Alzheimer's Disease International

Factsheet 5

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Caring for people with dementia around the world

Life expectancy is rising in almost every country. The World Health Organization has estimated that by 2020 there will be over a billion people over the age of 60 in the world. In our present state of knowledge this means that, inevitably, more older people are likely to develop dementia. As their own powers decline, how do their fellow-citizens organise their care?

First Responses

In most developed countries, the advice sought by people with dementia and their families is usually initially medical. People expect dementia to be diagnosed by a doctor. Often, if symptoms become more marked, the patient is referred to a specialist psychogeriatrician. In poorer countries, not only are doctors more scarce, but elderly people and their relatives may be less willing to consult them with problems such as failing memory, deteriorating speech or increasingly bizarre behaviour, either because mental illness is feared and stigmatised, or because doctors are perceived as having little or nothing to offer.

Cultural responses to most illnesses differ; dementia is no exception. For example, in India cases of dementia involving anger and hot temper may be more easily recognised than those involving forgetfulness[1]. In poor agricultural societies, few demands may be made of the elderly, and dementia may not be noticed so quickly, nor be so serious in its consequences, as in faster-moving, more complex cultures.

Different types of dementia may be responded to in different ways: for example, in China medical help may be sought after a stroke, but not in response to failing powers of memory[2]. It is widely held that symptoms of dementia such as deteriorating memory, if present without signs of physical deterioration, may be dismissed simply as the inevitable consequence of old age; this has been reported not only from relatively poor countries[3], but also among working-class Londoners[4], and may be true of other groups of people in the developed world.

Providing appropriate help from medical and social welfare services may be hindered if people with dementia and their relatives are unaware of what help is available, or if they perceive it as not appropriate for them; or if the service-givers remain ignorant of their needs. Difficulties of service delivery are particularly likely for people who have been international migrants, and most acute for those who do not speak the national language. Many countries now contain substantial numbers of such people, who may be more comfortable using their original language as dementia progresses.

Help from Families

Patterns of support provided by the most obvious source, the immediate family, are not only extremely varied, due to cultural influences, but subject to massive and continuing processes of change. Statistics from all 18 countries studied since 1950 show an increasing percentage of elderly people living alone. In Switzerland, for example, the percentage almost doubled, from 16 to 29, between the 1960 and 1980 Censuses[5]. In developed economies, families are small and extremely mobile, and subject to conflicting demands of jobs, housing and child-care. The scope for a potential caring role is often drawn very tightly within the family: spouses, daughters, daughters-in-law and sons provide the great majority of care. Few carers are found from among more distant family relationships. Few families are flexible enough to enable the caring role to be shared.

In poor countries, there may be a widely-held belief that the extended family acts as a safety net for these problems; a growing body of evidence suggests that this practice is increasingly compromised.

Consider the following widely reported trends:

- Fewer children born to each couple
- Increasing divorce
- Fewer three-generational households, more elderly living on their own
- More middle-aged women returning to work once their children reach school age
- More young people migrating to the cities, leaving many elderly people isolated in rural areas
- Decreasing filial piety in those countries (especially in the Far East) where until recently it was very strong

These trends suggest a growing pressure on carers, and a greater likelihood that for many elderly people there will simply be no relatives around to care. Even worse, there are suggestions from some small-scale, technologically primitive societies that elderly people with dementia may be allowed to die prematurely[6].

Providing additional help

The first option is to provide assistance for those people who can and do wish to remain in their own homes. Sometimes the next-door neighbour or some other volunteer helper can do this, but usually a more professional and organised approach is needed. Community nurses or social workers are often well-trained and appropriately placed, but less educated helpers –

aides, or home help workers – can do the job just as well, if provided with appropriate supervision. Where medical services are provided by auxiliaries, as in many villages in poor countries, it is vital that they are trained in the care of the elderly, including people with dementia. In some villages everyone joins in the caring, but this is unlikely to be true of the towns.

Experimental schemes in Britain such as that in Newham, East London, and Ipswich[7] have recruited volunteers, trained them, and fitted them on a one-to-one basis to elderly people with dementia living at home. This 'good neighbouring' practice is unlikely to come about by chance in the sprawling, restless cities of the richer world. It is decreasingly likely to be found even in the villages of Europe and North America. Poor countries might generate their own techniques of help: this is something for individual national Alzheimer societies to consider. Self-help groups and volunteers with brief training can become effective helpers for those with dementia living at home.

Residential Care

An increasingly popular solution for frail elderly people, including those with dementia, in much of the richer world is that of residential segregation: the creation of organised 'homes' where the residents' needs are supplied by younger, paid workers. The percentage of elderly people living in such establishments varies hugely from country to country: 11-12 per cent in the Netherlands, for example, but less than half that figure in neighbouring France and Belgium[8].

Most rich countries have created various types of residential home based on the dimensions of physical disability and nursing need, quality of the physical environment (often with several 'classes' recruiting to different qualities of homes on the basis of ability to pay) and mental competence. Some explicitly exclude people with dementia; others cater specifically for them. This type of specialist home is known as a domus in Britain, a lodge in Australia, and a cantou (meaning 'fireside') in France[9].

These may have the advantage of a specially trained and dedicated staff. New buildings can incorporate features particularly suited to residents with dementia, such as an enclosed garden, large unambiguous signs on doors, and circular walks for 'wanderers'. One lodge in Australia, provided for people who have lived in the 'bush', the harsh Australian outback, reflects their life-style, offering views of open countryside and opportunities for sitting around the campfire[10].

However, pressure for admission to some traditional types of residential care is now very strong. Many applicants are already mentally impaired. Others deteriorate soon after admission.

The extent of dementia and cognitive impairment among elderly people in residential care is very considerable. In Britain, the numbers with dementia in residential homes have ranged from one in seven to about four out of five. A substantial minority of residents (about one in six) suffer from severe dementia[11,12]. In nursing homes the figures have been, if anything, even higher. Figures from the USA, Japan and five European countries report that in all residential institutions for the elderly, between 42 and 66 per cent suffer from moderate or severe cognitive impairment[13].

While the populations of some countries continue to find the practice of segregating their elderly impractical or abhorrent, there are strong indications that demand is growing almost everywhere, especially when economies begin to boom, elderly people can accumulate substantial wealth, and younger families are keen to escape the fate of caring for them.

References

1 L Cohen (1995), Towards an anthropology of senility: anger, weakness and Alzheimer's in Banaras, India, Med. Anth. Quart., 9, 3, 314-334

2 H C Liu et al (1994), Assessing cognitive abilities and dementia in a predominantly illiterate population of older individuals in Kinmen, Psychol. Med., 24, 763-770

3 V Chandra et al (1994), Studies of the epidemiology of dementia: comparisons between developed and developing countries, Ageing: Clinical and Experimental Research, 6, 307-321

4 A Bowling (1989), Contact with general practitioners and differences in health among people over 85 years, J. Roy. Coll. Gen. Pract., 39, 52-5

5 G Sundstrom (1992), Care by families: an overview of trends, in Caring for Frail Elderly People, Paris: OECD, 15-55

6 P A Pollitt (1996), Dementia in old age: an anthropological perspective, Psychol. Med., 26, 1061-1074

7 J Askham and C Thompson (1990), Dementia and home care, London: Age Concern

8 B Cooper (1994), Health-care policy and planning for the demented: an international perspective, in F A Huppert et al (eds), Dementia and Normal Aging, London: Cambridge U. P., 519-551

9 B Ineichen (1988), Cultural concepts of care, in A Wimo et al (eds), Health Economics of Dementia, Wiley, 99-111

10 K Bennett (1997), Cultural issues in designing for people with dementia, in M Marshall (ed), State of the Art in Dementia Care, London: Centre for Policy on Aging, 164-9

11 B Ineichen (1997) Mentally ill old people in nursing and residential homes: a review, submitted for publication

12 C Jagger and J Lindesay (1997), Residential care for elderly people: the prevalence of cognitive impairment and behaviour problems, Age and Ageing, 26, 475-480

13 B E Fries et al (1997) Cross-national comparisons of nursing home residents, Age and Ageing, 26, Suppl 2

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