

GUEST EDITORIAL

Dementia: toward contextual understanding

Introduction

Dementia is a cause of significant burden across countries and cultures. Many issues related to mental health problems among older people living in low- and middle-income countries (LMICs) have been highlighted in the literature. However, much of the work in LMICs examines these issues through Western international perspectives. The dearth of local contextually relevant investigations forces academics to rely on universal facts and concepts, discounting uniqueness of the context and cultures.

There have been many studies on dementia among older people living in India. Many issues have been systematically examined, instruments developed and validated and the nature of cognitive impairment, its prevalence, and risk factors identified (Indo-US Cross National Dementia Epidemiological Study, 2000). Many other investigations have also examined these issues in different parts of the country (Shaji *et al.*, 2005; Das *et al.*, 2006; Raina *et al.*, 2009; Mathuranath *et al.*, 2010; Saldanha *et al.*, 2010). However, these investigations unquestioningly employed standard Western perspectives.

Vellore data

Vellore was part of the 10/66 Dementia Research Group (10/66 DRG), which is the Alzheimer's Disease International's (ADI) effort to bring together researchers based around the globe. Investigators from diverse centers in different countries in Asia, Africa, and Latin America used common and standard methodology/approaches. Many papers arising from the effort have been published as part of 10/66 DRG publications.

Nevertheless, the Vellore center has also been publishing its separate analysis of the data collected in Vellore in order 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 protocols using standard analysis and interpretation and (ii) specific analysis of the Vellore data to highlight local and contextual issues. The contrasting findings from these different approaches highlight the differences between international/universal and contextual/local perspectives.

Diagnostic dilemmas

Community surveys have documented different prevalence rates for dementia (Chandra *et al.*, 1998; Ferri *et al.*, 2005). The 10/66 DRG tested a variety of instruments individually and in combination to identify dementia in over 25 centers (Prince *et al.*, 2003). They combined the Community Screening Instrument for Dementia (CSID; Hall *et al.*, 1993), the Geriatric Mental State (GMS; Copeland *et al.*, 1986; 2002), and the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) 10-word-list-learning-task (Ganguli *et al.*, 1996) in a single package. Their algorithm identified 94% of dementia cases with false-positive rates of 15%, 3%, and 6% in the depression, high education, and low education groups, respectively (Prince *et al.*, 2003). The procedure worked equally well in Indian, Chinese, and Latin American centers, 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 (Prince *et al.*, 2003; 2004).

Despite the sophistication of the 10/66 DRG approach, alternative analysis and interpretation of the Vellore data highlight some problems (Jacob *et al.*, 2007a; Jacob, 2012). The prevalence of dementia at Vellore was 0.8%, 10.6%, 21.2%, and 63% using the Diagnostic and Statistical Manual IV (American Psychiatric Association (APA), 1994), the education-adjusted 10/66 algorithm (Prince *et al.*, 2004), the 10/66 Lancet algorithm (Prince *et al.*, 2003), and the Geriatric Mental State-Automated Geriatric Examination for Computer Assisted Taxonomy (GMS-AGECAT; Copeland *et al.*, 1986; 2002), respectively.

The wide range of prevalence in the same population mandates review. Information and criterion variance contribute to variations in the identification and prevalence rates of dementia. However, while there is agreement on the major criteria for diagnosis, even minor variations in information and criteria result in substantial variations in prevalence rates and in the people identified (Jacob *et al.*, 2007a). How do we arrive at best possible criteria, which produce true prevalence rates? How do we define the threshold for the age-related cognitive decline–mild cognitive impairment–dementia spectrum?

The symptoms of dementia and depression in late life are considered part of normal aging by the general population in India and are not perceived as requiring medical care (Patel and Prince, 2001). Primary health physicians rarely see dementia in their clinical work while community health workers can recall many individuals with such conditions. Many informants in this study (Jacob *et al.*, 2007a) did not complain of problems, although their relatives had significant cognitive impairment. The high levels of tolerance of such symptoms and disability are due to the low levels of expectation of older people. This has a significant impact on the diagnosis, as deterioration of social and occupational functioning is mandatory for a diagnosis of dementia by Diagnostic and Statistical Manual (DSM) criteria (APA, 1994).

The variation in prevalence rates demands a debate on the criteria for dementia in the community in general and for less literate populations in India in particular (Jacob *et al.*, 2007a). Can criteria employed in patients with symptoms who are brought to hospitals be employed in patients living in the community who have not sought treatment for symptoms or whose relatives have not considered symptoms as abnormal? Can criteria designed for specialist and tertiary centers, which manage patients who have passed through a referral system, be employed in the community? Should different populations have specific tailor-made criteria (e.g. adjusted for education and age) to diagnose the condition? Should we factor in the informant's ability to recognize abnormality and their tolerance of symptoms in assessing dementia? Should baseline function be accounted and should reporting impairment in occupational and social function be mandatory for a diagnosis?

Screening conundrum

The World Health Organization (WHO, 1990) and the 10/66 DRG (Shaji *et al.*, 2002) recommend the strategy of employing community health workers to identify mental illness in the community in resource-poor settings. They argue that it offers a cost-effective strategy, employing existing health workers without increasing their already high workload. Nevertheless, the Vellore data suggest otherwise. Trained health workers performed poorly against the DSM IV standard with sensitivity, positive predictive value and a false-positive rate of 12.5%, 11.1%, and 88.9%, respectively (Jacob *et al.*, 2007b). Their performance was modest when compared against the education-adjusted 10/66 DRG diagnosis (Prince *et al.*, 2004).

Positive predictive value and false-positive rate will be poor for all forms of screening (i.e. employing health worker or screening instruments), even with excellent sensitivity and specificity, at low levels of prevalence of dementia. Improvements in the accuracy of diagnosis will be marginal, when assessed by mathematical indices, even with an improvement in the diagnostic skill of health workers or indices of efficacy of screening instruments (Jacob *et al.*, 2007b).

An 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 significant clinical symptoms) (Jacob, 2003) and much less because of the skill of the person making the diagnosis. The reasons for the failure of the strategy of using health workers to identify mental disorders in the community include the fact that disorders with low prevalence cannot be diagnosed accurately at the community level unless a referral system is in place. Such a tiered system, which screens and confirms the diagnosis at multiple points in series (e.g. health worker, public health nurse, physician, and specialist), is required for accurate diagnosis. The failure to place such a diagnostic system, which employs health personnel to filter cases at multiple levels, has contributed to the failure of community psychiatry programs across 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 programs are to be successful (Jacob, 2007b).

Which screen?

A number of different and diverse instruments have been employed to screen for dementia (Cherbuin *et al.*, 2008). The more recent screens attempt to be education and culture fair (Prince *et al.*, 2011). However, despite the numerous instruments available, many challenges remain. These include: (i) instruments including the commonly used Mini-Mental Status Examination (Folstein *et al.*, 1975) are influenced by education and culture, making them inappropriate for use in societies with low literacy (MRC, 1998); (ii) education and culture fair screening tests available do not systematically test multiple cognitive domains; (iii) screening instruments with good sensitivity and specificity, when used in situations of low prevalence (e.g. community and primary care), result in very high false-positive rates as these rates are dependent on prevalence (Jacob, 2003; Jacob *et al.*, 2007b; Cherbuin *et al.*, 2008).

The Vellore instruments and strategies for screening were developed to attempt to overcome

these problems. They employed activities of daily living to test multiple cognitive domains and used patient and informant screens in combination (Stanley *et al.*, 2009). Their sensitivity, specificity, and positive predictive values were good when employed in the hospital setting. However, their false-positive rates were high in the community setting and positive predictive values were modest (30.5%). Screening instruments when employed to screen older people in the community perform poorly. The low prevalence of dementia in the community is bound to defeat the best of screens when employed to test all older people. Further improvement in positive predictive value is possible if screening is restricted to symptomatic older people (rather than when used to screen indiscriminately all older people living in the community).

Disability among older people

Disability among older people is a cause of significant burden. Studies from high-income countries have identified chronic diseases and depressive disorders as major determinants of disability among older people. The 10/66 DRG's cross-national study investigated the contribution of chronic diseases toward disability among the elderly and reported that dementia is the most important independent contributor in LMICs (Sousa *et al.*, 2009). However, the report did not examine the socio-economic and local determinants, which contribute to disability among older people. While the investigation identified common issues facing older individuals across nations, it did not highlight the local context nor identify particular environmental risk factors.

A separate analysis of the Vellore data identified advanced age, illiteracy, hunger, poor nutrition, and the cost of travel to primary health facility as contributing to disability (Duba *et al.*, 2011). The biomedical determinants included arthritis, hearing impairment, gastro intestinal and respiratory diseases, and dementia, which also increased the risk of disability significantly. Hypertension, diabetes, and depression were not associated with disability. Locally relevant social determinants combine with prevalent medical diseases to produce the disability burden among older people. There is a need to focus on local contexts and modifiable risk factors to design locally appropriate public health policies and interventions for older people in LMICs (Duba *et al.*, 2011).

Health equity and expenditure

The 10/66 DRG study on health equity and out-of-pocket expenditure documented the impact of

education and health insurance cover on access to healthcare and highlighted the risk of exclusion of the poorest older people (Albanese *et al.*, 2011). The Vellore data document higher disability among women and unskilled workers, who also reported the lowest out-of-pocket expenses (Duba *et al.*, 2011; Brinda *et al.*, 2012), arguing that lower out-of-pocket expenses are better explained by poor financial resources than by reduced need for care. Our analysis also showed that older people who spent more than 10% of their income (rather than the conventional 40%) on health were more prone to suffer from food scarcity, depressive symptoms, and suicidal ideas supporting the concept of different levels of financial expenses resulting in catastrophic health expenditure for different populations.

Conclusions

The different results and interpretations of these two approaches (i.e. universal/standard vs. contextually relevant) suggest the need for independent work and study of the local reality to inform national public health policy. The reality of India and LMICs, their problems, and opportunities demand uniquely tailored solutions. Transplanting knowledge structure, formations, and practices developed and employed in the West may result in a lack of goodness of fit. In addition, they may artificially force the data to fit universal theory. Large-scale industrial research, while attractive from the point of view of using common methodology, may not necessarily recognize locally relevant issues and contexts. Consequently, their relevance and impact on national public health policies will be marginal compared to regional investigations, analysis, and interpretations grounded in local reality. There is a need to empower researchers in LMICs, strengthen local research efforts, which incorporate regional knowledge, understand local contexts which attempt to look for regionally tailored solutions.

Context and local knowledge are critical to understanding health and illness. Universal abstractions may not fit local reality and artificially force structures. Mental health and illness in India and in LMICs needs to be understood and theorized independent of the West. Contexts should not only change medical practice but they should also be able to change medical perspectives.

Conflict of interest

The author was part of the 10/66 Dementia Research Group and was also involved in the independent analysis of the Vellore data.

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