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Impact of caregiving on informal caregivers of dependent older adults: a literature review

Repercusión del cuidado en los cuidadores informales de la persona mayor dependiente: revisión de la literatura

Impacto da assistência aos cuidadores informais do idoso dependente: uma revisão da literatura

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ABSTRACT

The objective of this review was to synthesize the impact of caregiving on informal caregivers of dependent older adults in Latin American countries. This is a descriptive literature review study. A search for bibliographic sources was conducted using SciELO database and Google Scholar search engine. The selection criteria were as follows: original full-text articles related to the topic, published in Spanish and English between 2019 and 2023. The PRISMA flow diagram was used to help structure the search strategy. Five themes emerged from the analysis: i) sociodemographic profile,; ii) impact of caregiving on the health of the informal caregiver, ; iii) impact of caregiving on the family, ; iv) cognition, ; and v) meanings of caregiving. It is concluded that care provided by informal caregivers to dependent older adults in Latin America has an impact on their health, society, and family. Nursing professionals must provide informal caregivers with the necessary knowledge for them to adequately perform their caregiving roles, thus contributing to the promotion on their well-being.

Keywords: caregiving; informal caregiver; dependent older adult.

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Scientific contribution:

This study highlights the responsibility of nursing professionals in educating and supporting informal caregivers to prevent or minimize the negative impacts of caring for a dependent older adult at home.

INTRODUCTION

Demographic aging is a social achievement; however, it also poses a challenge as it leads to significant socioeconomic, political, and healthcare system changes (1). The main cause of this phenomenon is the decline in fertility rates and, to a lesser extent, migration, particularly among young people (2).

According to the literature, there are currently 962 million people aged 60 or older worldwide, representing 13% of the total population. Within this demographic group, the annual growth rate is 3%. In Europe, 25% of the population consists of older adults. Projections estimate that by 2030, there will be approximately 400 million long-lived individuals worldwide (3). Cuba is no exception to this reality.

In Latin America and the Caribbean, population aging is occurring in a rapid and significant manner. According to estimates, the population group aged 60 and older represents 11%, and by 2030, it is projected to increase to 17%. By 2050, it will constitute a quarter of the region's inhabitants (3). In this context, by the end of 2023, according to the Statistical Yearbook of Health of Cuba, 24.4% of the population was 60 years old and older (4), placing the country within Group III of aging (>15%).

With aging, the biomedical, psychological, and social needs of older adults increase, which influences the structure and dynamics of the family as the basic unit of society (1). Under these circumstances, their care is provided at home, so the family or one of its members becomes their informal caregiver (5). This individual postpones or limits personal or professional achievements and modifies personal routines and habits (6). In addition, they have less time for themselves and experience adverse feelings and sensations such as sadness, fatigue, insomnia, guilt, and hopelessness. Moreover, there is often a worsening of any preexisting chronic conditions they may have.

Therefore, the objective of this research study was to synthesize the published evidence regarding the impact of caregiving on informal caregivers of dependent older adults in Latin American countries.

MATERIALS AND METHODS

A narrative review, also referred to as a traditional or descriptive review (7), was conducted on a specific topic. The aim was to summarize knowledge related to a scientific question through the systematic selection and synthesis of relevant literature. For its development, the stages proposed by Arksey and O'Malley (8) were followed: i) identification of the research question; ii) identification of relevant studies; iii) selection of appropriate studies; iv) data graphing and recording; and v) summary and presentation of results.

Stage 1. Identification of the Research Question

The research question is identified as: What is the impact of caregiving on informal caregivers of dependent older adults in Latin American countries?

Stage 2. Sources of Information and Literature Search

The literature search and analysis were conducted from January to June 2024 in the SciELO and Dialnet databases, as well as the Google Scholar search engine. For the search strategy, health science descriptors (MeSH and DeCS) were considered, representing the following keywords in English: c*are, caregiver, informal caregiver, primary caregiver, main caregiver, old person, older adult, and dependence*. These were associated with the Boolean operators AND, OR, and NOT. Theses, editorials, brief communications, memoirs, conference proceedings, review articles, and clinical cases were excluded.

Original full-text articles that adhered to the study topic and were published in Spanish or English between 2019 and 2023 were considered eligible. Duplicate articles, studies involving populations that included adolescents or children, studies in which the dependence of older adults was not clearly evidenced, and those not conducted within the primary level of care were excluded.

Stage 3. Selection of Appropriate Studies

En un inicio, se identificaron 1870 artículos. De ellos, se eliminaron 720 duplicados y 493 que no respondían al objetivo de la investigación, lo que resultó en un total de 1213 eliminados. Luego se realizó la revisión de los 657 artículos restantes, teniendo en consideración los criterios de inclusión y exclusión. De estos, se excluyeron 631 debido a factores relacionados con el título, el resumen y el país. Con respecto a los títulos, estos debían contener al menos dos de las palabras clave utilizadas en la estrategia de búsqueda, tal como lo plantean Esquivel et al. (9).

Later, the 26 articles most likely to be selected were read. Of these, 17 articles were excluded because their study population did not consist of informal caregivers, there was no clear evidence of older adult dependence, and they were not conducted at the primary level of care. This way, nine articles remained and were evaluated following the criteria of the Critical Appraisal Skills Programme (CASPe) and the Equator Network guidelines (9) to determine their validity, reliability, and applicability according to the study design. The critical appraisal was conducted by two independent peer reviewers using a double-blind method. Subsequently, all discrepancies among the authors regarding the final selection of articles were discussed and resolved. None of them were excluded.

Figure 1 shows the results of the article search process, from initial identification to final inclusion.

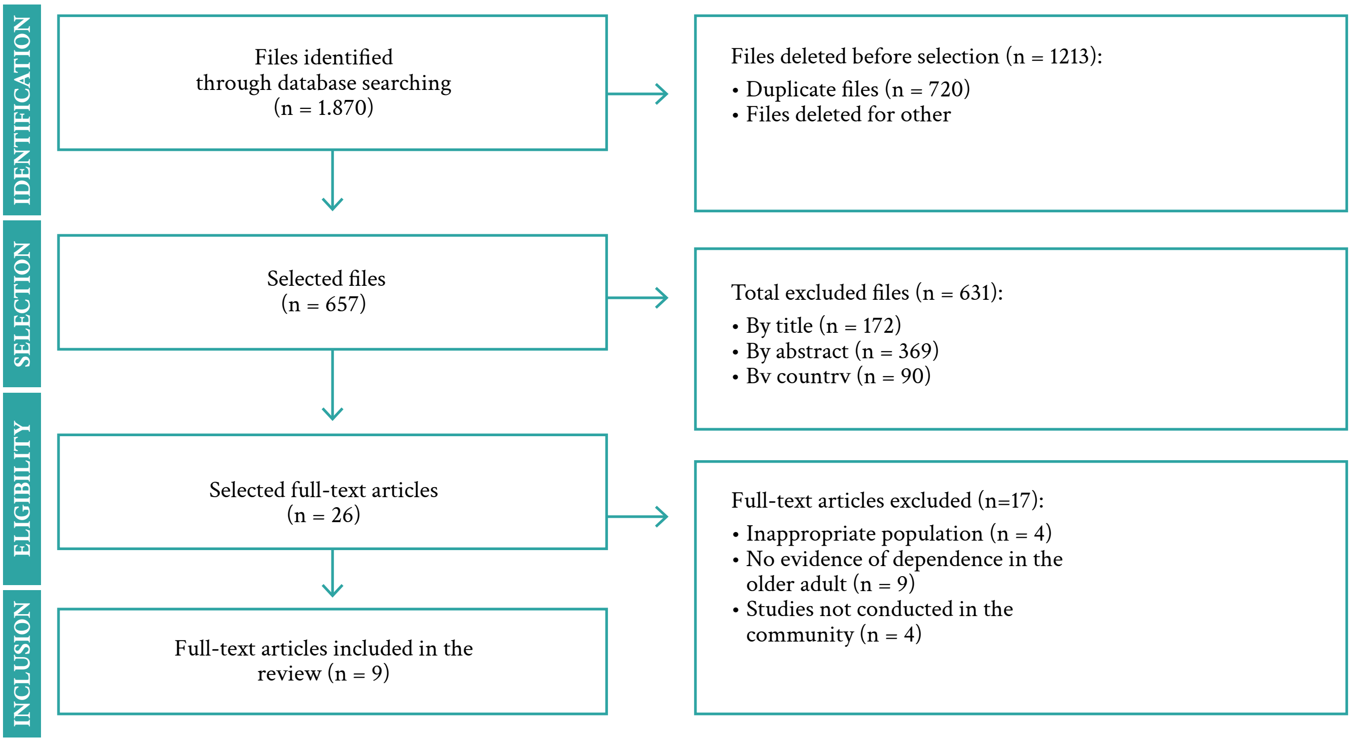

Figure 1. PRISMA flow diagram process for study selection.

Stage 4. Charting and Recording Relevant Data

In this stage, the extraction process was standardized. The collected data were organized in a Microsoft Excel document and grouped into seven categories: themes, title, year of publication, authors, country, objectives, and study contributions.

Stage 5. Summary and Presentation of Results

The information obtained from the articles was analyzed according to the most prevalent themes. This allowed for the assignment of analytical categories.

DEVELOPMENT AND DISCUSSION

In scientific literature, researchers often use different terms to refer to the same construct (10). This is the case of the term "informal caregiver," adopted in this study, which may also appear as "primary caregiver" or "main caregiver." These terms refer to the person who takes care of the patient and does so voluntarily and without receiving any payment.

Of the nine articles selected, 77.8% used a quantitative approach, while 22.2% employed a qualitative approach. Six of the studies were descriptive, and only the study by Salazar-Barajas et al. (11) followed a descriptive-correlational design. 44.5% of the studies were published in nursing journals; 22.2% were published in medical and multidisciplinary journals, in each case, and 11.1% were published in rehabilitation journals.

Geographically, the studies were distributed as follows: Chile, Mexico, and Ecuador, with two studies each; and Cuba, Peru, and Colombia, with one study each. Furthermore, five themes emerged from the articles analyzed: i) sociodemographic profile of informal caregiving, ii) impact of caregiving on the health of the informal caregiver, iii) impact of caregiving on the family, iv) cognition, and v) meanings of caregiving.

The summary of the selected articles is shown in Table 1, organized by theme and year of publication. The sociodemographic profile of the informal caregiver was not included, as it was analyzed in all articles except for the study conducted by Padilla-García et al. (12).

Table 1. Summary of the Selected Articles

Theme	Authors	Title	Year	Country	Objectives	Contribution
Impact of caregiving on the caregiver's health	Salazar-Barajas et al. (11)	Family functioning, caregiver burden, and quality of life of caregivers of older adults with functional dependence	2019	Mexico	To determine the caregiver's burden and quality of life when caring for an older adult.	Intense burden, poor quality of life.
	Fernández y Herrera (13)	The effect of informal caregiving on the health of family caregivers of dependent older adults in Chile	2020	Chile	To evaluate the effect of providing informal care on caregivers' health.	Caregivers were less likely to perceive their health as good or excellent compared to non-caregivers.
	Chango and Guarate (14)	Caregiver burden among caregivers of dependent older adults	2021	Ecuador	To determine the prevalence of caregiver burden among caregivers of dependent older adults.	Intense burden.
	Olarte et al. (15)	Knowledge and burden among primary caregivers of dependent older adults	2021	Colombia	To determine the knowledge levels and caregiver burden among primary caregivers of dependent older adults in the municipality of San Gil Santander.	34.0% showed no signs of overburden, while another 34.0% showed excessive burden.
	Padilla-García et al. (12)	Caregiver burden among caregivers of dependent older adults	2022	Ecuador	To identify the presence of role overload and associated negative experiences among caregivers of dependent older adults in families from Ingapirca, Ecuador.	Overburdening was evident. Main reported symptoms included role overload, considerable reduction in time of self-care time, psychological distress, and social distancing.
	Sargenton-Savon et al. (16)	Biopsychosocial factors influencing primary caregivers of patients diagnosed with dementia syndrome	2023	Cuba	Biopsychosocial factors influencing primary caregivers of patients diagnosed with dementia syndrome.	The factors influencing the overload of primary caregivers of patients with dementia syndrome are female, emotional ties to the spouse, and the degree of cognitive impairment.
Repercusión del cuidado en la familia	Salazar-Barajas et al. (11)	Funcionamiento familiar, sobrecarga y calidad de vida del cuidador del adulto mayor con dependencia funcional	2019	México	Identificar la relación entre el funcionamiento familiar y la calidad de vida del cuidador del adulto mayor.	A mayor funcionamiento familiar, mayor será la calidad de vida del cuidador ($p < ,05$).
Cognition	Navarrete-Mejía et al. (17)	Profile of the caregiver of older adults in a pandemic situation due to SARS-COV-2, Lima, Peru	2020	Peru	Profile of caregivers of older adults during the SARS-CoV-2 pandemic in Lima, Peru.	Findings revealed an average caregiver age of 33.48 years, with predominance of female caregivers. They have no training in hand washing or stress management in older adults. They have low levels of self-confidence and high levels of anxiety or stress during caregiving.
	Olarte et al. (15)	Knowledge and burden among primary caregivers of dependent older adults	2021	Colombia	To determine the knowledge levels and caregiver burden among primary caregivers of dependent older adults in the municipality of San Gil Santander.	Knowledge deficit in body mechanics techniques, stress management, and the importance of using personal protective equipment.

Table 1. *(Continuation).*

Theme	Authors	Title	Year	Country	Objectives	Contribution
Meanings of caregiving	Espinosa et al. (18)	Hidden human cost in the lived experience of caregivers of older adults with Alzheimer’s disease	2021	Mexico	To explore the phenomenon of the hidden human cost in the life experience of informal caregivers of older adults with Alzheimer's disease.	The analysis revealed the metacategory “hidden human cost”, comprising two main categories: hidden human cost in the caregiver (with four subcategories) and coping with the hidden human cost (with three subcategories).
	Campos-Romero et al. (6)	Living the experience of caring for an older family member while being employed: conflicting roles	2021	Chile	To reveal the life experience of people who combine caregiving for a dependent older relative and paid work.	The phenomenon was revealed in the comprehensive category of role multiplicity, composed of the subcategories of distress/overwhelm and guilt.

Sociodemographic Profile

Caregiving encompasses two components: affective and moral. The affective component becomes evident when the caregiver loves and respects the person being cared for. On the other hand, the moral component is present insofar as caregiving involves obligations and duties derived from family ties (19, 20).

The analysis of the selected studies identified the following sociodemographic variables of informal caregivers of dependent older adults: sex (6, 11, 12-18), age (6, 11, 13, 15-18), education (6, 11, 13, 15-17), family ties (6, 11, 13), marital status (11, 13, 14, 16), occupation (11, 13, 15, 16), hours of daily caregiving (6, 11, 17), and duration of caregiving (6, 15, 16, 18).

A predominance of females was identified (6, 11, 13-18), which may be related to the traditional role of women as the primary caregivers (20). Female caregivers meet the needs of the person being cared for, but put their family and social life plans at risk. However, in recent years, there has been a growing trend of men taking on caregiving responsibilities within the family context (18).

The average age range of informal caregivers of dependent older adults is between 33.48 and 59 years. This translates into people who are actively employed up to those of retirement age. Apart from that, it has been determined that women, daughters, homemakers, and individuals living with the patient are more likely to become informal caregivers (13).

In general, informal caregivers who are employed have less time to care for the patient, and it is common for them to quit their jobs and isolate themselves from their work and family environments. Similarly, older caregivers are associated with age-related chronic diseases as well as a range of cognitive and physical limitations that influence how they perform their caregiving role.

The informal caregiver's level of education becomes a factor that protects their health. Those with a higher level of education tend to have more cognitive resources and better access to information to cope with caregiving. In this regard, Delgado-Barrera et al. (21) suggest that the level of education attained by caregivers, whether university or basic, is ideal for caring for family members and for functioning within society.

Furthermore, the following variables are essential for analyzing the impact of caregiving on informal caregivers: family ties (6, 11, 13), marital status (11, 13, 14, 16), occupation (11, 13, 15, 16), hours of daily caregiving (6, 11, 17), and duration of caregiving (6, 15, 16, 18).

Informal caregivers are typically family members of the dependent person. A predominance of daughters fulfilling this caregiving role was identified (6, 11, 13); however, sons, wives, nephews, and grandchildren also provide care (13). The family relationship between the dependent person and the informal caregiver is considered an important aspect, since the closer the kinship, the stronger the perception of caregiving as an obligation (9). These caregivers often experience health-related issues.

In terms of marital status, married informal caregivers of dependent older adults predominate (11, 13, 16). However, in the study conducted by Espinosa et al. (18), the respondent was single. Regarding occupation, some informal caregivers balance household tasks and work-related activities while also caring for their relatives (11, 13, 15, 16). This implies greater physical and emotional strain, family neglect and, consequently, an increased caregiving burden.

Regarding the number of caregiving hours per day, Sargenton-Savon et al. (16) identified informal caregivers who provided round-the-clock or 24-hour care. However, the majority devoted between 11 and 14 hours per day to caring for the dependent older adult (6, 11, 17). In terms of the duration of caregiving, reports indicate that informal caregivers provide care for periods ranging from one to seven years (6, 15, 16, 18).

In the authors' opinion, informal caregivers of dependent older adults are forced to make changes in their family and social environment because they perform multiple tasks that require time and energy. Family relationships—whether between spouses or children—are sometimes negatively affected when they are not well consolidated. Similarly, social relationships are often compromised, as it is common for informal caregivers to leave their jobs due to the burden of caring for their relatives.

The literature reports that caring for dependent older adults at home is a common condition in both developed and developing countries (21). Thus, informal caregivers meet the basic needs of the older adult under their care and contribute to healthcare systems, playing a crucial role in preventing hospital admissions (20). In this way, the informal caregiver becomes the main resource of the dependent older person, at the expense of their own health.

Repercusión del cuidado en la salud del cuidador informal

This topic refers to the effects that caregiving has on the physical, mental, and social health of the informal caregiver. When the caregiver is a family member who lives with the dependent older adult, they become trapped in a vicious circle of caregiving, which ultimately leads to health issues such as insomnia, bulimia or anorexia, irritability, feelings of guilt, social isolation, and abandonment by other family members, among others.

In recent years, research in Latin America on informal caregivers of older adults has focused on anxiety, depression (22, 23), caregiver burden (24–26), loneliness (22, 23), and social support (24, 26, 27). All of these are variables that affect their health. However, the conducted systematization revealed that caregiver burden (11, 14–16) and perceived health (13) were the variables most frequently explored by researchers in studies on informal caregivers of dependent older adults.

Informal caregivers who provide care to dependent older adults are exposed to stressful situations that lead to caregiver burden. According to Zarit et al. (28), caregiver burden is defined as the impact on the caregiver's emotional and physical health, social life, and economic situation as a consequence of caring for their family member.

The systematized studies (11, 12, 14-16) have in common that they used the Zarit Scale to measure the burden on informal caregivers. On the other hand, the research conducted by Salazar-Barajas et al. (11) and Olarte et al. (15) measured the levels of dependency of the older adult using different assessment instruments.

Dependency is defined as the result of a process that begins with the onset of a deficit in a person's bodily functioning as a result of illness, aging, or accident (29). Salazar-Barajas et al. (11) assessed dependency using the Barthel Index, which measures functional capacity for performing activities of daily living, and found severe, moderate, total, and minimal dependency in older adults, with the latter being the most prevalent.

Olarte et al. (15) used the Katz Index to assess the activities of daily living and the assistance required by the older adult to perform them. They identified moderate and severe disabilities in aspects such as mobility, dressing, eating, bathing, continence, and toilet use. This situation makes these people dependent on their informal caregivers.

In the authors' opinion, dependency is an aspect that healthcare professionals should consider, as it is often one of the first human responses observed in older adults. In addition, this condition affects the family, but especially the informal caregiver, who prioritizes the care of the dependent older adult and neglects their own health.

Regarding caregiver burden, researchers found that informal caregivers of dependent older adults most frequently experienced mild burden (11) and severe burden (11, 14-16). This condition manifested through psychological tension, reduced personal time, and social distancing (12). In addition, interviewees associated severe burden with a lack of caregiving assistance and with the dependence of older adults (15), as well as with somatosensory, psychological, and social family alterations (16).

Sargenton-Savon et al. (16) found that the emotional bonds of the spouse, female gender, and the degree of cognitive impairment of the dependent individual—in this case, individuals with dementia syndrome—were factors associated with informal caregiver burden. According to the literature, it is common for caregivers who are themselves ill to postpone their own care to prioritize that of the dependent person, which often leads them to avoid seeking healthcare services (11).

Health perception refers to the overall assessment an individual makes of their own health based on their personal concept of it. It is a subjective variable of overall health status and is commonly used in surveys at the primary care level (10). Fernández and Herrera (13) found that, in Chile, informal caregivers of dependent older adults are less likely to perceive themselves as having good or excellent health compared to individuals who are not caregivers.

In summary, caring for a dependent individual is a demanding task for informal caregivers, as it involves long days and extended hours of constant dedication. This situation generates high levels of stress, emotional exhaustion, fear, and feelings of guilt in caregivers, resulting in a burden that negatively impacts their health (13). Nevertheless, caregivers can demonstrate an extraordinary ability to adapt to the circumstances they are required to face (30).

This means that health professionals, specifically nurses, should develop strategies aimed at educating informal caregivers and raising awareness among other family members so they can become actively involved in the care of the dependent relative.

Impact of Caregiving on the Family

Family is the first human group, the fundamental unit of society. Within it, the personality of its members develops comprehensively, and changes occur in relation to the life cycle. During this process, motives and behaviors related to health are reinforced (31). Thus, the family plays a role in protection, as well as in the onset and recovery from illness among its members. Similarly, it serves as the most powerful and reliable support network in health, illness, and death (32). Therefore, when a family member gets sick, it is expected that all members collaborate in providing care, which reflects proper family functioning.

On the other hand, family functionality is defined as the set of interpersonal relationships that arise among family members and, in turn, maintain a unique identity. A study conducted in Mexico by Salazar-Barajas et al. (11) showed that caregivers perceived normal family functionality. This indicates that family members are involved in the care of the dependent older adult. However, it was also found that another group of informal caregivers reported moderate to severe family dysfunction. These findings confirm that not all families take on caregiving responsibilities adequately, which negatively affects the health of the informal caregiver.

Lastly, the family is a system in which each member interacts reciprocally (33). Therefore, when its members do not collaborate in the care of the dependent older adult, a paranormative crisis arises. This becomes a traumatic event (29) that can affect the caregiver's health, leading to the consequent loss of family homeostasis (33). Thus, nursing professionals must possess the competencies required to intervene and educate each family member living with a dependent older adult.

Cognition

Cognition is another aspect explored in studies by Latin American researchers (15, 16). The systematization made it possible to identify the study by Olarte et al. (15) in Colombia, in which informal caregivers were aware of the benefits of feeding the older dependent person and used the appropriate position to perform this activity. However, they lacked knowledge of body mechanics techniques and therefore relied on their own strength when changing positions. In addition, they did not use stress management techniques, failed to protect themselves, and were unaware of the degree of dependence of the older adult. In this context, although family support provides opportunities for rest, informal caregivers need to learn how to use rest effectively for the benefit of their own health.

The SARS-CoV-2 pandemic was another health challenge faced by informal caregivers while caring for their relatives. In a study conducted in Peru, caregivers reported not being trained in proper handwashing techniques or in stress management for the older adult, and not all of them were vaccinated. Furthermore, they stated that they were not informed about the appropriate caregiving measures related to the pandemic. In many households, they lacked adequate protective supplies, such as hand sanitizers and face masks. This situation was reflected in low levels of self-confidence in caring for the older adult and high levels of distress or stress during caregiving (17). Stress is a phenomenon influenced by multiple factors that affect an individual's physiological, psychological, and behavioral responses to internal and external stimuli from their environment (34). It also represents a physiological and psychological coping mechanism, which is always essential for performing tasks when facing either challenging or threatening stressors (17).

The systematization revealed the following coping strategies used by informal caregivers during the pandemic: strengthening emotional bonds with the person they care for and fostering emotional support within the family (35). Therefore, the more knowledge the informal caregiver has about illness and the processes experienced by the dependent older adult, the better they will be able to meet their needs, which will, in turn, have a positive impact on their well-being.

Meanings of Caregiving

This topic is related to the meanings that informal caregivers attribute to caregiving through the expression of their positive and negative experiences. The systematization made it possible to identify studies related to the hidden human cost (18) and the roles of conflicts between caring for an older family member and being employed (6).

The human cost is defined as the invisible or silent price paid when spending long periods caring for a family member, which entails physical, emotional, economic, and social burdens for caregivers (36). Espinosa et al. (18) identified two main categories regarding the caregiver's life experience: the impact of the hidden human cost and coping strategies. Within the first category, four subcategories were identified: social relationships as a caregiver, economic hardship, living another person's life, and perceived burden. The analysis revealed that informal caregiving affects social relationships due to confinement and abstention resulting from caregiving responsibilities. Caregivers often depend on other household members for financial support, as they have no time to work. Additionally, they face anger, stress, and fear, which can lead to insomnia, lower back pain, and migraines caused by physical and emotional exhaustion resulting from excessive workload and lack of rest associated with caregiver burden. From the second category, three subcategories emerged: faith-based coping, recreational activities, and remembering the reason for caregiving. The analysis highlighted the strategies adopted by informal caregivers to cope with the stress and fatigue generated by their caregiving role.

The experience of being employed while caring for a dependent older adult was studied by Campos-Romero et al. (6) in Chile. The study identified the category of role multiplicity, which reflects the tension informal caregivers feel during their workday as they remain concerned about what is happening at home. This is expressed through their desire to fulfill their responsibilities in both settings, often leading to frustration when faced with situations that exceed their organizational capacity and are beyond their control. This category comprises two subcategories: distress/overwhelm and guilt. The first one refers to the change in the family member's role, adjustments in daily routines, and the demands of caregiving. The second one emerges in caregivers' narratives as a strong, complex, and ambiguous feeling that stems from managing multiple roles. Interviewees describe experiencing guilt for not performing adequately at work, ambivalence in how they allocate their time, and inappropriate responses to certain behaviors of the older adult. The responsibility they feel for the work and care of the dependent older person is evident, even to the detriment of their own health. The research shows that informal care arises without prior planning, in which the family relies on one of its members, regardless of his or her employment status. This person, in turn, assumes more caregiving responsibilities and is identified by the dependent person as the sole caregiver.

The meanings attributed to caregiving become essential elements for nursing professionals when designing strategies that involve the family in the care of the dependent older adult. Another important aspect to consider is the transmission of knowledge and skills to both the informal caregiver and the rest of the family so that the care provided aligns with the specific needs of the older adult.

The study identified as limitations the fact that not all investigations reported the illnesses that caused dependence in older adults, nor the human responses that led to caregiver burden among informal caregivers.

CONCLUSIONS

Caregiving among informal caregivers of dependent older adults in Latin American countries has a significant impact on their physical, psychological, and social health, as well as on the relationships they establish with other family members. Nursing professionals should provide informal caregivers with the necessary knowledge to adequately perform their caregiving roles, thereby contributing to the promotion of their well-being. Finally, it is recommended to develop multidisciplinary interventions aimed at preventing or minimizing the negative consequences of caregiving.

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MGP: conceptualization, formal analysis, research, methodology, validation, visualization, writing of the original draft, writing - review & editing.
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