ABSTRACT
Some recent studies from Vellore, Tamil Nadu, on dementia have been published in international journals as part of international data, analysis and interpretation. They have also been published separately employing local perspectives and analysis. The different results and interpretations of these two approaches to the same data suggest the need for independent work and study of the local reality to inform national public health policies.

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INTRODUCTION
Dementia and depression among older people account for a major burden of disease across countries and cultures. Research from high-income countries has examined many issues related to mental health problems in older people. Many of the findings reported from western/international studies seem to form the bedrock of academic discussions in India. The dearth of Indian investigations forces Indian academics to rely on foreign facts and perspectives. The uniqueness of the context of India and its distinctive cultures are often discounted. Indian clinicians, teachers and researchers routinely cite many of these foreign facts and perspectives, often as gospel truth.

INDIAN DATA
There have been studies on dementia among older people from India. The work of Mary Ganguli, Vijay Chandra and colleagues as part of the Indo-US Cross-National Dementia Epidemiology Study at Ballabgarh, Haryana, was a systematic attempt at documenting issues.1 Instruments were developed and validated; the nature of cognitive impairment, its prevalence and risk factors were identified. A PubMed search also revealed many other studies, which have been published from India. However, these are isolated efforts from Kolkata, Kochi, Thiruvananthapuram, Pune and Kashmir. Many of these investigations unquestioningly employ western concepts and perspectives and often reported observations grossly comparable to western literature on the subject.

VELLORE DATA
The Alzheimer’s Disease International7 brought together researchers based around the globe to form the 10/66 Dementia Research Group (10/66 DRG).3 There are about 25 community sites in different countries in Asia, Africa and Latin America using common and standard methodology. The papers arising from the effort have been published as part of 10/66 group publications. Vellore was part of the 10/66 DRG. In addition, the Vellore centre has also been publishing its separate analysis of the data collected in Vellore to highlight the unique issues facing older people in India. Consequently, we have two sets of analyses and interpretations: (i) Vellore data as part of 10/66 analysis using standard analysis and interpretation; and (ii) specific analysis of the Vellore data to highlight local and contextual issues. They study standard issues and also attempt to examine the unique context of India. A few concerns that highlight the differences between the international and the Indian context and consequently perspectives are briefly mentioned.

DILEMMAS IN DIAGNOSING DEMENTIA
Investigations have documented different rates of prevalence for dementia in community surveys.3,10 The reported prevalence has been lower in India (1.36%–3.50%) compared to the West (5.9%–9.4%). While true differences in population prevalence exist (attributed to differing genetic and environmental factors, life expectancy, duration with disease- and age-specific incidence), variation in rates may also be contributed by the use of different survey procedures (one-stage/two-stage), assessment schedules and diagnostic criteria. The instruments and criteria to diagnose dementia have mainly been validated in high-income countries. The comparison of rates of dementia in different countries and cultures requires procedures, which can be used across cultures (culture fair). These instruments should also not be affected by variations in the educational levels of the population (education fair).

The 10/66 DRG tested a variety of instruments individually and in combination to identify dementia in over 25 centres in low- and middle-income countries including India.11 These studies documented that the Community Screening Instrument for Dementia (CSID)12 was useful in distinguishing people with dementia from those with low education but without dementia. The Geriatric Mental State (GMS)13,14 could distinguish people with dementia from those who suffered from depression. The CERAD 10-word-list-learning-task15 also showed potential as an education and culture fair test. Using all three tests together in a single package produced the best results with the algorithm identifying 94% of cases with dementia with false-positive rates of 15%, 3% and 6% in the depression, high-education and low-education groups, respectively.11 The procedure worked equally well in Indian, Chinese and Latin American centres, in dealing effectively with different educational levels and coping well with the effects of language and culture. The 10/66 DRG developed computer algorithms for diagnoses.11,16

Despite the sophistication of the 10/66 DRG approach, the Vellore data, analysis and interpretation argue that major issues are brushed under the carpet. We used the 10/66 DRG population studies protocol to interview 1000 people living in the community, over 65 years of age.11 The prevalence of dementia differed markedly ranging from 0.8% by Diagnostic and Statistical Manual

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IV standard to 63% using the Geriatric Mental State (Table I). The wide variation in rates of prevalence suggests that it is a complex task to diagnose clinical dementia. These issues are briefly highlighted.

**Variance in information and criteria.** This is a common reason for differences in reliability of different diagnostic procedures. The different informants, interview schedules and diagnostic criteria definitely contribute to variations in the threshold and the type of patients identified. Such variance has been contributing to the different estimates of incidence and prevalence of dementia in different parts of the world. While this has major implications in clinical practice and in research, efforts at achieving congruence between the major diagnostic systems are under way. However, while there is agreement on the major criteria for diagnosis, even minor variations in information and criteria can result in wide variations in the patient identified. These need to be re-evaluated.

**Different settings and differing demands on diagnostic tools.** The problems in identification are compounded when the diagnosis is made in community settings. It raises many issues. Which criteria should be used to diagnose dementia in the community? Can criteria used in patients with symptoms who are brought to hospitals be used in patients living in the community who have not sought treatment for symptoms or whose relatives have not considered symptoms to be abnormal? Can criteria designed for specialist and tertiary centres, which manage patients who have passed through a referral system, be used in the community? Should different populations have specific tailor-made criteria (for example, adjusted for education, age, etc.) to diagnose the condition? Should the informant’s ability to recognize abnormality and their tolerance of symptoms be weighted in assessing dementia? Should baseline function be accounted for and should reporting impairment in occupational and social function be mandatory for a diagnosis? Are age-related cognitive decline, mild cognitive impairment and dementia discrete entities or is there a continuum?

The symptoms of dementia and depression in late life are considered as part of normal ageing in India and are not perceived as requiring medical care. Primary healthcare physicians rarely see dementia in their clinical work while community health workers can recall many individuals with such conditions. Many informants in this study did not complain of problems although their relatives had significant cognitive impairment. The high tolerance of such symptoms and disability could be due to the low level of expectation of the family from their older relatives. This has a significant impact on the diagnosis, as the deterioration of social and occupational functioning is mandatory for a diagnosis of dementia by DSM criteria. The variation in rates of prevalence demands a debate on the criteria for dementia in the community in general and for less literate populations in India in particular.

**HEALTH WORKER SCREENING CONUNDRUM**

The WHO recommends the strategy of using community health workers to identify mental illness in the community in resource-poor settings. Such a strategy has been recommended for India for the past 35 years. However, this approach has been successful only in the small pilot projects set up by the WHO and has not been evaluated in identifying dementia in older people. The 10/66 DRG also suggest such an approach for case finding in the community. The community health workers were trained in the identification of dementia and were asked to nominate people with dementia living in their catchment area. The positive predictive value and false-positive rate were 64.7% and 35.3%, respectively. The suggested approach offered a cost-effective strategy, using existing health workers without increasing their already high workload, particularly relevant to the resource-poor countries of the developing world.

Nevertheless, the Vellore data suggest otherwise. Health workers were trained in the recognition of dementia using the 10/66 module. They were given the list of participants who lived within their catchment area and asked to nominate people with dementia on the basis of their knowledge of the local community. The sensitivity was low and the specificity was high for the health worker diagnosis against the standard dementia diagnosis. The positive predictive value and false-positive rates were poor when compared with the DSM IV standard (Table II) and modest when compared against the education-adjusted 10/66 DRG diagnosis. The negative predictive values and false-negative rates were good against both measures. Subjects identified to have dementia by the community health worker did not differ significantly from those whose diagnosis of dementia was missed on the following variables: age, sex, marital status, literacy, income, measures of poverty, severity of cognitive impairment, neuropsychiatric morbidity, depression, disability and caregiver strain.

The results of the study suggest that the training produced modest results when compared with detailed assessment procedures. The WHO and the 10/66 DRG, who proposed this strategy, only assessed patients identified as dementia by the health worker and obtained a reasonable positive predictive value. However, a systematic evaluation of the approach in a large community sample has produced less than satisfactory results. The lack of statistically significant association between those correctly diagnosed to have dementia by health workers and those who were missed on sociodemographic and clinical variables suggests an inability to refine or refocus the training programme.

The results of this study do not compare favourably with other studies on psychosis and epilepsy done in India using different methods of screening. One possible explanation for the poor results in this study could be that the spectrum of age-related cognitive decline, mild cognitive impairment and dementia in the community may make the identification of the threshold for dementia more difficult than the recognition of psychosis or epilepsy. Psychosis and epilepsy are clinically discrete and much easier to diagnose.

It can also be argued that training was inadequate and better teaching modules and more time will help improve the ability of

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**TABLE I. Prevalence of dementia based on different criteria**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Prevalence (95% CI)</th>
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<tbody>
<tr>
<td>Geriatric Mental State (using AGE CAT)</td>
<td>63.4% (60.3%–66.4%)</td>
</tr>
<tr>
<td>10/66 algorithm (Prince et al., 2003)</td>
<td>21.2% (18.7%–23.9%)</td>
</tr>
<tr>
<td>Education adjusted 10/66 algorithm</td>
<td>10.6% (8.8%–12.7%)</td>
</tr>
<tr>
<td>Diagnostic and Statistical Manual IV</td>
<td>0.8% (0.4%–1.6%)</td>
</tr>
</tbody>
</table>

**TABLE II. Comparison of health worker diagnosis compared with DSM IV diagnosis of dementia**

<table>
<thead>
<tr>
<th>Index</th>
<th>Value (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity</td>
<td>12.5</td>
</tr>
<tr>
<td>Specificity</td>
<td>99.2</td>
</tr>
<tr>
<td>Positive predictive value</td>
<td>11.1</td>
</tr>
<tr>
<td>False-positive rate</td>
<td>88.9</td>
</tr>
<tr>
<td>Negative predictive value</td>
<td>99.3</td>
</tr>
<tr>
<td>False-negative rate</td>
<td>0.7</td>
</tr>
</tbody>
</table>
health workers to screen for dementia in the community. Nevertheless, from a theoretical perspective, the positive predictive value and false-positive rate will be modest at low levels of prevalence of dementia. For example, even if we assume that we are able to train health workers to improve their diagnostic skill and achieve a sensitivity of 90% as well as a specificity of 90%, the low levels of prevalence of dementia in the community (e.g. even 10%), will result in a positive predictive value and false-positive rate of 50%. The improvements in accuracy of diagnosis will be marginal, when assessed by mathematical indices, even with improvement in diagnostic skill of health workers.23

Improvement in diagnostic accuracy is more often achieved by artificially increasing the prevalence in the population tested (e.g. clinic- or hospital-based testing and in those who complain about or are brought with clinical symptoms)25 and much less because of the skill of the person making the diagnosis. This is also applicable to other illnesses in the community with low rates of prevalence.

The strategy of using community health workers to identify mental illness in the community in low- and middle-income countries has been successful only in the small pilot projects set up by the WHO and has not been useful on a mass scale.21 The reasons for the failure of the strategy are many but include the fact that disorders with low prevalence cannot be diagnosed accurately at the community level unless a referral system is in place which screens and confirms the diagnosis at multiple points in series (for example, health worker, public health nurse, physician).19 The failure to place such a diagnostic system, which uses health personnel to filter cases at multiple levels, has contributed to the failure of community psychiatry programmes across resource-poor settings in low- and middle-income countries. There is a definite need to put in place a tiered health worker network at the community level if screening programmes have to be successful.19,21 There is a need to re-examine the issues related to diagnosis of conditions with low rates of prevalence at the community level.

SELECTING SCREENING STRATEGIES
Several instruments have been used to screen patients for dementia.26 However, despite the availability of numerous instruments, many challenges remain. These include: (i) many instruments, including the commonly used Mini-Mental Status Examination,27 are influenced by education and culture, making them inappropriate for use in societies with low literacy;28 (ii) the education- and culture-free screening tests available do not test multiple cognitive domains systematically; (iii) even screening instruments with good sensitivity and specificity, when used in situations of low prevalence (for example, community and primary care), result in very high false-positive rates23,25,26 as these rates are dependent on prevalence.

Activities of daily living, which are not influenced by education and culture, were used to develop the Vellore screening instruments for dementia. Patient and informant versions were developed to reduce false-positive rates.29 The patient and informant screens, using 10 items each, assessed cognitive domains of memory, aphasia, agnosia, apraxia and loss of executive functions. The instruments were validated in the hospital and in the community setting against the standards of DSM IV18 and the education-adjusted 10/66 DRG diagnosis of dementia.16

The psychometric properties and inter-rater reliability of these screening instruments were good when used in the hospital and in the community setting. Their sensitivity, specificity and positive predictive values were good when used in the hospital setting. While the sensitivity and specificity of the patient screen and the informant version were good, their false-positive rates were high in the community setting (Table III).29 However, the false-positive rates reduced when these instruments were used in combination. Yet, the positive predictive values for dementia were modest when the combination of patient and informant screens were used. Such results demand that those positive on such screens need to be evaluated again for the confirmation of a diagnosis of dementia. Further improvement with a reduction in positive predictive value is possible, if screening is used only in symptomatic older people (rather than when used to indiscriminately screen all older people in the community).19

CONCLUSION
The studies from Vellore on dementia have been published in international journals as part of international data, analysis and interpretation. They have also been published separately using local perspectives and analysis. The different results and interpretations of these two approaches to the same data suggest the need for independent work and study of the local reality to inform national public health policy.

Despite independence from the British for over 60 years, Indian academics continue to be subject to slavery of a different kind. The reality of India, its problems and opportunities demand unique solutions. Transplanting knowledge structure, formations and practices developed and used in the West may result in a lack of goodness of fit. Context and local knowledge are critical to understanding health and illness in India.19 Universal abstractions may not fit local reality and artificially force structures. Mental health and illness in India needs to be understood and theorised independently of the West. Contexts should not only change medical practice but should also be able to change medical perspectives.

ACKNOWLEDGEMENT
The studies and issues reported in this article formed the basis of the Dr Venkoba Rao Oration at the IXth Annual Conference of the Indian Academy of Geriatrics held at Vellore, Tamil Nadu, 4–5 November 2011.

REFERENCES

| Table III. Comparison of Vellore Screening Instruments for Dementia against DSM IV criteria for dementia |
|-----------------|------------|------------|-----------------|
| Instrument      | Sensitivity (%) | Specificity (%) | Positive predictive value (%) |
| Patient version | 66.7       | 77.6       | 8.3             |
| Informant version | 100.0    | 79.2       | 13.0            |
| Patient and informant version | 66.7 | 95.3 | 30.5 |