

Care arrangements for people with dementia in developing countries

The 10/66 Dementia Research Group*

SUMMARY

Background Rapid demographic ageing will soon lead to large increases in the numbers of persons with dementia in developing countries. This study is the first comprehensive assessment of care arrangements for people with dementia in those regions.

Methods A descriptive and comparative study of dementia care; caregiver characteristics, the nature of care provided, and the practical, psychological (Zarit Burden Interview, General Health Questionnaire) and economic impact upon the caregiver in 24 centres in India, China and South East Asia, Latin America and the Caribbean and Africa.

Results We interviewed 706 persons with dementia, and their caregivers. Most caregivers were women, living with the person with dementia in extended family households. One-quarter to one-half of households included a child. Larger households were associated with lower caregiver strain, where the caregiver was co-resident. However, despite the traditional apparatus of family care, levels of caregiver strain were at least as high as in the developed world. Many had cutback on work to care and faced the additional expense of paid carers and health services. Families from the poorest countries were particularly likely to have used expensive private medical services, and to be spending more than 10% of the per capita GNP on health care.

Conclusions Older people in developing countries are indivisible from their younger family members. The high levels of family strain identified in this study feed into the cycle of disadvantage and should thus be a concern for policymakers in the developing world. Copyright © 2004 John Wiley & Sons, Ltd.

KEY WORDS — dementia; Alzheimer's disease; developing countries; caregivers; stress; psychological; cost of illness

INTRODUCTION

In the developing world, we know next to nothing of dispensations for older people affected by dementia. We can infer, given the dearth of health and welfare services for older people that families and other informal caregivers are the mainstay of support (Li *et al.*, 1989; Phanthumchinda *et al.*, 1991; Shaji *et al.*, 1996). However, we also know little of the impacts upon these caregivers and their local communities.

The 1998 consensus meeting of the 10/66 Dementia Research Group identified the formal assessment of these parameters as an urgent research priority (The 10/66 Dementia Research Group, 2000). This 10/66 pilot project is a preliminary investigation. We aimed to: (a) translate, and investigate the applicability of established measures of care arrangements and of the impact of providing care on caregivers, in a variety of countries and cultures; (b) recruit thirty persons with mild to moderate dementia, living in the community, with identified caregivers, in each of the participating centres; and (c) describe their living arrangements, the nature of the care provided, and the consequences for caregivers in terms of practical, psychological and economic impact.

While the sample size in each centre was small this would be the first study of its kind. Furthermore, it would allow us to make tentative comparisons of data between different developing countries and with previous reports from developed countries. To facilitate

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this comparison we used broadly the same caregiver interview schedule that had been applied in the 14 centre European EUROCARE study (Murray *et al.*, 1999; Schneider *et al.*, 1999). We aimed to collect comparable data from centres in India, China and South East Asia, Latin America and the Caribbean, and Africa.

METHODS

Centres and participants

The 24 centres contributing data were all members of the 10/66 Dementia Research Group. Fourteen centres were in Latin America; Argentina (Buenos Aires); Brazil (São Paulo, Botucatu and São José do Rio Preto), Chile (Santiago/ Valparaiso), Cuba (Havana), Dominican Republic (Santo Domingo), Guatemala (Guatemala City), Mexico (Mexico City and Guadalajara), Panama (Panama City), Peru (Lima), Uruguay (Montevideo) and Venezuela (Caracas). Six centres were in India; Bangalore, Chennai (2), Goa, Hyderabad and Thrissur. Three centres were in China and SE Asia; China (Beijing and Hong Kong SAR) and Taiwan (Taipei). Nigeria (Anambra) was the sole African centre. In each centre the caregiver pilot study focused upon the participants with mild to moderate dementia, living in the community, who had been recruited for the purposes of a dementia diagnosis pilot study (Prince *et al.*, 2003). While we had sought to recruit 30 persons in each centre, in the event some contributed slightly fewer, some more. Recruitment methods differed, depending upon local circumstances. Centres were asked, where feasible, to identify 'community cases' of dementia, either from a recent local population-based research study, or by snowball sampling a district, using community health care workers and local people as key informants to nominate possible cases. These cases were therefore not identified on the basis of prior contact with specialist services. We did permit centres to recruit on the basis of service contact where there was no practicable alternative. This decision was predicated on the assumption that, since none of our centres was in a position to offer continuing care, index consultation was unlikely to have influenced unduly future patterns of service use. Local clinicians confirmed the clinical diagnosis of DSM-IV dementia, completing pro formas describing their findings, and rating dementia severity using the Clinical Dementia Rating Scale (Morris, 1993) mild (1) to moderate (2) severity criteria. Each participant had to have an informal caregiver, who was the informant for the caregiver pilot

study; a preliminary open-ended interview established that the person being interviewed was most directly responsible for providing care.

Measures

All study instruments were translated and back translated, by local investigators who were fluent in both English and the local language or languages to be used in the study. The local language version was reviewed by local key informants, such as elderly persons without cognitive impairment, community leaders, and health workers or researchers to check its acceptability and conceptual validity.

- (1) Clinical characteristics were identified using the Community Screening Interview for Dementia (CSI 'D') (Hall *et al.*, 1993; Prince *et al.*, 2003) which combines a test of cognitive function administered to the person with dementia (COGSCORE), and an informant interview, enquiring after the participant's daily functioning and general health (RELSCORE). Six common behavioural symptoms of dementia; agitation, aggression, repeated vocalisations, wandering, sleep disturbance and incontinence were coded from spontaneous mentions in answers to an open-ended question to the caregiver, 'What do you find difficult about caring for your relative?'. These data were summarised in a single variable as the number of behavioural symptoms of dementia.
- (2) Psychological impact for the caregiver was assessed using the 12-item General Health Questionnaire (GHQ-12) (Goldberg *et al.*, 1997) as a measure of psychiatric morbidity, and the Zarit Burden Interview (ZBI) (Zarit *et al.*, 1980; Zarit *et al.*, 1986; Whitlatch *et al.*, 1991) as a measure of caregiver strain. The ZBI has 22 items that assess the caregiver's appraisal of the impact their involvement has had on their lives. It includes questions such as; 'Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?' and 'Do you feel strained when you are around your relative?'. It has been very widely used in the USA and Europe, and also in Taiwan (Chou *et al.*, 1999) and Japan (Arai *et al.*, 1997; Hirono *et al.*, 1998), but not in developing countries. Its items when reviewed by our research teams were felt to have strong face validity across a wide range of cultures. However, some concerns were expressed that the strong tradition of duty of

care and veneration of elders in cultures such as India and China may make it difficult for caregivers to acknowledge strain where it existed. Practical impact was assessed using the Time Spent In Week Before Interview With Dependent (Gilleard *et al.*, 1984) enquiring after all contact time between caregiver and cared for person, whether or not care was being provided. The Caregiver Activity Survey (Davis *et al.*, 1997) assesses the time spent by the caregiver in the last 24 hours in specific caregiving activities; communicating, using transport, dressing, eating, looking after one's appearance, and supervising.

- (3) Economic impact was assessed using the Client Service Receipt Inventory (Chisholm *et al.*, 2000), a comprehensive assessment of direct and indirect economic costs for mental health services, adapted for use in the developing world. It elicits information on type and cost of accommodation, income (from all sources) for the person with dementia and the principal caregiver, the occupation of the caregiver, the extent to which the caregiver had cut back on or stopped work in order to provide care, unpaid care provided by family or others in the community, paid care inputs and their costs, and the use (and associated costs) of a variety of health care services.

Analysis

For ease of presentation, descriptive data was aggregated at the level of the four 10/66 regional networks; India and South East Asia, China and SE Asia, Latin America and the Caribbean and Africa. A substantial proportion of between centre variance was generally accounted for by region. An exception was made for the economic analyses, where Beijing was separated from the much more economically developed centres of Hong Kong and Taiwan. The descriptive data were analysed and are presented under four headings; the characteristics of the person with dementia and of the caregiver, the practical and psychological impact upon the caregiver of caring for a person with dementia, the economic impact, and the pattern of health service use.

RESULTS

In all, we interviewed 706 people with dementia and their principal caregivers, 179 in India, 91 in China

and South East Asia, 416 in Latin America and the Caribbean, and 20 in Nigeria.

Characteristics of people with dementia, and their caregivers

All of the people with dementia, because of our selection criteria, lived in their own homes. In each centre most lived in households with at least three other people, often more (Table 1). A quarter or more (a half in India) lived in three-generation households with one or more children under the age of 16. The majority of people with dementia in each region were women, and had limited education. Less than one-fifth in India and Nigeria, and around half in China and Latin America received any kind of pension. However, a higher proportion contributed to household finances after taking into account other sources of income including rental receipts and savings. A high proportion, particularly in India and Nigeria, were still regarded by the caregiver as the head of household. In all centres the principal caregiver was generally a woman, and most frequently a spouse or a child; except for India daughters-in-law were less involved. The large majority of caregivers were co-resident with the person with dementia. The effect of household crowding upon Zarit Burden Interview score was modified by the residential status of the main caregiver ($F = 7.1$, $p = 0.008$, $\eta^2 = 1.1\%$). Where the caregiver was co-resident, increased crowding was associated with lower caregiver strain. Where the caregiver lived elsewhere, crowding was strongly positively associated with caregiver strain.

Practical impact of caring for a person with dementia

There were very large between centre differences in the reported time that the principal caregiver spends with the person with dementia, and, even more strikingly, in the reported amount of time that the caregiver spends in assisting with specific activities of daily living. (Table 2). For both measures, Latin American and Caribbean caregivers report longer times, Indian caregivers intermediate times, and Chinese caregivers shorter times. These regional differences are seen for each of the care tasks. The same pattern of regional differences was also noted for the hours of additional informal (friend and family) care reported. Time spent assisting with ADL was, as might have been expected, strongly and significantly correlated with clinical dementia rating (0.23), CSI

Table 1. Characteristics of people with dementia, and their caregivers in developing countries

	India and S Asia <i>n</i> = 179	China and SE Asia <i>n</i> = 91	Latin America and Caribbean <i>n</i> = 416	Nigeria <i>n</i> = 20
<i>The household</i>				
Median household size (interquartile range)	4 (3–5)	3 (2–4)	3 (2–4)	3 (2–4)
One or more children 16 years or under	52%	26%	30%	35%
<i>The person with dementia</i>				
Female	52%	63%	59%	37%
Married	59%	53%	48%	No data
Did not complete primary education	48%	59%	32%	No data
Head of household	52%	26%	34%	65%
Contributing to family income	44%	80%	70%	20%
Government or occupational pension	19%	41%	56%	15%
Disability pension	1%	7%	4%	5%
<i>The Caregiver</i>				
Female	75%	59%	84%	95%
Married	91%	91%	60%	80%
Age				
<40	26%	10%	17%	30%
40–64	54%	54%	52%	70%
65+	20%	36%	31%	0%
Relationship to person with dementia				
Wife	29%	21%	26%	45%
Daughter	15%	25%	34%	40%
Daughter-in-law	24%	8%	3%	10%
Husband	11%	18%	9%	0%
Son	17%	18%	7%	5%
Son-in-law	2%	6%	0%	0%
Co-resident with person with dementia	98%	75%	88%	55%
Employed	30%	41%	35%	50%
Receiving caregiver benefit	0%	5%	3%	0%

Table 2. Practical and psychological impact of caring for people with dementia in developing countries

	India And S Asia <i>n</i> = 179	China and SE Asia <i>n</i> = 91	Latin America and Caribbean <i>n</i> = 416	Nigeria <i>n</i> = 20
Median (interquartile range) hours per day spent with person with dementia	4 (4–6)	3 (2–7)	6 (3–8)	4 (4–4)
Median (interquartile range) hours per day spent assisting with ADL	3 (0–6)	3 (0–4)	5 (2–9)	9 (6–12)
Hours of informal support per week				
None	62%	80%	59%	45%
1–10	27%	3%	18%	30%
11+	11%	17%	23%	25%
Mean (SD)				
Zarit Caregiver Burden	25.9 (18.2)	26.7 (15.2)	34.3 (16.4)	50.3 (8.1)
Range (by centre)	16.5–35.1	23.4–31.6	25.1–58.4	—
Median (interquartile range) GHQ score	4 (0–6)	2 (0–5)	4 (2–6)	5 (3–7)
GHQ cases (3 or above)	62%	46%	64%	95%
Range (by centre)	40–72%	33–65%	33–97%	—

'D' informant score (0.33) and number of behavioural symptoms (0.21). It was also positively correlated with hours of additional informal support (0.09). However, it was only weakly inversely correlated with number of co-residents (-0.04), and not associated with whether or not the principal caregiver was a co-resident. None of these variables explained any of the between centre or region variance in reported time spent assisting with ADL.

Psychological impact

Eighteen out of 24 centres had mean ZBI scores of between 23 and 37. The low outliers were two Indian centres, Chennai (16.4) and Goa (16.2), the high outliers three Latin American centres, Panama (39.2), Montevideo (43.0), and Guadalajara (58.4), and Anambra, Nigeria (50.3). The distribution of scores was roughly normal in all centres except for Chennai and Goa where it was positively skewed, with 30% and 17% of caregivers, respectively, reporting no burden. This floor effect was not apparent in other centres. The scale was highly internally consistent in all centres with Cronbach's alpha ranging from 0.80 to 0.94. Twenty-nine percent of the variance in ZBI was accounted for by centre, but most of this (71%) was within rather than between regions. Using a cut-point of 3 or more on the GHQ-12, 19 out of 24 centres recorded a prevalence of psychiatric morbidity of

between 40 and 75%. Scores were generally somewhat higher in the Latin American centres than in India or China. The low outliers were Hong Kong and Buenos Aires (33%), and the high outliers Montevideo (90%), Guadalajara (97%) and Anambra (95%). The psychometric properties and validity of the GHQ-12 are well established cross-culturally.

Economic impact

The per capita monthly gross national product (GNP) in developing countries varied from \$US11 in Nigeria to between \$US350-650 for the more affluent Latin American centres. Two centres would not normally be considered to be developing regions, Taiwan (GNP \$US1068) and Hong Kong SAR (GNP \$US1972). Three aspects of adverse economic impact were noted (Table 3).

- (1) In every centre a substantial proportion of caregivers had cut back on their paid work, or stopped work altogether in order to care for the person with dementia. Much care was also provided by other family members, and by friends and neighbours in the local community. Some of these informal caregivers had also cut back on their paid work to care.
- (2) Informal care was commonly supplemented by formal paid care inputs, both during the day, and to some extent at night.

Table 3. Economic impact of caring for people with dementia in developing countries

	India and S Asia <i>n</i> = 179	China <i>n</i> = 30	Taiwan and HK <i>n</i> = 61	Latin America and Caribbean <i>n</i> = 416	Nigeria <i>n</i> = 20
Per capita GNP/ month	\$37	\$63	\$1524	\$327	\$11
Principal caregiver has cut back on paid work to care	17%	14%	18%	26%	84%
Additional caregiver has cut back on paid work to care	6%	0%	3%	7%	55%
Paid daytime carer	10%	30%	23%	24%	10%
Paid nighttime carer	5%	30%	20%	10%	10%
Median (interquartile range) of healthcare costs for person with dementia (US\$ per month)	0.6 (0-3.6)	1.0 (0.2-4.9)	9.9 (4.7-26.5)	3.5 (0.3-11.3)	14.1 (5.4-26.9)
Comparative index of healthcare costs (as % of per capita GNP)					
0% (no costs)	36%	20%	5%	9%	5%
1-10%	40%	63%	93%	77%	0%
more than 10%	24%	17%	2%	14%	95%

Table 4. Use of health services by people with dementia in developing countries, in the three months prior to interview

	India and S Asia <i>n</i> = 179	China and SE Asia <i>n</i> = 91	Latin America and Caribbean <i>n</i> = 416	Nigeria <i>n</i> = 20
Government primary care	5%	36%	45%	5%
Proportion of these consultations carried out at home	0%	12%	4%	0%
Government hospital	6%	54%	51%	90%
Proportion of these consultations carried out at home	9%	10%	5%	0%
Private doctor	56%	10%	42%	80%
Proportion of these consultations carried out at home	7%	33%	9%	6%
Hospital admission	11%	7%	14%	15%
Traditional healer	1%	12%	2%	40%
No services	33%	18%	11%	5%

(3) People with dementia were relatively heavy consumers of health services (Table 4).

In all centres, monthly health care costs, averaged over three months and calculated as the sum of payments for services, medicines and travel to access services, amounted to a substantial proportion of per capita gross national product (GNP) (Table 3). This was particularly the case for the poorer regions; the Indian centres, Beijing, China and Anambra, Nigeria. At the centre level there was a non-significant but strong inverse correlation between a country's per capita GNP and the proportion of families spending more than 10% of per capita gross national product on health care (correlation coefficient -0.39 , $p = 0.06$, $n = 24$). In all centres other than Beijing and Havana (which have universal, free public health care systems), the use of relatively expensive private medical services was particularly prominent. Again, at centre level (omitting Beijing and Havana) there is an inverse correlation between per capita gross national product and the proportion of people with dementia using private doctors services (correlation coefficient -0.43 , $p = 0.04$, $n = 22$).

DISCUSSION

This is the first systematic, comprehensive assessment of care arrangements for people with dementia in the developing world, and of the impacts upon their family caregivers. Some aspects seem to be similar the world over. As in the EUROCARE study with data from 14 European countries, most caregivers in developing countries are older women caring for their husbands or younger women caring for a parent (Schneider, *et al.*, 1999). Caring is associated with substantial psychological strain as evidenced by high rates of psychiatric morbidity and high levels of caregiver strain. These parameters were again very similar

to those reported in the EUROCARE study. However, some aspects are radically different. People with dementia in developing countries typically live in large households with extended families. We present some evidence to support the notion, prevalent in traditional countries, that large extended family units may decrease the strain experienced by the caregiver. However, this effect is small, applies only where the principal caregiver is co-resident and indeed seems to operate in the opposite direction where the caregiver is non-resident, perhaps because of the increased potential for family conflict.

One of the key findings from this study, from the development perspective, is that caregiving in the developing world is associated with substantial economic disadvantage. A high proportion of caregivers have had to cut back on their paid work to care. Many caregivers need and obtain additional support, and while this is often informal unpaid care from friends and other family members, paid caregivers are also relatively common. People with dementia in developing countries are heavy users of health services, and associated direct costs are high. Compensatory financial support is negligible; few older people in developing countries receive government or occupational pensions, and virtually none of the people with dementia in this study received disability pensions. Caregivers are commonly in paid employment, and almost none received any form of caregiver allowance. The combination of reduced family incomes and increased family expenditure on care is obviously particularly stressful in lower income countries where so many households exist at or near to subsistence level. While health care services are cheaper in low income countries, in relative terms families from the poorer countries spend a greater proportion of their income on health care for the person with dementia. They also tend selectively to use the more expensive services of private doctors. This seems unlikely to be

explained by selection bias, since the centres that selected participants on the basis of service contacts tended to be more economically developed. One may speculate that it reflects the caregivers' perception of the unresponsiveness of the cheaper government medical services. One aspect of unresponsiveness identified in our study is that almost all consultations were carried out in the clinic setting rather than in the home of the person with dementia. Quite apart from the inconvenience of travel, it is difficult to make a proper holistic assessment of the needs of the person with dementia and their caregivers without access to the home environment. However, the private doctor services seemed to be just as clinic-based as those of their government counterparts. In the developing world, government health services typically involve long waits in crowded waiting rooms for brief consultations, where the focus is upon 'treatable' acute pathologies; private doctors may offer some advantages in these respects.

In stark contrast with the developed world, people with dementia in developing countries commonly live in three-generation households, with their children and their grandchildren. Older people with dementia cannot therefore legitimately be viewed as a separate group in these societies. For as long as their needs and those of their caregivers are unmet, the psychological strain and economic disadvantage that impacts on all family members will feed in to the cycle of impoverishment, educational disadvantage, and gender inequality that constitute the major barriers to successful social and economic development. The clear message is that dementia is a development issue, and as such a proper concern for policymakers in developing countries.

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