present investigation.

Data collection occurred between November/2010 and February/2011, in the homes of the elderly / caregivers. The mean interview time was 45 minutes, and they were conducted in two stages: with the elderly and with their caregiver.

### Step 1: Instruments used for data collection in the elderly

1. In relation to their sociodemographic profile, we selected the following variables: gender, age, education, marital status, living arrangement and presence of caregiver;

2. To evaluate fragility, we used the *Edmonton Frail Scale* (EFS), validated for the Portuguese language<sup>(18)</sup> and that contains nine domains, distributed over 11 items, namely: a) the cognitive area, with the clock test (1 item); b) general state of health (2 items); c) functional independence (1 item); d) emotional support (1 item); e) use of medications (2 items); f) nutrition (1 item); g) humor (1 item); h) continence (1 item); i) functional performance lift and walk, timed for balance and mobility (1 item). Scoring ranges from 0 to 17 points, and the scores for analysis of fragility are: 0 – 4 points = presents no fragility; 5-6 = apparently vulnerable, 7-8 = minor fragility; 9-10 = moderate fragility; 11 or more = severe fragility. The higher score represents more severe fragility<sup>(18)</sup>.

3. To evaluate functional independence, we employed the *Functional Independence Measure* (FIM) scale, which was validated for the Portuguese language<sup>(19)</sup> and evaluates the combined performance of conducting 18 tasks, including the scale of self-care, transfers, locomotion, sphincter control, communication and social cognition, which includes memory, social interaction and problem solving. Each of these activities is evaluated and receives a score that ranges from 1 (total dependence) to 7 (complete independence), for a minimum score of 18 and a maximum score of 126 points<sup>(19)</sup>.

### Step 2: Instruments used for data collection with the caregiver

1. The sociodemographic profile of the caregiver was identified by the variables of gender, age, marital status, education, degree of kinship, and if she lived with the elderly;

2. To verify the caregiver burden, we used the *Zarit Burden Interview* (ZBI), developed in 1987<sup>(20)</sup> validated

and adapted for the Portuguese language in 2002<sup>(21)</sup>. This instrument has 22 items that assess caregiver burden, associated with functional capacity of patients, their behavior disorders and everyday situations. Each item is scored on a scale of 0 to 4, with: never = 0, rarely = 1, sometimes = 2, frequently = 3, and always = 4. The total score is calculated by summing all items, and it can range from 0 to 88 points. Thus, the higher the score, the greater the burden<sup>(21)</sup>.

For data analysis, we constructed a spreadsheet in the *Excel*<sup>®</sup> program, where the data were organized for double entry and validated by a comparison of the keyed information. After validation, the spreadsheet was imported to the statistics program, *Statistical Package for Social Science* (SPSS<sup>®</sup>) version 11.5 for *Windows*, where statistical analyses were performed.

For the analyses of quantitative variables, we employed measures of central tendency (mean, median) and dispersion (standard deviation), and for the categorical variables we used the Pearson correlation test, with a significance level of 0.05.

The research project was approved by the Committee on Ethics in Research at the School of Nursing of Ribeirão Preto, University of São Paulo (Process 1169/2010), according to Resolution n° 196/96 of the National Health Council. The Terms of Free and Informed Consent were signed in duplicate. One copy was given to the elderly and the caregiver, and the other was kept by the researcher.

## RESULTS

Of the 240 subjects interviewed, 153 (63.8%) were classified, according to the *Edmonton Fragility Scale*, as: 38.6% apparently vulnerable, of whom 55.9% were female and 44.1% male; 28.8% with mild fragility – 70.5% female and 29.5% male; 17.6% with moderate fragility – 66.7% female and 33.3% male; and, 15.0% presented with severe fragility – 65.2% female and 34.8% male.

In general, it was found that of the 153 (63.8%) elderly considered fragile, the majority was of the female gender; married; lived with a spouse; and, did not need a caregiver (Table 1).

Among the apparently vulnerable elderly, 91.4% had complete or modified independence; regarding the mild fragility, 86.7% had complete or modified independence; of those with moderate fragility, 44.5% were totally dependent, and of the severely fragile, 43.5% had minimal dependence / supervision (Table 2).

Of the 153 fragile elderly, 60 had caregivers, and all agreed to participate. Of these, 75% were female. With respect to age, 57.8% of the women were between 29-59 years, and of those aged 60 years or older, 73.3% were male.

**Table 1** – Social profile of fragile elders living at home, according to age, education, gender, marital status, living arrangement and caregiver presence. Ribeirão Preto-SP, 2011. (n = 153)

Variable	n	(%)	Mean (SD)	Median	Variation observed
<b>Age</b>	-	(-)	76.2 (8.2)	76	60 – 94
<b>Education (years)</b>	-	(-)	4.4 (4.7)	4.0	0 – 25
<b>Gender</b>					
Male	56	(36.6)			
Female	97	(63.4)			
<b>Marital status</b>					
Single	9	(5.9)			
Married	84	(54.9)			
Divorced	6	(3.9)			
Separated	1	(0.65)			
Widower	52	(34)			
Unknown	1	(0.65)			
<b>Household arrangements</b>					
Alone	22	(14.4)			
Only with spouse	41	(26.8)			
Spouse and children	21	(13.7)			
Spouse, children, son- or daughter-in-law	4	(2.6)			
Only with children	7	(4.6)			
Three generations together	18	(11.8)			
Only with their grandchildren	2	(1.3)			
Others	38	(24.8)			
<b>Has caregiver</b>					
No	93	(60.8)			
Yes	60	(39.2)			

**Table 2** – Classification of fragility syndrome, according to the measure of functional independence of the elderly living at home. Ribeirão Preto-SP, 2011. n = 153

FIM	Total dependency	Dependency Maximum / moderate	Dependency Minimum / supervision	Independence modified / full	Total
	n (%)	n (%)	n (%)	n (%)	N (%)
<b>Fragility</b>					
Apparently vulnerable	0 (0)	0 (0)	5 (8.6)	53 (91.4)	0 (0)
Minor Fragility	0 (0)	0 (0)	6 (13.3)	39 (86.7)	45 (29.4)
Moderate fragility	2 (7.4)	2 (7.4)	12 (44.5)	11 (40.7)	37 (24.2)
Severe fragility	1 (4.3)	3 (13.1)	10 (43.5)	9 (39.1)	23 (8.5)

For the item “*having a partner*”, married and cohabiting caregivers were included. For the answer “*not having a partner*”, unmarried, widowed, separated and divorced were considered. The majority (58.3%) of caregivers reported having a partner.

Referring to education, both the female (40.0%) and male (40.0%) caregivers had studied between five and eight years. With regard to the degree of kinship, 45% were a child of the elderly; 68.3% of the caregivers lived with the elderly in the same household, and 75% reported having knowledge about the care of the elderly.

The caregiver burden was assessed by the burden scale of the *Zarit Burden Interview*. The score varied between 4 and 79, with a mean of 24.48 and a standard deviation of 13.6. It was observed that approximately 8% of the caregivers obtained scores equal to or greater than 44, which demonstrated a level of burden of moderate to high.

There was evidence of a negative correlation between the cognitive FIM and the *Zarit Burden Interview*, that is, the higher the caregiver burden, the lower the level of functional independence in the cognitive domain.

By applying the correlation between fragility and burden, a correlation was identified between fragility and burden; in other words, the higher the level of fragility, the greater the caregiver burden (Table 3).

**Table 3** – Distribution of Pearson correlation between caregiver burden related to age, total FIM score and MMSE of the elderly living at home. Ribeirão Preto, 2011

	Age	FIM total	FIM motor	FIM cognitive	Fragility
Zarit total	- 0.121	- 0.210	- 0.114	- 0.317*	0.152

\*p<0,05

## DISCUSSION

Most of the elderly were female, which is consistent with the global data that suggest that the proportion of women is higher than men in the composition of the elderly population<sup>(22)</sup>. The present study had a higher number of married elderly, however; in the literature, we encountered a prevalence of widowers<sup>(23)</sup>. The greater number of married individuals may be related to the prevalence of elderly living with their spouse in their living arrangements. In the study of living arrangements in Latin America and the Caribbean, it was found that, among the most prevalent were bigenerational arrangements and, secondly, couples. This type of arrangement calls attention to the fact that couples are close in age, and this suggests that they may be caregivers for their spouses<sup>(24)</sup>.

Normally, the elderly need specific conditions for their care, due to diminishing capacity occurring over a period of years<sup>(25)</sup>, which makes the presence of the caregiver fundamental to their daily lives. But, in this study, the majority of fragile elderly reported having no caregiver. This condition may be related to the fact that a large percentage of elderly in the sample (38.6%) were considered apparently vulnerable and with mild fragility (28.8%), situations that have not yet led these elderly to become dependent on others for daily activities.

Fragility in the elderly involves complex interactions of biological, psychological and social factors that interact and culminate in a state of heightened vulnerability that is replaced by the appearance of elderly fragility, leading to situations of dependency<sup>(26,27)</sup>.

The fact of depending on another person to perform the basic activities of daily living is closely related to fragility, as shown in the study conducted in Fortaleza-CE, with elderly whose diagnosis was Alzheimer's disease and who were totally dependent<sup>(28)</sup>.

Recent studies demonstrated that the greatest burden of care falls on the informal caregiver. Therefore, it should be the subject of more attention, in order to avoid situations that can lead to their high levels of burden<sup>(29,30)</sup>.

The predominance of married female caregivers, who are daughters of the elderly, is also a frequent characteristic encountered in diverse studies, both nationally<sup>(25,31)</sup> and internationally<sup>(29)</sup>. These findings reinforce the social role of women, with a historically determined function as the provider of care.

In this research, caregiver burden, according to the Zarit scale, was verified in 8% of caregivers, which differs from the study conducted in Portugal with caregivers of dependent elderly, in which 41% of caregivers presented severe burden<sup>(29)</sup>. This difference can be explained when it is established that 43.5% of the elderly respondents in this study had severe fragility with minimal dependence / supervision, while we expected there to be severe fragility and a higher level of dependency.

The mean score of caregiver burden, assessed by the Zarit scale, was 24.48, but these data differ from a study conducted in Santa Catarina with 66 caregivers of dependent elderly, who obtained a mean score higher than the present study – 32.12<sup>(25)</sup>.

The fragility presented by the elderly may be related to the burden of work of the caregiver, namely, the greater the fragility of the elderly, the greater the burden of her caregiver. These data were also encountered in research conducted by a home care program with 40 elderly who did not have social and functional conditions to attend to other types of health services, and their home caregivers<sup>(26)</sup>. These data demonstrated the relationship of burden with work of the caregiver of the more dependent elderly. Thus, there was a negative correlation between the variables of the cognitive FIM and caregiver burden. The cognitive impairment may also have implications on the daily life of caregivers, and contribute to high levels of burden and emotional distress.

In a study conducted with 47 caregivers from Veranópolis – RS, it was found that the elderly with caregivers needed more support to perform their activities of daily living (ADL), especially those included in personal care. This shows the relationship of daily aid with the need for a caregiver<sup>(32)</sup>. Regarding the care process, it appears that the more dependent the elderly person is, the more he will need care, which overburdens the caregivers who perform that daily care<sup>(31)</sup>.

In research conducted with caregivers of elderly with Alzheimer's disease, it was concluded that there was an altered quality of life and that, the more functional impairment the elderly person presented, the higher the depressive symptom scores would be<sup>(33)</sup>. In this context, caregivers presented higher incidence of depression and other psychiatric symptoms and proved to be more vulnerable to health related problems when compared to people of the same age who were not caregivers;

they participated in fewer social activities and had more occupational problems <sup>(20)</sup>.

## CONCLUSION

Among caregivers of fragile elderly, it was found that almost all were married females, who were daughters of the elderly. Among the elderly, the study showed that the greater the degree of fragility the greater the level of functional dependence, which elevates the level of burden on the caregiver, whose role is critical to the care of the frail elderly. But, their activities can be overwhelming due to the unpreparedness regarding the role they play, and this can cause problems for their health. Therefore, it is necessary to evaluate the work of the caregiver and her burden. It is therefore up to the nurse, both in nursing consultation as well as during

home visits, to know the health problems and the social issues of the family, in order to then develop plans of care in conjunction with its members.

It should be stressed, then, that to assess and identify the burden on the caregiver is an important aspect of care for the elderly, because the excess burden can compromise the quality of care and interfere in family relationships.

The present study was conducted with a sample population, in a city in the interior, and involved the elderly of the census tracts drawn in the sample. The proposal was to evaluate only those considered fragile elderly and their caregivers who lived at home. In the literature no data exist on caregiver burden of fragile elderly, because the study about this phenotype is still recent. Therefore, considering that the nurse is a professional caregiver, it is up to her to perform assessment and implementation of care.

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