The Reminiscence Tea House

David Truswell, Mary Leung, Tom Lam and Gill Tan describe the development of the Reminiscence Tea House project, challenging stigma and providing peer support and information for the UK Chinese community.

China has the largest number of people with dementia in the world (Chan et al 2013) yet much of this goes undetected. One recent study argues that as much as 90% of dementia cases in China are undetected (Chen et al 2013). The stigma surrounding dementia in the Chinese community is severe (Liu et al 2008; Elliott et al 1996), creating additional emotional burdens for people living with dementia and their carers who do not understand the illness and are afraid of asking for help or who feel services will not be available if they ask.

For migrant Chinese in the UK this cultural stigma prevents people seeking help and advice from within the UK Chinese community. Fear and suspicion of mainstream health services and the lack of understanding of Chinese patients in those services, including their language support needs, increases the reluctance of Chinese people to seek help from the NHS.

Eddie Chan, chief executive of the Chinese National Healthy Living Centre (www.cnhlc.org.uk) has many harrowing stories of people from the Chinese community in London living with dementia or caring for those who live with dementia who struggle for many frightening years in isolation, not understanding what is happening, afraid to mention their fears within the Chinese community and afraid to approach mainstream services.

The Chinese National Healthy Living Centre, located in London’s Soho, has been providing health-related services and advice to Chinese migrants in the capital since 1987. There are 500,000-600,000 Chinese people living in the UK.

Project overcame language barrier

Mrs Y is a lady in her nineties in the early stages of dementia who was more and more reverting to her native Cantonese. She lived on her own in London. Her grandchildren lived outside the capital and were very worried about her, but they were unable to communicate well with her as they mostly spoke only English.

The dementia peer support and information project helped the grandchildren to get support and carers’ training from the Alzheimer’s Society while Mrs Y herself got a Chinese boh RL with help from the local Chinese community centre. Respite care in a nursing home was made available to her after she fell and broke her arm at home.

Now the project is helping Mrs Y and her grandchildren to look for a permanent nursing home with other Chinese residents. In this way the project has taken a different guidance and support role with each party, namely the grandmother, the grandchildren and the various voluntary and statutory agencies.
and 50% live in Greater London. The centre also has a national profile in promoting healthy living and improving access to health services for Chinese people across the UK, having established working links with local health providers. But developing dementia awareness and support is the next big step and it became possible to contemplate taking it when the centre was successful in obtaining funding over three years from the City Bridge Trust in London.

Challenge of stigma
Dementia is highly stigmatised in Chinese society with the traditional term for dementia having connotations of mental illness and stupidity (Loo 2014). The Chinese medical profession has recently stressed the need for a new term to reduce stigma and encourage people to present earlier for diagnosis. The derogatory term used for dementia in the Chinese language and the very low level of diagnosis of dementia in China are indicators of the profound stigma associated with the disease and the lack of familiarity Chinese people have with providing understanding support for those living with the disease. It is mistaken to assume that Chinese immigrants arrive with a culturally ingrained sense of filial duty towards family and community elders with dementia honed by decades of intergenerational experience. This is not the case: the Chinese history of dementia is of a shunned disease with little acknowledgement in their culture. Chinese people form one of the most dispersed of the minority ethnic communities in the UK, with support networks strongly focused on family ties. Support networks of the kind found in other ethnic groups, in churches, temples, synagogues, mosques and gurdwaras, are less in evidence. Community centres are relatively rare and people often travel some distance to attend centres outside the area they live in.

UK Chinese are much more heterogeneous in origin than is generally appreciated with Chinese merchant seamen settled in English ports such as London and Liverpool since the late 19th century. Subsequent waves of Chinese migration through the 20th century include those from former British colonies such as Hong Kong, Malaysia and Singapore in the 1950s and 1960s, the Vietnamese refugees of the 1970s and 1980s who were chiefly ethnic Chinese migrants, and the mainly mainland Chinese from the 1990s onwards. These migrant waves include populations with very different social backgrounds, skill sets, educational attainment, language skills and social aspirations.

The cultural stigma associated with dementia has to be set alongside a common distrust of health services arising from political coercion in these countries of origin. Some migrants have fled countries that used mental health services as a vehicle to suppress political dissent. It is well known that lack of understanding and stigma result in late presentation to services of people living with dementia from black and minority ethnic communities (Moriarty et al 2011).

Compounding the physical
health complexities that have often developed by the time dementia is diagnosed, Chinese migrants may have further issues that can include language and communication problems more complex than the simple need for an interpreter. For example, they may never have spoken English or be able to speak their formerly fluent English only in a fragmented way. They may have never been literate in Chinese script and have had little contact outside

the non-Chinese community during their time here due to long and unsocial hours working in the catering or garment industries. Their children, who were brought up here and are attempting to care for them, may not speak any Chinese language so that an additional barrier is put up.

Chinese solutions to dementia’s challenges

The Chinese National Healthy Living Centre has connections with the Chinese medical community internationally and has Chinese speaking clinicians working in senior roles in the NHS in its steering group. Bilingual and trilingual volunteers and staff in the centre’s dementia project reflects the diversity of the target group. Chinese and European medical practice are both employed by the centre, which has links with London based NHS trusts such as Central and North West London NHS Foundation Trust. The Dementia Peer Support and Information Project, to give it its full name, is the largest scale undertaking of its kind that we know of in the UK, and from the outset the intention has been to build on learning from previous experience. The Alzheimer’s Society Connecting Communities Project (Alzheimer’s Society 2013), Tom’s Club in Haringey (Innovation Health and Wealth 2012) and the Race Equality Foundation’s recent work in raising dementia awareness in black and minority ethnic communities (Clayton et al 2013; Truswell 2013) have informed the project’s development.

The first priority of the project has been to establish a dignified Chinese term for dementia and a simple, high-quality information leaflet in Chinese explaining dementia. The term that the project has settled on is a combination of Chinese characters producing a word in Chinese ‘Tui-zhi-Zheng’. ‘Tui’ means decreasing or decline; ‘zhi’ can be explained as the ability to think or remember things, and ‘Zheng’ means disease or syndrome. Rather than invent its own leaflet, the project has adapted one entitled Defeating Dementia by Alzheimer’s Research UK.

By starting with a reputable and easily available poster in English, the project has been able to concentrate its energies on the quality of the translation, something that involved having the Chinese version translated back into English as an additional check. A benefit of taking this degree of care has been that it has led to Alzheimer’s Society to review the information it had previously translated into Cantonese.

The leaflet and the new term for dementia have formed the backbone of an outreach initiative in which a series of workshops have been piloted to offer information and support:

Next steps for the dementia project

Over the three years, the project aims to ensure:

- the stigma attached to the illness in the Chinese community lessons
- through enhanced awareness more Chinese people benefit from early diagnosis
- Chinese care in London receive structured peer support and are attached to a learning network
- Chinese people with dementia see an improvement in the quality of their lives
- better understanding of dementia, partly by working with Chinese and UK media, and partly by promoting use of the new translation for dementia ‘Tui-zhi-Zheng’

in a number of London boroughs. These outreach sessions have, in one case, been turned into a regular themed event at a community venue in Woolwich, which has been called the Reminiscence Tea House. Indebted to dementia cafés elsewhere in London, the Reminiscence Tea House came about after project volunteers visited them and drew inspiration for delivering practical activities in this way.

As time has gone on the project has realised from participant feedback that they want more information on dementia, a focus on practical activities relevant to Chinese culture and a mixed attendance including both people living with dementia and their carers. So the Reminiscence Tea House has taken the dementia café model but given it a Chinese ‘personality’, for instance by adopting a more psycho-educational influenced approach incorporating traditional Chinese beliefs and colloquial terms to help people...
come to a better understanding of cognitive impairment and to encourage more acceptance.

Presentations on dementia and how the brain works are given by Chinese speakers – both Cantonese and Mandarin are spoken – along with activities and games that are more common in the Chinese community.

The Chinese National Healthy Living Centre has now held its workshops in Lambeth, Camden, Newham, Tower Hamlets, Westminster and Islington while also running professional workshops for NHS, local authority and voluntary sector managers and practitioners. One of the authors, retired clinical psychologist Mary Leung, is working on the development of a Chinese version of the Mini Mental State Examination (MMSE) assessment tool. So far the project has followed up 200 phone inquiries referred by organisations participating in the workshops.

The purpose of the workshops is to show how brain and body functions interact, taking into consideration environmental, behavioural and emotional factors, and why dementia has the consequences it has. They aim to demystify and allay fear of dementia. At the Reminiscence Tea House, each event has been tied to a different theme, such as “how the brain works” and “dementia referral pathways”. Feedback is sought from participants both through simple questionnaires and verbally by asking for responses in Chinese. Having been running in Woolwich for a year now, the project has begun to receive its first reports of an increase in people of Chinese ethnicity being diagnosed with dementia in primary care.

References
Innovation Health and Wealth: Support for carers of people with dementia (2012) Case study - Tom’s Club provides structured therapeutic support in a social setting. NHS Institute for Innovation and Improvement (webpage).

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