



# Relationship between caregiver burden of older adults and sleep: a mixed-methods study<sup>a</sup>

*Relação entre sobrecarga do cuidador da pessoa idosa e o sono: estudo de métodos mistos*

*Relación entre la sobrecarga del cuidador de personas mayores y el sueño: un estudio de métodos mixtos*

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## ABSTRACT

**Objective:** to assess the relationship between caregiving burden and sleep health among caregivers of older adults, and to understand their perceptions of this relationship. **Method:** a mixed-methods study was conducted with 73 caregivers. Data collection included a sociodemographic and occupational questionnaire, Zarit Burden Interview, Sleep Diary, Pittsburgh Sleep Quality Index, and semi-structured interviews. Quantitative data were analyzed using descriptive and bivariate statistics ( $p < 0.05$ ), and qualitative data were processed using IRAMUTEQ software and Bardin's content analysis. **Results:** 67.1% of participants presented moderate to severe caregiver burden, associated with irregular sleep schedules, shorter sleep duration, and poorer sleep quality. Additionally, 47.9% reported poor sleep quality, more prevalent among women, urban residents, and those responsible for household tasks. Narratives revealed that burden interferes directly with sleep, causing nighttime awakenings and daytime sleepiness. A support network was identified as a protective factor. **Final considerations and implications for practice:** caregiver burden negatively impacts sleep quality, highlighting the need for supportive public policies and underscoring the relevance of nursing in home care, particularly in the early identification and management of burden and in the promotion of caregiver well-being.

**Keywords:** Caregivers; Aged; Occupational Health Policy; Caregiver Burden; Sleepiness.

## RESUMO

**Objetivo:** avaliar a relação entre a sobrecarga do cuidado com a saúde do sono de cuidadores e conhecer quais são as concepções desses profissionais sobre a relação entre a sobrecarga do cuidado e o sono. **Método:** estudo de métodos mistos realizado com 73 cuidadores. A coleta de dados envolveu questionário sociodemográfico e ocupacional, Inventário de Sobrecarga de Zarit, Diário do Sono, Índice de Qualidade do Sono de Pittsburgh e entrevistas semiestruturadas. Os dados quantitativos foram analisados por estatística descritiva e bivariada ( $p < 0,05$ ), e os qualitativos foram processados no software IRAMUTEQ, segundo análise de Bardin. **Resultados:** 67,1% dos participantes apresentaram sobrecarga moderada a severa, associada aos horários irregulares, à menor duração e à pior qualidade do sono. Além disso, 47,9% relataram má qualidade do sono, mais prevalente entre mulheres, moradoras da zona urbana e responsáveis pelo lar. As narrativas revelaram que a sobrecarga interfere diretamente no sono, provocando despertares noturnos e sonolência diurna. A rede de apoio foi apontada como fator protetivo. **Considerações finais e implicações para a prática:** a sobrecarga impacta negativamente o sono dos cuidadores, evidenciando a necessidade de políticas públicas de suporte e apontando implicações para a enfermagem, especialmente na atenção domiciliar, no reconhecimento e enfrentamento precoce da sobrecarga e na promoção do cuidado ao cuidador.

**Palavras-chave:** Cuidadores; Idoso; Política de Saúde do Trabalhador; Sobrecarga do Cuidador; Sonolência.

## RESUMEN

**Objetivo:** evaluar la relación entre la sobrecarga del cuidado y la salud del sueño de cuidadores de personas mayores, así como comprender sus concepciones sobre dicha relación. **Método:** estudio de métodos mixtos realizado con 73 cuidadores. La recolección de datos incluyó cuestionario sociodemográfico y ocupacional, Inventario de Sobrecarga de Zarit, Diario del Sueño, Índice de Calidad del Sueño de Pittsburgh y entrevistas semiestructuradas. Los datos cuantitativos fueron analizados mediante estadística descriptiva y bivariada ( $p < 0,05$ ), y los cualitativos procesados con el software IRAMUTEQ y análisis de contenido según Bardin. **Resultados:** el 67,1% de los participantes presentó sobrecarga moderada a severa, asociada con horarios de sueño irregulares, menor duración y peor calidad del sueño. Además, el 47,9% reportó mala calidad del sueño, siendo más prevalente entre mujeres, residentes urbanos y responsables del hogar. Las narrativas revelaron que la sobrecarga interfiere directamente en el sueño, provocando despertares nocturnos y somnolencia diurna. La red de apoyo fue señalada como factor protector. **Consideraciones finales e implicaciones para la práctica:** la sobrecarga impacta negativamente en el sueño de los cuidadores, lo que refuerza la necesidad de políticas públicas de apoyo e implica a la enfermería en la atención domiciliar, especialmente en la identificación y manejo precoz de la sobrecarga y en la promoción del cuidado del cuidador.

**Palabras-clave:** Cuidadores Anciano; Política de Salud Ocupacional; Carga del Cuidador; Somnolencia.

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## INTRODUCTION

Sleep is a basic need, and sleep health has become an emerging topic today, especially given the evidence that sleep deprivation or poor quality can have significant health impacts. These effects range from inflammatory and metabolic processes to psychological impairments, resulting in biopsychosocial harm to human health.<sup>1</sup> Among the factors that influence sleep quality, the length of the workday and night or alternating shift work stand out, which can significantly compromise individuals' rest and sleep quality.<sup>2</sup>

Among the different groups of workers, elderly caregivers are particularly vulnerable to sleep disorders, experiencing multiple aspects of impaired sleep, such as high rates of sleep deprivation and daytime sleepiness, as well as longer wake time after falling asleep and frequent awakenings during the night.<sup>1-3</sup> These consequences are strongly associated with factors inherent to the care activity, such as the time dedicated to care, the daily workload, and the behavioral disorders of the person being cared for.<sup>4</sup>

Given this scenario, it is essential to recognize that, although paid elderly caregivers have some labor rights, there is still no specific regulation that guarantees adequate protection for these professionals. Furthermore, even though elderly care is often informal, it constitutes an essential work activity that demands recognition in health and public policy. This work requires caregivers to sacrifice personal resources and intense dedication, which, combined with a lack of formal support, can result in burnout, directly compromising essential aspects of quality of life, such as nutrition, rest, and sleep.<sup>5-8</sup> Therefore, it is crucial to implement measures that ensure better working conditions and adequate support, preventing negative impacts on caregivers' physical and mental health.<sup>7,8</sup>

Some studies described in a systematic review pointed to a possible relationship between work overload, sleep, and caregiving activities. However, approximately 48.1% of the studies included in this review focused specifically on assessing caregivers' sleep quality.<sup>9</sup> Aspects such as habitual bedtimes and wake-up times, as well as the irregularity of these times between weekdays and weekends, remain underexplored in the context of caregivers of older adults.<sup>9</sup> Furthermore, such studies tend not to consider subjective factors related to the experience or experience of caregiving, highlighting important gaps in the scientific literature.

Given this scenario, we sought to expand the assessment of parameters related to caregivers' sleep and its relationship with workload, using mixed methods to better understand this complex relationship. The adoption of mixed methods enhances the explanatory scope of the results through the integration of quantitative and qualitative data, enabling not only the quantification of the association between workload and sleep, but also understanding how caregivers perceive, feel, and cope with the challenges involved in this experience. Therefore, this study aimed to evaluate the relationship between care burden and the sleep health of caregivers and to understand these professionals' conceptions about the relationship between care burden and sleep.

## METHOD

This is a convergent mixed-methods study with sequential data collection. In this approach, qualitative data can explain the quantitative findings through data integration, providing deeper insight into the results.<sup>10</sup> The quantitative study adopted a cross-sectional, analytical design, while the qualitative investigation followed Thematic Content Analysis. To ensure methodological rigor, the criteria of the Guidelines Mixed Methods Appraisal Tool were followed, which encompasses elements common to STROBE and COREQ.<sup>11</sup>

The study was conducted in a city in the interior of Paraíba, Brazil, chosen as the demographic setting due to the high rate of elderly individuals with clinical and functional impairments compared to other cities in the macro-region.<sup>12</sup> Participants were selected using a nominal Primary Health Care (PHC) report, identifying formal and informal caregivers of dependent elderly individuals registered with the e-SUS system as individuals/family members. For sample size calculation, the public domain program OpenEpi version 3.0 was used, considering a universe of (N=2,704), a 22% prevalence of functional disability in the Northeast region of Brazil, a 95% confidence level, and a sampling error of 5%, resulting in an "n" equivalent to 73 participants.<sup>12,13</sup>

Participants were selected using the simple random sampling method, meeting the eligibility criteria: minimum age of 18 years and working as a caregiver for at least three months (in the case of more than one caregiver, the primary caregiver was the one responsible for providing care most of the time). This study included all caregiver profiles working with dependent older adults to account for the diversity within the caregiving context. Thus, the following participants were included: 1) formal caregivers who have technical training or a specific course for providing care (formal-paid); 2) family caregivers, usually children, spouses, or other relatives, without prior training and unpaid (informal-family); 3) informal caregivers who, despite having no family ties or technical training, provide care for financial compensation (informal-paid). Individuals with a clinical diagnosis of sleep disorders or use of hypnotics/anxiolytics were excluded, as these could be confounding factors in the analyses. Three losses/refusals were replaced by a new draw.

Data collection occurred in a single phase, at two distinct points between May and August 2023, following approval by the Research Ethics Committee (Opinion No. 5,841,761) and after participants signed the Informed Consent Form (ICF). Initially, participants were contacted in person, where the research objectives were presented and their rights were clarified, including the freedom to participate voluntarily and the possibility of withdrawing at any time without prejudice.

After formal acceptance of participation, data collection began using the following instruments: I) A sociodemographic and occupational questionnaire that collected information on gender, age, marital status, education level, income, primary occupation, type of caregiver, and degree of kinship with the older adult; II) Zarit Burden Interview (ZBI), which assesses caregiver burden based on 22 questions, with answers ranging from "never" to "almost always"

(scores ranging from 0 to 4 per item). The total score can reach up to 88 points, with the following cutoff points: zero to 20 points (low or no burden), 21 to 40 points (moderate burden), and 41 to 88 points (moderate to severe burden);<sup>14</sup> III) Pittsburgh Sleep Quality Index (PSQI), which assesses subjective sleep quality over the past month, generating an overall score ranging from zero to 21 points, with higher scores indicating poorer sleep quality, with cutoff points. Scores zero to five represent good sleep quality, while scores greater than five indicate poor sleep quality.<sup>15</sup> The IV) Sleep Diary was also provided, which recorded bedtime and wake-up times, as well as sleep duration on weekdays and weekends, allowing for the calculation of irregular sleep duration between weekdays. Subsequently, a return date was scheduled for sleep diary collection, enabling the second data collection phase of the study.

During the second data collection phase, when the sleep diary was collected, an open-ended or in-depth interview was conducted, corresponding to the qualitative framework of the investigation. For this technique, a semi-structured interview was used to guide the interview. The interview was recorded (using a conventional recorder) with the participant's permission and later transcribed for greater reliability. It should be noted that the transcripts were not sent to the participants for comment or validation. The interview was based on two central questions about sleep habits and elderly care activities, and eight secondary questions to further explore the topics, with additional questions on possible points mentioned by the participant, such as satisfaction with sleep, conception of what sleep quality is, care routine and possible difficulties in sleeping/waking.

It is worth noting that, for the in-depth interview phase, the sample was defined using the data saturation technique, following Minayo's recommendations,<sup>16</sup> which establishes a consensus of 20 to 30 interviews. Thus, of the 73 caregivers who participated in the initial phase of the investigation, 27 completed the interview. The data collection process was conducted collaboratively among the researchers, who had varying levels of scientific training and experience in qualitative studies. Regular meetings were held throughout the research to monitor the progress of the study, critically reflect on the findings, and establish methodological consensus. During this process, both researchers observed that data saturation was reached by the 26th interview.

To confirm this, an additional interview was conducted, after which it was decided to discontinue data collection.

Each interview lasted approximately 15 minutes on average and was conducted in the participants' homes, in an appropriate, quiet location that guaranteed their privacy and comfort. Repeat interviews were not necessary. The interviews were conducted by two researchers: a master's student in the *Stricto Sensu* graduate program in Public Health and a senior nursing student. They ensured that only one researcher and the respective participant remained in the room during each interview. Both researchers had prior experience conducting qualitative research and working in the field of gerontological and geriatric nursing.

It should be noted that there was no pre-existing relationship between the researchers and the participants prior to the start of data collection.

Quantitative data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 20.0. The chi-square goodness-of-fit test was used for frequency distribution analyses, and the Mann-Whitney test was used to compare sleep variables according to care burden groups. A significance level of  $p < 0.05$  was adopted in all analyses. For qualitative analysis, the transcripts were converted into a textual corpus format for processing using the R Interface for Multidimensional Text and Questionnaire Analysis (IRAMUTEQ®) software, version 0.7 alpha 2. Textual analysis was performed using the Descending Hierarchical Classification (DHC) proposed by Reinert's method, in which text segments are classified according to their respective vocabularies, represented in the form of dendrograms and textual classes, based on their proximity and branches, with words having a frequency equal to or greater than five ( $\chi^2 > 3.84$ ;  $p < 0.05$ ).<sup>17</sup>

To confirm the findings evidenced by the classes generated in the dendrogram and organize the data obtained in the textual processing, the content was analyzed based on the Content Analysis technique proposed by Bardin. The results were processed and interpreted to ensure the significance and validity of the findings through the application of statistical operations using IRAMUTEQ® software. This enabled the identification and classification of the information emerging from the structural analysis of the classes represented in the dendrogram. The final analysis was conducted by integrating quantitative and qualitative data to identify convergences, divergences, and complementarities.

## RESULTS

Seventy-three caregivers of elderly individuals participated in the study, of which 93.2% were informal/family caregivers and 61.6% were children caring for their parents. The prevalence of caregivers was female (87.7%), literate (86.3%), and living in urban areas (72.6%). The mean age observed was  $46 \pm 10.37$  years, with an average monthly family income of R\$2,000.00 (minimum wage in effect during the collection period = R\$1,320.00) and with varied occupations (Table 1). Poor sleep quality was observed in 47.9% of the total sample, being more prevalent in women ( $\chi^2 = 5.58$ ;  $p = 0.018$ ), urban residents ( $\chi^2 = 15.89$ ;  $p = 0.0001$ ) and homemakers ( $\chi^2 = 11.56$ ;  $p = 0.0001$ ) (Table 1).

It was observed that 45.2% of participants had moderate to severe overload and 21.9% had moderate overload. Higher levels of overload were associated with sleeping later on weekdays, waking earlier, and having shorter sleep duration on weekdays and weekends, as well as poorer sleep quality. There were no differences in sleep duration between weekdays and weekends (Table 2).

Regarding the qualitative results, understanding the living conditions and factors related to care, health, and sleep of caregivers of homebound elderly individuals was constructed through the process of coding and categorizing the narratives presented in the interviews. The IRAMUTEQ® software used

**Table 1.** Comparison between sleep quality groups, according to the sociodemographic and occupational characteristics of caregivers, Paraíba, 2024 (n = 73).

Variables	n (%)	Sleep Quality (IQSP)		Sig. P-value
		Good	Bad	
Sex				
Male	09 (12,3%)	08 (88,9%)	01 (11,1%)	0,018 <sup>A</sup>
Female	64 (87,7%)	30 (46,9%)	34 (53,1%)	
Marital Status				
Single	27 (37%)	14 (51,9%)	13 (48,1%)	0,98 <sup>A</sup>
Married	31 (42,5%)	15 (48,4%)	16 (51,6%)	
Divorced	05 (6,8%)	03 (60%)	02 (40%)	
Separated	05 (6,8%)	03(60%)	02 (40%)	
Widowed	02 (2,7%)	01(50%)	01 (50%)	
Stable Union	03 (4,1%)	02 (66,7%)	01 (33,3%)	
Literacy				
Yes	63 (86,3%)	32 (50,8%)	31 (49,2%)	0,29 <sup>A</sup>
No	10 (13,7%)	06 (60%)	04 (40%)	
Residential Area				
Urban	53 (72,6%)	20 (37,7%)	33 (62,3%)	0,0001 <sup>A</sup>
Rural	20 (27,4%)	18 (90%)	02 (10%)	
Occupation				
Retired	12 (16,4%)	08 (66,7%)	04 (33,3%)	0,004 <sup>A</sup>
Public Servant	15 (20,5%)	08 (53,3%)	07 (46,7%)	
Farmer	12 (16,4%)	12 (100%)	00 (0%)	
Homemaker	16 (21,9%)	05 (31,2%)	11 (68,7%)	
Self-Employed	08 (11%)	03 (37,5%)	05 (62,5%)	
Unemployed	06 (8,2%)	02 (33,3%)	04 (66,7%)	
Formal Caregiver	03 (4,1%)	00 (0%)	03 (100%)	
Other	01 (1,4%)	00 (0%)	01 (100%)	
Relationship				
Children	45 (61,6%)	27 (57,1%)	18 (42,9%)	0,17 <sup>A</sup>
Grandchildren	06 (8,2%)	05 (83,3%)	01 (16,7%)	
Spouse	05 (6,8%)	03 (60%)	02 (40%)	
Son-in-law/Daughter-in-law	07 (9,6%)	03 (42,8%)	04 (57,2)	
No Relation	02 (2,7%)	00(0%)	02 (100%)	
Others	08(11%)	01 (12,5%)	07 (87,5%)	
Caregiver Type				
Formal-Paid	03 (4,1%)	01 (33,3%)	02 (66,7%)	0,25 <sup>A</sup>
Informal-Family	68 (93,2%)	37 (54,4%)	31 (45,6%)	
Informal-Paid	02 (2,7%)	00 000%)	02 (100%)	

<sup>A</sup>Chi-square. Source: Survey data (2024).

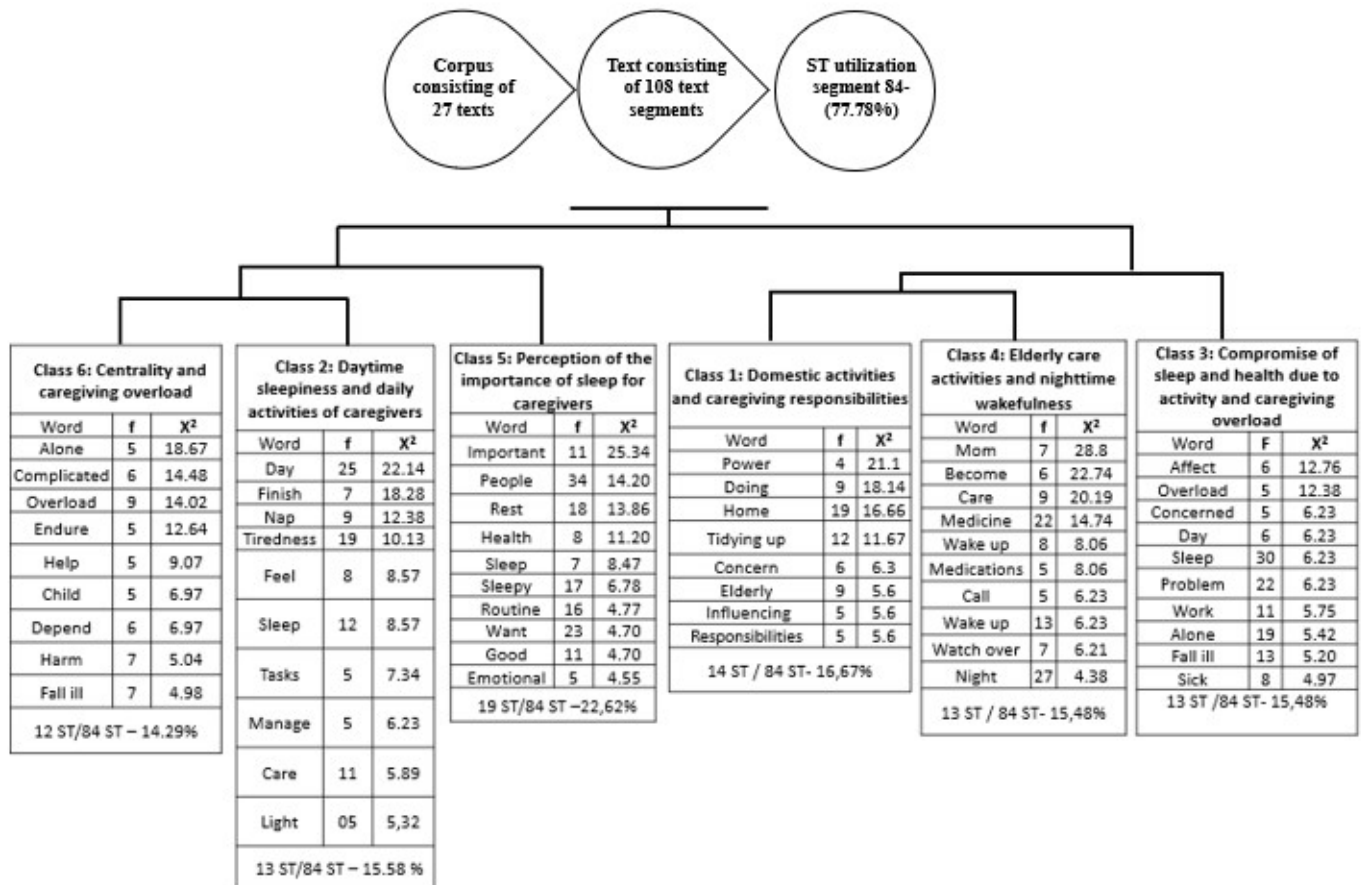
Descending Hierarchical Classification (DHC), with a 77.78% success rate for processing and analyzing the empirical material.

Thus, DHC identified six textual classes, as shown in the dendrogram shown in Figure 1.

**Table 2.** Comparison of caregivers' sleep variables according to care burden levels on weekdays and weekends, Paraíba, 2024 (n = 73).

Sleep Variables	Mean Rank			p-value
	Mild/None	Moderate	Moderate to Severe	
Week				
Bedtime	32,00	22,13	39,96	0,010 <sup>b</sup>
Wake-up time	42,38	28,16	28,73	0,021 <sup>b</sup>
Sleep duration	40,36	42,56	22,02	0,001 <sup>b</sup>
Weekend				
Bedtime	32,29	25,38	37,89	0,104 <sup>b</sup>
Wake-up time	39,88	24,19	32,88	0,043 <sup>b</sup>
Sleep duration	42,33	32,97	26,02	0,011 <sup>b</sup>
Irregular sleep duration	27,90	30,13	37,21	0,190 <sup>b</sup>
Sleep quality	18,35	32,41	52,79	0,001 <sup>b</sup>

<sup>b</sup>Mann-Whitney test. Source: Research data (2024).



**Figure 1.** Dendrogram representing the distribution of classes according to the descending hierarchical classification of the perception of the sleep-wake cycle and the influence of caregiving activities. Paraíba, Brazil, 2024.

**Source:** Prepared based on research data using IRAMUTEQ software (2024).



In the dendrogram, the primary corpus was divided into two major branches, composed of six classes described in Figure 1. Based on Bardin's theoretical-methodological framework, the textual classes supported the construction of a large thematic category called "Caregiver's Perception of Caregiving Activities and Their Influence on Sleep, Health, and Workload," corresponding to all aspects addressed in the interviews. The qualitative data, through this category, allowed for further interpretation of the subjective factors of caregiving activities, presenting points of convergence with the quantitative data set.

### Caregiver's perception of caregiving activities and their influence on sleep, health, and workload

In this category, the discourses characterized the sleep impairment caused by caregiving activities for the elderly. Participants emphasized that caregiving for the elderly compromises the biological domain related to sleep and influences other dimensions of their lives:

*Caring for someone, especially an elderly person, has a huge impact, not just on sleep, but on life as a whole. You end up getting sick and you can't even take care of yourself properly. So, if you don't even have time to take care of your health, consider getting enough sleep (CARE 02).*

*No one here at home sleeps anymore. We have to keep shepherding him. He's choking, in pain, and can't tell what's wrong. That's it. There's no way to sleep or be healthy in these conditions (CARE ??).*

*I wake up several times a night. And the next day it feels like I haven't slept at all. I'm tired and weak, but I also can't stop to nap (CARE 18).*

*I don't think it's just my sleep, but my health as well. I'm finding myself more tired, irritable, and, above all, stressed. I don't know if it's because I'm not sleeping well or because of exhaustion from caring for someone [...] (CARE 20).*

*It's affected my sleep, my health, my interactions with family, church, and travel. It influenced everything. Today I can't do things I used to and enjoyed doing because I have to take care of her. [...] my reality doesn't let me sleep as much as I'd like, nor be healthy or do what I want (CARE 25).*

Among sleep impairments, the narratives pointed to sleep fragmentation, whether due to excessive concern about the elderly person's health status:

*It's impossible not to have an influence. [...] I feel worried, so I have to watch him 24 hours a day. We just pray to God that he doesn't get sick, because when he does, we don't sleep, having to watch him day and night (CARE 03).*

*I think everyone who has an elderly person at home and needs to care for them has the same problem. When night falls, they get up many times. And they can't sleep well because they're worried (CARE 27).*

*I think everyone who cares for elderly people has a slight effect on their sleep, because you go to bed worried about that person, if they're okay at night, if they're sleeping. This affects your sleep; it feels like you can't rest because of the worry (CARE 07).*

*[...] There's so much going on in your head that you end up not being able to sleep well at night, and before you know it, it's almost dawn [...]. Sometimes the worry is so great that I wake up for no reason (CARE 21).*

There were also reports that showed changes in caregivers' sleeping and waking times, non-restorative sleep and greater degrees of daytime sleepiness, resulting from the care provided to the elderly at home.

*[...] during the night I can't sleep because there's a pause in my sleep, so I end up only taking short naps. So I wake up feeling tired. When I can, I try to nap during the day to make up for the sleep I lost at night, but it's not the same. At least, for me, it's not. I don't feel well, sometimes I wake up even more tired (CARE 04).*

*It completely impacted my sleep [...]. My children say I'm always staggering around the house, dozing off. And, worse, it's true (CARE 10).*

*I spend the day very sleepy, sleeping in corners, and I end up getting irritated easily, or sometimes even for no reason. And, depending on how much I spend at night caring for him, it's hard to actually sleep, I can't even (CARE 21).*

*At night it feels like torment, I hardly sleep at all [...]. You wake up often and have that broken sleep, which, for me, isn't something restorative [...]. I feel even more tired (CARE 23).*

*When I go to do the activities I always do at home—washing dishes, sweeping the house, that kind of thing - I do it feeling sleepy and exhausted (CARE 26).*

The family member's work overload triggered feelings of excessive responsibility in some caregivers, leading them to perceive themselves as solely responsible for caring for the elderly:

*[...] caregiving does compromise sleep, a lot, because I'm the only person she can count on, and it's like I don't have the right to feel tired (CARE 22).*

*"I'm alone for everything: the house, taking care of her, and having to deal with whatever comes up. I wanted to ask for help, but I have no one (CARE 27).*

*It's a burden, but I know he depends on me, and I have to put up with it. It's not his fault this happened. But I just want to sleep worry-free and do my own things again (CARE 15).*

*I feel overwhelmed. Alone to do everything (CARE 26).*

Caregiving has implications for most caregivers' social lives; however, how these changes are addressed varies greatly. Some caregivers' reports point to a well-structured support network as a decisive factor in coping positively with this responsibility, which reduces the level of overload and promotes better sleep quality:

*Yes, sometimes it does. Since she depends on us to eat, bathe, and get up, we have to go and help. But at least I'm not alone; we agree and share who will do what, and it doesn't overburden anyone (CARE 05).*

*I also have a very well-established support network; there are three of us siblings taking care of her, so by sharing the tasks, it doesn't overburden or compromise anyone's sleep [...] we only wake up in emergencies (CARE 16).*

## DISCUSSION

The results indicated that caregivers' sleep quality is compromised by care overload, with caregivers with greater burden having shorter sleep durations and waking up earlier, regardless of the day of the week. These sleep patterns were also observed in studies with education workers, such as teachers, who reported longer sleep durations on weekends after more intense work periods.<sup>18,19</sup> The association between greater care overload and poorer sleep quality in this study corroborates the findings of international studies, such as those conducted with North American, Spanish, and Mexican professionals.<sup>5,6,19</sup> It is important to highlight that the impact of care overload on caregivers' waking and sleeping times, as well as on their sleep quality and duration, is continuous, occurring on both weekdays and weekends, and affecting their right to rest. In this sense, Article 6 of the Consolidated Labor Laws (CLT), which seeks to balance the interests of employers and employees, also reinforces the importance of workers' health and well-being, ensuring their need for rest. Adequate sleep is essential for physical and mental health, in addition to reducing costs related to absenteeism, turnover, and medical treatments.<sup>20</sup>

It is important to note that no sensitivity analysis was performed to separate the different types of caregivers included in this study, which could be an opportunity for future research. However, the methodological approach adopted aimed to encompass the true diversity of profiles involved in caring for dependent older adults, and it is noteworthy that the majority of the sample consisted of informal family caregivers. Furthermore, although there are specific characteristics inherent to each caregiver profile, the

results showed consistent impacts on the association between greater workload and worse sleep parameters.

In the qualitative data, it was observed that the main sleep disturbances related to caregiving activities include frequent awakenings during the night, characterizing sleep fragmentation, which is associated with shorter sleep duration and quality, as evidenced in the quantitative analyses. Furthermore, many caregivers reported increased daytime sleepiness, often associated with reduced nighttime sleep due to continuous caregiving for the elderly person. These narratives are similar to data from caregivers in the United States, who reported dissatisfaction with sleep due to habits acquired during caregiving, such as sleeping outside the bedroom and inconsistent bedtimes and wake-up times. This highlights that, although caregiving activities are often informal, they constitute a job that imposes constant demands, without providing adequate conditions for sleep management and self-care.<sup>21</sup>

Another factor reported by caregivers was excessive worry, which leads to frequent awakenings to assess the elderly person's health status or perform routine caregiving activities. These reports are similar to those of caregivers in São Paulo, who describe poor sleep quality due to frequent and excessive worry.<sup>22</sup> Thus, the literature indicates that feelings of worry resulting from nighttime surveillance of an elderly person can lead not only to interruptions/impairments to the caregiver's sleep, but also to greater emotional fragility, physical disorders, mental instability, and, consequently, illness.<sup>23</sup>

In addition, home care is sensitive to a lack of support and guidance, which impacts reduced personal time, withdrawal from leisure activities, unemployment, and limited emotional relationships.<sup>24</sup> There is no formal support network for caregivers, and the occupational health policy does not encompass this category, which generally works informally. As a result, there is a shortage of care for caregivers themselves, particularly medical and nursing care, in addition to a lack of guaranteed labor rights and salary appreciation, which are fundamental to ensuring their quality of life and well-being. This impacts burden and lack of rest, negatively impacting the physical and mental health of these individuals.<sup>25</sup>

In the study in question, these realities were expressed both by the level of moderate to severe burden and by the statements of caregivers who reported disruptions in daily activities, family relationships, and a lack of time for self-care. Although it is a challenging activity that demonstrates high levels of burden, sleep impairment, and lack of public policy coverage, participants' statements observed that having a well-structured support network is a protective factor for caregivers' health and sleep habits. This reality is consistent with data found in a study conducted in Porto Velho, which suggests that a lack of family support may be one of the factors associated with illness, physical exhaustion, and emotional burden.<sup>23</sup>

A social support network is essential for caregivers to share tasks, anxieties, and joys, thus proving to be an important aspect for reducing burden and maintaining the caregiver's quality of life

within the socio-family context.<sup>22</sup> In this sense, it is also essential that there is a close watch and continuous support from healthcare professionals, especially during home visits conducted by nurses, doctors, and other PHC staff, in order to recognize early signs of exhaustion, offer guidance, and promote care actions that involve both the elderly person and their caregiver.<sup>22,23</sup>

Furthermore, factors related to care are not limited to caregiver sleep. Place of residence showed a significant relationship with sleep quality, as poorer sleep quality was observed in urban residents compared to those in rural areas. From this perspective, some studies have shown that more lively nightlife and increased noise pollution, resulting from noise in urban areas, can contribute to sleep impairment, while factors such as less exposure to light and more regular bedtimes and wake-up times, present in rural areas, are protective factors for better sleep quality and duration.<sup>26,27</sup>

Furthermore, poorer sleep quality was found in women compared to men, corroborating a population-based household survey conducted in 2013 throughout Brazil.<sup>28</sup> The frequency of sleep problems in women is a reality experienced in several countries around the world, showing a predisposition twice as high for difficulty sleeping or increased nighttime awakenings compared to men.<sup>29</sup>

This study observed an association between the occupation of primarily caring for the home and a higher prevalence of impaired sleep quality in women. Although alternative dynamics for homemaking exist, women still predominantly perform this role, balancing it with other daily responsibilities. The burden attributed to women, whose caregiving activities are naturalized in a way that seems exclusive and inherent to women, may have led to care overload and compromised the sleep quality of the women in this study.<sup>30,31</sup>

Furthermore, similar findings were found in a health survey conducted in Campinas, São Paulo, in which participants who primarily provided home care presented a higher frequency of sleep disorders, depression, and greater use of benzodiazepines, a fact attributed, among other factors, to socially designated domestic roles and responsibilities.<sup>1</sup>

In addition to the aforementioned factors of impaired sleep, well-being, and increased caregiver burden, the informality of elderly care activities reflects a structural problem that limits the recognition of this type of work and the full inclusion of these workers in public health policies. Although it is an essential activity for maintaining the quality of life of the elderly population, the care provided by family members or informal caregivers is still often invisible, without adequate regulation and without guarantees of labor and social security rights.<sup>32</sup> Therefore, formal recognition of the caregiver's work is essential to guarantee access to public policies that ensure training, psychological support and decent working conditions, fundamental elements for preserving the health of the caregiver and the effectiveness of health care as a fundamental human right for well-being and quality of life.<sup>33,34</sup>

## **FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE**

The study revealed moderate to severe levels of burden among elderly caregivers, directly impacting sleep quality and patterns. Quantitative and qualitative analysis reinforced how burden interferes with sleep schedules, causing nighttime awakenings and daytime sleepiness. These findings highlighted the urgent need for public policies that promote the appreciation and protection of informal caregivers, guaranteeing their right to rest and health.

Although the data were obtained without the direct participation of nursing staff, the results have important implications for practice, especially in primary care and home care. The prevalence of work overload and poor sleep quality highlights the need for nursing staff to comprehensively assess caregivers, addressing physical, emotional, occupational, and relational aspects. Furthermore, it is essential to implement educational and psychosocial strategies focused on self-care, routine reorganization, and sleep hygiene, as well as strengthening social support networks. Thus, nursing plays a fundamental role in promoting caregiver health and the sustainability of home care for older adults.

Furthermore, the combination of mixed methods in this research broadens the understanding of the results and favors the development of more sensitive interventions, constituting a strength of this research. However, although the findings of this research contribute to the understanding of the relationship between work overload and the sleep health of caregivers of older adults, it is important to consider some limitations. This is a cross-sectional study conducted in a sociocultural and economic context typical of the Northeast region of Brazil. It may not be directly applicable to other regions of the country or to international contexts that present distinct dynamics of care, infrastructure, and support networks. Self-reported instruments are used, which rely on the subjective perception of participants. Furthermore, a larger sample size could contribute to multivariate analyses, which allow for more rigorous control of confounding factors. These limitations do not compromise the relevance of the results, but they highlight the need for further research to deepen and broaden understanding of the topic and highlight the urgency of regulating informal work and promoting effective interventions aimed at improving the quality of life of caregivers.

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## **DATA AVAILABILITY RESEARCH**

The contents underlying the research text are included in the article.



## CONFLICT OF INTEREST

No conflict of interest.

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Study design. Patrício de Almeida Costa. Matheus Figueiredo Nogueira. Jane Carla de Souza.

Data acquisition. Patrício de Almeida Costa. Maria Eduarda Wanderley de Barros Silva. Matheus Figueiredo Nogueira. Jane Carla de Souza.

Data analysis and interpretation of results. Patrício de Almeida Costa. Maria Eduarda Wanderley de Barros Silva. Matheus Figueiredo Nogueira. Jane Carla de Souza.

Writing and critical review of the manuscript. Patrício de Almeida Costa. Maria Eduarda Wanderley de Barros Silva. Matheus Figueiredo Nogueira. Jane Carla de Souza.

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Responsibility for all aspects of the content and integrity of the published article. Patrício de Almeida Costa, Maria Eduarda Wanderley de Barros Silva, Matheus Figueiredo Nogueira, and Jane Carla de Souza.

## **ASSOCIATED EDITOR**

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