Original Article

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Depressive symptoms and sleep in aged caregivers in a context of high social vulnerability

Sintomas depressivos e sono de idosos cuidadores inseridos em contexto de alta vulnerabilidade social

Síntomas depresivos y sueño de ancianos cuidadores inmersos en un contexto de alta vulnerabilidad social

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ABSTRACT

Objective: To evaluate the relationship between depressive symptoms and sleep quality in aged caregivers of elderly people, in a context of high social vulnerability.

Methods: A Cross-sectional study conducted between July 2019 and March 2020 with 65 aged caregivers of elderly people that were treated in five Family Heath Units from São Carlos, São Paulo. Instruments to characterize the caregivers and to evaluate the depressive symptoms and sleep quality were used in data collection. The Kruskal Wallis and Spearman Correlation tests were adopted.

Results: 73.9% of the caregivers presented poor sleep quality and 69.2% did not have depressive symptoms. In the caregivers with severe depressive symptoms, the mean sleep quality score was 11.4; in those with mild depressive symptoms, it was 9.0; and in those without depressive symptoms, it was 6.4. There was a direct and moderate correlation between sleep quality and depressive symptoms.

Conclusion: There is a relationship between depressive symptoms and sleep quality in aged caregivers.

Keywords: Depression. Sleep. Caregivers. Aged. Social vulnerability. Nursing. Primary health care.

RESUMO

Objetivo: Avaliar a relação entre sintomas depressivos e qualidade do sono de idosos cuidadores de idosos em contexto de alta vulnerabilidade social.

Métodos: Estudo transversal, realizado de julho/2019 a março/2020 com 65 idosos cuidadores de idosos, atendidos por cinco Unidades de Saúde da Família, em São Carlos, São Paulo. Instrumentos para caracterizar os cuidadores, avaliar os sintomas depressivos e a qualidade do sono foram usados na coleta de dados. Os testes Kruskal Wallis e Correlação de Spearman foram adotados.

Resultados:73,9% dos cuidadores apresentaram sono de má qualidade e 69,2% não apresentaram sintomas depressivos. Nos cuidadores com sintomas depressivos severos, o escore médio de qualidade do sono foi 11,4, nos com sintomas depressivos leves foi 9,0 e naqueles sem sintomas depressivos foi 6,4. Houve correlação direta e moderada entre qualidade do sono e sintomas depressivos.

Conclusão: Existe relação entre sintomas depressivos e qualidade do sono em idosos cuidadores.

Palavras-chave: Depressão. Sono. Cuidadores. Idoso. Vulnerabilidade social. Enfermagem. Atenção primária à saúde.

RESUMEN

Objetivo: Evaluar la relación entre síntomas depresivos y calidad del sueño de ancianos cuidadores de ancianos en contexto de alta vulnerabilidad social.

Métodos: Estudio transversal, realizado de Julio/2019 a Marzo/2020 con 65 ancianos cuidadores de ancianos, atendidos por cinco Unidades de Salud de la Familia, en São Carlos, São Paulo. En la recopilación de datos se utilizaron instrumentos para caracterizar a los cuidadores, evaluar los síntomas depresivos y la calidad del sueño. Se adoptaron las pruebas de Kruskal Wallis y el coeficiente de correlación de Spearman.

Resultados:73,9% de los cuidadores presentaron sueño de mala calidad y 69,2% no presentaron síntomas depresivos. En los cuidadores con síntomas depresivos graves, la puntuación media de la calidad del sueño fue de 11,4, en aquellos con síntomas depresivos leves fue de 9,0 y en aquellos sin síntomas depresivos fue de 6,4. Hubo una correlación directa y moderada entre la calidad del sueño y los síntomas depresivos.

Conclusión: Existe una relación entre los síntomas depresivos y la calidad del sueño en ancianos cuidadores.

Palabras claves: Depresión. Sueño. Cuidadores. Anciano. Vulnerabilidad social. Enfermería. Atención primaria de salud.

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INTRODUCTION

The increase in the elderly population brings in new demands and challenges for public health. The elderly people are the most affected by chronic conditions, which can cause sequelae and limitations, leading the individual to a situation of partial or total dependence, with consequent need for a caregiver. Given the increase in the number of elderly people in the Brazilian context, combined with new family arrangements, there is a greater number of elderlies who are taking care of other elderlies[1].

Aged caregivers who live in a context of poverty are more vulnerable to stressors[2], due to the lack of social, economic, cultural and political resources. In addition, aspects regarding safety, diet, education, and access to health and social care services may be inadequate, exposing these individuals to worse living and health conditions, which may compromise the care provided[3].

In the context of aging, stands out the high prevalence of depressive symptoms[3] and sleep-related complaints[4]. For a long time, it was believed that sleep disorders were a consequence of depression. Today, it is known that the association between these two variables are a complex bidirectional relationship, since people with persistent sleep disorders can also develop depression[5]. A longitudinal research, conducted with 10,704 middle-aged and elderly Chinese, found a bidirectional relationship between sleep duration and depression, and short sleep duration was considered a risk factor for depression; also depression induced short periods of sleep[6]. In addition, it was identified in Portuguese elderly people that the sleep quality acts as a mediator between depression and quality of life, i.e. the coexistence of these two variables may mean worse quality of life[7].

There is evidence in the literature that depressive symptoms are related to sleep complaints among the elderly[4,5,8] and among caregivers[9,10], however these studies are scarce when it comes to aged caregivers. Studying the relationship between these variables is important for the prevention of future conditions and also because when associated, they are difficult to treat and may indicate a worse prognosis[5], besides compromising both quality of life[7] and well-being of individuals and generate high costs for health services[11]. It is necessary that aged caregivers have their physical and mental health preserved, so that they can provide good quality care[1].

That said, the objective of this study was to evaluate the relationship between depressive symptoms and sleep quality in aged caregivers of elderlies in a context of high social vulnerability.

METHOD

Study design, period and location

This research has an observational, cross-sectional, and quantitative design, based on STROBE guidelines (Strengthening the Reporting of Observational Studies in Epidemiology). It was conducted from July/2019 to March/2020 in São Carlos, interior of São Paulo, in five Family Health Units (FHUs) inserted in a context of high social vulnerability. The FHUs are in different regions of social vulnerability, according to the São Paulo Social Vulnerability Index (Índice Paulista de Vulnerabilidade Social - IPVS). The IPVS was created by the State Data Analysis System (*Sistema Estadual de Análise de Dados* - SEADE) based on the socioeconomic and demographic characteristics of residents in the state of São Paulo, comparable to each other for the municipalities. There are seven levels of vulnerability collected by the IPVS: Group 1 (extremely low vulnerability), Group 2 (very low vulnerability), Group 3 (low vulnerability), Group 4 (medium vulnerability), Group 5 (high vulnerability – urban sectors), Group 6 (very high vulnerability) and Group 7 (high vulnerability – rural sectors).

Population and sample

The population consisted of individuals aged 60 years or older, registered and living in the urban area of the FHUs in the municipality and who cared for the elderly. Inclusion criteria were age equal to or greater than 60 years old; living in the coverage area of a FHU in a context of high social vulnerability (IPVS 5), located in the urban sector; being the main caregiver of an elderly person who lived in the same house; understand the interview questions. The exclusion criteria used were death; change of address; unavailable after three attempts on different days and times.

A list with the names of 167 aged caregivers was provided by the five FHUs. Among these elderlies, 49 had no interest in participating in the study, 32 were not located by the researchers after three attempts on different days and times, 18 no longer lived at the address provided, and three had died. Therefore, the final sample of this study consisted of 65 aged caregivers.

Considering as a population the 167 aged caregivers of the elderly registered in the FHUs, the 65 participants in this study constituted a sample at 95% confidence level and a margin of error of 10% - calculated using the SurveyMonkey® platform.

Ethical aspects

All ethical aspects regarding research involving human beings were complied, according to Resolution 466/2012. The study was approved by the Research Ethics Committee of the *Universidade Federal de São Carlos*, on 04/22/2019, CAAE: 08175419,5,0000,5504. A Free and Informed Consent Form (FICF) was provided to the participants, the objectives of the study were presented and explained, and signed in two copies (one for the aged caregivers and other for the researchers). After reading and signing the FICF, data collection started.

Data collection procedures

An initial contact was made with the health teams of the FHUs to identify the residences to be covered. A visit was made to the aged caregivers with the community health agent. In this visit, the aged caregivers were informed about the objectives of the study and other ethical issues, then were invited to participate in the research. For those who accepted, a home interview was scheduled. Data collection was performed in a single session, individually, at the home of the aged caregivers, in a space provided by the elderly. Each interview lasted an average of 90 minutes.

To avoid potential sources of bias in data collection, the interviews were conducted by previously trained undergraduate and graduate students, and to participants were guaranteed privacy, the right to refuse to answer any question and the confidentiality of answers. If any participant refused to answer any question, the interviewers were instructed to respect the participant's will and avoid judgments. Moreover, to avoid bias, the data collection protocol included previously validated scales to evaluate depressive symptoms and sleep in aged caregivers.

Instruments

The characterization data of the aged caregiver and the context of care were collected from a questionnaire prepared by the researchers, with the following variables: gender (male/female), age (in years; 60 to 74 years/75 years or older), marital status (with partner/without partner), years of education, personal and family income (in BRL), multimorbidity (two or more self-reported diseases or conditions, namely: arterial hypertension, diabetes mellitus, heart disease, stroke, gastrointestinal disease, depression, peripheral vascular disease, neurological disease, impaired hearing and/or vision, anxiety, anemia, cancer, dyslipidemia, arthritis, lung problems, back pain and dizziness), number of daily medications, pain (yes/no), degree of kinship with the elderly person being cared for (spouse/father, mother/father-in-law/sister(s)/other), for how many years have been providing care, how many days a week and how many hours a day have been caring for the elderly person, participation in training to perform the task of caring for the elderly (yes/no) and if they receive help to take care of the elderly (yes/no).

The Pittsburgh Sleep Quality Index (PSQI) was used to evaluate sleep quality. This is an instrument translated, adapted, and validated in Brazil, consisting of 19 self-reported questions, which are grouped into seven components: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication and daytime dysfunction. The global score ranges from 0 to 21, and the higher the score, the worse the individual's sleep quality. Scores equal to or greater than five indicate the presence of poor sleep quality and sleep disturbances. Sleep quality of individuals can be categorized as follows: good sleep quality (0 to 4 points), poor sleep quality (5 to 10 points) and presence of sleep disturbances (11 to 21 points)[12].

The Geriatric Depression Scale, Brazilian version with15 items, was used to screen for depressive symptoms. The sum of the scores obtained can range from zero to 15, with zero to five being: absence of depressive symptoms, six to ten points: mild depressive symptoms and from 11 to 15 points: severe depressive symptoms[13].

Data analysis

The data obtained were coded and inserted into a spreadsheet in Microsoft Office Excel, version 2019, with double entry of data by different typists, allowing to correct possible typing errors. Then, they were analyzed using the Stata statistical package, version 13.

Descriptive data were analyzed estimating frequency distributions, means and standard deviations (SD) for numerical variables of the study. Proportions were estimated for categorical variables. The Kolmogorov-Smirnov test was used to test the normality of the variables. Considering the non-parametric distribution, the Spearman's Correlation Test was used to analyze the relationship between sleep quality and depressive symptoms. The correlation rank was classified as weak (<0.3); moderate (0.3 to 0.59); strong (0.6 to 0.9) and perfect (1.0). For the analysis of the difference between the means of the ranks, the Kruskal-Wallis Test was used. The significance level adopted was 5%.

RESULTS

The sample of this study consisted of 65 aged caregivers. Table 1 shows the sociodemographic characteristics and the context of care of the participating aged caregivers.

Table 2 shows the health characteristics of aged caregivers in a context of high social vulnerability.

Figure 1 shows the median scores and percentiles of measures of sleep quality according to the classification of depressive symptoms in aged caregivers.

Table 1 – Distribution of elderlies who care for other elderlies in a context of high social vulnerability according to sociodemographic aspects and context of care (n=65). São Carlos, São Paulo, Brazil, 2019-2020

Variables	n (%)	mean (±standard deviation)
Gender		
Female	37 (56.9)	
Male	28 (43.1)	
Age (years)		69.1 (±6.4)
Age group		
60 to 74 years	51 (78.5)	
75 years or older	14 (21.5)	
Marital status		
With partner	61 (93.9)	
without partner	4 (6.1)	
Years of education		3.1 (±2.8)
Personal income		1,240.44 (±1,006.7)
Family income		2,390.49 (±1,162.5)
Who receives care		
Spouse	58 (89.2)	
Father/Mother	3 (4.6)	
Other	2 (3.1)	
Father-in-law/mother-in-law	1 (1.5)	
Brother/Sister	1 (1.5)	
Time of care (years)		11.1 (±12.8)
Daily hours of care		17.9 (±8.3)

Table 1 – Cont.

Variables	n (%)	mean (±standard deviation)
Weekly days of care		6.9 (±0.4)
Previous training		
No	63 (96.9)	
Yes	2 (3.1)	
Receives help with care		
No	38 (58.5)	
Yes	27 (41.5)	

Source: Research Data, 2020.

Table 2 – Distribution of elderlies who care for other elderlies in a context of high social vulnerability according to health aspects, depressive symptoms and sleep quality (n=65). São Carlos, São Paulo, Brazil, 2019-2020

Variables	n (%)	mean (±standard deviation)
Multimorbidity		
Yes	62 (95.4)	
No	3 (4.6)	
Number of daily medications		
Two or more	47 (72.3)	
One	10 (15.4)	
None	8 (12.3)	
Pain		
Yes	59 (90.8)	
No	6 (9.2)	
GDS-15 scale score*		4.6 (±3.4)
Depressive symptoms		
Absence of depressive symptoms	45 (69.2)	
Mild depressive symptoms	15 (23.1)	
Severe depressive symptoms	5 (7.7)	

Table 2 – Cont.

Variables	n (%)	mean (±standard deviation)
PSQI scale score**		7.3 (±4.1)
Sleep quality		
Poor	33 (50.8)	
Good	17 (26.1)	
Presence of sleep disturbances	15 (23.1)	

Source: Research Data, 2020. *GDS-15 = Geriatric Depression Scale version 15 items; **PSQI = Pittsburgh Sleep Quality Index.

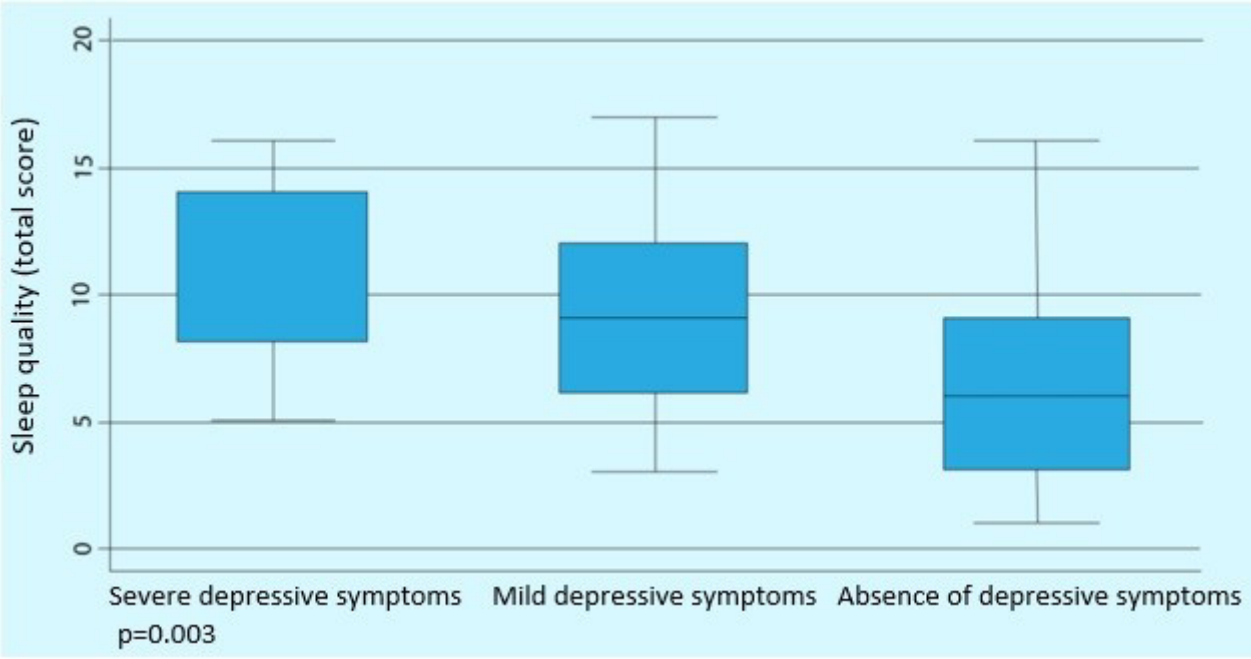

Figure 1 – Boxplot – Sleep quality and depressive symptoms (n=65). São Carlos, São Paulo, Brazil, 2019-2020
Source: Research Data, 2020

Statistical significance was identified using the Kruskal Wallis Test in the analysis of the difference between rank means (p=0.013). The mean sleep quality score among aged caregivers with severe depressive symptoms was 11.4 (sd=5.2) and the median was 14.0, among aged caregivers with mild depressive symptoms it was 9.0 (sd=3 .8) and the median was also 9.0 and among aged caregivers without depressive symptoms it was 6.4 (sd=3.7) and the median 6.0.

Figure 2 shows the correlation analysis between sleep quality scores and depressive symptoms.

There was a direct correlation of moderate magnitude between sleep quality scores and depressive symptoms (Rho=0.33; p=0.008), i.e., the higher the score in the evaluation of depressive symptoms, the worse the sleep quality of aged caregivers and vice versa.

DISCUSSION

In this study, the profile of the aged caregiver in context of high social vulnerability corroborates several research presented in this discussion, which describe a female aged caregiver with a mean age of less than 75 years. Aged caregivers, for the most part, had poor sleep quality (73.9%) and absence of depressive symptoms (69.2%). Poor sleep quality was directly proportional to depressive symptoms.

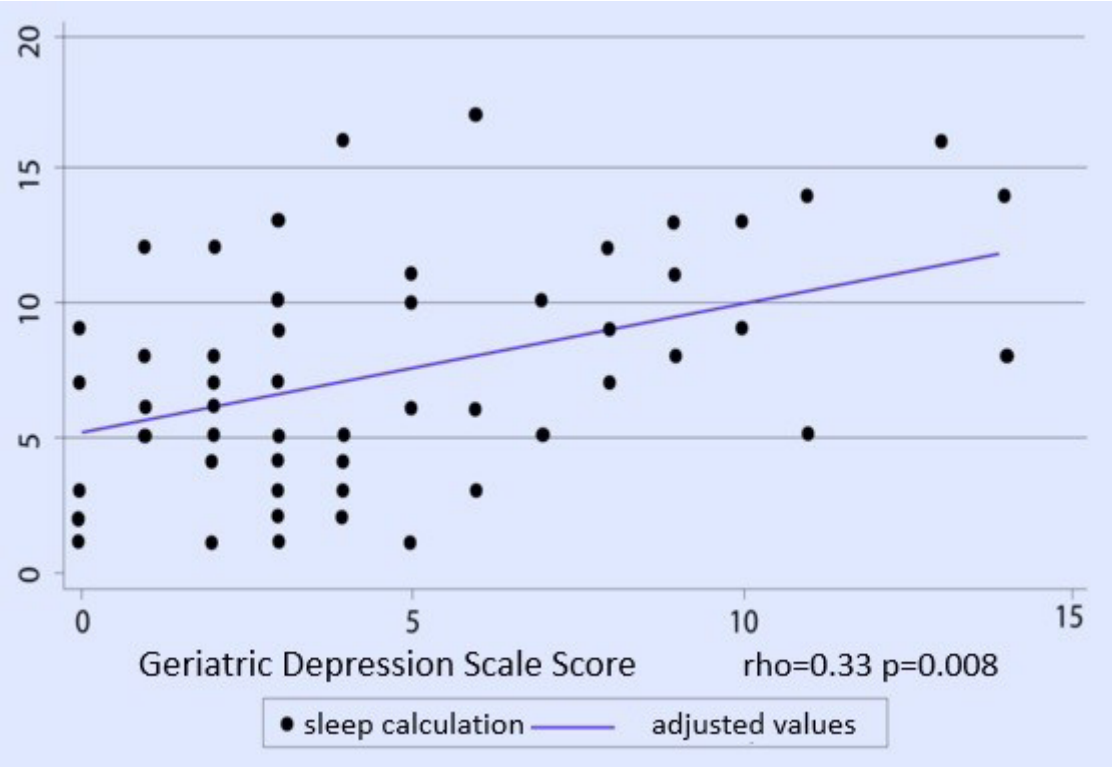

Figure 2 – Scatter plot according to sleep quality and depressive symptoms of aged caregivers (n=65). São Carlos, São Paulo, Brazil, 2019-2020
Source: Research Data, 2020

There was a significant percentage of aged caregivers who scored for mild or severe depressive symptoms (30.8%), as this is extremely important for FHUs care. A systematic review of Brazilian studies identified that the estimated prevalence of depressive symptoms in elderlies of community was 21.0%, lower than that found in this study[14]. However, our data corroborate with findings from the national literature considering elderly people[3] and aged caregivers[15] in contexts of social vulnerability.

Depressive symptoms may occur due to several factors, whether psychological, biological or social. In the elderly person, complaints related to these symptoms can be neglected or misunderstood by the individual, making screening even more necessary[16,17]. Underdiagnoses can harm the health of the caregiver and worsen the condition of pre-existing diseases[16].

The need for care can arise suddenly, making the caregiver to adapt to their routine and give up other activities, such as leisure and self-care. Negative feelings such as exhaustion, insecurity and burden can happen and are closely linked to the incidence of depressive symptoms among caregivers[18]. In contexts of high social vulnerability, this outcome can be even more severe and negatively impact the caregiver's quality of life and the care provided. Given the sudden responsibility for care and aging, which can bring with it limitations in the development of daily activities, aged caregivers may present depressive symptoms over time, considering that the feeling of disability may arise given such limitations[18].

As previously mentioned in the literature[19], a study conducted with 567 primary caregivers of elderly people with disabilities in China identified an inversely proportional relationship between social support and depression[20]. Poverty is related to worse mental health, and this relationship is mediated by social support[21]. In this study it is highlighted the lack of previous training for caregivers, as well as the absence of help from other people to develop the task of caring. Such conditions may indicate insufficient social support and generate anguish, worry and, consequently, depressive symptoms.

With regard to sleep quality, most elderly caregivers had poor sleep quality. Research on the sleep quality of aged caregivers in contexts of social vulnerability is scarce. However, a systematic review identified the negative impact of care on the mental and physical health of the informal caregiver, with greater intensity of these effects, especially in women, spouses and with a greater workload spent on

care[22], profile that is similar to that found in this research. A study that aimed to evaluate depression, sleep disorders and perceived stress among informal caregivers in 58 low, middle and high-income countries identified that a greater number of activities of care increased the chances of depression and sleep disorders, as well as the average score of perceived stress, regardless of the country's income level[9].

The literature points out that, when performing the task of caring alone, the elderly can manifest emotional suffering, anxiety and loneliness and present sleep disorders [23]. In addition to the lack of support for providing care, insufficient financial resources and the presence of multimorbidities are also related to the poorer sleep quality in aged caregivers[24].

It should be noticed that the aged caregiver is also an elderly person. In this sense, their body undergoes physiological changes regarding the sleep quality, quantity and architecture. The reduction of NREM sleep stage 3 (considered deep), the disorganization of circadian rhythms due to the atrophy of the suprachiasmatic nucleus, the decrease in melatonin secretion and the worsen of the sense organs responsible for the perception and decoding of temporal signals can contribute to complaints related to the quality of nocturnal sleep in elderly people[24]. However, these complaints can be considered as "normal" of aging and end up being neglected by health professionals[25].

There was a positive correlation between sleep quality scores and depressive symptoms, i.e., caregivers with more depressive symptoms had worse nighttime sleep quality and vice versa. Similar results were already identified in the literature in the elderly people[4,5,8] and in aged caregivers[9–11,17]. A cross-sectional study conducted in the United States with 43 caregivers of elderly people with dementia, with a mean age of 65 years, aimed to identify factors related to the sleep of family caregivers. Most caregivers (91.7%) had poor sleep quality, and caregivers with depressive symptoms reported more difficulty to sleep when compared to those without depressive symptoms[17].

The marked and daily experience caused by the context of care can motivate several negative symptoms in the aged caregiver, giving rise to or aggravating conditions of depressive symptoms. This scenario can produce symptoms of anxiety and constant concern, setting the caregiver always in a state of alert. Studies show that elderly individuals with the affected psychological state have a longer latency period to start sleeping, with recurrent awakenings, which negatively affect the quality and quantity of sleep[23]. Moreover, there is evidence that biological mechanisms involved in sleep disorder coexist with depressive conditions[5,12,26].

The task of caring for other implies adaptations in the caregiver's life[17]. When he/she is also an elderly person, the needs of the caregiver and the elderly cared for can coexist, which generates a cognitive overload and a series of dilemmas capable of impacting the caregiver's mental health[18].

A systematic review and meta-analysis aimed to evaluate the effectiveness of interventions to improve sleep in unpaid caregivers of the elderly and identified, after analyzing 21 studies, that interventions improved sleep duration and sleep quality, but not sleep disturbances. Even for sleep quality, the existing evidence is of low quality[27]. This highlights the demand for interventions that improve sleep quality in caregivers, and that consequently can improve depressive symptoms, since both variables are related.

CONCLUSION

There was a direct and moderate correlation between the sleep quality scores and depressive symptoms scores, i.e., the more depressive symptoms, the worse the sleep quality of aged caregivers and vice versa.

This study has as limitations the cross-sectional design, the small sample size and the specificity of regions of high social vulnerability. In this sense, causality between the variables cannot be attributed, nor the results generalized. However, it reveals as potentialities the fact of studying aged caregivers inserted in the community and not having been selected based on sleep disorders or depressive symptoms.

It is suggested to be conducted longitudinal research incorporating variables such as cognitive decay, anxiety, burden, family functionality and social support, since they can influence the context of care. Furthermore, with the development of the present study, concern emerged with aged caregivers who live in regions of high social vulnerability who are not supported by the Family Health Units, which can present even more negative results and were not included in our sample. Thus, future investigations that enable data collection with individuals living in vulnerable regions and unassisted by health and assistance programs are recommended.

The findings of this research reinforce the importance of Primary Health Care professionals to perform early screening of depressive symptoms and sleep quality in aged caregivers. The results can support the development of assertive interventions in order to prevent or minimize these conditions, as both depressive symptoms and sleep complaints can add damage to the health of the caregiver and the provision of care. Given the growing number of aged caregivers, it is expected the development of public policies and actions aimed at health promotion and the prevention injuries in search for a better quality of life, safety and support for elderly people inserted in the context of care.

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