SEVEN
publicações acadêmicas

SOCIOECONOMIC REALITY OF INFORMAL CAREGIVERS OF DEPENDENT INDIVIDUALS AT HOME: SCOPE REVIEW

REALIDADE SOCIOECONÔMICA DE CUIDADORES INFORMAIS DE PESSOAS DEPENDENTES EM DOMICÍLIO: REVISÃO DE ESCOPO

REALIDAD SOCIOECONÓMICA DE LOS CUIDADORES INFORMALES DE PERSONAS DEPENDIENTES EN EL HOGAR: REVISIÓN DEL ALCANCE

https://doi.org/10.56238/sevened2025.036-055

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ABSTRACT

An informal caregiver is someone who assumes this role due to an emotional or kinship bond with the person needing assistance, without receiving training or payment. To understand how financial burdens affect the lives of caregivers of dependent adults, it is essential to know the economic reality of these individuals and the financial difficulties they face, especially regarding the expenses necessary for adapting to and maintaining care over time. The objective is to map the available evidence in the literature on the socioeconomic reality of informal caregivers of dependent individuals at home. This is a scoping review, based on the guidelines proposed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). The guiding question used was: "What is the socioeconomic reality of informal caregivers of dependent adults?" The searches were conducted in the MEDLINE, EMBASE, Web of Science, SCOPUS, LILACS, BDENF databases and on the ProQuest platform to include grey literature using the descriptors "family caregiver", "financial stress", "home care" and "adult". Twenty-four studies were selected, and it was observed that the caregivers were adults, mostly over 40 years old, women, with low income/education levels, and spouses of the patients. Furthermore, they were mostly unemployed, resided in urban areas, and faced difficulties related to social isolation. The patients were adults whose dependency was related to dementia, cancer,

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mental illness, disabilities, or the use of invasive medical devices. It is concluded that the results can improve the knowledge of professionals on this topic, aiming to enhance care and provide support for the development of policies aimed at this population.

Keywords: Caregivers. Financial Stress. Home Nursing. Adult.

RESUMO

O cuidador informal é aquele que assume tal função devido ao vínculo afetivo ou de parentesco com a pessoa que necessita de assistência, sem receber treinamento ou pagamento. Para compreender como os encargos financeiros afetam a vida dos cuidadores de adultos dependentes, é essencial conhecer a realidade econômica desses indivíduos e as dificuldades financeiras enfrentadas, especialmente diante das despesas necessárias para a adaptação e manutenção dos cuidados ao longo do tempo. Objetiva-se mapear as evidências disponíveis sobre a realidade socioeconômica de cuidadores informais de pessoas dependentes em domicílio. Trata-se de uma revisão de escopo, baseada nas orientações propostas pelo *Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews* (PRISMA-ScR). Como pergunta norteadora: “Qual a realidade socioeconômica dos cuidadores informais de adultos dependentes?” As buscas ocorreram nas bases de dados MEDLINE, EMBASE, Web of Science, SCOPUS, LILACS, BDENF e na plataforma ProQuest para inclusão da literatura cinzenta através dos descritores “cuidador familiar”, “estresse financeiro”, “assistência domiciliar” e “adulto”. Foram selecionados 24 estudos, observa-se que os cuidadores eram adultos, majoritariamente acima de 40 anos, mulheres, baixa renda/escolaridade e cônjuges dos pacientes, além disso encontravam-se majoritariamente desempregados, residiam em áreas urbanas e enfrentavam dificuldades com relação ao isolamento social. Os pacientes eram adultos, cuja dependência relacionava-se a demências, câncer, doenças mentais, deficiências ou uso de dispositivos médicos invasivos. Conclui-se que a partir dos resultados pode-se aprimorar o conhecimento de profissionais sobre a temática, visando qualificar a assistência e fornecer subsídios para o desenvolvimento de políticas destinadas a essa população.

Palavras-chave: Cuidadores. Estresse Financeiro. Assistência Domiciliar. Adulto.

RESUMEN

Un cuidador informal es alguien que asume este rol debido a un vínculo emocional o familiar con la persona que necesita asistencia, sin recibir capacitación ni remuneración. Para comprender cómo las cargas financieras afectan la vida de los cuidadores de adultos dependientes, es fundamental conocer la realidad económica de estas personas y comprender las dificultades financieras que enfrentan, especialmente en lo que respecta a los gastos necesarios para adaptarse a la situación y mantener los cuidados a lo largo del tiempo. El objetivo es analizar la evidencia disponible en la literatura sobre la realidad socioeconómica de los cuidadores informales de personas dependientes en el hogar. Se trata de una revisión exploratoria, basada en las directrices de la extensión PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses). La pregunta guía fue: "¿Cuál es la realidad socioeconómica de los cuidadores informales de adultos dependientes?". Las búsquedas se realizaron en las bases de datos MEDLINE, EMBASE, Web of Science, SCOPUS, LILACS y BDENF, así como en la plataforma ProQuest para incluir literatura gris, utilizando los descriptores "cuidador familiar", "estrés financiero", "cuidado domiciliario" y "adulto". Se seleccionaron veinticuatro estudios y se observó que los cuidadores eran adultos, en su mayoría mayores de 40 años, mujeres, con bajos ingresos y

nivel educativo, y cónyuges de los pacientes. Además, la mayoría estaban desempleados, residían en zonas urbanas y enfrentaban dificultades relacionadas con el aislamiento social. Los pacientes eran adultos cuya dependencia se debía a demencia, cáncer, enfermedad mental, discapacidad o el uso de dispositivos médicos invasivos. Se concluye que los resultados pueden mejorar el conocimiento de los profesionales sobre este tema, con el objetivo de optimizar la atención y brindar apoyo para el desarrollo de políticas dirigidas a esta población.

Palabras clave: Cuidadores. Estrés Financiero. Atención Domiciliaria de Salud. Adulto.

1 INTRODUCTION

The dependent person is one who needs assistance to perform basic activities of their daily life and, therefore, requires supervision, help and special care, regardless of the cause that has led to their dependence. In the elderly population, several reasons for dependence are observed, such as cognitive loss or loss of muscle mass, prolonged hospitalizations, falls, or complications resulting from chronic non-communicable diseases (Magalhães *et al*, 2024).

However, there is currently an increase in the number of young people who are dependent, mainly due to external causes, such as accidents or violence. In addition, in the global scenario, the significant increase in young adults affected by conditions that were more common among the elderly population, such as stroke and cardiorespiratory arrest, factors linked to a sedentary lifestyle, inappropriate habits, and high levels of stress (Demoner *et al*, 2025), is worrying.

In this context, caregivers are indispensable figures in the care of dependent people, and can be classified as formal and informal. The formal caregiver is one who has training, remuneration and follows defined schedules to perform their duties. The informal or family caregiver is the one who assumes care due to the affective or kinship bond with the person who needs assistance, performing this activity without training or payment, often dedicating himself fully to this function (Leite *et al*, 2023).

In Brazil, there is no specific aid from the federal government for informal caregivers. Within the disability retirement, an additional 25% is offered to patients who need constant help. This benefit is exclusive to retirees with permanent disability who prove the need for assistance in daily activities such as feeding, dressing, bathing, and getting around (Rozendo *et al*, 2023).

Although intended for dependent patients, not all caregivers are entitled to this benefit, being exclusive to retirees due to disability. Considering the context of informal care and the absence of adequate support for this population, this reality can result in physical exhaustion, anxiety, and overload for caregivers, due to the lack of preparation to meet the high demands required in providing care to a dependent family member, not only emotionally but also financially (Rodrigues *et al*, 2022).

Therefore, in addition to the difficulties related to learning care and the caregiver's personal and family organization, the question arises about how the caregiver organizes himself to deal with care-related expenses. This is because, in addition to the pre-existing financial burdens with their own subsistence and health, they start to assume the expenses

with consultations, exams, hospitalizations, and supplies necessary for the person being cared for (Brito *et al,* 2025).

To understand how financial burdens affect the lives of informal caregivers of dependent adults, it is essential to know the economic reality of these individuals. This sheds light on the financial difficulties faced by families and caregivers, especially in the face of the expenses necessary for the adaptation and maintenance of care over time. It is essential to explore the characteristics of caregivers in the context of home care, with an emphasis on financial issues.

In addition, understanding the main expenses and strategies used by caregivers to obtain the necessary resources can provide valuable information to support the formulation of public policies that offer greater support to this population. Therefore, the objective of this study was to map the evidence available in the literature on the socioeconomic reality of informal caregivers of dependent people at home.

2 METHODOLOGY

2.1 TYPE OF STUDY

This is a scoping review, which followed the guidelines proposed by the *Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews* (PRISMA-ScR) (Page *et al*, 2021). For the construction of the research question, the mnemonic PCC (P-population, C-concept and C-context) was used. Being considered: P-informal caregivers of dependent adults, C-financial reality, C-home care: What is the socioeconomic reality of informal caregivers of dependent adults? Auxiliary questions were used to deepen the review: What are the consequences brought to the caregiver's life in the face of financial complications?

2.2 SELECTION OF STUDIES

The inclusion criteria were: scientific articles published in full, available free of charge, with a quantitative focus; official materials; regardless of the language of publication (Concept); in individuals over 18 years of age who are dependent on care (Population); in a home care environment; regardless of the country of origin and/or language of publication (Context), in addition to Course Completion Work, Dissertations and/or Theses included through the grey literature. Qualitative studies and study protocols were excluded, with no publication of results.

2.3 DATA COLLECTION

For the initial search, combinations of terms available in the *Medical Subject Headings* (MeSH) were used: *Caregivers*, *Financial Stress*, *Home Nursing*, *Adult* in the PUBMED, EMBASE, Web of Science, SCOPUS, Latin American and Caribbean Literature on Health Sciences (LILACS), Nursing Database (BDENF) and the ProQuest platform to include gray literature. In the Virtual Health Library (VHL), the following Health Sciences Descriptors (DeCS) were used: Family caregiver, Financial stress, Home care, Adult. In order to increase the number of articles, a cross-search was used between the keywords using the Boolean connector *AND* following the same combination in all search locations, namely: "*Caregivers AND Financial Stress AND Home Nursing AND Adult".* Data collection took place between October and November 2024.

2.4 DATA ANALYSIS AND PROCESSING

According to the adaptation of the PRISMA-ScR recommendations (Page *et al*, 2021), data selection occurred in the following steps: 1) Initial search in search strategies; 2) Analysis of title and abstract and exclusion of those who did not fit any of the criteria; 3) Full reading of the selected works; and 4) Evaluation of the reference list of sources selected from the full text and/or included in the review.

To facilitate the extraction of the information presented in the studies, the free online platform RAYYAN® was used, which helps in conducting reviews by exporting the information from the databases, creating a selection of content from the articles that facilitate their choice, namely: identification, title, year of publication, indexing base, journal, level of evidence, objective, study design, main results and conclusion.

For the level of evidence, the following were considered: level I systematic reviews or meta-analyses of Randomized Controlled Clinical Trials (RCTs); level II evidence obtained from at least one well-designed RCT; level III well-designed clinical trials without randomization; level IV study with a non-experimental design such as descriptive correlational research or case studies; level V obtained from systematic reviews of descriptive or qualitative studies; level VI from a single descriptive or qualitative study; and level VII evidence originating from the opinion of authorities and/or a committee of experts (Galvão, 2006).

The data were mapped in a descriptive way, using simple frequency counting of concepts, populations, and other characteristics that contemplate the research questions. A

descriptive qualitative analysis of the content was also conducted, including basic data coding. From the analysis of the articles, a conceptual map was constructed to outline the results. The articles were identified with the letter A (article) and the number corresponding to their availability in the text. Example: A1

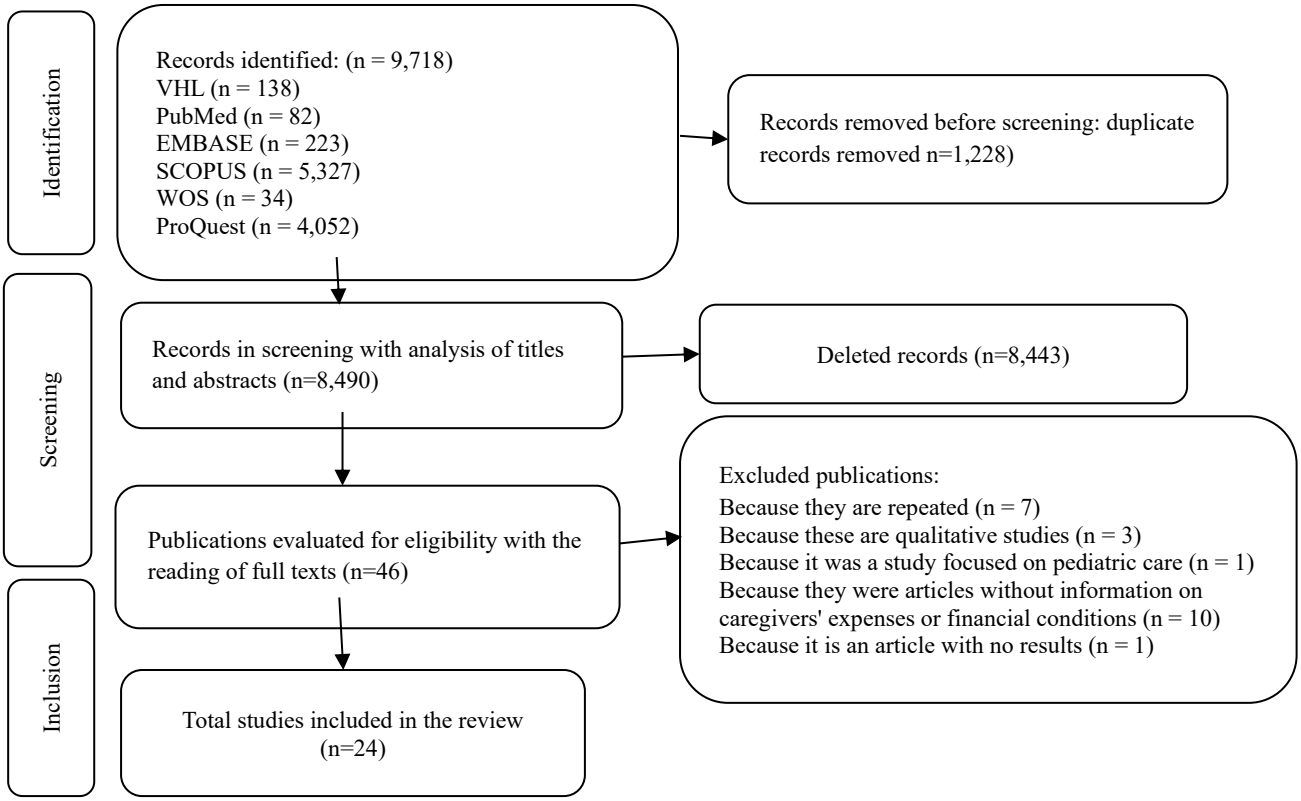
The project was registered in the *Open Science Framework* (OSF) Platform, as it is a scoping review carried out from public domain data, it was not submitted to the Human Research Ethics Committee, but all the ethical principles contained in Resolution No. 466/2012 were followed.

3 RESULTS AND DISCUSSIONS

Among the 9,718 articles located in the databases, 24 were part of this review. The selection of articles is described in the following flowchart (Figure 1).

Figure 1

Flowchart according to PRISMA-ScR criteria. Maringá, PR, Brazil 2024



Source: Adaptation of the PRISMA-ScR flowchart (Page *et al*, 2021).

All studies (n=24) were published in English, with a mainly cross-sectional study design. The population of informal caregivers was adult, mostly over 40 years of age (mean of 51.9). The number of caregivers included in the surveys ranged from 29 to 3,047 (mean 352), most of them women, being spouses or daughters of the patients.

Regarding the care recipient, all were dependent and adults over 18 years old. As a diagnosis that led them to dependence, we find mainly dementia, stroke, cancers, patients with mental illnesses who need help in activities of daily living, as well as individuals with disabilities, whether resulting from accidents or chronic issues.

In addition to dependence, some patients used enteral nutrition, home mechanical ventilation, and hemodialysis and outpatient chemotherapy treatments, which required locomotion and availability of follow-up by caregivers, factors that were predictive of increased expenses. The characterization of the articles selected for review is presented in the following table (Table 1).

Table 1

Characterization of the articles that make up this review (n=24). Maringá, PR, Brazil, 2025

ID	Author/Journal/Year/Country	Type of study/ Sample	Main results	Level of evidence
A1	Papastavrou et al Adv Nurs Cyprus 2007	Descriptive cross-sectional study/172 dyads	Regarding education, elementary school graduates had a higher burden compared to master's/doctoral holders. Regarding income, caregivers with high income had lower scores on the burden scale.	IV
A2	Güneş et al HealthMED Turkey 2012	Cross-sectional descriptive study/102 caregivers	Low education and being the patient's spouse were associated with a higher level of financial burden.	IV
A3	Akpan-Idiok et al Pan Afr Med J Nigeria 2014	Cross-sectional descriptive study/210	The caregivers studied had trivial burden or no overload. Informal caregivers experienced the following forms of burden: physical, psychological,	IV

		caregivers	financial and social, with the psychological and social forms of burden being the ones of greatest magnitude.	
A4	Aggar et al ACT Australia 2014	Cross-sectional study/119 caregivers	Approximately one-quarter (24%) provided care for more than 40 hours per week. Most caregivers (80%) provided transportation assistance for their frail elderly relative. Assistance with communication (37%) and self-care (36%) were the least frequent support activities provided	IV
A5	Dhandapani et al Surg Neurol Int India 2015	Descriptive cross-sectional study/70 caregivers	87% of caregivers reported that caregiving contributed to financial strain; Caregiver burden was significantly higher among caregivers who were unemployed, had low incomes, could not meet their needs comfortably, spent <8 hours a day on caregiving activities, and those who were ill.	IV
A6	Hartnett et al Clin J Oncol Nurs USA 2016	Cross-sectional descriptive study/50 caregivers	Caregivers who reported an income of less than $90,000 per year noted greater financial burden. Participants without a college degree had higher levels of financial burden. Unemployed or retired caregivers reported higher levels of schedule disruption than those who were employed. Most were not prepared for the potential changes in their lives, such as time demands, adjustments in work schedules.	IV
A7	Nortey et al Int J Equity Health Ghana 2017	Retrospective cross-sectional study/108 caregivers	Approximately 62% of caregivers indicated that their finances worsened as a result of caregiving. The average time of care per month was estimated at 219.5 (±25.9) hours.	IV
A8	Liu et al	Observational	Caregivers reported increased medical	IV

	Medicine Taiwan 2017	study/160 caregivers	bills and expenses with hiring a caregiver, resulting in a frugal lifestyle.	
A9	Crouch et al RRH USA 2017	Cross-sectional study/1,248 caregivers	Other factors associated with fair/poor health included caregiver burden, employment status, and income. Caregivers with a high level of burden were more likely to report poor to fair health. Employed caregivers had lower odds of reasonable to poor health than caregivers who were not employed. Finally, the odds of self-reported fair/poor health decreased with income. Caregivers with high levels of caregiving burden were more likely to experience financial strain, emotional strain, and physical strain.	IV
A10	Strange et al UoR USA 2018	Correlational study/29 caregivers	Most of the participants had two other adults living in the household. The results showed that there was no statistically significant difference between income levels (48%).	IV
A11	Wu et al Ann Palliat Med China 2020	Cross-sectional study poll/242 dyads (patient and caregiver)	For family members who directly cared for disabled stroke patients, 22.7% felt that the stress of care was too high, and 26.9% of respondents answered that the financial pressure of hospitalization was heavy. The proportion of family members who had financial pressure was more extensive than those with caregiving stress;	IV
A12	Tough et al Int J Equity Health Switzerland 2020	Cross-sectional study/118 dyads	Caregivers with higher incomes, educational level, and subjective social position, and those who owned their own home or who did not indicate any financial hardship reported a lower	IV

			propensity for caregiver burden.	
A13	DiGiacomo et al ACT Australia 2020	Cross-sectional study/3,047 caregivers	132 caregivers reported that they experienced one or more types of financial stress. The demographic variables that were found to be associated with the experience of financial stress were having a spouse/partner, owning/buying housing, not having a paid job, and a family income of $60,000 (AUD) or less. Of the 132 caregivers who reported financial stress, (n=49) reported more than one type of financial stress. The most commonly reported stress-related indicator was seeking help from community organizations or friends/family (n=88) followed by inability to pay bills on time (n=58).	IV
A14	Chhetri et al JNMA Nepal 2020	Cross-sectional descriptive study/123 caregivers	Most caregivers (60) had mild to moderate burden and 53 had moderate to severe burden. The overall mean overload score was 39.30 ± 11.68.	IV
A15	Chiari et al Dement Geriatr Cogn Dis Extra Italy 2021	Cross-sectional study/92 dyads	Longer duration of illness, being a wife or partner, and having more days off work reduced caregiver distress and, consequently, burden. Likewise, financial suffering increased psychological suffering and, consequently, overload. On the other hand, the delay in diagnosis, the age of the caregiver and the representatives of the family or social network had a 100% direct effect on the caregiver's burden.	IV
A16	Schaffler-Schaden Brain Sci Austria	Multicenter cross-	Regarding employment, caregivers who work part-time had a higher burden of	IV

	2021	sectional study/113 caregivers	financial stress than caregivers who work full-time. There were no male caregivers who worked part-time. In general, working caregivers had a lower burden than retired caregivers	
A17	French et al Clin Nutr United Kingdom 2022	Multicenter cross-sectional study/339 caregivers	Employment status, type of illness, number of nights on PNH (home enteral nutrition), time on PNH, and number of hours on PNH were not associated with subjective workload.	IV
A18	Zhang et al BMC Geriatr USA 2023	Longitudinal study/1,065 caregivers	After multivariate adjustment, caregivers of PCD in the high burden class of comorbidity scored 0.46 points higher of burden of physical care than those in the class of low burden of comorbidity.	IV
A19	Metin et al Support Care Cancer Turkey 2023	Cross-sectional study/113 caregivers	In assessing the financial situation of caregivers, 69% paid extra fuel costs, 60.2% paid taxi or public transportation costs, 48.7% made additional payments for medications covered by health insurance, and 44.2% paid exam fees to receive treatment for their patients. It was found that 42.5% of caregivers experienced financial and economic difficulties due to the costs of treating and caring for their patients.	IV
A20	Folwarski et al Clin Nutr Poland 2024	Multicenter cross-sectional study/90 caregivers	Individual perceptions of quality of life were significantly correlated with financial satisfaction, life satisfaction, income per person in the household, sleep quality, and depression. 51.2% of caregivers were dissatisfied with their financial situation.	IV
A21	Płaszewska-Żywko et al BMC Nurs Poland	Cross-sectional study/58	Caregivers scored significantly higher in the general strain domain than caregivers. Considering the financial	IV

	2024	caregivers	situation, no statistical significance was revealed in the general strain subscale; however, differences were observed in the distribution of the isolation and disappointment variables between the groups of financial situation.	
A22	Agyemang-Duah et al BMC Prim Care Ghana 2024	Cross-sectional study/1,853 caregivers	Compared to urban caregivers, rural caregivers reported that they had no financial problems due to loss of income; There was an association between caregivers' income and burden. Lastly, participants without financial support needs have a reduced stress load compared to those with financial support needs.	IV
A23	Marega et al SPPE Gambia 2024	Cross-sectional descriptive study/161 caregivers	The results show that most caregivers (n=100) had financial problems, (n=63) missed work, (n=60) had difficulty concentrating at work, and (n=136) had unexplained treatment expenses almost always. Regarding the degree of financial burden (n=89), they presented high levels of financial burden.	IV
A24	Edward et al Psycho-Oncol USA 2024	Cross-sectional study/34 dyads	Most participants had COST scores ≤ 24. More than half of the dyads were made up of married couples. Other caregivers included adult children (26%), friends (12%), or someone else (38%). More than half of the dyads indicated that a caregiver in the dyad had taken paid or unpaid time off to care for the patient.	IV

Source: The authors (2025).

The results will be presented in two strands, firstly the socioeconomic information of the caregivers, such as monthly/annual income, level of education, employment, expenses

related to care and financial help received and then the variables that impact the financial reality.

Regarding the socioeconomic characterization of caregivers, not all articles provided detailed and numerical information on family income and care-related expenses, which is a difficulty found in the study.

Among the articles that included this information, the caregivers had a monthly income between US$ 99.50 (R$ 240) (A8) and US$ 4,773 (R$ 45,751) (A13); and annually between US$ 75,000 (R$ 462,375) (A10) and US$ 90,000 (R$ 553,743) (A7).

An interesting finding was observed with regard to caregivers who reported higher education, and an increase in the number of caregivers who had completed higher education and complementary training such as specializations and postgraduate studies was identified in the most recent studies (A7; A12; A4; A19).

Caregivers who lived in rural areas generally had a lower level of education than those living in urban areas. In addition, they were more frequently unemployed when compared to those who lived in urban centers (A16; A23; A10).

With regard to employment, most caregivers were unemployed (A4; A8; A6; A22; A24; A20). In addition, it was identified that a significant portion was retired, which is justified by the fact that most of them were in an older age group (A18; A5).

The comparison between employed men and women revealed that the majority of female caregivers worked part-time and received lower wages. Consequently, they had a lower monthly income than male caregivers and faced greater difficulties in dealing with the expenses associated with home care (A17).

Regarding expenses related to the needs of the family member under their care, many caregivers reported independently bearing the health costs of patients. In addition, they showed discomfort and concerns about their ability to meet their own needs, those of their families and the demands of care (A12; A6). Only two studies reported that caregivers received help from other family members or some type of government assistance to cover the costs of care (A12; A24).

Next, information related to the variables that impact the financial reality of the informal caregiver will be presented, namely: factors associated with socioeconomic status, increase in monthly expenses, loss of employment and lack of support network.

Caregivers who faced a greater burden of financial stress often associated this situation with economic difficulties. Those with lower incomes were more likely to obtain high

scores in questionnaires designed to measure stress levels, in addition to reporting a worsening of their financial condition after assuming the role of caregivers, closely linked to the increase in expenses and health conditions of their family members (A7; A2; A8; A21; A3).

Studies have also associated a greater financial burden with a lower level of education. It was observed that caregivers with complete higher education had significantly lower levels of stress related to their financial reality compared to those who had only completed high school (A7; A12; A2). The level of education had different reports, most caregivers had completed high school (A12; A4; A16; A15; A11).

The age of the family member cared for was also analyzed as a hypothesis. It was observed that, as age increases, the caregiver faces greater financial difficulties. These challenges are associated with increased care demands and the appearance of comorbidities typical of the aging process (A12; A2; A8; A16).

With regard to the individual cared for, the degree of proximity between him/her and the caregiver was identified as a predictive factor of greater financial stress. Being a woman and occupying the role of the patient's wife was pointed out as an element that intensifies the burden and financial difficulties faced, since, in general, women assume not only the role of caregiver but also the sole provider of the home (A8; A16; A3; A22).

Caregivers reported an increase in monthly expenses after taking on the role of caregiver, especially due to the need to hire help for domestic activities and the increase in expenses with medical consultations, exams, medications, transportation/fuel, and prolonged hospitalizations (A12; A8; A9; A20; A5).

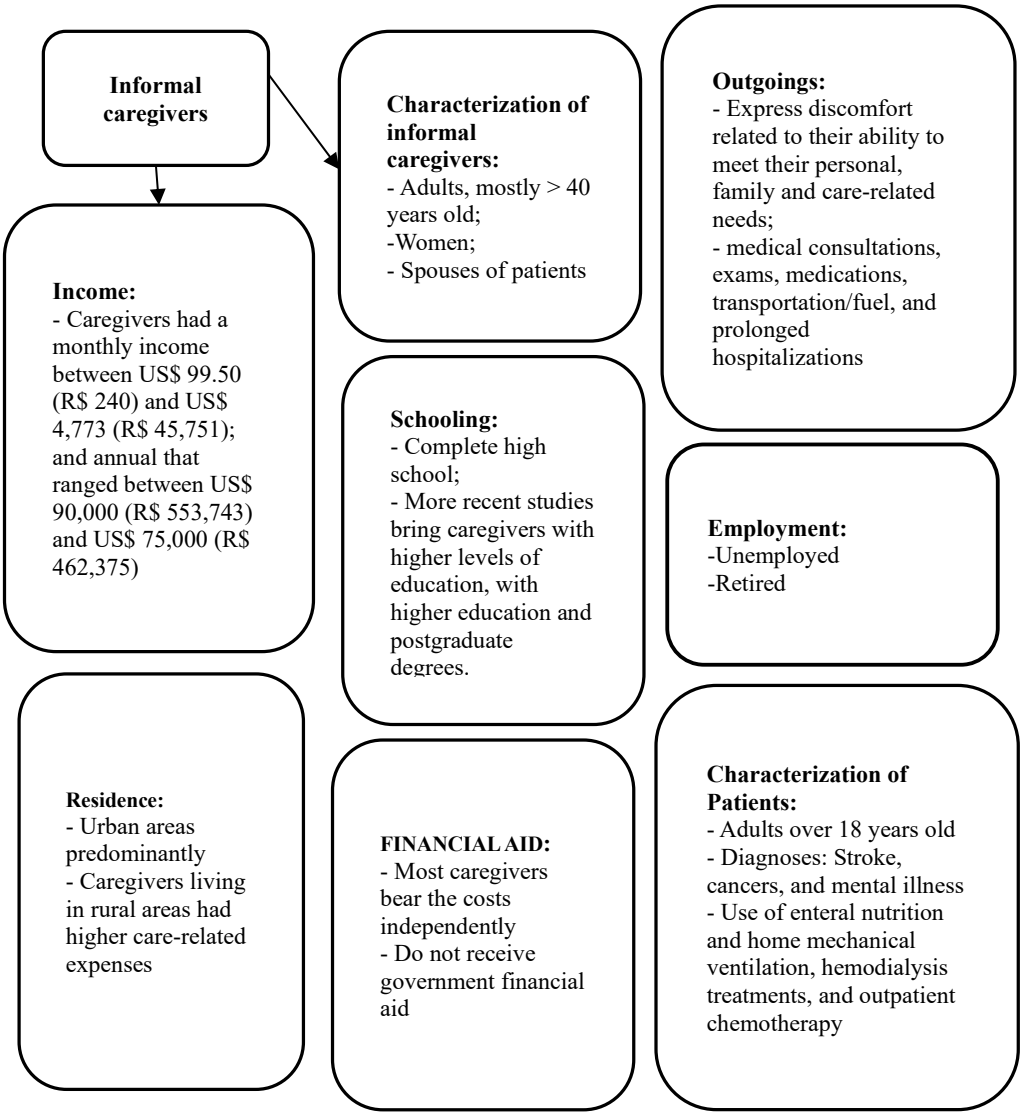
Finally, the place of residence and the number of hours dedicated to care were identified as a predictor for higher expenses related to the care activity. Caregivers living in rural areas reported significantly more financial hardship and expenses compared to those in urban areas (A16; A23; A10).

In addition, most caregivers were exclusively dedicated to care, without having an employment relationship. This situation is often attributed to lack of time and the high number of absences from work, which makes it necessary to quit work to meet the demands and needs of the family member under their care (A6; A5).

Based on data analysis, a conceptual map was constructed outlining the main information related to the financial reality of informal caregivers (Figure 2).

Figure 2

Conceptual map of the characterization of Informal Caregivers (n=24). Maringá, PR, Brazil, 2025



Source: The authors (2025).

According to the literature, four out of five informal caregivers are women, usually wives or daughters of patients. Historically and socially, the responsibility for care has been attributed more frequently to women, reflecting a cultural pattern sometimes based on machismo, which prepares them to assume this function and often judges them when they do not fulfill it, with men being placed in the position of caregivers generally due to the absence of women in the family who can assume such responsibility (Sousa *et al*, 2023; Sousa *et al,* 2024).

Concomitantly, the female population presents higher levels of stress and overload resulting from care, since in most cases they do not have an established support network that helps them and allows them to develop moments of leisure and rest, experiencing a loss of their freedom and autonomy and abandonment of their individuality and personal life to the detriment of informal care (Silva *et al*, 2025; Renk *et al*, 2022).

In the financial issue, it is observed that female caregivers face a greater impact in terms of dismissals, social isolation and financial difficulties. This scenario occurs mainly due to the fact that most male caregivers receive higher salaries and, when taking care of a dependent family member, dedicate fewer hours a day to this function, often having resources to hire formal caregivers, in addition to, in general, having a better structured support network, receiving help in sharing the care provided to the family member, being able to maintain their work activities (Gomes *et al*, 2023; Marques *et al*, 2024).

In addition, caregivers suffer, on a larger scale, the loss of employment compared to men. This fact is related to historical issues of prejudice and sexism, in addition to reflecting the reality of many women who dedicate themselves fully to home care. They are often dismissed from their jobs due to the high number of absences caused by the high demands associated with providing care to dependent family members, presenting difficulties in managing expenses related to care and adapting to the new reality (Méndez *et al*, 2024).

It can be observed that most caregivers were advanced in age (over 50 years old), and were mostly composed of people who were already withdrawing from the labor market and often had retirement as their only source of income. Considering that aging is associated with increasing limitations and reduced functional capacity, the presence of older informal caregivers can intensify financial stress and spending. In addition to bearing the expenses of the dependent family member, these caregivers remain responsible for their own health costs, such as medications, consultations, and exams, necessary due to advancing age (Teles *et al*, 2023; Bernardi *et al*, 2023).

Concomitantly, the advanced age of caregivers has the potential to worsen their quality of life and health and for the appearance of related diseases and bad life habits, a great load of stress and abandonment with their own health care, projecting their attention and income to prioritize the needs of their family members. Many caregivers report not having the time and conditions to seek care even for routine consultations or periodic exams related to maintaining their own health (Cavalcanti *et al*, 2025; Castanheira *et al*, 2025).

Caregivers living in rural areas generally have a lower level of education, which is associated with greater financial difficulties. In addition, they face social isolation, high care costs, especially related to commuting, and difficulties in finding a job, being more often unemployed, these caregivers have greater difficulties in adapting to extra expenses related to care. Being an informal caregiver in rural areas was also linked to a higher incidence of psychological problems, such as depression, anxiety, and burnout, related to social isolation caused not only by caregiving, but also by difficulties in leaving home, in addition to concerns about unemployment and income (Almeida *et al*, 2023; Silva *et al*, 2025).

As observed in practice, most caregivers were unemployed, having to resign their jobs mainly due to the need to dedicate many hours to care. A relationship between caregivers' unemployment and the time allocated to care can be observed, revealing that most of them dedicate themselves fully to this activity, presenting difficulties in the physical, psychological, social, and financial spheres, facing difficulties both in getting and maintaining a job (Costa *et al*, 2024).

Although informal care is provided free of charge, the financial costs associated with it can involve high expenses with consultations, exams, and procedures for both the family member under care and the caregiver. In addition, there are expenses with adaptations of devices for the home, medications, specific foods, enteral nutrition, oxygen therapy, among others (Lacerda *et al*, 2021).

Regarding monthly family income, few studies address this variable. In the literature, the financial reality of informal caregivers is usually superficially addressed, being associated only with the presence or absence of financial stress. When this information is included, it is commonly related to the economic stress of caregivers, but it does not detail what the specific costs are, how caregivers organize themselves to deal with these expenses, or what impact these financial burdens have on the lives and reality of caregivers (Regina *et al*, 2024).

It can be observed that, many times, the caregiver is prepared only to know how to handle certain devices and perform the necessary care for his family member at home, and it is unknown whether this individual has the financial conditions to maintain all the expenses arising from the demands of the care provision, in addition to maintaining his own quality of life. These caregivers, in general, give up expenses related to their own life to prioritize meeting the needs of their family members. What is often observed are caregivers who dedicate a good part of their income to the costs of caring for family members and end up sick due to concern about their income, stressed and lacking in the maintenance of their own

health, who sometimes cannot continue to take care of their family members and end up also becoming dependent at some point in their lives (Silva *et al*, 2022; Minayo *et al*, 202).

The review identified that 50% of the included studies were published between 2020 and 2024, reinforcing the typical profile of informal caregivers. Although this review is contemporary, it has some limitations. The heterogeneity of the studies is highlighted, all of which are classified as cross-sectional studies, in addition to the small number of the population evaluated. In addition, although the collection that made up this review is considerable and recent studies, there is a lack of research that brought robust information on the income of informal caregivers, expenses related to home care and how much of this income was destined to this care, in addition to better characterizing caregivers, bringing information related to previous comorbidities and other aspects that also impact their expenses.

4 CONCLUSION

From the above, it was possible to identify the main evidence about the socioeconomic reality of informal caregivers of dependent adults. The results showed that most caregivers were women >40 years old, with low income and schooling, and were mainly spouses or daughters of the patients, reiterating an already known stereotype. Regarding the financial reality, most faced difficulties related mainly to unemployment, costs with exams, hospitalizations and medication for the family member, in addition to difficulties in maintaining care for their own health, dedicating all energy, time and resources to the family member and their needs.

The results aim to contribute to the improvement of the knowledge of professionals on the subject, in order to qualify care and instigate the development of research that focuses on understanding this aspect of informal care, aiming to provide subsidies for the development of policies and financial aid for this population.

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