10/66 Dementia Research Group

10/66 Dementia Research Group is part of Alzheimer's Disease International

Dementia prevalence in low and middle income countries may be substantially underestimated

The 10/66 Dementia Research Group has recently published a paper in *The Lancet*, presenting new epidemiological data on dementia prevalence among nearly 15,000 older people in 11 sites in Latin America, China and India.

The major conclusion of the study is that we must revisit the notion that dementia is much less prevalent in the poorer countries. This was true for the DSM-IV dementia diagnosis, but not for the '10/66 Dementia Diagnosis' developed specially by our group to diagnose dementia across a wide variety of cultures, and validated in 26 centres in Latin America, India, China and Africa.

With the widely used DSM-IV criteria, dementia diagnosis requires deterioration in memory and other cognitive functions. Difficulties in carrying out normal activities must also have been reported, usually by a family member or other informant. We found that, particularly in the least developed countries, family members did not report disability, even in the presence of marked memory problems.

We suggest that:

- In less developed regions, impairment in the performance of normal activities may be less noticeable, because of the high levels of support that are provided to older people.
- Lack of awareness may play a part. Cognitive decline in the elderly may be considered part of ageing, and thus normal.
- Even when decline has been noted by family members, they could be reluctant to disclose this information because of the culture of respect towards the elderly.

These factors may all lead to an underestimate of the true prevalence of dementia when using DSM-IV criteria in less developed countries.

Llibre Rodriguez, Ferri et al, Prevalence of dementia in Latin America, India, and China: a population-based cross-sectional survey. *The Lancet*, Vol. 372, Issue 9637, 9 August 2008

Wide media coverage

This paper has generated impressive media coverage. It has appeared, for example, in; The Washington Times, Washington Post, The Hindu (Indian national broadsheet newspaper), New Scientist, BBC Mundo (Spanish service), Sveriges Radio (Swedish National Radio), US Department of Health and Human Services, Alzheimer's Research Forum.

'He is old, that is why he has lost his memories'

Chennai, India

Mr A is now 78 years old. He was a farmer from the rural area of Tamil Nadu in southern India. Mr A migrated to Chennai 20 years ago to live with his three sons, their wives and their children, who all live together.

Mr Jotheeswaran asks Mr A his name, but he cannot remember and lays down his head, mute

Mr A was interviewed three years ago for the baseline wave of the Indian 10/66 study, when he received a diagnosis of 10/66 dementia. At that time Mr A had only moderate memory problems – his family did not perceive a problem.

Three years later Mr Jotheeswaran, the 10/66 Indian project coordinator, went back to carry out the follow-up interview. He hardly recognized Mr A, who was wandering out into the street from the open gate of his house. Mr A could not answer any questions, not even to give his name. His family said that 'he was not himself any more' and that they were very concerned by his irritability and aggressiveness. Still they felt that this was normal considering his age. They declined our offer to book a free appointment with the local hospital doctor.

NEWS FROM THE CENTRES

Venezuela

Venezuela is in Northern South America, bordering the Caribbean Sea. It has a tropical climate and is rich in oil and natural gas. In 1999 the country began a political, legal, economical and social transition process. The new Constitution of the Bolivarian Republic of Venezuela (CBRV) established that it is a responsibility of the State to guarantee the right to health. Article 84 orders the creation of a national health public system. Article 85 establishes that financing of the national health public system is the responsibility of the State.

The total population is 26,414,815 of whom 5.1% are elderly. Life expectancy at birth is 73.5 years. Literacy is over 90%. GDP per capita is $12,200, but there are nearly 10 million people who live below the poverty line.

The total expenditure on health is now approximately 4.7% of GDP. In 1990 health services were decentralized, but this led to very uneven development, depending on the local authorities. The health system is now integrated, with public and private subsectors. In 2000, two-thirds of the population had some kind of health insurance. There are about 290 hospital and 4,650 ambulatory/clinics in the Country. In 2000, there were 17.6 beds per 10,000 inhabitants, more than half located in the most developed states. In 2000, there were only 20.7 doctors and 0.7 nurses per 10,000 inhabitants. Structural changes were made to the health care system in 2003, aiming to provide health care to 171 poorer barrios (districts) with the participation of 200 Cuban doctors.

A busy street in urban Caracas, Venezuela

People's Health Centres were created with a coverage of one doctor for 250 families in a health team consisting of a health worker, a nurse, a community health promoter and a health committee that provides medicines at low cost. People Clinics will also be created with specialist doctors and diagnostic equipment. The Clinics will offer emergency and ambulatory care 24 hours and 12 hours a day respectively. 'People Hospitals' constitute the third level of the health system. Mental Health is a priority area. Case registers have been established together with specialized centres. Psychiatric hospitals and long-stay establishments (psychiatric colonies), are still the cornerstone of the service.

In time, mental health services, ambulatory and hospital care are meant to be integrated into the health system with effective community participation.

Some other papers recently published by 10/66

First results from the 10/66 'Helping carers to care' intervention

Findings from the randomised controlled trials in Goa, India, and in Moscow suggest that the 'Helping carers to care' intervention can be highly effective in reducing carer strain.

Dias A et al. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PLoS ONE*. 2008 Jun 4;3(6):e2333.

Gavrilova SI et al. Helping carers to care -The 10/66 dementia research group's randomized control trial of a caregiver intervention in Russia. *Int J Geriatr Psychiatry*. 2008 Sep 23.
[Epub ahead of print]

Dependency in the Dominican Republic

Dependency (the need for care) is nearly as common in the Dominican Republic as in rich countries, with 12% of older people affected. Dementia was by far and away the most common underlying health condition. People with dementia had more extensive and more complex care needs, and their caregiver experienced more strain.

Acosta D et al. The epidemiology of dependency among urban-dwelling older people in the Dominican Republic; a cross-sectional survey. *BMC Public Health*. 2008 Aug 13;8:285.

Dementia in Cuba

Dementia in Cuba is as common as in the European EURODEM studies, and is associated with older age, less education, shorter legs and smaller skull circumferences. Dementia (rather than stroke, other physical health conditions and depression) makes the largest single contribution to needs for care and caregiver strain.

Llibre Rodriguez J et al. The prevalence, correlates and impact of dementia in Cuba. A 10/66 Group population-based survey. *Neuroepidemiology* (in press)

Managing behavioural problems in dementia in rural China

Dr Zhaorui Liu, the Chinese 10/66 project coordinator, is carrying out the randomised controlled trial of the 10/66 'Helping Carers to Care' intervention as part of the population-based studies. Those with dementia and their families are offered the chance to participate in the trial. If they consent they are randomised to receive the intervention immediately, or after a six month follow-up period. The 10/66 intervention targets the main carer, but includes members of the extended family. It aims to provide basic education about dementia and specific training on managing problem behaviours.

Here Dr Liu tells us about Mr Zheng (76) and Jia, Mr Zheng's wife (74), a farmer in Fang Shan District, Beijing.

'It was really hard to interview Mr Zheng. He did not want to answer any of our questions. His wife, Ms Jia, was very embarrassed about her husband's behaviour. Eventually we could only obtain some information from Ms Jia and a psychiatrist from our team made a formal diagnosis of dementia.

'Ms Jia told us how her husband had changed in the past three years, how he used to be a kind person – not bad-tempered and occasionally violent as he is now. He had lost all his interests except smoking and he would fly into a rage and become violent when cigarettes ran out. Moreover, he had become suspicious and often accused his neighbours of stealing his belongings. But the thing that troubles Ms Jia most is her husband wandering in the bedroom all night, restless.

'Ms Jia told us she felt disgraced because of her husband's behaviour but she could do nothing to control him. Ms Jia also complained that her own health had deteriorated as a result; she had lost weight, become anxious and cannot sleep. Ms Jia told us they were poor farmers with no income or pension, and could not afford medical attention. With their consent, they joined the 'Helping carers to care' intervention trial.

'Considering Mr Zheng's behavioural symptoms and Ms Jia's low awareness of dementia, we conducted five targeted interventions for Ms Jia. She began to understand that Mr Zheng's behaviour was nothing he could control, that it was caused by his disease, dementia. She learnt to be more tolerant of her husband and to follow our tips and suggestions for managing his problem behaviours. We hope that the intervention will reduce Ms Jia's distress and possibly improve Mr Zheng's life as well.'

The 10/66 China team

Rural house in Fangshan (Beijing)

Diagnosis in Cuba

In Cuba, we validated the 10/66 dementia diagnosis and the DSM-IV dementia criterion (our survey diagnoses) against the Cuban doctor's clinical diagnosis. 10/66 dementia corresponds more closely than DSM-IV dementia with the clinical diagnoses. DSM-IV criteria were selectively missing mild to moderate cases of dementia.

Prince MJ et al. The 10/66 Dementia Research Group's fully operationalised DSM-IV dementia computerized diagnostic algorithm, compared with the 10/66 dementia algorithm and a clinician diagnosis: a population validation study. *BMC Public Health*. 2008 Jun 24;8:219.

Encouraging change

This story illustrates many of our experiences regarding behavioural and psychological symptoms of dementia – these symptoms are particularly distressing for carers, are poorly understood, and often lead to feelings of shame and stigma. Clinicians often focus on the classical cognitive symptoms of dementia, for example memory loss. Fortunately, education of the caregiver and advice on making changes around the home – modifying the way that they care for their relative and respond to the problem behaviours – can all make a big difference. Scientifically rigorous randomised controlled trials are the best way to persuade policymakers to adopt these approaches.

The 10/66 intervention has already proved to be effective in Russia and India. Soon we can expect more results from the trials in China, Venezuela, Peru, Mexico and the Dominican Republic.

Events

International Conference on Alzheimer's Disease (ICAD)

Chicago, USA
26–31 July 2008

Members of the 10/66 Dementia Research Group attended the ICAD conference. Prof Juan Llibre from Cuba presented findings from the recent Lancet paper (see front page), and Renata Sousa presented new data on disability and dependency from low and middle income countries, modelling and validating the WHO-DAS scale.

Alzheimer Ibero-American Conference

Buenos Aires, Argentina
5–8 August 2008

The 10/66 Dementia Research Group successfully presented a symposium and a number of other interventions (Prof M Prince, Dr Daisy Acosta, Dr A Salas, Dr M Guerra, Dr AL Sosa, Dr I Jimenez and Dr Cleusa Ferri) at the Alzheimer Ibero-American Conference.

International Mental Health (IMH)

London, UK
26–28 August 2008

At King's College, on the occasion of the celebration of the 10/66 Dementia Research Group's 10th birthday, Dr Nori Graham (Honorary Vice President of ADI) and Professor Martin Prince told the story of the project. They mentioned the seeds planted in Chennai in 1998, described the growth of the network, and the scope of the 37 publications so far.

The work of the group continues. Dr Zhaorui Liu, Dr Richard Uwakwe and Dr Ivonne Jimenez presented data and interesting results from their local 10/66 studies in China, Nigeria and Puerto Rico.

NEWS

We are back in the field!

The 10/66 follow up study has now started in Dominican Republic, Cuba, Peru and India. Participants from the baseline are being traced, re-contacted and re-interviewed around three years after the first interview. It has been good to reengage with the older people, their families, and the communities who have already contributed so much to the project. The follow-up studies in China, Mexico, Venezuela and Argentina will be starting shortly.

10/66 website revised

www.alz.co.uk/1066

We have completely updated and revised our 10/66 website, with support from ADI. The new site has sections for study participants, the general public, researchers and policymakers. It is a rich source of information about the project, and new findings as they appear. All of the materials for the project (protocols, interviews, data entry systems) can be downloaded, and there are links to all of the papers and reports. In line with our commitment to maximise the output from the 10/66 studies, researchers external to our group can now apply online to use the 10/66 datasets for scientifically legitimate and ethical purposes.

Visit the site and register for updates NOW!

How to contact us

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