

Looming dementia epidemic in Asia

Dementia is increasing fast in Asia placing a huge burden on a growing army of carers, who are mainly family members. Jane Parry and Cui Weiyuan report on how dementia is starting to receive the recognition it deserves.

Yin Jiliang, 73, looked forward to retirement as a time when he and his wife Su Zhiying, 76, could relax and enjoy the fruits of their labour, but instead he has another full-time job – taking care of his wife, who was diagnosed with dementia in 2001.

“Every morning I get up at six, and I prepare myself well before waking her up at seven. The first thing to do is to take her to the toilet. She is no longer able to use the toilet alone,” says Yin. He also helps Su brush her teeth, have a wash, take a walk, eat a meal. Su is unable to do any of these things independently.

“She eats very slowly, about one hour on average per meal. Sometimes I doze off sitting at the table while she has her meal,” he explains. “Every night I set the alarm for 3.30 a.m. to wake her up to pee. Afterwards I often can’t get back to sleep, making sleep deprivation the most difficult thing for me.”

Su is fortunate that her loving husband is able to take care of her, and Yin says their adult children, family and friends are sympathetic and supportive. Living in Beijing, the couple can also receive specialist care at the Dementia Care and Research Centre at Peking University’s Institute of Mental Health. There Yin can tap into a network of others caring for people with dementia.

“It’s nice to get to know and to talk to other relatives and to be able to share experiences with them. Some relatives complain that the partners they take care of are extremely difficult to deal with. In that sense, I am lucky. My wife is the over-happy type and seldom makes any trouble,” he says.

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Huali Wang

China’s population is ageing fast. Life expectancy in China has gone from 68.4 years in 1990 to 73.8 in 2008; combined with the one-child policy this development will lead to a massive demographic shift in the coming decades. The elderly support ratio, the number

of people in the population aged 15 to 64 divided by those aged 65 and above, which was 1:9 in 2010 will become 1:3 by 2050, China’s Population Research Bureau predicts. The proportion of over-65s to China’s total population is estimated to rise from 7.8% in 2005 to 16.3% in 2030, according to data from the Organisation for Economic Co-operation and Development.

China has recognized that dementia will be a significant problem associated with an ageing population, but current initiatives will have to be scaled up fast to meet growing demand. So far there is not even a national estimate of the burden of dementia.

“There is a great challenge to get dementia on the health policy agenda, but much has been achieved in the past decade,” says Dr Huali Wang, vice chair and vice secretary-general of Alzheimer’s Disease Chinese (ADC). This research and advocacy organization is working to get dementia higher up on the health policy agenda.

Alzheimer disease is the most common cause of dementia, but it is often used as an umbrella term for several conditions causing dementia.

“Dementia care was listed as one of the priorities of mental health services in the Mental Health Plan 2002–2010 and ADC is currently working with the medical community to get it included in the upcoming Major Mental Health Plan,” explains Wang. “The government has realized the burden of dementia ... but we need to take action to get a general estimate and we also need more investment in educating the media and government,” she says.

China’s experience with this pressing public health issue is just one of several in Asia. Of the 35 million people currently living with dementia globally, 58% live in low- and middle-income countries and by 2050 this figure is projected to reach 71% of the total. Eastern Asia and southern Asia will see dementia growth rates more than double in the coming 20 years, Latin America will see increases of 134% to 146% and North Africa and the Middle East can expect a 125% rise, ac-



Yin Jiliang and his wife Su Zhiying at an award ceremony for Excellence in Home Care for People with Dementia in Beijing, China

cording to research by Alzheimer Disease International (ADI).

High-income countries already have a sense of the cost of dementia. In 2010, north America and western Europe accounted for over two-thirds of the estimated US\$ 604 billion worldwide cost of dementia, attributed almost equally to the indirect costs of informal care and the direct costs of medical and social care. In the rest of the world, informal caregivers bear the brunt of the burden, medical and social support are underdeveloped or non-existent and the enormity of the looming dementia epidemic is not yet widely appreciated.

In the Asia Pacific region, only Australia, Japan and the Republic of Korea have formulated public health policies directly targeting the burden of dementia. Yet it is China and India that account for the lion's share of dementia prevalence in the region. Like China, India is waking up to this.

Courtesy of Alzheimer Disease Chinese



Su Zhiying, who has suffered with dementia for the past 10 years, prepares dumplings for her husband Yin Jiliang

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Marc Wortmann

“It took quite some time to convince the officials of the need to include dementia in the list of conditions eligible for government support,” says Dr K Jacob Roy, national chairman of the Alzheimer and Related Disorders Society of India. “Our goal is to make dementia a national health priority, considering the fact that there are over 100 million people over 60 years of age and 3.7 million people with dementia.”

“The problem is that dementia is not yet integrated in primary care arrangements and it needs to be in the future,” says Marc Wortmann, executive director of ADI. The job of identifying elders showing signs of dementia usually falls on relatives. This is particularly so in countries where primary health care is underdeveloped and screening programmes for cognitive decline cannot be implemented.

“In most parts of the world most people with the disease go undiagnosed,”

says Wortmann. “One of the problems in developing countries is ... [the] lack of a primary care system.”

A recent WHO initiative to encourage countries to pay more attention to mental health problems is the mental health Gap Action Programme (mhGAP).

The WHO mhGAP Intervention Guide was launched in October 2010. It is for use by health-care workers in the management of a range of mental disorders, including dementia. There are simple protocols and flowcharts, providing a guidance process for diagnosis and descriptions of psychosocial interventions including those for caregivers. Implementation of the programme has begun in a few countries, including Ethiopia, Jordan, Nigeria, Panama and Sierra Leone.

“In low- and middle-income countries specialist numbers are never going to be enough, and dementia care will need to involve community health workers, primary care doctors and nurses in a community-based programme,” says Dr Tarun Dua, a medical officer in WHO’s Evidence, Research and Action on Mental and Brain Disorders unit.

The term “Alzheimer’s” was coined by Emil Kraepelin in 1910, in honour of his colleague Alois Alzheimer. A doctor at Frankfurt’s state asylum, Alzheimer studied a 51-year-old woman, known as

Auguste D, who exhibited cognitive and language deficits and experienced hallucinations and delusions that made her both paranoid and aggressive. Five years later he got the chance to examine her brain and found it had shrunk dramatically and that there were abnormalities in and around the cells.

“While the scale of the global dementia epidemic is daunting, the wide variety of responses at the grassroots level is cause for optimism”, says Wortmann. A host of creative interventions are being developed, from children in China’s Hong Kong Special Administrative Region being trained at school to spot dementia in their grandparents, to a low-cost, home-based intervention in India to support families of people with dementia using locally available resources.

“My optimism has to do with the fact that we can do more than people think, we can use psychosocial interventions to give people a better quality of life, and there is enough in the pharmaceutical pipeline to assume that medical research will find something,” he says.

But in terms of developing dementia policies, most of the action is still in Europe. “Developments in India are promising but we need to do more in Asia,” says Wortmann. “Public awareness is growing but in most countries governments are not picking up on that and starting programmes.” ■