

ALZHEIMER'S DISEASE: The benefits and problems of postponing institutional care Heinz Redwood

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➤ Introduction

Why benefits and problems? Surely anything that makes it possible to keep Alzheimer's patients at home or in the community and delay their entry into institutional care must be beneficial! Well,..... yes and no. It certainly helps the payer to keep expenditure in check; but do patients and caregivers also benefit? That depends. And some of the factors on which it will depend are complex.

➤ Stages of Alzheimer's disease

It is a progressive condition, advancing from mild to moderate and eventually to severe status. The scope for postponing institutional care is greatest at the mild stage. It becomes questionable in the moderate phase and extremely difficult in severe disease. The progression is illustrated by way of examples:

MILD (mean duration 2 years)

"Common deficits include decreased ability to manage finances, to prepare meals for guests, and to market for oneself and one's family".

MODERATE (mean duration about 1.5 years)

"Deficits are of sufficient magnitude as to prevent catastrophe-free, independent community survival.... For those who are not properly watched and/or supervised, predatory strangers may become a problem. Very common reactions for persons at this stage who are not given adequate support are behavioral problems such as anger and suspiciousness."

MODERATELY SEVERE (mean duration 2.5 years)

Patients "require assistance in putting on their clothes properly....lose the ability to bathe independently....subsequently become incontinent....begin to confuse their spouse with their deceased parent"...and so on.

(B. Reisberg and E.H. Franssen) [1]

Eventually, patients tend to lose intelligible speech and the ability to walk without assistance. They become totally dependent and, in the majority of cases, need institutional care. The medical and economic 'burden' of Alzheimer's disease

This has been estimated in terms of DALYs [Disability-Adjusted Life Years, being the sum of years of normal life expectation lost as a result of the disease plus the number of years lived with disability].

For all forms of dementia (of which Alzheimer's makes up about two-thirds), DALYs for 1990 were estimated as about 2.87 million years in the industrialised world, and expected to rise to around 4.32 million years by 2020. [2]

In 1990, about 83% of dementia patients were estimated to be over the age of 60, and 61% were women, whose life expectation is longer than men's and who are therefore more likely to survive to the oldest age groups in which the prevalence of Alzheimer's is highest. In these estimates, dementia ranked 8th among all forecast causes of DALYs in 2020: 5th for women, after major depression, ischaemic heart disease, cerebrovascular disease, and osteoarthritis; and 10th for men, for whom the same diseases plus respiratory cancers, alcoholism, traffic accidents, lung disease, and self-inflicted injuries rank higher. By any standard, Alzheimer's Disease must be regarded as a major medical, social, economic, financial, personal and family problem. Unless and until a cure is found ...

For the present, Alzheimer's Disease cannot be arrested, let alone cured, but it can be managed. That is a great step forward from the situation, not all that many years ago, when the disease was rarely recognized and many of its symptoms at the moderate-to-severe stages were regarded as 'certifiable'.

In its manageability, Alzheimer's has much in common with other chronic diseases. After all, arthritis, asthma, many cancers, and the more severe forms of heart disease cannot be cured either, but we have learnt to treat and manage them quite effectively and far better than 20 or 30 years ago. The great difference between these and Alzheimer's is the fact that an unusually high

proportion of management effort for Alzheimer's takes place outside the strictly medical sphere: not so much in hospitals but in nursing homes, in sheltered accommodation and, above all, at home with caregivers.

This emphasis could change somewhat in coming decades with the advent of more effective drugs and the development of gene therapy which may gradually 'medicalise' treatment. However, gene therapy is still future music and effective, targeted drug treatment is only just beginning. Moreover, these innovative forms of medical treatment will be expected to replace or diminish institutional care. This will make the role of the domestic caregiver more important than ever.

Why postpone institutional care?

There is a wide international consensus that one of the main objectives of modern management of Alzheimer's Disease should be the postponement of having to place patients in institutional care (nursing homes, hospitals etc).

Why? - Obvious: payers save money and patients prefer it. Here we should pause before swallowing it all in one gulp. The first part of the assertion needs to be qualified, and the second prompts a 'That Depends' response. It is precisely in these areas that Alzheimer's Disease differs from, for example, asthma and arthritis. Undeniably, public or private sector health insurers will save money if, and for as long as, institutional care can be postponed. The literature of health economics is unanimous on this point. As long ago as 1983, a U.S. estimate of average net annual direct costs per Alzheimer patient was \$ 9,578 of which \$ 5,326 (or 55.6%) was 'nursing homes', whereas social service agencies (home care) amounted to \$ 1,774 (18.5%). [3] More recently, monthly costs (average for all stages of the disease) were compared for formal (professional) and informal (family caregiving) care in community and residential settings. For informal care, "hours of care were multiplied by the hourly wage rate for home health aids and personal care attendants":

Monthly costs per patient in 1996 were estimated as \$ 1549 in community settings and \$ 3130, i.e. roughly double, in residential settings (assisted living facility or nursing home). Moreover, the formal cost in residential and community settings was \$ 3,130 and \$ 683, respectively, because

over half of community costs were 'informal' (family). By contrast, 98% of residential costs were 'formal' i.e. actually billed and payable. [4]

A Swedish study has compared costs per patient per day (1995 values and exchange rates) in different settings. These ranged from Swedish Kronor [SEK] 4,474 (\$ 627) for hospitalisation in a department of internal medicine, through SEK 2,416 (\$ 339) in a geriatric clinic, SEK 1169 (\$ 164) in a nursing home, SEK 697 (\$ 98) in a home for the elderly, to nil (sic) for living at home or with a relative. [5]

These estimates demonstrate clearly the financial advantages of postponing institutional care. It is a lot cheaper for the payer, even when (as in the American study) home care is costed in. However, the 'formal' cost of community (but not institutional) settings rises steeply as the patient passes from 'mild' to 'severe' Alzheimer's Disease.

There is therefore - under U.S. conditions - a triple economy scale. Firstly, by maintaining home care for as long as possible. Secondly, by giving the patient community care in preference to residential care when that is medically feasible and acceptable. Thirdly, by managing the disease so as to delay, if possible, the advance of those symptoms which are generally associated with the moderate and severe stages. Although the precise economics will differ in Europe, the basic principle remains the same.

'Real life' problems

So much for health economics and payers' preferences. In real life, circumstances and motives are more complex than the simplistic emphasis on saving money. Of course it is desirable to contain expenditure 'other things being equal'. The trouble is that, in real life, other things are generally far from equal. In Alzheimer's Disease, they are shockingly unequal.

In health care finance and expenditure, the Law of Unintended Consequences often plays havoc with the neat savings calculations of budget holders. Alzheimer's is no exception. What are the consequences of 'burden shifting' from formal payers to unpaid caregiver at home? There is plenty of evidence to show that putting excessive pressure on caregivers (even the most willing volunteers) tends to damage their health seriously: "Care givers are more likely to have health problems and to be taking medications than non-care givers. Care givers are stressed, lack sleep, are fatigued, and have somatic complaints, anxiety and depression. Stress, depression and immunosuppression are three times more common in care providers than in non-care providers. Psychotropic drugs are used by 30% of care givers,

twice as much as by elderly non-care givers....If the patient is depressed, then it is more likely that the care giver will become depressed." [6]

Quite apart from personal stress and distress, these conditions also cost health insurers money. However, because such costs are not directly linked with Alzheimer's, they will be overlooked by budget holders and health accountants.

Means and ends

The postponement of institutional care is indeed desirable in principle. In practice, the situation of the carer needs to be brought into the financial and social equation. Postponement for its own sake is not good enough. The means by which it is to be achieved are as important as the aim itself.

For patients, the aim is to hold their cognitive and functional capacities for as long as possible, and thereby retain quality in their lives. This can be achieved (or partially achieved) only by combining medical management and medical advances with adequate caregiver support. Medical management includes earlier and more reliable diagnosis, (as a result of which the mild and moderate phases of Alzheimer's Disease can be managed more effectively) as well as the development and use of innovative drugs. In the UK, a study based on modeling has concluded that"...a reduction in the need for institutional care of just a few weeks would be enough to offset drug costs of up to £ 500 (approx. \$ 800) for six months' treatment....there is at least the potential for symptomatic drug therapies like the acetylcholinesterase inhibitors to yield savings in residential care that might offset their purchase cost." [7]

It has yet to be proven that such postponement can be routinely achieved. Different patients respond differently to different drugs. Selecting the right patient for the right drug is therefore one of the keys to successful pharmaceutical management. Ultimately, drug cost is not the prime consideration, although payers are mistakenly inclined to regard it as such.

The key role of caregivers

Meanwhile, the position of caregivers is crucial in achieving postponement of institutional care: "...the development of incontinence, the failure of patients to recognise the family member who is the principal caregiver, the nature and severity of behavioural and psychological signs and symptoms, and caregiver stress levels appear to be potent influences on the decision to institutionalise." [8]

In the U.S., the Alzheimer's Association and the National Alliance for Caregiving have asked for recognition and support of "caregivers as essential members of the health care team" and for more support for caregivers from the authorities. [9] "Who cares? Families Caring for Persons with Alzheimer's Disease", Washington, D.C.1999

Training of caregivers, as well as social and financial support, and appropriate measures to maintain the health care of caregivers need to be developed as integrated programmes. This would make it easier to apply medical advances effectively in domestic and community settings, without forcing patients unnecessarily or prematurely into institutional care or precipitating a breakdown of caregiving. In an ageing society, this should be a high priority for health care.

En partenariat avec Health and Age

FOOTNOTES

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