

Profile of older adults caring for other older adults in contexts of high social vulnerability^a

Perfil de idosos que cuidam de outros idosos em contexto de alta vulnerabilidade social

Perfil de adultos mayores que cuidan de otros adultos mayores en contexto de alta vulnerabilidad social

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ABSTRACT

Objective: To characterize older adult caregivers who care for other older adults in the context of high social vulnerability. **Methods:** Descriptive cross-sectional study, conducted with 40 older adult caregivers using: Mini Mental State Examination, Katz Index, Lawton's Instrumental Activities of Daily Living Scale, Geriatric Depression Scale and the Frailty phenotype proposed by Fried. The previously scheduled interviews were conducted in the home of the caregiver. For the data analysis, the statistical software Stata 11.0 was used, descriptively. **Results:** There was a predominance of females, age range 60-69 years, married, with primary education, who were retired. They had no health insurance. Most were pre-frail, hypertensive and independent in both instrumental activities and basic activities of daily living. They showed no evidence of depressive symptoms or cognitive impairments. **Conclusion:** To know the profile of the older adult caregiver is essential to support health services in planning quality care.

Keywords: Caregivers; Geriatric Nursing; Older Adult; Social Vulnerability.

RESUMO

Objetivo: Caracterizar os cuidadores idosos que cuidam de outros idosos em contexto de alta vulnerabilidade social. **Métodos:** Estudo descritivo e transversal, realizado com 40 cuidadores idosos utilizando-se: questionário para caracterização do cuidador, Mini Exame do Estado Mental, Índice de Katz, Escala de atividades instrumentais de vida diária de Lawton, Escala de Depressão Geriátrica e o fenótipo de fragilidade proposto por Fried. Para as análises, utilizou-se o Stata versão 11.0, de forma descritiva. **Resultados:** Houve predomínio do sexo feminino, da faixa etária de 60 a 69 anos, de indivíduos casados, com ensino primário, aposentados. Não possuíam plano de saúde. A maioria era pré-frágil, hipertensa e independente tanto para as atividades instrumentais quanto para as atividades básicas de vida diária. Não apresentavam indícios de sintomas depressivos, nem de alterações cognitivas. **Conclusão:** Conhecer o perfil dos cuidadores idosos é imprescindível para subsidiar os serviços de saúde no planejamento de uma assistência de qualidade.

Palavras-chave: Cuidadores; Enfermagem Geriátrica; Idoso; Vulnerabilidade Social.

RESUMEN

Objetivo: Caracterizar el perfil de los adultos mayores que cuidan de otros adultos mayores en contextos de alta vulnerabilidad social. **Métodos:** Estudio descriptivo y transversal, realizado con 40 cuidadores que utilizó: cuestionario para caracterización del cuidador, Mini Examen de Estado Mental, Índice de Katz, Escala de Actividades Instrumentales de Vida Diaria de Lawton, Escala de Depresión Geriátrica y el Fenotipo de Fragilidad de Fried. Para los análisis, se utilizó el Stata versión 11.0. **Resultados:** Predominaron las mujeres, la franja etaria entre 60 y 69 años, casadas, con escolaridad primaria, jubiladas. No tenían seguro salud. La mayoría era pre-frágil, hipertensa e independiente, tanto para las actividades instrumentales como para las actividades básicas de la vida diaria. No presentaban indicios de síntomas depresivos ni de alteraciones cognitivas. **Conclusión:** Conocer el perfil de los ancianos cuidadores es imprescindible para subsidiar los servicios de salud en la planificación de una atención de calidad.

Palabras clave: Cuidadores; Enfermería Geriátrica; Anciano; Vulnerabilidad Social.

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INTRODUCTION

Brazil is experiencing a moment of demographic transition due to the rapid, intense and progressive increase in the older adult population and, concomitant to this, there is also a change in the epidemiology of diseases, from infectious diseases to chronic nontransmissible diseases.¹ The chronicity of health problems and longevity of the population may contribute to the increase of functionally limited older adults who are, therefore, dependent on a caregiver.²

According to the gerontological literature, women are mainly responsible for caring for older adults. Generally, these women are middle-aged or older, wives or daughters, who live with the older adult and do not receive help to perform the care.²

Results of a meta-analysis of 168 studies published over 30 years regarding older adult caregivers showed that spouse caregivers were, older, low income, women that lived with the person being cared for.³

In Brazil, the number of older adults caring for other older adults is increasing.⁴ Older adult caregivers in contexts of poverty are more exposed to situations of vulnerability, with more damage to the quality of life and well-being of these individuals. These caregivers can be affected by comorbidities, which may contribute to prejudice the care provided. Social vulnerability determines certain requirements for individual, family and social resources to meet the needs of the older adults.⁵

Given the above, knowing the profile of the older adult caregiver becomes essential to support health services in planning quality care. Thus, the older adult caregivers may also offer quality care and preserve their physical and cognitive health. Furthermore, the literature presents many studies of the profile of older adult caregivers, however, national studies on the profile of caregivers who are older adults and are in contexts of high social vulnerability are scarce.⁵ Thus, this study aimed to characterize the profile of older adult caregivers who care for other older adults in contexts of high social vulnerability.

METHODS

This was a descriptive, cross-sectional quantitative study. It was carried out in São Carlos (SP), in the context of coverage of five Family Health Units (FHU), of the "Cidade Aracy" Regional Health Administration (ARES), which presents the highest social vulnerability.

Firstly, contact was made with these five FHUs. At that time, the community health agents provided a list with the names and addresses of possible older adult caregivers. Thus, the households to be visited were identified. In the company of the community health agent, a home visit was made to the older adult carers, who received information about the aims of the study, the voluntary nature of their participation, the confidentiality of the data collected and how the data would be used. After providing this information, they were invited to participate in the study. For the individuals who agreed to participate, the interview was scheduled.

The population consisted of people aged 60 or older, caring for older adults, registered and residing in the catchment area of the five FHUs of the "Cidade Aracy" Regional Health Administration (ARES). All caregivers (n = 40) who met the following inclusion criteria were interviewed: being 60 years of age or older; being the primary caregiver of an older adult residing in the same house and understanding the interview questions. The exclusion criteria were: having a hearing or vision limitation that would affect participation in the study.

Data collection started after reading and signing the consent form and occurred in one session, from September to October 2015. A questionnaire was applied for the evaluation of sociodemographic and health aspects and scales were used for the assessment of functional capacity, depressive symptoms, cognitive status and frailty.

The socio-demographic and health questionnaire was previously constructed by the researchers, including information on gender, age, marital status, education, family structure, current work, retired, income, number of children, health care insurance, presence of comorbidities, smoking and alcohol consumption.

To evaluate the functional capacity the Katz Index of Independence in Activities of Daily Living⁶ and Lawton's Instrumental Activities of Daily Living Scale.⁷ In relation to the Katz Index, which measures basic activities of daily living, there are three possible scores for each item evaluated according to the level of dependency of the patient: independent, needs help and dependent. The score ranges from zero to six points, and the older adult demonstrates independence, moderate or severe dependence. In relation to Lawton's Scale, the final score can range from seven to 21 points, with seven points indicating total dependence, eight to 20 points indicating partial dependence and 21 points, independence.

To screen for depressive symptoms, the 15 item version of the Geriatric Depression Scale was used. With the sum of the final scores obtained, from zero to five points indicating no evidence of depressive symptoms and from six to 15 points indicating the presence of depressive symptoms.⁸

To assess the cognitive status the Mini-Mental State Examination screening test was used, according to the following cutoff scores: 17 for illiterate people; 22 for older adults with between one and four years of education; 24 for those with between five and eight years of education, and 26 for those who had nine years of study or more.⁹

For the evaluation of frailty, the definition proposed by Linda Fried was adopted.¹⁰ There are five elements of the operational definition of the syndrome or of the frailty phenotype: 1) unintentional weight loss of 4.5 kg or more; 2) fatigue assessed by self-report; 3) low grip strength measured with a portable hydraulic dynamometer in the dominant hand; 4) low level of energy expenditure measured in kilocalories, assessed from self-reports of exercise and housework; 5) low speed of gait indicated by the mean time taken to cover the distance

of 4.6m. The presence of three or more of the five phenotype characteristics indicate frailty, one or two characteristics indicate pre-frailty and no characteristics indicates a robust or non-frail older adult.

The data obtained were coded and entered into an electronic spreadsheet and analyzed using the Stata version 11.0 program. Descriptive statistics were used and the results were presented in frequency tables with absolute (n) and percentage (%) values for the categorical variables, and position and dispersion measures (mean, standard deviation, median, minimum and maximum values) for the continuous variables.

All ethical guidelines governing research with human subjects were observed and respected, according to Resolution 466/2012 of the National Health Council. This study was approved by the Research Ethics Committee of the Federal University of São Carlos, under authorization number 1.071.650, on 09.06.2015, CAAE 45115615.0.0000.5504.

RESULTS

The sample consisted of 40 older adult caregivers. Table 1 presents the distribution of the older adult caregivers according to sociodemographic characteristics.

There was a predominance of females (67.5%), of the 60-69 years age group (55.0%), who were married (87.5%). The caregivers lived with their spouses (92.5%) and children (50.0%). The majority had elementary education, which corresponds to between one and four years of education (40.0%), followed by those that were illiterate (35.0%). Most of them did not currently work (82.5%) and were retired (72.5%). The older adult caregivers presented, a mean of 70.1 years of age (SD = 8.2), 1.8 years of schooling (SD = 2.3) and a monthly income of R\$781.20 (SD = 382.0) (Table 1).

The older adult caregivers had a mean of 5.5 children (SD = 3.1). They did not have health insurance (90.0%) and the condition of hypertension (62.5%) was most often reported. The majority of these caregivers had never smoked (42.5%), or consumed alcohol (90.0%). The caregivers were independent both regarding IADL (52.5%) and BADL (72.5%). Table 2 presents the distribution of the older adult caregivers according to cognitive and mood characteristics.

The majority of the older adult caregivers did not present depressive signs (57.5%) according to the Geriatric Depression Scale (GDS), which showed a mean of 4.5 points (SD = 2.8). In the MMSE, 92.5% presented no evidence of cognitive impairment, with a mean of 21.5 points (SD = 4.7) (Table 2). Table 3 shows the distribution of the older adult caregivers, according to the characteristics of frailty.

Regarding the frailty criteria, 52.5% scored positive for weight loss, 62.5% for physical inactivity, 35.0% for fatigue, 57.5% for low handgrip strength and 57.5% for slow gait speed. The majority of the caregivers were pre-frail (50.0%), followed by non-frail (40.0%) and frail (10.0%) (Table 3).

DISCUSSION

The results showed a predominance of women among the older adult caregivers (67.5%). These data are corroborated by both the national^{2,11} and international literature.¹² The female predominance among the family caregivers reflects the socio-cultural role of women, historically determined in the Western context, since, naturally, it is up to women to provide care, whether wife, daughter or sister, and men to provide sustenance and administer the finances.²

In the present study, the majority of the older adult caregivers were in the 60-69 years age group (55.0%). The mean age was 70.1 years (SD = 8.2), ranging between 60 and 98 years. Other researchers have found older adults caring for other older adults.²

Currently there is an increase in the number of older adults that care for other older adults, as both are living longer. With increased longevity, there is growing trend in the number of older adults.¹³ Authors indicate that younger caregivers have more energy to take care of older individuals.²

Regarding marital status, the majority of the older adult caregivers of this study were married (87.5%). The participation of women in the labor market and new family arrangements contribute to the reduction of family members available to perform the care for the older adults, causing the older adult spouses to become the first choice. Authors report that married women may demonstrate greater commitment to care, as they have more responsibility and experience in the home in relation to the family when compared to single women.¹⁴ Authors claim that when the older adult caregivers are the partners, there is an marital obligation to care for the spouse, as, with the marriage and living together, a commitment to a common life in health and sickness was made.¹⁵

Many of the older adult caregivers resided together with the older adult (92.5%), as confirmed by the literature.^{11,12,16} Living together with their spouses causes wives to potentially become the caregivers of their husbands. This may be favorable for the care of the older adult, as their care needs can be readily fulfilled.¹⁶

On the issue of income, the older adult caregivers did not currently work (82.5%) and were retired (72.5%). They had a mean income of R\$781.20 (SD = 382.0). Older adult caregivers are often unable to perform gainful activity outside the home, as no other person is available to take care of the older adult. This situation can impact on the monthly family income.¹⁷ In this sense, the pension becomes the only source of income of these families, with the older adult being the fundamental provider.¹⁸ The great socioeconomic inequality and living in a context of poverty can promote chronic stress throughout the life and affect the physical and cognitive domains of both the caregiver and the older adult receiving the care.²

The restriction of financial resources puts the older adults in a situation of great social vulnerability and can expose them to the risk of illness, worsen of pre-existing conditions or even compromise the treatment, since many older people use medications which are not always provided by National Health System.^{17,18}

Table 1. Distribution of older adult caregivers according to sociodemographic aspects. São Carlos - SP, 2015

Variables	Categories	n	(%*)	Mean (SD)	[Min-Max]	Median
Gender	Female	13	32.5			
	Male	27	67.5			
Age				70.1 (8.2)	[60-98]	68.5
Age group	60-69	22	55.0			
	70-79	14	35.0			
	80 and more	4	10.0			
Marital status	Married	35	87.5			
	Single	1	2.5			
	Divorced	1	2.5			
	Widowed	3	7.5			
Family structure**	Lives alone	0	0.0			
	Lives with spouse	37	92.5			
	Lives with children	20	50.0			
	Lives with grandchildren	10	25.0			
Years of study				1.8 (2.3)	[0-12]	1.0
Education	Never attended school	14	35.0			
	Func. illit.***	3	7.5			
	Literate	2	5.0			
	Elementary	16	40.0			
	Prep. high school****	1	2.5			
	High school	1	2.5			
	Higher	3	7.5			
Currently working	Yes	7	17.5			
	No	33	82.5			
Retired	Yes	29	72.5			
	No	11	27.5			
Income				781.2 (382.0)	[0-2000]	780.0

* The sum of the percentage frequencies that did not reach 100.0% are due to the fact that some variables in the study protocol were not answered by all the older adults. SD = standard deviation; ** The sum of the percentage frequency of the family structure variable is greater than 100.0%, because the older adults could live with spouses, children and grandchildren simultaneously; *** Func. illit.: Functional Illiterate; **** Prep. High school: Preparatory high school.

Table 2. Distribution of older adult caregivers according to cognitive and mood aspects. São Carlos - SP, 2015.

Variables	n	(%)	Mean (SD)	[Min-Max]	Median
GDS score			4.5 (2.8)	[0-9]	4.0
GDS results					
Without depressive signs	23	57.5			
With depressive signs	17	42.5			
MMSE score			21.5 (4.7)	[9-29]	22.0
MMSE result					
With indications of impairment	3	7.5			
Without indications of impairment	37	92.5			

SD: standard deviation; GDS: Geriatric Depression Scale; MMSE: Mini-Mental State Examination.

Table 3. Distribution of older adult caregivers according to frailty aspects. São Carlos - SP, 2015

Variables	Categories	n	(%*)
Weight loss	Not frail	16	40.0
	Frail	21	52.5
Physical activity	Not frail	14	35.0
	Frail	25	62.5
Fatigue	Not frail	26	65.0
	Frail	14	35.0
Grip strength	Not frail	17	42.5
	Frail	23	57.5
Gait speed	Not frail	17	42.5
	Frail	23	57.5
Frailty level	Not frail	16	40.0
	Pre-frail	20	50.0
	Frail	4	10.0

* The sum of the percentage frequencies that did not reach 100.0% are due to the fact that some variables in the study protocol were not answered by all the older adults.

Regarding education, 40.0% of the older caregivers had from one to four years of study, with a mean of 1.8 years of education (SD = 2.3), ranging between zero and 12 years. Other studies have also detected low education among older adult caregivers.^{11,15,17}

The period when these older adults were born and raised can explain the low rate of education. In the early twentieth century, formal education was not valued and precarious socio-economic conditions hindered access to schools, with no encouragement from parents. In this sense, the boys accompanied their fathers in agricultural work, while girls helped their mothers with housework, with childhood education being a privilege for a minority.¹⁶

Negative outcomes such as mental health problems, frailty and chronic conditions may be associated with low education, to the extent that the worse life habits, greater social exclusion, lower level of information, low socioeconomic status and lack of awareness of the health care needs impede the free access to health services early in search of health promotion and prevention of harm.¹⁵

Low education can directly influence the act of caring and may lead to a drop in the quality of the care provided. Difficulties in the comprehension of the disease process, difficulties with the care and lack of access to services and information may appear given the low education of the caregivers, which could lead to stress and emotional strain.¹⁷

Researchers highlight that it is extremely important to know the level of education of older caregivers, as it is they who will interact with the health team when accompanying the older adult to the service. Low education can hinder the comprehension of the caregiver regarding what happens with the older adult and

may represent a barrier in the health education process, which requires integrity of the learning ability of people. Special attention of the professionals in relation to the caregivers may be required considering their insufficient knowledge. Professionals must guide them regarding the various resources, aiming to achieve the desired goals and prevent possible misconceptions.¹⁵

In this study, the disease that was most present among the older adult caregivers was hypertension (62.5%). Similar data were found in the literature.¹⁹ The prevalence of chronic and noncommunicable diseases constitutes a common epidemiological panorama in the aging population. Increased longevity causes older adults to have experience with these diseases for long periods, which can compromise their quality of life. Other authors point out that hypertension can manifest in the older caregiver due to the many stressors present in the act of caring.^{14,17}

By devoting a lot of time to the care, caregivers often neglect their own health, and caregivers of older adults are more susceptible to health problems. In this sense, it is a major challenge for health professionals to deal with the emergence of diseases in the older caregiver, which justifies the need for assistance from other family members in the care of the older adult.²

Caregivers with advanced age may have chronic diseases that hinder the performance of their activities or that can trigger or worsen pre-existing health problems, leading to limitations in the older caregiver.²⁰

Regarding smoking and alcohol consumption, 57.5% of the older adult caregivers had had contact with cigarettes and 10.0% with alcohol. Authors say that smoking can be seen as a method to ease tensions in times of insecurity for the older caregivers.¹⁷ The literature suggests that the association of smoking and alcohol consumption with chronic conditions and the aging effect of the body can increase the susceptibility of older adults to diseases (such as COPD, for example) and disability,²¹ resulting in worsening of health.

The appearance of one or more chronic diseases can affect the functional capacity of older adult caregivers. In this study, as expected, the majority of the older caregivers were independent in both instrumental activities (52.5%) and basic activities of daily living (72.5%). This result can be explained by the profile of the sample, i.e., individuals residing in the community. Researchers also corroborated the findings of this study, which showed that the older adult caregivers presented worse performance in the IADL compared to the BADL.²

The literature suggests that the advanced activities of daily living are the first to be compromised with longevity, followed by the instrumental activities, due to diseases that affect the health of the older adults and aging itself. The basic activities, which are related to self-care, are the last to suffer impairment. When the older adults lose their autonomy and independence, the need arises for a carer.¹⁶

In the context of care, authors state that it is important to reflect on the functional capacity of caregivers, since physical

conditions can affect caregivers, putting at risk their functional ability.¹³ Chronic diseases may appear as a result of advancing age and thus, increase the susceptibility to disability, which may be more intense in a setting of caring for another older adult.²

Although the majority of the older adult caregivers did not present depressive symptoms, 42.5% needed more attention. The mean score in the Geriatric Depression Scale was 4.5 points (SD = 2.8), ranging between zero and nine points.

The presence of depressive symptoms was high in this study compared to other studies with caregivers.²² Perhaps this can be explained due to the context of major difficulties that these caregivers are in.

The older adult caregivers go through changes in their lives as a result of the care, i.e., there is less time for leisure and social life, which may worsen when this care is in a context of high social vulnerability. Such changes can lead to feelings of depression, negatively impacting the quality of life of the caregiver.¹⁴

Research shows that older adult caregivers have more depressive symptoms and lower life satisfaction when compared to older adults who are not caregivers,³ a phenomenon corroborated in this study. Receiving little social support also makes the older adult caregivers feel more depressive symptoms, when compared to younger adult caregivers of middle age.³

Researchers point out that older caregivers may experience depressive symptoms due to the responsibility of caring, overload and their own aging and physical impairment. Over the years, older caregivers feel unable to perform tasks as before, which causes them to suffer anxiety and worries.²⁰

According to the MMSE, 7.5% of the older adult caregivers showed evidence of cognitive impairment. The mean score was 21.5 points (SD = 4.7), ranging between nine and 29 points. Researchers have affirmed that the maintenance of cognitive health facilitates the adoption of adequate and healthy practices, both for the health of the caregiver as well as for that of the older adult receiving the care. They have also reported that cognitive functions may be impaired in scenarios of poverty, large socioeconomic inequalities and lack of institutional support.²

Regarding frailty, 10.0% of the older adult caregivers were frail, 50.0% pre-frail and 40.0% were not frail, taking into consideration the phenotype proposed by Linda Fried. The findings of this study were corroborated by the national literature.²³⁻²⁵

The predominance of pre-frail older adults reiterates the need for interventions to prevent the advance of pre-frail condition to those of frailty. This attitude would prevent adverse health outcomes and improve the quality of life of the older adults.²³

Studies indicate that when basic needs are not met, because of scarce financial resources, continued deprivation of benefits and opportunities and social inequality, disadvantages are accumulated throughout life, which are added to the losses associated with aging.²⁵ In this sense, older adults in situations of high social vulnerability may be at risk of disease and worsening

of pre-existing conditions. In addition, low education, reduced access to health services and lack of social support cause the older adults to present a more fragile health condition.¹⁸

In this study, 52.5% of the older caregivers reported unintentional weight loss in the previous year. This prevalence was much higher than that recorded in the literature.²⁵ Authors point out that this result can be explained due to the high valuation by society of a slim body, leading participants of some studies to overestimate the value of a loss of casual weight.²⁵ On the other hand, researchers say that older adults may suffer from nutritional problems (e.g., malnutrition) that can anticipate the development of frailty, being considered to be potential markers of the syndrome.²³

In this study, 62.5% of the older adults were deficient in the "physical activity" criterion. Results of one study also showed that among frail older adults, 17.5% presented low levels of physical activity. These authors claim that the decline in physical activity by older adults can be related to reduced mobility, muscle weakness, postural instability, malnutrition and sarcopenia.²³ The international literature also corroborates the findings of this study in relation to frailty. Studies around the world have used the phenotype of Fried to identify the prevalence of frailty syndrome. This prevalence ranged from 4% to 17% of older adults.^{26,27}

This study presents some limitations. These findings should be considered preliminary because of the small sample size, which may limit generalization of the results. In addition, the design of this study was not a sample of the population, which can lead to an underestimation of the prevalence of frailty and cognitive decline.

It is suggested that further studies take into account frailty, cognition and depressive symptoms of older adult caregivers in contexts of high social vulnerability, as they are scarce in the literature.

CONCLUSION

The results showed that the majority of the older adult caregivers were female (67.5%), of the 60-69 years age group (55.0%), married (87.5%), living with their spouses (92.5%) and their children (50.0%), with elementary education (40.0%), that did not work (82.5%) and were retired (72.5%). They presented an mean monthly income of R\$781.20 and mean of 5.5 children. Most had no health insurance (90.0%). Hypertension was the pathology most reported by the caregivers (62.5%). Approximately 57.5% of these caregivers had had contact with smoking and 90.0% did not consume alcohol. With regard to activities of daily living, most were independent for both IADL (52.5%) and BADL (72.5%). There was a predominance of older adult caregivers without indications of depressive symptoms (57.5%) or cognitive impairment (92.5%). Regarding frailty, 10.0% of the older adult caregivers were frail, 50.0% pre-frail and 40.0% were not frail. Regarding the frailty criteria, the caregivers scored positive for weight loss (52.5%), physical inactivity (62.5%), fatigue (35.0%), low handgrip strength (57.5%) and slow gait (57.5%).

The results of this study contribute to the planning of systematic care individualized for the profile of older adult caregivers, privileging tasks related to health promotion and the prevention of problems such as depression, dementia and frailty, within the Family Health Strategy.

Thus, it is essential for health professionals to provide adequate support for older adult caregivers. Regarding the practical implications of these findings, it is suggested that support groups can be implemented to ensure the monitoring of these caregivers, to meet their demands and to improve their quality of life.

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