

## Comparative study between formal and informal caregivers of older adults

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**Abstract** *This study was aimed to compare the health conditions and burden of formal and informal caregivers of older adults. Cross-sectional and comparative study with a quantitative approach. The data were collected in 2014 in São Carlos/SP, using the Zarit Burden Interview and the SRQ 20 (Self Reported Questionnaire). Results: The sample included 15 formal and 35 informal caregivers. Among the formal caregivers, women were predominant (86.7%), with a mean age of 36.7, mean of 13.7 years of education, mean workload of 7.5 hours per day, 26.7% were diagnosed with emotional distress and they the majority mentioned feeling “a little overloaded” (40%). Concerning the informal caregivers, women were predominant (85.7%), 42.9% were the children of the older adult, with a mean age of 55.2 years, mean of 7.1 years of education, length of time as caregiver of 6.5 years, mean of 19.8 hours per day taking care of the older adult, 17 (48.6%) presented mild overload and 16 (45.7%) presented emotional distress. Conclusions: The results revealed important differences and attention is needed to planning interventions to improve health and work conditions of these people.*

**Key words** *Psychological stress, Caregivers, Older adults*

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## Introduction

The results of the latest National Household Sample Survey (PNAD) revealed that in Brazil, the number of older adults 60 years of age or more increased from 21.7 million in 2009 to 27.8 million in 2014. Among the oldest adults the increase is even greater. In 2009, Brazil registered 9.7 million people over 70 years of age, while in 2014, the population of this age group reached 12.2 million older adults<sup>1</sup>.

With this panorama of population growth, a change in the epidemiological profile of the population can be noted, with high prevalence of chronic diseases, cognitive impairments, sensory decline, accidents and social isolation. This causes loss of functional capacity in older adults making them dependent on others for the provision of daily care<sup>2</sup>.

In this context, the task of caring, represented by the role of the caregiver, includes actions that are intended to assist the older adult prevented physically or mentally from performing the practical tasks of activities of daily living and self-care. A caregiver is defined as being the person that is responsible for caring for a sick or dependent person, facilitating the performance of their daily activities, such as feeding, personal hygiene, providing routine medication and accompanying them to the health services, or carrying out other things required in their daily lives<sup>3</sup>.

With the task of caring for the older adult, which is generally uninterrupted, in activities such as bodily care, feeding, elimination, environment, offering medications and other situations, the caregiver can experience stressful situations and overload<sup>4</sup>.

Due to the stressful demands that caregivers and families go through caring for an older adult, it is important to evaluate and minimize the burden of the professional responsible for the care<sup>5</sup>.

The overloads of activities generated for caregivers can lead to the development of psychiatric symptoms and even the necessity to use psychotropic medications, which can compromise the ability of the caregiver to take care of the older adult. The care activity can have social and economic effects that compromise all aspects of the lives of the people involved<sup>6</sup>.

Independent of whether the care is formal or informal, these caregivers need professional support and a space for sharing doubts and anxieties. Integral health care for the caregiver should be based on the ability to establish the health needs of this population and to plan and evaluate the

health interventions related to care for the person individually in each context.

From this perspective, the present study sought to evaluate the health status, level of overload and emotional distress of formal and informal caregivers of older adults who have undergone treatment in three different levels of complexity: a hospital, outpatient clinic and long-term care institution, thus promoting the improvement of planning integral healthcare actions for these people.

## Method

This was an observational, cross-sectional, comparative and quantitative study to verify socio-demographic and health data and the level of overload and emotional distress of caregivers of older adults.

Participants were recruited in 2 groups. In the first, informal caregivers were identified in the medical care for the older adult in the School Health Unit (USE), considered a medium complexity outpatient clinic that serves users referred by the public health network of the São Carlos region. In addition, informal caregivers were recruited from the older adults attending the UFSCar University Hospital, which is integrated into the Network (Primary and Secondary Care Units), providing healthcare by providing observation/hospitalization services and emergency care to the population. The second group was represented by formal caregivers of a Philanthropic Long-term Institution, which at the time housed approximately 37 older adults.

The total sample consisted of 50 caregivers (15 formal and 35 informal) and the analysis of the sample power, presented as outcome emotional distress (total score), using the PASS application (Power Analysis and Sample Size), 2002 version, for a significance level of  $\alpha = 0.05$  and a sample size of  $n = 50$ , revealed a priori statistical power of  $1 - \beta = 66.4\%$ .

The inclusion criteria considered were, to be an informal caregiver, family member or person close to the older adult, such as a neighbor or friend that provided the care, without any kind of contract or payment for the purpose of care; and to be a formal caregiver, considered to be a person of legal age, with complete elementary and/or high school education, with specific training from an officially recognized institution for the activity of care and receiving remuneration for the activity, with or without a connection to the

institution. The exclusion criterion for participants was to be less than 18 years of age.

Data collection was performed in the first half of 2014, through interviews with the caregivers, after approval from the Research Ethics Committee of the Federal University of São Carlos, through the *Plataforma Brasil*, Authorization No. 416.459, on 10/15/2013. To obtain the data, an instrument was used with the following variables and scales:

Instrument to characterize the caregiver: covers the aspects: gender, age, marital status, relationship, knowledge about the disease, realization of a formal course, hours dedicated to caring, care activities, whether there is support, and self-reported diseases.

Zarit Burden Interview: developed by Zarit and Zarit<sup>7</sup>, translated and validated for the Brazilian culture by Scazufca<sup>8</sup>. This scale contains 22 items and objectively assesses the perceived impact of the care on the physical and emotional health, social activities and financial condition. The responses to the 22 items is given according to a five-point scale that describes how each statement affects the person. The total range is obtained by summing all the items and can range from 0 to 88. The higher the score, the greater the perception of the burden due to the care. The following scores were used as cutoff points, according to the international study of Ferreira et al.<sup>9</sup>, intense burden, scores between 61 and 88; moderate to severe, between 41 and 60, moderate to mild, between 21 and 40; and no burden, scores lower than 21 points. Note that this scale was validated for the assessment of informal caregivers, therefore, for this study only the last question of the scale (How overloaded do you feel?) was used for the formal caregivers.

Self Reported Questionnaire (SRQ-20): This tool, developed in 1980 by Harding et al.<sup>10</sup> and validated in Brazil in 1986 by Mari and Willians<sup>11</sup>, aims to detect emotional distress in the general population. The scores can range from 0 to 20 and the cutoff point of 7/8 was used, based on a Brazilian study to differentiate cases with emotional disorders.

Data analysis was performed using the Statistical Package for the Social Science (SPSS), version 20.0, program for descriptive and univariate analysis, both for the categorical variables (frequency tables) and quantitative variables (measures of central tendency and variability). The means of the categorical variables were statistically analyzed using Student's t-test. Pearson's correlation calculation was also performed

for the quantitative variables. Correlations were considered to be weak ( $r < 0.3$ ), moderate ( $0.3 \leq r < 0.7$ ) or strong ( $r \geq 0.7$ ). The bivariate analysis included measures of association in contingency tables for the qualitative variables, with the chi-squared test. The mean positions of the emotional distress measures (SRQ 20) were analyzed using the nonparametric Mann-Whitney test with Bonferroni correction. The level of significance was  $\alpha = 0.05$ .

## Results

Table 1 shows the profile of the 50 interviewed caregivers, 15 formal caregivers evaluated in ILPI and 35 informal caregivers of the University Hospital (UH) and the School Health Unit (USE). The sample had a prevalence of females regarding both the formal and informal caregivers. Having a partner and using religion as a support, were more frequently reported by both the formal and informal caregivers. It should be noted that the level of education of the formal caregivers was higher compared to the informal caregivers, with these represented by people with more than 9 years of education. Regarding the burden it was noted that the majority of both felt a little overloaded, however, the informal caregivers also reported 'a lot' (25.7%) and 'extreme' (14.3%) overload, emotional distress was more reported by the informal caregivers (45.7%) compared to the formal caregivers (26.7%). Finally, regarding the self-reported diseases, back problems were highlighted by the formal caregivers (38.5%) and Systemic Arterial Hypertension (45.7%) by the informal caregivers.

Table 2 presents the means of age, education, length of time as the caregiver, daily working hours, emotional distress and burden. The informal caregivers were found to be older, with less education, more time performing the caregiver function, longer daily working hours and higher frequency of emotional distress. It should be noted that for these caregivers it was possible to apply the complete burden scale (Zarit), obtaining the mean value of 30.9, which corresponds to moderate to light overload.

After the application of Pearson's correlation for the prevalence of emotional distress for each of the two types of caregivers, no association was found between the type of caregiver or care type and the proportion or prevalence of emotional distress ( $r = 0.208$ ,  $p = 0.345$ ). The Mann-Whitney test also did not detect a statistically signifi-

**Table 1.** Distribution of the main differences between Formal and Informal Caregivers, of the ILPI and the caregivers of the USE and HU combined. São Carlos, 2014.

Profile of caregivers	ILPI		USE/HU	
	N°	(%)	N°	(%)
Gender				
Female	13	86.7	30	85.7
Male	02	13.3	05	14.3
Education				
1 to 4 years	-	-	15	42.9
5 to 8 years	-	-	6	17.1
9 years or more	15	100	14	40
Have partner?				
Yes	08	53.3	25	71.4
No	07	46.7	10	28.6
Social support (yes)				
Religious institution	10	66.7	08	22.9
Group support (health)	01	6.7	04	11.4
Burden				
Not even a little	03	20	08	22.9
A little	06	40	11	31.4
Moderate	04	26.7	02	5.7
A lot	02	13.3	9	25.7
Extreme	0	0	5	14.3
Emotional distress				
Yes	04	26.7	16	45.7
No	11	73.3	19	54.3
Self-reported diseases				
Arterial hypertension	1	6.7	16	45.7
Diabetes	-	-	10	28.6
Back problems	6	38.5	10	28.6
Total	15	100	35	100

**Table 2.** Distribution of the means of Age, Education, Daily working hours, Remuneration, Length of time as the caregiver, Weekly hours, Emotional distress among the Formal Caregivers of ILPI and the Informal Caregivers of the USE and HU combined. São Carlos, 2014.

Mean (standard deviation) / Caregiver Profile	ILPI			USE/HU		
	M (sd)	Minimum	Maximum	M (sd)	Minimum	Maximum
Age	36.7(8.5)	21	50	55.2(15.4)	19	83
Education	13.7(2.9)	11	23	7.1(3.9)	1	13
Daily work hours	7.3(2.6)	5	12	19.8	6	24
Length of time as caregiver	6.2(5.9)	1	18	6.5(4.8)	1	20
Emotional distress	4.5(3.9)	0	11	6.9(3.9)	0	14
Burden (ZARIT)	-	-	-	30.9(14.3)	5	63

cant difference ( $p = 0.40$ ) between the mean burden positions for the two care types.

Regarding the aspects related to the health of the formal caregivers, lower back pain (38.5%) was highlighted as the main complaint. The in-

formal caregivers reported arterial hypertension (40%) followed by lower back pain (28.6%) for the self-reported diseases. The others (dyslipidemia, diabetes, heart disease, osteoporosis, arthritis/osteoarthritis, others) were little reported.

Emotional distress was assessed through the SRQ 20, revealing that for the formal caregiver the issue “sleeping badly” was the most reported (53.3%), followed by “feeling tense, nervous or worried” (40%) and “feeling tired” (40%). For the informal caregivers the issue “feeling tense, nervous or worried” was the most reported (80%), followed by “feeling sad recently” (62.9%) and “sleeping badly” (60%).

According to the activities that the formal caregivers performed in the Activities of Daily Living of the older adults, only physical activity was less performed in the context of the ILPI, with only 33.3% of the caregivers performing this activity with the older adults. The other activities, especially regarding the ADLs (hygiene, elimination, feeding, medication, sleep/rest) were performed by 86.7% of the caregivers. The following actions were most performed by the informal caregivers: accompanying to consultations (97.1%), assistance with medication (88.6%) and feeding (68.6%). Physical activity was also the activity less stimulated activity by the caregivers, with a total of 80%.

## Discussion

One point that draws attention in the study is the prevalence of women in both groups, formal and informal caregivers, a fact already recorded in the literature<sup>12-15</sup>. To understand the reasons that lead women to work of this nature and how they relates to it, it is essential to propose targeted actions that take into account the specificities of the gender.

All the formal caregivers interviewed reported more than nine years of education, courses and training in relation to care for older adults, this shows the concern of the institution with hiring qualified professionals to offer a service based on the legislation for ILPI's, considered to be a very positive feature. However, it is necessary to highlight the need for the ongoing education of this team and for participatory and multidisciplinary management, to encourage dialogue and to make these professionals feel a fundamental part of the therapeutic process<sup>16</sup>.

Regarding the support received outside the institution, the men did not report seeking help, while the women cited religious support as a form of support for the work. Religion can be considered a factor of motivation and support for the health professionals, providing support for the nurses in improving the service provided.

Furthermore, this is an element that can help in the professional-patient relationship<sup>17</sup>.

Regarding the health complaints, the caregivers presented health impairments and injuries directly related to their work process, such as back problems, which demonstrates the need to monitor the progress of these cases, in order to preserve the functional health of these caregivers. In this study, the formal caregivers had a higher prevalence of back pain than the informal caregivers, suggesting that it is not only age that is related to the physical symptoms, but also the performance of the caregiver role. Pinqart & Sørensen<sup>18</sup>, in a meta-analysis, found that caregivers of older adults have impaired physical health when compared to non-caregiver groups.

Practicing work gymnastics and the adaptation of the workload to the health characteristics of each caregiver can be incorporated in an attempt to minimize these complications. With the team integrating and seeking solutions for this, it is a focus of attention that has great potential to be explored, since the institution already has health and leisure professionals, equipment and spaces for this.

The study also contributed to the knowledge about symptoms of the burden experienced by the caregivers of older adults working in the ILPI, revealing that the interviewed caregivers more often felt “a little” (40%) and “moderately overloaded” (26.7%). In a study with caregivers of cancer patients, Maronesi et al.<sup>19</sup> found 18.7% of the study population to presented overload, with a lower percentage compared to informal caregivers (47%), a factor that relates to the results found in this study.

In other studies, such as those of Kappaun and Gomez<sup>20</sup> and Meneghini et al.<sup>21</sup>, overload was one of the complaints most reported by nursing professionals, because it is a profession that often requires physical exertion. Even with data showing less burden, it is important to be aware of the symptoms of overload, as nurses often present characteristics of burnout syndrome.

In a complementary way to the investigation of the feeling of overload, physical and psychological problems that characterize the emotional distress of the caregiver were evaluated. A total of 26.7% of the caregivers were diagnosed with emotional distress, and more of them reported poor quality of sleep and feelings of tension and fatigue, data similar to those found in the study of Silva et al.<sup>22</sup>. This can again be related to the intense daily work of the formal caregivers and the fact that the number of older adults in their care is greater than that of the informal caregivers.

This report shows the specifics of the work process in work schedules and also the stress to which these caregivers are subjected, where there are some feelings of worry and tension in the caregivers, with many aspects possibly involved, such as the severity of the patient's disease, the daily and continuous coexistence associated with the care, the dependency of the older adult and the lack of preparation of the caregivers for coping, which may also impact on the quality of their sleep<sup>23</sup>.

The unpreparedness of the caregivers is difficult to solve in the short-term, with it being necessary to know the profile of these individuals, as they experience different problems that are related to the socio-economic and cultural conditions of each family, so that more targeted assistance can be provided, adjusting the actions to the reality of each and adapting the guidelines for each type of caregiver and patient.

Considering this, Duarte<sup>24</sup> sought to prepare guidelines for a care policy for older adults, designing a comprehensive training program aimed at developing qualified workers to assist the most dependent older adults, according to a axis of uniform guidance. This program had as its aim a "gerontology view" from the professionals working with older adults, as well as guidance for the trainers of caregivers for older adults and for the caregivers themselves, becoming a reference in older adult caregiver courses in Brazil, which can be considered a milestone for the development of actions directed toward formal caregivers.

Regarding the characteristics of the informal caregivers, as well as the sample of formal caregivers, women were prevalent, totaling 85.7% of the respondents. However, 5 male subjects participated in the study, with a greater mean age (61.8 years) compared to the females (55.4 years). Cardona *et al.*<sup>25</sup>, in a similar study performed in the city of Medellin, Colombia, showed similar results, where 81.6% of the sample was composed by females, with a mean age of 56.5 years and 73.7% report housewife as their occupation<sup>5,12</sup>.

The majority declared education of between 1 and 4 years of study, for 42.9%, followed by more than 9 years (40%), the result shows a curious fact, where two groupings can be found. The difference in schooling may be related to the data collection having been performed in a School Hospital and School Health Unit, where both present different institutional profiles, one presenting a greater coverage of the city's population and the other presenting an admission policy where only a few have the privilege of access.

Pereira *et al.*<sup>12</sup>, in a study performed in the Emergency Unit of the Clinical Hospital of the Ribeirão Preto Medical School (HCFMRP), presented a population with from 1 to 4 years (33.9%) of education. However, in a study performed in Curitiba, 71% had more than 8 years of study<sup>15</sup>. Cultural habits and the context in which the person is included are still delimiting factors for the opportunities of the population, a fact that should be taken into account when considering levels of education.

The self-reported working hours showed an mean of 19 hours per day for the women and approximately 11 hours for the men, another important factor was that the mean length of time as the caregiver was longer for the women (6.9 years) than for the men (3.8 years). With regard to the question of the number of hours, many caregivers reported taking care of the older adult for 24 hours a day, when asked about the time of sleeping, many reported sleeping poorly due to providing care at night. These means were higher than those found in the study of Gratao *et al.*<sup>2</sup>, with a mean of 15.6 hours/day, referring to caregivers of older adults with dementia, who require great demand. This is divergent to the study of Pereira *et al.*<sup>12</sup>, which showed a mean of 4.6 hours/day care for older adults after a stroke.

The number of hours of care during the day and number of days of the week the caregiver assumes the care task are closely linked. Caregivers who spend more time with patients are more likely to experience depression and anxiety<sup>26</sup>.

Often the feeling of exhaustion or fatigue of the caregivers associated with the range of symptoms characterized in the individual suffering from overload is the result of great dedication and effort in the care activity, in which the caregivers ignore their own needs, constituting a psychosocial problem<sup>12</sup>.

Analyzing the responses to the Zarit Scale, the worry and the difference that the weight regarding the family relationship has on the caregiver's perception can be noted. By using the last question of the scale, generally 11 caregivers reported being just a little overloaded, while 9 reported being very overloaded. A certain fear of the caregivers and feelings of guilt were noted when cases of distress related to the care for the older adult were reported. When evaluating 35 caregivers in Colombia, Ocampo *et al.*<sup>27</sup> presented results similar to this study, where, with the application of the Zarit scale, 40% presented mild overload and 54.2% no overload.

In the study of Seima *et al.*<sup>15</sup>, of the 208 caregivers interviewed, approximately 26% presented

moderate to severe overload, relating to the data of this study, where 25.7% of the sample said that they felt very overloaded. Regarding the mean score found in the study of 30.9 (moderate to light burden), other studies found overload values close to this, such as in the study of Rodrigues et al.<sup>28</sup> that obtained a mean of 26.5. In general, the majority of studies found the family caregivers presented a mild to moderate degree of overload, relating to this study in addition to having similar characteristics such as gender<sup>4,12,15,28</sup>.

By assuming responsibility for the care, informal caregivers are limited in their performance of duties that used to be daily in their lives and they start to only take care of the needs of the older adult, failing to live their lives and pursue their interests. This increases in the level of burden and emotional distress causes negative feelings, such as loneliness and social isolation<sup>29</sup>.

In addition to the perceived burden, when assessing the emotional distress, approximately 80% reported feeling nervous and tense, followed by reports of feelings of sadness and complaints related to sleep duration, similar data to those found in the study by Morais et al.<sup>30</sup>, where 44.3% of the sample showed signs of overload, the most reported being: feeling tense or worried (73.8%), sleeping poorly (63.9%) and feelings of sadness (55.7%). Regarding the SRQ 20, only the overload level had a significant correlation with emotional distress ( $p < 0.05$ ), a fact already reported in other studies<sup>4</sup>.

When the caregiver is a family member, the task of caring can be perceived as more stressful which can even cause conflicting situations in the family<sup>4</sup>.

Less than half of the sample presented emotional distress, however, it was noticeable that the question of age, education and working hours during the week had relationships with emotional distress.

Knowledge through information obtained from validated instruments is needed so that actions can be implemented and evaluated to ensure better care for these caregivers and their older adult family members, considering that they deserve special attention regarding the psychological aspect.

## Conclusion

The data revealed that the informal caregivers presented higher levels of emotional distress, feelings of sadness and daily working hours (19.8 hours) compared to the formal caregivers, who showed feelings of fatigue, poor sleep and a mean of 7.3 hours of daily work. The consequences of informal care may be related to the fact that the caregiver is a close person or family member.

Thus, this emphasizes the importance of more trained professionals to attend older adults and the implementation of public policies aimed at this population, which should address different contexts, such as planning interventions aimed at improving the health and working conditions of these individuals.

Although the sample was small, the study was extremely relevant to characterize the profile of these caregivers and assess ways to minimize and even avoid overload and emotional stress. According to the current population situation in Brazil, the country needs to pay attention to the new demands related to the aging process so that this does not become a problem for professionals and family members.

The gerontologist is a key professional to promote integral healthcare for the caregiver of the older adult, which is focused on optimizing the quality of life, through the transmission of information, to train a team able to improve the conditions of the services provided, impacting positively in solving the problems of the caregivers and older adults. Thus, it is suggested that the geriatric and gerontology services plan formal and informal support strategies, coordinated by gerontologists professionals for the healthcare of caregivers of older adults.

The results of this study contribute to the planning of a systematization of individualized care respecting each profile, privileging tasks related to health promotion and the prevention of overload and emotional distress in the caregivers of older adults.

### **Collaborations**

MAA Diniz, BRS Melo, KH Neri, FG Casemiro worked on the methodology, design and final draft; CCLO Gaioli, LC Figueiredo and ACM Gratão worked on the study, design and final draft.



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