Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys

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Background. Current trends in population aging affect both recipients and providers of informal family caregiving, as the pool of family caregivers is shrinking while demand is increasing. Epidemiological research has not yet examined the implications of these trends for burdens experienced by aging family caregivers.

Method. Cross-sectional community surveys in 20 countries asked 13 892 respondents aged 50+ years about the objective (time, financial) and subjective (distress, embarrassment) burdens they experience in providing care to first-degree relatives with 12 broadly defined serious physical and mental conditions. Differential burden was examined by country income category, kinship status and type of condition.

Results. Among the 26.9–42.5% respondents in high-, upper-middle-, and low-/lower-middle-income countries reporting serious relative health conditions, 35.7–42.5% reported burden. Of those, 25.2–29.0% spent time and 13.5–19.4% money, while 24.4–30.6% felt distress and 6.4–21.7% embarrassment. Mean caregiving hours per week in those giving any time were 16.6–23.6 (169.9–205.8 h/week per 100 people aged 50+ years). Burden in low-/lower-middle-income countries was 2- to 3-fold higher than in higher-income countries, with any financial burden averaging 14.3% of median family income in high-, 17.7% in upper-middle-, and 39.8% in low-/lower-middle-income countries. Higher burden was reported by women than men and for conditions of spouses and children than parents or siblings.

Conclusions. Uncompensated family caregiving is an important societal asset that offsets rising formal healthcare costs. However, the substantial burdens experienced by aging caregivers across multiple family health conditions and geographic regions threaten the continued integrity of their caregiving capacity. Initiatives supporting older family caregivers are consequently needed, especially in low-/lower-middle-income countries.

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Introduction

A global 'caregiving crisis' (Carter, 2008) is widely forecast owing to dramatic demographic transitions and health trends that strain conventional healthcare mechanisms (Wiener, 2003). Rapid population aging (Wiener, 2003; Carter, 2008; Bloom, 2011; Lee, 2011) is accompanied by increases in age-related morbidity and disability (Vogeli *et al*. 2007; Christensen *et al*. 2009). The old age dependency ratio is accordingly projected to double by 2050 and triple by 2100 (Lee, 2011). Confronted with the resultant growth in long-term care (LTC) needs and critical shortages of professional resources (Jacobzone, 2000; Wiener, 2003; Carter, 2008; Christensen *et al*. 2009; Levine *et al*. 2010; Kakuma *et al*. 2011), public health systems increasingly seek community solutions, including deinstitutionalization, laws mandating care of dependent relatives, and 'cash-for-care' incentives (Jacobzone, 2000; Bolin *et al*. 2008; Levine *et al*. 2010). Such initiatives will doubtlessly compound the burden of family caregivers (Jacobzone, 2000; Awad & Voruganti, 2008; Lamura *et al*. 2008) who already shoulder the vast majority of LTC responsibilities without pay or compensation for forgone wages (Jacobzone, 2000; Wiener, 2003; Carter, 2008; Levine *et al*. 2010).

However, informal caregiving systems are simultaneously dwindling (Ekwall *et al*. 2007) due to sociodemographic trends towards delayed childbearing, smaller families, more divorce and remarriage, more female employment and dual-earner households, higher migration and globalization, and less intergenerational co-residency (Wiener, 2003; Heitmueller, 2007; Bolin *et al*. 2008; Lamura *et al*. 2008). As a result of these trends, the burden of chronic care increasingly falls on family caregivers who are themselves aging (Jacobzone, 2000; Wiener, 2003; Levine *et al*. 2010; Kakuma *et al*. 2011; Lee, 2011) and vulnerable to the burdens of caregiving, which include financial strain (Hickenbottom *et al*. 2002; Carmichael & Charles, 2003; Heitmueller & Inglis, 2007; Bolin *et al*. 2008; Kusano *et al*. 2011), depression (Pinquart & Sörensen, 2003a, 2007; Haley *et al*. 2009; Opree & Kalmijn, 2012; Papastavrou *et al*. 2012), sleep disruption (Happe & Berger, 2002), mobility limitation (Fredman *et al*. 2008, 2009), immunosuppression (Kiecolt-Glaser *et al*. 1991), neuroendocrine dysregulation (Brummett *et al*. 2008; Kring *et al*. 2010), general physical morbidity (Vitaliano *et al*. 2003; Pinquart & Sörensen, 2007; Haley *et al*. 2010), and even excess mortality (Schulz & Beach, 1999; Christakis & Allison, 2006).

Although the above trends lead experts to conclude that informal care is among the most pressing public policy challenges of our time (Wiener, 2003), credible data evaluating current burden among family caregivers are few and fragmentary. Most evidence on caregiving has been collected incidentally in research on specific conditions (Hickenbottom *et al*. 2002; Prince, 2004; Torti *et al*. 2004; Awad & Voruganti, 2008; National Alliance for Caregiving in collaboration with AARP, 2009), often based on small convenience samples in industrialized countries that focused on particular relationships and burdens. Few large population-based estimates of condition- or region-specific burden exist (Hickenbottom *et al*. 2002; Prince, 2004; Wimo *et al*. 2007; Awad & Voruganti, 2008), while multinational assessments are generally confined to overviews and meta-analyses of small-scale studies (Pinquart & Sörensen, 2003a, 2005, 2006, 2007, 2011; Torti *et al*. 2004). For instance, a recent meta-analysis of kinship differences in 168 caregiver studies over the last three decades identified no pertinent cross-national surveys (Pinquart & Sörensen, 2011), while a systematic review of 93 studies on dementia caregivers (Torti *et al*. 2004) identified no contemporary large-scale cross-national surveys, leading experts to conclude that culturally inclusive large-scale studies are sorely needed (Torti *et al*. 2004; Pinquart & Sörensen, 2011). The small amount of cross-national research undertaken in this area to date has focused largely on topical issues such as service use (Lamura *et al*. 2008), palliative caregiving (Gysels *et al*. 2012), dementia caregiving (Schneider *et al*. 1999), and compound caregiving (Opree & Kalmijn, 2012) in small European samples. While these studies document significant objective and subjective burden among family caregivers (Schneider *et al*. 1999; Gysels *et al*. 2012), virtually no broad-based population data exist on the magnitude of the burden experienced by family caregivers across developed and developing countries.

The current report presents data on this issue based on cross-sectional community epidemiological surveys of older (aged 50+ years) family caregivers in 20 countries participating in the World Health Organization (WHO) World Mental Health (WMH) Survey Initiative (Kessler & Üstün, 2008). We examine both objective and subjective burdens associated with a wide range of family health problems. We focus on older caregivers based on concerns about the aging of the world population (Opree & Kalmijn, 2012), the rising share of caregiving provided by older family members (Heitmueller & Inglis, 2007; Bolin *et al*. 2008; Opree & Kalmijn, 2012), and the vulnerability of older caregivers to burden due to their own pre-existing health problems and functional limitations (King & Brassington, 1997; Schneider *et al*. 1999).

Method

Sample

Surveys were administered in 10 countries classified by the World Bank (World Bank, 2009) as high income (Belgium, France, Germany, Israel, Italy, the Netherlands, Northern Ireland, Portugal, Spain, USA), five as upper-middle income (São Paulo in Brazil, Bulgaria, Lebanon, Mexico, Romania), and five as low/lower-middle income (Colombia, Pondicherry in India, Iraq, Nigeria, Shenzhen in the People's Republic of China). A total of 13892 respondents aged 50+ years (7265 in high-income, 4077 in upper-middle-income, and 2550 in low-/lower-middle-income countries) were interviewed about family burden. All but five surveys were based on national household samples. The exceptions were two surveys of urban areas (Colombia, Mexico) and three of specific metropolitan areas (São Paulo, Brazil; Pondicherry, India; Shenzhen, People's Republic of China). Interviews were conducted face-to-face in respondent households after obtaining informed consent. Human Subjects Committees monitored the study and approved recruitment and consent procedures in each country. Response rates ranged from 45.9% in France to 98.6% in Pondicherry and averaged 71.8%. Further details about WMH design have been presented elsewhere (Harkness *et al.* 2008; Heeringa *et al.* 2008; Pennell *et al.* 2008).

Subsampling within interviews was used to reduce respondent burden. The family burden questions were consequently administered to between a random 15% (Portugal) and 100% (in five surveys) of respondents. The number of such respondents aged 50+ years ranges from 233 to 287 respondents in six surveys (Belgium, Colombia, Lebanon, Mexico, Pondicherry and Portugal) to highs of 1110–1904 in five others (Israel, Northern Ireland, Romania, São Paulo and the USA). Because of this wide sample size variability, analyses were implemented in pooled cross-national samples disaggregated into high-, upper-middle-, and low-/lower-middle-income countries.

Measures

Burden was conceptualized according to the traditional distinction between objective and subjective (Awad & Voruganti, 2008; Idstad *et al.* 2011). Questioning began by asking respondents how many living first-degree relatives of four types they had (parents, siblings, spouses, children) and whether one or more of each type had each of 12 broadly defined classes of health conditions: four physical (cancer, serious heart problems, permanent physical disability like blindness or paralysis, any other serious chronic physical illness) and eight mental (serious memory problems such as senility or dementia, mental retardation, alcohol or drug problems, depression, anxiety, schizophrenia or psychosis, manic-depression, any other serious chronic mental problem). We did not assess the number of each kinship type with each condition but only whether any kin of each type had each condition. The condition list was purposefully kept short based on concerns that respondents might provide superficial answers to longer lists, the intent being to provide an operational definition of 'serious' by beginning with a short set of exemplar conditions to establish an implicit threshold before asking a more general question about 'any other' comparably serious condition. To the extent that respondents experience some family health conditions as burdensome but not 'serious', this approach underestimates conditions.

Respondents reporting at least one first-degree relative with at least one condition were then asked: 'Taking into consideration your time, energy, emotions, finances, and daily activities, would you say that (his/her/their) health problems affect your life a lot, some, a little, or not at all?' This question was asked only once, implicitly asking respondents to consider all conditions of all first-degree relatives. Respondents who answered 'a lot' or 'some' were then asked two questions about subjective burden: how much their family members' health conditions caused them to be either psychologically distressed ('worried', 'anxious', or 'depressed') or embarrassed ('a lot', 'some', 'a little', 'not at all'). Additional yes/no questions then assessed whether respondents helped with practical tasks (e.g. washing, getting around, housework) and spent more time keeping company or giving emotional support to their ill relatives than they would otherwise. This strategy of asking about 'additional' time due to relative conditions was designed to adjust for between-country differences in normal amount of interaction with relatives. Respondents were also asked whether they had any financial burden (either money spent or earnings foregone) due to their relatives' conditions and, if so, average monthly amount of this burden. Responses were converted to median national household income equivalents to adjust for between-country differences in currency.

First-degree relatives were selected as the focus to create a well-defined network for sampling purposes. While respondents could doubtlessly have reported caregiving activities involving other kin (e.g. grandparents, grandchildren) and non-relatives, it was less clear whether respondents would have reliable information regarding serious mental and physical health problems in these broader networks, leading to

Table 1. *Prevalence and reported burden of family health problems*

	Total sample								Subsample with family health problems							
	Country income level								Country income level							
	High (n=7265)		Upper-middle (n=4077)		Low/lower-middle (n=2550)		Total (n=13892)		High (n=3079)		Upper-middle (n=1327)		Low/lower-middle (n=579)		Total (n=4985)	
	%	(s.e.)	%	(s.e.)	%	(s.e.)	%	(s.e.)	Estimate[a]	(s.e.)	Estimate[a]	(s.e.)	Estimate[a]	(s.e.)	Estimate[a]	(s.e.)
Prevalence of family health problems																
Parent	11.6	(0.5)	8.7	(0.5)	9.6	(0.8)	10.5	(0.3)	27.4	(1.0)	26.5	(1.4)	35.7	(2.2)	28.2	(0.7)
Spouse	10.2	(0.5)	7.8	(0.5)	6.0	(0.7)	8.8	(0.3)	24.0	(1.0)	23.8	(1.4)	22.3	(2.0)	23.7	(0.7)
Child	9.7	(0.5)	7.5	(0.6)	5.9	(0.7)	8.4	(0.3)	22.8	(0.9)	22.7	(1.6)	22.1	(2.2)	22.7	(0.7)
Sibling	21.3	(0.6)	15.6	(0.8)	10.9	(1.0)	17.9	(0.4)	50.0	(0.9)	47.4	(1.9)	40.5	(2.5)	48.2	(0.8)
Any physical	33.5	(0.7)	24.6	(0.9)	22.0	(1.4)	29.0	(0.5)	78.7	(0.7)	74.6	(1.6)	81.6	(1.6)	78.1	(0.6)
Any mental	19.4	(0.6)	15.3	(0.7)	9.6	(0.9)	16.5	(0.4)	45.6	(1.0)	46.4	(1.7)	35.6	(2.4)	44.5	(0.8)
Any physical or mental	42.5	(0.7)	32.9	(1.0)	26.9	(1.4)	37.2	(0.6)	100.0	(–)	100.0	(–)	100.0	(–)	100.0	(–)
Mean number[a]	0.8	(0.02)	0.6	(0.02)	0.4	(0.02)	0.7	(0.01)	1.9	(0.04)	1.7	(0.04)	1.5	(0.05)	1.8	(0.02)
Burden of family health problems																
Any burden	17.6	(0.6)	14.0	(0.8)	9.6	(1.0)	15.2	(0.4)	41.2	(1.0)	42.5	(1.8)	35.7	(2.5)	40.8	(0.8)
Any time	12.4	(0.5)	8.3	(0.6)	7.2	(0.8)	10.4	(0.3)	29.0	(0.9)	25.2	(1.5)	26.7	(2.3)	27.8	(0.7)
Any financial	5.8	(0.3)	6.4	(0.6)	4.6	(0.6)	5.8	(0.3)	13.5	(0.6)	19.4	(1.6)	17.2	(1.5)	15.4	(0.6)
Distress[b]	10.9	(0.4)	10.1	(0.6)	6.6	(0.8)	9.9	(0.3)	25.5	(0.8)	30.6	(1.3)	24.4	(2.2)	26.6	(0.7)
Embarrassment[b]	2.7	(0.2)	7.1	(0.5)	2.5	(0.4)	3.9	(0.2)	6.4	(0.5)	21.7	(1.3)	9.2	(1.0)	10.4	(0.5)

Data are given as percentage (s.e.) or as estimate (s.e.).

s.e., Standard error.

[a] Mean number of family health problems out of 48 (12 types of problems for each of four types of family members).

[b] 'A lot' or 'some' distress or embarrassment reported in response to questions about intensity of these feelings.

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Table 2. *Individual-level and population-level time and financial burdens of family health problems*

	Country income level							
	High		Upper-middle		Low/lower-middle		Total	
	Estimate	(s.e.)	Estimate	(s.e.)	Estimate	(s.e.)	Estimate	(s.e.)
Time, hours per week								
Individual level, mean[a]	16.6	(1.3)	23.3	(2.4)	23.6	(2.8)	18.9	(1.2)
Per 100 in the population, total[b]	205.8	(3.2)	193.4	(3.6)	169.9	(6.1)	196.7	(2.8)
Financial, mean percentage of median household income								
Individual level[c]	14.3	(1.3)	17.7	(1.2)	39.8	(7.6)	23.9	(1.7)
Per 100 in the population[d]	0.83	(0.02)	1.13	(0.04)	1.83	(0.06)	1.39	(0.03)
n_1[e]	859		318		154		1331	
n_2[e]	410		184		111		705	
n_3[e]	7265		4077		2550		13 892	

Data are given as estimate (s.e.).

s.e., Standard error.

[a] Individual-level reports of hours per week spent with or doing things for ill family members.

[b] The population-level estimate was obtained by multiplying the individual-level estimate by the proportion of respondents who reported spending any time.

[c] Individual-level reports of financial burden were converted to percentages of median household income in the country. The means of these transformed scores among respondents who reported any financial burden are reported here. For example, the mean monthly financial impact of family illness (due either to out-of-pocket expenses or foregone income) across countries among respondents who reported such costs was equal to 23.9% of the median monthly household income in the country.

[d] The population-level estimate of financial burden was obtained by multiplying the individual-level estimate by the proportion of respondents who reported such burdens. The resulting estimate can be interpreted as the total financial costs of family health problems as a percentage of total household income in the country.

[e] n_1 = subsample of responded who devoted any time to family health problems; n_2 = subsample of respondents with any financial burden due to family health problems; n_3 = total sample, including respondents who had no family health problems.

burden dimensions in total-sample multivariate models: (i) women reported significantly more burden than men on all indicators other than financial burden, with ORs of 1.3–1.8; (ii) the previously married reported significantly less distress and less time on relative conditions than the married (0.6–0.8); (iii) education was positively associated with having any financial burden (1.1) and with magnitude of financial burden among those having any (1.1). However, little geographic consistency was found in these patterns, with the only statistically significant patterns found in more than one country income group being higher ORs of distress (1.9–2.2) and time spent (1.8–2.3) by women than men in both high- and upper-middle-income countries.

Variations in burden by kinship and condition

Total-sample multivariate models show spouse and child conditions associated with highest and sibling conditions lowest burden across all outcomes other than amount of financial burden, where relationship type is not significant (Table 3). This result is probably conservative, as the most plausible bias in such reports would be for less severe conditions of siblings to be under-reported relative to those of spouses, parents and children. Correction for such bias would yield even stronger evidence for lowest burden associated with sibling conditions. These patterns are generally consistent across high- and upper-middle-income country groups. For low-/lower-middle-income countries, though, child problems are associated with substantially higher relative effects on time, financial burden, and distress, with relative effects of spouse conditions closer to those of parent and sibling conditions.

The same total-sample multivariate models found significant variation in burden by type of condition for all indicators other than amount of financial burden (Table 4). However, little consistency exists in the most burdensome conditions across outcomes. Results not reported in the table also failed to detect geographic consistencies in differential burden across conditions for individual outcomes. The most consistent pattern is for mental retardation to be associated with elevated odds of both devoting any time (1.8 in the total

Table 3. *Differential burdens of family health problems by type of relative*[a]

	Country income level								
	High		Upper-middle		Low/lower-middle		Total		
	Estimate	(S.E.)	Estimate	(S.E.)	Estimate	(S.E.)	Estimate	(S.E.)
Any burden, compared with siblings								
Parent	1.4	(1.2–1.7)*	1.5	(1.2–1.9)*	1.7	(0.9–3.2)	1.4	(1.3–1.6)*
Spouse	2.4	(2.0–3.0)*	2.1	(1.6–2.9)*	2.0	(1.0–4.2)	2.2	(1.9–2.6)*
Child	1.6	(1.4–1.9)*	2.1	(1.6–2.8)*	4.7	(2.1–10.6)*	1.8	(1.6–2.1)*
χ^2_3	111.8*		51.1*		14.5*		151.3*	
Any time, compared with siblings								
Parent	1.7	(1.4–2.1)*	1.5	(1.1–2.0)*	1.5	(0.9–2.7)	1.6	(1.4–1.9)*
Spouse	2.5	(2.1–3.0)*	2.0	(1.4–2.9)*	1.8	(0.8–3.7)	2.3	(2.0–2.7)*
Child	1.5	(1.2–1.8)*	1.6	(1.2–2.1)*	3.8	(1.8–7.7)*	1.6	(1.4–1.8)*
χ^2_3	101.9*		27.5*		13.0*		115.9*	
Any financial burden, compared with siblings								
Parent	1.4	(1.1–1.9)*	1.8	(1.3–2.6)*	1.4	(0.7–2.7)	1.5	(1.2–1.9)*
Spouse	2.9	(2.3–3.6)*	3.6	(2.4–5.3)*	1.8	(0.8–3.7)	2.9	(2.4–3.5)*
Child	2.1	(1.6–2.7)*	2.2	(1.6–3.0)*	3.0	(1.5–6.1)*	2.2	(1.8–2.6)*
χ^2_3	84.3*		52.2*		10.3*		136.5*	
Distress, compared with siblings								
Parent	1.2	(1.0–1.5)*	1.4	(1.1–1.8)*	3.1	(2.0–4.9)*	1.3	(1.2–1.5)*
Spouse	1.9	(1.6–2.3)*	2.2	(1.6–3.2)*	3.1	(1.8–5.4)*	2.0	(1.7–2.4)*
Child	1.7	(1.4–2.1)*	2.5	(1.8–3.4)*	9.0	(3.8–21.6)*	2.0	(1.7–2.4)*
χ^2_3	59.7*		46.0*		34.0*		106.7*	
Embarrassment, compared with siblings								
Parent	1.5	(1.1–2.0)*	1.4	(1.0–2.0)*	2.5	(1.5–4.2)*	1.5	(1.2–1.8)*
Spouse	2.3	(1.7–3.0)*	2.2	(1.5–3.2)*	4.5	(1.7–12.0)*	2.3	(1.9–2.9)*
Child	2.3	(1.7–3.0)*	2.3	(1.7–3.3)*	2.8	(1.3–5.9)*	2.2	(1.8–2.7)*
χ^2_3	49.1*		35.3*		15.8*		92.5*	
Amount of time, among those devoting any time								
Parent	1.0	(0.8–1.3)	1.2	(0.9–1.6)	2.5	(1.7–3.6)*	1.2	(1.0–1.4)
Spouse	1.3	(1.0–1.6)*	1.3	(0.9–1.9)	1.6	(1.0–2.7)*	1.3	(1.1–1.6)*
Child	1.2	(1.0–1.6)*	1.2	(0.9–1.5)	1.6	(1.0–2.6)	1.3	(1.1–1.5)*
F_3	3.8	(0.010)	0.8	(0.475)	8.2	(0.000)	3.5	(0.016)
Amount of financial burden, among those with any								
Parent	1.0	(0.8–1.4)	0.8	(0.6–1.2)	0.5	(0.2–1.4)	0.9	(0.7–1.3)
Spouse	1.0	(0.8–1.3)	0.9	(0.7–1.2)	1.4	(0.4–4.3)	1.0	(0.8–1.2)
Child	1.0	(0.7–1.3)	1.0	(0.7–1.2)	3.0	(1.2–7.8)*	1.2	(0.9–1.5)
F_3	0.1	(0.981)	0.4	(0.784)	5.9	(0.001)	1.3	(0.260)
n_1[b]	3079		1327		579		4985	
n_2[b]	859		318		154		1331	
n_3[b]	410		184		111		705	

Data are given as odds ratio (S.E.) for the first five outcomes, all of which are dichotomies, and incidence density ratio (S.E.) for the last two outcomes, which are continuous.

S.E., Standard error.

[a] Based on multivariate models (logistic for dichotomous outcomes; generalized linear models for continuous outcomes with log link function and Poisson error distribution) with predictors that included a separate count variable (coded 0–4) for the number of types of relatives with each of the 12 health problems, a separate count variable (coded 0–12) for the number of types of health problems experienced by each of three types of relatives (parents, spouse, children, compared with the implicit contrast category of siblings), and demographic controls (respondent age, gender, marital status, and level of educational attainment). All equations were estimated in a pooled dataset across either the entire set of 20 countries or in the high-, upper-middle-, and low-/lower-middle-income countries. Romania was removed from the models for financial burden, as this aspect of burden was not assessed in Romania.

[b] n_1 = total subsample of respondents with family health problems; n_2 = subsample of responded who devoted any time to family health problems; n_3 = subsample of respondents with any financial burden due to family health problems.

* $p < 0.05$ level (two-sided test).

Table 4. *Differential burdens of family health problems by type of problem in the total sample (n = 4985)*[a]

	Any burden		Any time		Any financial burden		Distress		Embarrassment		Amount time		Amount financial	
	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)	IDR	(95% CI)	IDR	(95% CI)
Physical disorder														
Cancer	1.0	(0.8–1.3)	1.0	(0.8–1.2)	0.7	(0.5–1.0)	1.1	(0.9–1.4)	1.1	(0.8–1.5)	1.0	(0.8–1.5)	0.7	(0.4–1.2)
Heart problems	1.0	(0.9–1.2)	0.9	(0.7–1.0)	0.8	(0.7–1.0)	1.2	(1.0–1.4)	0.6	(0.5–0.8)*	0.9	(0.7–1.2)	0.8	(0.5–1.2)
Physical disability	1.2	(1.0–1.5)	1.4	(1.1–1.8)*	1.0	(0.8–1.4)	1.2	(0.9–1.4)	0.9	(0.6–1.3)	1.2	(1.0–1.6)	0.8	(0.4–1.4)
Other serious chronic illness	1.2	(1.0–1.4)	1.2	(1.0–1.5)	1.0	(0.8–1.3)	1.2	(1.0–1.4)*	0.8	(0.6–1.1)	0.9	(0.7–1.2)	0.8	(0.4–1.5)
χ^2_4	8.1		21.3*		7.9		6.6		20.3*		1.6	(0.175)	0.7	(0.569)
Mental disorder														
Serious memory problem	1.4	(1.1–1.8)*	1.5	(1.1–1.9)*	0.9	(0.6–1.3)	1.2	(0.9–1.5)	1.2	(0.8–1.6)	0.9	(0.7–1.2)	1.1	(0.6–2.0)
Mental retardation	1.4	(1.0–2.0)*	1.8	(1.2–2.6)*	1.8	(1.2–2.8)*	1.4	(1.0–2.0)	1.0	(0.7–1.6)	1.2	(0.9–1.6)	1.0	(0.6–1.6)
Alcohol/drug problem	1.1	(0.9–1.4)	0.8	(0.6–1.0)	0.8	(0.6–1.2)	1.1	(0.9–1.4)	1.6	(1.2–2.2)*	0.6	(0.5–0.9)*	0.8	(0.4–1.6)
Depression	1.0	(0.7–1.3)	0.9	(0.7–1.2)	0.7	(0.5–1.1)	0.9	(0.7–1.2)	0.8	(0.5–1.1)	1.0	(0.7–1.4)	0.5	(0.3–0.9)*
Anxiety	1.1	(0.8–1.4)	0.9	(0.7–1.2)	0.6	(0.4–0.9)*	1.2	(0.9–1.5)	0.7	(0.5–1.1)	0.7	(0.5–1.0)*	1.3	(0.8–2.1)
Psychosis	0.9	(0.6–1.4)	1.1	(0.7–1.7)	0.8	(0.4–1.6)	1.0	(0.6–1.6)	1.0	(0.4–2.0)	1.1	(0.7–1.8)	4.2	(1.3–12.8)*
Manic-depression	0.6	(0.4–0.9)*	0.6	(0.4–1.0)	0.8	(0.4–1.6)	0.5	(0.3–0.9)*	0.6	(0.2–1.6)	0.8	(0.5–1.2)	1.0	(0.5–1.8)
Other serious chronic illness	1.1	(0.7–1.6)	1.3	(0.9–1.9)	1.6	(1.0–2.5)*	0.9	(0.6–1.4)	0.9	(0.5–1.7)	1.8	(1.2–2.6)*	0.3	(0.1–1.1)
χ^2_8/F_3[b]	23.3*		45.4*		31.0*		18.7*		23.9*		3.1	(0.002)*	1.7	(0.088)
χ^2_{12}/F_{12}[b]	26.7*		57.3*		36.9*		26.1*		54.1*		2.4	(0.005)*	1.3	(0.188)

OR, Odds ratio; CI, confidence interval; IDR, incidence density ratio.

[a] Based on multivariate models (logistic for dichotomous outcomes; generalized linear models for continuous outcomes with log link function and Poisson error distribution) with predictors that included a separate count variable (coded 0–4) for the number of types of relatives with each of the 12 health problems, a separate count variable (coded 0–12) for the number of types of health problems experienced by each of three types of relatives (parents, spouse, children, compared with the implicit contrast category of siblings), and demographic controls (respondent age, gender, marital status, and level of educational attainment). All equations were estimated in a pooled dataset across the entire set of 20 countries. Romania was removed from the models for financial burden, as this aspect of burden was not assessed in Romania.

[b] χ^2 Tests were used for the first five (dichotomous) outcomes and F tests for the last two (continuous) outcomes.

* $p < 0.05$.

Table 5. *Significant population attributable risk proportions of time and financial burdens due to family health problems*

	Country income level							
	High ($n=3079$)		Upper-middle ($n=1327$)		Low/lower-middle ($n=579$)		Total ($n=4985$)	
	Time	Financial	Time	Financial	Time	Financial	Time	Financial
Type of relative								
Parent	18.6	16.2	14.9	–	19.4	–	18.8	–
Spouse	31.3	31.0	26.6	38.0	–	–	27.3	20.9
Child	11.8	19.9	20.4	22.3	40.1	33.8	19.0	36.5
Sibling	–	–	–	–	–	15.2	–	–
Type of health problem								
Physical	39.0	22.0	41.5	26.1	32.3	16.4	39.7	25.6
Mental	27.3	35.3	32.4	18.8	21.0	26.5	29.4	31.3

sample; 1.6–2.1 across country groups) and having any financial burden (1.8 in the total sample; 1.4–3.3 across country groups). Physical disability is the only other family condition consistently (across all country groups) associated with elevated odds relative to other conditions of devoting any time (1.4 in the total sample; 1.3–2.1 across country groups), while memory problems are the only other condition associated with elevated odds relative to other conditions of devoting time in high- and upper-middle-income countries (1.5 in the total sample; 1.5–1.6 across country groups). In interpreting this result, though, it must be recalled that our ascertainment method is biased against detecting between-disorder variation in burden because we assessed only conditions rated 'serious'. While significant differential burden presumably exists due to between-condition variation in severity, these differences are beyond the scope of the present study.

In a similar way, our failure to find strong between-condition variation in psychological distress does not mean that serious conditions are not distressing (as indicated by 24.4–30.6% of respondents reporting distress associated with serious relative health conditions) but rather that the magnitude of this distress does not differ significantly across conditions. The bias against detecting such differences due to our truncation of the severity distribution makes it all the more striking that two particular conditions are consistently associated with differential embarrassment: relative heart problems with comparatively low embarrassment (in the total sample 0.6; 0.3–0.6); and relative alcohol/drug problems (in high-/upper-middle-income countries) with comparatively high embarrassment (in the total sample 1.6; 1.7–2.0). Relative alcohol/drug problems (in the total sample 0.6; 0.1–0.9) and anxiety (in the total sample 0.7; 0.2–0.8) are the only two conditions associated with

low differential time devoted to caregiving, while relative depression (in the total sample 0.5; 0.2–0.8) and psychosis (in the total sample 4.2; 3.0–4.1 in high-/upper-middle-income countries) are the only conditions associated with differential financial burden in more than one country income group.

Interactions between kinship and condition

Analyses not reported in the tables found that interactions between kinship and condition types are globally significant in predicting both amount of time and amount of financial burden among those with any in the total sample. However, inspection of detailed data patterns found few consistencies across country income groups. The latter were confined to models for time. In particular, six kinship–condition combinations were found to have significant differential effects on time across two or more country income groups: parent depression (in the total sample 1.7; 2.6–3.3 in upper-middle- and low-/lower-middle-income countries), spouse physical disability (1.8; 2.1–2.8), spouse depression (in the total sample 2.6; 2.0–4.8 in high-/upper-middle-income countries), spouse other mental illness (in the total sample 2.6; 1.8–3.7), child mental retardation (in the total sample 1.4; 1.5–3.6), and child other mental illness (in the total sample 3.3; 2.6–5.0 in high-/upper-middle-income countries). As with the above results regarding differential burden by kinship and condition, these interactions are likely to be conservative.

PARPs

A total of five significant patterns are noteworthy in the PARP estimates (Table 5). First, sibling health problems are generally associated with insignificant

PARPs, meaning that little time or financial resources are devoted in the aggregate to ill siblings. Second, PARPs are consistently highest for spouses and generally lower for parents than children in high-/upper-middle-income countries, but highest for children in low-/lower-middle-income countries. These differences reflect the joint influences of two factors: (i) roughly equivalent prevalence of reported health conditions across kinship types in high-/upper-middle-income countries *versus* much higher prevalence of parent than spouse/child problems in low-/lower-middle-income countries (see Table 1); and (ii) highest individual-level associations for spouses in high-/upper-middle-income countries and for children in low-/lower-middle-income countries, with generally lower associations for parents than either spouses or children in all country income groups (see Table 3).

Third, despite between-kinship differences, conditions of parents, spouses, and children all account for meaningful components of burden in all three country income groups. Fourth, the sums of PARP estimates across kinship types are consistently less than 100. This reflects the fact that the effects of compound caregiving are not captured in the condition-specific and kinship-specific PARP estimates. Fifth, while the PARPs for physical conditions are almost always higher than those for mental conditions, with the exception of financial burden in high- and low-/lower-middle-income countries, comparative importance of mental conditions is much higher than expected from relative prevalence (see Table 1) due to generally higher individual-level associations of mental (especially mental retardation and memory problems) conditions than physical conditions with most burden dimensions (see Table 3).

Discussion

The above results are broadly consistent with more focused studies of specific conditions such as dementia (Prince, 2004; Torti *et al.* 2004; Wimo *et al.* 2007), stroke (Hickenbottom *et al.* 2002) and schizophrenia (Awad & Voruganti, 2008) in documenting that many older caregivers experience significant burdens associated with serious family health conditions. Our estimate of 16.6–23.6 mean caregiving hours per week among those with any is broadly consistent with a pooled estimate of 26.8 h per week obtained in a meta-analysis averaging estimates across many smaller studies (Pinquart & Sörensen, 2003*b*), but our large-scale representative samples and wide range of conditions allowed us to go beyond this previous type of aggregation by producing true population-level estimates. The magnitude of these estimates is

staggering. The 205.8 h/week per 100 people aged 50+ years devoted to family caregiving in high-income countries translates in the USA (with roughly 60 million people aged 50+ years) into approximately 3.2 million full-time-equivalent older adults working as informal family caregivers. The 0.83% average household income among people aged 50+ years in high-income countries devoted to family caregiving translates in the USA alone into US$5.3 billion per year, equivalent to the average annual salaries of over 130 000 US workers. The individual-level financial burdens in low-/lower-income countries are especially striking, with 39.8% of median household income devoted to family caregiving among the 4.6% of respondents with this burden (compared with 14.3–17.7% of household income among the 5.8–6.4% of respondents with this burden in high-/upper-middle-income countries).

Caregivers in the low-/lower-middle-income group are especially burdened. The higher relative burden for children and siblings in low-/lower-middle-income compared with higher-income countries is consistent with previous evidence of greater 'familism' in developing countries; i.e. with the fact that the relationships of parents with adult children and of adult siblings with each other are not nearly as attenuated in developing than developed countries (Youn *et al.* 1999; Torti *et al.* 2004; Losada *et al.* 2006). The much higher magnitude of financial burden in low-/lower-middle-income than richer countries presumably reflects the well-documented fact that government resources and supports for family caregivers are relatively low in these countries (Maulik & Darmstadt, 2007; Prince *et al.* 2007; Beaglehole *et al.* 2008), although strong social norms encouraging intra-familial financial support could also play a role (Youn *et al.* 1999; Izuhara, 2004; Lin & Yi, 2011). It is important to recall that these cost estimates are lower bounds because they exclude costs associated with self-defined non-serious conditions and with care recipients who are not first-degree relatives. It is more difficult to quantify psychological burdens, but finding as we did that 6.6–10.1% of the population aged 50+ years has meaningful distress and 2.5–7.1% meaningful embarrassment related to serious first-degree family health problems shows clearly that psychological burdens are non-trivial.

Our results on variations in burden are also consistent with most previous studies and meta-analyses in finding higher caregiving burdens for women than men (Bedard *et al.* 2000; Harwood *et al.* 2000; Yee & Schulz, 2000; Navaie-Waliser *et al.* 2002; Torti *et al.* 2004; Pinquart & Sörensen, 2006). Although our finding that greater burden was associated with health conditions of spouses and children than parents and

siblings is also consistent with previous empirical research and large recent meta-analyses (Chumbler *et al.* 2003; Pinquart & Sörensen, 2011), our lack of data on co-residence prevented any assessment of the extent to which this variation is attributable to differences in residential propinquity (Siegler *et al.* 2010). Nor did we consider complex kinship profiles (e.g. variation in burden by number of siblings or birth order in caring for elderly parents) or complex caregiving profiles (i.e. caring for multiple relatives with multiple conditions). Our evidence that higher burden is associated more with mental than physical conditions also confirms previous research (Hastrup *et al.* 2011; Pinquart & Sörensen, 2011), although our exclusive focus on self-defined serious conditions prevented closer study of between-condition differences and almost certainly led to an underestimate of true differences in burden across different types of conditions.

The above results must be interpreted in light of possible sample biases (i.e. that older adults caring for severely ill family might have been less likely than others to participate in the survey, or conversely that we had a 'healthy caregiver effect' whereby those who participated were more robust than those who refused), limitations in focus (i.e. exclusion of non-serious conditions and conditions of care recipients who were not first-degree relatives) and measurement (i.e. short checklists rather than more comprehensive and objective assessments of family health conditions, short assessments of caregiver burden, failure to obtain information on the number of each kinship type with health conditions), and the fact that the small sample sizes in individual countries required us to carry out analyses at a high level of geographic aggregation. Due to our broad focus we failed to consider some important variables previously addressed in more focused studies, such as independent observer-based and perceived health effects on the caregivers themselves (Pinquart & Sörensen, 2003*b*, 2007; Vitaliano *et al.* 2003; Torti *et al.* 2004), caregiver 'load' (Gallo *et al.* 2011; Opree & Kalmijn, 2012), general quality of life (Ekwall *et al.* 2007), and opportunity costs (Carmichael & Charles, 2003; Heitmueller & Inglis, 2007). Also beyond the scope of the present study were possible burden offsets such as pre-morbid relationship, caregiving rewards (e.g. enhanced closeness with care recipients or sense of mattering), coping styles and traits (e.g. resilience, self-efficacy, locus of control), and service availability (Schneider *et al.* 1999; Nomura *et al.* 2005; Ekwall *et al.* 2007; Lamura *et al.* 2008; Poulin *et al.* 2010; Winter *et al.* 2010; Lockenhoff *et al.* 2011; Morse *et al.* 2012). Future epidemiological research would benefit from tandem assessments of caregiver and care recipient health status as well as multi-level studies of the effects of national social policies and cultural norms/expectations on caregiver burdens.

Notwithstanding these limitations and despite some evidence of differential burden by gender, kinship type and condition, the consistency of the basic data patterns reported here is striking in arguing for the existence of substantial caregiver burden comparable with that suggested in cross-national comparisons of smaller, more focused, and less representative samples (Schneider *et al.* 1999; Torti *et al.* 2004). This uniformity indicates that important basic aspects of caregiving burden extend across a range of serious mental and physical conditions, health delivery systems and cultures. When seen against the backdrop of global population trends, this consistency adds compelling evidence to concerns that the shrinking and aging family caregiving system is becoming increasingly strained as it responds to rising demand. Policy makers need to recognize the importance of maintaining the well-being and functional capacities of this aging cadre of family caregivers in light of the vital role they play in the worldwide healthcare and human services delivery systems. While formal interventions that help reduce the burden of family caregivers exist, most address narrow needs of condition-specific caregivers in industrialized countries, and few of these have been rigorously evaluated (Sörensen *et al.* 2002; Stoltz *et al.* 2004; Torti *et al.* 2004). The data presented here suggest that more broad-based programs are needed not only in industrialized countries but perhaps even more so in developing countries to reduce both the objective and subjective burdens of family caregivers.

Declaration of Interest

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