10/66 Dementia Research Group

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

African ancestry: a protective factor for dementia?

Cuba: the waiting room of a local lab for blood and DNA tests

In the National Institute of Aging US-Nigeria study, older Nigerians have a low prevalence and incidence of dementia, and the genetic risk factor APOE e4 seems to be less powerful. Could this be because West Africans are genetically protected?

This is the hypothesis that the 10/66 Dementia Research Group will test in the various 'admixed' populations included in the network. In Cuba, Dominican Republic, Mexico and Venezuela, African and Caucasian (European) populations have intermixed over at least four centuries. In some of these centres, particularly Peru, many participants have significant native American ancestry. Using recently developed genetic techniques, typing 60 SNP genotypes that are very differently distributed between the three

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The 10/66 10th anniversary celebrations: all welcome!

The 10/66 Dementia Research Group was born in India in 1998. We have successfully completed pilot studies in 26 centres worldwide, and population-based studies in seven Latin American countries, India and China. Twenty-six 10/66 publications have appeared in peer-reviewed scientific journals. We continue to work closely with ADI, to provide the evidence on the impact of dementia, the needs of people with dementia and their caregivers.

We will celebrate this anniversary 26-28 August 2008, during the IMH conference 'Mental Health for All, Young and Old'.

http://www.iop.kcl.ac.uk/virtual/?path=/international/conference/

Helping carers to care

The 10/66 'Helping carers to care' intervention is to be made available across the ADI network

At the ADI conference in October 2007 we ran a successful workshop on the 'Helping carers to care' caregiver education and training intervention. We heard about the development of the intervention package from Dr Cleusa Ferri and Dr Daisy Acosta, and its implementation in India (Dr Amit Dias), Peru (Mariella Guerra), Venezuela (Dr Aquiles Salas and Raul la Rosa). The intervention consists of five sessions, each lasting 30 minutes to one hour. The intervention is simple (designed to be administered by community health workers and volunteers) but effective. Our first randomised trials, in India and Russia, suggest clear benefits for the caregiver and possible additional benefits for the person with dementia. We were touched, at the Caracas workshop, to hear the very personal story told by Carmen Hernandez de Marcano and her caregiver Servia Marcano who both felt that they had been helped by the intervention, and by their contacts with Raul la Rosa from the Venezuela 10/66 team.

We are very pleased to announce that ADI has now raised funds to make the 'Helping Carers to Care' intervention more widely available in four cultural versions – for China and SE Asia, for India and south Asia, for Africa and Latin America – and in five languages; English, Mandarin, Spanish, Tamil and Hindi. The materials will include a training film, training packs, an intervention manual and information packs for the caregivers.

See the editorial by Dr Nori Graham on page 2.

Editorial

Dr Nori Graham

ADI and 10/66: a ten year partnership

Alzheimer's Disease International (ADI) aims to raise world awareness about dementia and its impact on families mainly through helping to establish and support national Alzheimer Associations, currently seventy seven in number. Accurate, scientifically established information of prevalence is immensely valuable in the raising of awareness about dementia. It greatly assists national associations to advocate effectively to professionals, policy makers and governments for resources to meet the needs of people with dementia and their carers. Further, the need for symptoms to be recognised, for proper assessment and diagnosis, and for support services can only be made when precise prevalence figures are available. In addition, countries need to have data on the patterns of care in their own countries so that carers can be helped in ways appropriate to their culture.

Nearly ten years ago ADI decided to support the 10/66 team led by Professor Martin Prince. This team, now generously funded from a variety of sources but initially given seed-corn funding by ADI has since carried out high quality studies of the prevalence and impact of dementia in ten low and middle income countries (China, India, Nigeria, Cuba, Brazil, Dominican Republic, Venezuela, Mexico, Argentina, and Peru). The team has now completed studies of prevalence, impact, health service utilisation, and risk factors in eight developing countries.

The methodologies used by the 10/66 investigators have enabled them to make comparisons between low-income and high income countries with great confidence. At the recent ADI conference held in Caracas in October 2007 new prevalence figures were announced that suggested that there has previously been a major underestimate of the prevalence of dementia in low income countries, perhaps because, in traditional settings, family members are accepting of cognitive decline especially in the early stages. It has also become clear that dementia requires as much care in low and middle income countries as it does in those with high incomes.

The 10/66 team carrying out this ground-breaking research has moved on to develop an intervention package, called 'Helping carers to care'. This straightforward package, delivered by community workers, informs carers about dementia and provides them with strategies to manage some of the common associated problems. At the ADI Caracas conference a stimulating workshop reported experiences with this package. Its use has a significantly positive effect on the ability of carers to manage problems and reduce their levels of stress. In 2008, facilitated by ADI through its network of national Alzheimer Associations across the world, high quality translations will roll out this package through videos and manuals translated into local languages (Tamil, Hindi, Mandarin, Spanish, and English). This will represent a fitting achievement in celebration of the tenth birthday of the affiliation of the 10/66 Dementia Research Group with ADI.

My Tepoztlán voyage with 10/66

Gabriela Rojas

When I started working on the 10/66 pilot study my colleagues and I found the application of the 10/66 protocol quite difficult. But our doubts slowly cleared as we progressed with the study. In the beginning we would take several hours to complete the first full 10/66 interviews. We gradually improved and started to obtain better interviews in less time as we mastered the entire instrument.

The first challenge was door knocking. We needed to be trusted and accepted by the elderly people and their families. Actually, in most cases the doors of their homes opened wide for us – the harder task was to leave and move on.

In June 2006, Dr Ana Luisa Sosa, the principal investigator of the Mexican population-based study, offered me the local coordinator post for the rural area of Tepoztlán in Mexico. I accepted at once, moving to Tepoztlán with my newly acquired 10/66 survey skills, relatively little previous experience, and a lot of enthusiasm for the task in hand. Others can judge how well I did, but I am sure that the 10/66 voyage has changed my life.

The most rewarding aspect was that I had to spend a great deal of time with elderly people. I was told their life stories, I listened to their complaints and problems and received many lessons for life. But more importantly I found myself emotionally engaged with each and all of them, and therefore with my job. Throughout the 10/66 field work I have improved professionally and developed personally. Being part of the study has been very satisfactory and stimulating, for my academic, professional and personal development. It has been hard to fulfil the demanding expectations and to sort out the daily challenges, but today I am proud and pleased to be part of the 10/66 Group.

News from the centres

China

China's total population is 1.3 billion (1,321 million). Just over one-third live in cities. 7.9% are aged 65 and over, life expectancy is 71 years for men and nearly 75 years for women. The GDP per capita is $2,042, with considerable inequality between the prosperous cities and poorer rural regions.

The 10/66 survey of 2,162 older people was carried out in urban Xicheng district in the heart of old Beijing, close to Tianmen square (1160 persons) and in rural Daxing, 80 kms outside of Beijing (1002 persons). The field work was carried out by public health doctors from the community health services in the two communities. Those with dementia, and their caregivers were invited to participate in the randomised controlled trial of the 10/66 caregiver intervention – 32 have been completed so far. The trial is to be completed soon in the Fangshan district. The baseline fieldwork in China was sponsored by the World Health Organisation. The three year follow up, starting shortly is sponsored by the Wellcome Trust.

In China, financing, coverage and access to healthcare depends upon where you live. In urban China, government employees benefit from the comprehensive Governmental Insurance Scheme (GIS) which covers around 90% of all costs including consultations, admissions and medications. Public and private company employees benefit from the Urban Employee Basic Health Insurance Scheme (BHIS) cofunded by employers and workers. Children and retired people can join the BHIS with a personal annual contribution of 50 to 300 Yuan. This covers around 80% of costs (60% for children and retirees), after the patient has paid the first 1,500 Yuan (about 200 US $). Discounts are available for poor people, those with mental disorders, and retirees.

Prof Martin Prince and the local team in Daxing, the rural town where over 1,000 participants were interviewed at baseline

Xicheng, China: Announcing the 10/66 study on the BuGaoLan, the street notice board

In rural China, the government contributes to a common fund which covers health care costs but only proportionate to the amount contributed by the individual. Rough estimates suggest that nearly 70% of rural Chinese do not have any meaningful health insurance. China's estimated 500,000 unemployed people also fall through the net, but this problem is to be addressed in a new reform from mid 2008.

Pension coverage in China is mostly limited to employees of the state-owned firms in urban areas (who receive 60% of final salary on retirement). This excludes most of the two-thirds of the Chinese population living in the countryside. According to the National Bureau of Statistics (NBS), only 46% of urban employees were covered in 2004, but the figure is only 11% for rural areas. Those who were unemployed or working in the informal sector receive no pension. Social protection for older people in China is under threat, as

1) the population ages rapidly,
2) there are fewer children available to care (the 'one child policy'),
3) fewer people work in state owned enterprises
4) pension provision in the private and informal sectors has been slow to develop.

Our survey findings reflected some of the stark urban/ rural differences outlined above. In Beijing most older people benefited from retirement pensions. Very few rural Daxing residents had pensions; the overwhelming majority lived with, and were supported by their children. In contrast, 46% of people with dementia in Beijing were looked after by paid carers, the highest proportion in any 10/66 centre. In rural Daxing only 7% of participants (as opposed to nearly 40% among the urban sample) had used any health care services in the previous three months. Cost and distance (the long trip from their village to the health centre in the town) are likely to have been barriers.

Dementia prevalence. In the 2005 ADI consensus we estimated 5,980,000 people with dementia in China (Ferri C. et al. Lancet 2005). Our 10/66 survey results, weighted back to the China urban/ rural population distribution, suggest a much smaller number of DSM IV dementia cases (2,730,000) but a very similar figure of 6,370,000 applying our previously validated 10/66 dementia criterion. 10/66 dementia is broader and more inclusive than DSM IV, tending to include more mild and recent onset cases.

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Dr Ana Luisa Sosa Ortiz – 10/66 Mexican principal investigator

African ancestry: a protective factor for dementia?

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source populations we can estimate the proportion of each participants' genome that derives from African, European and native American ancestors.

In November 2007, Professor Juan Llibre Rodriguez from the Medical University of Havana and Dra. Beatriz Macheco Teruel Director of National Center of Medical Genetics came from Cuba to London to join Prof Paul McKeigue (University of Edinburgh) and 10/66 investigators to analyse the effect of ancestry upon dementia, stroke and cardiovascular risk factor profile. The results were interesting and informative. These will be presented at conferences, and published in peer-reviewed scientific journals as soon as possible.

Building research capacity – 10/66 PhD studentship

Dr Ana Luisa Sosa Ortiz is the principal investigator of the 10/66 project in Mexico. She is the head of the Cognition and Behaviour Unit at the National Institute of Neurology in Mexico City. Dr Sosa is one of the recipients of the seven PhD studentships funded by the Wellcome Trust. She recently finished her first three month visit to the Institute of Psychiatry in London, as part of her studies. The theme of her PhD is Mild Cognitive Impairment (MCI) and the early diagnosis of dementia in Low and Middle Income Countries (LAMIC). The identification of people at higher risk of evolving towards Alzheimer's disease or other dementias is as important in LAMIC as it is in western countries. Early diagnosis can lessen distress for both patient and family, maximize health and wellbeing, and prolong autonomy. It can assist caregivers and the whole family in planning future care arrangements and financial matters. Dr Rob Stewart and Dr Emiliano Albanese will supervise Ana Luisa's activities both in London and from distance. Dr Sosa is a leading academic in Mexico, in the next three years she will develop specific transferable skills beyond completing a University of London PhD. Ana Luisa's entire research group in Mexico will benefit from her experience as well as the 10/66 follow up study which is about to start in her country.

The 10/66 Dementia Research Group at international conferences

Past events

- In October 2007 over 50 10/66 researchers were among the 700 attendees at the **Caracas** ADI conference. Our one plenary and seven parallel session presentations and four posters will shortly be made available for download on the new revised 10/66 website.
- We presented our findings in an invited keynote lecture at the World Psychiatric Association Conference in **Melbourne**, Australia, on 30 November and in **Kyoto**, Japan, in October 2007 at the International Psychogeriatric Conference.
- The 10/66 DRG research program was presented at the recent Institute of Psychiatry, KCL, Health Service and Population Research Department Open Day, held in **London** in February 2008.

Forthcoming events

- The 6th Meeting of Alzheimer Ibero America in **Buenos Aires**, 6–8 August 2008.
- The ICAD – the 11th International Conference of Alzheimer's Disease and Related Disorders – **Chicago**, Illinois – 26 to 31 July 2008.
- The WPA epidemiology conference (11–14 May 2008) in **Saskatchewan**, Canada.
- The World Epidemiology Conference (20–24 September 2008) Porto Alegre, **Brazil**.

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