

10/66 Dementia Research Group

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

What is the 10/66 Dementia Research Group?

- Only 10% of all dementia research is conducted in developing countries, where roughly 66% of all people with dementia live
- The 10/66 Dementia Research Group is a collective of researchers, coordinated from London, and working in low and middle income countries
- 10/66 was formed in 1998 to address the serious lack of dementia research in developing countries.



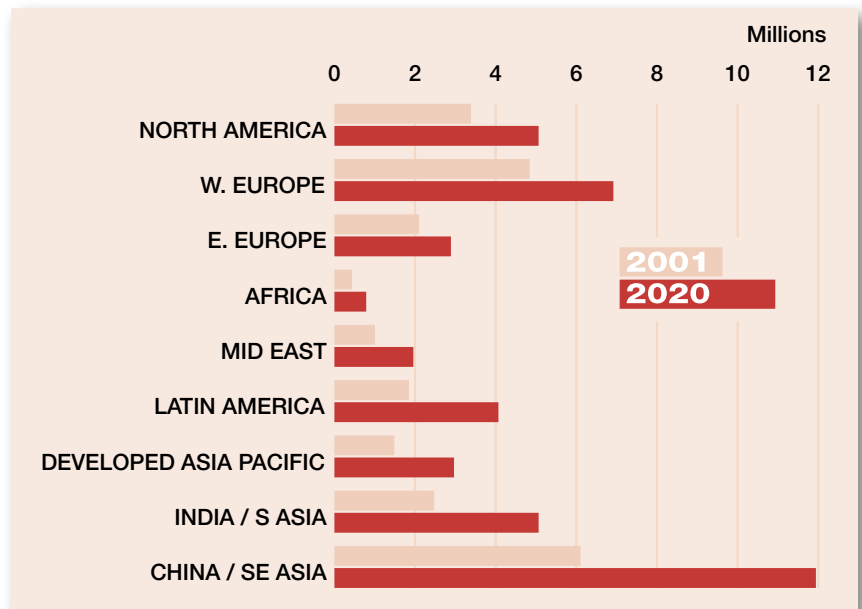
The 10/66 Research Programme

Dementia affects 24 million people worldwide, two thirds of whom live in low and middle income countries. In those regions people with dementia are often terribly neglected: with limited access to health and social care, and very little research into their needs. Since 1998, the 10/66 Dementia Research Group has been working to put the spotlight on these forgotten millions. From ten centres around the world, researchers have been collecting information to present policymakers with an accurate picture of the extent of the problem, its causes and consequences, and in particular the care needs of people with dementia.

ADI report on the global impact of dementia

In December 2005 an ADI sponsored report published in the Lancet announced that a new case of dementia arises every seven seconds. 24.3 million people currently have dementia doubling every twenty years to 81.1 million by 2040. The rate of increase is predicted to be three to four times higher in developing regions than in developed areas. By 2040 there will be as many people with dementia in China alone as in the whole of the developed world put together.

Projected increase in numbers of people with dementia, 2001 – 2020



10/66 Dementia Research Group awarded major new Wellcome Trust grant

In March 2006 we received the exciting news that 10/66 had been awarded a programme grant by the Wellcome Trust for £1.5 million (US\$3 million) to follow up 16,000 participants from the 10/66 population-based studies in China, Mexico, the Dominican Republic, Cuba, Peru, Argentina and Venezuela. This will allow us to identify possible risk factors for developing dementia, including cardiovascular health, poor diet and genes. We will also be trying to understand more about differences in rates of dementia, mortality, stroke and depression across countries and cultures. We will keep you posted on our progress.

Editorial

Professor Martin Prince
10/66 Director



Eight years ago, when 25 investigators from all over the world gathered at the ADI conference in Cochin, India, I had no inkling that, by 2007, we would

be working together on a project of this scale. This has happened mainly because of the dedication and hard work of our Principal Investigators and research groups in the 18 low and middle income countries where we have been working. Their enthusiasm stems from a commitment to the cause of raising awareness through research,

and from a shared recognition that working together we are much more than the sum of our parts. However, the biggest and most important task still lies ahead. Our evidence, and all of the hard work that has gone in to collecting it, will be wasted unless we can get key messages across effectively to those with the power to make a difference – governments, policymakers, health and social care professionals, Alzheimer associations and other advocacy groups. Health and welfare systems need to reform, and quickly, to ensure that the growing numbers of older people with dementia receive proper care and support. 10/66 had a successful meeting in Bellagio in April 2006, planning our dissemination strategy. This includes a 'short list' of 40 papers for submission to scientific journals the first of which should be appearing this year. However,

successful dissemination needs to happen locally, regionally and internationally and needs to target public awareness and policymakers, not just the readers of scientific journals. This newsletter is a key part of our dissemination plan. It will be distributed to an extensive list of stakeholders. Each 10/66 project centre will also produce its own newsletter for local communities and national stakeholders. We are forging links with policymakers in each of the countries where we are working. We will be producing regular policy briefings on key topics of interest arising from our work. These, together with project newsletters and other information about our work, will be made available on the new 10/66 website. Do join with us – spread the word, give us your feedback, contribute to the debate.

My career in the 10/66 Dementia Research Group

Jotheeswaran Thiyagarajan

Two years ago, I graduated in psychiatric social work from Loyola College in Chennai, India. My very first job was as a research assistant for the 10/66 project. Each day for 15 months I travelled to the study catchment area on my old motorcycle. I personally carried out 400 of the 1000 interviews completed in my centre. I learnt a lot about the lives of older people in this semi-urban district. Older people in India demand and receive a lot of respect, so I was not confident to begin with about building rapport. In time, I realised that most older people were open and easy to engage – the study went well, with high levels of participation. I witnessed a lot of hardship, and plenty of older people living with physical and mental health problems including dementia. I also saw many examples of healthy ageing. I wanted to learn more, and

determined to develop my research interest in ageing and dementia in my country. I was promoted to be co-coordinator of the project in Chennai. Prof Krishnamoorthy (the 10/66 principal investigator in Chennai) encouraged me to participate in research conferences and I won an 'outstanding young researcher' award in the Neurosciences India Group Annual Courses in Clinical Neurosciences. Then, with Profs Krishnamoorthy and Prince, I applied successfully to the Wellcome Trust, a UK-based biomedical research charity, for a Training Fellowship. I am now attending a Master's Degree at the Institute of Psychiatry, King's College London. I am learning all the technical skills of research design, data management, and data analysis that I will need in my future career, and writing research papers from the Chennai study, which we hope to publish later this year. When I return to India, I will

have 18 months more funding from the Wellcome Trust to follow up all those with dementia and cognitive impairment from the baseline survey. We aim to find out how dementia progresses, and also to understand more about the apparent low level of

awareness among relatives of older family members' memory problems. Perhaps we are not asking the right questions to identify impairment? Perhaps people with early dementia are really not impaired, because they get high levels of support and care from family members? I am looking forward to contributing to our understanding of these problems in our community, while developing my career as an Indian social science researcher.



Work of the 10/66 Dementia Research Group



Pilot studies (1999-2001) in 26 centres in Latin America and the Caribbean, Africa, India, Russia, China and SE Asia:

- demonstrated the feasibility and validity of a one-stage culture and education-fair diagnostic protocol for population-based research – the '10/66 Dementia diagnostic algorithm' (published in the *Lancet* in 2003)
- indicated high levels of caregiver strain in all world regions – the first such data from developing nations
- showed that Behavioural and Psychological Symptoms of Dementia (BPSD) were little understood and particularly difficult for caregivers to manage
- led to the development of a simple structured 10/66 caregiver intervention, for use by community health workers, educating the family about dementia, and training the caregiver to deal with behavioural problems.

Population-based studies (ongoing from 2002) in India, China, Cuba, Brazil, Dominican Republic, Peru, Mexico, Argentina, Venezuela and Nigeria:

- will recruit over 20,000 participants in 10 countries, making this one of the largest ever international studies of health and ageing
- are providing information on the prevalence and impact of dementia, including care needs, health services and economic costs
- will give a comprehensive picture of the lives of older people in the 10 countries, with much information on general health (cardiovascular risk factors, stroke, heart disease, diabetes, depression) as well as lifestyles, disability, living arrangements and social and economic circumstances
- are funded by the Wellcome Trust, the US Alzheimer's Association, the World Health Organization and FONDACIT (Venezuela).

News from the 10/66 centres

Spreading the word

In this section we aim to keep our readers up to date with what happens in our centres worldwide. One centre will contribute in each new issue. We hope to tell the 'back-story' behind the data – the ups and downs for the investigators and research workers; older people's lives and experiences; the villages, towns and cities where they live; their culture, habits and traditions. These are at the heart of the 10/66 programme.

10/66 operates locally and thinks globally. Our local centres have been busy engaging with the communities where the research was carried out. Daisy Acosta organised a community meeting in Santo Domingo, Dominican Republic. Poverty and income insecurity were key issues. One 85 year old lady, divorced and with no pension or family support, told of how she sold bottled water in the street to survive. How would she manage, she asked, were she to fall ill?

In Peru, Mariella Guerra organised a meeting with key stakeholders; community leaders, doctors, social workers, fire chiefs, Alzheimer association staff.

News media can be targeted to spread the message more widely; in Dominican Republic the 10/66 study made front page news in the national paper *Listin Diario*. The Peruvian national newspaper *El Comercio* reported on the 10/66 studies in Peru and other Latin American countries. In Argentina, Raul Arizaga had the opportunity to explain on national television the origins of the name 10/66, and the need for more preparation for the coming epidemic of Alzheimer's disease in that country. These are all major achievements given the very low prior levels of awareness and attention to the topic.

10/66 Dementia Research Group members

COUNTRY	PRINCIPAL INVESTIGATOR
Argentina	Raul Arizaga
China	Yueqin Huang
Cuba	Juan de Jesus Llibre Rodriguez
Dominican Republic	Daisy Acosta
India, Chennai	ES Krishnamoorthy
India, Vellore	Prof KS Jacob
Mexico	Ana Luisa Sosa-Ortiz
Nigeria	Richard Uwakwe
Peru	Mariella Guerra
Russia	Natalya Mikhaylova
Venezuela	Aquiles Salas
United Kingdom, co-ordinating centre	Martin Prince, Cleusa Ferri, Renata Sousa, Emiliano Albanese

Key messages from the Berlin ADI conference

At this year's ADI conference in Berlin, we had the opportunity, in two plenary presentations, to speak directly to ADI's member associations, and the wider ADI family of carers, professionals, people with dementia, and researchers. With complete data from India, China, Cuba, Dominican Republic and urban Peru (12,800 older participants in all) there was plenty to discuss.

The prevalence of dementia

- We may have been underestimating the prevalence of dementia in developing countries, which in the 10/66 studies is generally similar to that in the developed world. This has important implications for numbers of people affected in those regions

Needs for care

- Dementia accounts, independently, for one third to one half of 'needing much care' – it is much more important than physical health problems

Caregiver strain

- Living with a person with dementia is strongly associated with caregiver psychological strain, and is much more stressful than care of an older person with physical health problems
- Caregivers of those with dementia are 3 to 5 times more likely to suffer from depression

Help-seeking from health care services

- Unlike physical health problems, dementia does not predict use of health care services (in some centres, people with dementia are actually less likely than others to receive care)
- Barriers to accessing health care for people with dementia include:
 - More advanced cognitive impairment
 - Older age
 - Poverty

Building research capacity

In every 10/66 centre there is now a core group of young researchers, experienced in the methodology of population research and in the clinical assessment of dementia and other mental disorders. The scale of the project has raised the profile of dementia research in universities. Local clinicians also are taking more interest in older people's health. 10/66 data belongs to the local centres, who are encouraged to analyse and disseminate it in international and regional journals. The pooled data from all centres will be kept in a data sharing archive. The Wellcome Trust has funded seven PhD studentships, for one student from each centre to work in London and in their own country, analysing data from all centres. At the end of their studies they will receive a University of London PhD. One of the first of these studentships has been awarded to Dr Zhaorui Liu, from Peking University Institute of Mental Health, working on comparisons of the economic cost of dementia between centres. Zhaorui Liu will be visiting London in the next few months with her colleague Dr Yan Fang to plan her studies, and to work on four new papers from the Chinese centre covering rural-urban differences, the randomised controlled trial of the caregiver intervention, the evaluation of the health worker 'casefinder' procedure and the validation of the 10/66 dementia diagnosis.



The 10/66 China team (from left) Dr Weimin Dang, Prof Yueqin Huang, Prof Martin Prince, Prof Li-Shuran, Dr Yan Fang and Dr Zhaorui Liu

How to contact us

10/66 Dementia Research Group
Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, UK
Tel: +44(0)20 7848 5072 Fax: 020 7277 0283
Email: 1066drg@iop.kcl.ac.uk or go to our website at www.alz.co.uk/1066

Alzheimer's Disease International
64 Great Suffolk Street, London, SE1 0BL
Tel +44 20 7981 0880
Fax +44 20 7928 2357
Email: info@alz.co.uk

