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Sleep and family functionality of older caregivers in high social vulnerability: a cross-sectional study

Sono e funcionalidade familiar de idosos cuidadores em alta vulnerabilidade social: um estudo transversal

Sueño y funcionalidad familiar de ancianos cuidadores en alta vulnerabilidad social: un estudio transversal

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Abstract

Objective: to analyze the relationship between quality of sleep and family functioning of older caregivers in a context of high social vulnerability. **Method:** a cross-sectional, quantitative study, carried out with 65 older caregivers, in the period from July 2019 to March 2020, from the following instruments: characterization questionnaire, Pittsburgh Sleep Quality Index to assess sleep quality and Family APGAR to assess family functionality. Pearson's chi-square and Fisher's exact tests were used, with a significance level of 5%. **Results:** most of the older caregivers were female, with a mean age of 69.1±6.4 years, married, caring for their spouse, with no previous training or help from third parties. About 50.8% of the participants reported bad sleep, and 66.2% had good family functioning, 16.9% moderate dysfunction, and 16.9% high family dysfunction. There was no statistically significant relationship between the total scores of the instruments on sleep and family functioning. There was statistical significance only between family functioning and other sleep disturbances caused by worry (p=0.019). **Conclusion and implications for practice:** there was a higher proportion of family dysfunction among older caregivers who had sleep disturbances as a function of very frequent worrying compared to the others.

Keywords: Caregivers; Geriatric Nursing; Aged; Family Relations; Sleep.

Resumo

Objetivo: analisar a relação entre qualidade do sono e funcionalidade familiar de idosos cuidadores de idosos em contexto de alta vulnerabilidade social. **Método:** estudo transversal, quantitativo, realizado com 65 idosos que cuidavam de idosos, no período de julho de 2019 a março de 2020, a partir dos seguintes instrumentos: questionário de caracterização, Índice de Qualidade do Sono de Pittsburgh para avaliar a qualidade do sono e APGAR de Família para avaliar a funcionalidade familiar. Os testes qui-quadrado de Pearson e exato de Fisher foram utilizados, com nível de significância de 5%. **Resultados**: a maioria dos idosos cuidadores era do sexo feminino, com média de 69,1±6,4 anos, casada, que cuidava do cônjuge, não possuía treinamento prévio tampouco ajuda de terceiros para cuidar. Cerca de 50,8% dos participantes referiram sono ruim e 66,2% apresentaram boa funcionalidade familiar, 16,9%, moderada disfunção e 16,9%, elevada disfunção familiar. Não houve relação estatisticamente significante entre os escores totais dos instrumentos sobre sono e funcionalidade familiar. Houve significância estatística apenas entre a funcionalidade familiar e outros distúrbios do sono causados por preocupação (p=0,019). **Conclusão e implicações para a prática:** houve maior proporção de disfunção familiar entre idosos cuidadores que apresentavam distúrbios do sono em função de preocupação muito frequente quando comparados aos demais.

Palavras-chave: Cuidadores; Enfermagem Geriátrica; Idoso; Relações Familiares; Sono.

Resumen

Objetivo: analizar la relación entre la calidad del sueño y la funcionalidad familiar de los cuidadores de ancianos en un contexto de alta vulnerabilidad social. **Método:** estudio transversal, cuantitativo, realizado con 65 ancianos que cuidaban de ancianos, de julio de 2019 a marzo de 2020, utilizando los siguientes instrumentos: cuestionario de caracterización, Índice de Calidad del Sueño de Pittsburgh para evaluar la calidad del sueño y APGAR de Familia para evaluar la funcionalidad familiar. Se utilizaron las pruebas de chi-cuadrado de Pearson y exacta de Fisher, con un nivel de significación del 5%. **Resultados:** la mayoría de los cuidadores de ancianos fueron mujeres, con una edad promedio de 69,1 ± 6,4 años, casadas, que cuidaban de su cónyuge, no contaban con formación previa ni ayuda de otras personas para cuidarlos. Aproximadamente del 50,8% de los participantes informaron que no dormían bien y el 66,2% tenía una buena funcionalidad familiar, el 16,9% disfunción moderada y el 16,9% disfunción familiar alta. No hubo relación estadísticamente significativa entre las puntuaciones totales de los instrumentos sobre el sueño y la funcionalidad familiar. Solo hubo significación estadística entre la funcionalidad familiar y otros trastornos del sueño causados por la preocupación (p = 0,019). **Conclusión e implicaciones para la práctica**: hubo una mayor proporción de disfunción familiar entre los cuidadores ancianos que tenían trastornos del sueño debido a una preocupación muy frecuente en comparación con los demás.

Palabras clave: Cuidadores; Enfermería Geriátrica; Ancianos; Relaciones familiares; Sueño.

INTRODUCTION

Population aging is a worldwide achievement that has reached an expressive growth.[1] Chronic non-communicable diseases are common among the older adults, who live or will live with them for a long period of time. Thus, there may be side effects and disability, causing the older adults to present limitations in performing their activities of daily living, becoming dependent on a caregiver.[1,2]

In the Brazilian context, older adults care is usually provided by a family member at home.[1] Because of the aging population, new family arrangements, and the insertion of younger women in the labor market, the literature shows that older adults are taking care of other older adults.[2,3]

Many times, this care is suddenly assumed because the older adult is the only caregiver option among the available family members. In addition, he or she does not receive support from other people for the caregiving task, besides not being psychologically or technically prepared to perform the new role, which can culminate in a situation of extreme anxiety.[4]

Older caregivers inserted in environments of high social vulnerability are more vulnerable to stressors, which may be affected by multi-morbidities, resulting in harm to the care provided.[5] In view of the above, factors such as family dysfunction and sleep-related complaints may arise in the face of this new reality and thus interfere with the quality of care provided.

Studies were found in the literature that sought to analyze the relationship between family functionality and sleep complaints among the older adults,[6,7] however, are scarce. Such studies have shown that family dysfunction is associated with sleep complaints among the older adults,[6,7] however, gaps should be investigated. Therefore, it is questioned whether this relationship exists in older caregivers inserted in poverty contexts. Understanding the relationship between family functionality and sleep of older caregivers is important and pertinent, especially in scenarios of high social vulnerability, since both family dysfunction and sleep complaints can compromise the health, quality of life, and well-being of the older adults.[7] It is of fundamental importance that both the physical and mental health of older caregivers is preserved in order for them to provide good quality care.[8] The objective of this study was to analyze the relationship between sleep quality and family functioning of older caregivers in a context of high social vulnerability.

METHOD

Observational, cross-sectional study, based on quantitative research assumptions. This is a section of a larger study entitled "Factors associated with poor sleep quality in older caregivers". It was carried out in the city of São Carlos (SP) with older adults patients from five Family Health Units (FHUs) inserted in a context of high social vulnerability. Currently, the municipality of São Carlos has 21 USFs, which are inserted in different social vulnerability areas according to the Paulista Social Vulnerability Index (IPVS) elaborated according to socioeconomic and demographic aspects of the individuals residing in the state of São Paulo. There are seven levels of vulnerability captured by the IPVS: Group 1 (very low); Group 2 (very low); Group 3 (low); Group 4 (medium); Group 5 (high - urban sectors); Group 6 (very high) and Group 7 (high - rural sectors).

The population consisted of registered older adults individuals aged 60 years or older who lived in the urban area covered by the FHU and who cared for the older adults. The inclusion criteria were: being at least 60 years old; being registered in a FHU inserted in a context of high social vulnerability (IPVS 5); being the primary caregiver of the older adults and living in the same household as the older adults who receive care, who were dependent for at least one Basic Activity of Daily Living (BADL - evaluated by the Katz Index) or Instrumental Activity of Daily Living (IADL - evaluated by the Lawton and Brody Scale). The exclusion criteria were: severe hearing and/or visual difficulties perceived at the time of data collection, which could hinder communication; classification as independent of all older adults at home, both for BADL and IADL; death of one of the older adults of the dyad; change of address; not being found after three attempts on different days and times.

By means of a list provided by the professionals of the five FHUs, with 168 households, which were composed of at least two older adults, the sample was selected. All of them were visited. Among them, 49 did not indicate interest in participating in the study, 32 were not found by the researchers after three attempts on different days and times, 18 no longer lived at the address informed, three had died, and one of the households had independent older adults for BADL and IADL. Therefore, the final sample of this study was composed of 65 older caregivers. By considering as population the 168 older caregivers registered at the mentioned FHUs, the 65 participants of this study constituted a sample with a confidence level of 95% and margin of error of 10% - calculation performed through the Survey Monkey® platform.

First, contact was made with the mentioned FHUs to identify potential research participants. With the help of community health agents, a list with the names and addresses of the older caregivers was prepared. Then, home visits were made to all the older caregivers to verify the inclusion and exclusion criteria of the participants. The older adults who met the inclusion criteria were invited to participate in the research. During this visit, they were informed about the study objectives and other ethical issues, and then invited to participate in the study. In case of acceptance, a new home visit was scheduled for the signing of the Free and Informed Consent Term (FICT) and the interview. Data collection lasted approximately two hours and was carried out at the older caregivers' homes, individually, in a space provided by the participant. Eight previously trained undergraduate and graduate students conducted the interviews from July 2019 to March 2020.

To characterize the participants and the care context, a questionnaire was prepared with the following socio-demographic and health data: gender; age; marital status; education; family and individual income; number of medications in use; multi-morbidities;

pain; degree of kinship; how long the care has been provided; how many hours and days in the week are dedicated to this care; whether they have taken any preparatory course on caring for the older adults; whether they receive help with the care task.

The Pittsburgh Sleep Quality Index, validated for Brazil, was adopted to assess the quality of sleep. It consists of 19 questions grouped into seven components, namely: subjective sleep quality; sleep latency; habitual sleep efficiency; sleep duration; sleep disturbances; use of sleep medication; and daytime dysfunction. The total score of the instrument can range from zero to 21 points, and the higher the score, the worse the sleep quality assessment. The overall score allows differentiation of sleep quality, i.e., good quality sleep (< 5 points), poor quality sleep (5 to 10 points), and presence of sleep disorders (11 to 21 points).[9,10]

The Family APGAR was used to evaluate family functionality. This instrument was validated in the Brazilian context and is composed of five questions that allow the measurement of family members' satisfaction regarding five components considered basic in the unity and functionality of any family, that is, adaptation, companionship, development, affection, and resolute capacity. Its final score can vary from zero to 20 points after the sum of all the questions answered. Thus, family functionality can be classified as: high family dysfunction (0-8 points); moderate family dysfunction (9-12 points) and good family functionality (13-20 points).[11,12]

The Katz Scale was used to assess the functional capacity for BADL, such as: bathing; ability to get dressed and use the bathroom; transference; continence and feeding. The instrument is composed of two options of answers, depending on the level of dependence of the interviewee, who may be independent or dependent. At the end, the interviewer can verify in how many activities the older person is independent and in how many activities he or she proves to be dependent.[13,14]

The Lawton and Brody Scale was used for the evaluation of functional capacity in IADLs, such as: telephone use; use of transportation; shopping; housework; preparing meals; using medications and handling money. For each of these activities, the older adults can score one for complete dependence, two for partial dependence or three for independence. At the end, the score can vary between seven and 21 points, that is, seven points mean complete dependence, from eight to 20 points, partial dependence, and 21 points, independence.[15,16]

In the descriptive analysis of the data, proportions were estimated and the differences between groups were analyzed using Pearson's chi-square test and Fisher's exact test. A 5% significance level was adopted. The data obtained was coded and entered into a spreadsheet by two different typists and analyzed with the support of the statistical package Stata, version 13.

All ethical standards established in Resolution No. 466/2012 of the National Health Council were respected and only after authorization from the Municipal Health Secretariat and approval of the Ethics Committee the interviews were initiated. It is also noteworthy that the FICT was prepared with relevant information about the research and, after reading and signing the FICT, data collection began.

RESULTS

The sample of this study consisted of 65 older caregivers. Table 1 presents the socio-demographic characteristics of the participating older caregivers.

Table 2 presents the health aspects of older caregivers in a context of high social vulnerability.

Regarding the context of care, it was observed that 89.3% of the older caregivers were spouses of the older adults care receiver. They had been providing care for an average of 11.1±12.8 years, for 17.9±8.3 hours a day and 6.9±0.4 days a week. Most had no previous training (96.9%) and did not receive help with the caregiving task (58.5%).

As for family functionality, 66.2% of the older caregivers presented good family functionality, 16.9%, moderate dysfunction, and 16.9%, high family dysfunction. Table 3 presents the relationship between family functionality and sleep of older caregivers.

No statistically significant results were found between the variables sleep and family functionality. Table 4 presents the percentage distribution of the older caregivers in relation to the sleep disorders pointed out in the PSQI instrument and family functionality.

Statistically significant results were found between family functionality and other sleep disturbances caused by worry

Table 1. Distribution of the older adults who care for other older adults in the context of high social vulnerability according to sociodemographic aspects. São Carlos, SP, Brazil, 2019-2020 (n=65).

Variables	n (%)	mean (SD)
Sex		
Male	28 (43.1)	
Female	37 (56.9)	
Age (years)		69.1 (6.4)
Age group		
60 to 74 years	51 (78.5)	
75 years or more	14 (21.5)	
Marital status		
With partner	61 (93.9)	
Without partner	4 (6.1)	
Years of schooling		3.1 (2.8)
Personal income (in reais)		1,240.44 (1,006.70)
Family income (in reais)		2,390.49 (1,162.54)

Source: Prepared by the authors. SD - Standard Deviation.

Table 2. Distribution of older adults who care for other older adults in context of high social vulnerability according to health aspects, sleep quality and functional capacity. São Carlos, SP, Brazil, 2019-2020 (n=65).

Variables	n (%)	mean (SD)
Multimorbidity		
No	3 (4.6)	
Yes	62 (95.4)	
Use of medication		
Two or more	47 (72.3)	
One	10 (15.4)	
None	8 (12.3)	
Pain		
Yes	59 (90.8)	
No	6 (9.2)	
Quality of sleep		
Bad	33 (50.8)	
Good	17 (26.1)	
Presence of sleep disorders	15 (23.1)	
Total Sleep Quality Score		7.3 (4.1)
BADL		
Independence	48 (73.9)	
Dependence on one activity	16 (24.6)	
Dependency on two activities	1 (1.5)	
IADL		
Partial dependency	41 (63.1)	
Independene	24 (36.9)	

Source: Elaborated by the authors. BADL - Basic Activities of Daily Living; IADL - Instrumental Activities of Daily Living; SD - Standard Deviation.

(p=0.019). There was a higher proportion of family dysfunction among the older caregivers who had sleep disturbances due to very frequent worrying when compared to the others.

DISCUSSION

This study investigated the relationship between sleep quality and family functionality of older caregivers of other older people. There was no significant relationship between total sleep quality score and family functionality. Statistically significant results were found only between family functionality and other sleep disturbances caused by worry (p=0.019). There was a higher proportion of family dysfunction among the older caregivers who had sleep disturbances due to worry of very frequent when compared to the others.

Most of the older caregivers in this study scored for poor sleep quality. Divergent data was identified in the international literature.[17] Perhaps this discrepancy was found due to the context in which the caregivers of this study are inserted. It is believed that the context of high social vulnerability, marked by the scarcity of cultural, recreational, financial, social, and health resources, can expose individuals to health-related damage,[5,18,19] including the impairment of nighttime sleep.

On the other hand, the performance of the caregiving task can also culminate in this dissatisfaction regarding nighttime sleep. As the older caregivers exercise, alone, the care, without support from other people and without previous preparation, they may manifest emotional distress, anxiety, depressive symptoms, which, consequently, would affect the quality of night sleep.[20] This is in line with the characteristics of the care context identified in this study, which revealed a predominance of caregivers who were not trained to provide care, who did not receive help from others, who provided care for many years, for several hours a day.

Regarding family functionality, most of the older caregivers in this study presented good functionality. A research conducted with 148 older caregivers identified that most of the older caregivers also scored for good family functioning and the factors associated with high satisfaction with family relationships were: reciprocity and sufficiency of emotional support and absence of burden in the provision of instrumental help. It was highlighted that the quality of support is more important than the quantity and that emotional support is the most considerable type when it comes to older caregivers' satisfaction with family functioning.[21] Another national study of 298 older caregivers of their spouses showed that most of the older adults scored for good family functioning. High levels of stress, depressive symptoms, and presence of cognitive impairment are predictors of low levels of family functioning, and having a higher number of children predicted higher levels of family functioning.[22]

The predominance of good family functioning can be identified among the older adults who live with their spouse and are inserted in mixed household arrangements. The perception that there are people available to assist in daily activities is an important factor that can provide stress reduction, increased psychological well-being, and a positive view of family functioning. Long-lasting marital relationships bring tranquility to the older adults, and being inserted in the home context, in the midst of loved ones, it reflects on a positive perception of life, and the positive evaluation of family functionality can mean success and a high sense of self-fulfillment.[23,24]

Good family functioning can also be verified in contexts, in which the older adults are more physically active, that is, independent in relation to BADL and IADL. The reduced demand on the part of the older adults receiving care also influences the perception of family functioning. Dependence is considered a stressful factor that can overcome the coping mechanisms of the older adults's family members.[23] This aspect is also in line with the context of care in the sample of this study, considering that most of the older adults receiving care were independent for BADL.

Table 3. Percent distribution of older caregivers according to sleep characteristics and family functionality. São Carlos, SP, Brazil, 2019-2020 (n=65).

Variables	n (%)	Family Functionality			*p*
		High dysfunction n (%)	Moderate dysfunction n (%)	Good functionality n (%)	
Total Sleep Quality Score					
Good	17(26.1)	3(17.7)	4(23.5)	10(58.8)	0.775[1]
Bad	33(50.8)	5(15.2)	4(12.1)	24(72.7)	
Presence of sleep disorder	15(23.1)	3(20.0)	3(20.0)	9(60.0)	
Subjective quality of sleep					
Good	43(66.1)	7(16.3)	8(18.6)	28(65.1)	0.930[1]
Bad	22(33.9)	4(18.2)	3(13.6)	15(68.2)	
Sleep latency					
Short	46(70.8)	8(17.4)	8(17.4)	30(65.2)	1.000[1]
Long	19(29.2)	3(15.8)	3(15.8)	13(68.4)	
Duration of sleep					
Recomended	37(56.9)	6(16.2)	8(21.6)	23(62.2)	0.571[1]
Not recomended	28(43.1)	5(17.9)	3(10.7)	20(71.4)	
Sleep efficiency					
Efficient	32(49.2)	6(18.8)	5(15.6)	21(65.6)	1.000[2]
Not efficient	33(50.8)	5(15.1)	6(18.2)	22(66.7)	
Use of sleeping medication					
Infrequent or null	53(81.5)	9(17.0)	11(20.8)	33(62.2)	0.234[1]
Very frequent	12(18.5)	2(16.7)	0(0.0)	10(83.3)	
Daytime dysfunction					
Little daytime indisposition	45(69.2)	6(13.3)	8(17.8)	31(68.9)	0.528[1]
A lot of daytime indisposition	20(30.8)	5(25.0)	3(15.0)	12(60.0)	

Source: Elaborated by the authors. [1] Fisher's Exact; [2] Pearson's chi-square.

In this study, there was no statistical significance between the variables sleep quality and family functioning. This phenomenon can be explained by the small sample size. According to a research conducted in the United States, adults and older adults who had poor sleep quality reported dissatisfaction in relation to family functionality. Harmonious family relationships, based on offering emotional support and comfort, can minimize the damage from stressful events that influence sleep. On the other hand, family conflicts can generate negative emotions and impact, directly and negatively, nighttime sleep.[7] This data diverges from those described, although they were surveyed with elders who are not caregivers.

Scholars have pointed out that social and family factors also modify the quality of sleep.[25] Moreover, they reported that conflicting family relationships can have a negative impact on the physical, social, and emotional health of individuals. In this sense, the sleep of the older adults may be impaired in a dysfunctional context.[7]

In this study, the only sleep variable that showed statistical significance in relation to family functionality was the existence of worry. There was a higher proportion of family dysfunction among the older caregivers who presented impaired sleep due to very frequent worrying when compared to the others. The literature points out that feelings of worry due to family disagreements and financial problems are common in the context where these older adults are inserted, which can generate anxiety and, as a consequence, damage to night sleep. The lack of financial resources, recurrent in a scenario of high social vulnerability, is one of the main causes of concern among individuals. The stress resulting from these conditions may be able to impair both family functionality and nighttime sleep.[8]

Table 4. Percent distribution of older caregivers according to sleep disorders and family functionality. São Carlos, SP, Brazil, 2019-2020 (n=65).

Variable	n (%)	Family Functionality			p*
		High dysfunction n (%)	Moderate dysfunction n (%)	Good functionality n (%)	
Waking up in the middle of the night or very early in the morning					
Not very often	29(44.6)	5(17.2)	5(17.2)	19(65.6)	1.000[2]
Very frequent	36(55.4)	6(16.7)	6(16.7)	24(66.7)	
Getting up to go to the bathroom					
Not very often	35(53.8)	6(17.1)	8(22.9)	21(60.0)	0.414[1]
Very frequent	30(46.2)	5(16.7)	3(10.0)	22(73.3)	
Having difficulty breathing					
Not very often	60(92.3)	10(16.7)	10(16.7)	40(66.6)	1.000[1]
Very frequent	5(7.7)	1(20.0)	1(20.0)	3(60.0)	
Frequent coughing/snoring					
Not very often	54(83.1)	8(14.8)	9(16.7)	37(68.5)	0.488[1]
Very frequent	11(16.9)	3(27.3)	2(18.2)	6(54.5)	
Feeling very cold					
Not very often	61(93.8)	11(18.0)	10(16.4)	40(65.6)	1.000[1]
Very frequent	4(6.2)	0(0.0)	1(25.0)	3(75.0)	
Feeling very hot					
Not very often	49(75.4)	8(16.3)	10(20.4)	31(63.3)	0.485[1]
Very frequent	16(24.6)	3(18.8)	1(6.2)	12(75.0)	
Having bad dreams/nightmares					
Not very often	58(89.2)	10(17.2)	8(13.8)	40(69.0)	0.174[1]
Very frequent	7(10.8)	1(14.2)	3(42.9)	3(42.9)	
Feeling pain					
Not very often	47(72.3)	8(17.0)	9(19.2)	30(63.8)	0.916[1]
Very frequent	18(27.7)	3(16.7)	2(11.1)	13(72.2)	
Others (preoccupation)					
Not very often	55(84.6)	6(10.9)	10(18.2)	39(70.9)	**0.019**[1]
Very frequent	10(15.4)	5(50.0)	1(10.0)	4(40.0)	

Source: Elaborated by the authors. [1] Fisher's Exact; [2] Pearson's chi-square

CONCLUSION AND IMPLICATIONS FOR PRACTICE

This study allowed us to analyze the relationship between sleep quality and family functionality of older caregivers in a context of high social vulnerability. No statistically significant relationship was found between such variables, rejecting the guiding hypothesis of the study. Although the findings have not confirmed the hypothesis, the data brings relevant contributions to Geriatric Nursing, which may foster public policies and support the planning of improvement actions that understand this specific public, aiming to improve the social and health conditions of these older people.

Educational activities such as campaigns, lectures, meetings, and the delivery of informational material aiming to raise awareness about the importance of quality nighttime sleep and its health benefits are strategies that can be used by Primary Health Care professionals. In addition, support groups and multi-professional home visits can also be used.

The study presented limitations. The research design adopted - cross-sectional study - does not allow the attribution of causality among the variables. Moreover, the small sample size and the social context of the older caregivers participating in the research were very specific, thus making it impossible to generalize the findings. The scarcity of literature involving the variables was also a limiting factor, making it difficult to compare the findings. As strong points, we highlight the innovative character of the studied theme and the fact that the evaluation was performed with older people from the community, not selected based on specific complaints about sleep or dissatisfaction regarding family functionality.

Intervention studies aimed at improving health aspects related to sleep and family functionality and longitudinal studies to verify the direction of the relationship between the variables are suggestions for future studies, aiming to understand, in a broader context, how such variables impact the health and quality of life of these individuals. It should also be considered that the insertion of variables, such as perceived stress, caregiver burden, and social support, can also contribute to a deeper analysis of this relationship in further studies.

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