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Guest Editorial

Dementia in Developing Countries

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The 10/66 Dementia Research Group (2000a) has drawn attention to the uneven distribution of research evidence worldwide; although two thirds (66%) of all persons with dementia live in developing countries, 10% or less of population-based research has been conducted in those regions. The study by Vas and colleagues on dementia in Mumbai, India, published in this issue of *International Psychogeriatrics* is therefore most welcome. Dementia has a very low profile in most developing countries. Families often view it as a normal part of aging, and few seek help despite experiencing significant strain (Patel & Prince, 2001; Shaji et al., in press). Unsurprisingly therefore it is accorded a low priority by policymakers in the developing world, and there is little sign of attention being given to the development of more responsive health care or social welfare services. Population-based research, well disseminated, can play an important role in increasing awareness at all levels of society.

Although the study by Vas and colleagues is welcome, it would be wrong to ignore some methodological shortcomings. Despite its title, this report cannot be considered to have provided an estimate of the prevalence of dementia in the population studied. No screening instrument is perfect; therefore a multistage design requires that in addition to all screen-positive participants, a sufficient number of randomly selected screen-negative participants should be interviewed in the definitive diagnostic phase to estimate the false-negative rate for the screen. The prevalence estimate can then be adjusted accordingly. This was not done for the Sandoz Clinical Assessment Geriatric Scale used in this study, an instrument that was not developed to screen for dementia cases in the community and had not been used previously for this purpose. The authors developed their own subscale using factor analysis to identify "cognitive items," and then applied an arbitrary cut point of 2 standard deviations above the mean. This cut point means that by definition, 2.5% of the population will screen positive (as the authors found), and excludes the possibility of estimating any higher prevalence than this. At best, given that the third-stage definitive dementia diagnosis procedures seem to have been meticulous, the authors have estimated the minimum prevalence of dementia in the population studied. It is probable, however, that the true age-specific prevalence of dementia is much higher than that reported here. It follows that the comparisons the authors make between the prevalence of dementia estimated in their survey and that estimated in other surveys using more conventional two-stage methodology are

also not well founded. In particular, readers should be wary of inferring too much from the fact that the prevalence reported here is lower than in some other studies from India, and much lower than most reports from the developed world. This could but should not be taken to confirm the view that dementia is rare and therefore as yet an insignificant public health priority in these regions.

This has, however, been a pioneering effort. Many useful lessons can be learned from the investigators' experience. Firstly, more is not necessarily better. In the first phase of this study they attempted to survey 30,000 persons aged 40 and over. By any standards this is an enormous undertaking, and one cannot but be impressed by the scale of their achievement, signified by the response rate of 82%. Early studies of dementia in the developing world tended to set the lower age limit for inclusion below the 65 years that is conventional in the developed world (10/66 Dementia Research Group, 2000b). The rationale for this decision is the contention that in the developing world, biological aging occurs more rapidly, hence those who would be considered to be middle-aged in developed countries could be properly thought of as aged. From evidence now available to us, we can be clear that this contention does not apply to dementia; early-onset dementia (before the age of 65) is as vanishingly rare in the developing as in the developed world (10/66 Dementia Research Group, 2000b). For the population-based study of dementia, it is thus highly inefficient to include participants under the age of 65 years. In this study 20,566 (84%) of the achieved sample of 24,488 was aged under 65 years. Ten cases of dementia were identified in this age group, a prevalence of only 0.0004%. Ninety-one (90%) of the 101 cases of dementia were identified in the remaining 3,922 participants aged 65 years and over. The investigators have explained their cursory first-phase screening methods on the basis that only thus could they manage the logistics of such a large survey. In retrospect, it would have been much better to have concentrated upon applying a more rigorous methodology to a much smaller number of participants in the age group most at risk for dementia.

Secondly, before the prevalence of dementia in unfamiliar settings is estimated, we first need to identify locally valid methods for case ascertainment. If these methods can be demonstrated to be valid cross-culturally, enabling meaningful comparisons to be made between countries and regions, then so much the better. In recent years much progress has been made in our understanding of what is required (10/66 Dementia Research Group, 2000b). Educational bias is a major problem. Items that can be used to discriminate between those with and without dementia in the west often fail to do so in developing countries where educational levels are very low and illiteracy is common. Even where the appropriateness of the method to the educational status of the population has been attended to, many items require some adaptation to render them culturally appropriate, or capable of being translated into the local language. Ganguli and colleagues (1995) have shown that most items in the Mini-Mental State Examination (MMSE) needed to be substantially revised or substituted to arrive at a culture- and education-fair assessment for use in northern India. The original version of the MMSE is unlikely to be an appropriate method for screening for dementia in any population with low levels of education and high levels of illiteracy.

New approaches have also been devised. One promising development has been the technique of screening informants to enquire after decline in the index person's cognitive and functional abilities (Jorm et al., 1991; Ritchie & Fuhrer, 1992). This approach has been shown in different cultures to be at least as effective as cognitive testing and is free of educational bias (Fuh et al., 1995; Law & Wolfson, 1995; Morales et al., 1995). The Community Screening Instrument for Dementia (CSI-D) (Hall et al., 1993) combines culture-fair cognitive testing of the participant and an informant interview into a single predictive algorithm. It is perhaps the best and most extensively validated culture- and education-fair dementia screening instrument (Hall et al., 2000). The cognitive component of CSI-D was developed from existing cognitive screening instruments with a view to identifying items that were equally discriminating for participants with high and low levels of education and literacy, and for participants from developed and less developed communities. The instrument has been used and validated to date in Cree American Indians (Hall et al., 1993; Hendrie et al., 1993), Nigerians in Ibadan, and African Americans in Indianapolis (Hendrie et al., 1995). The addition of the informant interview significantly improved the predictive power of the CSI-D in both Indianapolis and Ibadan. It has achieved 83% specificity at 87% sensitivity for a diagnosis of DSM-III-R dementia (Hall et al., 1993). The 10/66 Dementia Research Group (2000b) has been attempting to build on the CSI-D for a one-stage approach to dementia diagnosis. Pilot studies have been completed in 25 centers in Latin America, Africa, India, China, and Southeast Asia. One-stage comprehensive diagnostic procedures allow information on other psychiatric diagnoses to be collected for all participants, thus closely mimicking normal clinical practice and adding to the informativeness of the survey. Most importantly, given the high attrition rate between Stage 1 and Stage 2 interviews in developing countries research, they reduce bias in the assessment of prevalence and etiologic associations and simplify statistical analysis (10/66 Dementia Research Group, 2000b).

Thirdly, the investigators have focused their efforts upon the third-stage definitive dementia diagnosis, including allocation of dementia subtype diagnosis following a comprehensive clinic-based assessment. This included clinical, neurological, and radiological assessment, together with an informant history of the course and onset of the disorder. As with other similarly meticulous studies from the developing world, they report a predominance of cases of Alzheimer's disease (AD) with a ratio of 1:0.45 for AD to vascular dementia. Further detailed evaluation of representative series of dementia cases nested within epidemiological surveys can greatly increase their value. However, it is important to remember that these further evaluations can usefully include social as well as biological or clinical parameters. The investigators report that almost half of the persons with dementia in their survey were single or widowed. Anecdotally, they report having come across persons with dementia with no family member to care for them, who were reliant upon their neighbors for support. We need more studies of care arrangements for people with dementia in the developing world, which furthermore assess the impacts of caring upon family caregivers. In traditional societies the assumption is that the family should be available to provide care where needed.

With social and economic development, trends towards the globalization of culture, increasing workforce mobility, and emancipation of women are all tending to undermine the basis of this assumption. Data from future studies of this kind will help to inform the coming debate about the balance of roles and responsibilities for family, community, and state in traditional societies in rapid transition.

In conclusion, although there is a clear need for more research into dementia in developing countries, it is vital that we give proper emphasis to methodological rigor. A key role for these studies will be to provide an evidence base to drive and inform policy development; this can only be done with confidence when we are as sure as we can be of the validity of our methods. Future research will inevitably move beyond estimation of prevalence and incidence to identification of etiological factors (both genetic and environmental) and to estimates of the impact of dementia upon developing societies. A major challenge for the future will be the development and delivery of supportive and therapeutic interventions both for people with dementia and for their caregivers; again research can play an important role in promoting and evaluating new models of care.

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