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The impact of informal caregiving on older adults' physical and mental health in low- and middle-income countries: a cross-sectional, secondary analysis based on the WHO <u>S</u>tudy on global <u>AGE</u>ing and adult health (SAGE)

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Abstract

Objectives: A high proportion of care stemming from chronic disease or disability in low- and middle- income countries is provided by informal caregivers. The goal of this study was to determine the level of burden experienced by these caregivers, explore associated factors, and assess whether caregivers' and non-caregivers' health differed.

Design and setting: This cross-sectional study was a secondary analysis of data on caregivers' burden, health, and health risk factors in Ghana, India, and the Russian Federation (RF) collected as part of the WHO's Study on global AGEing and adult health (SAGE) - Wave 1.

Participants: Caregivers in Ghana (n = 143), India (n = 490), and Russia (n = 270) completed the measures.

Outcome measures: Factors associated (i.e., demographics and caregiving profile variables) with burden were explored among caregivers. Then, quality of life, perceived stress, depression, self-rated health, and health risk factors were compared between caregivers and matched non-caregivers (1:2).

Results: The largest caregiving sub-groups were spouses and adult children. Caregivers mostly cared for one person and provided financial, social/emotional, and/or physical support, but received little support themselves. Burden level ranged from was 17.37 to 20.03. Variables associated with burden were mostly country specific; however, some commonality for wealth, type of care, and caregiving duration was noted. Caregivers with a moderate or high level of burden reported lower quality of life and higher perceived stress than those experiencing low burden. Caregivers reported lower quality of life and self-rated health than non-caregivers.

Conclusion: Given the lack of support received and consequences of the burden endured by caregivers, policy and program initiatives are needed to ensure that caregivers can fulfill their role without compromising their own health.

Strengths and limitation of the study

- This is the first comprehensive study on informal caregiving burden among multiple LMICs.
- A key strength include that SAGE has nationally representative samples and with high response rates.
- One weakness of this survey is related to its interview length and this burden might have affected the quality of the responses to the caregiving-related questions as these were the last section of the interview.
- The cross-sectional design precludes causal inferences.

Competing interest statement

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Data sharing statement

No additional data available.

Introduction

Globally, the number of people aged 60 years or older is expected to grow by 56% between 2015 and 2030.[1] This demographic shift is accompanied by a health transition, whereby 23% of the total global burden of disease is now attributable to disorders in older adults.[2] Under the scenario where global prevalence of disabilities and diseases remain stable, the growth in the number of older adults alone is expected to increase demands for health care beyond the capacity of health care systems.[3] Therefore, there is less reliance on specialized care settings and more focus on delivering care in the community.[4] Within this context, informal caregivers provide a high proportion of the care needed and are an essential extension of the health care system.[4 5] The support that caregivers provide not only positively impacts on care recipients' quality of life (QOL),[6] but represents significant cost-saving to health care systems.[4]

Informal caregivers can be broadly defined as family members, partners, friends or neighbors who provide a wide range of unpaid assistance for individuals with chronic or disabling conditions.[5] In high-income countries (HICs), up to almost half of the population are (or have been) a caregiver and provide anywhere from 12-25 hours of informal assistance per week.[7 8] Caregivers are often responsible for specialized medical care, planning and coordinating care, monitoring patient's health status, ensuring treatment or medication adherence, and preventing adverse events.[4] Caregivers may also adopt the role of decision-maker, particularly if the care recipient is experiencing cognitive impairments.[4] For older care recipients, caregivers typically provide assistance with activities of daily living, potentially preventing accidents and further declines in functioning.[4] Emotional support is another frequent role; however, caregivers often experience the least confidence and greatest uncertainty in providing this support.[7]

Although caregiving is a valued societal resource, and often viewed positively by caregivers themselves, caregivers remain largely a hidden and underappreciated workforce.[9] Consequently, caregivers experience substantial burden, which might lead to the care recipients' institutionalization.[10] Burden is most apparent in caregivers' reporting of anxiety and depression. Depending on the caregiving profile (e.g., sex, age), caregivers' prevalence of anxiety and depression can exceed general population norms, and in some cases, those reported by care recipients.[7] Burden also has a negative impact on caregivers' physical health (e.g., fatigue, pain), particularly as caregivers are often older themselves and confront the demands of their own illnesses.[11] Further compromising their health, caregivers often prioritize the care recipients' health over their own, and do not access needed support or health services[7] or are less likely than non-caregivers to engage in preventive health behaviors.[12] This not only puts caregivers' health at risk, but ultimately the care recipients' health.[13] With the expected growth in the number of caregivers and changes in health care systems as well as the substantial burden endured, the caregiving role is now considered a public health priority.[14]

Despite the exponential increase in the number of caregivers worldwide, few studies have examined caregivers' health in low-and middle-income countries (LMICs).[15] LMICs have a higher prevalence of disability than HICs[16] and care recipients are more likely to rely on caregivers due to the lack of services or programs.[15] Therefore, it is reasonable to expect higher burden among caregivers in LMICs than those in HICs. A recent review by Thursh et al.[15] of 43 studies among caregivers of adults with a physical and/or mental illness in LMICs concluded that there is considerable physical, psychological, social, time, and financial burden on these caregivers. Although this is highly useful data, development of this evidence-base is still in its infancy. Studies published to date are limited by the small sample sizes, lack of quantitative data; diverse measures

used across LMICs, limiting comparisons across countries; and few studies use a non-caregiver comparison group. Furthermore, some health consequences of caregiving on caregivers have received little to no attention in LMIC studies, including quality of life, stress, depression, and health risk behaviors. Therefore, there is an urgent need for more methodologically rigorous research to examine caregivers' challenges in LMICs and develop an evidence base to inform policy and decision-making about health services for these caregivers.

The objectives of this population-based study were to a) describe the caregiving profile and level of burden experienced by caregivers in two LMICs (Ghana and India) and one upper-middle country (Russian Federation), b) examine how caregiver burden varied according to demographic and caregiving profile variables by country, c) assess whether health-related outcomes and health risk factors are associated with caregiving burden, and d) determine the extent to which caregivers' health-related outcomes and health risk factors differed from non-caregivers by country.

Methods

Design
This is a secondary, cross-sectional analysis of the data collected as part of the World Health Organization's (WHO's) multi-country Study on global AGEing and adult health (SAGE) - Wave 1 (2007 – 2010).[17] SAGE was designed to collect information on the ageing process in nationally representative samples across China, Ghana, India, Mexico, the Russian Federation, and South Africa. SAGE received approval from the WHO's Ethical Review Committee and the respective committees in each participating country. Written informed consent was obtained from all study participants. For this secondary data analysis, ethical clearance was obtained from Deakin University.

Participants
SAGE is a representative study of the population aged 50+ in each participating country, with a smaller sub-sample of adults 18 – 49 years old.[17] The methods for SAGE are extensively described elsewhere.[17] In brief, multistage, stratified cluster sampling methods were used in each country. Country-specific strata were typically defined by region/state/province/district and locality. For all countries, a primary sampling unit (i.e., enumeration areas, villages, or districts) was identified to generate a list of households. Households were classified into one of two mutually exclusive categories: a) '50+' (older) household, where the target respondent was aged 50+; or b) '18–49' (younger) household, where the target respondent was aged 18-49 years. All persons aged 50+ were selected from the older households, whereas one person aged 18-49 was selected from each younger household. Post-stratification weights were generated, adjusting for population distribution of age and sex in each country at the time of survey.[18]

The caregiver sub-sample was comprised of participants 50+ who identified themselves as the primary person providing care to an adult in their household in the past 12 months. Non-caregivers were 50+ participants who did not provide any care to someone else in their household. Those who identified caring for someone who was deceased or a child were excluded. Data from China, Mexico, and SA were not considered, because caregiving data were not collected, the caregiver sub-sample was too small, or an extremely skewed post-stratified weights distribution was observed.

Data collection
A standardized individual questionnaire was administered by trained interviewers.[17]

Demographic characteristics
Caregivers' demographics included sex, age group, locality, marital status, household size, wealth, education, and employment status. Education levels were based on the international standard classification of education.[19] An index of household wealth or permanent income was generated based on household ownership of durable goods, dwelling characteristics, and access to services.[20]

Caregiving profile and burden
Caregiving profile was defined by the relationship to the care recipient, number of people cared for in the household, reasons for and types of care provided, caregiving duration, and support received by the caregiver, including source. Caregiving burden was measured by 10 items focused on the perceived impact of caregiving. Each item was rated on a five-point scale ranging from 1 = none to 5 = extreme. The total score (range 10-50) was categorized by tertiles to identify cut-off scores for low, moderate, and high burden by country. Country-specific exploratory factor analyses (EFA) with oblique rotation identified one factor. Cronbach's alphas in the present study were greater than 0.85.

Quality of life
For QOL, a composite score was calculated by adding the eight items of the EUROHIS-QOL questionnaire[21] and rescaling responses from 0–100. The cross-cultural psychometric properties of this scale are well-documented, including unidimentionality, internal consistency (alpha range = 0.72–0.83 across multiple countries), and validity.[21 22] EFA, with oblique rotation for each country, overall found that a one-factor structure was also appropriate to use with caregivers. Cronbach's alphas in the present study were greater than 0.85.

Perceived stress
For perceived stress, two items from the Perceived Stress Scale, rated from 0 = never to 5 = very often, were summed.[23]

Depression
Depression was assessed using the 18-item algorithm from the World Mental Health Survey.[24] The rates of mild, moderate, and severe depression were calculated according to the algorithm described by Kulkarni & Shinde[25] and combined in subsequent analyses.

Self-rated health
For self-rated health (SRH), participants answered the question: *In general, how would you rate your health today?*[26] Responses were dichotomized as 'good health' (i.e., 1= very good, 2 = good, or 3 = moderate) or 'poor health' (i.e., 4 = bad or 5 = very bad). SRH has been found to be a reliable measure of health that is sensitive to an individual's perception of health.[26]

Lifestyle health risk factors
1. Body Mass Index (BMI) was calculated as weight (kg)/height (m^2) (measured by interviewer).[27]
2. Physical activity (PA) was determined based on participants' responses to the 16 items of the Global Physical Activity Questionnaire (GPAQ), an instrument with documented validity.[28] Participants were asked about their activities at work; transport, and leisure time, which was summarized as minutes per day of expended in moderate or vigorous PA.
3. The total number of servings of fruits bnd/or vegetables on an average day was calculated and classified as a) adequate ($\geq$ 4 servings) or b) low (< 4 servings).[29 30]

4. Tobacco use was categorized as a) never used or past user of tobacco or b) current smoker.[31]

Statistical analysis

Analyses were performed using SAS V9.3 and graphs were created using Stata V14.0. Unless otherwise specified, SAS survey estimation procedures were used to account for the complex, multistage probability-sampling design. Observed frequencies and sample sizes are provided for reference. The Rao-Scott Chi-Square test was used to compare the distribution of demographic characteristics between caregivers and non-caregivers and to describe the caregiving profile proportions across the variables of interest. To identify demographic and caregiver profile variables associated with burden, bivariate analyses were conducted (p < 0.25), followed by backward stepwise regression. The final model reported for each country includes age group, sex, marital status, and wealth tertile and any other factor significantly associated with burden in at least one country. Associations between burden level and health-related outcomes and risk factors were assessed using a linear or logistic regression model (including age group, sex, wealth tertile, and marital status as potential confounders). To compare caregivers' and non-caregivers' health, each caregiver was matched with two non-caregivers based on country, age group, gender, marital status, wealth tertile or education level, and strata. Caregivers and non-caregivers outcomes were compared using generalized linear models with either binary distribution and logit link for dichotomous outcomes or normal distribution and identity link for continuous outcomes (complex survey design was not considered). The Pooled effect size (ES) was calculated using a random-effects model, which assumes heterogeneity among countries and the true effect can be different for each country.[32]

Results

Caregivers' demographics

Table 1 compares the demographics of the caregivers (Ghana, n=143; India, n=490; Russia, n=270) and non-caregivers (Ghana, n=4112; India, n=6001; Russia, n=3304) by country. No differences based on sex and locality across countries were noted. In Ghana, caregivers were more likely to be younger, live in a large household, be wealthier, have higher education, and not retired. In India, caregivers were more likely to be younger or very old, living with a partner and in mid-size households. In Russia, living with a partner was also more frequent among caregivers than non-caregivers, as well as not currently working or not retired.

Objective 1 – Caregiving profile and level of burden

Table 2 presents the caregiver profile by country. Across countries, caregivers mostly cared for a spouse (Russia, India) or adult children (Ghana), for health-related reasons, and typically provided financial, social/emotional, and/or physical support. Only in Russia did more than half of caregivers provide personal care. Up to 20% of caregivers identified receiving some kind of support to help them with their role, mostly from a family member outside the household. Across countries, the largest caregiver sub-group (40.8% to 80.7%) had been in their role for at least six months. The mean burden score (possible range = 10-50) for caregivers in India was highest at 21.03 (SE = 0.43), followed by Ghana at 19.32 (SE=0.85) and Russia at 17.37 (SE=0.48).

Objective 2 – Variables associated with burden

Table 3 presents the results of the multivariate regression analyses. Demographic and caregiving profile variables significantly associated with burden varied by country; however, some level of commonality was noted for wealth, type of care, and caregiving duration. In countries for which these variables were significant, caregivers reporting poorer wealth, providing health support, and

caring for 1 to 5 months were more at risk of burden. Although providing health support was not significant in Russia, a similar pattern to the other two countries was noted. However, in Russia, personal care was associated with burden.

Age and type of relationship were also significant across at least two countries, but the direction of the relationship was different. In Ghana, younger caregivers reported higher burden than their older counterparts, but the opposite was observed in Russia. Similarly, in India being the spouse or partner was associated with higher burden, whereas in Russia this type of relationship was protective. In Russia, the sub-group of caregivers reporting higher burden based on type of relationship was the adult children.

Relationships between age, marital status, and reasons for needing care and burden were country specific. Only in Russia did women report significantly higher burden than men. In India, being without a partner was associated with higher burden. Reason for needing care was only significant in Ghana, with health-related reasons associated with higher burden.

Objective 3 – Burden level and caregivers' health

Caregivers' health outcomes and health risk factors (non-weighted) are described in Figure 1 and results of the analysis of factors associated with burden (weighted analysis) in Table 4. QOL scores for caregivers reporting moderate or high burden were 6 to 13 points lower than those reporting low burden. Caregivers experiencing moderate or high burden reported stress scores 0.63 to 1.26 points higher than those reporting low burden. Burden was not significantly associated with depression or SRH.

Few associations between burden level and health risk factors were noted (Table 4). In Ghana, caregivers with high burden were more likely to smoke and reported a lower BMI than those with low burden. In India, lower physical activity was noted among caregivers reporting moderate burden.

Objective 4 – Caregivers' and non-caregivers' health

Across countries, caregivers in comparison to non-caregivers reported lower QOL and poorer SRH. Findings emphasized the vulnerability of caregivers in Russia, whereby they reported significantly lower QOL, more perceived stressed, depression, and poorer SRH compared to non-caregivers (Figure 1). None of the pooled analyses were significant for health risk factors (Figure 2).

Discussion

Statement of key findings

LMICs face higher prevalence of chronic diseases and disability than HICs.[16] This, combined with limited access to formal services and programs in LMICs means that a high proportion of the care needed is provided by informal caregivers.[15] However, studies of the burden that caregivers experience come almost exclusively from HICs.[15] This lack of information, plus the growing populations of older adults, suggests an urgent need for more research to examine caregivers' challenges in LMICs. The present secondary analysis described the level of burden experienced by caregivers in Ghana, India, and Russia, explored associated factors, and assessed whether caregivers' and non-caregivers' health differed. The key findings are: a) Few caregivers reported receiving support to help them with their role, b) variables associated with burden were mostly country specific, but consistent with HIC studies, c) across countries, burden has an adverse impact

on caregivers' stress and QOL, and d) across countries, caregivers reported lower QOL and SRH than non-caregivers. Each key finding is discussed in turn.

Comparison with other studies

The prevalence of caregiving across countries was lower than what has been documented in HICs. This might in part be attributed to the stigma associated with some illnesses in LMICs.[33] In a study by Mwinituo et al.[33] caregivers of AIDS patients reported losing their jobs because of discrimination. Even participants who disclosed caring for someone in our study might have kept their caregiving role a secret from others in their community, which might explain the limited support received. Thara et al.[34] also noted the limited support received by caregivers in India. In the present study, if caregivers did receive support, it was outside the family household, emphasizing the need for external programs. Similar to other studies,[15] caregivers in this study, and particularly those in Russia, were providing a variety of time-consuming personal care: bathing, dressing, and toileting, which are known sources of strain for caregivers.

Similar to studies in HICs,[7] caregiving in LMICs is not without consequences on the level of burden reported. The lack of a clear pattern of associations among demographic and caregiving profile variables and burden emphasized the need for a tailored approach to policy and service development by country. Despite this variation, findings are mostly consistent with studies in HICs.[7] This means that those low-cost, evidence-based programs developed in HICs might be amenable to the context found in LMICs (after appropriate adaptations). Although only significant in Russia, many studies have corroborated the high burden among female caregivers.[7,15] Similar to the contradictory findings on age across Ghana and Russia, some studies have reported that younger caregivers have multiple competing demands and are thereby more at risk of burden, whereas others have found that as older adults are coping with their own declining health, they are more at risk of burden.[7] The higher burden associated with the marital status "without partner" in Ghana is similar to a study in Ethiopia,[35] and might indirectly emphasize the lack of support this caregiver sub-group receives. The findings pertaining to wealth in Ghana and India are consistent with studies in HICs associating lower income to high caregiver burden.[7] Previous studies[5,38] also substantiated the impact of the type of relationship to the care recipient on caregiver outcomes, with particular vulnerable sub-groups confirmed in the present analysis, including adult children.[7,35] Adult children are "sandwiched" between raising their own children and providing for their family as well as taking on additional caregiving responsibilities. However, this is a growing group of caregivers, because of the overall aging of the population. Spouses have been found to be at particular risk of financial burden,[35] which might explain findings in India. Beyond relationship type, Pinto et al.[36] found that the quality of the relationship was more associated with burden than were variables such as gender, marital status, and illness severity. Although household size has been found to be positively associated with caregivers' emotional distress,[37] it was not a significant variable in the multivariate model. One reason for this is that a global measure of burden was used, and household size might have an impact on different dimensions of burden.

One of the most common consequences of caregiving burden is poor QOL and mental health problems such as stress and depression.[15] Our finding that burden adversely impacted on caregivers' QOL has only been reported by one other LMIC study.[36] In this study, among the domains of QOL, general health received the lowest score. The present study is the only one to document that caregivers reported lower QOL than non-caregivers, representing a vulnerable segment of the population. A finding further strengthened by the one that caregivers were also more likely to rate their health as poor in comparison to non-caregivers. Although perceived stress did not differ

between caregivers and non-caregivers, across countries, caregivers' burden was positively associated with this outcome. Only one other LMIC study was found to report on caregivers' stress, finding that 39% of older caregivers in Zimbabwe reported chronic stress.[38] A concern is that stress can lead to other emotional and/or physical problems such as insomnia, headaches, and depression for caregivers, and compromise their ability to sustain caregiving.[39]

Studies in HICs have found that caregivers report more unhealthy behaviors after taking on their role, such as low fruit and vegetable intake, increased use of tobacco, low physical activity, and being overweight.[7] No comparable study in LMICs was found. In the present study, few significant findings were noted for the relationship between level of burden and health risk factors. Our finding that burden is associated with lower physical activity is in line to the findings by Beesley et al.[12] reporting that 54% of caregivers of women with ovarian cancer did not meet the guidelines for physical activity. In addition, 37% consumed more than two alcoholic beverages per occasion, and 10% were smokers. In the present study, the relationship between smoking and burden was only significant in Ghana.

Strengths and weaknesses of the study
This is the first comprehensive study on informal caregiving burden among multiple LMICs. Key strengths include that SAGE has nationally representative samples and with high response rates.[17] One weakness of this survey is related to its interview length[17] and this burden might have affected the quality of the responses to the caregiving-related questions as these were the last section of the interview. The cross-sectional design precludes causal inferences.

Conclusion
In contrast with the available evidence of the impact of caregiving in HICs, little is known about taking on this role in LMICs. The present comprehensive caregiver study is the first of its kind internationally that informs our understanding of caregivers in India, Ghana, and Russia. Few caregivers reported receiving support to help them with their role. Variables associated with burden were country specific, but commonly included wealth, type of care, and caregiving duration, which is consistent with HIC studies. Across countries, burden had an adverse impact on caregivers' stress and QOL and caregivers reported lower QOL and SRH than non-caregivers. These findings contribute to the growing evidence-base on the substantial burden endured by caregivers in LMICs and the consequences of this role on their health. The findings of this study, in combination with those of other studies, can facilitate advocacy efforts aimed at improving support for caregivers in LMICs and strengthen their capacity to sustain their role.

Table 1: Sociodemographic characteristics of the sample by caregiver status and country, SAGE Wave 1 (2007/10)

	Ghana			India			Russian Federation		
	Main caregiver n (%)[¥]	Non-caregiver n (%)[¥]	p-value	Main caregiver n (%)[¥]	Non-caregiver n (%)[¥]	p-value	Main caregiver n (%)[¥]	Non-caregiver n (%)[¥]	p-value
Sample size	143 (3.3)	4112 (96.7)		490 (7.6)	6001 (92.4)		270 (6.1)	3304 (93.9)	
Sex									
Male	68 (42.9)	2155 (52.7)	0.067	222 (47.0)	3047 (51.3)	0.29	88 (30.94)	1175 (39.5)	0.062
Female	75 (57.1)	1957 (47.3)		268 (53.0)	2954 (48.7)		182 (69.06)	2129 (60.5)	
Age									
50– 59	76 (52.9)	1599 (39.5)		259 (57.5)	2645 (47.8)		101 (38.4)	1233 (45.3)	
60–69	37 (25.8)	1147 (27.5)	0.006	167 (30.3)	2045 (31.0)	0.0002	80 (36.3)	890 (23.9)	0.071
70+	30 (21.3)	1366 (33.1)		64 (12.2)	1311 (21.3)		89 (25.3)	1181 (30.8)	
Locality									
Urban	72 (46.4)	1663 (40.8)	0.285	117 (24.2)	1542 (29.2)	0.33	220 (78.4)	2499 (72.0)	0.365
Rural	71 (53.6)	2449 (59.2)		373 (75.8)	4459 (70.8)		50 (21.6)	805 (28.0)	
Marital status*									
Without partner	56 (37.4)	1792 (41.2)	0.409	51 (8.7)	1625 (24.2)	<0.0001	52 (28.2)	1520 (42.8)	0.023
With partner	87 (62.6)	2320 (58.8)		439 (91.3)	4376 (75.8)		218 (71.8)	1784 (57.2)	
Household size									
1-2	12 (7.1)	873 (20.2)		65 (12.6)	649 (11.1)		173 (67.5)	2278 (73.4)	
3–4	26 (23.2)	903 (21.5)	0.002	99 (23.1)	1137 (16.9)	0.017	66 (21.1)	714 (19.3)	0.281
5–6	40 (27.1)	970 (24.4)		111 (20.8)	1744 (28.5)		31 (11.4)	307 (7.3)	
7+	65 (42.6)	1365 (33.9)		215 (43.5)	2468 (43.5)		**		
Wealth tertile*									
Poorer	37 (24.8)	1384 (31.4)		170 (37.5)	1840 (32.9)		78 (22.2)	1165 (33.5)	
Middle	37 (28.2)	1426 (35.3)	0.022	142 (33)	2016 (33.9)	0.52	102 (39.7)	1128 (35.0)	0.148
Wealthier	69 (47.0)	1298 (33.3)		177 (29.5)	2108 (33.3)		90 (38.1)	1006 (31.5)	
Education									
Never been to school	**			266 (56.3)	3064 (50.9)		**		
Primary not completed	76 (50.2)	2679 (64.8)	0.004	50 (9.9)	685 (10.1)	0.42			0.264
Primary completed	10 (9.4)	451 (11.0)		68 (14.4)	850 (14.7)		16 (6.9)	368 (7.4)	

Secondary completed	57 (40.5)	958 (24.1)		106 (19.5)	1402 (24.3)		206 (81.3)	2283 (73.5)	
Higher education completed	**			**			48 (11.7)	651 (19.1)	
Employment status									
Never worked or not currently working	35 (24.9)	735 (17.6)	<0.0001	223 (45.8)	2764 (45.3)	0.21	47 (18.0)	471 (11.2)	0.026
Retired	6 (3.1)	524 (13.4)		63 (8.4)	820 (11.7)		148 (55.6)	1748 (47.9)	
Currently working	102 (72.0)	2838 (69.0)		204 (45.8)	2417 (43.0)		75 (26.4)	1083 (40.8)	

Note. ¥ = weighted %. * = with partner, includes married or cohabiting and without partner, includes divorced and widowed. ** = categories combined due to low frequencies. *** = index of household wealth or permanent income was generated based on household ownership of durable goods, dwelling characteristics, and access to services; this index was transformed in country-specific wealth tertiles.

Table 2: Caregiving profile by country, SAGE Wave 1 (2007/10)

	Ghana N = 143 n (%)	India N = 490 n (%)	Russian Federation N = 270 n (%)
Types of relationship with care recipient			
Spouse/partner	40 (29.4)	291 (59.1)	172 (57.0)
Daughter/son or daughter/son in-law	56 (37.3)	112 (24.5)	41 (12.6)
Parent/parent in-law	19 (19.3)	62 (11.6)	50 (24.1)
Others	19 (14)	25 (4.8)	7 (6.3)
Number of people in household needing care			
1	101 (73.7)	434 (83.8)	255 (96.4)
2	19 (16.2)	47 (11.7)	11 (2.7)
3+	23 (10.1)	9 (4.5)	4 (0.9)
Reasons for needing care			
Health-related reason	88 (72.3)	467 (95.6)	230 (88.9)
Other reason	47 (27.7)	23 (4.4)	40 (11.1)
Types of care provided*			
Financial	98 (68.8)	239 (54.5)	62 (23.7)
Social/Emotional	67 (51.8)	252 (47.3)	206 (72.1)
Health	62 (46.6)	281 (63.2)	88 (39.7)
Physical	58 (47.0)	227 (46.0)	137 (52.2)
Personal care	29 (23.7)	205 (45.4)	162 (67.9)
Types of personal care**&			
Bathing	20 (70.8)	131 (58.3)	128 (80.0)
Eating	10 (33.2)	127 (64.9)	56 (33.1)
Dressing	17 (60.4)	100 (59.1)	94 (59.8)
Toileting	14 (49.6)	112 (64.5)	42 (20.1)
Moving around	10 (39.5)	110 (47.7)	98 (56.1)
Incontinence	8 (30.7)	50 (30.3)	12 (7.8)
Caregiving duration			
< 30 days (1 month)	16 (10.5)	159 (34.1)	54 (23.2)
1 - < 6 months	10 (8.8)	118 (25.1)	25 (7.3)
≥ 6 months	115 (80.7)	213 (40.8)	191 (69.5)
Received any kind of support (yes)	30 (24.1)	77 (11.9)	68 (20.4)
Support received by caregivers***&			
Financial	25 (20.2)	72 (11.0)	31 (8.0)
Emotional	4 (3.2)	16 (2.4)	45 (10.9)
Health	4 (4.0)	10 (1.6)	24 (4.7)
Physical	7 (6.2)	10 (1.2)	24 (7.0)
Personal	2 (1.8)	12 (1.7)	21 (8.7)
Other	1 (0.4)	1 (0.02)	0
Source of support**&			
Family outside household	26 (85.5)	55 (68.2)	57 (88.7)
Neighbours/community	4 (13.6)	33 (40.4)	11 (12.3)
Government	0	3 (2.4)	20 (14.4)
Church	2 (7.8)	0	2 (3.6)
NGO	0	0	2 (2.7)
Other	2 (5.3)	0	3 (2.7)

Note. ¥ = weighted %. *For caregivers of more than one adult in the household, relationship defined in the following order, spouse, child, parent, child-in-law, and parent-in-law and duration accumulated across all care recipient. **Among those reporting providing personal care. ***Among those reporting receiving any type of support. & Participants answered yes/no for each option independently.

Table 3: Associations between burden and demographic and caregiving profile variables by country, SAGE Wave 1 (2007/10)**

	Ghana (N = 138)				India (N = 489)				Russian Federation (N = 264)			
	Estimate	95% CI	p-value	overall p-value	Estimate	95% CI	p-value	overall p-value	Estimate	95% CI	p-value	overall p-value
Sociodemographic variables												
Sex (ref = male)												
Female	1.04	(-1.6, 3.7)	0.44	-	0.05	(-1.7, 1.8)	0.96	-	2.51	(0.3, 4.8)	0.03	-
Age (ref = 50-59 years)												
60–69 years	-3.56	(-6.3, -0.8)	0.01	0.04	-1.27	(-3.3, 0.7)	0.21	0.29	2.35	(0.6, 4.1)	0.01	0.02
70+ years	-1.72	(-5.0, 1.6)	0.30		0.74	(-1.7, 3.2)	0.55		1.65	(-0.4, 3.7)	0.12	
Marital status (ref = with partner)*												
Without partner	-0.50	(-3.1, 2.1)	0.70	-	4.44	(1.7, 7.2)	0.002	-	-1.91	(-5.6, 1.7)	0.30	-
Wealth (ref = wealthier)												
Poorer	3.42	(0.9, 5.9)	0.01	0.03	2.20	(0.4, 4)	0.02	0.04	0.05	(-2.7, 2.8)	0.97	0.89
Middle	0.36	(-2.2, 3.0)	0.78		0.33	(-1.7, 2.3)	0.75		0.48	(-2.0, 2.9)	0.69	
Caregiving profile												
Relationship with care recipient (ref = spouse or partner)												
Daughter/son or daughter/son in-law	0.96	(-1.8, 3.7)	0.49	0.24	0.11	(-2.0, 2.2)	0.92	<0.0001	2.86	(0.5, 5.2)	0.02	0.004
Parent/parent in-law	-1.65	(-5.2, 1.9)	0.36		-5.83	(-8.5, -3.2)	<0.0001		0.82	(-3.5, 5.1)	0.71	
Others	2.34	(-1.4, 6.1)	0.22		-4.89	(-8.1, -1.7)	0.003		4.35	(-0.6, 9.3)	0.09	
Reason for needing care (refer = Health-related)												
Not Health-related	-7.64	(-10.1, -5.2)	<0.0001	-	-2.70	(-6.2, 0.8)	0.13	-	-1.17	(-4.2, 1.8)	0.44	-
Types of care provided (ref = yes)												
No health support	-2.72	(-5.1, -0.3)	0.03	-	-2.26	(-3.9, -0.6)	0.01	-	-2.03	(-4.4, 0.4)	0.09	-
No personal care	0.7	(-2.4, 3.8)	0.65	-	-1.31	(-2.9, 0.2)	0.10	-	-3.17	(-5.1, -1.2)	0.002	-
Caregiving duration (ref = < 1 month)												
1 to 5 months	9.17	(2.9, 15.5)	0.005	0.002	0.65	(-1.6, 2.9)	0.57	0.53	2.42	(-0.9, 5.7)	0.15	0.04
≥ 6 months	-0.64	(-4.8, 3.5)	0.76		-0.70	(-2.7, 1.3)	0.48		-0.99	(-3.4, 1.4)	0.42	

Note. Ref = reference group. Lower sample size, as some participants did not have data on the co-variates. Burden is the dependent variable, by country. Linear regression model for caregiving burden (dependent variable) including all factors significantly associated with burden in at least one of the countries. Only variables that were significant in the bivariate analyses (p < 0.25) were considered in the multivariate model. * = with partner, includes married or cohabitating and without partner, includes divorced and widowed. ** = all models controlled for sex, age, marital status, and wealth.

Table 4: Associations between health-related outcomes and health risk factors and burden level by country, SAGE Wave 1 (2007/10)

	Burden	Ghana					India					Russian Federation				
		n	Diff or OR	95%CI	p-value	overall p-value	n	Diff or OR	95%CI	p-value	overall p-value	n	Diff or OR	95%CI	p-value	overall p-value
Health-related outcomes																
Quality of life (Diff.)	Low*	45	64.0 (2.3)	-	-		151	67.0 (1.5)				77	64.0 (2.1)	-	-	
	Mod	45	-13.50	(-18.7, -8.3)	<0.0001	<0.0001	167	-6.20	(-9.9, -2.5)	0.001	<0.0001	95	-1.70	(-6.0, 2.6)	0.434	0.017
	High	48	-13.30	(-19.8, -6.9)	0.0001		172	-8.80	(-12.2, -5.3)	<0.0001		91	-12.0	(-20.5, -3.4)	0.007	
Perceived stress (Diff.)	Low*	45	5.21 (0.36)	-	-		151	4.26 (0.26)	-	-		77	4.79 (0.29)	-	-	
	Mod	45	0.98	(0.15, 1.82)	0.021	0.046	167	0.97	(0.43, 1.51)	0.001	0.0002	94	0.67	(0.06, 1.27)	0.032	0.037
	High	48	1.08	(0.06, 2.10)	0.039		172	1.26	(0.64, 1.88)	<0.0001		92	0.83	(0.14, 1.52)	0.020	
Depression (Diff.)	Low/Mod**	6/90	1	-	-		39/318	1	-	-		13/171	1	-	-	
	High	11/48	3.30	(0.8, 13.8)	0.099	-	38/172	1.46	(0.67, 3.20)	0.341	-	11/91	2.72	(0.50, 14.8)	0.248	-
Poor SRH (OR)	Low/Mod**	20/90	1	-	-		44/318	1	-	-		46/172	1	-	-	
	High	12/48	0.72	(0.25, 2.04)	0.535	-	49/172	1.36	(0.68, 2.71)	0.388	-	42/92	1.39	(0.74, 2.62)	0.303	-
Health risk factors																
BMI (Diff.)	Low*	43	25.97 (1.7)	-	-		149	9.81 (0.57)	-	-		71	7.56 (0.96)	-	-	
	Mod	44	-1.69	(-5.51, 2.13)	0.380	0.029	166	0.62	(-0.86, 2.10)	0.409	0.575	82	1.63	(-0.85, 4.11)	0.194	0.287
	High	47	-3.53	(-7.04, -0.02)	0.049		172	-0.21	(-1.48, 1.07)	0.751		81	1.63	(-0.51, 3.77)	0.132	
Physical activity* (Diff.)	Low	44	198 (40)				143	157 (25)				73	235 (24)			
	Mod	39	-33	(-121, 55)	0.460	0.110	164	-49	(-95, -3)	0.038	0.087	88	-30	(-96, 35)	0.361	0.617
	High	44	39	(-41, 119)	0.330		166	-26	(-92, 40)	0.434		91	-26	(-98, 46)	0.467	
> 4 servings of fruits or vegetables (OR)	Low	13/45	1	-	-		56/151	1	-	-		26/74	1	-	-	
	Mod	16/45	1.16	(0.40, 3.35)	0.950	0.889	57/167	0.99	(0.52, 1.89)	0.710	0.835	30/86	0.91	(0.28, 2.97)	0.436	0.277
	High	15/48	1.27	(0.48, 3.36)	0.708		48/172	1.22	(0.58, 2.56)	0.549		20/81	1.85	(0.71, 4.81)	0.109	
Current smoker& (OR)	Low/Mod**	4/90	1	-	-		149/318	1	-	-		30/172	1	-	-	
	High	9/48	4.05	(1.09, 15.1)	0.037	-	87/172	1.39	(0.81, 2.39)	0.239	-	15/92	2.88	(0.81, 10.2)	0.101	-

Note. Diff. = Difference. Burden scores (exposure) were classified in country-specific tertiles. The regression model was adjusted for age group, sex, wealth tertile and marital status. * = mean and SE presented for the reference group. ** low/moderate burden tertile collapsed. *** = Physical activity includes activities at work; transport, and leisure time, summarized as minutes per day expended in moderate or vigorous physical activity. & = participants who never used tobacco or stopped smoking versus current smokers, regardless of quantity and frequency.

Figure 1: Comparison of health-related outcomes between caregivers and non-caregivers (matched controls) by country, SAGE Wave 1 (2007/10)

Quality of life				Caregivers	Non-caregivers
Country	N	ES (95% CI)	Weight (%)	Mean (SE)	Mean (SE)
Ghana	429	-2.22 (-5.22, 0.79)	25.41	56.2 (1.44)	58.4 (0.95)
India	1469	-1.07 (-2.41, 0.28)	39.90	62.4 (0.61)	63.5 (0.49)
Russian Federation	861	-4.37 (-6.29, -2.44)	34.70	58.1 (0.85)	62.5 (0.65)
Overall		-2.51 (-4.75, -0.26)	100.00		

Perceived Stress				Caregivers	Non-caregivers
Country	N	ES (95% CI)	Weight (%)	Mean (SE)	Mean (SE)
Ghana	429	0.17 (-0.21, 0.54)	26.55	5.9 (0.18)	5.8 (0.11)
India	1469	-0.17 (-0.38, 0.03)	36.58	5.2 (0.09)	5.4 (0.06)
Russian Federation	861	0.27 (0.07, 0.47)	36.87	5.7 (0.09)	5.4 (0.07)
Overall		0.08 (-0.23, 0.39)	100.00		

Depression				Caregivers	Non-caregivers
Country	N	OR (95% CI)	Weight (%)	N (%)	N (%)
Ghana	429	1.73 (0.87, 3.42)	19.78	18 (12.6%)	22 (7.7%)
India	1469	1.01 (0.75, 1.35)	57.37	77 (15.7%)	153 (15.6%)
Russian Federation	861	2.03 (1.19, 3.48)	22.85	24 (9.0%)	24 (4.5%)
Overall		1.39 (0.70, 2.07)	100.00		

Self-rated health as poor				Caregivers	Non-caregivers
Country	N	OR (95% CI)	Weight (%)	N (%)	N (%)
Ghana	429	2.46 (1.39, 4.34)	11.53	33 (23.1%)	31 (10.9%)
India	1469	1.17 (0.90, 1.53)	49.37	93 (19%)	163 (16.7%)
Russian Federation	861	1.71 (1.27, 2.30)	39.10	88 (32.6%)	120 (22.3%)
Overall		1.53 (0.97, 2.09)	100.00		

Note. Pooled effect sizes were calculated (random effects) using DerSimonian & Laird's method[32] with weighting assigned by within and between country study variation. ES = Effect Size, OR=Odds Ratio, CI=Confidence Interval

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Figure 2: Comparison of risk factors between caregivers and non-caregivers (matched controls) by country, SAGE Wave 1 (2007/10)

Note. Pooled effect sizes were calculated (random effects) using DerSimonian & Laird's method[32] with weighting assigned by within and between country study variation. ES = Effect Size, OR=Odds Ratio, CI=Confidence Interval

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The impact of informal caregiving on older adults' physical and mental health in low- and middle-income countries: a cross-sectional, secondary analysis based on the WHO Study on global AGEing and adult health (SAGE)

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The impact of informal caregiving on older adults' physical and mental health in low- and middle-income countries: a cross-sectional, secondary analysis based on the WHO <u>S</u>tudy on global <u>AGE</u>ing and adult health (SAGE)

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Abstract

Objectives: A high proportion of care stemming from chronic disease or disability in low- and middle- income countries is provided by informal caregivers. The goal of this study was to determine the level of burden experienced by these caregivers, explore associated factors, and assess whether caregivers' and non-caregivers' health differed.

Design and setting: This cross-sectional study was a secondary analysis of data on caregivers' burden, health, and health risk factors in Ghana, India, and the Russian Federation (RF) collected as part of the WHO's <u>S</u>tudy on global <u>AGE</u>ing and adult health (SAGE) - Wave 1.

Participants: Caregivers in Ghana (n = 143), India (n = 490), and Russia (n = 270) completed the measures.

Outcome measures: Factors associated (i.e., demographics and caregiving profile variables) with burden were explored among caregivers. Then, quality of life, perceived stress, depression, self-rated health, and health risk factors were compared between caregivers and matched non-caregivers (1:2).

Results: The largest caregiving sub-groups were spouses and adult children. Caregivers mostly cared for one person and provided financial, social/emotional, and/or physical support, but received little support themselves. Burden level ranged from was 17.37 to 20.03. Variables associated with burden were mostly country specific; however, some commonality for wealth, type of care, and caregiving duration was noted. Caregivers with a moderate or high level of burden reported lower quality of life and higher perceived stress than those experiencing low burden. Caregivers reported lower quality of life and self-rated health than non-caregivers.

Conclusion: Given the lack of support received and consequences of the burden endured by caregivers, policy and program initiatives are needed to ensure that caregivers can fulfill their role without compromising their own health.

Strengths and limitation of the study

- This is the first comprehensive study on informal caregiving burden among multiple low- and middle-income countries..
- A key strength is SAGE has nationally representative samples, with high response rates.
- One weakness of this survey is related to its interview length and this burden might have affected the quality of the responses to the caregiving-related questions as these were the last section of the interview.
- The cross-sectional design precludes causal inferences.

Competing interest statement

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Data sharing statement

No additional data available.

Introduction

Globally, the number of people aged 60 years or older is expected to grow by 56% between 2015 and 2030.[1] This demographic shift is accompanied by a health transition, whereby 23% of the total global burden of disease is now attributable to disorders in older adults.[2] Under the scenario where global prevalence of disabilities and diseases remain stable, the growth in the number of older adults alone is expected to increase demands for health care beyond the capacity of health care systems.[3] Therefore, there is less reliance on specialized care settings and more focus on delivering care in the community.[4] Within this context, informal caregivers provide a high proportion of the care needed and are an essential extension of the health care system.[4 5] The support that caregivers provide not only positively impacts on care recipients' quality of life (QOL),[6] but represents significant cost-saving to health care systems.[4]

Informal caregivers can be broadly defined as family members, partners, friends or neighbors who provide a wide range of unpaid assistance for individuals with chronic or disabling conditions.[5] In high-income countries (HICs), up to almost half of the population are (or have been) a caregiver and provide anywhere from 12-25 hours of informal assistance per week.[7 8] Caregivers are often responsible for specialized medical care, planning and coordinating care, monitoring patient's health status, ensuring treatment or medication adherence, and preventing adverse events.[4] Caregivers may also adopt the role of decision-maker, particularly if the care recipient is experiencing cognitive impairments.[4] For older care recipients, caregivers typically provide assistance with activities of daily living, potentially preventing accidents and further declines in functioning.[4] Emotional support is another frequent role; however, caregivers often experience the least confidence and greatest uncertainty in providing this support.[7]

Although caregiving is a valued societal resource, and often viewed positively by caregivers themselves, caregivers remain largely a hidden and underappreciated workforce.[9] Consequently, caregivers experience substantial burden, which might lead to the care recipients' institutionalization.[10] Burden is most apparent in caregivers' reporting of anxiety and depression. Depending on the caregiving profile (e.g., sex, age), caregivers' prevalence of anxiety and depression can exceed general population norms, and in some cases, those reported by care recipients.[7] Burden also has a negative impact on caregivers' physical health (e.g., fatigue, pain), particularly as caregivers are often older themselves and confront the demands of their own illnesses.[11] Further compromising their health, caregivers often prioritize the care recipients' health over their own, and do not access needed support or health services[7] or are less likely than non-caregivers to engage in preventive health behaviors.[12] This not only puts caregivers' health at risk, but ultimately the care recipients' health.[13] With the expected growth in the number of caregivers and changes in health care systems as well as the substantial burden endured, the caregiving role is now considered a public health priority.[14]

Despite the exponential increase in the number of caregivers worldwide, few studies have examined caregivers' health in low-and middle-income countries (LMICs).[15] LMICs have a higher prevalence of disability than HICs[16] and care recipients are more likely to rely on caregivers due to the governments' difficulties in financing the public healthcare system and ensuing lack of services or programs.[15] In support, Marten et al.[17] documented as little as 1.2% of India's gross domestic product (GDP) was spent on health, while Ghana was slightly more at 3.6%.[18] The median government health expenditure as a percentage of GDP in LMICs is estimated to be 2.0%, which is in comparison to the 11% spent in Canada and 17.5% for the USA.[19-21] This inadvertently creates deficits in available services in LMICs, with many public health practitioners supplementing their

government incomes through the privatization of healthcare services.[22] To access chronic illness care individuals must either pay a user fee at public facilities as a means of financing the delivery of healthcare services or must use private facilities due to the inaccessibility of services through publicly funded facilities.[23][24] User fees and private services pose significant financial barriers, which leaves a significant proportion of the population in LMICs unable to access health services.[17] Hence, individuals often turn to informal sources of health care, including their family caregivers. Within this context, it is reasonable to expect higher burden among caregivers in LMICs than those in HICs. A recent review by Thursh et al.[15] of 43 studies among caregivers of adults with a physical and/or mental illness in LMICs concluded that there is considerable physical, psychological, social, time, and financial burden on these caregivers. Although this is highly useful data, development of this evidence-base is still in its infancy. Studies published to date are limited by the small sample sizes, lack of quantitative data; diverse measures used across LMICs, limiting comparisons across countries; and few studies use a non-caregiver comparison group. Furthermore, some health consequences of caregiving on caregivers have received little to no attention in LMIC studies, including quality of life, stress, depression, and health risk behaviors. Therefore, there is an urgent need for more methodologically rigorous research to examine caregivers' challenges in countries other than HICs and develop an evidence base to inform policy and decision-making about health services for these caregivers.

The objectives of this population-based study were to a) describe the caregiving profile and level of burden experienced by caregivers in two LMICs (Ghana and India) and one upper-middle country (Russian Federation), b) examine how caregiver burden varied according to demographic and caregiving profile variables by country, c) assess whether health-related outcomes and health risk factors are associated with caregiving burden, and d) determine the extent to which caregivers' health-related outcomes and health risk factors differed from non-caregivers by country.

Methods

Design

This is a secondary, cross-sectional analysis of the data collected as part of the World Health Organization's (WHO's) multi-country Study on global AGEing and adult health (SAGE) - Wave 1 (2007 – 2010).[25] SAGE was designed to collect information on the ageing process in nationally representative samples across China, Ghana, India, Mexico, the Russian Federation, and South Africa. SAGE received approval from the WHO's Ethical Review Committee and the respective committees in each participating country. Written informed consent was obtained from all study participants. For this secondary data analysis, ethical clearance was obtained from Deakin University.

Participants

SAGE is a representative study of the population aged 50+ in each participating country, with a smaller sub-sample of adults 18 – 49 years old.[25] The methods for SAGE are extensively described elsewhere.[25] In brief, multistage, stratified cluster sampling methods were used in each country. Country-specific strata were typically defined by region/state/province/district and locality. For all countries, a primary sampling unit (i.e., enumeration areas, villages, or districts) was identified to generate a list of households. Households were classified into one of two mutually exclusive categories: a) '50+' (older) household, where the target respondent was aged 50+; or b) '18–49' (younger) household, where the target respondent was aged 18-49 years. All persons aged 50+ were selected from the older households, whereas one person aged 18-49 was selected from

each younger household. Post-stratification weights were generated, adjusting for population distribution of age and sex in each country at the time of survey.[26]

The caregiver sub-sample was comprised of participants 50+ who identified themselves as the primary person providing care to an adult in their household in the past 12 months. Non-caregivers were 50+ participants who did not provide any care to someone else in their household. Those who identified caring for someone who was deceased or a child were excluded. Data from China, Mexico, and SA were not considered, because caregiving data were not collected, the caregiver sub-sample was too small, or an extremely skewed post-stratified weights distribution was observed.

Data collection
A standardized individual questionnaire was administered by trained interviewers.[25] Translation of the questionnaire was led by the World Health Survey team based on the WHO guidelines (available at http://www.who.int/substance_abuse/research_tools/translation/en/). The steps to translation included forward translation, expert panel back-translation, pre-testing, and final version.

Demographic characteristics
Caregivers' demographics included sex, age group, locality, marital status, household size, wealth, education, and employment status. Education levels were based on the international standard classification of education.[27] An index of household wealth or permanent income was generated based on household ownership of durable goods, dwelling characteristics, and access to services.[28]

Caregiving profile and burden
Caregiving profile was defined by the relationship to the care recipient, number of people cared for in the household, reasons for and types of care provided, caregiving duration, and support received by the caregiver, including source. The 10-item Impact of Caregiving Scale captured the difficulties encountered by caregivers in carrying out their roles and responsibilities over the last 12 months. Each item was rated on a five-point scale ranging from: 1 = none to 5 = extreme. Similar to another study[29] exploratory factor analysis (EFA) with oblique rotation, for each country, identified one factor (using Eigenvalue, scree plot, and parallel analysis). Cronbach's alpha ranged from 0.88 – 0.93 across countries.

Quality of life
For QOL, a composite score was calculated by adding the eight items of the EUROHIS-QOL questionnaire[30] and rescaling responses from 0–100. The cross-cultural psychometric properties of this scale are well-documented, including unidimentionality, internal consistency (alpha range = 0.72–0.83 across multiple countries), convergent validity with relevant physical and mental health measures, and discriminant validity.[30 31] EFA, with oblique rotation for each country, overall found that a one-factor structure was also appropriate to use with caregivers. Cronbach's alphas in the present study were greater than 0.85.

Perceived stress
For perceived stress, two items from the Perceived Stress Scale, rated from 0 = never to 5 = very often, were summed.[32]

Depression
Depression was assessed using the 18-item algorithm from the World Mental Health Survey version of the Composite International Diagnostic Interview.[33] The diagnosis of mild, moderate, and severe

depression was based on the International Classification of Diseases, 10th revision (ICD-10), Classification of Mental and Behavioural Disorders, Diagnostic Criteria for Research (DCR).[34] The algorithm described by Kulkarni & Shinde[35] was initially used to define mild, moderate, and severe depression, with mild and moderate depression combined for subsequent analyses.

Self-rated health

For self-rated health (SRH), participants answered the question: *In general, how would you rate your health today?*[36] Responses were dichotomized as 'good health' (i.e., 1= very good, 2 = good, or 3 = moderate) or 'poor health' (i.e., 4 = bad or 5 = very bad). SRH has been found to be a reliable measure of health that is sensitive to an individual's perception of health.[36]

Lifestyle health risk factors

1. Body Mass Index (BMI) was calculated as weight (kg)/height (m^2) (measured by interviewer).[37]
2. Physical activity (PA) was determined based on participants' responses to the 16 items of the Global Physical Activity Questionnaire (GPAQ), an instrument with documented validity.[38] Participants were asked about their activities at work; transport, and leisure time, which was summarized as minutes per day of expended in moderate or vigorous PA.
3. The total number of servings of fruits and/or vegetables on an average day was calculated and classified as a) adequate (≥ 4 servings) or b) low (< 4 servings).[39 40]
4. Tobacco use was categorized as a) never used or past user of tobacco or b) current smoker.[41]

Statistical analysis

Analyses were performed using SAS V9.3 and graphs were created using Stata V14.0. Unless otherwise specified, SAS survey estimation procedures were used to account for the complex, multistage probability-sampling design. Observed frequencies and sample sizes are provided for reference. The Rao-Scott Chi-Square test was used to compare the distribution of demographic characteristics between caregivers and non-caregivers and to describe the caregiving profile proportions across the variables of interest. The literature was used to identify candidate variables to explain burden. Demographic and caregiver profile variables associated with burden, were identified using bivariate analyses (p < 0.25), followed by backward stepwise regression. Backward regression was favored, because there are few studies that could have guided the a priori selection of covariates that would have been meaningful for each country. The final model reported for each country includes age group, sex, marital status, and wealth tertile and any other factor significantly associated with burden in at least one country. Associations between burden level and health-related outcomes and risk factors were assessed using a linear or logistic regression model (including age group, sex, wealth tertile, and marital status as potential confounders). To compare caregivers' and non-caregivers' health, each caregiver was matched with two non-caregivers based on country, age group, gender, marital status, wealth tertile or education level, and strata. Caregivers and non-caregivers outcomes were compared using generalized linear models with either binary distribution and logit link for dichotomous outcomes or normal distribution and identity link for continuous outcomes (complex survey design was not considered). The Pooled effect size (ES) was calculated using a random-effects model, which assumes heterogeneity among countries and the true effect can be different for each country.[42]

Results

Caregivers' demographics

Table 1 compares the demographics of the caregivers (Ghana, n=143; India, n=490; Russia, n=270) and non-caregivers (Ghana, n=4112; India, n=6001; Russia, n=3304) by country. No differences based on sex and locality across countries were noted. In Ghana, caregivers were more likely to be younger, live in a large household, be wealthier, have higher education, and not retired. In India, caregivers were more likely to be younger or very old, living with a partner and in mid-size households. In Russia, living with a partner was also more frequent among caregivers than non-caregivers, as well as not currently working or not retired.

Objective 1 – Caregiving profile and level of burden
Table 2 presents the caregiver profile by country. Across countries, caregivers mostly cared for a spouse (Russia, India) or adult children (Ghana), for health-related reasons, and typically provided financial, social/emotional, and/or physical support. Only in Russia did more than half of caregivers provide personal care. Up to 20% of caregivers identified receiving some kind of support to help them with their role, mostly from a family member outside the household. Across countries, the largest caregiver sub-group (40.8% to 80.7%) had been in their role for at least six months. The mean burden score (possible range = 10-50) for caregivers in India was highest at 21.03 (SE = 0.43), followed by Ghana at 19.32 (SE=0.85) and Russia at 17.37 (SE=0.48).

Objective 2 – Variables associated with burden
Table 3 presents the results of the multivariate regression analyses. Demographic and caregiving profile variables significantly associated with burden varied by country; however, some level of commonality was noted for wealth, type of care, and caregiving duration. In countries for which these variables were significant, caregivers reporting poorer wealth, providing health support, and caring for 1 to 5 months were more at risk of burden. Although providing health support was not significant in Russia, a similar pattern to the other two countries was noted. However, in Russia, personal care was associated with burden.

Age and type of relationship were also significant across at least two countries, but the direction of the relationship was different. In Ghana, younger caregivers reported higher burden than their older counterparts, but the opposite was observed in Russia. Similarly, in India being the spouse or partner was associated with higher burden, whereas in Russia this type of relationship was protective. In Russia, the sub-group of caregivers reporting higher burden based on type of relationship was the adult children.

Relationships between age, marital status, and reasons for needing care and burden were country specific. Only in Russia did women report significantly higher burden than men. In India, being without a partner was associated with higher burden. Reason for needing care was only significant in Ghana, with health-related reasons associated with higher burden.

Objective 3 – Burden level and caregivers' health
Caregivers' health outcomes and health risk factors (non-weighted) are described in Figures 1 and 2 and results of the analysis of factors associated with burden (weighted analysis) in Table 4. QOL scores for caregivers reporting moderate or high burden were 6 to 13 points lower than those reporting low burden. Caregivers experiencing moderate or high burden reported stress scores 0.63 to 1.26 points higher than those reporting low burden. Burden was not significantly associated with depression or SRH.

Few associations between burden level and health risk factors were noted (Table 4). In Ghana, caregivers with high burden were more likely to smoke and reported a lower BMI than those with low burden. In India, lower physical activity was noted among caregivers reporting moderate burden.

Objective 4 – Caregivers' and non-caregivers' health
Across countries, caregivers in comparison to non-caregivers reported lower QOL and poorer SRH. Findings emphasized the vulnerability of caregivers in Russia, whereby they reported significantly lower QOL, more perceived stressed, depression, and poorer SRH compared to non-caregivers (Figure 1). None of the pooled analyses were significant for health risk factors (Figure 2).

Discussion
Statement of key findings
LMICs face higher prevalence of chronic diseases and disability than HICs.[16] This, combined with limited access to formal services and programs in LMICs means that a high proportion of the care needed is provided by informal caregivers.[15] However, studies of the burden that caregivers experience come almost exclusively from HICs.[15] This lack of information, plus the growing population of older adults, suggests an urgent need for more research to examine caregivers' challenges outside HICs. The present secondary analysis described the level of burden experienced by caregivers in Ghana, India, and Russia, explored associated factors, and assessed whether caregivers' and non-caregivers' health differed. The key findings are: a) Few caregivers reported receiving support to help them with their role, b) variables associated with burden were mostly country specific, but consistent with HIC studies, c) across countries, burden has an adverse impact on caregivers' stress and QOL, and d) across countries, caregivers reported lower QOL and SRH than non-caregivers. Each key finding is discussed in turn.

Comparison with other studies
The prevalence of caregiving across countries was lower than what has been documented in HICs. This might in part be attributed to the stigma associated with some illnesses in LMICs.[43] In a study by Mwinituo et al.[43] caregivers of AIDS patients reported losing their jobs because of discrimination. Another explanation for the potential lower than expected report rate is cultural expectations, as caregiving amongst collectivistic cultures is often deeply rooted and embedded in life experiences as an expected part of life and passed down from parent to child over many generations.[44] Even participants who disclosed caring for someone in our study might have kept their caregiving role a secret from others in their community, which might explain the limited support received. Thara et al.[45] also noted the limited support received by caregivers in India. In the present study, if caregivers did receive support, it was outside the family household, emphasizing the need for external programs. Similar to other studies,[15] caregivers in this study, and particularly those in Russia, were providing a variety of time-consuming personal care: bathing, dressing, and toileting, which are known sources of strain for caregivers.

Similar to studies in HICs,[7] findings of this secondary analysis emphasised that caregiving in two LMICs and one upper-middle income country is not without consequences on the level of burden reported. The lack of a clear pattern of associations among demographic and caregiving profile variables and burden emphasized the need for a tailored approach to policy and service development by country. Despite this variation, findings are mostly consistent with studies in HICs.[7] This means that low-cost, evidence-based, caregiver programs, e.g., self-directed coping

skills programs, developed in HICs might be amenable to the context found in LMICs and upper-middle income countries, after appropriate adaptations. Although only significant in Russia, many studies have corroborated the high burden among female caregivers.[7][15] Similar to the contradictory findings on age across Ghana and Russia, some studies have reported that younger caregivers have multiple competing demands and are thereby more at risk of burden, whereas others have found that as older adults are coping with their own declining health, they are more at risk of burden.[7] The higher burden associated with the marital status "without partner" in Ghana is similar to a study in Ethiopia,[46] and might indirectly emphasize the lack of support this caregiver sub-group receives. The findings pertaining to wealth in Ghana and India are consistent with studies in HICs associating lower income to high caregiver burden.[7] Previous studies[5,38] also substantiated the impact of the type of relationship to the care recipient on caregiver outcomes, with particular vulnerable sub-groups confirmed in the present analysis, including adult children.[7][46] Adult children are "sandwiched" between raising their own children and providing for their family as well as taking on additional caregiving responsibilities. However, this is a growing group of caregivers, because of the overall aging of the population. Spouses have been found to be at particular risk of financial burden,[46] which might explain findings in India. Beyond relationship type, Pinto et al.[47] found that the quality of the relationship was more associated with burden than were variables such as gender, marital status, and illness severity. Although household size has been found to be positively associated with caregivers' emotional distress,[48] it was not a significant variable in the multivariate model. One reason for this is that a global measure of burden was used, and household size might have an impact on different dimensions of burden.

One of the most common consequences of caregiving burden is poor QOL and mental health problems such as stress and depression.[15] Our finding that burden adversely impacted on caregivers' QOL has only been reported by one other LMIC study.[47] In this study, among the domains of QOL, general health received the lowest score. The present study is the only one to document that caregivers reported lower QOL than non-caregivers, representing a vulnerable segment of the population. A finding further strengthened by the one that caregivers were also more likely to rate their health as poor in comparison to non-caregivers. Although perceived stress did not differ between caregivers and non-caregivers, across countries, caregivers' burden was positively associated with this outcome. Only one other LMIC study was found to report on caregivers' stress, finding that 39% of older caregivers in Zimbabwe reported chronic stress.[49] A concern is that stress can lead to other emotional and/or physical problems such as insomnia, headaches, and depression for caregivers, and compromise their ability to sustain caregiving.[50]

Studies in HICs have found that caregivers report more unhealthy behaviors after taking on their role, such as low fruit and vegetable intake, increased use of tobacco, low physical activity, and being overweight.[7] No comparable study in LMICs was found. In the present study, few significant findings were noted for the relationship between level of burden and health risk factors. Our finding that burden is associated with lower physical activity is in line to the findings by Beesley et al.[12] reporting that 54% of caregivers of women with ovarian cancer did not meet the guidelines for physical activity. In addition, 37% consumed more than two alcoholic beverages per occasion, and 10% were smokers. In the present study, the relationship between smoking and burden was only significant in Ghana.

Strengths and weaknesses of the study
This is the first comprehensive study on informal caregiving burden among two LMICs and one upper-middle income country. Key strengths include that SAGE has nationally representative

samples and high response rates.[25] One weakness of this survey is related to its interview length[25] and this burden might have affected the quality of the responses to the caregiving-related questions as these were the last section of the interview. Also, the sample size of the primary SAGE study was determined by the country specific teams and the sample size for the secondary analysis is limited to those who completed the Impact of Caregiving section. There is no information about how many participants were caregivers, but might have refused to complete this section. The questionnaire was created for the purpose of the primary SAGE study, with the burden scale developed by the World Health Survey team (details of the development process are not available). However, EFA of the burden scale in each country followed by reliability analysis have supported the key psychometric properties of the scales used in this secondary analysis. However, EFA of the burden scale in each country followed by reliability analysis have supported the key psychometric properties of these. The cross-sectional design precludes causal inferences. Another limitation is that as the SAGE data were collected to assess the health of the participant completing the survey, but they were not asked about the health of the care recipient beyond what has been reported in this secondary analysis and the caregiver data cannot be linked to the care recipient (even if they also participated in the SAGE survey).

Conclusion
In contrast with the available evidence of the impact of caregiving in HICs, little is known about taking on this role in LMICs. The present comprehensive caregiver study is the first of its kind internationally that informs our understanding of caregivers in India, Ghana, and Russia. Few caregivers reported receiving support to help them with their role. Variables associated with burden were country specific, but commonly included wealth, type of care, and caregiving duration, which is consistent with HIC studies. Across countries, burden had an adverse impact on caregivers' stress and QOL and caregivers reported lower QOL and SRH than non-caregivers. These findings contribute to the growing evidence-base on the substantial burden endured by caregivers in LMICs and the consequences of this role on their health. The findings of this study, in combination with those of other studies, can facilitate advocacy efforts aimed at improving support for caregivers in LMICs and strengthen their capacity to sustain their role.

Figure legends
Figure 1: Comparison of health-related outcomes between caregivers and non-caregivers (matched controls) by country, SAGE Wave 1 (2007/10)

Figure 2: Comparison of risk factors between caregivers and non-caregivers (matched controls) by country, SAGE Wave 1 (2007/10)

Authors' contribution
All authors have made substantial contributions to, a) the conception of this secondary analysis study (SL, LO, SB, PL, LH), data analysis (LO, SL, SC), and/or interpretation of data (SL, LO, SB, PL, LH, PK), and b) drafting the article (SL, LO) and/or revising it critically (SB, PL, LH, PK, SC). All authors have read and approved the final version of the manuscript and agreed to be accountable for all aspects of this study.

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Table 1: Sociodemographic characteristics of the sample by caregiver status and country, SAGE Wave 1 (2007/10)

	Ghana			India			Russian Federation		
	Main caregiver n (%)[¥]	Non-caregiver n (%)[¥]	p-value	Main caregiver n (%)[¥]	Non-caregiver n (%)[¥]	p-value	Main caregiver n (%)[¥]	Non-caregiver n (%)[¥]	p-value
Sample size	143 (3.3)	4112 (96.7)		490 (7.6)	6001 (92.4)		270 (6.1)	3304 (93.9)	
Sex									
Male	68 (42.9)	2155 (52.7)	0.067	222 (47.0)	3047 (51.3)	0.29	88 (30.94)	1175 (39.5)	0.062
Female	75 (57.1)	1957 (47.3)		268 (53.0)	2954 (48.7)		182 (69.06)	2129 (60.5)	
Age									
50–59	76 (52.9)	1599 (39.5)		259 (57.5)	2645 (47.8)		101 (38.4)	1233 (45.3)	
60–69	37 (25.8)	1147 (27.5)	0.006	167 (30.3)	2045 (31.0)	0.0002	80 (36.3)	890 (23.9)	0.071
70+	30 (21.3)	1366 (33.1)		64 (12.2)	1311 (21.3)		89 (25.3)	1181 (30.8)	
Locality									
Urban	72 (46.4)	1663 (40.8)	0.285	117 (24.2)	1542 (29.2)	0.33	220 (78.4)	2499 (72.0)	0.365
Rural	71 (53.6)	2449 (59.2)		373 (75.8)	4459 (70.8)		50 (21.6)	805 (28.0)	
Marital status*									
Without partner	56 (37.4)	1792 (41.2)	0.409	51 (8.7)	1625 (24.2)	<0.0001	52 (28.2)	1520 (42.8)	0.023
With partner	87 (62.6)	2320 (58.8)		439 (91.3)	4376 (75.8)		218 (71.8)	1784 (57.2)	
Household size									
1-2	12 (7.1)	873 (20.2)		65 (12.6)	649 (11.1)		173 (67.5)	2278 (73.4)	
3–4	26 (23.2)	903 (21.5)	0.002	99 (23.1)	1137 (16.9)	0.017	66 (21.1)	714 (19.3)	0.281
5–6	40 (27.1)	970 (24.4)		111 (20.8)	1744 (28.5)		31 (11.4)	307 (7.3)	
7+	65 (42.6)	1365 (33.9)		215 (43.5)	2468 (43.5)		**		
Wealth tertile*									
Poorer	37 (24.8)	1384 (31.4)		170 (37.5)	1840 (32.9)		78 (22.2)	1165 (33.5)	
Middle	37 (28.2)	1426 (35.3)	0.022	142 (33)	2016 (33.9)	0.52	102 (39.7)	1128 (35.0)	0.148
Wealthier	69 (47.0)	1298 (33.3)		177 (29.5)	2108 (33.3)		90 (38.1)	1006 (31.5)	
Education									
Never been to school	**			266 (56.3)	3064 (50.9)		**		
Primary not completed	76 (50.2)	2679 (64.8)	0.004	50 (9.9)	685 (10.1)	0.42			0.264
Primary completed	10 (9.4)	451 (11.0)		68 (14.4)	850 (14.7)		16 (6.9)	368 (7.4)	

Secondary completed	57 (40.5)	958 (24.1)		106 (19.5)	1402 (24.3)		206 (81.3)	2283 (73.5)	
Higher education completed		**			**		48 (11.7)	651 (19.1)	
Employment status									
Never worked or not currently working	35 (24.9)	735 (17.6)	<0.0001	223 (45.8)	2764 (45.3)	0.21	47 (18.0)	471 (11.2)	0.026
Retired	6 (3.1)	524 (13.4)		63 (8.4)	820 (11.7)		148 (55.6)	1748 (47.9)	
Currently working	102 (72.0)	2838 (69.0)		204 (45.8)	2417 (43.0)		75 (26.4)	1083 (40.8)	

Note. ¥ = weighted %. * = with partner, includes married or cohabiting and without partner, includes divorced and widowed. ** = categories combined due to low frequencies. *** = index of household wealth or permanent income was generated based on household ownership of durable goods, dwelling characteristics, and access to services; this index was transformed in country-specific wealth tertiles.

Table 2: Caregiving profile by country, SAGE Wave 1 (2007/10)

	Ghana N = 143 n (%)	India N = 490 n (%)	Russian Federation N = 270 n (%)
Types of relationship with care recipient			
Spouse/partner	40 (29.4)	291 (59.1)	172 (57.0)
Daughter/son or daughter/son in-law	56 (37.3)	112 (24.5)	41 (12.6)
Parent/parent in-law	19 (19.3)	62 (11.6)	50 (24.1)
Others	19 (14)	25 (4.8)	7 (6.3)
Number of people in household needing care			
1	101 (73.7)	434 (83.8)	255 (96.4)
2	19 (16.2)	47 (11.7)	11 (2.7)
3+	23 (10.1)	9 (4.5)	4 (0.9)
Reasons for needing care			
Health-related reason	88 (72.3)	467 (95.6)	230 (88.9)
Other reason	47 (27.7)	23 (4.4)	40 (11.1)
Types of care provided*			
Financial	98 (68.8)	239 (54.5)	62 (23.7)
Social/Emotional	67 (51.8)	252 (47.3)	206 (72.1)
Health	62 (46.6)	281 (63.2)	88 (39.7)
Physical	58 (47.0)	227 (46.0)	137 (52.2)
Personal care	29 (23.7)	205 (45.4)	162 (67.9)
Types of personal care**[&]**			
Bathing	20 (70.8)	131 (58.3)	128 (80.0)
Eating	10 (33.2)	127 (64.9)	56 (33.1)
Dressing	17 (60.4)	100 (59.1)	94 (59.8)
Toileting	14 (49.6)	112 (64.5)	42 (20.1)
Moving around	10 (39.5)	110 (47.7)	98 (56.1)
Incontinence	8 (30.7)	50 (30.3)	12 (7.8)
Caregiving duration			
< 30 days (1 month)	16 (10.5)	159 (34.1)	54 (23.2)
1 - < 6 months	10 (8.8)	118 (25.1)	25 (7.3)
≥ 6 months	115 (80.7)	213 (40.8)	191 (69.5)
Received any kind of support (yes)	30 (24.1)	77 (11.9)	68 (20.4)
Support received by caregivers***[&]**			
Financial	25 (20.2)	72 (11.0)	31 (8.0)
Emotional	4 (3.2)	16 (2.4)	45 (10.9)
Health	4 (4.0)	10 (1.6)	24 (4.7)
Physical	7 (6.2)	10 (1.2)	24 (7.0)
Personal	2 (1.8)	12 (1.7)	21 (8.7)
Other	1 (0.4)	1 (0.02)	0
Source of support**[&]**			
Family outside household	26 (85.5)	55 (68.2)	57 (88.7)
Neighbours/community	4 (13.6)	33 (40.4)	11 (12.3)
Government	0	3 (2.4)	20 (14.4)
Church	2 (7.8)	0	2 (3.6)
NGO	0	0	2 (2.7)
Other	2 (5.3)	0	3 (2.7)

Note. [¥] = weighted %. *For caregivers of more than one adult in the household, relationship defined in the following order, spouse, child, parent, child-in-law, and parent-in-law and duration accumulated across all care recipient. **Among those reporting providing personal care. ***Among those reporting receiving any type of support. & Participants answered yes/no for each option independently.

Table 3: Associations between burden and demographic and caregiving profile variables by country, SAGE Wave 1 (2007/10)**

	Ghana (N = 138)				India (N = 489)				Russian Federation (N = 264)			
	Estimate	95% CI	p-value	overall p-value	Estimate	95% CI	p-value	overall p-value	Estimate	95% CI	p-value	overall p-value
Sociodemographic variables												
Sex (ref = male)												
Female	1.04	(-1.6, 3.7)	0.44	-	0.05	(-1.7, 1.8)	0.96	-	2.51	(0.3, 4.8)	0.03	-
Age (ref = 50-59 years)												
60–69 years	-3.56	(-6.3, -0.8)	0.01	0.04	-1.27	(-3.3, 0.7)	0.21	0.29	2.35	(0.6, 4.1)	0.01	0.02
70+ years	-1.72	(-5.0, 1.6)	0.30		0.74	(-1.7, 3.2)	0.55		1.65	(-0.4, 3.7)	0.12	
Marital status (ref = with partner)*												
Without partner	-0.50	(-3.1, 2.1)	0.70	-	4.44	(1.7, 7.2)	0.002	-	-1.91	(-5.6, 1.7)	0.30	-
Wealth (ref = wealthier)												
Poorer	3.42	(0.9, 5.9)	0.01	0.03	2.20	(0.4, 4)	0.02	0.04	0.05	(-2.7, 2.8)	0.97	0.89
Middle	0.36	(-2.2, 3.0)	0.78		0.33	(-1.7, 2.3)	0.75		0.48	(-2.0, 2.9)	0.69	
Caregiving profile												
Relationship with care recipient (ref = spouse or partner)												
Daughter/son or daughter/son in-law	0.96	(-1.8, 3.7)	0.49	0.24	0.11	(-2.0, 2.2)	0.92	<0.0001	2.86	(0.5, 5.2)	0.02	0.004
Parent/parent in-law	-1.65	(-5.2, 1.9)	0.36		-5.83	(-8.5, -3.2)	<0.0001		0.82	(-3.5, 5.1)	0.71	
Others	2.34	(-1.4, 6.1)	0.22		-4.89	(-8.1, -1.7)	0.003		4.35	(-0.6, 9.3)	0.09	
Reason for needing care (refer = Health-related)												
Not Health-related	-7.64	(-10.1, -5.2)	<0.0001	-	-2.70	(-6.2, 0.8)	0.13	-	-1.17	(-4.2, 1.8)	0.44	-
Types of care provided (ref = yes)												
No health support	-2.72	(-5.1, -0.3)	0.03	-	-2.26	(-3.9, -0.6)	0.01	-	-2.03	(-4.4, 0.4)	0.09	-
No personal care	0.7	(-2.4, 3.8)	0.65	-	-1.31	(-2.9, 0.2)	0.10	-	-3.17	(-5.1, -1.2)	0.002	-
Caregiving duration (ref = < 1 month)												
1 to 5 months	9.17	(2.9, 15.5)	0.005	0.002	0.65	(-1.6, 2.9)	0.57	0.53	2.42	(-0.9, 5.7)	0.15	0.04
≥ 6 months	-0.64	(-4.8, 3.5)	0.76		-0.70	(-2.7, 1.3)	0.48		-0.99	(-3.4, 2.4)	0.42	

Note. Ref = reference group. Lower sample size, as some participants did not have data on the co-variates. Burden is the dependent variable, by country. Linear regression model for caregiving burden (dependent variable) including all factors significantly associated with burden in at least one of the countries. Only variables that were significant in the bivariate analyses (p < 0.25) were considered in the multivariate model. * = with partner, includes married or cohabitating and without partner, includes divorced and widowed. ** = all models controlled for sex, age, marital status, and wealth.

Table 4: Associations between health-related outcomes and health risk factors and burden level by country, SAGE Wave 1 (2007/10)

	Burden	Ghana					India					Russian Federation				
		n	Diff or OR	95%CI	p-value	overall p-value	n	Diff or OR	95%CI	p-value	overall p-value	n	Diff or OR	95%CI	p-value	overall p-value
Health-related outcomes																
Quality of life (Diff.)	Low*	45	64.0 (2.3)	-	-		151	67.0 (1.5)				77	64.0 (2.1)	-	-	
	Mod	45	-13.50	(-18.7, -8.3)	<0.0001	<0.0001	167	-6.20	(-9.9, -2.5)	0.001	<0.0001	95	-1.70	(-6.0, 2.6)	0.434	0.017
	High	48	-13.30	(-19.8, -6.9)	0.0001		172	-8.80	(-12.2, -5.3)	<0.0001		91	-12.0	(-20.5, -3.4)	0.007	
Perceived stress (Diff.)	Low*	45	5.21 (0.36)	-	-		151	4.26 (0.26)	-	-		77	4.79 (0.29)	-	-	
	Mod	45	0.98	(0.15, 1.82)	0.021	0.046	167	0.97	(0.43, 1.51)	0.001	0.0002	94	0.67	(0.06, 1.27)	0.032	0.037
	High	48	1.08	(0.06, 2.10)	0.039		172	1.26	(0.64, 1.88)	<0.0001		92	0.83	(0.14, 1.52)	0.020	
Depression (Diff.)	Low/Mod**	6/90	1	-	-		39/318	1	-	-		13/171	1	-	-	
	High	11/48	3.30	(0.8, 13.8)	0.099	-	38/172	1.46	(0.67, 3.20)	0.341	-	11/91	2.72	(0.50, 14.8)	0.248	-
Poor SRH (OR)	Low/Mod**	20/90	1	-	-		44/318	1	-	-		46/172	1	-	-	
	High	12/48	0.72	(0.25, 2.04)	0.535	-	49/172	1.36	(0.68, 2.71)	0.388	-	42/92	1.39	(0.74, 2.62)	0.303	-
Health risk factors																
BMI (Diff.)	Low*	43	25.97 (1.7)	-	-		149	9.81 (0.57)	-	-		71	7.56 (0.96)	-	-	
	Mod	44	-1.69	(-5.51, 2.13)	0.380	0.029	166	0.62	(-0.86, 2.10)	0.409	0.575	82	1.63	(-0.85, 4.11)	0.194	0.287
	High	47	-3.53	(-7.04, -0.02)	0.049		172	-0.21	(-1.48, 1.07)	0.751		81	1.63	(-0.51, 3.77)	0.132	
Physical activity* (Diff.)	Low	44	198 (40)				143	157 (25)				73	235 (24)			
	Mod	39	-33	(-121, 55)	0.460	0.110	164	-49	(-95, -3)	0.038	0.087	88	-30	(-96, 35)	0.361	0.617
	High	44	39	(-41, 119)	0.330		166	-26	(-92, 40)	0.434		91	-26	(-98, 46)	0.467	
> 4 servings of fruits or vegetables (OR)	Low	13/45	1	-	-		56/151	1	-	-		26/74	1	-	-	
	Mod	16/45	1.16	(0.40, 3.35)	0.950	0.889	57/167	0.99	(0.52, 1.89)	0.710	0.835	30/86	0.91	(0.28, 2.97)	0.436	0.277
	High	15/48	1.27	(0.48, 3.36)	0.708		48/172	1.22	(0.58, 2.56)	0.549		20/81	1.85	(0.71, 4.81)	0.109	
Current smoker& (OR)	Low/Mod**	4/90	1	-	-		149/318	1	-	-		30/172	1	-	-	
	High	9/48	4.05	(1.09, 15.1)	0.037	-	87/172	1.39	(0.81, 2.39)	0.239	-	15/92	2.88	(0.81, 10.2)	0.101	-

Note. Diff. = Difference. Burden scores (exposure) were classified in country-specific tertiles. The regression model was adjusted for age group, sex, wealth tertile and marital status. * = mean and SE presented for the reference group. ** low/moderate burden tertile collapsed. *** = Physical activity includes activities at work; transport, and leisure time, summarized as minutes per day expended in moderate or vigorous physical activity. & = participants who never used tobacco or stopped smoking versus current smokers, regardless of quantity and frequency.

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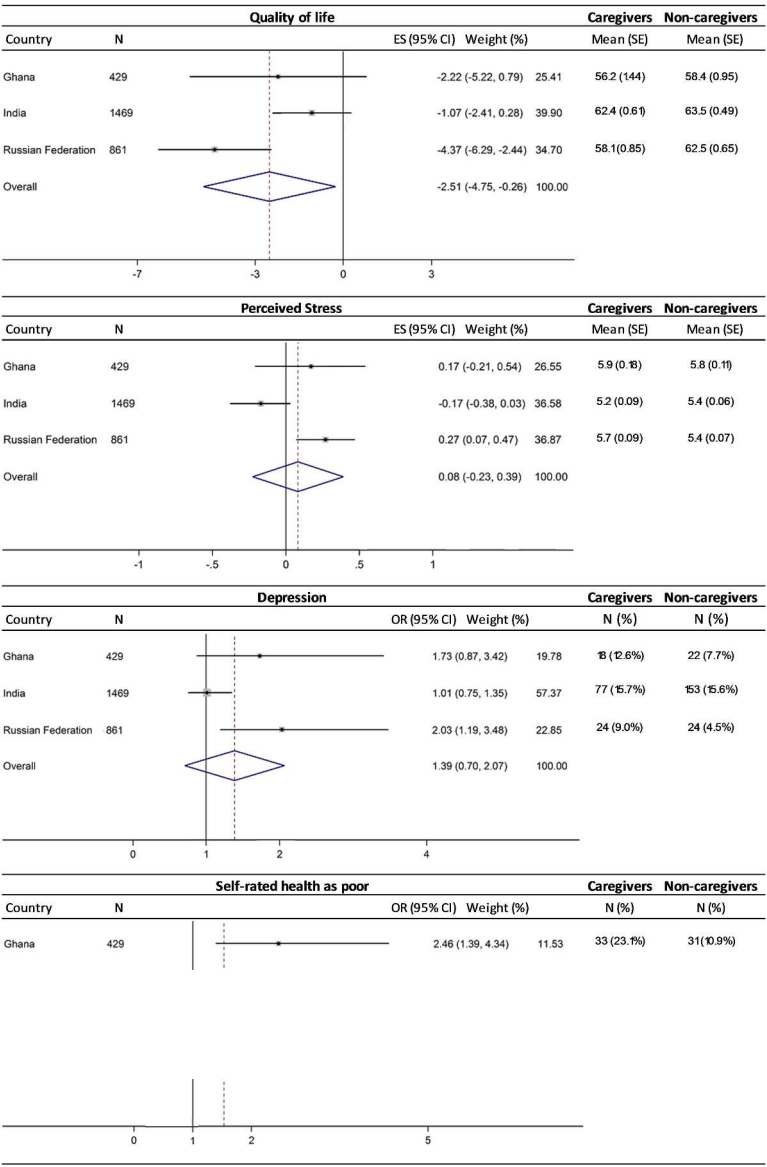50
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Figure 1: Comparison of health-related outcomes between caregivers and non-caregivers (matched controls) by country, SAGE Wave 1 (2007/10)
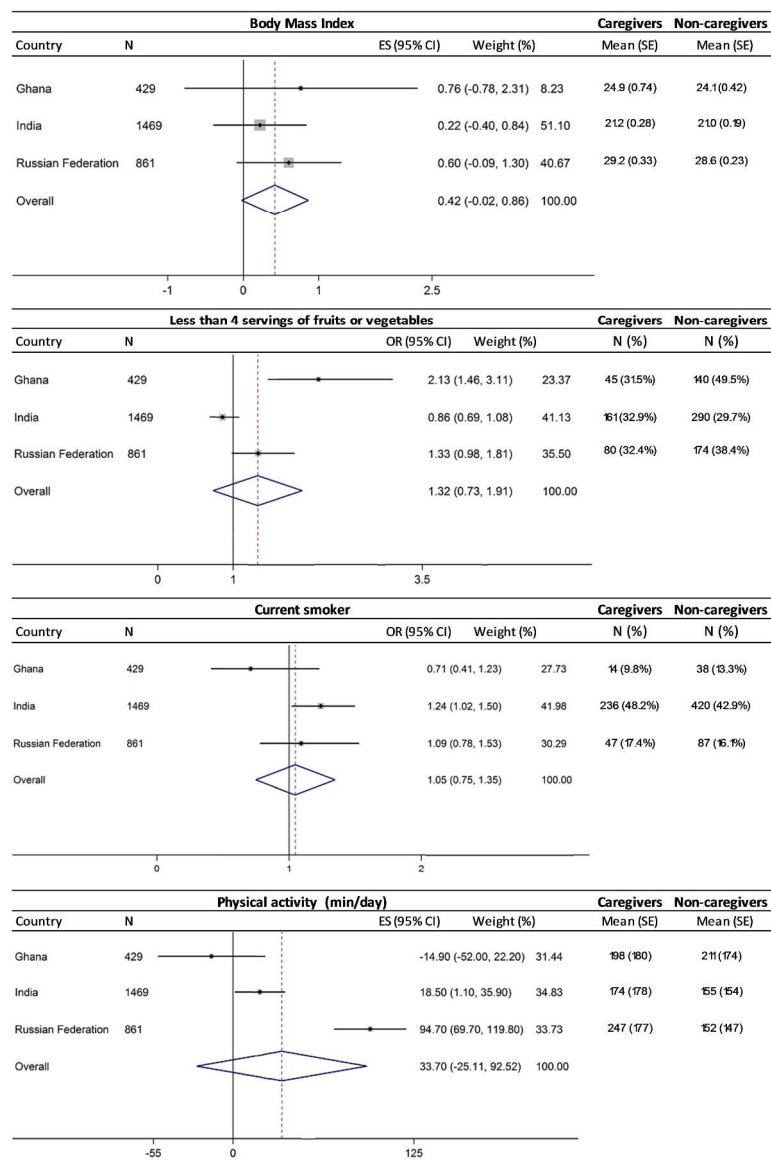
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Figure 2: Comparison of risk factors between caregivers and non-caregivers (matched controls) by country, SAGE Wave 1 (2007/10)

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