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RESEARCH LETTER

The impact associated with caring for a person with dementia: a report from the 10/66 Dementia Research Group's Indian network

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In most developing countries health services are not orientated to the needs of older people, and welfare provision is rudimentary (The 10/66 Research Group, 2000; Shaji *et al.*, 2002). Care has been considered to be the responsibility of families, however, the integrity of this traditional arrangement is increasingly threatened by rapid socio-cultural and economic change (Patel and Prince, 2001). Findings from the 10/66 Dementia Research Group's international pilot studies on care for people with dementia are presented elsewhere in this issue (The 10/66 Research Group, 2003). In two Indian centres; Goa (rural/semi-urban) and Chennai (urban); we sought to clarify the impact of dementia on caregivers (30 in each centre) by comparing their economic and psychological status and perceived strain with those of co-residents of older persons from the control groups free of dementia (60 in each centre), and of caregivers and co-residents of older persons with moderately severe depression (30 in each centre). The use of health services by the older people, and associated costs were also compared. In Goa, dementia and depression cases were suggested by community key informants prompted by vignettes. In Chennai, cases were recruited from a hospital outpatient department. In both centres dementia diagnoses (DSM-IV criteria/Clinical Dementia Rating mild or moderate) were confirmed by clinical examination. None of the participants in Goa and only one in Chennai had received a diagnosis of dementia prior to the study. Depression was confirmed by a score of above 18 on the Montgomery Asberg Depression Rating Scale. Caregiver mental health was assessed using the General Health Questionnaire (GHQ-12), scores of 3 and over indicating likely mental disorder, caregiver strain with the Zarit Burden Interview. The Client Service Receipt Inventory assessed health care costs covering use of private, public hospital and primary health care. Further information is provided in the companion paper (ref). The instruments were translated and back translated into the local languages of Konkani and Tamil.

Caregivers of people with dementia spent significantly longer providing care than did caregivers and co-residents of depressed person and controls (Table 1). The highest proportion of time was spent communicating, supervising, and helping with eating and toileting. Caregiver strain was notably higher among caregivers of people with dementia. They were 16 times more likely to have a common mental disorder than co-residents of controls and twice as likely as co-residents of people with depression. Economic strain was indicated by the high proportion of dementia caregivers giving up work to care, coupled with the increased likelihood of high health care costs. This was explained by the propensity for people with dementia to use expensive private medicine rather than free government services.

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Table 1. The impact of caring for a person with dementia, relative to caring or coresidence with a person with depression or a control, free of dementia

	Dementia Prevalence ratio (95% CI) and prevalence %	Depression Prevalence ratio (95% CI) and prevalence %	Controls, free of Dementia (reference group) Prevalence ratio (95% CI) and prevalence %
Health Service Use (Chennai)			
Visit to Primary care	3.9 (0.3–43.6)	—	1.0 (ref)
	7%	0 %	2%
Visit to Public Hospital	—	—	1.0 (ref)
	0%	0%	17%
Visit to Private Doctor	3.2 (2.0–5.3)	1.8 (1.0–3.4)	1.0 (ref)
	76%	43%	24%
Health Service Use (Goa)			
Visit to Primary care	0.8 (0.3–2.0)	1.8 (1.0–3.5)	1.0 (ref)
	17%	40%	22%
Visit to Public Hospital	2.0 (0.4–2.3)	2.7 (0.6–11.1)	1.0 (ref)
	10%	13%	5%
Visit to Private Doctor	2.0 (1.1–3.6)	1.0 (0.4–2.2)	1.0 (ref)
	47%	23%	23%
Economic strain			
High health care costs	3.0 (1.5–5.8)	2.0 (1.0–4.1)	1.0 (ref)
	30%	20%	10%
Caregiver has cut back on work to care	10.6 (2.4–46.4)	2.0 (0.3–13.6)	1.0 (ref)
	18%	3%	2%
Practical and psychological strain			
Caregiver mental disorder	16.0 (5.9–43.1)	8.5 (3.0–24.1)	1.0 (ref)
(GHQ score 4+)	53%	28%	3%
	Mean (SD)	Mean (SD)	Mean (SD)
Time (hours) spent	4.1 (5.4)	0.7 (2.7)	0.5 (3.5)
caregiving	$F = 18.4$, df 2, $p < 0.001$		
Caregiver strain	16.3 (16.1)	5.8 (9.4)	1.7 (5.6)
	$F = 41.6$, df 2, $p < 0.001$		

A limitation of this preliminary study was the purposive sampling for the three groups, differing somewhat between the two centres. A more definitive, unbiased and generalisable study would be nested within an epidemiological survey of a representative population, as in the next stage of the 10/66 research program. However, dementia cases in Chennai, despite the index consultation leading to their recruitment, had generally not been given a diagnosis and were not offered continuing care, hence the index consultation was unlikely to have influenced future service use. This is borne out by the similarity of the findings between the two centres. The extensive use of health services among the controls gives the lie to the notion that they were atypically healthy. For these reasons we would argue that our study design is likely to be unbiased, and that the preliminary findings of considerable negative impact upon dementia caregivers are likely to be valid.

In many developing countries, caregiver strain has not been acknowledged; a near mythical strength is attributed to the abilities of families to cope. This distracts from the need for a rational debate regarding the future balance between family and state support and hinders evidence-based policymaking. We suggest prioritising home-based support, training and education for caregivers, these services being provided by existing outreach services. Future research should focus on the evaluation of the cost-effectiveness of such interventions. The 10/66 Dementia Research group's Indian network has developed a basic intervention for administration by generic primary care health workers. This will be evaluated in randomized controlled trials in Chennai and Vellore in India, together with Beijing, Moscow and the Dominican Republic.

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