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ORIGINAL ARTICLE

Evaluation of loneliness and its associated factors in caregivers of patients with dementia: a cross-sectional study.

Evaluación de la soledad y factores asociados en cuidadores de pacientes con demencia: Estudio transversal.

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Abstract

Objective:

To identify the levels of loneliness and the factors associated with the prevalence of loneliness in caregivers of patients with dementia.

Methods:

An observational cross-sectional study was conducted, including unpaid caregivers of patients with dementia who were receiving home care in Bogotá, Colombia. The prevalence of loneliness was estimated using the UCLA Loneliness Scale. Participants were also assessed regarding their satisfaction with providing care and whether they felt they received the necessary emotional support from family and friends. The association between loneliness and the patient's clinical variables, as well as the sociodemographic characteristics of the caregiver, was evaluated by calculating the odds ratio (OR) between the groups.

Results:

A total of 52 caregivers of patients with dementia were included. Severe loneliness was present in 5.77% of caregivers, while 26.92% experienced moderate loneliness. All caregivers reported feeling satisfied with providing care to their relatives, and 71% felt that their family or friends provided the emotional support they required. Loneliness was more common among caregivers of patients with total functional dependence (OR 4.061, P = 0.0278). Conversely, the perception of receiving emotional support from family and friends was identified as a potential protective factor against loneliness (OR 0.184, P = 0.0104).

Conclusions:

The prevalence of loneliness in this study is lower than that reported in previous studies. All caregivers reported satisfaction in providing care; most perceived adequate emotional support from family and friends. These factors could be contributing to the lower prevalence of loneliness observed.

English version

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Conflict of interest:

The principal investigator and the associated researchers involved in this research work declare that they have no conflicts of interest.

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Resumen

Objetivo:

Identificar los niveles de soledad y los factores asociados en cuidadores de pacientes con demencia.

Métodos:

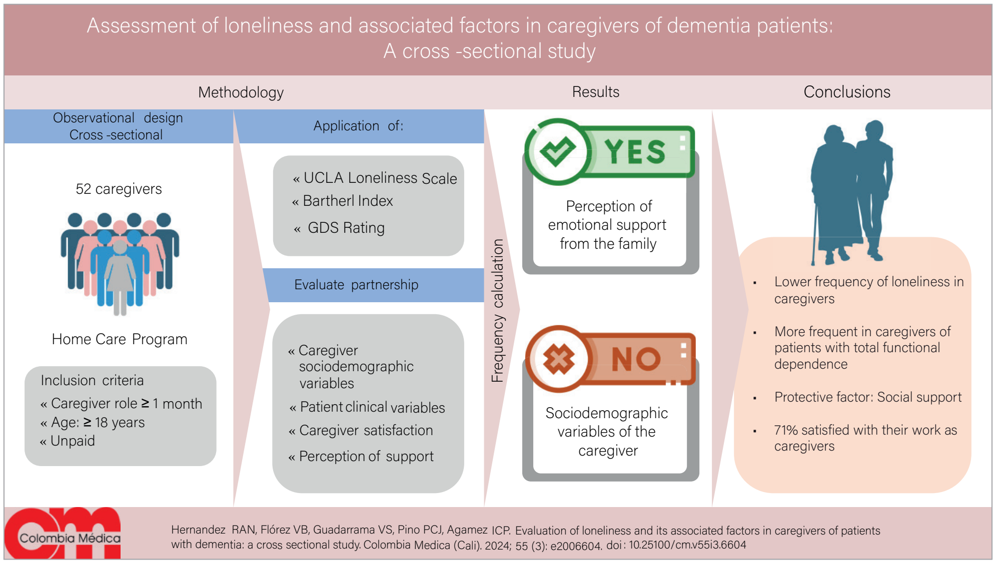
Estudio observacional de corte transversal que incluyó cuidadores no remunerados de pacientes con demencia en atención domiciliaria en Bogotá, Colombia. La prevalencia de soledad se estimó mediante la aplicación de la escala de soledad de la UCLA. Se evaluó si los participantes se encontraban satisfechos con el cuidado y si sentían que recibían el apoyo emocional que requerían de familiares y amigos. La asociación de la soledad con las variables clínicas del paciente y sociodemográficas del cuidador se evaluó calculando el OR entre ambos grupos.

Resultados:

Se incluyeron 52 cuidadores de pacientes con demencia, El 5.77% de cuidadores presentaron soledad severa y 26.92% moderada. Todos los cuidadores reportaron sentirse satisfechos al brindar cuidado a sus familiares, y 71% consideraba que su familia o amigos les brindaban el apoyo emocional que requerían. La soledad fue más frecuente en los cuidadores de pacientes con dependencia funcional total (OR: 4.061, P= 0.0278). Por otro lado, la percepción de apoyo emocional por parte de familiares y amigos se encontró como posible factor protector para soledad (OR: 0.184, P= 0.0104).

Conclusiones:

La prevalencia de soledad encontrada en este estudio es menor comparada con la reportada en estudios previos. Todos los cuidadores reportaron sentirse satisfechos al brindar cuidado y la mayoría percibía adecuado apoyo emocional de familiares y amigos. Estos factores podrían estar relacionados con menores niveles de soledad encontrados en el presente estudio.



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Remark

1) Why was this study conducted?

Care for caregivers of patients with dementia improves quality of life, is cost-effective, and could save resources. These caregivers face significant emotional, financial, and physical challenges. Internationally, it has been identified that nearly half of the caregivers experience moderate loneliness and 17.7% experience severe loneliness.

2) What were the most relevant results of the study?

6% of caregivers experienced severe loneliness, and 27% experienced moderate loneliness. All caregivers reported being satisfied with the care they provided their relatives, and 71% felt that their family or friends provided the necessary emotional support.

3) What do these results contribute?

This is the first study of its kind conducted in Colombia. The results contrast with findings from studies in other countries. Home care could facilitate a trusting relationship and provide caregivers with information, accompaniment, and training, which may explain the lower prevalence of moderate to severe loneliness in our study. Similarly, family functionality, related to this study's high perception of emotional support, could also explain the lower prevalence of loneliness.

Introduction

Caregiving refers to attending to the needs and well-being of another person. In older adults with special characteristics that increase their need for care, caregiving typically includes assistance with basic and instrumental activities of daily living, emotional support, communication, and coordination of care with other family members and healthcare providers [1].

The 2020 Lancet Commission report on dementia prevention, intervention, and care recommends attention to family caregivers because specific interventions aimed at caregivers have lasting effects on depression and anxiety symptoms, improve quality of life, are cost-effective, and could save resources [2].

It is estimated that nearly half of all caregivers providing assistance to older adults are caring for someone with dementia. Caregivers often cite love and a sense of duty as their motivations for taking on the responsibility of caring for a family member or friend living with dementia [3]. People with dementia require increasing levels of supervision and personal care as the disease progresses; as the symptoms of the person with dementia worsen, caregivers may experience greater emotional stress and depression, as well as new or exacerbated health problems [4]. Compared to caregivers of people without dementia, twice as many caregivers of people with dementia report significant emotional, financial, and physical difficulties. However, some caregivers find providing care to someone with cognitive impairment highly rewarding, and greater satisfaction in providing care to people with dementia is associated with greater emotional support from family and friends [3].

It is necessary to identify symptoms present in caregivers of patients with dementia, especially those symptoms related to a decline in quality of life. According to international statistics, nearly half of caregivers of people with dementia experience moderate loneliness, and 17.7% experience severe loneliness. Higher levels of stress and social isolation have been found to be related to loneliness [5]. The objective of this study was to identify the frequency and level of loneliness in caregivers of patients with dementia in the Colombian context, considering the negative impact of loneliness on caregivers' mental health.

Loneliness is often understood as the discrepancy between desired and perceived social contact. The UCLA Loneliness Scale conceptualizes loneliness as a unidimensional construct that can vary in frequency and intensity [6]. The use of scales in health allows for objectively measuring the presence and severity of certain constructs. In this case, the UCLA Loneliness Scale was used, which includes questions related to happiness when doing things alone, having someone to talk to, tolerance for loneliness, the perception of understanding from the environment, the need for someone to call or write, the feeling of being completely alone, the ability to approach others, the need for companionship, the ease of making friends, and the perception of being overlooked. Scores below 30 points are related to loneliness, with scores between 20 and 30 indicating moderate loneliness and scores below 20 indicating severe loneliness, according to validation studies of the scale in the Colombian population [7].

Materials and Methods

This study adopts an observational cross-sectional design aimed at exploring the frequency and level of loneliness among unpaid caregivers of patients diagnosed with dementia in a home care program in Bogotá, Colombia. The program served an average of 1,000 patients monthly. To be admitted to the home care program, patients must have a Barthel score of 40 or less; patients with dementia may belong to the chronic care program if the dementia is in a mild or moderate stage, while those with advanced dementia receive care through the palliative care program.

Given the exploratory nature of the study, an observational cross-sectional design was chosen. No sample size calculation was performed. Convenience sampling was used, including patients evaluated between March 1 and June 30, 2024. Inclusion criteria were being a family caregiver of a patient with dementia for one month or more, being over 18 years old, not receiving payment for caregiving, and agreeing to participate in the study. Caregivers of patients who could not be contacted, those with a diagnosis of mental illness, caregivers of deceased patients at the time of the survey, and those who did not wish to participate in the study were excluded. Each caregiver was asked to provide written consent to participate in the study. Participants were selected from the program's database and contacted by phone to present the study and request their participation. A visit was then scheduled to obtain informed consent, collect sociodemographic variables (including sex, education level, and occupation of the caregivers), administer the UCLA Loneliness Scale [7], the Barthel Index [8], the GDS classification for patients diagnosed with Alzheimer's disease [9], and ask questions about satisfaction with care and perceived emotional support.

The UCLA Loneliness Scale includes 10 questions with a 4-point Likert response option. It has been validated in Colombia for caregivers of chronic patients, with a content validity index for most items above 0.8. Regarding face validity, 86% or more of participants reported adequate understanding, recall, judgment, and appropriateness of the items, indicating acceptable content and face validity for use in this context [7]. The collected data were recorded in an electronic spreadsheet to facilitate subsequent analysis. No follow-up was conducted with participants after data collection.

No potential confounding variables or interactions were explored, and there was no loss of information.

Data analysis was performed through frequency calculations. Scores on the UCLA Loneliness Scale were classified considering that scores below 20 points indicate severe loneliness and scores between 20 and 30 points indicate moderate loneliness [7]. To evaluate the possible association of loneliness with the patient's clinical variables, the caregiver's sociodemographic variables, satisfaction with care, and perceived emotional support, the odds ratio (OR) was calculated between the group of caregivers with loneliness and the group without perceived loneliness.

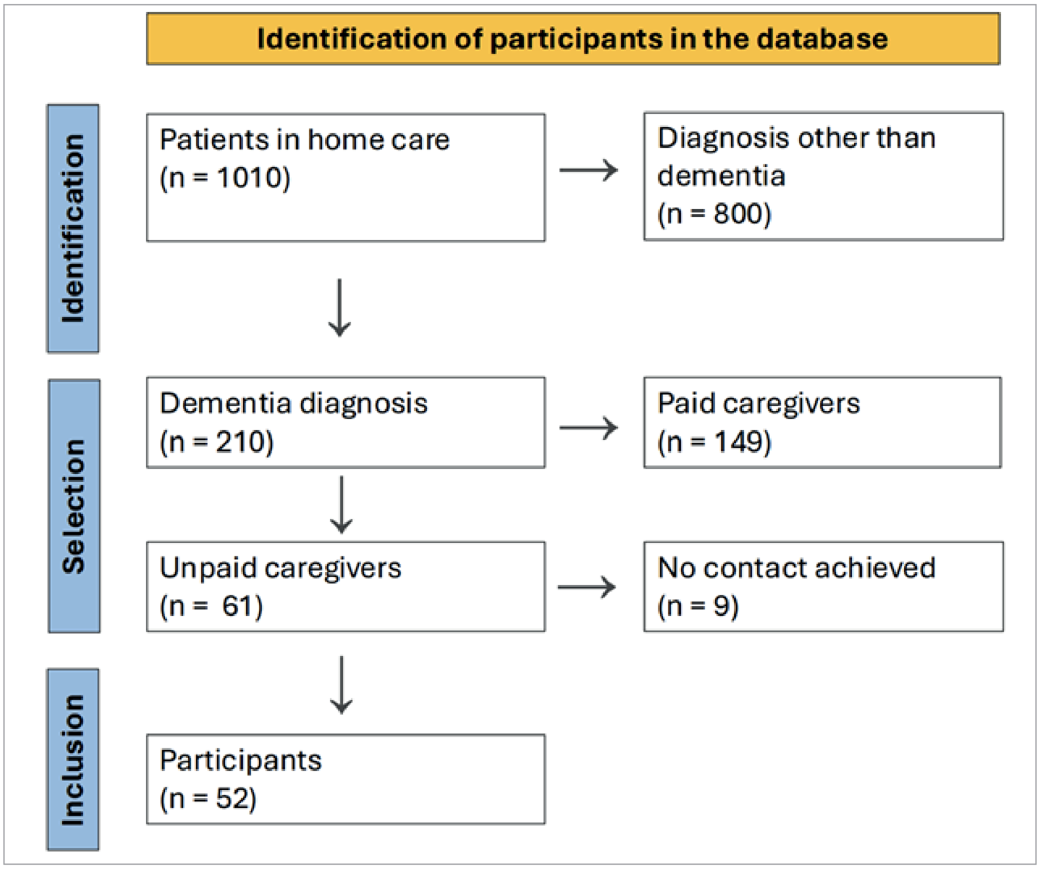

Figure 1. Recruitment Flowchart. Flow diagram for the identification, selection, and inclusion of participants

This study adheres to the recommendations for biomedical research of the World Medical Association's Declaration of Helsinki. Although it is a no-risk investigation, informed consent was obtained from all participants. The research protocol was presented and approved by the IPS Forja Empresas ethics committee.

Results

A total of 210 patients diagnosed with dementia were identified in the program, of which 61 had unpaid caregivers. It was not possible to contact 9 potential participants, so 52 caregivers were included. The recruitment flowchart of the participants can be seen in Figure 1, the sociodemographic characteristics of all caregivers are shown in Table 1, and those of the patients are shown in Table 2. The average age of the surveyed caregivers was 61 years (SD 10), while the patients they cared for had an average age of 85 years (SD 12) and presented severe functional dependence, with an average score of 23 (SD 19) on the Barthel Index. 88% of these patients were in a chronic home care program. 69% of the caregivers were children of the patients, and 79% were women. 50% of the caregivers had higher education, and 42% were unemployed. The predominant type of dementia was Alzheimer's, affecting 40% of the patients, with 72% having severe dementia. The distribution by dementia severity can be seen in Table 3. Unemployed, retired, and jobless caregivers dedicated themselves full-time to caring for the patient. On the other hand, employed and self-employed caregivers divided their time between work and caring for the patient with dementia.

Table 1. Description of the sociodemographic variables of the caregivers.

Variable	Category	n	%
Relationship	Daughter/son	36	69
	Wife/husband	11	21
	Sister/brother	2	4
	Stepdaughter/stepson	1	2
	Mother	1	2
	Son-in-law	1	2
Sex	Female	41	79
	Male	11	21
Schooling	Incomplete primary	2	4
	Complete primary	2	4
	Incomplete secondary	2	4
	Complete secondary	11	21
	Technical	9	17
	Superior	26	50
Occupation	Employed	5	10
	Unemployed	11	21
	Independent	5	10
	Pensioner	9	17
	Retired	22	42

The Global Deterioration Scale (GDS) classifies the severity of dementia in patients with Alzheimer's Disease. According to the score, it is categorized into stage 1 (normal), stage 2 (subjective memory complaint), stage 3 (mild cognitive impairment), stage 4 (mild dementia), stage 5 (moderate dementia), stage 6 (moderately severe dementia), and stage 7 (severe dementia).

Severe loneliness was experienced by 5.77% of caregivers (score less than 20 on the UCLA scale), and 26.92% experienced moderate loneliness (score between 20 and 30), as shown in Table 4. All caregivers reported being satisfied with the care they provided their relatives, and 71% felt that their family or friends provided the necessary emotional support. The sociodemographic variables of the caregiver that were analyzed were not associated with levels of loneliness. Being over 60 years old (OR: 0.75, 95% CI: 0.23-2.41, *p*= 0.629), being female (OR: 1.39, 95% CI: 0.32-6.05, *p*= 0.6669), being the patient's spouse (OR: 0.72, 95% CI: 0.16-3.16, *p*= 0.6669), having higher education (OR: 0.84, 95% CI: 0.26-2.68, *p*= 0.7676), or being economically active as an employee or self-employed (OR: 0.181, 95% CI: 0.021-1.562, *p*= 0.1200) were not associated with the prevalence of loneliness. Total functional dependence of the patient was more frequently associated with the prevalence of loneliness in caregivers (OR: 4.061, 95% CI: 1.16-14.15, *p*= 0.0278). However, no association was found between dementia severity and the perception of loneliness (OR: 3.44, 95% CI: 0.94-12.65, *p*= 0.0628). Regarding the perception of emotional support from family and friends, it was identified as a potential protective factor against loneliness (OR: 0.184, 95% CI: 0.05-0.67, *p*= 0.0104). Finally, satisfaction with care was not significantly associated with the prevalence of loneliness (OR: 0.493, 95% CI: 0.009-25.900, *p*= 0.7264).

Table 2. Description of the sociodemographic variables of the patients.

Variable	Category	Total		Dementia severity					
				Mild		Moderate		Severe	
		n	%	n	%	n	%	n	%
Program	Chronic	46	88	3	100	18	94.7	25	83.3
	Palliative	6	12	0	0	1	5.3	5	16.7
Dementia type	Alzheimer's disease	21	40	0	0	9	47.4	12	40
	Frontotemporal	1	2	0	0	1	5.3	0	0
	Vascular disease	7	13	0	0	2	10.5	5	16.7
	Brain trauma	2	4	0	0	1	5.3	1	3.3
	Parkinson's disease	6	12	1	33.3	1	5.3	4	13.3
	Multiple etiologies	6	12	0	0	3	15.8	3	10
Not specified		9	17	2	66.7	2	10.5	5	16.7

Table 3. Severity of dementia in patients with Alzheimer's Disease

Global Deterioration Scale	n	%
4	1	5
5	5	24
6	7	33
7	8	38

The Global Deterioration Scale (GDS) classifies the severity of dementia in patients with Alzheimer's Disease. According to the score, it is categorized into stage 1 (normal), stage 2 (subjective memory complaint), stage 3 (mild cognitive impairment), stage 4 (mild dementia), stage 5 (moderate dementia), stage 6 (moderately severe dementia), and stage 7 (severe dementia).

Scores below 30 points are associated with loneliness. A score between 20 and 30 is related to moderate loneliness, and a score below 20 points is associated with severe loneliness.

Discussion

It is striking that only 33% experienced moderate or severe loneliness, a finding that contrasts with other international studies reporting higher prevalences. According to a recent systematic review and meta-analysis, the pooled prevalence of loneliness in caregivers of patients with dementia is 50.8%, with studies reporting loneliness prevalences ranging from 16% to 72% [10]. These studies have been conducted in Europe, the United States, and Asia; however, this is the first study of its kind conducted in Colombia.

The average age of the surveyed caregivers was 61 years. It has been found that older adults caring for people with dementia have higher levels of stress, depression, and loneliness compared to those who are not caregivers. Loneliness is a fundamental factor in the direct mediation of perceived stress, which also contributes to it indirectly, given its relationship with depressive symptoms, which are also associated with the development of stress [11].

Although a significant proportion of the surveyed caregivers were older adults, only 6% experienced severe loneliness, and 27% experienced moderate loneliness, with 71% feeling that their family or friends provided the emotional support they required. The perception of social support could partly explain the lower proportion of caregivers experiencing moderate and severe loneliness, as adequate social support has been described as a protective factor against the development of loneliness and depression in caregivers. It is also related to a positive perception of aging and improves the quality of life [12]. In this sense, patients in home care programs can establish trusting relationships with the care team by getting to know the patient-family unit closely. Additionally, it contributes to a more positive perception of aging, thanks to the information and training provided by the home care team [13]. This expands the caregiver's support network and may be related to the perceived social support among the caregivers who participated in the study.

In addition to the above, all caregivers reported feeling satisfied with providing care to their loved ones. This could also be another protective factor against loneliness, as the relationship between levels of caregiving satisfaction and the perception of well-being and quality of life has been reported [14,15].

Considering that home care in Colombia is intended for older adults confined to their homes due to functional or social problems, as well as high-risk elderly individuals, the home care health team plays a fundamental role in expanding the social support network and strengthening the caregiver's

Table 4. Results of the UCLA scale.

UCLA scale score	N	%	95% confidence interval
<20	3	5.77	0.00-12.11
20-30	14	26.92	14.87-38.98
>30	35	67.31	54.56-80.06

knowledge about the activities to be performed with the patient. This can contribute to greater satisfaction in providing care to their loved ones, knowing that they have the continuous support of the health team, which offers not only medical but also social, spiritual, and psychological support to both the patient and the family during the illness and grieving process [16].

Finally, it was found that 79% of the caregivers were women, a finding consistent with the literature. It is described that, traditionally, most family caregivers are women in most cultures, and they tend to provide care for longer periods than men. Additionally, traditional gender roles condition women to assume family and caregiving responsibilities, meaning that caring for a family member with dementia can conflict with caring for their own family, constituting an additional source of stress and overload [17,18]. Despite this, all female caregivers in our study reported being satisfied with their caregiving role.

Limitations

The study's sample size was limited, and the sample was recruited by convenience, which poses a risk of selection bias in this study. Most participants were caring for a person with advanced dementia, so the results may not be representative of caregivers of people with less advanced dementia. Despite the mentioned limitations, this is the first study of its kind conducted in Colombia, contributing to the expansion of local literature regarding the mental health and quality of life of caregivers of patients with dementia, thus providing a contribution to the diagnosis of the current situation in our context. The prospective design of the research helps mitigate recall bias; additionally, given the primary source of information, the data are grounded in the usual scenario of patients and families receiving home care in Bogotá, Colombia.

Most participants were women, and while the representation of women is consistent with the higher frequency of caregiving roles performed by women, there is an underrepresentation of men. However, considering that women provide care more frequently than men, the results are applicable and useful given the primary caregiver role traditionally assigned to women due to traditional gender roles [17,18].

In this study, no analysis of confounding variables was performed, constituting another limitation of the study.

Conclusions

Caring for people with dementia becomes more demanding as the disease progresses and is associated with increased emotional stress and depression in caregivers. Higher levels of stress and social isolation are related to the perception of loneliness, which is associated with a decline in the caregiver's quality of life. In this study, a lower prevalence of loneliness was found among caregivers of patients with dementia compared to international literature. Most participants felt that their family or friends provided the emotional support they required, and all were satisfied with the care they provided to their loved ones. Emotional support from family and friends could be related to lower levels of loneliness. Further studies are needed to evaluate the intervention of these factors as determinants of quality of life in caregivers of patients with dementia.

Referencias

1. Gaugler JE, Kane RL, Kane RA. Family care for older adults with disabilities: toward more targeted and interpretable research. Int J Aging Hum Dev. 2002; 54(3): 205-31. doi:10.2190/FACK-QE61-Y2J8-5L68.Gaugler JE, Kane RL, Kane RA. Family care for older adults with disabilities toward more targeted and interpretable research. Int J Aging Hum Dev. 2002;54(3):205–231. doi: 10.2190/FACK-QE61-Y2J8-5L68. [PubMed] [CrossRef] [Google Scholar]

2. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020; 396(10248): 413-446. doi: 10.1016/S0140-6736(20)30367-6.

3. The Alzheimer's Association. Alzheimer's disease facts and figures. Alzheimers Dement. 2021; 17(3): 327-406. doi: 10.1002/alz.12328

4. Lei L, Maust DT, Leggett AN. Functional decline over time and change in family and other unpaid care provided to community-dwelling older adults living with and without dementia. J Gerontol B Psychol Sci Soc Sci. 2023; 78(10): 1727-1734. doi: 10.1093/geronb/gbad107.

5. Victor CR, Rippon I, Quinn C, Nelis SM, Martyr A, Hart N, et al. The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. Aging Ment Health. 2021; 25(7): 1232-1238. doi: 10.1080/13607863.2020.1753014

6. Ong AD, Uchino BN, Wethington E. Loneliness and Health in Older Adults: A Mini-Review and Synthesis. Gerontology. 2016; 62(4): 443-9. doi: 10.1159/000441651

7. Carreño-Moreno S, Chaparro-Díaz L, Cáliz Romero NE, Rivera Romero N. Validez de la escala de soledad UCLA en cuidadores de pacientes crónicos en Colombia. Investigación Enfermería Imagen Desarrollo. 2022; 24. doi: 10.11144/Javeriana.ie24.vesu

8. Mahoney FI, Barthel DW. Functional evaluation: The Barthel Index. Md State Med J. 1965; 14: 61-5

9. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry. 1982; 139(9): 1136-9. doi: 10.1176/ajp.139.9.1136

10. Liao X, Wang Z, Zeng Q, Zeng Y. Loneliness and social isolation among informal carers of individuals with dementia: A systematic review and meta-analysis. Int J Geriatr Psychiatry. 2024; 39(5): e6101. doi: 10.1002/gps.6101

11. Peavy G, Mayo AM, Avalos C, Rodriguez A, Shifflett B, Edland SD. Perceived stress in older dementia caregivers: mediation by loneliness and depression. Am J Alzheimers Dis Other Demen. 2022; 37: 1-8. doi:10.1177/15333175211064756.

12. Musich S, Wang SS, Kraemer S, Yeh CS. The association of psychological protective factors with caregiver mental health outcomes. Geriatr Nurs. 2023; 50: 174-180. doi:10.1016/j.gerinurse.2023.01.020

13. Ayuso MS, Rodríguez ÁN. Valoración de enfermería para la evaluación de sobrecarga del cuidador en atención domiciliaria. Horizonte Sanitario. 2018; 17(3): 179-87. DOI: 10.19136/hs.a17n3.2147

14. National Academies of Sciences, Engineering, and Medicine. Social isolation and loneliness in older adults: opportunities for the health care system. Washington, DC: The National Academies Press; 2020: 77-78. Doi: 10.17226/25663

15. Cejalvo E, Martí-Vilar M, Merino-Soto C, Aguirre-Morales MT. Caregiving role and psychosocial and individual factors: A systematic review. Healthcare (Basel). 2021; 9(12): 1690. doi: 10.3390/healthcare9121690

16. Parra OLM. La atención domiciliaria en los sistemas de salud de México, Argentina, Brasil y Colombia. Trabajo de grado. Universidad de Ciencias Aplicadas y Ambientales: Bogotá, Colombia; 2017.

17. Schaffler-Schaden D, Krutter S, Seymer A, Eßl-Maurer R, Flamm M, Osterbrink J. Caring for a relative with dementia: Determinants and gender differences of caregiver burden in the rural setting. Brain Sci. 2021; 11(11): 1511. doi: 10.3390/brainsci11111511

18. Poisson VO, Poulos RG, Withall AL, Reilly A, Emerson L, O'Connor CMC. A mixed method study exploring gender differences in dementia caregiving. Dementia (London). 2023; 22(8):1862-1885. doi:10.1177/14713012231201595