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Role adoption, anxiety, depression and loneliness in family caregivers of patients with chronic diseases

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Highlights: (1) More than half of the caregivers reported moderate or severe anxiety and loneliness. **(2)** Caregivers with low role adoption levels presented more anxiety, depression and loneliness. **(3)** Satisfactory adoption of the caregiver role reduces anxiety, depression and loneliness. **(4)** Role adoption should be intervened to reduce the impact on caregivers' mental health.

Objective: to describe and explore the relationship of loneliness, anxiety and depression with adoption of the caregiver role among individuals caring for people with chronic diseases in Colombia. **Methods:** this was an exploratory and cross-sectional study involving 960 primary caregivers of individuals with chronic diseases. We applied the Caregiver Role Adoption Scale, the University of California at Los Angeles Loneliness Scale, and the Anxiety and Depression Scale. Principal component and multiple correspondence analyses were performed for clustering. **Results:** among the participating caregivers, 40.8% reported experiencing depression, 59% reported anxiety, 54.6% reported moderate to severe loneliness, and 88.6% reported satisfactory adoption of the caregiver role. Caregivers who presented basic or insufficient role adoption levels tended to have higher scores for anxiety, depression and loneliness. **Conclusion:** adoption of the caregiver role is a mediator in the anxiety, depression and loneliness levels among caregivers. Strategies aimed at supporting caregivers should include training for the caregiver role to mitigate the negative impacts of anxiety, depression and loneliness.
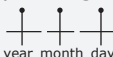
Descriptors: Chronic Disease, Caregivers; Anxiety; Depression; Loneliness; Role Playing.

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Introduction

Chronic diseases have been a prominent and pressing global concern for several decades[1]. Although substantial global efforts have been made, the results have been limited, primarily due to the weaknesses in registration and notification systems for these diseases. Available data indicate a concerning trend of increasing burden of diseases over the last three decades, with chronic diseases in older adults contributing significantly to these statistics[2]. This escalating burden and its underlying causes can be attributed to factors such as population aging, increased life expectancy at birth, and ongoing exposure to risk factors[2]. Some studies have shown that chronic non-communicable diseases (CNCDs) were responsible for 1.62 billion Disability-Adjusted Life Years (DALYs), with a substantial increase from 43.2% in 1990 to 63.8% in 2019[3]. As of 2019, CNCDs recorded an incidence of 13,100 million new cases, prevalence of 7,100 million cases, and 42 million deaths, representing an 18.5% increase when compared to the 2010 figures. In descending order, the diseases with the highest DALYs in 2019 were cancer, cardiovascular diseases, chronic respiratory diseases, digestive diseases, neurological disorders and mental disorders[2].

The global issue of CNCDs is undeniably significant, and efforts have primarily concentrated on assessing the extent of their burden. However, it is crucial to recognize that these diseases also exert far-reaching effects at other levels, particularly within families and on family caregivers[4]. The progressive functional decline and multidimensional dependence resulting from CNCDs oftentimes require the designation of a family caregiver. This is particularly common in regions like Latin America, characterized by low- and middle-income countries, where patient care remains predominantly a family responsibility[5]. Family caregivers find themselves thrust into their role due to unforeseen circumstances, oftentimes lacking sufficient preparation for the complex care required in various settings, including the home environment. They must assist with basic activities of daily living, administer medications, manage invasive devices, coordinate medical appointments, make crucial decisions and address various health-related challenges concerning the patient[6].

Compounded by the context marked by social isolation and limited support within which caregivers operate, the substantial caregiving responsibilities involved in caring for individuals with CNCDs exert detrimental effects on their well-being. Notably, anxiety and depression are extensively documented outcomes in the literature[7]. A meta-analysis comprising 93 studies on caregivers of dependent aged individuals revealed high prevalence of depression in this caregiving population. Moreover, it identified a correlation between high levels of depressive symptoms in informal caregivers and reduced social support levels, encompassing both perceived and received dimensions[7].

Loneliness is prevalent among caregivers of individuals with CNCDs, with studies indicating that both the objective and subjective stress associated with daily patient care directly contribute to feelings of loneliness. In turn, these feelings are linked to an increased manifestation of depressive symptoms[8]. In a study conducted in the United Kingdom[9], it was found that 43.7% of the caregivers reported experiencing moderate loneliness, whereas 17.7% reported severe loneliness. Family caregivers frequently face a reduction in their personal space and in their opportunities for social interaction. They oftentimes grapple with losses and deprivations within their interpersonal relationships and are frequently distanced from their social circles due to their full-time commitment to caregiving. These circumstances expose them to heightened feelings of loneliness[10].

Some studies have documented the relationship between anxiety and depression, with loneliness frequently playing a mediating role. However, our understanding of how caregiver role adoption contributes to the development of these conditions remains limited[11]. This study aims at assessing anxiety, depression, loneliness and caregiver role adoption in family caregivers of individuals with CNCDs. A number of research studies suggest that caregivers who are more adept at fulfilling their caregiving role and feel empowered in it are better equipped to use available resources, such as social and family support. They may also engage in better self-care practices, potentially leading to reduced loneliness and fewer psychological issues among caregivers[12]. The primary objective of this study is to describe and explore the relationship between loneliness, anxiety, depression and adoption of the caregiver role among individuals caring for people with chronic diseases in Colombia.

Method

Type of study

A descriptive, exploratory, and cross-sectional study adhering to the recommendations outlined in

the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional studies[13].

Data collection setting

The study was conducted in Bogotá, Cundinamarca (Cund.), Colombia, among family caregivers who were either enrolled in or attended family caregiver support programs, associations, and community organizations devoted to caregivers of individuals with chronic diseases.

Period

The study was conducted from the second half of 2020 to the second half of 2021.

Population and sample

This study included family caregivers of individuals with chronic diseases in Colombia through non-random sampling. The eligible participants were caregivers aged at least 18 years old, acting as the primary family caregiver for the patient, possessing intact mental status (Pfeiffer score of 0 to 2 errors), and living in Colombia. Caregivers who were hired professionals were excluded.

In total, the researchers compiled a list of 1,480 potential participants. Along with the study title and objectives, invitations to participate were sent to them via e-mail or telephone messages. The individuals who expressed interest and contacted the researchers underwent verification of the inclusion criteria, received detailed explanations about the study objectives, and were screened to determine whether they self-reported proficiency in the information and communication technologies required for completing the online form.

Procedures for data collection

Data collection involved hetero-administered procedures, which included conducting telephone interviews with willing participants and distributing online surveys through Google Forms for those who self-reported high technological proficiency. To mitigate potential biases, meticulous setup options were implemented in Google Forms to prevent missing data. An introductory section was provided as an example of correct form completion to minimize errors and enhance data accuracy. Additionally, the research assistants received extensive training not only in accurately applying questionnaires but also in creating a trustworthy atmosphere. This approach

aimed at encouraging the participants to respond honestly, fostering an environment conducive to open communication. Information was collected from a total of 672 caregivers through the online form and 288 caregivers via telephone interviews.

Instruments for data collection

The sample was characterized using a survey designed to assess family caregivers and patients[14]. This questionnaire encompassed details pertaining to the demographic, social and clinical aspects both of caregivers and of individuals with CNCDs. It included questions regarding factors such as age, gender, schooling level, time as caregiver, and level of support received in caregiving.

The role adoption assessment resorted to the Caregiver Role Adoption Scale, which measures the transition into the caregiving role of individuals with chronic diseases. This questionnaire was developed based on Meleis' Theory of Transitions, specifically tailored to the caregiving context[15]. Furthermore, it underwent validation in a population of caregivers of individuals with CNCDs in Colombia[15]. The psychometric properties of this instrument were evaluated for construct validity using Varimax, Quartimax and Equimax rotation tests in conjunction with a principal component extraction method. These analyses revealed a three-factor structure: a) Role Responses (items 1 to 7); b) Role Organization (items 8 to 15); and c) Role Tasks (items 16 to 22). The Cronbach's alpha coefficient for the total scale was above 0.8. The questionnaire comprises 22 items, each answered on a Likert-type response scale from 1 to 5. For interpretation purposes, scores within the range of 22 to 60 points indicate insufficient role adoption, scores between 61 and 77 denote basic adoption, and scores between 78 and 110 mean satisfactory adoption of the caregiver role[15].

Loneliness was assessed using the University of California at Los Angeles (UCLA) Loneliness Scale[16], which consists of ten questions. This scale presents a one-factor structure, analyzed through Varimax rotation with an explained variance of 71.6%. Its Cronbach's alpha coefficient is 0.94. In its validated Spanish version, tested in an adult population[16], lower scores indicate greater loneliness. However, for statistical analysis in this study, the item scores were inverted, meaning that higher scores now represent higher loneliness levels. Consequently, severe loneliness is defined as 31 or more points, moderate loneliness falls within the range of 20 to 30 points, and no loneliness corresponds to scores below 20 points.

Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS)[17], which comprises 14 items: seven devoted to measuring anxiety and the other seven for depression. This scale has been employed in community settings to assess these constructs and has shown satisfactory sensitivity (ranging between 0.74 and 0.84) and specificity (from 0.78 to 0.8). Examined within a similar population of adult patients, the psychometric properties of the scale indicate adequate construct validity, featuring a two-factor structure that explains 44.84% of the variance and internal consistency with a Cronbach's alpha coefficient of 0.85. To interpret the scale, scores between zero and seven points suggest normal state (no symptoms), scores between 8 and 10 indicate doubtful status, and scores equal to or greater than 11 mean clinical concern related to anxiety and depression.

Data treatment and analysis

The information gathered was organized in a Microsoft Excel spreadsheet and subjected to analysis using the R program. The qualitative variables (both nominal and ordinal) were assessed by calculating counts and proportions, whereas the primary variables had their ranges examined.

The quantitative variables underwent the following analyses: a) The characterization variables were evaluated using mean and standard deviation; b) The loneliness, anxiety, depression and role adoption scores were examined in terms of proportions; and c) Multivariate cluster analysis was performed employing principal component and cluster techniques to explore interrelationships among the study variables. Statistical significance was determined for values with a p-value below 0.05.

Ethical aspects

This study was approved by the Ethics Committee of the Nursing School at the National University of Colombia (AVAL-028-2019). Before participating in the study, the family caregivers provided their virtual informed consent by signing it.

Results

A total of 960 family caregivers answered the questionnaires. They were predominantly female (85%), with a mean age of 50.47 years old. Most of them were married (35.63%), engaged in house chores (58%) and had a low socioeconomic status (86.87%). Of the caregivers, 47.6% were children of the patients with CNCDs, 79.9% had been caregivers since the time of diagnosis, and 55.1% perceived their relationship with their relative as very good. Table 1 provides a detailed characterization of the caregivers.

Regarding the individuals with CNCDs, it was observed that they were predominantly female (61.35%) and that their mean age was 67.92 years old (Standard Deviation [SD] = 20.45). Among them, 50% were pluripathological patients, with a mean of 10.97 (SD = 11.55) years since their diagnosis. Furthermore, 55.42% of the patients had a single caregiver who devoted a mean of 16.97 hours a day to caregiving (SD = 8.38).

Most of the family caregivers participating in the study obtained satisfactory scores in role adoption. When the doubtful and clinical problem scores were combined, depression and anxiety had 40.8% and 58.9% prevalence, respectively. On the other hand, loneliness was not a significant issue for most of the participants, with only 45.4% reporting it. Table 2 provides a detailed breakdown of the results for these variables based on the score ranges.

Table 1 - Sociodemographic characterization of the participating caregivers (n = 960). Bogotá, Colombia, 2021

Variables		n = 960	Percentage
Gender	Female	816	85%
	Male	144	15%
Age	Mean (SD*)	50.47 (14.02)	
	Married	342	35.63%
	Divorced	113	11.77%
Marital status	Single	294	30.63%
	Common law marriage	172	17.92%
	Widowed	39	4.06%

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Variables		n = 960	Percentage
Schooling level	None	23	2.40%
	Elementary School	179	18.65%
	High School	293	30.52%
	Technical level	191	19.90%
	University studies	192	20%
	Graduate studies	80	8.33%
Occupation	Full-time employee	219	22.81%
	Student	20	2.08%
	Homemaker	531	55.31%
	Freelance	190	19.79%
Socioeconomic level	Low	834	86.87%
	Average	119	12.39%
	High	7	0.72%
Relationship with the care recipient	Friends	37	3.85%
	Partners	197	20.52%
	Siblings	31	3.23%
	Adult children	457	47.60%
	Others	104	10.83%
	Parents	134	13.96%
Caregiving since the time of diagnosis	Yes	767	79.9%
	No	193	20.1%
Perception regarding quality of the relationship with the patient	Very good	529	55.1%
	Good	373	38.8%
	Fair	56	5.83%
	Poor	2	0.21%

*SD = Standard Deviation

Table 2 - Results corresponding to anxiety, depression, loneliness and role adoption in caregivers by score ranges (n = 960). Bogotá, Colombia, 2021

Variables	Score ranges	Percentage
Depression level	No depression (from zero to seven points)	59.2%
	Doubtful depression (from eight to ten points)	21.0%
	Clinical problem (eleven points or more)	19.8%
Anxiety level	No anxiety (from zero to seven points)	41.0%
	Doubtful anxiety (from eight to ten points)	21.1%
	Clinical problem (eleven points or more)	37.8%
Loneliness level	No loneliness (19 points or less)	45.4%
	Moderate loneliness (from 20 to 30 points)	35.8%
	Severe loneliness (31 or more points)	18.8%
Role adoption level	Insufficient role adoption (from 22 to 60 points)	0.6%
	Basic role adoption (from 61 to 77 points)	10.7%
	Satisfactory role adoption (78 points or more)	88.6%

A Principal Components Analysis (PCA) was performed, as depicted in Figure 1, using the total scores related to Role Adoption, Anxiety, Depression and Loneliness. The analysis focused on the first two dimensions, which collectively accounted for 80.6% of the total variance. Furthermore, these first two dimensions explained over 75% of the variance in the totals. This suggests a positive association between the total scores for anxiety and depression, indicating that caregivers with higher anxiety levels tend to also have higher depression levels. In fact, as measured by Pearson's linear correlation coefficient, the linear association degree between these two scores is $r = 0.696$ ($p < 0.001$). Conversely, the scores for anxiety and depression on the Hospital Depression and Anxiety Scale present a moderate negative association with role adoption ($r = -0.337$). Additionally, the scores for anxiety, depression and role adoption did not show significant correlations with the loneliness score, as indicated by $r = 0.141$, $r = 0.126$ and $r = 0.256$, respectively.
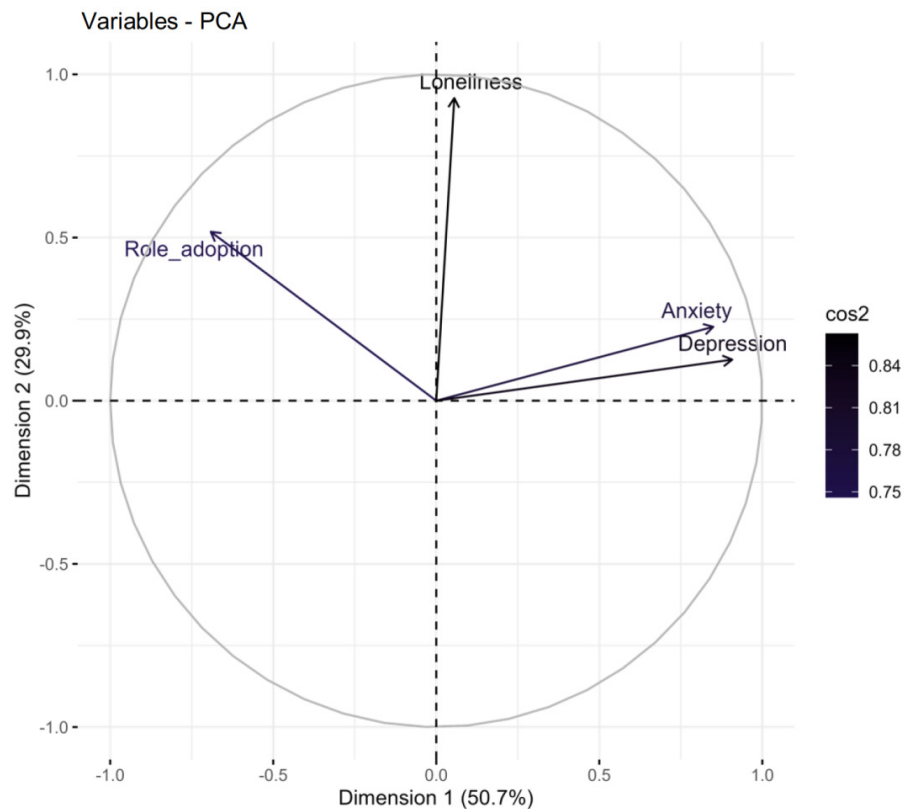

Figure 1 - Principal Component Analysis of the total scores for anxiety, depression, loneliness, and role adoption (n = 960). Bogotá, Colombia, 2021

In further analyses performed with the caregivers' sociodemographic variables, no significant associations were identified with the total scores on the various scales. However, a minor decrease in Role Adoption was noticed among caregivers of female patients, caregivers who were not parents or had occupations as students, and those belonging to average and high socioeconomic levels. Additionally, a Multiple Correspondence Analysis was carried out using the score ranges, as illustrated in Figure 2. This analysis explained 40.7% of the associations between the score categories. It is noteworthy that caregivers experiencing anxiety and depression issues were more frequently linked to moderate loneliness level and to basic role adoption. Conversely, those with lower depression and anxiety levels did not report experiencing loneliness.

Figure 3 presents a clustering analysis using the total scores for role adoption, anxiety, depression and loneliness. Employing the k-means method, the analysis revealed the possibility of grouping caregivers into three different categories. The first group comprised 120 caregivers characterized by normal anxiety and depression levels, satisfactory role adoption and severe loneliness, explaining 64.6% of the variance (EV). The second group included 341 caregivers with clinical-level anxiety and depression, basic role adoption and moderate loneliness, explaining 68.4% of the variance (EV). Finally, the third group consisted of 499 participants presenting normal anxiety and depression levels, no loneliness and significant role adoption, explaining 64.9% of the variance (EV).
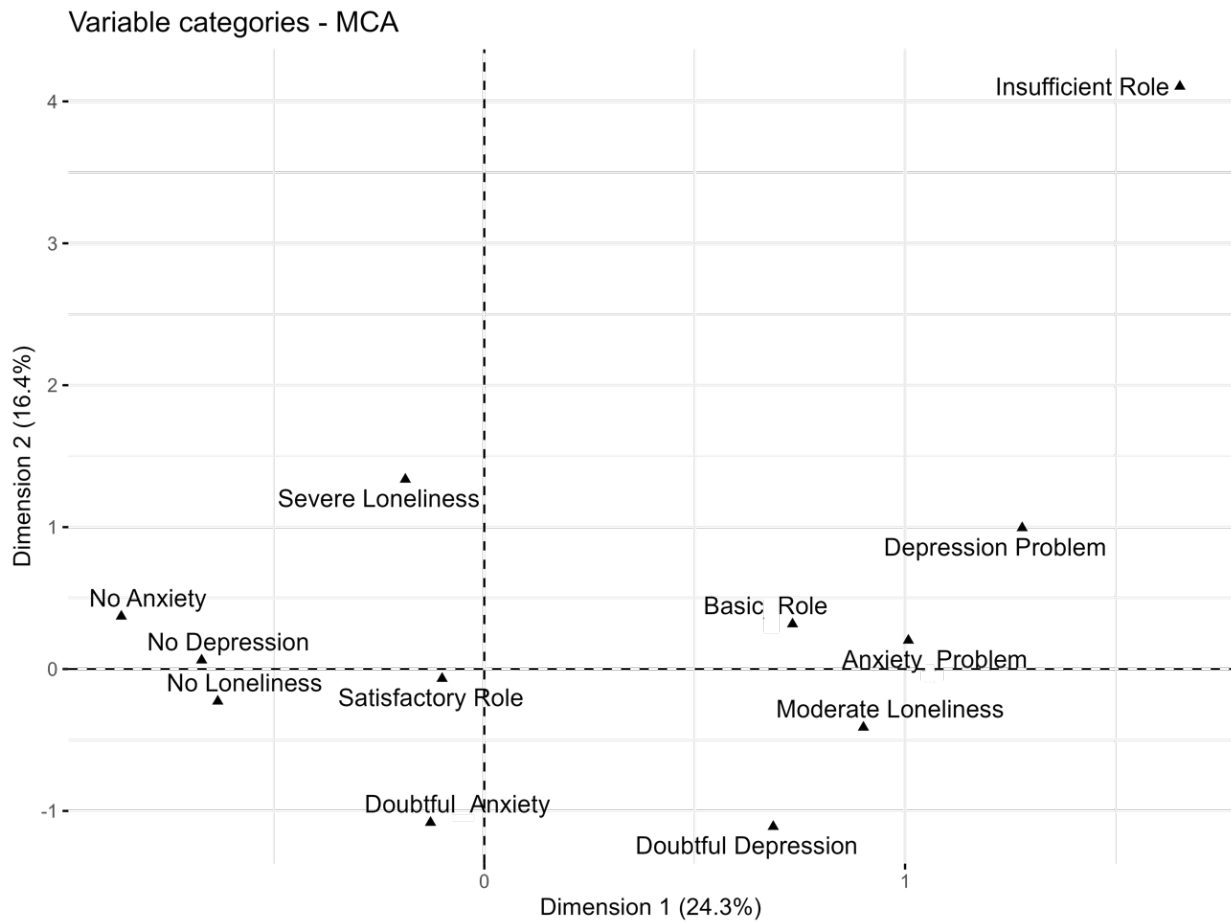
Variable categories - MCA

Figure 2 - Representation of the classification corresponding to the anxiety, depression, loneliness and role adoption scores with Multiple Correspondence Analysis (n = 960). Bogotá, Colombia, 2021
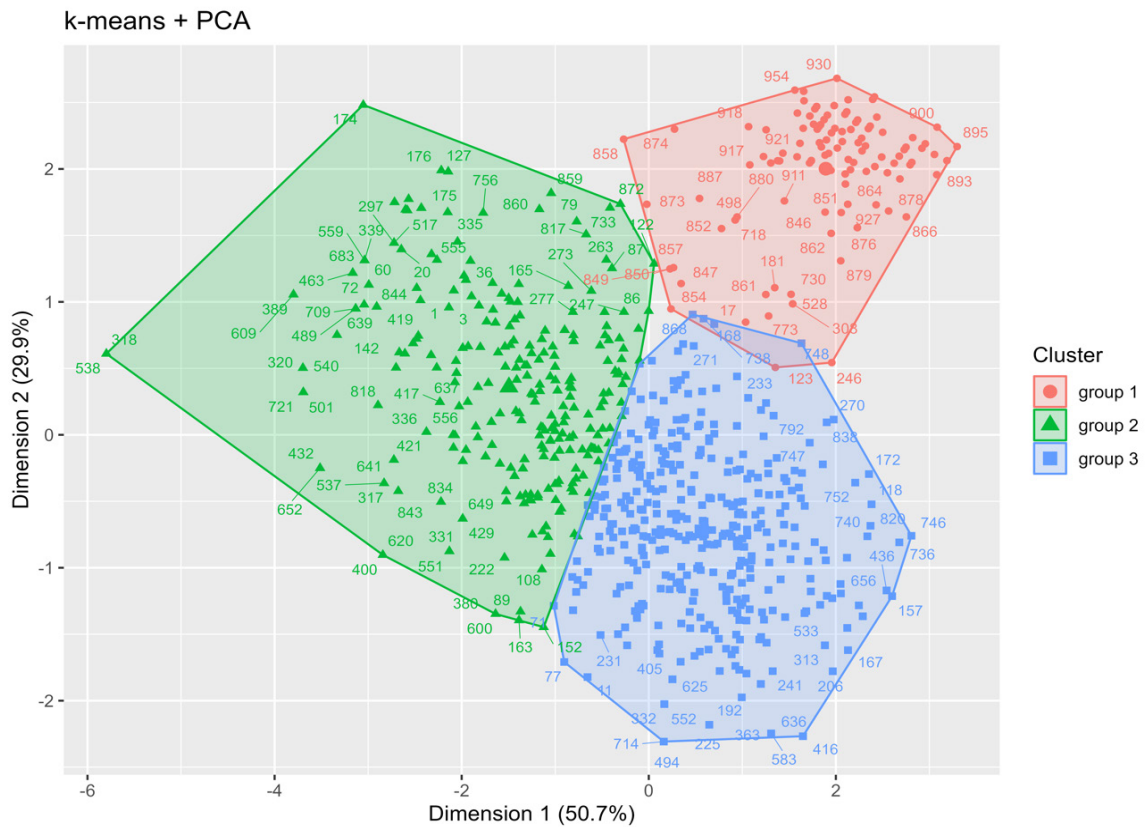
k-means + PCA

Figure 3 - Clustering analysis of the caregivers using k-means and three groups (n = 960). Bogotá, Colombia, 2021

Lastly, a Principal Component Analysis was performed within each of the three groups using the total scores of the variables. In group 1, a positive association between the Anxiety and Depression total scores was observed, while both presented a negative association with the Loneliness score. Remarkably, the total score for Role Adoption did not show any significant correlation with the other three variables. Conversely, in group 2, the caregivers obtained Role Adoption scores that were negatively associated with the total Loneliness score, and Depression displayed a moderate positive association with Loneliness. Finally, in group 3, Role Adoption presented a negative association with Depression, whereas Anxiety and Loneliness were positively associated and, in turn, showed no correlation with the other two variables (Role Adoption and Depression).

Discussion

This study has unveiled various aspects concerning anxiety, depression, loneliness and role adoption among caregivers of individuals with CNCDs within the Colombian context, given the limited available evidence. Firstly, a notable finding is the high prevalence of role adoption at satisfactory levels, with 88.6% of the caregivers self-classifying themselves at this level. It is worth noting that the caregiver role adoption level exerts direct impacts on their responses, organizational strategies and tasks they undertake in this role[15].

In terms of responses, it has been established that assuming the caregiving role, especially when faced with high caregiving demands in an isolated and poorly supported context, leads to adverse effects on quality of life[18], caregiver burden[19], and anxiety and depression[7]. Organization of the caregiving role and the specific tasks performed by caregivers have been documented to directly influence the outcomes in individuals with CNCDs. Simultaneously, these outcomes reciprocally affect caregivers in a symbiotic relationship[20]. Hence, expanding our understanding of the caregiver role adoption process and promoting its seamless transition should be among the top priorities in this field. This effort aims at enhancing outcomes not only for the caregivers but also for the patients themselves[21].

In this study, 59% prevalence of anxiety was found and depression stood at 40.8%, both showing scores in the borderline range on each scale. Notably, the prevalence of anxiety surpassed the 42.3% reported in a prior meta-analytic study[7] involving caregivers of individuals with cancer, whereas depression had a prevalence very close to the 46.55% reported in the same study. It is important to emphasize that both anxiety and depression are confirmed issues within the Colombian population of caregivers. Although anxiety appears to be more prevalent than depression, it is crucial to maintain a focus both on research and on caregiver support. This emphasis is warranted since the literature widely documents the influence of anxiety as a predictor of depression[22].

The findings of this study indicate satisfactory adoption of the caregiving role alongside a notable prevalence of anxiety and depression. Additionally, high prevalence of loneliness was observed, with 54.6% of the study participants reporting some loneliness degree. This discovery closely aligns with the 60.7% prevalence of loneliness reported in a prior study conducted in the United Kingdom[9]. It is evident that perceived loneliness is an undeniable issue among family caregivers of individuals with chronic conditions, largely stemming from the all-encompassing nature of the caregiving role.

In the current study, data were collected on variables that might influence this sense of isolation. For instance, 55.42% of the patients reported having only one caregiver, 79.9% of the caregivers mentioned having provided care since the time of diagnosis, and a daily commitment of 16.97 hours to patient care was evident. Within this context, it is conceivable that caregivers are at higher risk of perceiving themselves as lonely. The demanding nature and substantial time commitment required for caregiving leave limited opportunities for caregivers to engage with their immediate support networks or allocate time for themselves. Moreover, the study revealed a significant and direct relationship between loneliness, depression and anxiety, which further corroborates the existing evidence on the interplay among these three variables. This underscores the pressing need for interventions aimed at mitigating these adverse effects on caregivers' health[23].

One of the most significant results of this study emerged from the clustering analyses. Caregivers with lower role adoption levels presented markedly higher levels of loneliness, anxiety and depression. This finding is in line with prior research from other countries[22] but represents a noteworthy addition to our understanding of caregivers' health in the Colombian context. This discovery gains particular significance when considering that family caregivers in Colombia carry out their roles within a context characterized by neglect, inadequate institutional support and countless economic challenges associated with providing care in a country with a medium to low *per capita* income[24]. An unprecedented finding within this study pertains to the mediating effect of caregiver role adoption on the other variables, underscoring the imperative to broaden the theoretical framework surrounding caregiving. Rather than being solely an instrumental task, this role is

constructed through interactions with significant others and evolves amidst continuous changes, requiring support through transitional care[25].

This study carries several implications for the Nursing practice. In the first place, understanding the role adoption process empowers nurses to recognize the unique challenges faced by caregivers and provide tailored support to help them navigate their newfound responsibilities. This may involve offering guidance and resources to enhance their caregiving skills. Secondly, acknowledging the prevalence of caregiver anxiety, loneliness and depression, nurses and the healthcare system can implement targeted interventions to address the caregivers' mental health needs. This might encompass providing counseling, easing connections with support groups and creating opportunities for social engagement. Additionally, offering respite care can be instrumental in alleviating the burdens placed on caregivers. Thirdly, by integrating this knowledge into the Nursing practice, health professionals can contribute to enhancing caregivers' well-being, promoting effective caregiving, and ultimately improving patient outcomes within the context of chronic disease management.

This study has its limitations, including intentional sampling, which restricts generalizability of the results beyond the study sample. However, we have provided a comprehensive description of the sample to enhance applicability of the findings to settings with individuals who share similar characteristics to our participants. Another noteworthy limitation is the potential impact of the COVID-19 pandemic on the variables of interest. The data were collected amidst government-mandated closures and isolation orders during the second and third waves of COVID-19 infections in Colombia. The pandemic has been documented to exacerbate anxiety, depression and loneliness due to social distancing[26]. As we did not control for this variable in our study, it is plausible that anxiety, depression and loneliness levels may have been significantly influenced not only by the caregiving role but also by the pandemic itself, which amplified pre-existing issues in caregivers.

Additionally, having resorted to diverse data collection methods, such as online forms and telephone calls, may have introduced bias. To mitigate this, the research team provided thorough training to the assistant research staff, equipping them with the necessary skills to assist the participants in answering the questionnaires and ensuring proper filling out of the online forms. Furthermore, it is worth noting that the sample primarily consisted of family caregivers with relatively high schooling levels, most having completed at least High School or Higher Education, with a mean age of 50 years old. These demographic characteristics suggest reasonable familiarity and proficiency levels with online surveys, which may help mitigate potential biases associated with online data collection methods. Nonetheless, it is essential to acknowledge the potential bias introduced by the varied data collection methods when interpreting the study findings.

Conclusion

The family caregivers of individuals with chronic diseases were predominantly women who devoted a substantial number of hours a day to caregiving, resulting in a cumulative commitment that encompassed the considerable caregiving demands arising from the dependence status of their family members. The study identified a significant relationship between caregiver role adoption and the responses to anxiety, depression and loneliness. Specifically, caregivers with lower role adoption levels presented significantly higher anxiety, depression and loneliness levels.

Further research is warranted in this domain to enhance our understanding of role adoption and to explore intervention studies aimed at easing a smoother transition for caregivers. These interventions might play a pivotal role in reducing the prevalence of anxiety, depression and loneliness among this population of caregivers.

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