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Centenarian caregivers: perception of burden, sociodemographic data and physical activity

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ABSTRACT. This study aimed to understand centenarian caregivers' perception of care burden according to sociodemographic characteristics and physical activity level. This is a descriptive study that used a mixed data (quantitative and qualitative) approach. Sixty-seven caregivers of centenarians from municipalities in Santa Catarina participated in this study. Interviews were held for application of questions about sociodemographic data, transport-related and leisure-time physical activity, caregiver burden, and suggestions for improving care. The data were collected in the centenarian's home where the caregiver worked. Quantitative data were analyzed using descriptive and inferential statistics and qualitative data by content analysis. The results showed that 58.2% of the caregivers were overburdened. Of these, 92.3% were females, 56.4% were 60-75 years old, 48.7% had 7 to 11 years of schooling, 53.8% were married, 66.7% were children of centenarians, the caregiving duration ranged from 1 to 5 years in 35.9%, and 69.2% cared for the older adult 24 hours/day. There was a statistically significant difference ($p = 0.01$) between the level of leisure-time physical activity and caregiving burden, with 64.9% of insufficiently active caregivers tending to be overburdened with the care demand. The suggestions of caregivers for improving centenarian care included having help from health professionals and relatives for care, infrastructure, and financial resources. Most burdened caregivers are insufficiently active and need assistance in taking care of their own health.

Keywords: aged 80 and over; caregivers; burden; physical activity.

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Introduction

As demonstrated by the 2010 demographic census, the life expectancy of Brazilians has been increasing over the years (Instituto Brasileiro de Geografia e Estatística [IBGE], 2010). This scenario has led to the emergence of the population of centenarians, which had increased in both developed and developing countries (Nações Unidas [UN], 2019). The number of centenarians worldwide was 500,000 in 2019; in Brazil, there were 24,232 centenarians in 2010 (IBGE, 2010).

Within this new scenario of population growth, an increase is observed in the prevalence of chronic noncommunicable diseases, cognitive impairment, sensory decline, accidents and social isolation, events that result in the functional dependence of older adults (Souza et al., 2015). Losses of functionality, autonomy and cognition tend to be present and become more pronounced at advanced ages, including the population of centenarians (Afonso, Tomás, Brandão, & Ribeiro, 2019). In the case of functional incapacity of the individual, the family takes on the caregiving role for the older adult, often without preparation, adequate knowledge or support to perform this task (Gratão et al., 2013).

The caregiving task, which is represented by the role of the caregiver, encompasses activities aimed at assisting the elderly person who is physically or mentally impaired to perform activities of daily living and self-care. Caregivers are defined as those who are responsible for taking care of sick or dependent persons, facilitating their daily activities such as eating, personal hygiene, provision of routine medication, and accompanying them to health services or other daily requirements (Couto, Castro, & Caldas, 2016).

The main source of support when caring for older adults continues to be the family (Figueiredo, 2007). In this system, family support tends to be provided by an informal caregiver, usually the spouse or other female close relatives, with adult and older women being the main providers of informal care (Figueiredo, 2007). Thus, the informal caregiver provides unpaid care, while the formal caregiver is minimally prepared and is paid for the care provided (Nardi, Santos, Oliveira, & Sawada, 2012).

In an attempt to care for and meet the demands related to the temporary or permanent functional incapacities of centenarians, informal caregivers are fully dedicated to the service for long hours of the day which, in some cases, can result in great physical and emotional burden (Gratão et al., 2013, 2012; Baptista et al., 2012). Studies report that the degree of functional dependence of older adults is directly related to the degree of caregiver burden; hence, the more dependent the older adult, the higher the degree of burden and the lower the quality of life of the caregiver (Nardi, Sawada, & Santos, 2013; Espín Andrade, 2012; Oliveira & D'Elboux, 2012).

It is therefore important to understand the physical, social and emotional barriers involved in caregiving within the context of collective health in order to promote better quality of life and to reduce the burden of caregivers and those they care for (Souza et al., 2015). Another important factor to be considered are the sociodemographic characteristics of caregivers, which can influence the burden of caring for centenarians.

Within this context, regular physical activity has shown numerous health benefits, affecting psychological, biological and social dimensions (Lopes & Benedetti, 2009; Schenkel et al., 2011; Batista & Ornellas, 2013; Mazo, Manosso Lanferdini, Dal'Agnol, Roncada, & Dias, 2014). Physical activity may thus be a tool that can contribute to improve the caregiver's health, preventing future physical and psychological stress. Studies indicate that research on caregivers of centenarians is still scarce (Sachdev et al., 2013; Kim, Boerner, Jopp, Rott, & Cimarolli, 2015; Jopp, Boerner, Ribeiro, & Rott, 2016). It is therefore important to investigate centenarian caregivers' perceptions of care burden according to their physical activity level (PAL) since regular physical activity can provide better physical, psychological and social conditions for these individuals.

Therefore, the aim of this study was to understand centenarian caregivers' perception of burden according to sociodemographic characteristics and PAL.

Methods

This is a descriptive study using a mixed (quantitative and qualitative) data approach. The study is part of the Multidimensional Study of Centenarians from Santa Catarina (SC100 Project), conducted by the Laboratory of Gerontology (LAGER), Center of Health and Sports Sciences (CEFID), State University of Santa Catarina (UDESC). One of the objectives of this project is to map the living conditions of centenarians from different municipalities in Santa Catarina (Mazo, 2017), including their caregivers. The SC100 Project was approved by the Ethics Committee of UDESC (Approval number 21417713.9.0000.0118). The present study followed the ethical guidelines of Resolution 466/12 of the National Health Council. All participants in the study signed the free informed consent form (TCLE).

Caregivers who met the following inclusion criteria were selected: being the main caregiver of the centenarian, caring for the older person at home, and residing in the municipalities of Grande Florianópolis, Joinville microregion, and Vale do Itajaí mesoregion, Santa Catarina state. Thus, 67 main caregivers of centenarians who lived at home participated in the SC100 Project between March 2015 and February 2019. Thirty-eight participants were from the Greater Florianópolis mesoregion, 17 from the Joinville microregion, and 12 from the Itajaí mesoregion.

Data were collected using the Multidimensional Assessment Protocol for the Centenarian Caregiver (Mazo, 2015), developed by LAGER/CEFID/UDESC. This protocol is composed of six blocks. Four blocks (1, 2, 3 and 6) were used in this study. Block 1 refers to identification of the caregiver and contains information about age group, sex, educational level, marital status, degree of kinship, caregiving duration, and hours of care/day.

Regarding Block 2, the perceived burden of caregivers was evaluated using the Zarit Burden Interview (ZBI), adapted and validated for the Brazilian culture (Scazufca, 2002). The ZBI consists of 22 items that are scored from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = frequently, and 4 = always), except for the last item in which the caregiver's perception of burden is questioned, with the following response options: 0 = not at all, 1 = a little, 2 = moderately, 3 = quite a bit, and 4 = extremely. At the end of application of the instrument, the total score is obtained by summing all items, which indicates the caregiver's burden. According to Ferreira et al. (2010), a score < 21 points is classified as the absence of burden, 21 to 40 points as moderate burden, 41 to 60 as moderate-severe burden, and 61 to 88 points as severe burden. In the present study, based on the scores proposed by Ferreira et al. (2010), a score of less than 21 points was classified as the absence of caregiver burden and a score of 21 or more points as the presence of caregiver burden.

The questions of Block 3 – transport-related and leisure-time physical activities of the International Physical Activity Questionnaire (IPAQ) adapted to older adults (Mazo & Benedetti, 2010) – were applied to assess the PAL of centenarian caregivers. This instrument assesses weekly energy expenditure with physical activities of moderate or vigorous intensity performed for 10 continuous minutes during a usual week (Mazo & Benedetti, 2010). For the analysis of PAL, caregivers who performed 150 minutes or more of transport-related and leisure-time physical activity per week were classified as sufficiently active and those who performed less than 150 minutes per week as insufficiently active (Craig et al., 2003).

The responses to the open-ended question of Block 6, ‘Suggestion for improving centenarian care’ were also analyzed. The following categories were defined using qualitative content analysis according to Bardin (2010). To ensure anonymity of the respondents, the testimonies of the caregivers were identified in the text with flower names and age.

The data were collected by trained researchers following the guidelines of the Interviewer’s Manual: Application and Analysis Protocol for Assessment of the Centenarian Caregiver (Mazo, 2015). First, the caregivers were contacted by telephone and/or personally, inviting them to participate in the study, and the day and time of the interview was scheduled. On the day of the interview, the caregivers signed the free informed consent form and application of the questions of the Multidimensional Assessment Protocol for the Centenarian Caregiver (Mazo, 2015) was started.

The sociodemographic and PAL data of the participants were tabulated, stored in Microsoft Excel®, and analyzed using the IBM Statistical Package for the Social Sciences (SPSS 20.0). Descriptive statistics (measures of central tendency and dispersion and simple and relative frequency) was used. The chi-squared test was applied to evaluate the association between PAL (sufficiently and insufficiently active) and the presence or absence of caregiver burden, adopting a level of significance of 5%.

Results

As can be seen in Table 1, considering the total sample, 58.2% (n = 39) of the centenarian caregivers were overburdened with the care demand. In addition, 92.3% (n = 63) of the participants were females, 59.7% (n = 40) were 60-75 years old, 46.2% (n = 31) had 7 to 11 years of schooling, 52.2% (n = 35) had no partner, 71.6% (n = 48) were children of the centenarians, the caregiving duration ranged from 1 to 5 years in 35.8% (n = 24), and 68.5% (n = 46) cared for the older adult 24 hours day⁻¹.

Associating leisure-time PAL with the presence or absence of care burden (Table 2) showed a significant difference (p = 0.01), with 64.9% of insufficiently active caregivers tending to be overburdened with the care demand. Regarding transport-related PAL, no significant difference was observed between caregivers who were overburdened and those who were not (p = 0.502).

The caregivers were asked about suggestions for improving centenarian care and the responses were organized into the following categories: lack of help from health professionals and the family for care; infrastructure and financial resources; entertainment and leisure. In addition, the responses were used concurrently with quantitative discussions in order to broaden the view on the reality experienced by caregivers.

Discussion

The sociodemographic characteristics of caregivers who were overburdened and those who were not were similar. Most caregivers were married women aged 60 to 75 years with 7 to 11 years of schooling, who were the daughter of the care recipient, had been taking care for 5 years, and dedicated 24 hours per day to this care. Similar results have been reported in previous studies in which most caregivers were female and married family members (Gratão et al., 2013; Nardi et al., 2013; Diniz et al., 2018).

According to Nunes, Brito, Duarte and Lebrão (2018), historically, women have taken on the role of caring for their most needy family members since this role has been seen as more feminine and because women had not yet entered the labor market. Although the social panorama has changed and nowadays it is impossible to imagine the labor market without the contribution of women, this change still represents a challenge for health professionals who need to expand their perspective and revise the stereotypes associated with caregiving as a female function (Gonçalves, Costa, Martins, Nassar, & Zunino. 2011; Mafra, 2011).

Table 1. Sociodemographic characteristics and care condition of centenarian caregivers according to the presence or absence of care burden (n = 67).

Variable	Absence of burden n (%)	Presence of burden n (%)
Sociodemographic characteristics		
Sex		
Female	27 (42.9)	36 (75.1)
Male	1 (25.0)	3 (75.0)
Age group (years)		
20 – 59	7 (33.3)	14 (66.7)
60 – 75	18 (45.0)	22 (55.0)
> 76	2 (40.0)	3 (60.0)
Not reported	1 (100)	0 (0)
Education (years of schooling)		
0 – 6	8 (36.4)	14 (63.6)
7 – 11	12 (38.7)	19 (61.3)
> 12	8 (57.1)	6 (42.9)
Marital status		
With a partner	11 (34.4)	21 (65.6)
Without a partner	17 (48.6)	18 (51.4)
Care conditions		
Degree of kinship		
Child	22 (45.8)	26 (54.2)
Grandchild	1 (50.0)	1 (50.0)
Spouse	0 (0.0)	2 (100.0)
None	2 (33.3)	4 (66.7)
Other	3 (33.3)	6 (66.7)
Caregiving duration (years)		
1 - 5	10 (41.7)	14 (58.3)
6 – 10	6 (35.3)	11 (64.7)
11 – 20	6 (46.2)	7 (53.8)
> 21	6 (43.8)	7 (56.2)
Hours of care/day		
< 7	1 (100.0)	0 (0.0)
8 – 12	3 (60.0)	2 (40.0)
24	19 (41.3)	27 (58.7)
Not reported	5 (33.4)	10 (66.6)
Total	28 (41.8)	39 (58.2)

Source: The authors (2021).

Table 2. Association between transport-related and leisure-time physical activity level and care burden of centenarian caregivers (n = 67).

Level of physical activity	Absence of burden n = 28	Presence of burden n = 39	x ² p value
	n (%)	n (%)	
Transport related			
Insufficiently active	20 (40.8)	29 (59.2)	0.502
Sufficiently active	8 (44.4)	10 (55.6)	
Leisure time			
Insufficiently active	20 (35.11)	37 (64.9) ^a	0.01*
Sufficiently active	8 (80.0)	2 (20.0)	

Legend: X² = chi-squared test; adjusted residual > [2]; *p < 0.05.

Regarding age group, most caregivers were between 50 and 59 years old. This finding might be related to the fact that the care recipients were mainly widowed centenarians and the caregivers were their children who were of advanced age themselves (Brandão, Ribeiro, Oliveira, & Paúl, 2017; Diniz et al., 2018; Gratao et al., 2013; Nardi et al., 2013; Yang, 2013; Freeman, Kurosawa, Ebihara, & Kohzuki, 2010). Nevertheless, the phenomenon of older adults taking care of other elderly people is very common and may result in a relationship that can cause suffering, illness and vulnerability for both (Muniz, Freitas, Oliveira, & Lacerda, 2016). Thus, middle-aged caregivers also represent a challenge since their functional reserves may become compromised and, at some point, negatively affect their performance, compromising the quality of care provided to the more dependent older adult. In addition, these caregivers may neglect self-care, increasing the risk of developing physical and emotional diseases that may compromise their health (Nunes et al., 2018).

The caregiver who is a family member assumes the care responsibility based on the initiative or determination of the family group. Three aspects can generally be observed: kinship, gender, and physical and emotional proximity (Jesus, Orlandi, & Zazzetta, 2018). Thus, the family member ends up assuming the caregiver role because he/she does not have the financial resources needed to hire someone (Amendola, Oliveira, & Alvarenga, 2011), since he/she has to help the elderly person with the tasks the person depends upon while simultaneously performing other tasks (Couto, Caldas, & Castro, 2018).

Furthermore, the observation of a predominance of female caregivers in this study and in the studies mentioned above highlights the central role of women as the main person responsible for caregiving in the family and its paradoxical consequences. According to Gutierrez and Minayo (2010), the central role given to women has important political implications since it is associated with the social justification of the absence and lack of responsibility of men in the healthcare sphere and the imprisonment of women in their traditional activities, which is a form of perpetuation of female oppression and their confinement to the domestic sphere.

In agreement with the results of the present study, the review by Oliveira and D'Elboux (2012) showed that caregiving is a predominantly female task performed by older women who have a low level of education and spend long periods of time caregiving without taking turns. Thus, caring for an elderly family member is another task that women assume in the domestic sphere, which directly affects their quality of life (Anjos, Boery, & Pereira, 2014).

A study showed that female caregivers, with less education, who spend more time with weekly care and longer residency with the elderly, similar to overload (Aires et al., 2020). This demonstrates the need for a balance between care functions dedicated to older adults and the caregiver's own health since, when caregivers adopt both physical and mental measures that benefit their health, they will become more prepared and able to cope with the daily challenges.

According to this reasoning, since caregivers are mainly characterized as being a female family member over 50 years of age who are fully dedicated to caregiving, there is a considerable difficulty for them to obtain a remunerated job in order to financially assist the household of the elderly person. This situation becomes a vicious cycle which cannot be broken because, if the centenarian needs specific health services and the caregiver, as part of the elderly's family, cannot pay for these services, he/she will have to spend more time taking the older adult to primary care centers and will be unable to devote time to his/her own health needs, with the caregiver thus becoming overburdened.

Within this context, the statements of some caregivers demonstrate the need for better infrastructure and financial resources in order to improve the care provided, for example:

Everything needs to be improved. Help with clothes, diapers and money (Cravo, 34 years).

To have a better living standard in order to walk with the centenarian (Tulipa, 65 years).

The doors of the house should be bigger to facilitate bathing and locomotion, there is only a bath chair, no wheelchair (Rosa, 69 years).

These statements and the constant citation of the need for help from qualified and specialized professionals provided by the Health Units suggest that, if more resources and specialized care were available at home, these caregivers would not be overburdened with the care demand and could devote more time to their own health. The need for caregivers to receive orientation about specialized care from the basic health network, which often provides insufficient support (Amendola, Oliveira, & Alvarenga, 2011).

Another negative issue regarding the burden of care and little participation of other family members is the caregiver's social isolation. Some reports of the caregivers suggest the need for some free time to have for themselves for activities that they could no longer do after they started caring for the older adult, as illustrated by the following statement:

Help from someone to take care of her, having someone more often to help me, to take turns in caring so I can go out for a while and have some free time (Bromélia, 65 years).

According to Lemos (2018), the burden of care negatively affects the social life of caregivers, preventing them from carrying out activities other than caring and limiting their free time. Caregivers often complain of overload, depression, stress and anxiety after they had to leave their job, their leisure activities and self-care aside, affecting their own quality of life as well as the care provided to the older adult (Moraes & Silva, 2009; Oliveira & D'Elboux, 2012). This fact has become a matter of concern considering that in recent years the

provision of informal care has been underdiagnosed as a condition that causes morbidities (Rico-Blázquez et al., 2014). Within this context, Morais et al. (2012) emphasize that the burden of care must be considered a multidimensional concept that comprises the biopsychosocial sphere and encourages the search for balance between the following factors: time available for care, financial resources, psychological, physical and social conditions, attributions, and role distribution.

On the other hand, although research on caregivers of centenarians is scarce, in a study conducted in Japan, Nishikawa et al. (2003) suggested that caregivers of centenarians are an example of successful informal care. In that study, the caregivers who were between 70 and 90 years old and were mainly women considered their work valued and satisfactory and assessed their health positively. In contrast, a subsequent study also carried out in Japan (Freeman et al., 2010) did not find that caregivers of centenarians are less burdened or have a lower prevalence of depression or better quality of life than caregivers of younger older adults. In addition, the authors observed that the burden of care was not associated with household income, relationship with the centenarian or positive impact of care.

Similar to the present study, Afonso et al. (2019), studying caregivers of centenarians, showed that most of them were children and dedicated an average of 15 hours to caregiving. In addition, female caregivers exhibited higher levels of care burden and those caring for more dependent centenarians experienced a higher subjective burden. The results of that study alert to the need for interventions at the health and community level adapted to the specificities of these caregivers, most of whom also face their own demands of the aging process.

Regarding transport-related PAL, there was no significant difference between overburdened caregivers and those reporting no overburden, with most caregivers in the two groups being insufficiently active, in agreement with the study by Muniz et al. (2016) in which 88.3% of the sample did not perform regular physical activities. Although physical activity is encouraged and its importance has been demonstrated in old age, according to Costa and Neri (2019), advancing age and a low level of income were found to be a major barrier to the engagement of older adults in activity physical and social activities designed to promote active aging. Physical inactivity is also common among caregivers since they may have fewer opportunities and time to engage in this activity.

In view of the burden of care, caregivers have less time to perform regular physical activity, in addition to living an intense routine that can lead to illness, as reported in the study by De Nardi, Rigo, Brito, Santos & Bós (2011) which demonstrated that caregiver need the support of other people, especially their family. The following statement illustrates this case:

The presence of family through visits would provide more peace of mind, it would alleviate the burden of caring alone. The centenarian is resistant to moving and, if there was an outsider for stimulating her, it would probably improve (Violeta, 54 years).

Nevertheless, caregivers identify and report the importance of physical activity to continue to be healthy. However, according to Nunes et al. (2018), due to the different factors related to tasks and obligations, in addition to caring for the older adult, caregivers reduce their social relationships, distancing themselves from affective and professional relationships and reducing their social network and opportunities for socializing and leisure, as well as physical activity and self-care (Amendola, Oliveira, & Alvarenga, 2011).

In the present study, both caregivers who were overburdened and those who were not exhibited low leisure-time PAL, characterizing them as insufficiently active; however, the level of physical inactivity was even higher in burdened caregivers compared to those reporting no overburden.

Regarding the lack of time for leisure and the lack of regular physical activity, also demonstrated by Silva, Silva, Nahas and Viana. (2011) who indicated tiredness and excessive work as barriers to leisure-time physical activity, the statement of caregiver Margarida confirms this argument:

The family could collaborate more. Especially on the weekend, they could come to take care of her so I could go out, it would be good for me and for her too (Margarida, 69 years).

In this respect, Inouye, Pedrazzani and Pavarini (2008) described that most caregivers of octogenarians performed at least one hour of physical activity per week since they had someone to divide the tasks on the weekends. This report highlights the importance of help with caring to reduce the burden and improve the quality of life of caregivers.

The limitations of the present study include the self-report of the centenarian caregiver's health conditions and the need for direct assessment of physical activity since the IPAQ does not provide such data

because it estimates the weekly energy expenditure with physical activity. In addition, the perception of burden may be distorted by the family bond by understanding that the caregiver has a duty of care and cannot feel burdened by the task.

Final considerations

This study identified the profile of caregivers of centenarians as being a daughter aged 60 to 75 years with 7 to 11 years of schooling, who had cared for the centenarian for 1 to 5 years, with a daily care workload of 24 hours. Due to the time of daily dedication, most of these caregivers are overburdened with the care demand. Furthermore, the overburdened caregivers had a low PAL, characterizing them as insufficiently active. In addition, situations such as financial difficulties, lack of infrastructure, lack of help from health professionals, and lack of family attention contribute to the increased burden of caregivers who have to devote many hours to the older adult, thus neglecting self-care, leisure time and physical activity. To prevent overburdening, caregivers need to have more time for their self-care, dedicating themselves especially to physical activity, which would be of benefit for their physical and psychological health. Also should receive social support, which would include a reduction of musculoskeletal problems, an increase of muscle strength, improved self-esteem, strengthening of social relationships and sharing the challenges they experience.

The results of the present study suggest the need for more studies focusing on the caregiver's health and on alternatives and the benefits of physical activity for this group. Intervention studies may also be useful to introduce caregivers to the universe of physical activity and to emphasize the need to engage in regular activities.

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