




# Psychotic experiences among informal caregivers: findings from 48 low- and middle-income countries

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## Abstract

**Purpose** Informal caregivers may be at high risk for psychotic experiences (PE) due to caregiving related stress, sleep issues, or other potential mechanisms, but this has not been previously investigated in the general adult population. Thus, we examined the association between caregiving and PE, and its mediators, in a large sample of adults from 48 low- and middle-income countries (LMICs).

**Methods** Cross-sectional, community-based data from the World Health Organization (WHO) World Health Survey were analyzed. Informal caregivers referred to those who provided help to a relative or friend (adult or child) in the past year, because this person has a long-term physical or mental illness or disability, or is getting old and weak. PE were assessed using the WHO Composite International Diagnostic Interview psychosis screen. Multivariable logistic regression and mediation analyses were conducted.

**Results** Data on 224,842 individuals were analyzed. The mean (SD) age was 38.3 (16.0) years (range 18–120 years) and 50.7% were females. After adjustment for age, sex, and country, in the overall sample, caregiving was associated with 1.67 (95%CI = 1.56–1.79) times higher odds for PE. Sleep/energy explained the largest proportion of the association between caregiving and PE (13.9%), followed by pain/discomfort (11.5%), perceived stress (7.6%), depression (6.2%), and cognition (3.5%).

**Conclusion** Caregivers in LMICs are at higher risk of PE. Future studies are warranted to gain a further understanding of the underlying mechanisms, and to assess whether addressing the identified mediators can lead to lower risk for PE among caregivers.

**Keywords** Psychotic experience · Informal caregiving · Low- and middle-income countries · Epidemiology

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## Introduction

The global population is ageing at an unprecedented speed due to increase in life expectancy resulting from medical and public health advances. By 2050, the world's population of people aged 60 years and over is expected to double (2.1 billion) from current figures. Furthermore, between 2020 and 2050, the number of people aged 80 years and over is projected to triple and reach 426 million [1]. Ageing of the population in low- and middle-income countries (LMICs) is outpacing that of high-income countries, and by 2050, two-thirds of the global population over 60 years of age will be residing in LMICs [1]. As people live longer, they also now live more years with disability [2], and the current demographic trend points to an ever growing number of people in need of long-term care, as well as the need to substantially increase the quantity of caregivers for these people. Globally, most people living with disabilities due to long-term illness or old age are provided informal care (i.e., unpaid support from friends or relatives) [3]. In LMICs, due to insufficient health and welfare systems, there may be a particularly heavy dependence on informal care [4].

Studies on the health status of informal caregivers is important as the health of the caregiver is vital to sustain informal care provision. For example, caregiving strain has been associated with a 1.63 times higher risk of caregiver death [5]. Although there is a multitude of studies on the mental health of caregivers, data on the association between caregiving and psychotic experiences (PE) are scarce. PE are attenuated forms of psychotic symptoms (e.g., delusions and hallucinations), which do not reach the clinical threshold for a psychosis diagnosis, and are highly prevalent in the general population [7.2% based on a meta-analysis [6]]. PE have been known to represent underlying vulnerability to clinical psychosis (e.g., schizophrenia) in a small minority of people with this condition [7], and are more broadly associated with an increased future risk for a multitude of other negative health outcomes, including suicidality [8], chronic physical conditions [9], non-psychotic mental disorders [10], and premature mortality [11].

Caregivers may be at particularly high risk for PE as previous studies have shown that caregivers are more likely to have pain, sleep problems, stress, cognitive problems, and depression [12–14], which have all been reported to be risk factors for PE [10, 15–18]. However, to the best of our knowledge, there is currently only one previous study on caregiving and PE. This large US study including only college students found that caregiving to COVID-19 patients was not significantly associated with PE [19]. However, the generalizability of this previous study is severely limited, given that the sample was relatively young and

highly educated, occurring in the midst of a pandemic in a high-income country. Furthermore, the short duration of COVID-19 caregiving, compared to chronic conditions such as dementia, may not be sufficient to contribute to chronic stress, pain, sleep problems, or other common effects of long-term caregiving.

Thus, the aims of the current study were to assess the association between caregiving and PE in a large predominantly nationally representative community-based sample of adults aged  $\geq 18$  years from 48 LMICs, and to identify potential mediators of this association. We hypothesized that caregiving would be associated with higher odds for PE, and that this association would be mediated by factors such as depression, pain/discomfort, sleep/energy, perceived stress, and cognition.

## Methods

### The survey

The World Health Survey (WHS) 2002–2004 was a cross-sectional, community-based study conducted in 70 countries from multiple continents. Details of the survey are provided elsewhere [20]. Briefly, stratified multi-stage random cluster sampling was done in 60 countries, while the rest conducted single-stage random sampling. Eligibility to participate was restricted to those aged 18 years or older with a valid home address, and Kish tables were used to guarantee that each member of the household had an equal probability of being selected. All countries used a standardized questionnaire. The individual response rate was 98.5%. Ethical boards at each study site provided ethical approval to conduct the study, and informed consent was obtained from all participants. Sampling weights were created for the purpose of adjusting for non-response and the population distribution based on the United Nations Statistical Division.

## Variables

### Psychotic experiences (PE)

The WHO Composite International Diagnostic Interview (CIDI) 3.0 (psychosis module) was used to obtain information on positive psychotic symptoms [21], which has been reported to be highly consistent with clinician ratings [22]. The hallucinations question did not include conditions associated with substance use or sleep-related states. Respondents were asked the following questions with answer options 'yes' or 'no': During the last 12 months, have you experienced

- (a) ‘An experience of seeing visions or hearing voices that others could not see or hear when you were not half asleep, dreaming or under the influence of alcohol or drugs?’ (hallucinations)
- (b) ‘A feeling that people were too interested in you or there was a plot to harm you?’ (delusions of reference and persecution)
- (c) ‘A feeling something strange and unexplainable was going on that other people would find hard to believe?’ (delusional mood)
- (d) ‘A feeling that your thoughts were being directly interfered or controlled by another person, or your mind was being taken over by strange forces?’ (delusions of control)
- (e) Individuals who answered affirmatively to at least one of the above-mentioned four questions were considered to have PE.

### Caregiving

Caregiving was assessed by the question “During the past year, did you provide help to a relative or friend (adult or child), because this person has a long-term physical or mental illness or disability, or is getting old and weak?”, and those who answered affirmatively were considered to be caregivers [23]. Similar questions have been used in previous surveys to identify caregivers [24].

### Mediators

The potential mediators in the association between caregiving and PE considered in this study included depression, pain/discomfort, sleep/energy, perceived stress, and cognition [10, 12–18]. Past 12-month depression was based on the Diagnostic and Statistical Manual of Mental Disorders-IV algorithm [25]. Two questions each were used to assess other potential mediators. The actual questions are provided in Table S1 (Appendix). Each item was scored on a five-point scale ranging from ‘never’ to ‘very often’ (perceived stress) or ‘none’ to ‘extreme/cannot do’ (pain/discomfort, sleep/energy, cognition). Based on the two questions for each health status, factor analysis with polychoric correlations was conducted to obtain a factor score which was converted to scores ranging from 0 to 100 with higher values signifying worse health status [26]. Data on perceived stress were not collected in Brazil, Hungary, and Zimbabwe.

### Control variables

Control variables included age and sex. Although factors such as marital status, wealth, education, household size, unemployment, poor self-rated health, and disability could also be potential confounders [23], preliminary analysis

showed that they have almost no influence in the association between caregiving and PE (See Table S2 of the Appendix for details on these additional variables and the results of regression models including these variables). Thus, these variables were not included in the models also to maximize sample size.

### Statistical analysis

Of the 70 countries, data were publicly available for 69 countries. Of these, ten countries were excluded due to a lack of sampling information. Furthermore, ten high-income countries were excluded as most of these countries used a shorter version of the questionnaire and did not collect information on PE, and also because the focus of our study was on LMICs. Moreover, Turkey was deleted due to lack of data on PE. Thus, the final sample consisted of 48 countries, which corresponded to 21 low-income, 17 lower middle-income, and 10 middle-income countries according to the World Bank classification at the time of the survey (2003). The data were nationally representative for all countries, except for China, Comoros, the Republic of Congo, Ivory Coast, India, and Russia. The countries included in the current study and their sample sizes are provided in Table S3 of the Appendix.

The statistical analysis was done with Stata 14.2 (Stata Corp LP, College station, Texas). All analyses omitted individuals with a self-reported lifetime diagnosis of psychosis ( $n = 2424$ ), as PE by definition exclude conditions that reach the clinical threshold for a diagnosis. Chi-squared tests and Student’s *t* tests were used to test differences in sample characteristics for categorical and continuous variables, respectively. Multivariable logistic regression analysis was done to assess the association between caregiving and PE. To assess whether the magnitude of the association between caregiving and PE differs by age groups (i.e., 18–44, 45–64,  $\geq 65$  years) and sex, we included the interaction terms caregiving  $\times$  age groups or caregiving  $\times$  sex in the model. A statistically significant interaction was found for age groups but not for sex. Thus, analyses stratified by age groups were also conducted.

To assess the degree of between-country heterogeneity in the association between caregiving and PE, we calculated the Higgin’s  $I^2$  based on country-wise estimates. This corresponds to the magnitude of heterogeneity that cannot be explained by sampling error with values of 25%, 50%, and 75% commonly being considered as low, moderate, and high levels of heterogeneity [27]. Meta-analysis with random effects was used to obtain overall estimates based on country-wise estimates.

Next, to provide insight into the extent to which various factors may explain the association between caregiving and PE, we conducted mediation analysis using the *khb* (Karlson Holm Breen) command in Stata [28]. This method is

applicable to logistic regression models, and decomposes the total effect (i.e., unadjusted for the mediator) of a variable into direct (i.e., the effect of caregiving on PE adjusted for the mediator) and indirect effects (i.e., the mediational effect). Using this method, the percentage of the main association explained by the mediator (i.e., mediated percentage) can also be estimated. Each potential mediator was included in the model individually.

All regression analyses including the mediation analysis were adjusted for age, sex, and country, except for the country-wise analysis which was not adjusted for country. Adjustment for country was conducted by including dummy variables for each country in the model in line with previous WHS publications [15, 17, 18]. The complex study design including sample weighting was taken into account in all analyses. Results from the regression analyses are shown as odds ratios (ORs) with 95% confidence intervals (CIs). The level of statistical significance was set at P-value under 0.05.

## Results

The final sample consisted of 224,842 individuals. The mean (SD) age was 38.3 (16.0) years (range 18–120 years) and 50.7% were females. The prevalence of PE and caregiving was 14.4% and 19.2%, respectively. Individuals with PE and caregivers both had significantly higher prevalence of female sex and depression, while they also had worse health status in terms of pain/discomfort, sleep/energy, perceived stress, and cognition (Table 1). The prevalence of PE was much higher among caregivers compared to non-caregivers (Fig. 1). For example, in the overall sample, the prevalence of PE was 21.8% among caregivers, while this figure was

11.9% among non-caregivers. After adjustment for age, sex, and country, in the overall sample, caregiving was associated with 1.67 (95%CI = 1.56–1.79) times higher odds for PE (Table 2). The association was most pronounced among the youngest age group (i.e., 18–44 years) (OR = 1.77; 95%CI = 1.62–1.93), and least among the oldest age group (i.e., ≥ 65 years) (OR = 1.35; 95%CI = 1.01–1.82). Country-wise analysis showed that caregiving was positively associated with PE (i.e., OR > 1) in all countries with this being statistically significant in the majority of countries (Fig. 2). The overall estimate based on a meta-analysis was OR = 2.00 (95%CI = 1.83–2.18) with a moderate-to-high level of between-country heterogeneity ( $I^2 = 69.5\%$ ). The pooled estimates by country-income level were similar: low-income countries OR = 2.11 (95%CI = 1.82–2.44); lower middle-income countries OR = 1.87 (95%CI = 1.63–2.14); upper middle-income countries OR = 2.04 (95%CI = 1.75–2.38). Finally, mediation analysis showed that sleep/energy explained the largest proportion of the association between caregiving and PE (13.9%), followed by pain/discomfort (11.5%), perceived stress (7.6%), depression (6.2%), and cognition (3.5%) (Table 3).

## Discussion

### Main findings

Caregiving was associated with an increased odds for PE among adults aged ≥ 18 years in LMICs, and interaction analysis showed that this association was particularly pronounced in those aged 18–44 years. Country-wise analysis showed that caregiving is positively and significantly

**Table 1** Sample characteristics (overall and by psychotic experience or caregiving)

Characteristic		Overall	Psychotic experience			Caregiving		
			No	Yes	P-value <sup>a</sup>	No	Yes	P-value <sup>a</sup>
Age (years)	Mean (SD)	38.3 (16.0)	38.3 (16.1)	38.2 (15.0)	0.599	38.4 (16.4)	38.0 (14.3)	0.023
Sex	Male	49.3	49.7	46.6	<0.001	49.7	47.5	<0.001
	Female	50.7	50.3	53.4		50.3	52.5	
Pain/discomfort <sup>b</sup>	Mean (SD)	26.1 (27.0)	24.4 (26.5)	37.1 (27.1)	<0.001	25.3 (27.2)	29.5 (26.2)	<0.001
Sleep/energy <sup>b</sup>	Mean (SD)	21.0 (26.1)	19.3 (25.4)	32.7 (27.5)	<0.001	20.1 (26.0)	25.0 (26.0)	<0.001
Perceived stress <sup>b,c</sup>	Mean (SD)	36.6 (27.5)	35.6 (27.2)	46.9 (26.9)	<0.001	36.3 (27.4)	37.8 (27.6)	0.001
Cognition <sup>b</sup>	Mean (SD)	19.6 (25.8)	18.1 (25.2)	29.8 (27.0)	<0.001	19.3 (26.0)	21.1 (24.7)	<0.001
	Depression							
	No	93.4	95.3	80.1	<0.001	93.9	90.8	<0.001
	Yes	6.6	4.7	19.9		6.1	9.2	

SD Standard deviation

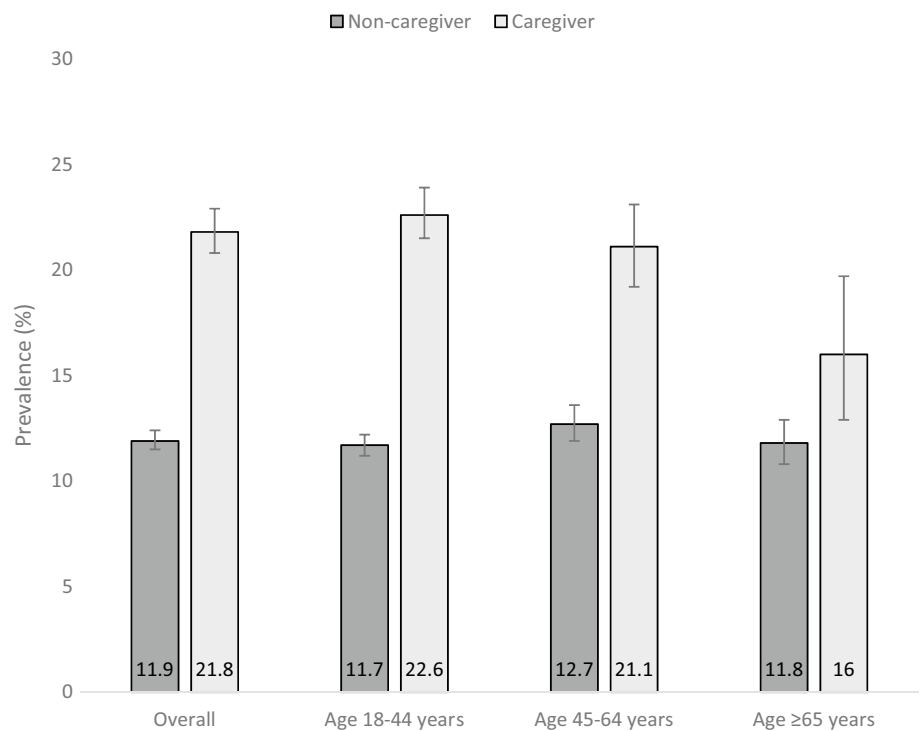
Data are % unless otherwise stated

<sup>a</sup>P-values were obtained by Chi-squared tests and Student's t-tests for categorical and continuous variables, respectively

<sup>b</sup>Based on a scale ranging from 0 to 100 with higher scores representing worse health status

<sup>c</sup>Data from Brazil, Hungary, and Zimbabwe were not available

**Fig. 1** Prevalence of psychotic experiences by caregiving status (overall and by age groups). Bars denote 95% confidence interval



**Table 2** Association between caregiving (or covariates) and psychotic experience (outcome) estimated by multivariable logistic regression (overall and by age groups)

		Overall		Age 18–44 years		Age 45–64 years		≥ 65 years	
		OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI
Caregiving	No	1.00		1.00		1.00		1.00	
	Yes	1.67***	[1.56,1.79]	1.77***	[1.62,1.93]	1.52***	[1.29,1.79]	1.35*	[1.01,1.81]
Age (years)		1.00	[1.00,1.00]	1.00	[0.99,1.00]	1.01*	[1.00,1.02]	1.02**	[1.01,1.04]
Sex	Male	1.00		1.00		1.00		1.00	
	Female	1.18***	[1.09,1.27]	1.17***	[1.07,1.28]	1.16*	[1.03,1.30]	1.29**	[1.07,1.57]

OR Odds ratio, CI Confidence interval

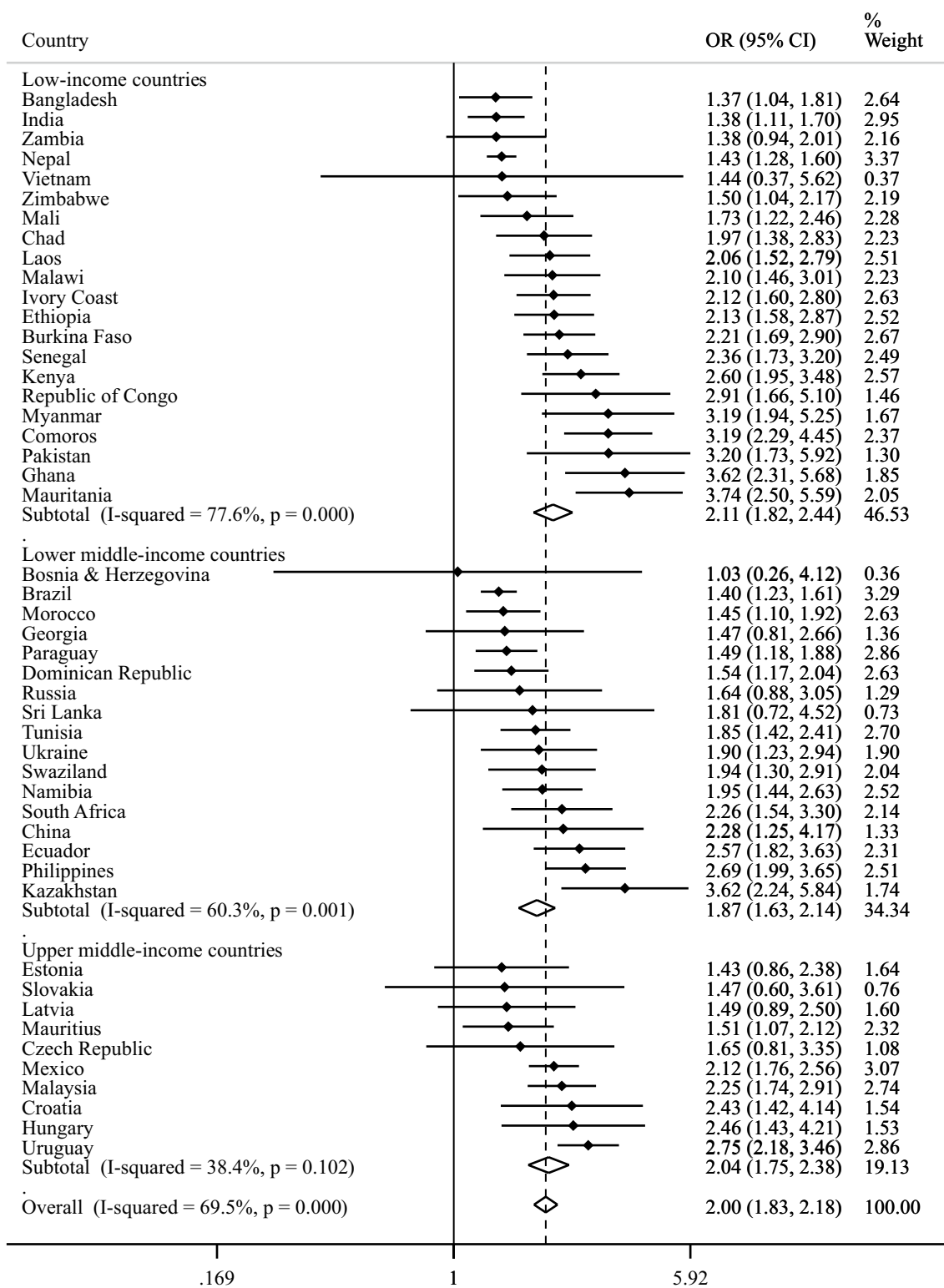
Models are adjusted for age, sex, and country

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

associated with PE in the majority of countries, with a moderate-to-high level of between-country heterogeneity. Mediation analysis showed that pain/discomfort and sleep/energy explained more than 10% of the association between caregiving and PE, with perceived stress, depression, and cognition explaining this association to a lesser degree. To the best of our knowledge, this is the first study on the association between caregiving and PE from the general adult population, while it is also the first study on this topic from LMICs.

### Interpretation of findings

Several hypotheses may explain the positive association between caregiving and PE found in our study. Based on our mediation analysis, sleep/energy and pain/discomfort explained more than 10% of the association. Caregivers may be at higher risk for sleep problems for worries related with the care-recipient’s health, the care recipient’s symptoms at night (e.g., nocturnal incontinence, wandering at night, hallucinations, agitation), or need to monitor the care



**Fig. 2** Country-wise association between caregiving and psychotic experiences estimated by multivariable logistic regression adjusting for age and sex. OR Odds ratio, CI Confidence interval. Subtotal and overall estimates were obtained by meta-analysis with random effects



**Table 3** Mediators in the association between caregiving and psychotic experiences

Mediator	Effect	OR [95%CI]	P-value	%Mediated
Pain/discomfort	Total	1.69 [1.57,1.81]	<0.001	11.5
	Direct	1.59 [1.48,1.70]	<0.001	
	Indirect	1.06 [1.05,1.07]	<0.001	
Sleep/energy	Total	1.69 [1.57,1.81]	<0.001	13.9
	Direct	1.57 [1.46,1.69]	<0.001	
	Indirect	1.08 [1.06,1.09]	<0.001	
Perceived stress <sup>a</sup>	Total	1.79 [1.65,1.96]	<0.001	7.6
	Direct	1.72 [1.57,1.87]	<0.001	
	Indirect	1.05 [1.03,1.06]	<0.001	
Cognition	Total	1.69 [1.58,1.81]	<0.001	3.5
	Direct	1.66 [1.55,1.78]	<0.001	
	Indirect	1.02 [1.01,1.03]	<0.001	
Depression	Total	1.72 [1.59,1.86]	<0.001	6.2
	Direct	1.66 [1.54,1.80]	<0.001	
	Indirect	1.03 [1.02,1.05]	<0.001	

OR Odds ratio, CI Confidence interval

Models are adjusted for age, sex, and country

<sup>a</sup>Data from Brazil, Hungary, and Zimbabwe were not available

recipient at night [29]. Sleep problems in turn may increase risk for PE via factors such as negative affect and alterations in perception [30, 31]. Physical effort exertion involved in caregiving such as lifting the care recipients or helping them with daily activities may lead to pain (especially chronic back pain), also through awkward postures [32], while sleep problems and psychological distress [33] induced by pain may increase risk for PE. Next, previous studies have shown that stress-related conditions and depression are the most common mental health problems in caregivers [34], and these explained 6.2–7.6% of the association. Factors such as complicated caregiving tasks, financial loss (e.g., lost productivity, treatment costs), restrictions in personal life, social isolation, illness-specific problems of the care recipient (e.g., aggression in dementia patients), and the uncertainty in terms of the prognosis of the care receiver's illness and duration of care may all induce stress and have a negative impact on the mental health of caregivers [34, 35]. Previous studies have shown that impaired hypothalamic–pituitary adrenal axis function in people exposed to stress may increase risk for PE [36]. Furthermore, PE often co-occurs with depression [37], and a bidirectional association may exist, resulting in the persistence and/or the exacerbation of both conditions [38]. Finally, cognition explained a very small proportion of the caregiving-PE relationship (3.5%). Caregiving may increase risk for cognitive impairment through sleep disruption, limited social support, and stress [14], while cognitive impairment may cause PE by influencing the interpretation of events [39].

However, the mediators assessed in our study explained a relatively small proportion of the association between caregiving and PE. Thus, it is likely that other factors also play a role. For example, previous studies have shown that caregivers are more likely to be lonely and socially isolated, possibly for having to limit time invested in leisure (e.g., social activities) or other relationships [40]. In turn, a positive association between loneliness and PE has been reported, and it has been hypothesized that this may be mediated by low self-esteem, social deafferentation, and stress [41]. Finally, caregivers may also be more likely to consume cannabis to cope with the stress associated with caregiving [42], and cannabis use has been reported to be a risk factor for PE [43].

The finding that the association between caregiving and PE was stronger among younger individuals may be reflecting the fact that caregiving may be more of a psychological burden among younger individuals as they struggle to balance the provision of care with multiple tasks pertaining to personal life, family responsibilities, and work commitments [44]. In particular, younger individuals are more likely to experience a double burden of taking care of their young children and also their elderly parents, while caregiving at young age may be more likely to interfere with career development and income generating activities than in older ages. For instance, adult child caregivers are more likely to view caregiving as “extra work” and experience added stress associated with the burden of role reversal [44]. This can potentially lead to a high risk for psychological distress and mental health problems including PE.

Finally, a moderate-to-high between-country heterogeneity in the association between caregiving and PE was observed with particularly high ORs in countries such as Mauritania, Ghana, and Kazakhstan (OR = 3.62–3.74). This may be related to differences in factors such as intensity of caregiving, disease profiles of the care recipient, acceptability of caregiving as a norm, and quality of welfare systems across countries. However, more research is needed to understand the between-country heterogeneity observed.

### Implications of the findings

The results of our study point to the possibility that addressing mental health and pain among caregivers may also lead to prevention of PE among caregivers. Cognitive behavioral therapy (CBT), mindfulness training, and relaxation have been shown to improve sleep among caregivers [29], while a small uncontrolled interventional study showed that CBT for insomnia leads to reductions in delusions among patients with persecutory delusions and insomnia [45]. Furthermore, psychosocial interventions (e.g., support groups or psychoeducational interventions) for caregivers have been shown to mitigate caregiver burden and distress [46].

Small randomized controlled trials for dementia caregivers in LMICs have shown that some interventions (e.g., information on dementia, guidance on behavior management, psychiatric assessment and psychotropic medication if needed) can potentially relieve caregiver strain and/or reduce psychological morbidity in this setting [47–49]. More recently, a meta-analysis showed that internet-based supportive interventions significantly improved depressive symptoms, perceived stress, anxiety, and self-efficacy among dementia caregivers [50], and this may also be an effective strategy in LMICs as availability of the internet is increasing. In regard to the level of pain, caregivers may be relieved by being trained appropriately on different modality of care and use of the equipment overall. Direct benefits and financial compensation (e.g., state-funded salaries or reimbursements through the health care system) may also alleviate some of the strain of informal caregiving, particularly for those with lower incomes [51]. However, to date, intervention studies with PE as the outcome are extremely scant and thus, future studies with PE as the outcome are necessary to make concrete recommendations. Specifically, future intervention studies for caregivers that focus on addressing the potential mediators identified in our study may also consider including PE as an outcome.

### Strengths and limitations

The strengths of the study include the use of a large predominantly nationally representative dataset from multiple LMICs. However, the study results should be interpreted in light of several limitations. First, data were self-reported and thus, reporting bias may exist. Second, the data were collected in 2002–2004, and it is, therefore, possible that the results do not necessarily reflect the current situation. However, we are not aware of any other population-based data with such a large number of LMICs that can be used to investigate the caregiving-PE relationship. Next, we lacked data on whether the care recipient had died, and thus, residual confounding due to this factor may exist, as bereavement has been associated with PE [52]. In addition, we lacked information on some characteristics of caregiving (e.g., intensity, duration). Thus, our estimate may be an underestimate as individuals with very little involvement in caregiving could have been considered to be caregivers. Finally, due to the cross-sectional nature of the study, temporal associations or causality cannot be established.

### Conclusions

In our study using a large community-based, predominantly nationally representative sample of adults from 48 LMICs, caregiving was associated with increased odds for PE. Our

findings add to previous literature on mental health status of caregivers by showing for the first time that caregivers may also be at higher risk for PE. Given that the health of the caregiver is of paramount importance to sustain the system of informal caregiving, and the fact that current demographic trends point to a continuing and increasing demand for informal caregiving, more research on how to improve mental health including PE of caregivers especially in the context of LMICs is warranted.

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### Declarations

**Conflict of interest** The authors have no conflicts of interest to declare.

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