How might a crisis in long-term care of people with dementia be averted

Introduction

The number of people with dementia in the United Kingdom is set to increase steadily over the next 50 years with an ageing population [1]. Although the rise in demand is long anticipated, the planning and provision of services for people with dementia across a spectrum of care appear to be failing to meet increasing need.

People with dementia are already disadvantaged. For example, early recognition of dementia and the provision of support by carers in the community is patchy [2], while people with acute health needs because of coexistent physical illness have poor outcomes and often experience unnecessary disability [3, 4].

Furthermore, such people with dementia may have limited rehabilitation because of unjustifiable pessimism and be excluded from appropriate end of life care [5].

To these disadvantages can be added an impending crisis in provision of long-term care. In this issue, MacDonald and Cooper report that, while approximately half of all people with significant dementia in the United Kingdom are now in care homes, the number of available long stay places has fallen by a sixth in the last decade [6]. The project current utilisation and demographic changes to predict future demand. They forecast that, by 2043, over double the present provision will be required to maintain the present level. The authors fear an impending crisis of care unless there is both a greater shift to community rather than residential provision, and also a new acceptance, by purchasers and providers, that the main function of long stay care for older people is to support people with dementia. There are consequent requirements for improved staffing and training. They acknowledge that their study is potentially limited by reliance on extrapolation of data on dementia frequency in care homes in the southeast of England to the United Kingdom as a whole, where some regions, particularly Scotland, have differences in infrastructure and funding arrangements. Although future projections must always be treated with caution, a massive increase in demand for long-term care seems inevitable.

Potential solutions

Shifting the balance of care

Several recent reports [7–9] recognise the need to invest in improved housing, health and social infrastructure in the community. The Wanless social care review [7], including a background paper on Dementia Care, explored some of the implications in detail. The authors advocated an increase in the size of community-based care packages for all those needing care, an improvement in carer support services and tailoring of care with housing services for those with significant cognitive impairment. In Scotland a shift in the balance of care to the community from institutions is the cornerstone of recent policy [8], and a recent review [9] called for implementation of several measures to support this including investment in sheltered housing with innovative design and assistive technology such as Telecare. The Department of Health in England is committed to a shift of 10% of old people with dementia from residential to non-residential forms of long-term care although recognising that special support will be needed for family carers.

Training

Recognition of dementia in non-specialist homes is poor [10] resulting in variable standards of care provision for such people. The Wanless Report also recommended a big increase in the number of carers and care home staff with specialist dementia training and skills. A wide variety of training initiatives and qualifications is being developed. It is essential that independent providers, particularly in care homes, are included in training initiatives and given encouragement and support from statutory health and social care authorities.

Profiling local needs

The implications of national policy must be considered more locally to address present and anticipated needs for dementia care. Regional and more local profiling of the needs of the local population [11] is required to determine any potential shortfalls in service provision. Such objective needs assessment should then facilitate future decision making about community services in that geographical area.
An integrated approach—both strategic and operational

There is widespread support for better coordination of care for people with complex needs through joint commissioning arrangements [12, 13], but fragmented and competing structures may impede effective integration. In Scotland, effective partnership and joint responsibility for integrated health care strategy and operational delivery by health boards and local authorities is a statutory requirement. The development of integrated care pathways for dementia may improve quality of care. NHS Quality Improvement Scotland (QIS) are currently setting standards for such integrated care pathways for various disorders, including dementia.

Positive commissioning

‘Free market forces’ tend to discriminate against people with dementia. A literature review [14] of care costs and dementia suggests that it may be more than a third for a care home providers. There is also some evidence that private homes tend to select privately funded residents with lower levels of dependency [15]. Ring-fenced purchasing policies and targeted benefit provision may require positive discrimination to assist currently disadvantaged vulnerable people with dementia. The Wanless Report [7] cites the example of the Australian government which, in 2005, launched a national framework to coordinate a strategic, collaborative and cost-effective response to dementia.

Conclusion

Demographic change is unavoidable but continued discrimination and exclusion of people with dementia from the full range of necessary health and social support in the twenty-first century is unacceptable. An imminent crisis of dementia care in the United Kingdom can be averted if the needs of people with dementia are accorded priority in designing appropriate, more inclusive systems of care. Health departments appear to have recognised highlighted key elements, but there is a requirement to learn from experience elsewhere and to acknowledge that both the status quo and even the current speed of transformation are inadequate. Transparent targets should be set for increasing community provision, use of assistive technology, training provision, local needs assessment, truly integrated health and social work planning, including the development of integrated care pathways, and proactive ring-fenced commissioning.

Determined and concerted action is necessary to ensure that positive principles are not mere pious platitudes but are translated into practical progress.

Conflict of interests

The author is a trustee of the Dementia Services Development Trust supporting the Dementia Services Development Centre at Stirling University. He was a member of the Range and Capacity Review group and is currently on a working group of NHS Quality Improvement Scotland developing standards for Integrated Care Pathways for Dementia.

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Editorials

References