# Mediator effect of caregiver burden on the association between disability and quality of life among older adults

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#### **Abstract**

Objective. To estimate the association of disability and quality of life considering the potential mediating role of caregiver burden among a sample of older Mexican adults and their caregivers. Materials and methods. Cross-sectional study with 93 dyads (elderly/caregivers) conducted in 2018 in five localities (urban and rural) of the State of Mexico. The quality of life (QoL) was determined using the WHO Quality of Life (WHOQoL) instrument. Disability was measured by assessing the basic activities of daily living (BADL), and the caregiver burden was evaluated by the Zarit Burden Interview (ZBI). **Results.** The results showed that BADL disability is associated with a lower QoL (total effect: -14.3; 95%Cl: -20.2,-8.4) and that a significant proportion of this association can be attributable to caregiver burden (25.0%; 95%CI: 17.9,43.2). **Conclusions.** Our findings show the need for designing effective interventions that prevent or ameliorate the adverse effects of caregiver burden.

Keywords: quality of life; disability studies; caregiver burden; mediation analysis

Salinas-Rodríguez A, Manrique-Espinoza BS, Montañez-Hernández JC. Efecto de la sobrecarga del cuidador en la asociación entre discapacidad y calidad de vida en adultos mayores. Salud Publica Mex. 2022;64:507-514.

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#### Resumen

Objetivo. Estimar la asociación entre discapacidad y calidad de vida considerando el potencial rol mediador de la sobrecarga del cuidador en una muestra de adultos mayores mexicanos y sus cuidadores. **Material y métodos.** Estudio transversal con 93 díadas (ancianos/cuidadores) realizado en 2018 en cinco localidades (urbanas y rurales) del Estado de México. La calidad de vida (CdV) se determinó utilizando el instrumento Calidad de vida-OMS (WHOQoL). La discapacidad se midió mediante la evaluación de las actividades básicas de la vida diaria (ABVD) y la carga del cuidador mediante el puntaje Zarit. Resultados. La discapacidad de ABVD se asocia con una CdV más baja (efecto total: -14.3; IC95% -20.2,-8.4), y una proporción significativa de esta asociación puede atribuirse a la carga del cuidador (25.0%; IC95%: 17.9,43.2). Conclusiones. Los hallazgos muestran la necesidad de diseñar intervenciones efectivas que prevengan o mejoren los efectos adversos de la carga del cuidador.

Palabras clave: calidad de vida; estudios de discapacidad; carga del cuidador; análisis de mediación

Disability is an adverse health condition, frequently related to aging, that can have deleterious consequences for individuals and communities. Disability has been shown to be associated with greater use of health

services, higher risk of dependency, institutionalization, lower quality of life (QoL) and higher all-cause mortality risk. <sup>1-3</sup> The reported prevalence of disability –as measured by limitations in basic activities of daily living

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(BADL)– ranges from 16.2 to 77.7% among older adults ages 50 and over in low and middle-income countries and is more prevalent in women than men.<sup>4</sup> In Mexico, the estimated national prevalence of BADL disability is 26.9%, with even higher prevalence among women and octogenarians.<sup>5</sup> With a rapidly aging population in Mexico, it is expected there to be an increasing burden of disability, as well as increased demand for health services and long-term care in this population in the coming years.<sup>6</sup>

The link between disability and quality of life among older adults has been widely documented.<sup>7-10</sup> In general, the findings show that disability —as measured through limitations in basic (BADL) and instrumental activities (IADL) of daily life—is associated with a lower quality of life.

Disability in older adults could also have an impact on their caregivers. Limitations in BADL and duration of care have been found to be the most important predictors of perceived burden by caregivers. Perceived burden among caregivers has been shown to increase with the number of limitations to BADL. However, a bidirectional relationship has also been found, where caregiver burden is a predictor of older adult disability and vice versa. 13

Previous studies have highlighted that the relationship between caregivers and care recipients could influence the QoL of the care recipients. Aside from the association between poor physical and psychological health and lower QoL, little is known about the role that caregiver burden could have on QoL of the care recipients. In fact, most studies have focused on the impact that caregiver burden has on the QoL of caregivers themselves. 16,17

Specific associations of disability, caregiver burden, and QoL in care recipients have been largely unexplored. In particular, it is important to understand the potential mechanisms that underlie the association between disability and QoL. Therefore, the aim of this study was to estimate the association of BADL disability and the QoL while considering the potential mediating role of caregiver burden. Our hypothesis is that a significant proportion of the association between BADL disability and QoL is attributable to caregiver burden.

# Materials and methods

## Study design, setting and participants

Data comes from the study "Economic impact of physical dependence in older adults and the burden of informal care", conducted in 2018 with a sample of 735 community-dwelling older Mexican adults aged 60 and

above. The participants in the study were residents of five communities (two urban and three rural) in the State of Mexico, located in central Mexico. Details of the study have been published elsewhere. For the present analysis, we included older adults who reported having an informal caregiver. A total of 93 dyads were identified. We obtained data on sociodemographic characteristics of the caregivers (sex, age, years of formal schooling), care activity (cohabitation with the care's recipient, years of care, and daily time of care), and level of burden.

## **Ethical approval**

The ethics and research committees of the *Instituto Nacional de Salud Pública* approved the study (IRB 1203-2018). All participants were provided with a detailed explanation of the study procedures and signed an informed consent letter.

#### **Measures**

Outcome

Quality of life (QoL). We assessed this variable using the World Health Organization (WHO) QoL instrument (WHOQoL). This eight-item questionnaire covers the following core domains (two items per domain): physical, psychological, social, and environmental. The results of the eight items are summed to obtain an overall score ranging from 0 to 100. The higher the score, the higher the quality of life.<sup>19</sup>

Main exposure

Disability was measured using the Katz scale,<sup>20</sup> which includes the assessment of the following basic activities of daily living (BADL): walking across a small room, bathing, dressing, eating, getting from bed to chair, and toileting. Participants were asked their ability to perform each task with no help, with help, or unable to do so. Older adults who reported any difficulty in any activity were classified as having BADL disability.

Potential mediator

The caregiver-perceived burden was measured using the Zarit Burden Interview – ZBI.<sup>21</sup> This instrument consists of 22 items that evaluate the caregiver-older adult relationship, as well as the condition of the caregiver's health and well-being. The responses are scored on a five-point Likert-type scale. Caregivers indicate how much they endorse each statement (0-never; 1-rarely; 2-sometimes; 3-quite frequently; and 4-nearly always)

in items 1-21, and how overwhelmed they feel in the role of caregiver (0-not at all; 1-a little; 2-moderately, 3-quite a bit; 4-extremely) in the last item. The total score ranges from 0 to 88, with higher scores denoting greater caregiver-perceived burden.

#### Covariates

Older adults' characteristics: sex (female=1), age, years of formal schooling, marital status (with partner=1), health insurance (yes=1), pension (contributory/non-contributory=1), paid job (yes=1), dwelling area (urban=1, rural=0). We also included 19 indicator variables for each of the following self-reported conditions that were obtained from the participants (1=present): hypertension, diabetes, hypercholesterolemia, heart disease (angina pectoris, heart failure), embolism, stroke or cerebral thrombosis, arthritis or rheumatism, bronchitis or pulmonary emphysema, osteoporosis, kidney chronic disease, tuberculosis, cataracts (one or both eyes), urinary incontinence, prostate disease (men only), and cancer (skin/melanoma, cervix, breast, prostate, stomach, leukemia / blood). With this information, we generated a dichotomous variable to express the presence of multimorbidity, defined as having two or more chronic conditions. We also measured the household socioeconomic status (SES) based on an asset index that estimates the permanent income of the household through the ownership of goods and household characteristics.<sup>22</sup> We used nine dichotomous variables (yes/no) that evaluated possession of household assets. The asset index was generated using a polychoric correlation matrix through a principal component analysis. The index is continuous, with higher values denoting a higher household SES.

Caregiver characteristics: sex (female=1), age, years of formal schooling, co-residence with the older adult, number of years caring for the older adult, and number of hours per day caring for the older adult.

## Statistical analysis

Descriptive statistics (means, standard deviations, or percentages, as appropriate) and linear regression models were used to analyze the association between disability, health-related quality of life, and caregiver burden. We use the method proposed by Imai and colleagues<sup>23</sup> to explore the potential mediating role of caregiver burden. In this method, robust estimates are provided for decompositions the total effects into direct and indirect effects, as well as the proportion of the total effect that is due to the mediator variable. Imai, Keele, and Yamamoto<sup>24</sup> also developed the algorithms

to conduct sensitivity analyses to assess the robustness of findings.

The modeling procedure includes the fitting of two linear regression models: (1) a model with disability and caregiver burden as the exposure variables and QoL as the outcome, and (2) a second model with disability as the exposure variable and caregiver burden as the outcome. In the first model, we included older adult characteristics such as sex, age, multimorbidity, years of formal schooling, union status, health insurance, labor pension, paid job, dwelling area, and household SES as covariates. In the second model, we included caregiver characteristics such as sex, age, years of formal schooling, co-residence with older adult, caregiver duration (years), and care time per day (hours), in addition to the variables related to older adults: sex, age, multimorbidity, and household SES.

The statistical analyses were conducted in Stata 17.0 using the "MEDIATION" module.<sup>25</sup> Differences were considered statistically significant if p < 0.05 and 95% confidence intervals (CIs) were given.

# Results

The study sample included 93 dyads (older adults and their caregivers). Table I displays the characteristics of the dyads. Among the older adults, prevalence of BADL disability was 51.6%, the mean age was 79.2 years (SD=9.4), and the mean formal schooling was 2.5 years (SD=3.1). Of the sample, 69.9% were female, 3.2% had paid job, 39.8% were married/cohabiting, and 43.0% had multimorbidity, defined as the presence of two or more chronic diseases. As for caregivers, the mean Zarit score was 19.9 (SD=13.3), 82.8% were female, and 86.0% lived with the older adult. Their mean age was 50.9 years (SD=15.0), their mean formal schooling was 9.1 years (SD=4.1), the mean duration of caregiving was 11.2 years (SD=11.4), and the mean care time per day was 13.5 hours (SD=9.4).

Table II shows the sociodemographic and health characteristics of older adults and their caregivers by disability status. Compared with older adults without disability, those with disabilities had lower WHOQoL scores (p < 0.01) and were older (p = 0.04). They also were more likely to be female (p = 0.01), reported more multimorbidity (p = 0.03), and were less likely to live with a partner (p = 0.03) or have a labor pension (p = 0.03). Among caregivers, the only significant difference was observed in the Zarit score. People caring for disabled older adults had a higher Zarit score than individuals caring older adults without disability (p < 0.01).

Table III displays the associations between disability, health-related quality of life, and caregiver burden

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Table I

SOCIODEMOGRAPHIC AND HEALTH CHARACTERISTICS

OF THE OLDER ADULTS AND THEIR CAREGIVERS.

Mexico, 2018

Number of dyads=93	Older adult	Caregiver
BADL disability	51.6	
Caregiver burden (Zarit score)		19.9 (13.3)
Sex (female)	69.9	82.8
Age	79.2 (9.4)	50.9 (15.0)
Years of formal schooling	2.5 (3.1)	9.1 (4.1)
Union status (with partner)	39.8	
Health insurance	88.2	
Labor pension	46.2	
Paid job	3.2	
Multimorbidity	43.0	
Dwelling area (urban)	79.6	
Household SES (assets index)	0.3 (2.0)	
Live with the older adult		86.0
Caregiver duration (years)		11.2 (11.4)
Care time per day (hours)		13.5 (9.4)
Cells are means (SD) or percentages BADL: basic activities of daily living SES: socioeconomic status		

adjusted by covariates. In the model with caregiver burden as the outcome, the presence of disability in the older adult was associated with higher Zarit scores ( $\beta=9.4,~95 \text{CI}\%:~3.4,15.3$ ). Meanwhile, in the model with WHOQoL scores as the outcome, disability status among the older adult and caregiver burden were significantly related to lower scores in the WHOQoL ( $\beta=-10.4,~95 \text{CI}\%:~-16.6,-4.3$  and  $\beta=-0.4,~95 \text{CI}\%:~-0.6,-0.2,$  respectively). Figure 1 shows these associations, which also represent the direct effects of BADL disability on caregiver burden and QoL, and the effect of caregiver burden on QoL.

Table IV shows the results of the mediation analysis. Using the approach of Imai and colleagues<sup>23</sup> we found that caregiver burden partially mediates the relationship between ADL disability and QoL. The mediating effect (indirect effect) of caregiver burden on QoL was -3.6 (95%CI: -6.9,-1.1), which accounted for 25% of the total effect (95%CI: 17.9,43.2).

# Discussion

The results of this study support the hypothesis about the mediating effect of the caregiver burden on the association between disability and quality of life in older adults. The findings show that BADL disability is associated with a lower QoL, and that a significant

Table II

CHARACTERISTICS OF THE OLDER ADULTS AND CAREGIVERS ACCORDING TO PRESENCE OF DISABILITY. MEXICO, 2018

Variables	No disability (n=45)	Disability (n=48)	p-value
Older adult			
Quality of life (WHOQoL score)	63.6 (11.6)	50.8 (14.8)	<0.01
Sex (female)	57.8	81.3	0.01
Age	77.1 (7.8)	81.2 (10.4)	0.04
Years of formal schooling	2.5 (2.9)	2.5 (3.2)	0.91
Union status (with partner)	51.1	29.2	0.03
Health insurance	93.3	83.3	0.14
Labor pension	57.8	35.4	0.03
Paid job	2.2	4.2	0.60
Multimorbidity	31.1	54.2	0.03
Dwelling area (urban)	80.0	79.2	0.92
Household SES (assets index)	0.5 (2.2)	0.2 (1.9)	0.51
Caregiver			
Caregiver burden (Zarit score)	15.8 (10.6)	23.7 (14.5)	<0.01

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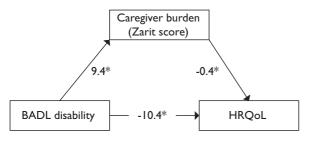
Sex (female)	86.7	79.2	0.33
Age	48.5 (13.9)	53.2 (15.7)	0.13
Years of formal schooling	9.2 (4.6)	9.3 (3.6)	0.93
Live with the older adult	91.1	81.3	0.17
Caregiver duration (years)	11.0 (10.9)	11.4 (12)	0.86
Care time per day (hours)	13.2 (9.4)	13.8 (9.4)	0.78

Cells are means (SD) or percentages p-value for a Chi-square o t tests SES: socioeconomic status WHOQoL:World Health Organization quality of life

Table III
Association between disability, quality of life, and caregiver burden. Mexico, 2018

Variables	Caregiver burden (Zarit score)		Quality of life (WHOQoL score)	
	β [95%CI]	p-value	β [95%CI]	p-value
Older adult				
BADL disability	9.4 [3.4,15.3]	<0.01	-10.4 [-16.6,-4.3]	<0.01
Sex (female)	-5.3 [-11.7,1.0]	0.100	-1.9 [-8.5,4.8]	0.573
Age	-0.2 [-0.5,0.1]	0.239	-0.1 [-0.4,0.2]	0.542
Years of formal schooling			0.6 [-0.5,1.6]	0.281
Union statusl (with partner)			-5.1 [-11.1,0.8]	0.088
Health insurance			-8.4 [-17.4,0.5]	0.064
Labor pension			1.9 [-3.6,7.3]	0.492
Paid job			-4.2 [-19.8,11.4]	0.596
Multimorbidity	3.9 [-2.1,9.9]	0.196	1.7 [-4.2,7.6]	0.567
Dwelling area (urban)			0.7 [-9.2,10.7]	0.882
Household SES (assets index)	0.5 [-1.1,2.2]	0.503	1.0 [-0.8,2.8]	0.293
Caregiver				
Caregiver burden (Zarit score)			-0.4 [-0.6,-0.2]	<0.01
Sex (female)	1.4 [-6.2,9.0]	0.717		
Age	0.1 [-0.2,0.3]	0.576		
Years of formal schooling	-0.4 [-1.2,0.4]	0.319		
Live with older adult	3.7 [-4.7,12.2]	0.382		
Caregiving duration (years)	0.0 [0.0,0.0]	0.794		
Care time per day (hours)	0 [-0.3,0.3]	0.986		

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\* p-value < 0.00 l

FIGURE 1. THE MEDIATING EFFECTS OF CAREGIVER BURDEN ON THE RELATION BETWEEN BASIC ACTIVITIES OF DAILY LIVING (BADL) DISABILITY AND HEALTH-RELATED QUALITY OF LIFE (HRQoL). MEXICO, 2018

Table IV

MODELS OF THE MEDIATING ROLE OF CAREGIVER
BURDEN IN THE RELATIONSHIP BETWEEN BADL
DISABILITY AND QUALITY OF LIFE. MEXICO, 2018

Effect	Estimate	95%CI
Total	-14.3	-20.2,-8.4
Direct	-10.4	-16.6,-4.3
Indirect	-3.6	-6.9,-1.1
% of the total effect mediated	25.0	-17.9,43.2

proportion of this association can be attributable to caregiver burden. To the best of our knowledge, this is the first study that explores the mediating role of the caregiver burden on the association between disability and quality of life among older adults.

Our results confirm what has been reported about the explored associations. Regarding the relationship between disability and QoL, multiple studies have shown that disability is related to the lower levels of QoL.26-28 Among older adults, disability could result from a chronic condition that gradually undermines functional capacity.<sup>29</sup> In fact, the onset of the chronic conditions represents the beginning of age-related functional declines that lead to disability, loss of independence, decrease in QoL, and even death.<sup>30,31</sup> One potential pathway for the link between disability and QoL is the uncertainty associated with the onset and development of chronic conditions, which include time, money, and energy to control their possible adverse effects, increases in health care costs, and, finally, a decrease in the quality of older adults' lives.32

With regard to the association between disability and caregiver burden, our results also confirm what has previously been reported about the role of BADL disability as

one of the strongest predictors of caregiver-perceived burden. <sup>11-13,33</sup> It has been hypothesized that disability increases the intensity of caregiving and the required number of specialized caregiving tasks, resulting in a higher caregiver burden —a plausible explanation for this association. <sup>34</sup> In that vein, disability is considered a general stressor within the framework of the Adapted Stress Model, which describes the relationships between various exposure factors that cause caregiver-perceived burden. <sup>11</sup>

Scientific evidence has also shown that caregiver burden may be associated with the quality of life of care recipients, although studies have been limited to individuals with specific conditions such as stroke<sup>35</sup> and dementia. 14,15 Our results confirm this association in a sample of apparently healthy community-dwelling older adults. The specific link between caregiver burden and quality of life in care recipients is not well established, 35,36 although it is possible that the stress associated with caregiver burden has a negative impact on various aspects of the QoL of older adults, especially for those considered in the instrument used in this research (WHOQoL), which includes the physical, psychological, social, and environmental domains. For example, a high caregiver-perceived burden may imply that the psychological needs of the care recipient are not being well taken care of. Future research could delve into the potential mechanisms that determine whether a greater burden on the caregiver is associated with a decrease in the quality of life of care recipients.

Finally, and regarding the interrelationships of disability, caregiver burden, and quality of life in care recipients, a longitudinal study of adult stroke survivors found that caregiver burden is negatively related to quality of life of care recipients, and when physical functionality, assessed through the Barthel index, improves, the quality of life also improves.<sup>37</sup> Although this is the study most similar to ours, it is difficult to benchmark our results because the two studies differ greatly in scope. Even so, it can be used for triangulation purposes. Both studies showed that disability and caregiver burden have independent associations with lower levels of QoL. However, this study contributes to the current body of evidence by establishing that caregiver burden plays a mediating role on the association between disability and QoL, which implies that a potential intervention to diminish the caregiver burden could have a positive effect on the care recipients' quality of life. Future studies must be conducted to confirm or refute this hypothesis.

Some limitations must be considered in this study. First, we used the short version of the WHOQoL (WHOQoL-BREF) as a measure of the QoL. This version includes only eight items, which means that we were unable to explore the specific domains of this scale (physi-

cal, psychological, social, and environmental) regarding disability and caregiver burden. Even so, our findings reveal significant associations between BADL disability and QoL with the mediating role of the caregiver burden. Second, although we used a robust analytical approach to estimate the mediating effect of the caregiver burden, the results must be interpreted with caution, since our study is cross-sectional and, therefore, precludes any causal inference. Third, it was not possible to identify the type of relationship or kinship that the caregiver had with the older adult, since the original study from which these data are derived focused on the responses of the older adult about disability-related health expenditures, and it did not include an in-depth examination of all aspects of caregivers but covered only a few sociodemographic characteristics, as well as overburden. It is likely that a high percentage of caregivers were members of the older adult's family, and these data should have been incorporated into our analysis.

This study has important implications for research and public policy. For research, our results show that the caregiver burden may mediate the relationship between disability and QoL; however, our data come from a cross-sectional study. In that vein, further studies, with a longitudinal design and in which the role of the caregiver burden is formally evaluated, are required in order to determine whether an intervention to reduce the burden could improve the QoL of older adults who receive care. In the realm of public policy, is necessary to design effective interventions that will prevent or ameliorate the adverse effects of the caregiver burden. In Mexico, for example, the creation of a National Care System is being considered. One its aims is to provide support for unpaid caregivers through a cash payment (for hiring a formal caregiver) and training in the provision of care.<sup>38</sup>

# **Ethical approval**

The ethics and research committees of the *Instituto Nacional de Salud Pública* approved the study "Impacto económico de la dependencia física en los adultos mayores y estimación de la carga asociada a los cuidados informales" ("Economic impact of physical dependency in older adults and estimation of the burden associated with informal care", No. 1203-2018). All participants were provided with a detailed explanation of the study procedures and signed an informed consent letter.

#### Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Declaration of conflict of interests. The authors declare that they have no conflict of interests.

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