Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey

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Objectives: In a multi-site population-based study in several middle-income countries, we aimed to investigate relative contributions of care arrangements and characteristics of carers and care recipients to strain among carers of people with dementia. Based on previous research, hypotheses focused on carer sex, care inputs, behavioural and psychological symptoms (BPSD) and socioeconomic status, together with potential buffering effects of informal support and employing paid carers.

Methods: In population-based catchment area surveys in 11 sites in Latin America, India and China, we analysed data collected from people with dementia and care needs, and their carers. Carer strain was assessed with the Zarit Burden Interview.

Results: With 673 care recipient/carer dyads interviewed (99% of those eligible), mean Zarit Burden Interview scores ranged between 17.1 and 27.9 by site. Women carers reported more strain than men. The most substantial correlates of carer strain were primary stressors BPSD, dementia severity, needs for care and time spent caring. Socioeconomic status was not associated with carer strain. Those cutting back on work experienced higher strain. There was tentative evidence for a protective effect of having additional informal or paid support.

Conclusions: Our findings underline the global impact of caring for a person with dementia and support the need for scaling up carer support, education and training. That giving up work to care was prevalent and associated with substantial increased strain emphasizes the economic impact of caring on the household. Carer benefits, disability benefits for people with dementia and respite care should all be considered. Copyright © 2012 John Wiley & Sons, Ltd.

Key words: dementia; developing countries; caregivers; stress; psychological; aged; epidemiologic studies

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Background

Alzheimer’s Disease International estimates 35.6 million people worldwide living with dementia, of whom 58% hail from low-income and middle-income countries (LMIC). Numbers are forecast to increase to 115.4 million by 2050, much of that increase occurring in middle-income countries (ADI, 2009). In LMIC, the reliability and universality of the family care system is often overestimated with traditional family structures under threat from social and economic changes accompanying economic development and globalization (Tout, 1989; Prince et al., 1999).

Socioeconomic status (assets and higher education levels of carers and care recipients) will be independently inversely associated with carer strain, whereas giving up work to care will be associated with higher strain.

(1) Mean carer strain will be as high as that observed in previous HIC studies.
(2) Female and spouse carers will report more carer strain.
(3) Carer strain will be associated with time spent caring and with BPSD more than with cognitive impairment.
(4) Socioeconomic status (assets and higher education levels of carers and care recipients) will be independently inversely associated with carer strain, whereas giving up work to care will be associated with higher strain.

Schulz and Martire (2004b) defined caregiving as ‘...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.’

The onset of caring is hard to define; it emerges naturally from support customarily given and received before the onset of dementia and may precede or post-date a formal diagnosis (Gaugler et al., 2003). Needs for care escalate over time, from support for instrumental activities of daily living (IADL—household, financial and social activities), to personal care, to what may be almost constant supervision and surveillance (Schulz and Martire, 2004a). According to a recent review, carers of people with dementia spend an average of 1.6 h daily assisting with personal care, a total of 3.7 h having included IADL or 7.4 h per day when supervision was included (Wimo et al., 2007). In high-income countries (HIC), important transitions include involvement of professional carers, institutionalization and bereavement. The negative consequences of caregiving have been widely studied (Schulz and Martire, 2004b).抄

There are few studies of carers of people with dementia from LMIC. The 10/66 Dementia Research Group’s multicentre pilot study included 706 carers in Latin America, India and China (10/66 Dementia Research Group, 2004), with a methodology that was similar to the EUROCare study of 280 spouse carers from 14 European countries (Schneider et al., 1999). Both studies recruited convenience samples, so findings may not have been representative. In both studies, most carers were women. In Europe, most couples lived on their own. In the 10/66 studies, people with dementia typically lived in large households with extended families, one-quarter to one-half of households including children under 16 years of age (10/66 Dementia Research Group, 2004). Whereas larger households attenuated slightly the strain for the main carer, traditional extended family care networks provided little protection; levels of carer strain were generally, still as high as in the EUROCare project.

In HIC female carers (Yee and Schulz, 2000; Gallicchio et al., 2002), spouses (Brodaty and Hadzi-Pavlovic, 1990), carers that live with the care recipient (Brodaty and Hadzi-Pavlovic, 1990), and those with low incomes or financial strain (Schneider et al., 1999; Covinsky et al., 2003; Andren and Elmstahl, 2007) are prone to high levels of strain or distress. Behavioural and psychological symptoms of dementia (BPSD—particularly apathy, irritability, anxiety, depression and psychosis) are strongly associated with carer strain (Pinquart and Sorensen, 2003). Cognitive impairment is less strongly implicated (Pinquart and Sorensen, 2003). Others’ availability to assist in providing care may be more important than non-specific indices of social support (Chang et al., 2001). Coping strategies may mediate associations between carer subjective strain and psychological morbidity (Pruchno and Resch, 1989; Cooper et al., 2008). Finally, poorer relationship quality and lack of past intimacy have also been reported to be associated with increased strain.

In the context of the 10/66 Dementia Research Group cross-sectional population-based surveys of dementia and ageing in Latin America, China and India (Prince et al., 2007), we aimed to investigate in each site, among those survey participants diagnosed with dementia, the relative contributions of care arrangements and characteristics of carers and care recipients to carer strain and to estimate the effect of site on carer strain, controlling for these factors. Specifically we aimed to test the following hypotheses...
Mental State, which applies a computer algorithm [Automated Geriatric Examination for Computer Assisted Taxonomy (AGECAT)] (Copeland et al., 1986) to allocate syndromal diagnoses of organicity (probable dementia), depression, anxiety and psychosis. Stage 1 non-hierarchical diagnoses were used so that all relevant co-morbid conditions could be identified.

Carer characteristics

Age, sex, marital status (coded for this analysis as currently married versus not currently married), occupation (in paid employment versus economically inactive), relationship to person with dementia (spouse versus child or child-in-law versus other relationship). Carer psychological morbidity was assessed using the Self Reporting Questionnaire [SRQ] (Mari and Williams, 1985).

Care arrangements

(a) The extent of care provided (see previous paragraphs) and the time in hours spent by the carer in the last 24 h in specific caregiving activities (Davis et al., 1997); communicating, using transport, dressing, eating, looking after one’s appearance and supervising.

(b) Data on the occupation of the carer, the extent to which the carer had cut back on or stopped work in order to provide care, unpaid care provided by family or others in the community and paid care inputs were assessed using the Client Service Receipt Inventory (Chisholm et al., 2000).

Carer strain

Carer-perceived strain was assessed using the Zarit Burden Interview (ZBI) (Zarit et al., 1980, 1986; Whitlatch et al., 1991). Twenty-two items assess the carer’s appraisal of the impact their involvement has on their lives. It has been very widely used in the USA and Europe and also in Nigeria (Uwakwe and Modebe, 2007), Taiwan (Chou et al., 1999), Korea (Kim et al., 2006), Colombia (Arango Lasprilla et al., 2009) and Argentina (Machnicki et al., 2009). It has been formally validated in China (Ko et al., 2008; Wang et al., 2008) and Japan (Arai et al., 1997). When used in the 10/66 pilot studies in 24 centres in Latin America, India, China and Africa, it was found to be practical, to be culturally relevant and to have robust psychometric

Characteristics of the person with dementia

Dementia severity was rated with the Clinical Dementia Rating (questionable, mild, moderate or severe) (Morris, 1993) and by cognitive impairment, measured using the Community Screening Instrument for Dementia (CSI’D’) COGSCORE (Hall et al., 1993). Severity of BPSD was assessed using the brief Neuropsychiatric Inventory (NPI-Q) (Kauf er et al., 2000), administered to an informant. The presence of urinary and/or faecal incontinence was assessed through a single question in the CSI’D’ informant interview. Mental disorders were identified through a structured clinical mental state interview, the Geriatric

(5) Those who employ paid carers will experience less strain, as will those reporting availability of alternative informal carers.

(6) Variation in mean carer strain will be largely accounted for by compositional differences (in characteristics of carers and care recipients and care arrangements) between sites.

Method

Survey participants diagnosed with 10/66 dementia and rated as needing care were eligible for this analysis. 10/66 dementia is a cross-culturally calibrated and validated diagnostic algorithm based on cognitive testing, clinical interview and informant report (Prince et al., 2003). Needs for care were identified through open-ended questions to a key informant: Who shares the home? What kind of help does the participant need inside and outside of the home? Who, in the family, is available to care? What help do you provide? Do you help to organize care? Is there anyone else in the family who is more involved in helping? What do they do? What about friends and neighbours, what do they do? The interviewer then coded whether the participant required no care, care some of the time or care much of the time. For the key informant, interviewers were instructed to recruit the person who knew the older person best. Where the older person needed care, then the main carer was selected. Coresidents and family members were prioritized unless others were better qualified. Time spent with the older person was the main criterion if there were several coresident carers. Survey participation was provided by King’s College London Research Ethics Committee and by local ethical review boards in each country.

Characteristics of carers and care recipients and accounted for by compositional differences (in care arrangements) between sites.
properties (10/66 Dementia Research Group, 2004). It was also responsive to change in the context of carer interventions in Russia (Gavrilova et al., 2009), India (Dias et al., 2008) and Peru (Guerra et al., 2011).

Analyses

We report, by site, numbers and proportion of those with dementia rated as needing care and eligible for inclusion in subsequent analyses. We describe ZBI score distributions in each site (means, standard deviations, medians and interquartile ranges). We assess the univariate effect of each covariate upon ZBI score in each site, reporting stratified ZBI scores with standard deviations and applying t-tests or one-way analysis of variance (ANOVA) as appropriate. These were then adjusted for the age and sex of the person with dementia and BPSD severity; the age, sex and marital status of the carer; carer psychological morbidity (SRQ score); the relationship between the carer and care recipient; the time spent providing ADL care; and the number of coresidents. We fitted the model separately for each site and then used a fixed effects meta-analysis to combine site-specific adjusted beta coefficients and their standard errors, reporting adjusted pooled mean differences with 95% confidence intervals and Higgins’ $I^2$ (Higgins and Thompson, 2002) with approximate 95% confidence intervals to estimate the degree of heterogeneity.

Results

The proportion of those with 10/66 dementia rated as needing care varied widely between sites and, other than in India, was higher in urban than in rural sites. Overall, of the 1345 people with 10/66 dementia, 677 (50.3%) were rated as needing care and were eligible for the care arrangements and carer strain interviews; 673 (99.4%) completed them (Table 1). ZBI scores distributions were only slightly positively skewed in most sites, and the medians were similar to the means. Mean scores for most sites ranged between 17 and 25 with higher mean scores in Cuba (27.9), rural Peru (27.4) and urban China (26.8) (Table 1). The proportion of the variance (eta²) in ZBI accounted for by site was 4.1%. The principal characteristics of carers and care recipients in each site are summarized in Tables 2 and 3.

Carer characteristics

Neither carer age nor occupation was associated with strain. Married carers reported less strain than

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**Table 1. Sample sizes, response rates, and distribution of Zarit Burden Interview scores by site**

| Site                  | Number of 10/66 dementia cases (95% CI) | Number (%) of dementia cases rated as needing care (95% CI) | Number (%) of eligibles with completed Zarit Burden Interview (95% CI) | Zarit Burden Interview Median (SD) | ZBI scores Mean (95% confidence intervals), after adjustment |
|-----------------------|--------------------------------------|------------------------------------------------------------|------------------------------------------------------------------------|-----------------------------------|-------------------------------------------------------------|
| Cuba                  | 316 (267–365)                        | 175 (55%) (95%)                                           | 167 (55%) (95%)                                                       | 27.9 (16.9)                       | 27 (16–39) 23.8 (17.0)                                      |
| Dominican Republic    | 250 (206–304)                        | 104 (44%) (95%)                                          | 103 (44%) (95%)                                                      | 24.5 (15.7)                       | 24 (11–36) 21.8 (15.3)                                     |
| Perú (urban)          | 129 (106–152)                        | 57 (44%) (95%)                                           | 57 (44%) (95%)                                                       | 20.2 (16.4)                       | 20 (11–31) 19.8 (14.9)                                     |
| Perú (rural)          | 114 (99–130)                         | 44 (39%) (95%)                                           | 44 (39%) (95%)                                                       | 22.9 (18.7)                       | 22 (11–35.5) 22.1 (18.6–26.4)                            |
| Venezuela             | 110 (90–131)                         | 51 (47%) (95%)                                           | 51 (47%) (95%)                                                       | 26.7 (17.5)                       | 26 (13–40) 26.1 (17.5–31.8)                               |
| Mexico (urban)        | 140 (118–162)                        | 91 (65%) (95%)                                           | 91 (65%) (95%)                                                       | 19.7 (14.9)                       | 19 (8–35.5) 19.2 (14.9–24.9)                              |
| Mexico (rural)        | 113 (97–130)                         | 45 (40%) (95%)                                           | 45 (40%) (95%)                                                       | 24.5 (14.9)                       | 24 (11–36) 24.3 (14.9–27.8)                               |
| China (urban)         | 86 (72–100)                          | 48 (56%) (95%)                                           | 48 (56%) (95%)                                                       | 22.7 (17.5)                       | 22 (9–35.5) 22.4 (17.5–28.3)                              |
| China (rural)         | 106 (86–126)                         | 42 (39%) (95%)                                           | 42 (39%) (95%)                                                       | 21.0 (13.9)                       | 21 (8–30) 20.7 (13.9–24.9)                                |
| India (urban)         | 73 (63–83)                           | 37 (51%) (95%)                                           | 37 (51%) (95%)                                                       | 20.2 (13.9)                       | 20 (8–31) 20.2 (13.9–24.9)                                |
| India (rural)         | 106 (86–126)                         | 42 (39%) (95%)                                           | 42 (39%) (95%)                                                       | 21.0 (13.9)                       | 21 (8–30) 20.2 (13.9–24.9)                                |
| Total                 | 1345                                 | 677 (50.3%)                                              | 673 (99.4%)                                                          | 23.8 (17.0)                       | 23.8 (17.0) 23.8 (17.0)                                    |

*Adjusted for care age, gender, marital status, relationship to person with dementia and carer psychological morbidity; the age and gender of the person with dementia and severity of behavioural and psychological symptoms of dementia; number of coresidents, time spent assisting with activities of daily living and time cutting back on work to care (as per model in Table 5).
non-married carers; although this effect was not statistically significant in any site, the pooled mean difference was substantial (−3.7, 95% confidence intervals −6.4 to −1.2) without significant heterogeneity across sites. There was also a consistent effect across sites for carers who were neither children nor spouses to report lower levels of strain compared with spousal carers. Children and children-in-law reported similar levels of strain to spousal carers. Carer psychological morbidity was strongly associated with carer strain in most sites. The meta-analysed mean difference was large (9.0, 95% confidence intervals 6.0 to 12.0), but there was a minor heterogeneity with an association in the reverse direction in rural India.

Characteristics of the person with dementia

Neither age nor sex was associated with carer strain. Co-morbid depression, psychosis and anxiety were each associated with carer strain. The adjusted meta-analysed mean differences were larger for psychosis (8.0, 95% CI 5.2 to 10.8) and anxiety (7.8, 95% CI 3.5 to 12.0) than for depression (3.2, 95% CI 0.4 to 5.9). None of these effects was adjusted for BPSD, as the NPI-Q scale includes items that assess the presence and severity of depression, hallucinations and delusions. There was moderate heterogeneity across sites for the effect of anxiety; however, this was in the size of the positive effect rather than the direction of association. Clinical severity of dementia (CDR) was also linearly positively associated with carer strain, with no heterogeneity across sites. BPSD severity (NPI-Q severity scale) was also linearly positively associated with carer strain, with approximately a one-point increase in ZBI score for every one point increase in NPI-Q severity (0.98, 95% CI 0.79 to 1.17). There was moderate heterogeneity but, again, only in the size of the positive effect. Only in three sites, Cuba, Venezuela and rural India, was there a significant univariate association between more impaired cognitive function (COGSCORE) and carer strain. After adjusting for covariates, including BPSD severity, the effect was consistently null across sites (−0.02, 95% CI −0.16 to 0.11).

Care arrangements

The pooled mean difference contrasting those needing ‘much care’ with those needing some care was 4.3, 95% CI 1.6 to 6.9, with no significant heterogeneity across sites (Table 4). Time spent assisting with ADL care was also associated with carer strain with a one-point increase in ZBI score for every one additional hour spent on ADL care (1.1, 95% CI 0.75 to 1.45) but with some heterogeneity in the size of the association across sites. Mean ZBI scores were higher for carers who had cut back or stopped work to care in all sites except for urban India, to a statistically significant degree in six of 11 sites. The pooled adjusted mean difference was 6.7, 95% CI 4.0 to 9.4. Paid carers were only common in Cuba, the Dominican Republic, urban Peru, Venezuela and urban China. In the first three of those sites, mean ZBI scores were lower among those who had used paid carers, whereas in Venezuela and urban China, carer strain was a little higher in that group. The adjusted pooled mean difference tended in the direction of less strain among those using paid carers (−3.2, 95% CI −6.7 to 0.2). A similar trend was observed for those who had made use of additional informal care (−2.2, 95% CI −4.7 to 0.4). More carers was not associated with a reduction in carer strain, although there was a trend in this direction with a half-point reduction in ZBI score for each additional resident (−0.52, 95% CI −1.16 to 0.11) and a large statistically significant linear effect in urban China.

Final model

The final model incorporating pooled data from all sites accounted for 33.7% of variance in carer strain, with 7.5% accounted for by site, 5.7% by carer characteristics (principally psychological morbidity), 12.0% by characteristics of the person with dementia (principally BPSD severity) and 8.7% by care arrangements (principally time assisting with ADL care and carer giving up work to care). Thus, the variance accounted for by site increased after adjusting for compositional differences in the characteristics of the carer, the person with dementia and the nature of the care arrangements. After adjusting for these factors, carer strain was highest in urban China, in Cuba and in Venezuela and lowest in rural Mexico, in rural China and in urban India (Table 1).

Discussion

A recent meta-analysis of studies of correlates of carer strain identified 228 studies, 89% using convenience samples (Pinquart and Sorensen, 2003). Associations with carer strain were more marked in representative samples, perhaps because of over-representation of severe dementia and stressed carers in convenience samples. The average sample size for most exposure/outcome combinations did not exceed 150 and was
often much less than this. With 673 carer/care recipient dyads from 11 sites in seven countries, ours is therefore one of the largest studies of strain among dementia carers and adds significantly to the limited evidence from LMIC. Furthermore, we have recruited representative population-based samples of people with dementia, with high response rates. We acknowledge several important limitations. Whereas the overall sample size was large, numbers in individual sites were sometimes small, and there may have been important heterogeneity of effects in the meta-analysis not captured by the relatively underpowered statistical tests. Although we studied many correlates of carer strain, several potentially important mediators were not assessed, including family relationships, premorbid quality of the relationship between carer and care recipient, carer personality and carer coping strategies. This may have explained the relatively low proportion of the variance in carer strain accounted for in the final model.

Mean ZBI scores ranged between 17.1 and 27.9 by site, lower than those for our pilot study convenience samples, which were between 23 and 37 for the majority of sites (10/66 Dementia Research Group, 2004). The mean ZBI score for the EUROCare study convenience samples was 36, with country means ranging between 28 and 52. In the systematic review

### Table 2

| Carer characteristics | Cuba, N (%) | Dominican Republic, N (%) | Peru (urban), N (%) | Peru (rural), N (%) | Venezuela, N (%) | Mexico (urban), N (%) |
|-----------------------|-------------|----------------------------|---------------------|-------------------|------------------|----------------------|
| Carer sex             |             |                            |                     |                   |                  |                      |
| Female                | 29.3 (16.6) | 24.7 (16.2)                | 18.2 (16.3)         | 27.2 (17.2)       | 23.5 (17.8)      | 21.1 (14.6)         |
| Male                  | 22.4 (15.5) | 23.6 (13.5)                | 32.5 (25.0)         | 30.0              | 17.3 (14.5)       | 10.5 (9.5)          |
| T statistic (p-value) | 5.0 (0.03)  | 0.1 (0.79)                 | 6.1 (0.02)          | 0.0 (0.88)        | 1.6 (0.21)        | 2.9 (0.09)          |
| Carer age             |             |                            |                     |                   |                  |                      |
| Effect per year of age (SE) | 0.18 (0.09) | 0.05 (0.10)                | 0.26 (0.13)         | 0.20 (0.36)       | 0.05 (0.14)       | -0.02 (0.18)        |
| T statistic (p-value) | 2.1 (0.04)  | 0.5 (0.60)                 | 1.0 (0.04)          | 0.5 (0.60)        | 0.4 (0.71)        | -0.1 (0.93)         |
| Carer marital status  |             |                            |                     |                   |                  |                      |
| Currently married     | 30.6 (17.2) | 26.1 (16.7)                | 19.7 (18.1)         | 32.8 (19.1)       | 22.1 (16.5)       | 22.9 (18.2)         |
| Not currently married | 27.5 (16.2) | 23.8 (15.3)                | 21.0 (18.7)         | 23.6 (14.5)       | 22.8 (18.4)       | 18.3 (12.5)         |
| T statistic (p-value) | 1.3 (0.26)  | 0.5 (0.50)                 | 0.1 (0.77)          | 0.9 (0.36)        | 0.0 (0.86)        | 1.1 (0.31)          |
| Carer education       |             |                            |                     |                   |                  |                      |
| Relation to person with dementia Spouse | 29.8 (16.4) | 29.1 (14.4) | 32.4 (18.7) | 32.0 (2.8) | 25.9 (18.1) | 20.3 (8.1) |
| Child or child-in-law | 30.5 (16.4) | 25.6 (14.9) | 20.4 (17.5) | 26.6 (21.9) | 23.0 (17.6) | 20.2 (15.7) |
| Other                | 21.4 (15.3) | 20.3 (16.6) | 16.6 (17.8) | 26.3 (3.8) | 20.9 (17.9) | 15.6 (5.4) |
| F statistic (p-value) | 5.3 (0.006) | 2.4 (0.10) | 3.1 (0.05) | 0.1 (0.93) | 0.2 (0.81) | 0.2 (0.80) |
| Carer psychological morbidity |         |                  |                     |                   |                  |                      |
| Non-case on SRQ (≤7)  | 25.1 (16.0) | 22.0 (15.2) | 12.0 (13.1) | 36.7 (10.3) | 18.5 (16.0) | 16.2 (11.9) |
| Case on SRQ (≥8)      | 36.4 (15.4) | 30.3 (15.5) | 27.5 (19.2) | 24.3 (17.4) | 39.2 (13.0) | 31.5 (11.9) |
| T statistic (p-value) | 16.7 (<0.001) | 6.4 (0.01) | 16.7 (<0.001) | 1.3 (0.28) | 25.7 (<0.001) | 11.7 (0.001) |

*Adjusted for carer age, gender, marital status, relationship to person with dementia and carer psychological morbidity; the age and gender of the person with dementia and severity of behavioural and psychological symptoms of dementia; number of coresidents and time spent assisting with activities of daily living.
of correlates of carer strain, the mean ZBI score was 29.9; again, the large majority of these studies used convenience samples, among which carer strain is likely to be higher.

Consistent with previous research (Yee and Schulz, 2000), female carers reported higher levels of strain, independent of the relationship to the person with dementia, the characteristics of the persons with dementia and care arrangements. Our hypothesis that spouse carers would report more strain was not supported. There is scant evidence to support this association from HIC studies (Sorensen et al., 2006), and cultural specificity is quite likely. The role of daughters-in-law has been extensively studied in Korea, with inconsistent findings regarding their experience of strain compared with that of children and spouses (Lee and Sung, 1997; Hong and Kim, 2008). In our study, only in China and in India were children-in-law sufficiently often identified as main carers to be studied as a separate group, and no significant differences were seen when compared with spouses and children.

The most substantial correlates of carer strain were the primary stressors BPSD, dementia severity, needs for care and time spent caring. The assessment of the extent of needs for care was pragmatic, with good face validity, but we did not have the opportunity to pre-assess validity or reliability across raters and countries. The additional strain associated with needing ‘much care’ supports its concurrent validity. Consistent with our hypothesis, the effects of BPSD were more prominent than those of cognitive impairment.

| Mexico (rural), 19.8 (13.6) | N (%) 19 | 26.6 (19.9) | N (%) 50 | 21.1 (15.2) | N (%) 15 | 22.9 (14.5) | N (%) 11 | 20.6 (12.3) | N (%) 23 | Reference category |
|-----------------------------|---------|-------------|---------|-------------|---------|-------------|---------|-------------|---------|-------------------|
| 15.9 (12.6) | N (%) 8 | 27.4 (23.1) | N (%) 22 | 12.5 (13.7) | N (%) 13 | 5.0 (4.2) | N (%) 2 | 22.4 (19.3) | N (%) 7 | −2.5 (−5.3 to 0.2) |
| 0.5 (0.49) | N (%) 0.0 | 0.88 | N (%) 2.5 | 0.13 | 2.8 (0.12) | N (%) 0.4 | 0.76 |
| −0.07 (0.19) | N (%) −0.10 | 0.16 | N (%) −0.18 | 0.20 | 0.30 (0.28) | N (%) 0.14 | 0.19 | 0.00 (−0.08 to 0.07) | N (%) 0.00 (−0.08 to 0.07) | Q = 23.1, 10 d.f., p = 0.01 |
| −0.4 (0.71) | N (%) −0.6 | 0.53 | N (%) −0.9 | 0.34 | 1.1 | N (%) 0.31 | 0.46 |
| 22.0 (16.0) | N (%) 6 | 20.5 (18.4) | N (%) 6 | 1.0 | N (%) 15.7 | N (%) 18.7 | 15.5 | 10.6 | Reference category |
| 17.7 (12.6) | N (%) 21 | 27.4 (21.0) | N (%) 66 | 17.7 (14.8) | N (%) 27 | 21.5 (14.4) | N (%) 10 | 21.4 (14.2) | N (%) 26 | −3.8 (−6.4 to −1.2) |
| 0.5 (0.50) | N (%) 0.6 | 0.44 | N (%) 1.2 | 0.28 | 0.3 | N (%) 0.57 | 0.3 | 0.57 |
| 3.23 (2.25) | N (%) 1.13 | (1.91) | N (%) −1.93 | (2.41) | 2.22 | (3.17) | N (%) 0.66 | (2.39) | 1.26 (−0.07 to 2.58) |
| 1.4 (0.16) | N (%) 0.6 | 0.56 | N (%) 0.8 | 0.43 | 0.7 | N (%) 0.50 | 0.3 | 0.79 |
| 19.8 (16.5) | N (%) 10 | 23.7 (19.8) | N (%) 17 | 16.5 | (15.2) | N (%) 8 | 18.3 | (9.0) | 21.6 | (15.1) |
| 18.0 (11.4) | N (%) 17 | 27.8 (21.1) | N (%) 55 | 17.3 | (15.2) | N (%) 20 | 20.7 | (16.6) | 20.4 | (12.9) |
| 0.1 (0.74) | N (%) 0.5 | 0.47 | N (%) 0.0 | 0.90 | 0.1 | N (%) 0.82 | 0.2 | 0.82 |
| 21.2 (13.4) | N (%) 5 | 25.4 (20.9) | N (%) 26 | 16.4 | (14.6) | N (%) 12 | 22.7 | (26.0) | 26.7 | (12.6) |
| 17.8 (13.3) | N (%) 16 | 28.2 (21.0) | N (%) 34 | 17.6 | (15.5) | N (%) 16 | 22.7 | (11.9) | 20.7 | (13.8) |
| 19.2 (15.1) | N (%) 6 | 26.2 (21.0) | N (%) 12 | 14.5 | (11.7) | N (%) 0 | 4.0 | (2.8) | −4.9 | (−9.7 to −0.05) |
| 0.1 (0.88) | N (%) 0.1 | 0.87 | N (%) 0.0 | 0.85 | 0.4 | N (%) 0.70 | 0.3 | 0.12 |
| 16.4 (13.2) | N (%) 18 | 25.7 (19.8) | N (%) 70 | 16.6 | (14.9) | N (%) 27 | 23.5 | (15.1) | 18.8 | (10.7) |
| 23.2 (12.8) | N (%) 9 | 66.0 (18.4) | N (%) 2 | 29.0 | N (%) 10 | 9.0 | (7.5) | 32.0 | (22.9) |
| 1.6 (0.21) | N (%) 8.1 | (0.006) | N (%) 0.7 | (0.42) | 2.5 | (0.15) | N (%) 4.2 | (0.05) |

Table 2 (continued)
### Table 3

The effect of the characteristics of the person with dementia on Zarit Burden Interview scores (t-test or ANOVA), with pooled adjusted mean differences by site

| Characteristics of the person with dementia | Cuba, N (%) | Dominican Republic, N (%) | Peru (urban), N (%) | Peru (rural), N (%) | Venezuela, N (%) | Mexico (urban), N (%) |
|---------------------------------------------|-------------|---------------------------|---------------------|-------------------|------------------|----------------------|
| **Age**<br>Effect per year of age (SD)    | -0.09 (0.16) | -0.43 (0.18)             | -0.37 (0.26)        | -0.41 (0.80)      | -0.02 (0.24)     | 0.30 (0.30)          |
| *T* statistic (p-value)                   | -0.57 (0.57) | -2.3 (0.02)               | -1.4 (0.16)         | -0.5 (0.62)       | -0.1 (0.94)      | 1.0 (0.31)           |
| **Gender**<br>Female                      | 28.5 (16.5)  | 21.9 (14.4)               | 17.9 (16.6)         | 24.6 (18.2)       | 21.7 (18.9)      | 20.6 (15.7)          |
| Male                                       | 26.2 (16.9)  | 30.3 (17.1)               | 25.5 (20.9)         | 31.4 (14.5)       | 25.6 (16.1)      | 17.2 (9.7)           |
| *T* statistic (p-value)                   | 0.6 (0.43)   | 6.6 (0.01)                | 2.9 (0.09)          | 0.5 (0.50)        | 0.5 (0.49)       | 0.5 (0.48)           |
| **Education**<br>Effect per level of education (SE) | 0.07 (1.24)  | -1.65 (1.59)              | 0.53 (2.19)         | 0.17 (5.14)       | -0.41 (2.83)     | 1.30 (2.15)          |
| *T* statistic (p-value)                   | 0.1 (0.96)   | 1.1 (0.30)                | 0.2 (0.81)          | 0.0 (0.97)        | 0.1 (0.89)       | 0.6 (0.55)           |
| **Depression**<br>No case level depression on GMS/AGECAT | 26.7 (15.6)  | 21.0 (16.8)               | 17.6 (17.0)         | 26.7 (23.2)       | 19.6 (15.7)      | 20.3 (14.9)          |
| Case level depression on GMS/AGECAT       | 31.3 (18.9)  | 25.7 (15.2)               | 27.2 (20.1)         | 27.7 (15.4)       | 25.9 (18.8)      | 19.3 (14.3)          |
| *T* statistic (p-value)                   | 2.6 (0.11)   | 1.8 (0.18)                | 4.4 (0.04)          | 0.0 (0.93)        | 3.0 (0.09)       | 0.1 (0.81)           |
| **Psychosis**<br>No psychotic symptoms on GMS/AGECAT | 26.0 (16.6)  | 21.8 (14.6)               | 17.3 (16.7)         | 25.7 (16.0)       | 16.5 (14.9)      | 17.7 (14.2)          |
| Case or subcase level psychosisis on GMS/AGECAT | 33.7 (15.1)  | 27.1 (16.4)               | 30.5 (20.3)         | 30.8 (19.3)       | 32.7 (17.0)      | 26.5 (13.9)          |
| *T* statistic (p-value)                   | 7.1 (0.008)  | 3.0 (0.09)                | 7.4 (0.04)          | 0.2 (0.64)        | 22.4 (<0.001)    | 3.3 (0.07)           |
| **Anxiety**<br>No case level anxiety      | 27.7 (16.4)  | 24.9 (15.9)               | 20.0 (18.7)         | 26.5 (16.9)       | 20.6 (16.7)      | 18.2 (13.0)          |
| Case level anxiety on GMS                 | 33.0 (20.5)  | 23.0 (15.0)               | 22.2 (15.1)         | 38.0             | 31.8 (18.3)      | 42.3 (19.1)          |
| *T* statistic (p-value)                   | 0.7 (0.41)   | 0.3 (0.61)                | 0.1 (0.73)          | 0.4 (0.53)        | 5.9 (0.02)       | 9.2 (0.004)          |
| **CDR**<br>Effect per level of CDR (SD)   | 3.6 (1.4)    | 5.0 (1.7)                 | 6.4 (2.7)           | 3.6 (5.8)         | 4.9 (2.8)        | 5.9 (3.3)            |
| *T* statistic (p-value)                   | 2.5 (0.01)   | 2.9 (0.01)                | 2.4 (0.02)          | 0.6 (0.56)        | 1.8 (0.08)       | 1.8 (0.08)           |
| **Severity of behavioural and psychological symptoms of dementia**<br>Effect per point on the NPI-Q total severity score (SD) | 0.81 (0.23) | 1.14 (0.17)               | 1.27 (0.31)         | 1.50 (0.81)       | 1.91 (0.23)      | 0.98 (0.32)          |
| *T* statistic (p-value)                   | 3.6 (<0.001) | 6.6 (<0.001)             | 4.1 (<0.001)        | 1.8 (0.10)        | 8.3 (<0.001)    | 3.1 (0.004)          |
| **Cognitive function**<br>Effect per point on the CStD’ total COGSCORE (SD) | -0.26 (0.14) | -0.25 (0.19)             | 0.11 (0.19)         | 0.61 (0.60)       | -0.46 (0.21)    | -0.08 (0.28)         |
| *T* statistic (p-value)                   | -1.8 (0.07)  | -1.3 (0.19)               | 0.6 (0.56)          | 1.0 (0.34)        | -2.2 (0.03)     | -0.3 (0.77)          |
| **Incontinence**<br>No incontinence       | 26.9 (17.0)  | 22.4 (14.4)               | 16.2 (17.6)         | 27.2 (18.2)       | 19.5 (16.6)      | 18.1 (14.5)          |
| Incontinence                              | 29.5 (16.0)  | 28.2 (18.6)               | 26.6 (22.5)         | 28.0             | 30.5 (20.1)      | 28.0 (18.0)          |
| *T* statistic (p-value)                   | 1.0 (0.32)   | 1.5 (0.13)                | 1.8 (0.07)          | -               | 2.1 (0.04)       | 1.1 (0.27)           |

GMS, Geriatric Mental State; AGECAT, Automated Geriatric Examination for Computer Assisted Taxonomy; CDR, clinical dementia severity.<br> Adjusted for carer age, gender, marital status, relationship to person with dementia and carer psychological morbidity; the age and gender of the person with dementia and severity of behavioural and psychological symptoms of dementia; number of coresidents and time spent assisting with activities of daily living.

Similar findings have been reported from studies in China (Wang et al., 2008), Argentina (Machnicki et al., 2009) and Colombia (Arango Lasprilla et al., 2009). When psychological symptoms were considered separately, there were independent effects of psychosis, anxiety and depression, assessed through structured clinical interview of the person with dementia, using the Geriatric Mental State. As in our pilot study (Ferri et al., 2004), effects of anxiety and psychosis were more prominent than those of depression. We also explored the effects of incontinence, given suggestions from qualitative research in India of its burdensome and stigmatizing nature (Shaji et al., 2002), and the high prevalence among people with dementia in our sample (Prince et al., 2011). Carer strain was consistently higher where the care...
recipient was incontinent. However, this effect was substantially confounded by BPSD in the pooled multivariable analysis.

There was no consistent evidence for an association between socioeconomic status and carer strain. In the univariate analysis, household assets were inversely associated with strain in rural Peru and Venezuela, with a strong but non-significant trend in the opposite direction in urban sites in China and India. Neither was there any consistent evidence to support associations between level of education, for the carer or the person with dementia, and carer strain. However, cutting back on work to care was significantly associated with higher carer strain in most sites with trends in the same direction in others. The meta-analysed effect size of 6.7 points on the ZBI was substantial.

Paid carers were relatively common only in the urban Latin American sites and in urban China, with no paid care reported in rural China or in India. In

Table 3 (continued)

| Mexico (rural), N (%) | China (urban), N (%) | China (rural), N (%) | India (urban), N (%) | India (rural), N (%) | Pooled fixed effect adjusted\* mean difference | Test for heterogeneity of estimates |
|----------------------|----------------------|----------------------|----------------------|----------------------|---------------------------------|---------------------------------|
| −0.22 (0.32)         | 0.00 (0.39)          | −0.37 (0.34)         | −0.38 (0.58)         | −0.21 (0.34)         | 0.00 (−0.12 to 0.12)            | Q = 6.0, 9 d.f., p = 0.74       |
| −0.7 (0.50)          | 0.0 (1.00)           | −1.1 (0.29)          | −0.7 (0.52)          | −0.6 (0.54)          |                                 | F = 0 (0–62)                    |
| 17.1 (13.9)          | 27.4 (20.8)          | 15.2 (14.0)          | 21.1 (12.7)          | 18.6 (14.1)          |                                 | Reference category             |
| N = 19               | N = 47               | N = 14               | N = 7               | N = 20               |                                 |                                 |
| 22.5 (11.4)          | 25.8 (21.0)          | 18.9 (16.0)          | 19.0 (18.3)          | 25.9 (12.8)          | 0.3 (−2.6 to 3.2)               | 10.3 (10 d.f.), p = 0.42       |
| N = 8                | N = 25               | N = 14               | N = 6               | N = 10               |                                 | F = 3 (0–61)                    |
| 1.0 (0.34)           | 0.1 (0.75)           | 0.4 (0.52)           | 0.1 (0.81)           | 1.9 (0.18)           |                                 |                                 |
| 6.40 (2.16)          | 1.14 (1.82)          | −0.39 (2.95)         | 3.44 (3.25)          | 4.76 (5.98)          | 0.60 (−0.72 to 1.93)            | 6.6 (8 d.f.), p = 0.58         |
| 3.0 (0.007)          | 0.6 (0.53)           | 0.1 (0.90)           | 1.1 (0.31)           | 0.8 (0.43)           |                                 | F = 0 (0–65)                    |
| 17.5 (13.2)          | 25.9 (20.8)          | 13.6 (13.7)          | 25.2 (15.1)          | 24.3 (17.2)          |                                 | Reference category             |
| N = 12               | N = 66               | N = 21               | N = 7               | N = 12               |                                 |                                 |
| 19.6 (13.6)          | 37.2 (18.9)          | 27.4 (14.4)          | 14.2 (13.3)          | 18.8 (11.1)          | 3.2 (0.4 to 5.9)                | Q = 8.9, 10 d.f., p = 0.55     |
| N = 15               | N = 6                | N = 7                | N = 6               | N = 18               |                                 | F = 0 (0–60)                    |
| 0.2 (0.69)           | 1.6 (0.21)           | 5.2 (0.03)           | 1.9 (0.20)           | 1.2 (0.29)           |                                 |                                 |
| 18.0 (13.6)          | 26.1 (21.1)          | 13.2 (13.5)          | 21.9 (15.9)          | 23.0 (13.8)          |                                 | Reference category             |
| N = 22               | N = 67               | N = 20               | N = 10              | N = 26               |                                 |                                 |
| 21.4 (12.3)          | 36.2 (13.9)          | 26.9 (14.5)          | 14.3 (11.2)          | 8.3 (4.3)            | 8.0 (5.2 to 10.8)               | Q = 10.4, 10 d.f., p = 0.41    |
| N = 5                | N = 5                | N = 8                | N = 3               | N = 4                |                                 | F = 4 (0–62)                    |
| 0.3 (0.62)           | 1.1 (0.30)           | 5.7 (0.03)           | 0.6 (0.46)           | 4.3 (0.05)           |                                 |                                 |
| 18.3 (12.6)          | 26.8 (20.7)          | 16.1 (14.3)          | 19.5 (16.2)          | 20.2 (14.4)          |                                 | Reference category             |
| N = 24               | N = 72               | N = 27               | N = 11              | N = 27               |                                 |                                 |
| 21.3 (20.8)          | 42.0                 | 23.5 (0.7)           | 28.0 (4.4)           | 7.8 (3.5 to 12.0)    | Q = 23.8, 9 d.f., p = 0.005     |
| N = 3                | N = 1                | N = 0                | N = 2               | N = 3                |                                 | F = 62 (25–81)                  |
| 0.1 (0.72)           | 0.1 (0.09)           | 0.1 (0.75)           | 0.8 (0.37)           |                                 |                                 |                                 |
| CDR −0.3 (4.3)       | 6.1 (3.9)            | 9.5 (3.6)            | 10.5 (4.5)           | 10.9 (2.9)           | 2.8 (1.1 to 4.5)                | Q = 5.4, 10 d.f., p = 0.86     |
| −0.1 (0.95)          | 1.6 (0.12)           | 2.6 (0.02)           | 2.3 (0.04)           | 3.8 (0.001)          |                                 | F = 0 (0–60)                    |
| 0.44 (0.38)          | 0.64 (0.63)          | 1.35 (0.60)          | 1.65 (0.60)          | 1.27 (0.37)          | 0.98 (0.79 to 1.17)             | Q = 21.9, 9 d.f., p = 0.009    |
| 1.2 (0.26)           | 1.0 (0.31)           | 2.3 (0.03)           | 2.8 (0.02)           | 3.4 (0.002)          |                                 | F = 59 (17–80)                  |
| 0.10 (0.33)          | −0.21 (0.23)         | −0.34 (0.30)         | −0.69 (0.34)         | −0.65 (0.24)         | −0.02 (−0.16 to 0.11)           | Q = 4.3, 8 d.f., p = 0.83      |
| 0.3 (0.76)           | −0.9 (0.37)          | −1.2 (0.26)          | −2.0 (0.07)          | −2.7 (0.01)          |                                 | F = 0 (0–65)                    |
| 17.2 (13.3)          | 17.7 (16.7)          | 5.9 (11.8)           | 15.3 (13.9)          | 17.1 (10.9)          |                                 | Reference category             |
| N = 17               | N = 53               | N = 12               | N = 4               | N = 22               |                                 |                                 |
| 15.5 (3.5)           | 36.4 (19.6)          | 22.8 (8.0)           | 27.8 (16.6)          | 53.0 (15.6)          | 2.4 (−1.1 to 5.8)               | Q = 6.8, 8 d.f., p = 0.56      |
| N = 2                | N = 16               | N = 6                | N = 5               | N = 2                |                                 | F = 0 (0–65)                    |
| 0.2 (0.86)           | 3.5 (0.001)          | 3.1 (0.007)          | 1.2 (0.26)           | 4.4 (<0.001)         |                                 |                                 |

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Latin America, the use of paid carers was generally associated with lower levels of strain for the main family carer. However, in urban China, there was a non-significant overall trend towards lower levels of strain among carers who reported additional informal support from other family members or friends. These effects were more prominent in Latin American sites, and indeed, few Chinese or Indian carers reported receiving additional informal support.

Variation in mean carer strain was not accounted for by compositional differences among sites. In fact, after adjusting for a range of relevant factors—carer age, sex, marital status, relationship to person with dementia and carer psychological morbidity; the age and sex of the person with dementia and BPSD severity; number of co-residents, time spent providing care and carer cutting back on work to care—the variance component accounted for by site increased from 4.1% to 7.5%, with particularly high adjusted marginal mean scores in Cuba and urban China. The reasons for these outliers are not immediately obvious, although urban China stood out in having a particularly high proportion of paid carers.
Table 4 (continued)

|                  | Mexico (rural), N (%) | China (urban), N (%) | China (rural), N (%) | India (rural), N (%) | India (rural), N (%) | Pooled fixed effect adjusted a mean difference | Test for heterogeneity of estimates |
|------------------|-----------------------|----------------------|----------------------|----------------------|----------------------|-----------------------------------------------|-----------------------------------|
| 19.8 (14.0)      | 17.8 (16.8)           | 2.8 (3.4)            | 6.0 (5.3)            | 15.8 (11.6)          | Reference category   |                                               | Q = 9.1, 8 d.f., p = 0.34          |
| 17.6 (12.9)      | 29.2 (21.1)           | 25.0 (12.6)          | 24.4 (14.2)          | 31.4 (12.5)          | 4.3 (1.6 to 6.9)     | I² = 12 (0–54)                                |                                   |
| 0.2 (0.66)       | 3.7 (0.06)            | 29.2 (<0.001)        | 4.6 (0.06)           | 11.4 (0.002)         |                      |                                               |                                   |
| 0.13 (0.81)      | 1.58 (0.56)           | 3.04 (0.46)          | 1.36 (0.87)          | 3.69 (1.81)          | 1.10 (0.75 to 1.45)  | Q = 30.4, 9 d.f., p < 0.001                   | I² = 70 (43–85)                   |
| 0.2 (0.87)       | 2.8 (0.006)           | 6.7 (<0.001)         | 1.6 (0.15)           | 2.0 (0.05)           |                      |                                               |                                   |
| −0.03 (1.31)     | 5.29 (3.78)           | −0.09 (1.93)         | 3.04 (2.02)          | −0.96 (1.89)         | 0.29 (−0.86 to 1.43) | Q = 5.6, 8 d.f., p = 0.70                     | I² = 0 (0–65)                     |
| 0.2 (0.99)       | 1.4 (0.17)            | 0.1 (0.96)           | 1.5 (0.16)           | 0.5 (0.62)           |                      |                                               |                                   |
| 17.1 (14.4)      | 25.5 (20.6)           | 9.3 (11.6)           | 22.0 (11.9)          | 15.7 (11.4)          | Reference category   |                                               |                                   |
| 21.4 (11.2)      | 44.2 (15.2)           | 22.1 (14.9)          | 19.3 (16.6)          | 30.1 (13.5)          | 6.7 (4.0 to 9.4)     | Q = 29.5, 8 d.f., p < 0.001                   | I² = 73 (47–86)                   |
| 0.7 (0.42)       | 3.9 (0.05)            | 5.9 (0.02)           | 0.1 (0.78)           | 9.7 (0.004)          |                      |                                               |                                   |
| 18.9 (13.4)      | 23.3 (17.6)           | 17.1 (14.9)          | 20.2 (14.9)          | 21.0 (13.9)          | Reference category   |                                               |                                   |
| 13.0             | 30.0 (22.9)           | −                  | −                    | −                    | −3.2 (−6.7 to 0.2)   | Q = 6.9, 6 d.f., p = 0.33                     | I² = 13 (0–75)                    |
| 0.2 (0.67)       | 1.9 (0.17)            | −                    | −                    | −                    |                      |                                               |                                   |
| 18.9 (15.6)      | 26.9 (21.1)           | 16.6 (15.0)          | 17.6 (11.2)          | 21.1 (12.2)          | Reference category   |                                               |                                   |
| 18.6 (12.4)      | 26.7 (17.2)           | 18.4 (15.6)          | 24.2 (20.2)          | 21.0 (14.8)          | −2.2 (−4.7 to 0.4)   | Q = 10.4, 8 d.f., p = 0.24                    | I² = 23 (0–64)                    |
| 0.0 (0.95)       | 0.0 (0.98)            | 0.1 (0.78)           | 0.6 (0.46)           | 0.0 (0.98)           |                      |                                               |                                   |
| −0.08 (1.42)     | −3.60 (1.57)          | 0.67 (1.59)          | 2.45 (2.75)          | −0.95 (1.14)         | −0.52 (−1.16 to 0.11)| Q = 6.4, 8 d.f., p = 0.60                     | I² = 0 (0–65)                     |
| −0.1 (0.96)      | −2.3 (0.02)           | 0.4 (0.68)           | 0.9 (0.39)           | −0.8 0.41            |                      |                                               |                                   |

(associated in that site with higher family carer strain) and a low proportion of carers giving up work to care. Holding dual positions of worker and carer could lead to role strain or alternatively provide an outlet to help carers better manage the demands placed upon them (Edwards et al., 2002).

Our findings underline the impact of caring for a person with dementia in LMIC and the need for scaling up carer support, education and training interventions (Prince et al., 2009). We have recently reported benefits on outcomes including carer strain and psychological morbidity in randomized controlled trials of the 10/66 Dementia Research Group’s ‘Helping Carers to care’ intervention in India, Russia and Peru (Dias et al., 2008; Gavrilova et al., 2009; Guerra et al., 2011). Our finding that giving up work to care was both prevalent and associated with substantial increased strain emphasizes the adverse economic impact of taking up a caring role on the main carer and the whole household. The lack of carer compensatory benefits and limited access to disability benefits should be a concern for policymakers (Prince et al., 2008).

**Authors’ contributions**

All of the authors worked collectively to develop the protocols and methods described in this paper. Martin Prince led the research group, and Cleusa Ferri acted as research coordinator. Juan Llibre Rodriguez (Cuba), Daisy Acosta (Dominican Republic), Mariella Guerra (Peru), Aqüies Salas (Venezuela), Ana Luisa Sosa (Mexico), KS Jacob (Vellore, India), Joseph D Williams (Chennai, India) and Yueqin Huang (China) were principal investigators responsible for the field work in their respective countries. Martin Prince wrote the first draft and conducted the analyses, with
inputs from Henry Brodaty and Richard Uwakwe. Other authors reviewed the manuscript and provided further contributions and suggestions. All authors read and approved the final manuscript.

Conflicts of interest

The 10/66 Dementia Research Group works closely with Alzheimer’s Disease International, which is a non-profit federation of 77 Alzheimer associations around the world. Daisy Acosta is currently Chair of Alzheimer’s Disease International (ADI). ADI is committed to strengthening Alzheimer associations worldwide, raising awareness regarding dementia and Alzheimer’s disease and advocating for more and better services for people with dementia and their caregivers. ADI is supported in part by grants from GlaxoSmithKline, Novartis, Lundbeck, Pfizer and Eisai.

Key points
- High levels of carer strain were found in population-based studies of carers of people with dementia in Latin America, India and China.
- The largest contributors to carer strain were primary stressors; behavioural and psychological symptoms, dementia severity, and care demands.
- Carers cutting back on work experienced higher strain. Informal or paid support may be protective.
- There is a need for carer support, education and training, and social protection for affected families.

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References

10/66 Dementia Research Group. 2004. Care arrangements for people with dementia in developing countries. Int J Geriatr Psychiatry 19(2): 170–177.

ADI. 2009. World Alzheimer Report 2009. Prince M.J., Jackson J (eds). Alzheimer’s Disease International; London.

Andren S, Elmfeldt S. 2007. Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: a cross-sectional community-based study. Int J Nurs Stud 44(3): 435–446.

Arai Y, Kudo K, Hosokawa T, et al. 1997. Reliability and validity of the Japanese version of the Zarit Caregiver Burden interview. Psychiatry Clin Neurosci 51(5): 281–287.

Arango Laquirila JC, Moreno A, Rogers H, Francis K. 2009. The effect of dementia patient’s physical, cognitive, and emotional/behavioral problems on caregiver well-being: findings from a Spanish-speaking sample from Colombia, South America. Am J Alzheimers Dis Other Demen 24(5): 384–395.

Brodaty H, Hadzi-Pavlovic D. 1990. Psychosocial effects on carers of living with persons with dementia. Aust NZ J Psychiatry 24(3): 351–361.

Chang BL, Brecht ML, Carter PA. 2001. Predictors of social support and caregiver outcomes. Women Health 33(1–2): 59–61.

Chisholm D, Knapp MRJ, Knudsen HC, et al. 2000. Client Socio-Demographic and Service Receipt Inventory-European version: development of an instrument for international research. EPSILON study 5. Br J Psychiatry 177(suppl.39): s28–s33.

Chou KR, LaMontagne LL, Hepworth FT. 1999. Burden experienced by caregivers of relatives with dementia in Taiwan. Nuns Res 48(4): 206–214.

Cohen CA, Colantionio A, Vernich L. 2002. Positive aspects of caregiving: rounding out the caregiver experience. Int J Geriatr Psychiatry 17(2): 184–188.

Cooper C, Katona C, Orrell M, Livingston G. 2008. Coping strategies, anxiety and depression in caregivers of people with Alzheimer’s disease. Int J Geriatr Psychiatry 23(9): 929–936.

Copeland JRM, Dewey ME, Griffith-Jones HM. 1986. A computerised psychiatric diagnostic system and case nomenclature for elderly subjects: GMS and AGECAT. Psychol Med 16: 89–99.

Covinsky KE, Newcomer R, Fox P, et al. 2003. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. J Gen Intern Med 18(12): 1006–1014.

Davis KL, Marin DB, Kane R, et al. 1997. The Caregiver Activity Survey (CAS): development and validation of a new measure for caregivers of persons with Alzheimer’s disease. Int J Geriatr Psychiatry 12(10): 978–988.

Dias A, Dewey ME, D’Souza J, et al. 2008. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. PLoS ONE 3(6): e2333.

Edwards AB, Zarit SH, Stephens MA, Townsend A. 2002. Employed family caregivers of cognitively impaired elderly: an examination of role strain and depressive symptoms. Aging Ment Health 6(1): 55–61.

Ferri CP, Ames D, Prince M. 2004. Behavioral and psychological symptoms of dementia in developing countries. Int Psychogeriatr 16(4): 441–459.

Gallicchio L, Siddiqui N, Langenberg P, Baumgarten M. 2002. Gender differences in burden and depression among informal caregivers of demented elders in the community. Int J Geriatr Psychiatry 17(2): 154–163.

Gaugler JE, Zarit SH, Pearlman LJ. 2003. The onset of dementia caregiving and its longitudinal implications. Psychol Aging 18(2): 171–180.

Gavrilova SI, Ferri CP, Mikhaylova N, et al. 2009. Helping carers to care: the 10/66 dementia research group’s randomized control trial of a caregiver intervention in Russia. Int J Geriatr Psychiatry 24(4): 347–354.

Guerra M, Ferri CP, Fonseca M, Banerjee S, Prince M. 2011. Helping carers to care: the 10/66 dementia research group’s randomized control trial of a caregiver intervention in Peru. Rev Bras Psiquiatr 33(1): 47–54.

Hall KS, Hendrie HH, Brittain HM, et al. 1993. The development of a dementia screening interview in two distinct languages. Int J Meth Psychiat Res 3: 1–28.

Higgins JP, Thompson SG. 2002. Quantifying heterogeneity in a meta-analysis. Stat Med 21(11): 1539–1558.

Hong GR, Kim H. 2008. Family caregiver burden by relationship to care recipient with dementia in Korea. Geriatr Nurs 29(4): 267–274.

Kaufe DL, Cummings JL, Ketchel P, et al. 2000. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry Clin Neurosci 12(2): 233–239.

Kim SW, Kim JM, Stewart R, et al. 2006. Correlates of caregiver burden for Korean elders according to cognitive and functional status. Int J Geriatr Psychiatry 21(9): 853–861.

Ko KT, Yip PK, Liu SI, Huang CR. 2008. Chinese version of the Zarit Caregiver Burden Interview: a validation study. Am J Geriatr Psychiatry 16(6): 513–518.

Kumamoto K, Arai Y, Zarit SH. 2006. Use of home care services effectively reduces feelings of burden among family caregivers of disabled elderly in Japan: preliminary results. Int J Geriatr Psychiatry 21(2): 163–170.

Lee YK, Sung KT. 1997. Cultural differences in caregiving motivations for demented parents: Korean caregivers versus American caregivers. Int J Aging Hum Dev 44(2): 115–127.

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Int J Geriatr Psychiatry 2012; 27: 670–682.
Machnicki G, Allegri RF, Dillon C, Serrano CM, Taragano FE. 2009. Cognitive, functional and behavioral factors associated with the burden of caring for geriatric patients with cognitive impairment or depression: evidence from a South American sample. Int J Geriatr Psychiatry 24(4): 382–389.

Mari JJ, Williams P. 1985. A comparison of the validity of two psychiatric screening questionnaires (GHQ-12 and SRQ-20) in Brazil, using Relative Operating Characteristic (ROC) analysis. Psychol Med 15(5): 651–659.

Morris JC. 1993. The Clinical Dementia Rating (CDR): current version and scoring rules [see comments]. Neurology 43(11): 2412–2414.

Pinquart M, Sorensen S. 2003. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. J Gerontol B Psychol Sci Soc Sci 58(2): 112–128.

Prince M, Acosta D, Chiu H, Szarufca M, Varghese M. 2003. Dementia diagnosis in developing countries: a cross-cultural validation study. Lancet 361: 909–917.

Prince M, Ferri CP, Acosta D, et al. 2007. The protocols for the 10/66 Dementia Research Group population-based research programme. BMC Public Health7(1): 165.

Prince M, Acosta D, Albanese E, et al. 2008. Ageing and dementia in low and middle income countries—using research to engage with public and policy makers. Int Rev Psychiatry 20(4): 332–343.

Prince MI, Acosta D, Castro-Costa E, Jackson J, Shaji KS. 2009. Packages of care for dementia in low- and middle-income countries. PLoS Med 6(11): e1000176.

Prince M, Acosta D, Ferri CP, et al. 2011. The association between common physical impairments and dementia in low and middle income countries, and, among people with dementia, their association with cognitive function and disability. A 10/66 Dementia Research Group population-based study. Int J Geriatr Psychiatry 26(5): 511–519.

Pruchno RA, Resch NL. 1989. Mental health of caregiving spouses: coping as mediator, moderator, or main effect? Psychol Aging 4(4): 454–463.

Schneider J, Murray J, Banerjee S, Mann A. 1999. EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer’s disease: I—Factors associated with carer burden. Int J Geriatr Psychiatry 14(8): 651–661.

Schulz R, Martire LM. 2004a. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. Am J Geriatr Psychiatry 12(3): 240–249.

Schulz R, Martire LM. 2004b. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. Am J Geriatr Psychiatry 12(3): 240–249.

Shaji KS, Smitka K, Praveen Lal K, Prince M. 2002. Caregivers of patients with Alzheimer’s disease: I—a qualitative study from the Indian 10/66 Dementia Research Network. Int J Geriatr Psychiatry 18: 1–6.

Sorensen S, Duberstein P, Gill D, Pinquart M. 2006. Dementia care: mental health effects, intervention strategies, and clinical implications. Lancet Neurol 5(11): 961–973.

Tout K. 1989. Ageing in Developing Countries. Oxford University Press: Oxford.

Uwakwe R, Modebe I. 2007. Disability and care-giving in old age in a Nigerian community. Niger J Clin Pract 10(1): 58–65.

Wang G, Cheng Q, Wang Y, et al. 2008. The metric properties of Zarit caregiver burden scale: validation study of a Chinese version. Alzheimer Dis Assoc Disord 22(4): 321–326.

Whitlatch CJ, Zarit SH, von Eye A. 1991. Efficacy of interventions with caregivers: a reanalysis. Gerontologist 31(1): 9–14.

Wimo A, Winblad B, Jonsson L. 2007. An estimate of the total worldwide societal costs of dementia in 2005. Alzheimers Dement (3): 81–91.

Yee JL, Schulz R. 2000. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. Gerontologist 40(2): 147–164.

Zarit SH, Reever KE, Bach-Peterson J. 1980. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 20: 649–655.

Zarit SH, Todd PA, Zarit JM. 1986. Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist 26(3): 260–266.