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ORIGINAL ARTICLE

Impact of caregiving on informal caregivers: older people at both ends of the caregiving spectrum

Impacto del cuidado en cuidadores informales: personas mayores en ambos extremos del cuidado

Impacto do cuidado em cuidadores informais: idososem ambos os extremos do espectro de cuidado

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ABSTRACT

Introduction: formal and informal caregiving impacts public health systems worldwide. Although not yet sufficiently recognized, it is related to another demographic and epidemiological development: population aging and rising dependency levels. This means that older adults are increasingly at both ends of the caregiving dyad. **Objective:** to describe the impact of caregiving on older adults who are informal caregivers. **Method:** a descriptive, cross-sectional study of 74 informal caregivers. Fourteen sociodemographic, psychological, and caregiving-related variables were studied using a characterization questionnaire and the Duke-UNC-11, Zarit and Goldberg scales. **Results:** sociodemographic variables showed similar patterns among caregivers in both population groups, with a predominance of middle-aged women and daughters of those they care for. However, variables associated with caregiving showed that older adults spend more time on caregiving tasks and do so with less support than other caregivers, which negatively impacted their health, although this appears to be offset by slight improvements in the levels of caregiver burden and anxiety-depressive symptoms. **Conclusions:** the conditions under which the caregivers studied are providing care affect older adults more, even though they show potential for recovery.

Keywords: informal caregivers; older adults; caregiver burden

RESUMEN

Introducción: los cuidados formales e informales impactan en los sistemas de salud pública en todo el mundo. Aún no suficientemente visibilizados, se relacionan con otro acontecimiento demográfico y epidemiológico: el envejecimiento de la población y el aumento de los niveles de dependencia, de forma tal que las personas mayores se encuentran cada vez con más frecuencia en ambos extremos de la díada del cuidado. **Objetivo**: describir el impacto del cuidado en personas mayores, cuidadores informales. **Método**: estudio descriptivo, trasversal en 74 cuidadores informales. Se estudiaron 14 variables sociodemográficas, psicológicas y asociadas al cuidado con la utilización de un cuestionario de caracterización, las escalas de Duke-UNC-11, de Zarit y de Goldberg. **Resultados**: las variables sociodemográficas mostraron patrones similares entre los cuidadores de ambos grupos poblacionales, donde primaron mujeres de edad media, hijas de aquellos a quienes cuidan. Sin embargo, las variables asociadas al cuidado mostraron que los mayores dedican más tiempo a la tarea de cuidar y lo hacen menos acompañados que el resto de los cuidadores, lo que repercutió negativamente en su salud, aun cuando parece compensarse con discretas mejorías en los índices de carga y sintomatología ansiosa depresiva que presentaron. **Conclusiones**: las condiciones en las que están ejerciendo el cuidado los cuidadores estudiados afectan en mayor medida a las personas mayores, aun cuando muestran posibilidades de recuperación.

Palabras clave: cuidadores informales; adultos mayores; carga de cuidado

RESUMO

Introdução: o cuidado formal e informal impacta os sistemas de saúde pública em todo o mundo. Emboraainda não seja suficientemente reconhecido, está relacionado a outrodesenvolvimento demográfico e epidemiológico: o envelhecimentopopulacional e o aumento dos níveis de dependência. Isso significa que os idososestão cada vez maisemambas as extremidades da díade cuidadora. **Objetivo:** descrever o impacto do cuidado emidosos, cuidadores informais. **Método:** estudodescritivo transversal com 74 cuidadores informais. Quatorzevariáveis sociodemográficas, psicológicas e relacionadas ao cuidado foramestudadas usando umquestionário de caracterização e as escalas Duke-UNC-11, Zarit eGoldberg. **Resultados:** as variáveis sociodemográficas apresentarampadrõessemelhantes entre os cuidadores em ambos os grupos populacionais, compredomínio de mulheres de meia-idade e filhas dos cuidadores. No entanto, as variáveisassociadas à prestação de cuidados mostraram que os idososdedicammais tempo àstarefas de cuidado e o fazemcom menos apoio do que outros cuidadores, o que impactou negativamente suasaúde, emboraissopareça ser compensado por leves melhorias nos níveis de sobrecarga do cuidador e nos sintomas de ansiedade e depressão. **Conclusões:** as condiçõesem que os cuidadores estudadosprestam cuidados afetammais os idosos, emboraestesapresentem potencial de recuperação.

Palavras-chave: cuidadores informais; idosos; sobrecarga do cuidador

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INTRODUCTION

Population aging has become an alarming situation, addressed by professionals and politicians around the world, seeking to mitigate and explain its consequences for socioeconomic development and respond to the challenge it represents. It is a process derived from the demographic transition, increasing life expectancy, decreasing mortality and fertility, as well as the survival rate of those over 60.

Cuba has negative population growth (-1.7%) and its reproduction rate, which has stalled at 0.75%, without ensuring population replacement for several years (1). Thus, the country is among the nations with "very advanced" aging in Latin America and the Caribbean; the aging rate is expected to reach 28% by the end of the 2020s and continue to increase to 35% by 2040.(2). Comparing the aging rate in 2000 (12.9%) with that reached in 2023 (24.4%), the percentage of older adults has doubled in just over 20 years, a process that took almost a century in North America and Europe(1).

This aging includes another, even more challenging aspect: the "aging of aging," which involves the growth of older adults, including those over 75. Therefore, the total number of older adults and their life expectancy are increasing. Geriatric life expectancy, or survival after age 60, ranges between 23 and 25 years in Caribbean countries, so people who turn 60 have the potential to live to approximately 85. This will lead to a 5.5-fold increase (approximately 80%) in the number of people over 75 years of age in the region. (3) This places Cuba, Puerto Rico, and Uruguay at a ratio of one person over 75 for every two between 60 and 75 years of age by the end of the 1930s.(2)

Thus, the reduction in the average family size, negative emigration, the aging of the elderly and the increase in chronic diseases have led to a reduction in the economically active population, increasing the dependency rate in Cuba to 596 per 1,000(1); all of this has generated a growing demand for care. However, in the last decade, there has been a mismatch between the demand for care and the ability to provide it satisfactorily, known as the care crisis(4), where the sectors involved (State, family, market, and community) have been affected by economic difficulties and the globalization of hegemonic and totalitarian societies. Therefore, caring for others is increasingly taking refuge in interpersonal relationships and less in institutions and health services(3,4), thus redefining informal care.(5)

An informal caregiver is someone who performs basic caregiving functions, usually related to family members or close relatives, without prior training and without receiving financial compensation for their work. Informal care is defined as the unpaid provision of physical, emotional, and social support to dependent individuals (the sick, elderly, or disabled). It is commonly a primary or main caregiver who devotes a significant amount of time to caregiving for at least six weeks, typically alone and assuming other duties indirectly related to caregiving.(6)

Within this group, older adults who care for other dependents are beginning to stand out. This percentage, which a few years ago hovered around one-tenth of caregivers, now exceeds one-third, reaching almost half of all caregivers in some studies.(7,8,9)

In this sense, one might ask: why should we address this reality? Old age, although not necessarily associated with illness or decrepitude, reveals biological and psychosocial changes that imply increasing vulnerability to the development and well-being of the elderly.(3,8,10) To this could be added that caring for others has been recognized as an extremely stressful task with high costs for those who perform it,(5,10) generating impacts on the personal level due to overwork and a lack of meeting needs; on the social level due to changes in family, relationship, and relationship dynamics, as well as on the economic level; and on health, resulting in elevated physical and psychological morbidity.(11,12)

This highlights the need to study and intervene with older adults who serve as caregivers. How are caregivers experiencing their role under current social conditions? Moreover, how are older adults who have had to take on this task due to the aforementioned caregiving crisis experiencing the impact of their role based on the biological and sociopsychological factors that determine their transition through this stage? These become pressing questions for the scientific and professional community.

Therefore, the objective of this study will be to evaluate the psychosocial conditions under which these older adults care for others, describing the impact it has on their health. It will provide a first insight into a dizzying and worrying reality that will allow older caregivers to be seen as an even more vulnerable group within the caregiving community.

METHOD

A descriptive, cross-sectional study was designed with 106 caregivers (N=106) who attended psychological counseling services at the Universidad de Oriente between September 2024 and February 2025. The demand for support and empirical evidence of health problems among the caregivers who attended generated the need for this study, particularly in light of the aging of the institution itself and the aging of many of the caregivers who came for counseling.

Based on a non-probability sample, inclusion criteria were defined to homogenize the sample and avoid bias in the results. A final selection was made of 74 caregivers (n=74) who met the following criteria:

- Be a primary caregiver and live permanently with the person they care for
- Have been a caregiver for at least 6 months
- Willingness to participate in the research

The elements studied were organized as follows:

a) Sociodemographic variables: age, sex, marital status, relationship to the person being cared for
b) Variables associated with caregiving: length of time caring, daily hours dedicated to caregiving, time of day caring, resources and support for caregiving, as well as the level of dependency of the person being cared for and the caregiver's health
c) c) Psychological variables: burden of caregiving, perception of social support, and presence of anxiety-depressive symptoms (ADS)

The instruments used were:

Caregiver Characterization Questionnaire: to assess sociodemographic and caregiving-related factors. This questionnaire was developed by the authors. Not yet validated, it has been used since 2016 in the study of informal caregivers.(13)

Duke-UNC-11 Scale: to measure social support perceived by caregivers. It includes the following dimensions: affective and confidential support. With an internal consistency measured with Cronbach's alpha of 0.92 and validated for Cuban caregivers.(14)

Caregiver Burden Scale: To assess the feeling of burden experienced by family caregivers. It shows satisfactory internal consistency, with a Cronbach's alpha coefficient of 0.9. It is one of the few instruments for measuring burden adapted to the Hispanic population. The version adapted to our setting was used.((15)

Goldberg Test: to assess levels of anxiety and depression in caregivers, it has two subscales with separate scoring, with adequate sensitivity (83.1%), specificity (81.8%), and positive predictive value (95.3%). The Spanish version, validated by Montón, Echevarría, and Campos in 1993, was used.(16)

Data analysis and statistical processing were performed using the SPSS software. Initially, a database was created with the information obtained from each caregiver. Then, based on the proposed objective, an absolute frequency distribution and average calculations were performed for all variables. In addition, the mean and standard deviation were used as measures of central tendency and dispersion for continuous variables.

The study design and implementation were based on the Declaration of Ethical Principles for Medical Research Involving Human Subjects of the World Medical Association and Chapter II of the Draft Code of Ethics of the Cuban Society of Psychologists. Data confidentiality and subject anonymity were guaranteed. Data were made available after the implementation of informed consent.

RESULTS

Table 1 shows the sociodemographic characteristics of the caregivers. A predominance of middle-aged women, daughters of the caregivers, was observed. One-third of all caregivers were older. It is worth noting that of those in the 36-59 age groups, 18.9% were between 57 and 59 years old, this means that, when added to the 29.7% who are over 60 years old, in just three years, nearly 50% of the caregivers studied in this population will be older.

Among older caregivers, the presence of men was observed at 22.7%. Furthermore, almost a third were mothers or fathers of the dependents; the absence of spouses was significant in both groups.

Table 1: Sociodemographic characteristics

Indicator		Frequency	Caregivers	Frequency	Older caregivers
Sex	Female	43	82,7%	17	77,3%
	Male	9	17,3%	5	22,7%
Age	18-35	5	6,8%	-	
	36-59	47	63,5%	14	57-59A 18,9%
	+ 60	18	24,3%	22	+ 6029,7%
	+ 70	4	5,4%	-	
Marital status	With a partner	26	50,0 %	10	45,5%
	Without a partner	26	50,0 %	12	54,5%
Relationship	Daughter/Son	34	65,4 %	15	68,2%
	Father or mother	5	9,6%	5	22,7%
	Other	13	25,0%	2	9,0 %

Table 2 shows the factors related to caregiving. It highlights how older caregivers care for people with higher levels of dependency, provide care for more hours per day (17.7 hours on average) and for a longer period of time (13.8 years on average) than the rest of the caregivers studied, who dedicate approximately 15 hours a day to caregiving and have been providing care for approximately 8.5 years. Similarly, older caregivers who have been providing care for their family member for more than 20 years (27%) doubled the number of other caregivers who have provided care for the same amount of time (13%). Similarly, older caregivers who reported providing care for 24 hours (45.4%) also outperformed the rest of the caregivers (32.7%).

Approximately 9 out of 10 older caregivers (86.4%) acknowledged that they provide caregiving all the time, compared to fewer among the rest of the caregivers (65.4%). Although it must be acknowledged that these percentages are high in each case, as more than half of both groups, do not have scheduled hours to care for others.

Overall, when evaluating the resources needed to provide care, older caregivers reported having fewer resources than other caregivers did. Similarly, they reported having worse health levels, and while three-quarters of both groups reported fair to poor health, almost twice as many older caregivers reported poor health as other caregivers with the same perception.

Table 2: Characteristics associated with caregiving

Indicator		Frequency	Caregivers	Frequency	Older caregivers
Level of independency	Total dependency	13	25,0%	8	36,4%
	Severe dependency	1	1,9%	1	4,5%
	Mild dependency	9	17,3%	4	18,2%
	Moderate dependency	29	55,8%	9	40,9%
Time of caregiver (year)	Mean	-	8,5 A	-	13,8 A
	DE	-	10,3	-	14,72
	+20 years of caregiving	7	13,0%	6	27,0%
Hours ay care	Mean	-	14,9H	-	17,7 H
	DE	-	7,3	-	6,68
	24 hours caregiving	17	32,7%	10	45,4%
Time of caregiving	Day	4	7,7%	-	-
	Night	5	9,6%	2	9,1%
	Early morning	9	17,3%	1	4,5%
	All the time	34	65,4 %	19	86,4%
Help to care	Receives help	36	69,2%	14	63,6%
Resources	Sufficient	15	28,8%	3	13,6 %
	Means	15	28,8 %	9	40,9 %
	Insufficient	22	42,3%	10	45,5%
Caregiver health	Good	14	26,9%,	5	22,7%
	Fair	28	53,8%	10	45,5 %
	Poor	10	19,2%	7	31,8 %

The analysis of the psychological characteristics presented in Table 3 highlights the high levels of caregiving burden and intense burden in both groups of caregivers. Similar results were found when assessing the presence of SAD, although it is noteworthy that older caregivers reported a slightly lower incidence of both symptoms, despite the appearance of separate signs of anxiety and depression that were not observed in the rest of the caregivers.

Almost three-quarters of caregivers felt supported in their task, a percentage that fell to just over half among older caregivers. The presence of confidential support and emotional support also decreased among the latter, with 63.6% and 45.5% respectively, compared to the rest of the caregivers, where such support reached 80.8% and 57.7%.

Table 3: Psychological Characteristics

	Indicators	Caregivers	Older caregivers
Care burden	No burden	17,3%	13,6 %
	Presence of burden	82,7%	86,4%
	Light burden	21,2%	22,7 %
	Heavy burden	65,5%	63,6%
Social Support	General	73,1 %	59,1 %
	Confidential	80,8 %	63,6%
	Affective	57,7%	45,5%
SAD	Presence of ADS	80,8%	72,7%
	Anxiety Symptoms	-	4,5
	Depressive Symptoms	1,9 %	9,1
	No presence	17,3%	13,6%

Finally, Chart 1 shows the variables that showed the greatest percentage differences between the two groups; the greatest differences were observed in the variables associated with care and the least in the psychological variables.

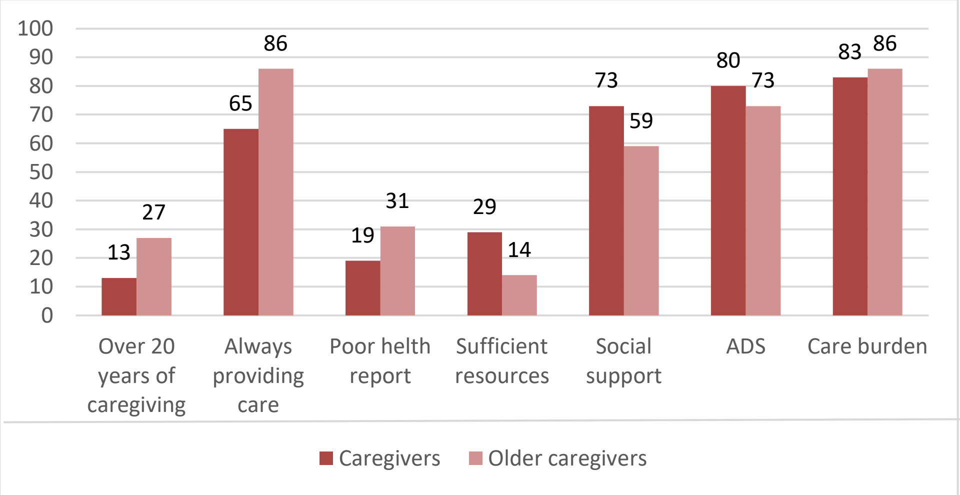

Chart 1: Variables with the greatest percentage differences and main impacts between caregivers and older caregivers.

DISCUSSION

The traditional caregiver profile(6,7) suggests middle-aged women, daughters of the people they care for, which coincides with the results presented in this study. Similarly, the growing presence of older adults as caregivers for other dependents has been highlighted in research both domestically and internationally. In some contexts, this reaches the majority among the caregivers studied(6,7,8), as is expected to happen in a few years among the group of caregivers in this research; making them an even more vulnerable population. Since in this case the difficulties associated with the role of caregiver are added to the biological, economic, and social problems that arise in old age.(3,8)

Among older adult caregivers, the number of men dedicated to this task is increasing, possibly associated with the predominant kinship, with children commonly being left to care for their parents. This is also explained by the small size of families and emigration in the country, which has limited the exercise of care from the traditional variants that place daughters-in-law, nieces, and granddaughters in the care of their relatives when daughters cannot assume this task.(5,6,17)

With respect to the kinship of caregivers, and contradictory to the results of other studies, very low percentages of the spouses exercising the role appeared to be the ones exercising the role. Caregiving work has increased significantly, and the role of mothers and fathers in caring for their dependent children has grown significantly, especially among older caregivers.(17,18) This could explain why older adult caregivers who have been caring for their family member for more than 20 years outnumber other caregivers who reported providing care for the same amount of time. This situation opens another point of controversy, since caregivers who are both parents and older adults also have concerns about the future and the care of their children when they are gone.(3,8,17,18)

Older adults care for more people with total, severe, and moderate levels of dependency than their counterparts in other age groups. This is explained by the older age of the caregivers and the longer they have been providing care, with the majority being the parents of these older caregivers. This also explains why they spend more hours a day caring and are mostly the ones providing care at all times.

Numerous studies assess the impact of patient behavior on caregiver health, but the level of dependency that would allow for objective assessment of the associated burden is rarely measured. This is essential for understanding the caregiving process and its consequences for caregivers, given that the work of caring at all times without taking time for oneself, along with high levels of dependency, is significantly associated with high physical and psychological morbidity.(8,11,17)

Although these factors associated with care presented crucial differences that put older caregivers at a disadvantage compared to other caregivers, the cumulative figures are alarming in both groups. The fact that 13% of caregivers and twice as many older caregivers have been providing care for more than 20 years; and that 32.7% of the former and almost half of the latter reported providing care for 24 hours without a planned break, coinciding with a high percentage of 65.4% and an even higher percentage of 86.4% who provide care at all times of the day, represents a picture of objective burden that will likely jeopardize the already damaged health of caregivers and point to the imminent possibility of caregiver collapse and/or surrender(18).

The majority of caregivers have insufficient or moderate resources to provide care, an issue reported by other foreign and Cuban research studies,(5,6,7) but it is noteworthy that older caregivers present a more deficient situation, with far fewer reporting having sufficient resources to perform the task. This aspect could be associated with the economic and material situation faced when transitioning into old age.(3,11,12)

Along the same lines, it could also be related to the much lower level of support for caregiving, reported by older caregivers—almost 20 percentage points less than the rest of the caregivers—when describing the confidential and emotional support they perceived in the performance of their tasks. These data generally coincide with the lack of recognition, support, and accompaniment that older adults receive in any social context.(3,8) This, combined with the current conditions in the country, leaves older adults, and even more so caregivers of this age, feeling lonely and vulnerable. Interventions should be planned to integrate and redefine the diamond of caregiving, including older adults as caregivers who, in turn, require care.(4,8)

The burden of caregiving is recognized as the main negative effect of caregiving,(5,9) it reached impressive levels in this study and was also present in more than half of the cases in an intense manner. These percentages are higher than in previous studies, where 70% of Cuban caregivers suffer from burden, and only half of these experience it intensely.(8,17,19) This reality could be due, once again, to the socioeconomic context in which caregiving is carried out today, subject to greater deficits and uncertainties, which underpin the negative experience.

These conditions explain the high percentages of caregivers reporting poor and average health, similarly found in other research,(9,12,17) The burden of care is also linked to SAD, which appeared to be elevated among the caregivers in the sample, as in other studies(11,19) and with similar results in older caregivers. In this sense, the appearance of symptoms of anxiety and depression in isolation is notable in these caregivers, but this is not the case in younger caregivers. This situation coincides with the mental health processes that occur in old age, primarily associated with disengagement, the presence of unresolved conflicts from previous stages, and maladjustment to the stage.(3,8,12,17)

The results showed that the caregiver's health is truly compromised, as they experience primarily emotional and social harm. These realities define the caregiver situation as a social and health problem that impacts the dependent person in need of care, their caregiver, their family, and society as a whole.(19) In this sense, it is essential to rethink social and health policies by making caregivers visible as a valuable resource, as well as recognizing the magnitude of informal caregiving.

Furthermore, it was observed that older adults have provided care for longer periods of time, with poorer health, less support and resources, yet still reported very similar levels of SAD and caregiving burden. This suggests the possible development and implementation of a greater number of psychosocial resources that mediate the impact of caregiving;(10,18,19) it is necessary to consider older adults not only as sick and dependent individuals, but also as caregivers and health managers, with specific needs in this role.

CONCLUSIONS

The caregivers studied provide care under very unfavorable conditions, which has generated high levels of caregiving burden and anxiety-depressive symptoms, affecting their overall health.

Older caregivers are less well-equipped to provide care, as they invest more time in it and have fewer resources and support. This, combined with the physical and psychosocial factors of age, constitutes a health problem affecting both caregivers and those they care for. This makes them dependent on caring for older adults, who perform the task without guarantees of health or time to do so. However, the levels of burden and anxiety-depressive symptoms, similar to those of other caregivers, could reflect resources and experiences developed with older age, which are articulated as a protective factor against the impact of caregiving. This topic deserves further study.

Family caregiving shows alarming indicators that could affect the social and health situation. It is necessary to develop health strategies that consider the elderly and dependents.

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