

Az 10/66 Dementia Research Group

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

Follow-up phase of 10/66 study is up and running!

Results from the follow-up study will provide sound data on incidence (new cases), risk factors and the impact of dementia and other chronic diseases among older people living in the community.

The second wave of the 10/66 population-based study is well under way in most of our centres:

CHINA In November 2008 Prof Yueqin Huang from Peking University, the 10/66 principal investigator for China, launched the local incidence phase of the 10/66 population-based study. The training sessions were held in Daxing, Beijing in November 2008.

CUBA Prof Juan Llibre Rodriguez coordinates the Cuban centres. He recently published a book on

dementia in Cuba (thousands of copies have been distributed across the country), presenting the results from the baseline study. Since 2006 the Cuban team engaged and

kept in contact with the participants on several occasions and over 95% of those who took part in the baseline phase of the study, were easily traced and re-interviewed. Professor Llibre started training his team back in June 2008, using the new study manual and the videos. Nearly 1,000 interviews have been carried out to date.

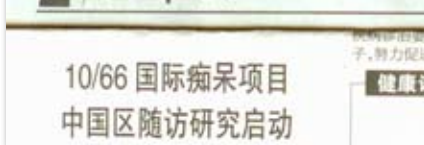
INDIA Under the supervision of Dr Joseph Williams, Mr AT Jotishwaran, Indian study coordinator, has successfully traced and interviewed participants *Continued page 2...*



Santo Domingo (DR) – Guillermina Rodriguez (study coordinator – left) and Daisy Acosta (principal investigator – right) visit at Christmas Ms Irene Arias Jimenez who was diagnosed with dementia at baseline



ABOVE The 10/66 Chinese team



LEFT The commencement of the follow up study was announced in the prestigious *Health News*, China's leading newspaper in the health field

DETAILS OF THE FOLLOW-UP STUDY

Country	Participants at baseline (response rates %)	Participants with 1066 dementia (%)	Follow up interviews carried out to date
Cuba	2934 (0.94)	316 (10.8)	916
Dominican Republic	1999 (0.95)	235 (11.7)	160
Peru	1927 (0.84)	165 (8.5)	1,000
Venezuela	1939 (0.80)	140 (7.1)	(started in March 09)
Mexico	1997 (0.85)	171 (8.5)	160
China	2162 (0.85)	137 (6.3)	23 (2,000 traced)
India	1998 (0.85)	181 (9.0)	200 (1,000 traced)

Follow-up study

... continued from page 1

diagnosed with dementia or cognitive decline at baseline. The preliminary data analysis is encouraging and once again confirmed the operational validity of the 10/66 diagnostic algorithm.

MEXICO Dr Ana Luisa Sosa and her team are re-interviewing participants. They started off with those who received a diagnosis of dementia at baseline.

PERU Dr Mariella Guerra, the local principal investigator, trained her team and started the follow up study in Autumn 2008. Hundreds of participants have been traced and re-interviewed both at the urban and rural centres.

VENEZUELA Dr Aquiles Salas, principal investigator, and his team are about to go back to the field in Caracas. Has carried out the training for his team on the study protocol for the follow up phase of the study.

NEWS

New release of the 10/66 baseline dataset

Version 2.0 of the 10/66 dataset is now available along with the complete list of labelled variables. This is the most advanced and definitive version of the 10/66 baseline data, fully accessible through our website (www.alz.co.uk/1066). This dataset represents a major improvement to our public archive, and is available for secondary analyses and open to internal as well as external investigators.

A Cloud at Twilight

A touching 10/66 Chinese movie on dementia



The 10/66 Chinese centre has produced and realized a movie on dementia to raise awareness of the disease in the general public. The movie tells the story of Professor Xueruan Xiao and his family, from his initial memory problems through the behavioural and psychological disturbances associated with dementia. An impressively realistic, touching and intense piece of art, realized under the close scientific collaboration and supervision of Prof Yueqin Huang and Dr Zhaorui Liu from the Institute of Mental Health, Peking University, and Prof Martin Prince from the Institute of Psychiatry, in London.

The movie is a pleasant drama which will greatly benefit 10/66's aim of dissemination. It also provides a vivid and sound introduction to dementia and its features and characteristics to the extent that the 10/66 Chinese team uses this movie at the commencement of the training course of the caregiver education and training intervention.

You can watch the movie trailer on the 10/66 website (www.alz.co.uk/1066).

The oldest 10/66 participant: 108 years



Angela Castillo Flores lives in San Juan, a remote village high up in the sierra in Mexico

Martin Prince visited Ana Luisa Sosa and the rest of the Mexican 10/66 team in December 2008. Ana Luisa and her four dedicated research staff, Gaby, Lic.Isaac Acosta, Tirco and Nijelli, have recruited over 2000 older people to participate in the 10/66 survey in Mexico City and surrounding rural areas. The urban catchment areas (Isidro Fabela, Santo Tomas Ajusco and Villa Coapa) were all in Tlalpan, a district in the south west of Mexico City. The rural catchment areas were all in the state of Morelos, between Mexico City and the state capital of Cuernavaca. These comprised the country town of Tepoztlan and nine smaller towns and villages – Tres Marias, Huitzilac, Amatlan, Coajomulco, Fierro del Toro, Ocotitlan, San Andres, San Juan, Sta Catarina. Several of these communities were high up in the Tepoztlan Sierra. The response rates were very high for the surveys – 84% of the older residents in Tlalpan and 86% of those living in rural Morelos agreed to take part in the study. Over 1700 donated a blood sample.

Angela Castillo Flores pictured here, lives in San Juan, a remote village high up in the sierra. At 108 years of age, she is the oldest surviving participant in the 10/66 studies, and remains in reasonably good health. She lives with her daughter and son-in-law in a small shack, filled with dense smoke from the wood fire in the living room. Her daughter fractured her hip last year. She endured a difficult car journey to the hospital, and the whole family had to club together to find the fees for the operation – medical insurance is a rarity in the rural Mexican site.

10/66 Dementia Research Group

How we work

10/66 Randomised Controlled Trials to test the effectiveness of the 10/66 intervention 'Helping Carers to Care' Mental and neurological disorders, including dementia, are highly prevalent and burdensome globally. The gap between what is needed and what is available to reduce the burden of both people who need care and their carers is very wide. Worldwide, most of the care of people with dementia is provided by family members and friends; and this is especially the case in low and middle income countries.

There is an urgent need to fill the gap between what is needed and what is available at present. The World Health Organization has launched the Mental Health Gap Action Programme (mhGAP), a global initiative to scale up services for mental, neurological and substance use disorders especially for countries with low and middle incomes. The 10/66 Dementia Research Group is carrying out a series of randomized controlled trials (RCT) to test the efficacy of the 10/66 intervention 'Helping Carers to Care' to contribute to fill this gap.

What is a Randomized Control Trial (RCT)?

Before an intervention can be widely used, it must be proved that it works. An RCT is an experiment to test if an intervention (typically



Dr Ana Luisa Sosa, 10/66 principal investigator, and her team on the Randomized Control Trial in Mexico city

a drug) is effective. Participants in a given population are randomly allocated to groups to receive or not the intervention under study. Health characteristics of participants in the two groups are compared before and after the intervention is delivered to determine to which extent the treated group may have benefited from receiving the intervention.

In which stage are we with the 10/66 Caregiver Intervention RCTs?

The 10/66 Dementia Research Group has now completed several RCTs in Russia, India, China and Latin America. The results for Russia

and India have been published in scientific journals and are very encouraging. The 10/66 intervention seems to benefit the caregivers, alleviating their distress and improving their quality of life. The experiments in Dominican Republic, Peru, Venezuela and China have been concluded and Mexico is on its way. We are now analysing the data and combined results will be available soon.

Details about the 10/66 intervention 'Helping Carers To Care' can be found on our website (www.alz.co.uk/1066) along with the complete study resources and materials.



Help needed for the activities of daily living



Dependency on family members and caregivers



Examples of forgetfulness especially of recent events and names

Cartoons are used to display typical situations that the caregiver faces and has to deal with. We produced different series to be used within different cultures. These three are from China.

Keep up-to-date with 10/66 publications

So far the 10/66 group has published:

- eight method
- six validation
- five prevalence
- six caregiving
- four health care
- two RCT papers.

Several more are under preparation. Get access to our website to learn more about our publications (http://www.alz.co.uk/1066/1066_publications.php) and our plans for the near future.

NEWS

Training video now available to 2/3rds of the world

Important progress has been made to make 'Helping Carers to Care', the 10/66 education and training intervention, widely available. The intervention manual, training and information packs for the carers are available in English, Spanish, Tamil and Mandarin. Also, a new Chinese training film now complements the existing English and Spanish versions. Watch the previews on the 10/66 website (www.alz.co.uk/1066).

Building research capacity

The 10/66 office is very busy in these early months of 2009.

Professor Juan J Llibre Rodriguez, principal investigator of the 10/66 Cuban centre, spent 3 months in London to work on a number of papers using the data generated from the Cuban DNA samples. In particular he will work with Prof Martin Prince on APOE genotypes and lipid profiles, stroke and dementia.



Prof Llibre and Dr Liu in London

Dr Zhaorui Liu, the 10/66 Chinese study coordinator, stayed 3 months in

London to carry on her work on costs of dementia. She is attending statistical and methodological courses at King's College London (KCL) while working on a couple of important papers for her PhD.

Mr AT Joteeswaran from India spent three months in London after having completed the field work in Chennai. He is currently working on a number of papers including the prospective validation of the 10/66 diagnosis of dementia and all causes of mortality. Also, Mr Joteeswaran has been awarded a prestigious full funded PhD fellowship by the Public Health Foundation of India and the Wellcome Trust. He will conduct his PhD on chronic diseases amongst the elderly in India with a particular focus on mental health and dementia.

Dr Ana Luisa Sosa from Mexico and Dr Mariella Guerra from Peru (10/66 principal investigators in their countries) are studying for their PhDs on early diagnosis of dementia and late life depression respectively. Early in 2009 they have obtained their PhD upgrades from the Institute of Psychiatry, KCL.

Miss Renata Sousa has completed and submitted 2 manuscripts on disability/ dependency as part of her PhD.

EVENTS

ADI Conference

Singapore, 25-28 March 2009. The 10/66 group held a workshop *Understanding and using research for advocacy through the ADI associations*

IFPE 16-19 April 2009 Vienna, Austria. M Prince presented the promising 10/66 results on prevalence of dementia subtypes in low and middle income countries

ICAD 11-16 July 2009 Vienna, Austria. Dr Cleusa Ferri and Prof Martin Prince have been invited to talk about numbers of people with dementia worldwide and caregiver interventions respectively

International Psychogeriatric Association (IPA)

1-5 September 2009 – Montréal, Canada

World Psychiatric Association (WPA)

Nigeria, regional meeting: 24-26 September 2009

How to contact us

10/66 Dementia Research Group
Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, UK
Tel: +44 20 7848 5072 Fax: +44 20 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

