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Original Article

Analysis of the program's benefits "Caring for Caregivers" for participating family caregivers

Análise dos benefícios do programa "Cuidando de quem cuida" para os cuidadores familiares participantes

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Abstract

Introduction: With the growth of the elderly population dependent on care, it becomes necessary for more people to take on the role of caregiver and for services to prepare to provide appropriate care to older individuals and their caregivers. In this context, the second edition of the program "Cuidando de quem cuida" ("Caring for Caregivers") was completed in 2023, aiming to support and guide caregivers of dependent elderly individuals. **Objectives:** To characterize participating family caregivers in terms of sociodemographic and health conditions and the time dedicated to caregiving; to compare their burden before and after the program; and to identify other possible benefits resulting from participation in the program. **Method:** A mixed-method, retrospective, cross-sectional, descriptive, and analytical study, based on data analysis from 22 participating family caregivers. Statistical tests allowed comparisons of caregiver burden before and after the program, as well as the identification of associations between caregiver characteristics and burden. Participants' opinions were submitted to thematic categorical analysis. **Results:** Half of the caregivers were between 41 and 59 years old; most had completed higher education, had an income above four minimum wages, and reported one or more clinical complaints. A statistically significant reduction in burden was identified. None of the caregivers' characteristics were associated with this outcome, leading to the inference that the only variable associated was participation in the program. In line with this, caregivers highlighted positive aspects of the program. **Conclusion:** Benefits from the program were evident, such as support, network building, and the expansion of resources for self-care. It is recommended to conduct a study with the inclusion of new participants, enhancement of data

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collection instruments, and inclusion of data from the dependent elderly individuals, as ways to guide future interventions.

Keywords: Self-Care, Caregivers, Caregiver Burden, Frail Elderly, Psychosocial Intervention.

Resumo

Introdução: Com o crescimento da população idosa dependente de cuidados, torna-se necessário que mais pessoas assumam o papel de cuidador e que serviços se preparem para oferecer cuidado adequado às pessoas idosas e seus cuidadores. Nesse contexto, foi concluído em 2023 a segunda edição do programa "Cuidando de quem cuida", que visa acolher e orientar cuidadores de pessoas idosas dependentes. **Objetivos:** Caracterizar os cuidadores familiares participantes quanto às condições sociodemográficas, de saúde e ao tempo dedicado ao cuidado; comparar sua sobrecarga antes e após o programa; identificar outros possíveis benefícios decorrentes da participação no programa. **Método:** Estudo misto, retrospectivo, transversal, descritivo e analítico, a partir da análise de dados de 22 cuidadores familiares participantes. Testes estatísticos permitiram estabelecer comparação entre sobrecarga antes e após o programa, além de verificar associação entre características dos cuidadores e sobrecarga. Opiniões dos participantes foram submetidas à análise categorial temática. **Resultados:** Metade dos cuidadores tinham entre 41 e 59 anos, a maioria realizou ensino superior com renda acima de quatro salários-mínimos e se referiram a uma ou mais queixas clínicas. Identificou-se redução estatisticamente significativa de sobrecarga. Nenhuma das características dos cuidadores esteve associada a esse desfecho, inferindo-se que a única variável associada foi a participação no programa. Em consonância, os cuidadores apontam aspectos positivos referentes ao programa. **Conclusão:** Evidenciaram-se benefícios advindos do programa, como acolhimento, criação de redes, ampliação de repertório para o autocuidado. Recomenda-se estudo com inclusão de novos participantes, aprimoramento de instrumentos de coleta de dados e inclusão de dados das pessoas idosas dependentes, como formas de orientar futuras intervenções.

Palavras-chave: Autocuidado, Cuidador Familiar, Desgaste do Cuidador, Idoso Dependente, Intervenção Psicossocial.

Introduction

According to the 2022 Demographic Census, the Brazilian population is aging, with 15.6% of the total population at that time composed of people aged 60 or over, which corresponds to 32.1 million individuals. Life expectancy in the country reached 75.5 years (Instituto Brasileiro de Geografia e Estatística, 2022). Although aging is a natural process, causing organic and functional changes, it also brings social consequences that impact other aspects of life (Santos et al., 2018).

Furthermore, in aging, chronic and degenerative diseases may arise that increase the likelihood of impairment of independence and autonomy over time (Santos et al., 2018). In addition, the Pan-American Health Organization (Organização Pan-

Americana de Saúde, 2019) reported that in Latin America, 40% of elderly people already need prolonged care – and the estimate is that this number will triple in the next 30 years.

Elderly people who lose autonomy and independence to perform basic activities of daily living require continuous monitoring to ensure their own care (Brasil, 2018). In this context, it becomes essential that one or more people take on the responsibility of care, performing the role of caregiver.

The Caregiver's Practical Guide of the Ministry of Health (Brasil, 2008) emphasizes that the caregiver is the one who looks after "the well-being, health, nutrition, personal hygiene, education, culture, recreation and leisure of the assisted person" (Brasil, 2008, p. 8). Being a caregiver of an elderly person implies assisting them in performing activities of daily living, accompanying them in external activities, and encouraging them to participate in cultural and educational activities (Batista et al., 2011).

According to the Classification of the Ministry of Social Welfare and Assistance, there are three categories of caregivers: formal, professional, and informal (Ministério da Previdência e Assistência Social como citado em Boaventura et al., 2016, p. 3194). The formal and professional caregivers play a fundamental role in providing support and guidance to family caregivers, contributing to the improvement of care and well-being, both of elderly people and their families.

The informal caregiver is one who provides care to the person at home, with or without a family bond, and is not paid for this service. Regarding this type of caregiver specifically, it is expected that they identify with the task of caregiving and have empathy for the target of the actions. The choice of the informal caregiver is determined in part by culture, often designating this role to individuals with a greater degree of kinship, of the female gender, physically and affectively closer, thus constituting a person who becomes a reference of refuge, whether by availability or by will, even without necessarily having any training to provide care (Boaventura et al., 2016).

The practice of caregiving requires dedication and availability of time on the part of the caregiver and is frequently permeated by a constant mix of feelings, such as concerns, anxiety, loneliness, frustrations, but also satisfaction and gratitude (Batista et al., 2011). The constant demands and challenges inherent in care often lead family caregivers to give up self-care in favor of caring for others. The neglect of self-care by the family caregiver can lead them to experience extreme situations, making them themselves the object of care, especially when the provision of long-term care and attention generates burden (Nogueira & Braúna, 2022).

With the increase of the dependent elderly population, the demand for caregivers and health services prepared to provide adequate care also grows. Although Brazilian legislation assigns the responsibility of care to the family, State and civil society, consistent policies are lacking to meet the needs of family caregivers. There are not enough programs and projects that value their demands and ensure their rights (Sousa et al., 2021). Until now, the State offers few basic health services to welcome and guide these caregivers (Minayo et al., 2021).

It is urgent to implement public policies that support caregivers and dependent elderly people, promoting specific training and support programs (Ceccon et al., 2021; Minayo et al., 2021). Despite legislative efforts and initiatives from Civil Society Organizations (CSOs), the current infrastructure is insufficient to meet caregivers' demands (Nogueira & Braúna, 2022). Therefore, it is necessary to develop and implement effective strategies, even if initially on a pilot and regional scale.

Given the scarcity of resources to serve the growing number of dependent elderly people, especially due to disabling conditions such as dementias, the Federal Government sanctioned Law No. 14,878, of June 4, 2024. This law establishes the National Policy for Comprehensive Care for People with Alzheimer's Disease and Other Dementias, providing support to families, interdisciplinary evaluation of clinical and psychosocial needs, and training of specialized professionals. However, for this initiative to be effective, its regulation and implementation are essential.

The absence of legislative support and regulation constitutes an unfavorable context for caregivers to perform their functions, fundamentally compromising the quality of care provided (Hedler et al., 2016). Thus, advances in structuring public support programs are crucial to guarantee the health and well-being of dependent elderly people, but also of their caregivers, due to their great potential, as expressed in various studies, to disseminate information about care, provide instrumental support for caregiving, and also expand caregiving resources for the caregiver themselves.

Studies such as those by Fialho et al. (2012), Reis et al. (2018), and Mattos et al. (2021) evidenced the benefits generated by programs aimed at informal caregivers of dependent elderly people. In Fialho et al. (2012), the intervention demonstrated benefits such as relief of anxiety and stress for the 40 participating family caregivers. In turn, Reis et al. (2018) analyzed different programs aimed at caregivers of elderly people with dementia, identifying positive aspects – such as guidance and training on dementia and care strategies, social interaction with other caregivers, and the application of the mindfulness technique for self-care. These factors helped caregivers to develop skills to cope with the demanding demands of caregiving, resulting in reduced stress and burden levels. Mattos et al. (2021) conducted a virtual support group for 10 family caregivers of elderly people with dementia during the COVID-19 pandemic, over 8 weekly meetings. The authors concluded that the group proved to be a valuable tool for caregivers, allowing access to information and guidance regarding the care of the elderly and their self-care, with a positive impact on their emotional state and well-being. Thus, it becomes clear that caregiver support programs are not only relevant, but essential.

Observing the insufficiency of public programs that welcome and support family caregivers in the western region and in other regions of the municipality of São Paulo, the program "Caring for Caregivers" was created in June 2022, an initiative of professionals from the Unified Health System (SUS) and members of the Butantã Regional Conducting Nucleus of the Protection Network for the Rights of the Elderly to welcome and guide informal and formal caregivers of dependent elderly people in the municipality of São Paulo. The program welcomes, in its majority, family caregivers and, in its second edition in 2023, also came to include formal caregivers.

The focus of the program is to encourage caregivers to maintain a self-care routine and to guide them to provide adequate care to the elderly person. Program participation criteria are: a) be 18 years old or over, b) self-identify as the main caregiver of an elderly person, c) be a caregiver of an elderly person considered dependent, d) be a caregiver linked to one or more services belonging to the Butantã assistance network.

The team responsible for coordinating "Caring for Caregivers" is composed of nine professionals from the Butantã Regional Conducting Nucleus of the Protection

Network for the Rights of the Elderly, which includes: three social workers, two psychologists, an occupational therapist, a nutritionist, a physiotherapist, and an administrative staff member of the Parque Previdência Coexistence and Cooperative Center (CECCO Previdência). Since its inception, the program has also counted on the participation of an Occupational Therapy student from the Universidade de São Paulo, supported by an annual scholarship granted by the Unified Scholarship Program (PUB-USP) in the 2022/2023 edition.

"Caring for Caregivers" comprises 16 meetings conducted by the aforementioned team and invited professionals, who are SUS professionals from the Butantã region and university faculty working in the field of Gerontology and Geriatrics. The meetings are held weekly, lasting 2 hours each, in an Auditorium at Parque Previdência, located in the Butantã region of the municipality of São Paulo.

According to Table 1, the program consists of meetings that include two moments, generally focusing on bodily dynamics for relaxation and group integration, followed by lectures aimed at the exchange of information that enable caregivers to care for themselves and elderly people appropriately. Between these moments, a brief break is reserved in which snacks are offered to participants: it is a moment of relaxation and allows informal exchanges among caregivers. At the end of each meeting, an evaluative moment is reserved in which caregivers record their opinions about the meeting.

Table 1. Schedule of meetings of the "Caring for Caregivers" Program.

Meeting	1st hour	Speakers' area of expertise	2nd h	Speakers' area of expertise
1	Project introduction	Physiotherapy, social work, administration and occupational therapy	Dynamic: circular dance	Physiotherapy, social work, administration and occupational therapy
2	Lecture: Biological savings; Dynamics: physical exercise	Physiotherapy	Lecture: aging process	Psychology
3	Dynamic: meditation	Administration	Lecture: social protection networks	Social assistance
4	Dynamic: conversation circle	Physiotherapy, social work, administration and occupational therapy	Dynamic: conversation circle	Physiotherapy, social work, administration and occupational therapy
5	Dynamic: circular dance	Physiotherapy	Lecture: relationship between caregiver and care	Psychology
6	Lecture: How to provide adequate nutrition for the elderly	Nutrition	Lecture: how to provide adequate nutrition for the elderly	Nutrition
7	Dynamic: Afro dance	Psychology	Lecture: dementia	Medicine
8	Dynamic: energetic exercise	Physiotherapy	Lecture: Warning signs: when to go to the Emergency Room	Nursing
9	Lecture: palliative care	Nursing	Lecture: decongestant activity	Psychology
10	Lecture: prevention of accident risks involving elderly people	Nursing	Lecture: daily care for elderly people	Medicine

Table 1. Continued…

Meeting	1st hour	Speakers' area of expertise	2nd h	Speakers' area of expertise
11	Dynamic: Tai Chi Pai Lin	Social assistance	Lecture: medication management	Pharmacy
12	Dynamic: circular dance	Physiotherapy and administration	Dynamic: conversation circle	Physiotherapy, social work, administration and occupational therapy
13	Lecture: non-pharmacological management of behavioral symptoms in dementia	Occupational Therapy	Lecture and dynamics: cognitive stimulation of caregivers and dependent elderly people	Occupational Therapy
14	Dynamic: music	Occupational Therapy	Lecture: dysphagia	Medicine
15	Dynamic: yoga	Social assistance	Lecture: guardianship and interdiction process	Social assistance
16	Trumpet musical presentation	Trumpet group	Closing and fellowship	Physiotherapy, social work, administration and occupational therapy

Source: own elaboration.

The program includes interviews before and after its implementation. In the initial interviews, the following are applied: a) a questionnaire to characterize caregivers in terms of sociodemographic aspects (age, sex, education level, family income, and whether the caregiver receives any benefits), how long the caregiver has been providing care to the older person, how many people live in the caregiver's household, and whether the older person usually receives visitors, and b) the Caregiver Burden Interview (ZBI), also known in our country as the Zarit Burden Scale (Scazufca, 2002). ZBI is applied in the program only to family caregivers. The Zarit Scale (Scazufca, 2002) measures the burden on caregivers of older adults. It contains 22 questions regarding feelings and situations experienced by the caregiver. The burden level of caregivers is rated with the following scores: <21 = little burden; between 21 and 40 = moderate burden; between 41 and 60 = moderate to severe burden; and between 61 and 88 = severe burden.

After the meetings are completed, individual reassessments are conducted with caregivers who attended at least 11 meetings (or the equivalent of 70%), applying again the Zarit Scale (Scazufca, 2002) and a semi-structured interview script to assess possible benefits produced by the program as reported by the participants.

Considering that the program "Caring for Caregivers" was conceived as a care strategy, this study aims to identify and analyze potential benefits of it for participating family caregivers. The specific objectives are: 1) to characterize the social, demographic, health, and caregiving profiles of participating family caregivers; 2) to identify and compare the presence and degree of caregiver burden before and after the program; 3) to learn participants' opinions about the program and potential strategies for its improvement.

Methods

This is a mixed-methods study, both qualitative and quantitative, retrospective, cross-sectional, descriptive, and analytical. It is retrospective because it aims to study records from a specific point in the past up to the present moment (Hochman et al., 2005; Marconi & Lakatos, 2005), which in this specific study refers to data collected from family caregivers participating in the "Caring for Caregivers" program, including their social, demographic, health characteristics, and reported caregiving burden.

The study is cross-sectional as it seeks to analyze these records within the same time frame (Rouquayrol, 1994). It is descriptive and analytical because, through statistical tools (Hochman et al., 2005), it aims to describe and analyze these records to objectively identify benefits resulting from participation in the program. Program benefits will also be assessed through participants' opinions about the program and suggestions for its improvement. These data will be analyzed using content analysis through thematic categorical analysis (Bardin, 1977).

The records related to the program for all participants – 1st and 2nd editions, held respectively in 2022 and 2023 – are stored in Google Drive spreadsheets. This information was organized into a database, in which each subject was identified by a number.

The selection and analysis of database records in this study followed the following criteria: participants could be of any gender and had to be family caregivers of dependent older adults providing full-time care, i.e., 24 hours a day, 7 days a week.

Dependent older adults were considered those assessed by professionals from the Butantã Network for the Protection of the Rights of Older People as frail according to the Multidimensional Assessment of the Older Person in Primary Care – AMPI-AB (São Paulo, 2014; Saraiva et al., 2020), an instrument widely used by the Municipality of São Paulo to guide care for this population across different levels of system complexity.

Records of formal caregivers of dependent older adults, formal and informal caregivers of healthy older adults, and family caregivers of dependent older adults who provide part-time care were excluded. In summary, caregivers who are not the primary caregivers of the dependent older person were excluded.

The study extracted, described, and analyzed information from the database that characterizes family caregivers regarding sociodemographic aspects such as age, gender, family income, education, degree of kinship with the dependent older adult; information related to the caregiver's health status, duration of caregiving, and whether they have other family members to assist them. Also extracted, described, and analyzed were data from the Zarit Scale (Scazufca, 2002) before and after the program, as well as participants' opinions and suggestions regarding the program.

Qualitative characteristics – related to social, demographic, health variables, care provided, presence and level of burden –, were evaluated for all caregivers using absolute and relative frequencies. Quantitative characteristics were described using mean and standard deviation or median and quartiles (Kirkwood & Sterne, 2006).

Next, "level of burden" was considered the dependent variable and main focus of the study. Statistical tests assessed whether there was a "reduction in burden level" after implementation of the program. Once this reduction was confirmed, possible associations between the "reduction in burden level" and variables potentially influencing this outcome were investigated. These variables included social, demographic, and health aspects, caregiving conditions, and participation in the program.

Possible associations were tested using chi-square or exact tests (Fisher's exact test or likelihood ratio test). Only the duration of caregiving was described in relation to improvement in classification using median and quartiles and compared using the Mann-Whitney test (Kirkwood & Sterne, 2006). The score and classification of burden were described before and after the intervention and compared using the paired Wilcoxon test (Kirkwood & Sterne, 2006). IBM-SPSS for Windows version 22.0 was used for statistical analysis, and Microsoft Excel 2013 was used for data tabulation. Tests were conducted with a 5% significance level.

Participants' opinions on the program and possible strategies for its improvement were obtained through qualitative analysis of this information. The thematic categorical analysis methodology was adopted, whereby the content of responses is coded and categorized according to predefined categories corresponding to the objectives, as well as categories not defined a priori but identified during the analysis process (Bardin, 1977).

This project was approved by the Research Ethics Committee of the Hospital das Clínicas da Faculdade de Medicina, Universidade de São Paulo – HCFMUSP – CAAE: 75660823.2.0000.0068. All participants signed the Free and Informed Consent Form.

Results and Discussion

Information on participants contained in the database was accessed to characterize the social, demographic and health profile of the group, in addition to identifying and comparing the presence and degree of burden of these caregivers before and after the program and identifying an association between burden and the characteristics of their profile.

According to Table 2, the data show that half of the caregivers are between 41 and 59 years old, and the other half are 60 years or older. The average age, more precisely, is 60.5 years. The majority of caregivers are female (86.4%) with higher education (45.5%), a household income above 4 minimum wages (36.4%), and clinical complaints (63.6%). It was found that 5 people reported physical complaints (23%), 3 reported psychological complaints (14%), and 3 reported metabolic complaints (14%). The median time dedicated to caregiving is 4.5 years, with 6 people (27%) having provided care for 2 years or less; 8 people, for 3 to 5 years (36%); 3 people, for 6 to 10 years (14%); and 5 people, for 11 years or more (23%). In general, participants receive some type of social benefit (77.3%), live in a household (the caregiver's) with 3 people (40.9%), and the older adult usually receives visits (86.4%).

Table 2. Distribution of family caregivers in the "Caring for Caregivers" Program according to social, demographic and health characteristics.

Variable	Description (N = 22)
Age range, n (%)	
Up to 59 years	11 (50)
60 years or older	11 (50)
Age (years), mean ± SD	60.5 ± 11.4
Sex, n (%)	
Female	19 (86.4)

Table 2. Continued…

Variable	Description (N = 22)
Male	3 (13.6)
Education Level, n (%)	
Elementary school	3 (13.6)
High school	9 (40.9)
Higher education	10 (45.5)
Salary Range, n (%)	
1/2 to 1 minimum wage	4 (18.2)
1 to 2 minimum wages	7 (31.8)
2 to 4 minimum wages	3 (13.6)
Above 4 minimum wages	8 (36.4)
Comorbidities, n (%)	
No	8 (36.4)
Yes	14 (63.6)
How long have you been caring for the elderly person (years), median (p25; p75)	4.5 (2.4; 10.5)
Do you receive any welfare benefits?, n (%)	
No	5 (22.7)
Yes	17 (77.3)
How many people live in the house?, n (%)	
1	1 (4.5)
2	8 (36.4)
3	9 (40.9)
4 or +	4 (18.2)
Does the elderly person(s) usually receive visitors?, n (%)	
No	3 (13.6)
Yes	19 (86.4)

Source: Source: own elaboration.

Half of the participants, that is, 11 individuals, are adults, while the other 11 are older adults who care for other older adults. The average age of the participants is 60.5 years. Thus, compared to other studies, the average age in present research was higher: in the study by Moura et al. (2019), the average age was 52.8 years; 53.56 years in the study by Gesualdo (2020); 57 years in Kobayasi et al. (2019); and 58 years in the study by Santos et al. (2018). Furthermore, the average age of participants in this study aligns with the age profile of the population in the Butantã region, where the program meetings were held. According to the São Paulo Inequality Map (Rede Nossa São Paulo, 2023), Butantã is ranked as the fifth district with the highest average age at death in the city (78 years). This suggests that the population in the region tends to reach older ages, which may result in greater dependence on care, either from family members or from other older adults who take on the role of caregiver.

The majority of participants are female, consistent with several studies. Kobayasi et al. (2019) and Ceccon et al. (2021) discuss that women predominantly provide care. Ceccon et al. (2021) and Monteiro et al. (2021) highlight that care provided by women reflects gender inequalities due to power relation gaps between the sexes, which have developed through historical and cultural aspects. Kobayasi et al. (2019) and Sousa et al. (2021) also found that the responsibility of caring for older adults falls on wives, daughters, daughters-in-law, nieces, and granddaughters, demonstrating the historical assignment of care work primarily to women.

The present study shows that, in general, caregivers have a high level of education, in contrast to other studies. In the integrative review on the quality of life of family caregivers of the oldest old, 12 studies were selected. Of these, 5 reported that the majority of caregivers had completed or incomplete primary education (Monteiro et al., 2021). In the research by Santos et al. (2018) and Ceccon et al. (2021), most caregivers had incomplete primary education, and in the study by Kobayasi et al. (2019), the largest portion had completed primary education.

As presented in Table 2, most caregivers have a household income above 4 minimum wages. This range, when combined with the income range of 2 to 4 minimum wages, represents the income level of half of the program participants, diverging from the sociodemographic profile of informal caregivers portrayed by Sousa et al. (2021). These data indicate that Brazilian reality is marked by deep social inequalities, and few family caregivers manage to organize financially to provide the best care for dependent older adults. In the analysis by Santos et al. (2018), participants' income was equal to or less than one minimum wage, and it is estimated that some caregivers left their jobs to dedicate themselves exclusively to caregiving. In the dissertation by Gesualdo (2020), caregivers' income ranged from 1 to 2 minimum wages. However, the family income level above 4 minimum wages among participants in this study is consistent with the economic profile of the Butantã population, according to the São Paulo Inequality Map (Rede Nossa São Paulo, 2023), which indicates that the region has a higher average income, reflecting the greater financial capacity of some families in the area to provide care.

Fourteen (63.6%) caregivers in the "Caring for Caregivers" program reported clinical complaints. The most relevant complaint was related to the musculoskeletal system (e.g., back pain and knee pain). Similarly, Moura et al. (2019) revealed that 68.6% of caregivers participating in the study had some clinical condition. Santos et al. (2018) stated that 85.71% of caregivers reported physical complaints, with the most common being back pain and musculoskeletal and connective tissue diseases. The study (Santos et al., 2018) emphasized that these caregivers did not undergo any type of treatment. Reis et al. (2018) found that caregivers experienced physical and emotional burden. Kobayasi et al. (2019) and Ceccon et al. (2021) identified emotional complaints that may result from the stress experienced daily.

The average time of caregiving provided by family caregivers to dependent older adults in this program was 4.5 years, with the largest number of caregivers providing care between 3 and 5 years. This finding is similar to that of other studies also involving dependent older adults and their caregivers. In the project by Gesualdo (2020), the largest portion cared for between 2 and 3 years, and in the studies by Ceccon et al. (2021) and Sousa et al. (2021), between 2 and 5 years. In the study by Moura et al. (2019), it was observed that most caregivers had been providing care for more than 5 years.

In general, caregivers receive some type of social benefit, live with two other people, and the older person being cared for usually receives visits. However, this study was not able to explore what types of social benefits participants received, the degree of kinship with the individuals living with the caregivers and older adults, nor the frequency of visits to the dependent older person (whether always, frequently, sometimes, or rarely). Future studies may be conducted to better explore these aspects.

Table 3 shows that both the score and the classification demonstrate a statistically significant reduction in caregiver burden after the intervention (p < 0.001). It can be observed that, for all caregivers, there was a decrease in the burden score on the Zarit Scale, with a reduction in the average burden of 9.1 (SD ± 4.2) points.

Table 3. Score and classification of family caregivers in the application of the Zarit Burden Scale/Caregiver Burden Interview, according to the assessment moment and comparison result.

Variable	Before	After	Improvement	p
Classification, n (%)				<0.001
Minimal or non-existent	0 (0)	3 (13.6)	11 (50)	
Slight to Moderate	10 (45.5)	13 (59.1)		
Moderate to Severe	9 (40.9)	5 (22.7)		
Severe	3 (13.6)	1 (4.5)		
Score				<0.001
Mean ± SD	44.5 ± 14.3	35.5 ± 13.8	9.1 ± 4.2	
Median (p25; p75)	43 (33; 54.5)	34 (24.8; 47.8)	9 (5; 12.3)	
Paired Wilcoxon test				

Source: Source: own elaboration.

The reduction in the Zarit Burden Scale score was also observed in similar interventions conducted by Fialho et al. (2012), who identified a reduction of 5.37 points in the average burden of 40 participants. In agreement, Shata et al. (2017) presented a decrease of 17.7 points in the average burden experienced by the 55 participants in the study.

Table 4 shows that none of the variables analyzed had a statistically significant influence on the improvement in the burden rating (p > 0.05), which suggests that the only variable associated with the outcome – reduction in burden – was the participation of caregivers in the program.

Table 4. Description of the improvement in the participants' overload classification using the Zarit scale according to the variables analyzed and the results of the statistical tests.

Variable	Improvement in ranking		Total (N = 22)	p
	No (N = 11)	Yes (N = 11)		
Age range, n (%)				0.670
Up to 59 years	6 (54.5)	5 (45.5)	11	
60 years or older	5 (45.5)	6 (54.5)	11	
Sex, n (%)				>0.999*
Female	9 (47.4)	10 (52.6)	19	

Table 4. Continued…

Variable	Improvement in ranking		Total (N = 22)	p
	No (N = 11)	**Yes (N = 11)**		
Male	2 (66.7)	1 (33.3)	3	
Education Level, n (%)				0.075#
Elementary school	3 (100)	0 (0)	3	
High school	3 (33.3)	6 (66.7)	9	
Higher education	5 (50)	5 (50)	10	
Salary Range, n (%)				0.804#
1/2 to 1 minimum wage	2 (50)	2 (50)	4	
1 to 2 minimum wages	3 (42.9)	4 (57.1)	7	
2 to 4 minimum wages	1 (33.3)	2 (66.7)	3	
Above 4 minimum wages	5 (62.5)	3 (37.5)	8	
Comorbidities, n (%)				0.659*
No	3 (37.5)	5 (62.5)	8	
Yes	8 (57.1)	6 (42.9)	14	
How long have you been caring for the elderly (years)				0.193£
median (p27; p75)	5 (4; 13)	4 (1.5; 10)	4.5 (2.4; 10.5)	
Do you receive any welfare benefits?, n (%)				>0.999*
No	2 (40)	3 (60)	5	
Yes	9 (52.9)	8 (47.1)	17	
How many people live in the house?, n (%)				0,606£
1	0 (0)	1 (100)	1	
2	5 (62.5)	3 (37.5)	8	
3	5 (55.6)	4 (44.4)	9	
4 or +	1 (25)	3 (75)	4	
Does the elderly person(s) usually receive visitors?, n (%)				0,214*
No	3 (100)	0 (0)	3	
Yes	8 (42.1)	11 (57.9)	19	
Chi-square test; * Fisher's exact test; # Likelihood ratio test; £ Mann-Whitney test				

Source: own elaboration.

In contrast, other studies have identified factors associated with the burden of informal caregivers of elderly people. Montoya et al. (2019) observed that a daily workday of 12 to 24 hours dedicated to care resulted in moderate burden in the caregivers participating in the study. Martins et al. (2023) found significant associations between perceived burden and caregivers who, in addition to providing care, are also elderly people and live in the same home environment as the person being cared for.

Below, we will present the benefits and suggestions for improvement reported by the 22 family caregivers participating in the two editions of "Caring for Caregivers". This information was organized and analyzed based on the thematic categorical analysis technique developed by Bardin (1977), as shown in Table 5. Thus, initially the information was analyzed and organized by thematic units and, then, these units were broken down into categories.

Table 5. Thematic units identified from information obtained from participants through interviews using a semi-structured script of questions.

Thematic units
a) Benefits
Care for the caregiver
Care for the elderly
Care for the elderly-caregiver dyad
b) Suggestions for improving the program
Improving informational support
Enhancing support for self-care

Source: Own elaboration.

To preserve the caregivers' identities, codes were assigned to participants (P), combining two pieces of information: the alphabetical order of names (P1 to P11) and the group number they belonged to (G1 or G2). Each of the three thematic units corresponds to categories highlighted in the text concerning the benefits attributed to the Program by the caregivers.

Benefits

• *Care for the caregiver*

Successive approximations to caregivers' responses regarding the category care for the caregiver revealed recognition of various forms of care adopted by the program team, extending from reception and listening to the expansion of the caregiver's repertoire of care strategies.

Caregivers expressed experiences of reception and listening by program professionals, through the following statements:

P6G1: "the professionals make themselves available to answer individual questions";

P7G1: "the team clarifies some doubts about the everyday aspects of care and we also learn things we were not informed about";

P9G2: "we receive free professional guidance on how to care for ourselves and our elderly, as well as the group we formed, so I feel more willing to take care of myself and my family member";

P6G2: "Caring for Caregivers has excellent professionals who made me take better care of myself";

P7G2: "the team and the group address more care strategies that I didn't know";

P11G2: "the team is committed, welcoming, attentive, and participative".

These reports highlight the importance of professional guidance and support to guide family members in caregiving. Abreu et al. (2009) emphasize that accessing and seeking knowledge about diagnosis, disease information, and community resources that can support care, such as caregiver support services and training courses, are strategies to alleviate caregiver burden.

The practice of listening and welcoming provided by the team and recognized by caregivers aligns with the literature. According to Castro et al. (2020a), welcoming and listening to caregivers to assist them in caring for dependent older adults, whether by increasing their knowledge about the disease or by offering social and/or emotional support, results in better quality of life.

The expansion of support networks (exchange of ideas, experiences, and feelings) was experienced by caregivers throughout the meetings and can be seen in the following statements:

P4G1: "I made friends and feel more experienced to take appropriate actions to care for my elderly";

P7G1: "sharing experiences with people, the testimonies... It was a combo of good things. Everything was great, including the reception";

P9G1: "the formation of friendships was significant for me";

P4G2: "for me it was a way to get to know and make friends, because since I don't go out, it's a way to see and talk to people";

P10G2: "I was able to make friends, which makes me feel more supported in providing care".

Caregivers' references to network expansion from the meetings concur with Gesualdo (2020), who, in her thesis, points out that support from institutions and services offering guidance and reception to caregivers provides opportunities to enhance social support and life. The author adds that support groups are important interventions to increase social support and reduce the negative psychological effects associated with caregiving.

It is reaffirmed that the expansion of support networks was significant for the social lives of the caregivers in this study, as it enabled the exchange of feelings, thoughts, and experiences about caregiving, the caregiver role, and the burden of care, often experienced in solitude. Ceccon et al. (2021) assess that social networks and support are important help measures for facing problems.

In harmony, Minozzo (2022) notes that exchanging experiences with other caregivers is a factor that promotes caregiver health. Sousa et al. (2021) indicate that caregivers need someone with whom they can share their feelings without judgment or criticism and a support network that enables self-care. In a study with family caregivers of older adults with Alzheimer's (Cruz et al., 2015), it was observed that most participants used the meeting time to share feelings of sadness, lack of patience, abandonment by other family members, and requests for psychological support.

Program professionals provide caregivers with opportunities to speak, continually validating their knowledge, experiences, and methods of handling challenging everyday situations. The promotion of feelings of self-esteem, self-confidence, and self-efficacy by the facilitation team is expressed in the following statements:

P2G1: "thanks to the guidance received, I pay more attention to what I do and feel more confident that I'm on the right path and everything I'm doing is within my reach";

P3G1: "the meetings prepared me to care for my sister";

P10G1: "the program also improved my self-esteem";

P2G1: "the program helped me gain self-confidence and realize that I'm not the only one going through this family caregiver situation. And it also made me realize that I must be in good health to care for others";

P8G2: "I feel more informed and prepared to provide care";

P3G2: "during the program I learned to be more prepared to care for my family member".

Regarding the promotion of feelings of self-esteem, self-confidence, and self-efficacy, "Caring for Caregivers" caregivers expressed a recovery of these, stating they feel more prepared to care for their family members. In contrast, the lack of preparedness for caregiving can generate insecurity in family members and risk developing stress, mood changes, and compromise their own health (Cruz et al., 2015).

In Sousa et al. (2021), several caregivers reported that learning about the clinical aspects of those they care for generates security and confidence to perform the caregiving role. Figueiredo et al., as cited in Castro et al. (2020a), after an educational program for family caregivers of older adults with dementia, reported various benefits, such as improvement in emotional regulation and awareness of the importance of self-care.

The program offers activities, especially practical ones, during meetings that relieve participants' stress and burden, as noted in the following statements:

P9G1: "the body-based activities reduce my stress";

P2G2: "I liked the physical activities and dynamics; they gave me more energy, more lightness to deal with the challenges of my caregiving";

P3G2: "during the program I learned to take better care of my health, my body";

P6G2: "this group helped me take care of my own body".

Participants appreciated the practical activities, which relieve stress and burden, combined with expanding their repertoire of occupational activities to relieve anxiety, demonstrating the profound impact self-care has on these caregivers' lives. Most often, these caregivers cannot take care of their own health due to the burden of daily and care activities for their family member.

Gesualdo (2020) notes that stress and burden arising from the needs of older adults can be reduced if caregivers understand the importance of emotional self-care. Abreu et al. (2009) describe that maintaining well-being activities and relaxation techniques on a daily basis are self-care strategies to ease burden and stress. Similarly, Moura et al. (2019) add that physical exercise and leisure activities may alleviate caregiver tension.

The expansion of their care repertoire regarding occupational activities for anxiety relief and self-care is evidenced in the following statements:

P6G1: "I found that I feel lighter when I put all my feelings on paper";

P8G1: "the team made us research self-care activities closer to our homes";

P2G2: "after the dynamic with the physiotherapist, now I know how to do stretches at home";

P7G2: "now I know how to breathe properly and meditate. That lesson stayed as homework".

Moura et al. (2019) expresses concern for informal caregivers of frail older adults, as self-care practices are often postponed due to attending to the elder's needs, posing risks to the caregiver's own health. Often, the caregiver neglects their health due to this responsibility and consequently suffers health deterioration. Castro et al. (2020a) emphasize that promoting care for the caregiver is indisputable, since, in addition to the risk of harm to the caregiver's health, their own health directly affects the quality of care provided to the older person.

- ***Care for the older adult***

Caregivers' testimonials show that "Caring for Caregivers" increased their competencies to attend to the diverse needs of the older adults in their care. Initially, the promotion of competencies to address emergency needs of the older adult was identified in the following statements:

P6G2: "I liked the lectures [...] on emergencies and emergency room care that helped me to know how to handle high-stress caregiving situations";

P7G2: "I liked the lectures on first aid and dysphagia";

P9G2: "I very much liked the lectures on first aid and warning signs".

In the integrative review of 10 articles on care models and support targeting informal caregivers of older adults (Castro et al., 2020b), 7 studies indicate that caregivers improved their understanding of the disease and the necessary care for the older person. Training these caregivers to support the health of older adults contributes to health promotion and prevention of complications, benefiting the quality of life of both the older person and their caregiver (Castro et al., 2020b).

Several caregivers also commented on the promotion of daily care competencies for the older adult, expressed in the following statements:

P5G1: "the team gives very good guidance regarding care [...] on how to give meals and medication and to have patience with the elderly and how to deal with them";

P6G1: "I better understood the elderly person's behavior and their daily difficulties, how to offer meals that help them eat, and guidance on administering medicine";

P1G2: "the lecture about medication helped me a lot to clarify my doubts about how to give medicine to the elderly, something I had more difficulty dealing with in caregiving";

P2G2: "the support network meeting for the elderly helped me know how to request packages of adult diapers through the health center";

P5G2: "after the program, I learned how to take care of my father on weekends, how to feed him and calm him, as well as strategies to reduce my fatigue".

In the systematic review of 12 articles on interventions with caregiver groups of older adults with dementia syndrome (Reis et al., 2018), it is evidenced that acquiring and applying new concepts and skills reduces caregiver burden, stress, and anxiety. These negative factors may be linked to lack of readiness for caregiving, as most caregivers take on responsibility due to necessity (Castro et al., 2020b).

• *Care for the caregiver–older adult dyad*

Participants repeatedly referenced the relationship between the caregiver–older adult dyad, expressing encouragement for promoting the abilities and participation of the older adult in activities, as in the following statements:

P4G2: "I discovered that my sister keeps her mind more active when I gave her a coloring book to paint; before she did nothing at home, now she has something to do";

P11G2: "one of the professionals helped me create simple memory stimulation activities to do with my elderly at home".

In the study by Cruz et al. (2015), encouraging the caregiver to promote the abilities and participation of a person with Alzheimer's in activities are resources that, together with medication, can help stabilize or slightly improve cognitive and functional deficits.

Reports were also identified about promoting caregiver empathy toward the older adult's needs:

P2G1: "the benefits as a participant were to take a deep breath before taking any action and be more understanding";

P7G1: "the fact of understanding that the other needs you and how important this affection and dedication can be. And also putting yourself in the other's place";

P8G1: "also, I became more patient in caring for my elderly, because through the lectures, I understood a bit more about what Alzheimer's is and the limitations it causes";

P11G1: "I created a stronger bond with my cared-for person";

P1G2: "in Caring, I learned about interaction, solidarity, patience, and empathy for those who depend on my care".

Reis et al. (2018) mention that caregiving satisfaction is directly linked to the quality of the action performed. Castro et al. (2020b) argue that care models and support for caregivers of older adults offer better life and health prospects for both the caregiver and the care recipient.
According to Pavarino et al., as cited in Castro et al. (2020a), empathy is defined as the ability to perceive another person's perspectives and feelings, understood through expressions and the way each individual reacts to different situations. Veiga & Santos (as cited in Castro et al., 2020a, p. 9) define empathy as the possibility for a person to experience another's emotions through understanding the other's emotional situation.

a) Suggestions for program improvement

Although many benefits were reported by caregivers, most of them suggested improving the program, especially in terms of informational support and self-care.

Regarding improvement of informational support, caregivers suggested that professionals conduct guidance and lectures on topics not previously addressed or deepen discussion of previously covered topics, as well as provide guidance materials at the end of each meeting, as shown below:

P3G1: "to have a lecture on care for bedridden people/how to turn a person in bed and deepen lectures on hygiene and feeding care";

P4G1: "to have more lectures on other aspects of caregiving";

P3G2: "there could be a meeting that talks about elderly care and its family bond. I feel that more relatives ignore the situation and I feel they abandoned my elderly";

P6G2: "I really like writing down what I learn, so it would be good to have the day's lesson material to complement my notes";

P7G2: "some lectures were rushed at the end, not covering all slides".

In evaluations, the importance of informational support is observed as a valuable resource for day-to-day caregiving with older adults. Minozzo (2022) considers that accessing diagnosis and disease information about the care recipient is a tool to reduce caregiver burden.

Additionally, Gesualdo (2020) emphasizes that being in an environment of guidance and reception, besides providing confidence and security, is perceived as added value for informal caregivers.

In the category deepening self-care support, it was found that 5 caregivers mentioned adding more body-based activities and activities to improve the program, through the following reports:

P8G1: "there could be more body-based activities and fewer lectures";

P1G2: "there should be more body-based activities, it should be more fun";

P4G2: "could increase the frequency of dynamics in the meetings";

P5G2: "we could do more outdoor activities, taking advantage of the Parque Previdência space";

P11G1: "the program should be extended to self-care".

It is clear that body-based activities are important for self-care and stress reduction in the caregiver's daily life. Moura et al. (2019) discuss that group physical exercise can be an effective strategy to alleviate stress. The demand for more body-based activities during the program is possibly a way for caregivers to maintain well-being activities in their routines.

Considering the totality of actions promoted by the program, it is possible to affirm that "Caring for Caregivers" brought benefits to family caregivers of dependent older adults. Analysis of these actions revealed positive repercussions in several areas of caregiving and personal life of these caregivers.

One main result observed was the strengthening of knowledge about the public service network supporting older adults and their caregivers. Through lectures and guidance, participants learned how to access high-cost medications, devices for urinary incontinence (adult diapers), prolonged home oxygen therapy, and the Continuity Benefit. This knowledge was fundamental to facilitate access to essential resources. Although most caregivers had a household income above four minimum wages, some participants lacked their own resources to acquire these and other important care items.

Another relevant outcome of the program was the strengthening of support among participants, which continued even after its completion. The creation of WhatsApp groups to share information, such as the monthly schedule of leisure and cultural events (e.g., Casa de Cultura do Butantã and Pinacoteca), contributed to building a community support network. This type of social support is essential to reduce feelings of isolation and emotional burden.

Furthermore, the Program expanded caregivers' self-care repertoire, encouraging them to practice well-being activities during the week. Many participants began to regularly adopt leisure and self-care activities they already knew but rarely practiced, such as walking. In addition, they incorporated new practices learned during the Program, such as meditation, physical exercise, and stretching, as recommended by professionals, and the practice of Lian Gong and Tai Chi Pai Lin. These self-care habits were important for improving caregivers' quality of life and mental health.

The lectures offered in the Program covered crucial topics for managing elderly care. These included discussions on the aging process, providing information on its natural factors and coping strategies. Also addressed were communication strategies with older adults with dementia, medication management, and identification of emergency and urgent situations. These orientations enabled caregivers to feel more confident when facing daily challenges and critical situations.

The Program promoted moments of rest and leisure for caregivers immediately after each meeting, reinforcing the importance of self-care. Thus, in addition to receiving self-care guidance, participants were encouraged to explore cultural and leisure activities in public spaces, which enriched their experiences and promoted greater social integration.

In summary, the "Caring for Caregivers" Program proved to be an effective initiative in welcoming and guiding family caregivers, such that the actions developed reflect improvements in participants' quality of life and in creating a support network that strengthens both caregivers and the older adults under their care.

Conclusion

Through this research, it was possible to learn about the social, demographic, and health profiles of the participating family caregivers, as well as the time devoted to caregiving. None of these characteristics statistically influenced the reduction in caregivers' burden levels, indicating that the reduction in burden resulted from participation in the program.

In addition to reducing the level of burden, the program provided other benefits reported by participants, such as welcoming and active listening by professionals, expansion of the repertoire of care strategies, creation of support networks, engagement in activities that relieve tension and promote well-being, training on topics related to the health of older adults, and encouragement of the active participation of older adults in activities. The benefits of the program reported by caregivers were directed both toward the caregiver and the older adult, as well as to the caregiver–older adult dyad.

The information collected and analyzed in this research provides valuable insights for the multidisciplinary team to improve the program in its future editions. It is hoped that this study will contribute to the development of new projects and programs for welcoming and guiding family caregivers of dependent older adults, in public care and follow-up services in the northern, southern, central, eastern, and western regions of the city of São Paulo. Although the study highlighted the importance of the "Caring for Caregivers Program, some gaps were identified that can be addressed in future research.

One of the observed limitations was the absence of significant associations between the caregivers' profiles and the burden reported by the groups analyzed. It is suggested that studies with a larger number of participants, including future groups, be conducted to verify whether variables other than program participation may influence these outcomes. This would make it possible to broaden the understanding of the factors that impact caregiver burden and guide more effective interventions.

Furthermore, it is recommended to improve the data collection instruments. It would be valuable to include questions that deepen information on economic, relational, and other dimensions of vulnerability. This information could help not only in identifying new factors associated with informal care for older adults but also, and most importantly, in addressing additional aspects that contribute to caregiver burden.

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Helga Juri Kojima participated in the development of the project, collection, analysis, interpretation of data, and writing of the article. Marina Picazzio Perez Batista participated in the conception of the project and its development, worked on the critical review of the article and approval of the version to be published. Cibele Marques supervised the actions of the scholarship holder, worked on the critical review of the article and approval of the version to be published. Almeida Maria Helena Morgani de Almeida guided the preparation and execution of the project, worked on the analysis and interpretation of data, on the writing and critical review of the article and on the approval of the version to be published.

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