



Prevalence of factors associated with the burden of informal caregivers of elderly people living in a low-income region

Prevalence of Factors Associated with the Burden on Informal Caregivers of Elderly Individuals Living in a Low-Income Area

Erica Sayuri Arakaki – Jundiaí School of Medicine

Vitória Silva Ferreira Ignacio – Jundiaí School of Medicine

SUMMARY

As the population ages, the number of dependent elderly individuals increases, making the presence of informal caregivers increasingly common. Therefore, studying this group is essential to ensure the well-being of both caregivers and older adults. The objective of this study was to analyze sociodemographic factors and aspects of care related to the burden of informal caregivers of older adults in a low-income region. This is a descriptive, cross-sectional study conducted in the São Camilo Primary Health Care Unit (UBS) in Jundiaí. Data collection occurred through previously scheduled home visits or at the UBS itself. Statistical analyses were performed using Student's t-test, ANOVA, and chi-square tests, with a significance level of 0.05, using SPSS 21.0 software. Nineteen caregivers and 19 older adults participated. Caregivers were predominantly female, married, literate, and with an income of up to two minimum wages. The majority of older adults were female, illiterate, and low-income. The mean age of caregivers was 52 years (± 12.18), with a mean education of 8 years (± 4.42). Among the elderly, the mean age was 81 years (± 6.58), with a mean education of 1 year (± 2.48). The median of the caregiver burden inventory was 28 points. There was a significant association between a smaller support network of the elderly and greater caregiver burden ($p=0.011$), as well as dependence in instrumental activities of daily living ($p=0.05$) and a lower MMSE score ($p=0.04$). It is concluded that the burden is greater when the elderly present cognitive loss and functional dependence.

Keywords: Caregiver Burden; Caregivers; Frail Elderly

ABSTRACT

With population aging, the number of dependent elderly individuals is increasing, making the presence of informal caregivers increasingly common. Therefore, it is essential to study this group to ensure the well-being of both, the caregiver and the elderly person. This study aimed to analyze sociodemographic factors and care-related aspects associated with the burden on informal caregivers of older adults in a low-income region. This is a cross-sectional descriptive study conducted in the area covered by São Camilo's Primary Healthcare Unit (Unidade Básica de Saúde – UBS, in Portuguese), in Jundiaí. Data collection took place through previously scheduled home visits or at the UBS itself. Statistical analyzes were performed using Student's t-test, ANOVA, and Chi-square test, with a significance level of 0.05, using SPSS version 21.0. Nineteen caregivers and nineteen elderly individuals participated. Most caregivers were female, married, literate, and had an income of up to two minimum wages. The elderly were mostly female, illiterate, and with low income. The mean age of the caregivers was 52 years (± 12.18), with an average of 8 years of schooling (± 4.42). Among the elderly, the mean age was 81 years (± 6.58), with an average of 1 year of education (± 2.48). The median score on the caregiver burden inventory was 28 points. A significant association was found between a smaller support network for the elderly and a higher caregiver burden ($p=0.011$), as well as between dependence

in instrumental activities of daily living ($p=0.05$) and lower MMSE scores ($p=0.04$). It is concluded that caregiver burden is greater when elderly individuals present cognitive decline and functional dependence.

Keywords: Caregiver Burden; Caregivers; Frail Elderly

1. INTRODUCTION

Population aging is a global phenomenon and brings with it several impacts. One of these is the increased prevalence of chronic noncommunicable diseases and conditions, leading to a progressive increase in the number of elderly individuals with functional limitations, requiring constant care (Nunes et al., 2018; Camarano, Kanso & Mello, 2004). However, in Brazil, this demographic and epidemiological transition occurred rapidly and unevenly, in a context of social and cultural inequalities (Gaúcha, 2019), resulting in the lack of an organized health system to adequately serve this growing population. The country's health model is geared towards spontaneous demands, and together with the lack of a formal support system for this population and the structural changes that occur in families (Gaúcha, 2019; Veras & Oliveira, 2018; Veras, 2016; Lima-Costa, Vaz & Mambrini, 2017), care for dependent elderly people ends up being provided by someone close, such as family, friends and/or neighbors, who take on such roles suddenly without being, in most cases, psychologically, technically and financially prepared (Nunes et al., 2018).

The primary caregiver is defined as the one who has full or major responsibility for the care provided to the dependent elderly person (Caldas, 2002; Pereira & Filgueiras, 2009). Informal caregivers are those who provide care without a formal relationship or any type of remuneration (Pereira & Filgueiras, 2009; Laham, 2003). The profile of primary and informal caregivers is often female, a spouse or daughter, and between 50 and 55 years of age (Nunes et al., 2018; Pereira & Filgueiras, 2009).

Faced with the task of caregiving, caregivers experience repercussions in their personal, family, social, and work lives, caused by the time they have freed up, social isolation, and new responsibilities they have assumed, leading to a state of overload (Loureiro, 2009; Costa et al., 2020). Burden has been defined as the impact of changes on the individual, caused by the inclusion or expansion of caregiving activities (Gaúcha, 2019; Monteiro, Mazin & Dantas, 2015), and is subdivided into two dimensions: objective and subjective. The objective dimension relates to the services provided, the difficulties and limitations imposed on social and professional life, and financial problems. The subjective dimension refers to the family's understanding and affection for the caregiver, their expectations regarding the dependent older adult, and the feelings generated by the caregiver status, as well as the discomfort it can cause (Monteiro, Mazin & Dantas, 2015).

In this sense, as a research hypothesis, it is believed that informal caregivers in low-income regions will present high levels of burden not only due to their caregiver status, but also due to sociodemographic factors that contribute to this burden.

2. OBJECTIVE

The aim of this study was to analyze the sociodemographic factors and aspects of care related to the burden of informal caregivers of older adults in a low-income region of the municipality of Jundiaí. Therefore, the aim is to contribute to the understanding of the main characteristics associated with caregiver burden, in order to assist in offering proposals for targeted interventions to prevent the development of this condition, with the aim of improving the quality of life of both the caregiver and the dependent older adult.

3. METHOD

3.1 LOCATION AND TYPE OF STUDY

The research was conducted at the São Camilo Basic Health Unit in the municipality of Jundiaí, São Paulo state. This UBS was chosen because it covers an area of high social vulnerability. The study is cross-sectional.

3.2 SAMPLE SIZE AND PARTICIPANT SELECTION

Patient recruitment occurred through the São Camilo UBS's own data information system, which surveyed the number of elderly individuals over 60 living in the region. Then, along with information provided by Community Health Agents (CHAs) about the area's residents, a sample was obtained. The Community Health Agents contacted the selected individuals prior to the survey collection to determine whether or not they would agree to participate. They were then contacted via phone calls or home visits to schedule an interview during which data collection actually took place. If it was impossible to contact individuals after two attempts, they were excluded from the study, and another participant was selected. Elderly individuals who met the inclusion and exclusion criteria and had ties to people who identified themselves as informal caregivers were selected, and these ultimately became the study participants. The objective of the sample selection procedure was for it to be representative of the territory, random, controlled and directed towards the focus of the study.

The inclusion criteria for dependent elderly individuals were as follows: being 50 years of age or older; having a functional dependence situation, according to the Mini-Mental State Examination and/or functional dependence, according to the Lawton Scale and/or Katz Index; and having signed the Free and Informed Consent Form (FICF). The exclusion criteria for the elderly were: patients with severe psychiatric illnesses, severe language and comprehension difficulties presented by the participant and perceived at the time of the evaluation or by prior knowledge through the medical records.

For elderly caregivers, the criteria were: being over 18 years of age, being the primary caregiver and providing assistance with daily activities for a family member or friend; having no formal employment relationship or remuneration for the role of caregiver; and having signed an Informed Consent Form (ICF). Exclusion criteria were: having serious psychiatric illnesses and severe language and comprehension problems.

3.3 DATA COLLECTION INSTRUMENTS

A socioeconomic questionnaire (Appendix 1) was administered, including the variables sex, age, race/color, marital status, length of formal education, literacy, number of family members, and income. Data on the caregiving relationship were also collected: length of time as the primary caregiver, frequency of assistance to the elderly person, geographic distance from the elderly person, whether the individual uses their own income to care for the elderly person, and whether they interrupted their studies due to their caregiver status.

The following instruments were also applied:

- a. Caregiver Burden Inventory (Valer DB, et al., 2015), which contains 24 questions divided into five domains: dependent time, personal life burden, physical, social, and emotional burden. Each domain has five questions, with the exception of physical burden, which contains four items. Each question is scored from 0 (strongly disagree) to 4 (strongly agree). Thus, each domain will range from 0 to 20, with the result for the physical burden domain being multiplied by 1.25 because it contains fewer questions. The instrument does not have a cutoff point for classifying burden; the higher the score, the greater the caregiver's burden. Thus, both the score for each domain and the overall score can be verified.
- b. Medical Outcomes Study (Griep RH et al., 2005), to assess the elderly participant's social support network, measured by the frequency with which the individual has access to material, affective, emotional, informational support and positive social interaction (according to the responses, a final score is reached for each of the dimensions, which varies from 20 to 100 points, with the higher the score achieved, the higher the level of social support)
- c. Katz Index (Lino VTS, et al., 2008), to assess performance in basic activities of daily living, which involve activities related to self-care such as eating, bathing, dressing, performing personal hygiene, moving and maintaining control over eliminations.
- d. Lawton Scale16 (Araújo F, et al., 2008), to assess performance in instrumental activities of daily living, which include the ability to prepare meals, shop, use transportation, take care of the house, use the telephone, manage one's own finances and take medication.
- e. Mini Mental State Examination (Melo DM, et al., 2015), for cognitive assessment and screening of dementia, through the analysis of several domains (spatial and temporal orientation, immediate and recall memory, calculation, language-naming, repetition, understanding, writing and copying of drawings).

3.4 PROCEDURES/ APPLICATION OF INSTRUMENTS

Once the project was approved by the Ethics Committee, data collection was implemented through home visits and calling residents over 60 years of age and their caregivers at the UBS.

In the case of home visits, the researchers accompanied the Community Health Agents on their home visits and administered the instruments, which were made available in printed form. Whenever possible, priority was given to the elderly person being unaccompanied.

with their family members or caregivers at the time of the interview. The aim was to administer the instruments in a quiet place. However, if a suitable location was not available, the research was conducted in the best possible space at the time.

A second strategy for data collection was to summon participants to the primary care unit (PHC). Data collection was conducted on a specific day, during which participants were approached. The researchers also administered the questionnaires in printed form. In this case, the research instruments could be administered in an office or private room.

First, the instruments were administered to the elderly population to select those with cognitive and/or functional problems. This was done in the following order: Mini-Mental State Examination, Katz Index, and Lawton Scale. If any cognitive and/or functional impairment was detected in the elderly participant, the Medical Outcomes Study (MOS) was administered immediately afterward. If no cognitive and/or functional impairment was identified, the elderly participant did not meet the inclusion criteria for the study, and in this case, the questionnaires were not administered further.

Then, after screening the elderly person with cognition and/or functionality problems, the socioeconomic questionnaire was applied to the primary caregiver, and then the Informal Caregiver Burden Assessment Questionnaire was applied.

During the administration of the instruments to both the elderly person and the caregiver, the interviewer demonstrated how to respond appropriately to the questionnaires and clarified any questions the interviewee might have. Prior training was provided to the interviewers on the proper application of the research instruments.

3.5 DATA ANALYSIS AND STATISTICS

For descriptive analysis, quantitative variables were analyzed using measures of central tendency and dispersion. Qualitative variables were measured using absolute and relative frequencies. The burden inventory score was summed and then dichotomized at the median, resulting in two categories: greater burden (29 or more) and lesser burden (28 or less).

For the analytical analysis, the tests performed depended on the nature of the outcome variable. For quantitative variables, mean comparisons were performed using the t-test or ANOVA. The Mini-Mental State Examination (MMSE), Katz's test, and Lawton's scores were compared regarding caregiver burden to assess whether the caregiver's greater burden was due to the older adult's more fragile state. For qualitative variables, the chi-square test was used.

A significance level of 5% was considered. The statistical program used for these analyses will be SPSS 21.0.

3.6 ETHICAL ASPECTS

Regarding confidentiality and anonymization of data: data were collected in a way that guaranteed the confidentiality and anonymization of participants. Therefore, information that could lead to the identification of the participant was translated into statistical numbers, not being revealed individually, taking into account that according to CNS Resolution No. 466 of 2012, item III.2.i, research must "provide procedures that ensure confidentiality and privacy, image protection and non-stigmatization of participants."

research participants, ensuring that the information is not used to the detriment of individuals and/or communities, including in terms of self-esteem, prestige and/or economic-financial aspects.”

4. RESULTS

Table 1 provides a descriptive sociodemographic analysis of the sample of elderly individuals and caregivers in absolute numbers (n) and percentages (%). The total sample consisted of 19 informal caregivers and 19 elderly individuals.

There is a higher prevalence of female caregivers, white or mixed race, married, literate, and with an income of up to two minimum wages. Most caregivers have comorbidities such as hypertension and diabetes. Regarding the characteristics of the elderly, the population is predominantly female, white, widowed, illiterate, and with an income of up to two minimum wages. Most elderly caregivers had comorbidities such as diabetes, hypertension, and dyslipidemia.

Table 1. Characterization of the sample: Elderly and caregiver (Jundiaí, 2023)

		Elderly		Caregiver	
		N	%	N	%
Sex	Feminine	15	78.90%	15	78.90
	Masculine	4	21.10%	4	21.10
Race/Color	Black	2	10.50%	2	10.50
	Brown	4	21.10%	8	42.10
	White	13	68.40%	9	47.40
	Yellow	0	0.00%	0	0.00
	Indigenous	0	0.00%	0	0.00
Marital status	Single	0	0.00%	6	31.60
	Married	4	21.10%	9	47.40
	Divorced	0	0.00%	0	0.00
	Widower	14	73.70%	2	10.50
	Stable union	1	5.30%	2	10.50
Knows how to read	Yes	8	42.10%	17	89.50
	No	11	57.90%	2	10.50
Knows how to write	Yes	7	36.80%	18	94.70
	No	12	63.20%	1	5.50
Income	Up to 1 SM	9	47.40%	5	26.30
	1-2 SM	10	52.60%	13	68.40
	2-4 SM	0	0.00%	1	5.30
	4-10 SM	0	0.00%	0	0.00
	Above 20 SM	0	0.00%	0	0.00
Diabetes	Yes	13	68.40%	3	15.80

	No	6	31.60% 16	84.20
	Yes	17	89.50% 8	42.10
HAS	No	2	10.50% 11	57.90
	Yes	10	52.60% 3	15.80
DLP	No	9	47.40% 16	84.20
	Yes	7	36.80% 5	26:30
Other diseases	No	12	63.20% 14	73.70

Source: Prepared by the authors.

Table 2 presents data related to caregiving. It is noteworthy that caregivers are usually children, who live in the same household, are constantly providing care, have used their own income for this purpose, and have at some point needed to stop studying or working.

Table 2. Care data (Jundiaí, 2023)

	Categories	N	%
Degree of kinship	Wife	2	10.50
	Son/daughter	15	78.90
	Grandchild	0	0
	Others	2	10.50
Frequency of help	Whenever necessary	2	10.50
	Once a week/alternate days	2	10.50
	Once a day	1	5.30
	All the time	14	73.70
Geographical distance	Same address	12	63
	Nearby home	7	36.80
	Distant home	0	0.00
Use of income	Yes	10	52.60
	No	9	47.40
Study/work suspension	Yes	10	52.60
	No	9	47.40

Source: Prepared by the authors.

Table 3 presents the age, education level, and score on the caregiver burden inventory. It can be seen that the caregiver has an average age of 52 years (± 12.182), with an average education level of 8 years (± 4.42). The elderly person has an average age of 81 years (± 6.587), with an average education level of 1 year (± 2.478). It is also evident that the median of the caregiver burden inventory is 28 points.

Table 3. Age, length of education and score on the workload inventory (Jundiaí, 2023)

	Caregiver Age	Study time (caregiver)	Caregiver Burden Inventory age	Elderly donor	Study time (elderly)
Average	52.89	8.74	33.26	81.05	1.84
Median	51	11	28	80	1
Standard deviation	3.182 4.42	Source:	24,599	6,587	2,478

Prepared by the authors.

Table 4 presents the relationship between the Caregiver Burden Inventory and the cognitive tests (MMSE). The cutoff point of 28 was used, as it represents the mean score on the Caregiver Burden Inventory in the sample, although the questionnaire does not have a cutoff point. A significant p-value ($p=0.04$) is noted, suggesting that older adults who score lower on the MMSE generate greater burden for the caregiver.

Table 4. Association of the Caregiver Burden Inventory with MMSE (Jundiaí, 2023)

	Caregiver Burden Inventory N Medium	Minor Burden	Standard Deviation	p-value
MEEM	(up to 28 points)	10	18.2	0.04
	Highest overload (29 points or more)	9	11.33	

Source: Prepared by the authors.

Table 5 shows the relationship between the Caregiver Burden Inventory score and the MOS questionnaire. A cutoff score of 28 was also used for analysis. A significant p-value ($p=0.011$) was observed, associating a lower score on the older adult's support network with higher scores on caregiver burden.

5. Association of the Caregiver Burden Inventory with MOS (Jundiaí, 2023)

	Caregiver Burden Inventory N Medium Minor	Burden	Standard Deviation	p-value
MOS	(up to 28 points)	10	61.6	0.011
	Greater overload (29 points or more)	9	42.22	

Source: Prepared by the authors.

Table 6 demonstrates the relationship between basic activities of daily living (measured by the KATZ test) and caregiver burden. Note that the p-value was not significant in any of the categories, preventing an association between them.



Table 6. Association of the Caregiver Burden Inventory with KATZ (Jundiaí, 2023)

	Caregiver Burden Inventory N		Average	Standard Deviation	p-value
KATZ SA	Lower overload (up to 10 28 points)		5	1,563	0.138
	Highest Overload (29 9 points or more)		3.78	1,856	
KATZ AP	Lower overload (up to 10 28 points)		0.7	0.949	0.349
	Highest Overload (29 9 points or more)		1.22	1,394	
KATZ AT	Lower overload (up to 10 28 points)		0.2	0.632	0.085
	Highest Overload (29 9 points or more)		1.22	1,641	

Source: Prepared by the authors.

Table 7 demonstrates the association between instrumental activities of daily living (measured by Lawton) and caregiver burden. It is noted that the p-value was significant ($p=0.05$) only when the elderly person was unable to perform instrumental activities of daily living, generating a burden on the caregiver.

Table 7. Association of the Caregiver Burden Inventory with Lawton (Jundiaí, 2023)

	Caregiver Burden Inventory N		Average	Standard Deviation	p-value
LAWTON SA	Minor Burden (up to 10 28 points)		4.9	2,132	0.00
	Highest Overload (29 9 points or more)		1.11	1,537	
LAWTON AP	Lower overload (up to 10 28 points)		1.9	1,524	0.086
	Highest Overload (29 9 points or more)		0.78	1,093	
LAWTON NC	Lower overload (up to 10 28 points)		2.2	1,751	0.005
	Highest Overload (29 9 points or more)		5.89	3.14	

Source: Prepared by the authors.

5. DISCUSSION

The profile of caregivers found in the study was female, with an average age of 52, and it was usually daughters who took on this role. A review by Baptista (2012), as well as the vast national and international literature on informal caregivers, indicates that women end up, most of the time, assuming this role because they are seen socially as “great caregivers”, that is, the role of caregiver is seen as a norm for women because they are inserted in the “role of mother”. Furthermore, Conceição (2021) also



obtained in their research an average age close to 50 years (40.4%), also coinciding with other studies (Anjos et al., 2015; Loureiro & Fernandes, 2015). However, it is noteworthy that in this research there was a percentage of 26% (n = 5) of caregivers over 60 years old, highlighting the population aging and the issue of the elderly caring for the elderly, as highlighted by Cronemberger (2023).

In this study, the majority of caregivers interviewed were literate, corroborating data from Conceição (2021), in which only 9.6% of participants were illiterate. This is relevant, since the caregiver's level of education can impact care, from understanding the dependent elderly person's clinical condition to functions such as understanding medication prescriptions and providing care guidance.

The elderly population is predominantly female, with an average age of 81 years (± 6.587), as found by Santos (2021). This is mainly due to women being less exposed to health risk factors such as tobacco and alcohol, in addition to the social factor that women are more concerned about their health than men, as described by Costa (2016). Furthermore, age over 80 indicates that dependence is related to changes in functionality and cognition, predominantly found in this age group, requiring, in this case, greater attention from health services for healthy aging. Furthermore, most dependent elderly individuals are illiterate, with an average of one year of schooling. This data is also observed by Santos (2021), who showed that 72% of his sample had incomplete elementary education, in accordance with the IBGE of 2022, in which 54.2% of illiterate people were over 60 years old, mainly due to the fact that in the past access to education was more restricted, especially for women.

The sum of the total scores of the Overload Inventory resulted in an average of 33.26, which is lower than that obtained in a national study conducted in a large urban center that used the same scale (Aires, 2017), with an average score of 36.4 (± 22.8). This may have occurred due to the small sample (n=19) obtained in the present study.

However, using a cutoff point of 28 points for the total score, which corresponds to the median obtained in the Caregiver Burden Inventory, it is observed that cognitive decline, identified by the lower score on the Mini-Mental State Examination (MMSE), is a factor of greater burden, with a significant p-value (p=0.04). Caldas (2022), in his qualitative study, shows that the dementia process in family members brings suffering generated by the memory of a loved one becoming increasingly dependent, when in the past they were fully active and independent. In this sense, cognitive decline brings not only physical but also emotional burden to the caregiver. Furthermore, the author also cites the reversal of family dynamics, in which there is a reversal of roles, with the one who previously provided care now needing care.

Regarding basic activities of daily living (BADLs), measured by the Katz scale, no association could be established, as none of the categories had a significant p-value. However, for instrumental activities of daily living (IADLs), measured by the Lawton scale, the p-value was significant when the older adult was unable to perform the activities independently. Both results are consistent with Nunes (2018), who described that caring for more dependent older adults increases caregiver burden, being 2.84 times greater for BADLs and 22.5 times greater for IADLs.

Furthermore, Etsuko (2003) in her research on functionality showed that ABVD are

the last to be compromised by aging or health problems, with a decline in advanced activities of daily living usually occurring initially, followed by instrumental activities of daily living, with the last being basic activities of daily living.

Therefore, the results presented in this research may not have been able to obtain a statistically significant p-value for BADL due to the small sample, since in addition to being responsible to a lesser extent for the caregiver's burden, it is the last to decline in the degree of functionality.

A significant p-value ($p=0.011$) was also observed in the association between the Caregiver Burden Inventory, with a cutoff score of 28 points, and the MOS instrument, which measured the older adult's support network. Marques (2011) described in his qualitative work on social support and the experience of family caregivers that caregivers need breaks from caregiving to ensure both physical and mental health. This is only possible when there is someone else to assume this caregiving role while the primary caregiver rests. Thus, the importance of establishing a support network for both the older adult and the caregiver is highlighted.

6. FINAL CONSIDERATIONS

Although population aging is already a reality in Brazil, public health policies remain scarce for this population. This results in a lack of healthcare, resulting in an informally organized health network that is unstructured to meet the necessary demands of this group.

Informal caregivers are usually female, with daughters around 50 years of age, responsible for daily caregiving. Burden is associated with cognitive and functional decline, most commonly observed in instrumental activities.

Given these findings, it is important to develop more Public Health Policies, with multidisciplinary teams, focused on these populations, both the elderly and caregivers, so that a structure that encourages healthy aging can be developed. To this end, the elderly person must receive assistance to reduce cognitive and functional decline, reducing the burden on the caregiver. Furthermore, support for caregivers is crucial, including information on caregiving, psychological assistance, and the creation of a support network to assist them in this task, enabling a better quality of life for both the caregiver and the elderly person.

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