

Loneliness, Anxiety, Depression, and Adoption of the Role of Caregiver of Older Adults with Chronic Diseases during COVID-19

Ana Laura Carrillo-Cervantes

<https://orcid.org/0000-0003-2920-4675>.
Universidad Autónoma de Coahuila, Mexico.
anacarrillo@uadec.edu.mx

✉ **Isaí Arturo Medina-Fernández**

<https://orcid.org/0000-0003-2845-4648>.
Universidad Autónoma de Coahuila, Mexico.
isai-medina@uadec.edu.mx.

Sonia Carreño-Moreno

<https://orcid.org/0000-0002-4386-6053>.
Universidad Nacional de Colombia, Colombia.
spcarrenom@unal.edu.co

Lorena Chaparro-Díaz

<https://orcid.org/0000-0001-8241-8694>.
Universidad Nacional de Colombia, Colombia.
olchapparod@unal.edu.co

Luis Carlos Cortéz-González

<https://orcid.org/0000-0002-1655-0272>.
Universidad Autónoma de Coahuila, Mexico.
lucortezg@uadec.edu.mx

Josué Arturo Medina-Fernández

<https://orcid.org/0000-0003-0588-9382>.
Universidad Autónoma del Estado de Quintana Roo,
Mexico.
josue.medina@uqroo.edu.mx

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Theme: Chronic Care.

Contribution to the subject: The COVID-19 pandemic has made some people perform other roles, such as caregivers of older adults with chronic conditions, which impacts mental and social health, such as anxiety, depression, and loneliness, and in turn has repercussions on the role of caregiver. Good adoption will allow for adequate development of such a role; however, this research identified that, as a global strategy to prevent COVID-19 infection, social distancing causes profound loneliness but allows caregivers to feel safe and free from risks to themselves and the people cared for when carrying out their activities, being a predictive variable for satisfactory adoption of the role.

Abstract

Objective: To determine the effect of loneliness, anxiety, and depression on adopting the role of caregiver of older adults with chronic conditions in a sample of Mexican caregivers during the COVID-19 pandemic. **Materials and method:** Predictive and correlational design. The study was conducted with 157 caregivers through the dyad characterization scale, the HADS scale, the UCLA scale, and the Caregiver role adoption scale. The analysis used descriptive and inferential statistics. **Results:** Most participants were female, with a mean care time of seven months. Mostly, the caregivers have anxiety as a clinical problem (27 %), doubtful depression (14.9 %), profound loneliness (66.2 %), and satisfactory adoption of the role (71.2 %). We found that the more significant the role of adoption, the lower the anxiety, depression, and loneliness levels ($p < .05$). The psychosocial factors, the age of the person cared for, the age of the informal caregiver, and the care time explained 36 % of the variance in role adoption ($F = 13.12; p < .01$), with loneliness as a predictive variable. **Conclusion:** The COVID-19 pandemic has impacted the caregivers' mental health and caused profound loneliness, the latter being a predictor for adopting the role.

Keywords (Source: DeCS)

Anxiety; depression; loneliness; caregivers; coronavirus infections.

4 Soledad, ansiedad, depresión y adopción del rol de cuidador de adultos mayores con enfermedad crónica durante la covid-19

Resumen

Objetivo: determinar el efecto de la soledad, la ansiedad y la depresión sobre la adopción del rol cuidador de adultos mayores con enfermedad crónica en una muestra de cuidadores mexicanos durante la pandemia de la covid-19. **Materiales y método:** diseño correlacional predictivo. Se realizó el estudio en 157 cuidadores mediante la encuesta de caracterización de la diada, escala HADS, escala UCLA y escala adopción del cuidador. El análisis fue con estadística descriptiva e inferencial. **Resultados:** la mayoría de los participantes fueron mujeres, con un tiempo medio de cuidados de siete meses. Los cuidadores en su mayoría tienen ansiedad como problema clínico en un 27 %, depresión dudosa con un 14,9 %, soledad severa con un 66,2 % y adopción satisfactoria del rol en el 71,2 %. Se encontró que a mayor adopción del rol, menor ansiedad, depresión y soledad ($p < 0,05$). Los factores psicosociales, la edad de la persona receptora de cuidado, la edad del cuidador informal y el tiempo de cuidado explicaron un 36 % de la varianza de la adopción del rol ($F = 13,12$; $p < 0,01$), siendo variable predictora la soledad. **Conclusión:** la pandemia de la covid-19 ha ocasionado un impacto en la salud mental y la soledad severa de los cuidadores, siendo esta última un predictor de la adopción del cuidador.

Palabras clave (Fuente: DeCS)

Ansiedad; depresión; soledad; cuidadores; infecciones por coronavirus.

Solidão, ansiedade, depressão e adoção do papel de cuidador de idosos com doença crônica durante a COVID-19

Resumo

Objetivo: determinar o efeito da solidão, ansiedade e depressão na adoção do papel de cuidador de idosos com doença crônica em uma amostra de cuidadores mexicanos durante a pandemia de COVID-19.

Material e método: desenho correlacional preditivo. O estudo foi realizado com 157 cuidadores utilizando a pesquisa de caracterização da díade, a escala HADS, a escala UCLA e a escala de Adoção do papel de cuidador. A análise realizou-se com estatística descritiva e inferencial. Resultados: a maioria dos participantes era do sexo feminino, sendo o tempo médio de atendimento de sete meses. A maioria dos cuidadores apresentou ansiedade como problema clínico (27%), depressão duvidosa (14,9%), solidão severa (66,2%) e adoção satisfatória do papel (71,2%). Constatou-se que quanto maior a adoção do papel, menor o índice de ansiedade, depressão e solidão ($p < 0,05$). Os fatores psicossociais, a idade da pessoa que recebe os cuidados, a idade do cuidador informal e o tempo de cuidado explicaram 36% da variância na adoção do papel ($F = 13,12$; $p < 0,01$), sendo a solidão variável preditora. Conclusão: a pandemia da COVID-19 tem impactado a saúde mental e a solidão severa dos cuidadores, sendo esta última uma variável preditora da adoção do papel de cuidador.

Palavras-chave (Fonte: DeCS)

Ansiedade; depressão; solidão; cuidadores; infecções por coronavírus.

Introduction

The world faces the challenge imposed by the increased demand for family care. In the case of Mexico, having a non-communicable disease and aging are the leading causes of dependence and, consequently, the ones that condition the need for care. In 2018, nearly 7.8 % of the total Mexican population was over 60 years old (1), which has implied a rapid growth of the aged population amid economic hardships and continuous dependence on families; furthermore, it is expected that the proportion will triple and reach 23 % by 2050. In turn, although mainly affecting the aged population, non-communicable diseases represent a general problem that, by 2017, had caused approximately 80 % of the overall mortality in Mexico. Such being the case, aging and 9.4 % overall prevalence of Type II Diabetes Mellitus (2), as a result of the fact that 71.3 % of the population is overweight and obese, pose a challenge for the health system, especially the high demand of care to be provided by informal caregivers (3).

Currently, the COVID-19 pandemic is added as a new challenge in increasing caregivers' demand. In Mexico, the reported cases are 2.46 million people and 231,000 deaths, whereas 71,454 infected individuals and 6,344 deaths are reported in Coahuila (4). This increase in cases generates a series of psychological and social responses in people, as they are generally subjected to chronic stress due to social isolation, uncertainty, concern about the risk of death, and complications due to the disease in the people cared for. In most cases, this situation exerts considerable effects on physical and mental health (5, 6).

Consequently, social isolation resulted in the non-activity of the therapeutic teams, as the care services were suspended during the quarantine, which had repercussions on the caregivers' tasks and limited their free time. It doubles the stress related to caring for people with chronic diseases in a context marked by fear of infection, generating in some caregivers more anxiety and less tolerance towards the people cared for (7).

According to recent studies, family caregivers of people with chronic conditions requiring long-term care are mainly women aged 40 to 60, with a higher proportion of daughters and wives (8–10). Frequently, family caregivers are members of the family group who take on the role suddenly due to the dependence condition of the person cared for. They are responsible for providing direct care related to feeding, bathing, getting dressed, mobilization, medication administration, and handling of devices, among other activities, in addition to providing emotional and spiritual support to the person cared for and, of course, making decisions and solving care-related problems (11, 12). Therefore, becoming the family caregiver of a dependent person is assuming a new role, a transition that implies new functions and, very probably, with a need for support that leads caregivers to search for training and knowledge to adopt the role with dexterity (13). Consequently, satisfactory adoption of the role im-

plies learning to perform the tasks inherent to it; in other words, provision of direct care and care management actions, such as organizing the environments, agendas, resources, and support networks to ease the performance of the role. These conditions favor suitable responses to the role, matching the caregivers' burden and quality of life (14).

Regarding the responses to the caregiver role, the literature reports several ones that can be classified as positive or negative, among which loneliness, anxiety, and depression are the most known. A study conducted in Sweden and Italy (15) reported a high prevalence of anxiety and depression in caregivers of older adults with dementia, with the following factors related to their higher prevalence: female gender, lacking family support or care takeover, not having any additional occupation other than that of caregiver, and inadequate behaviors of the subject cared for. In addition, the study pointed out that more hours of daily care and being aged between 40 and 54 years old were predictive variables for anxiety and depression symptoms. Anxiety and depression are such prevalent and complex problems in the caregivers that even studies conducted with caregivers of cancer patients have revealed higher scores in these variables compared to the patients themselves; they even triple the anxiety and depression levels compared to the people cared for (16). However, anxiety and depression are not independent variables, as the literature shows a correlation between them; anxiety is a predictor of depression. In combination, both are variables associated with a more significant burden and lower quality of life in the caregiver (17, 18).

Regarding loneliness, it is a prevalent phenomenon not only in the dependent aged population but also in their family caregivers, who often state that they perform their roles marked by loneliness and social isolation (19). A study conducted in Spain (20) with caregivers of people with dementia revealed prevalence values between 25 % and 30 % for loneliness and that family dysfunction, lower social support, and fewer leisure activities were related to its higher prevalence. In addition, maladaptive thoughts and behaviors associated with the cultural environment, such as the belief that care issues must be solved inside the house and that a good caregiver does not ask for help, negatively influence the perception of loneliness. Furthermore, the evidence supports the theory that loneliness might play a mediating role between that of the caregiver and depression symptoms, which urges us to continue studying these variables together and to determine their relationship dynamics aiming to propose interventions that mitigate their effects on family caregivers of dependent people (21).

The objective of this study was to determine the effect of loneliness, anxiety, and depression on the adoption of the role of caregivers of older adults with chronic conditions in a sample of Mexican caregivers during the COVID-19 pandemic.

Materials and methods

Design

According to Burns and Grove's proposal, this study is classified as descriptive, correlational, predictive, and cross-sectional (22). It was conducted during the first half of 2021 in Saltillo, Coahuila, Mexico.

Sample

With the aid of the G Power program (23), a sample size of 112 family caregivers was calculated, considering a 0.5 probability of type 1 error, 90 % power ($1-\beta = 0.9$), and size effect of 0.3. The latter was considered due to findings reported in previous studies about the correlation between loneliness, anxiety, and depression (21). The sample collected consisted of 157 family caregivers, a sufficient number according to prior calculation.

For study viability purposes, purposeful sampling was conducted, including family caregivers aged at least 18 in the research and those who had performed such roles for a minimum of three months and self-declared as primary family caregivers. In addition, Pfeiffer's test (24) was used to confirm that the participants had their mental state preserved.

Data collection

Data collection was conducted from January to June 2021, considering that, in Mexico, aged people and their caregivers were then in confinement, and, given the limitations associated with the COVID-19 pandemic, the data were collected through Google surveys. The variables to be measured, their instruments, and the psychometric properties are presented below.

Characterization of the dyad

It was carried out based on the dyad characterization survey proposed by Chaparro and Cols (25). This survey includes 42 items investigating the sociodemographic profile and the care time in hours and months, in addition to the self-perception about the impact on the care provided. The survey is validated in Spanish for the Colombian context, with good content validity tests and CVR values above 0.7 reported for all the items. The research team performed a review and semantic adjustment of the items for this study. No difficulties associated with non-understanding items were detected during the administration of this survey to the study sample.

Anxiety and depression

They were assessed using the HADS scale for anxiety and depression (26). Such instrument has seven items that assess anxiety and

another seven for depression, measuring the variables using a Likert-type scale from 0 to 3 with 21 points as its maximum possible score. In terms of reliability, the instrument's Cronbach alpha is 0.83. The scale can be self- or hetero-applied, considering that the higher the score, the higher the anxiety and depression levels. In addition, it has cutoff points to classify the variables into levels: normal, from 0 to 7 points; doubtful, from 8 to 10 points; and an indication of a clinical problem with scores above 10 points.

Loneliness

It was measured with the University of California in Los Angeles (UCLA) scale (27). This questionnaire can be self- or hetero-applied and consists of ten questions. In terms of reliability, the internal consistency of the questionnaire has a Cronbach alpha of 0.94. In order to interpret the score, it should be considered that the higher it is, the lower the loneliness level; therefore, there is evidence of profound loneliness if the person reports 19 or fewer points, of moderate loneliness if 20-30 points are reported, and of no anxiety, if the patient reports at least 31 points.

Adoption of the caregiver role

It was assessed with the Caregiver role adoption scale (14). This instrument assesses the role transition and has diverse construct validity evidence for three factors or dimensions: responses, organization, and role tasks. Regarding reliability, the instrument's internal consistency has a Cronbach alpha of 0.8 or higher in the full scale and the subscales. The instrument can be self- or hetero-applied and includes the following strata: insufficient adoption of the role, 22-60 points; basic adoption of the role, 61-77 points; and satisfactory adoption of the role, 78-110 points.

Ethical considerations

Participation in this study was voluntary, and acceptance to participate was validated through an informed consent filled out electronically using a Google form in which the data were collected. This form did not allow progressing with the questions if such confirmation was not previously made, concluding data collection if no consent to participation was provided. The study was endorsed by the Ethics and Research Committee of the Nursing School belonging to Universidad Autónoma de Coahuila.

Data analysis

It was performed with the SPSS statistical package, version 24. The qualitative variables, including nominal and ordinal ones, were analyzed through the distribution of absolute and relative (proportions) frequencies. Statistical data such as mean, standard deviation, minimum and maximum were used, building 95 % confidence intervals (95 % CIs) to analyze the continuous quantitative variables. In addition, an analysis was performed with Pear-

son's correlation coefficient to explore the correlations, with prior adherence to the requirements regarding fit to the standard model or evidence of a size effect below 0.20 (28). Finally, a multiple linear regression model was prepared to adopt the caregiver role.

Results

A total of 157 family caregivers with a mean age of 45 years old ($SD = 13.75$) were included, primarily female (75.2 %, $f = 118$), married, and homemakers (48.4 %, $f = 76$), with pre-university schooling level (42.7 %), and seven months as mean care time. Regarding the characteristics of the people cared for, their mean age is 62 years old, and they are mostly the caregivers' mothers (51.6 %), with Elementary School as the most prevalent schooling level (42 %, $f = 63$), no partner (49.68 %, $f = 78$), and needing help to perform activities requiring mobility (60.5 %, $f = 95$) and activities associated with eliminations (28.7 %, $f = 64$). In most cases, the person cared for has only one caregiver (56.76 %, $f = 89$). The sociodemographic characteristics and profiles of the caregivers are presented in Table 1.

Table 1. Sociodemographic variables of the informal caregivers and the older adults cared for

Characteristics of the informal caregivers	Fr	%	Characteristics of the people cared for	Fr	%
Gender			Gender		
Female	118	75.2	Female	86	54.8
Male	39	24.8	Male	71	45.2
Marital status			Marital status		
Single	33	21	Single	49	31.2
Married	76	48.4	Married	59	37.6
Separated	15	9.6	Separated	10	6.4
Widowed	5	3.2	Widowed	30	19.2
Consensual union	28	17.8	Consensual union	9	5.7
Occupation			Occupation		
Household chores	76	48.4	Household chores	71	45.2
Employee	38	24.2	Employee	18	11.5
Self-employed	21	13.4	Self-employed	20	12.7
Student	8	5.1	Student	8	5.1
Other	14	8.9	Unemployed	26	16.6
			Retiree	24	14
Schooling			Schooling		
Elementary School	33	21	Elementary School	63	42
High School	19	12	High School	23	14.6
Pre-University Level	67	42.7	Pre-University Level	44	28.1
Higher Education	38	24.2	Higher Education	18	11.5
Person cared for			Perception of burden		
Mother/Father	81	51.6	Very high	23	14.6
Spouse	30	19.1	High	41	26.1
Friend	11	7	Moderate	27	36.3
Grandfather/Grandmother	8	5.1	Low	36	22.9
Neighbor	7	4.5			
Son/Daughter	20	12.7			

$n = 157$; % = Percentage

Source: Own elaboration

Table 2 shows the values obtained in the variables of interest, noting that the ICs mostly perceive normal anxiety and depression levels, profound loneliness, and satisfactory adoption of the role during confinement due to COVID-19.

Table 2. Descriptive statistics of the variables of interest

Variables	Percentage	Mean	SD	95 % CI	
				Lower Limit	Higher Limit
HADS		22.70	4.12	22.03	23.38
Anxiety		7.35	4.44	6.63	4.56
Normal	55.4				
Doubtful	17.6				
Clinical problem	27				
Depression		4	3.50	3.43	4.56
Normal	80.4				
Doubtful	14.9				
Clinical problem	4.7				
Loneliness		32.56	7.93	31.27	33.85
No loneliness	8.8				
Moderate loneliness	25				
Profound loneliness	66.2				
Role		82.85	11.56	80.96	84.74
Insufficient adoption of the role	4.1				
Basic adoption of the role	24.7				
Satisfactory adoption of the role	71.2				

SD = Standard Deviation; CI = Confidence Interval.

Source: Own elaboration

Table 3 shows the values obtained in the correlations test. It was found that the higher the age of the people cared for, the lower the depression and anxiety levels in the ICs; also, the longer the care time, the higher the anxiety and depression levels.

The overall score for depression and anxiety was negatively correlated with the loneliness scale and the “Responses” dimension of the role scale, i.e., the higher the anxiety and depression levels, the higher the perception of loneliness and the lower the recognition enjoyed by the ICs for their activities.

Likewise, the higher the anxiety, depression, and loneliness levels, the greater the role adoption; in other words, the greater the task performance, response, and care organization. Finally, the lower the loneliness level, the more satisfactory the role adoption and its three dimensions.

Table 3. Correlation of the variables

	1	2	3	4	5	6	7	8	9	10
1. Age of the older adult	1		-0.195**							
2. Care time		1	0.163*							
3. HADS			1			-0.239**			-0.232**	
4. Anxiety				1		-0.393**	-0.302**	-0.194*	-0.349**	-0.182*
5. Depression					1	-0.339**	-0.339**	-0.307**	-0.286**	-0.248**
6. UCLA						1	0.573**	0.338**	0.645**	0.365**
7. Role							1			
8. Tasks								1		
9. Responses									1	
10. Organization										1

Note: ** = $p < .001$; * = $p < .05$. HADS = Hospital Anxiety and Depression Scale; UCLA = Loneliness Scale.

Source: Own elaboration.

The psychosocial factors, the age of the person cared for, the age of the informal caregiver, and the care time explained 36 % of the variance in adopting the role ($F = 13.12$; $p < .01$), with the perception of loneliness ($\beta = -0.147$) as a predictive factor.

Table 4. Multiple linear regression model to measure the predictors for adopting the role of caregiver

Variable	B	SD	B	t	P-value	95 % CI for Exp (β)	
						Lower	Higher
Anxiety	-0.015	0.230	-0.006	-0.067	0.947	-0.471	0.440
Depression	-0.015	0.230	-0.006	-0.067	0.093	-0.471	0.440
UCLA	-0.487	0.288	-0.147	-1.693	0.000	-1.056	0.082
Age of the person cared for	0.754	0.109	0.520	6.946	0.453	0.540	0.969
Age of the caregiver	0.034	0.045	0.051	0.752	0.411	-0.055	0.123
Time as a caregiver (months)	-0.047	0.058	-0.056	-0.824	0.311	-0.161	0.066

Note: DoF = Degrees of Freedom, F calc. = Snedecor's F-distribution, p = Significance Level, B= Beta, SD = Standard Deviation, t = Student's t-test.

Source: Own elaboration

Discussion

The current study allowed determining the effect of loneliness, anxiety, and depression on the adoption of the role of caregiver in a sample of Mexican caregivers during the COVID-19 pandemic. In such a sense, providing care during the pandemic is an action inherent to life, the result of a construction specific to each promotion and protection situation, and a consequence of external factors that can affect family care and health (29).

Feminization of care was found, with 75.2 %, a lower frequency than that reported in Medellín, Colombia, where 92.6 % frequency was found, or Argentina, where 70 % frequency of female gender was ver-

ified (30, 31). As already noted, women have been related to care, being something naturalized and deemed a moral obligation. The main consequences of such naturalization are the following: non-appreciation of care work, the persistence of marked gender stereotypes, and persistence of representing a caregiver's form of love and abnegation (32, 33).

On the other hand, we found that the mean care time was seven months, with the shortest period reported in two studies from Colombia, with mean values of 37 and 137 months, respectively (34, 35). The scarcity of health professionals and the reduced response to recurrent population consultations in health centers and hospitals during the pandemic made several people assume a new role: family care. The mean of months indicates the need to be a family caregiver during the COVID-19 pandemic; however, the time required for this transition is variable and depends on the nature and magnitude of the change. Therefore, it is frequent for family caregivers to take on the role in a short period, which does not allow them to reflect or question what they know, what they do not know, the burden it will represent for their lives, or even if they want to assume this role, as often there is no alternative in the face of this reality (13).

Likewise, in this study, the anxiety level found had a mean of 7.35 ($SD = 4.44$), while depression obtained a mean of 4 ($SD = 3.50$). The anxiety level reported in caregivers from Mexico City is lower, with a mean of 7.83 ($SD = 4.53$), whereas depression has a higher value: 5.85 ($SD = 5.27$) (36). Similarly, they were lower than the levels reported in Italy, as anxiety obtained a mean of 8.8 ($SD = 4.2$) and depression reached a value of 7.1 ($SD = 4.4$) (37). Anxiety and depression can result from the burden caused by care itself and the social isolation conditions imposed by COVID-19. During data collection, Mexico was under strict isolation, where the people cared for were only allowed to go out of their homes for emergencies. Along with this, there were restrictive measures for the general population, as access to public places was only allowed to one person per family, and there was a constant concern about the health status of relatives and higher mortality risk due to COVID-19 (38, 39).

Profound loneliness was found in 66.2 % of the caregivers participating in this study, a percentage higher than the one reported in Brazil, where 23.8 % of loneliness was found (40). This finding can be due to the data obtained in the current study, as they were collected during the confinement period. In addition, care cannot fall solely on one individual; it must be shared with the entire family because the burden and costs it generates are very high and can only be managed with the egalitarian and fair organization of family work (41). However, this organization was hindered by the global epidemiological situation, as one of the strategies for self-care and family care in the face of COVID-19 was reducing interaction with other relatives.

Another impact on the caregivers was the adoption of the role, which was satisfactory in 71.2 % of the cases. Given the need to provide care during the pandemic, informal caregivers assume the role, unaware of the burden it will represent in their lives (42). Coupled with the above, during the pandemic, caregivers might feel comfortable when providing care despite having to perform an increasing number of tasks, such as specific care measures and risk control for COVID-19 prevention.

We also found that the caregivers who acted as such for extended periods had higher anxiety and depression levels, which the caregiver role can explain. They undertake a large number of tasks that can place them in a situation of high vulnerability, such as negative affect states, which increase the risk of feeling emotionally trapped, even with feelings of guilt that can cause capitulation or inability to continue meeting their sick family member's needs (43).

However, when the anxiety and depression levels are high, there is a deeper perception of loneliness. This extended time devoted to caring for a family member constitutes a propitious reality for the caregivers to develop physical and mental health disorders, resulting from this responsibility and the high demand to care for another person without due training or the necessary support to do so (42).

It was identified that the higher the anxiety and depression levels, the greater the role adoption; it may be due to reflection by the caregivers, which emerges as time passes, as the caring role demands gradually come to light. They usually develop care skills and adequately take on new functions and roles despite their frequent concern regarding care and their activities (42).

It is important to note that role adoption increases as loneliness decreases because the family caregivers organize their role, knowing the support the care recipient needs and how they need it. However, although other actors such as the family and close people are involved, it is the family caregivers who decide to seek support, organize, and enliven the relationships with the people supporting them, seeking to maintain such aid active, in force, and motivated to carry out activities most appropriately (13).

In such a sense, loneliness, anxiety, depression, and care characteristics, such as the age of the person cared for, age of the caregiver, and care time, exert 36 % influence on the adoption of the role. That said, disease situations have a progression and are associated with the role of adoption and refinement of the care task phases, which, due to their mutual nature, allow growth of the individuals and the dyad. These relationships are modulated by time, family, social networks, and the context, which made most caregivers take on roles or accelerate their adoption due to the COVID-19 pandemic (44).

Far from being a simple redistribution of time and tasks, this new role exerts a significant effect on their livelihoods, considering that they not only had to face the mental health changes caused by this

health emergency, and that they needed to do so in isolation and far from their loved ones, but that they also have undergone changes in their roles (32).

Conclusion

Family care during confinement due to COVID-19 was mainly the responsibility of married women and homemakers who mainly cared for their parents. Normal anxiety and depression levels were prevalent, and the participants presented with moderate loneliness and satisfactory adoption of the caregiver role. Similarly, anxiety, depression, loneliness, age, and care time influence the adoption of the role by 36 %, with loneliness as a predictive factor.

Nursing professionals' intervention is necessary to improve the negative affect states, provide more outstanding social support from a comprehensive perspective, and always consider the characteristics of family care.

Conflicts of interest: The authors declare no conflicts of interest.

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