Ageing and Society **20**, 2000, 369–375. Printed in the United Kingdom

© 2000 Cambridge University Press

Ageing update

Dementia in a socio-cultural context: an idea whose time has come

MURNA DOWNS*

Dementia studies are currently dominated by biomedical and psychological models that focus on the individual without regard to their socio-cultural context (Bond 1992, 1999; Lyman 1989; Harding and Palfry 1997; Whitehouse *et al.* 2000). There is now a growing interest in how socio-cultural factors may mediate the experience of, and response to, dementia (Holstein 1998). The purpose of this review is to examine this growing interest in the socio-cultural context of dementia with reference to earlier developments in disability studies (Oliver 1990; Thomas 1999) and ageing research in general (Estes *et al.* 1984). The implications of placing dementia in a socio-cultural context for research, policy and practice will be discussed.

Most of the theoretical work on dementia has been devoted to pointing out the inadequacies of biomedical and psychological models in which problems are attributed solely to an individual's neuropathology with a simultaneous neglect of socio-cultural factors (Binney and Swan 1991; Lyman 1989; Harding and Palfry 1998; Kitwood 1998). The study of dementia, it is argued, has been limited by the broader 'biomedicalisation of ageing' whereby problems of ageing have been attributed to the 'tragedy' of the individual's pathology rather than as a function of an inadequate societal response. Robertson (1991) describes how people so labelled are referred to as 'victims' or 'sufferers'. All difficulties in the person's life are attributed to their underlying disease with a consequent neglect of social and environmental factors that may ameliorate or prevent such 'symptoms'.

Ageing research has been slow to acknowledge the heterogeneity of the ageing experience along the lines of gender (Arber and Ginn 1995), ethnicity (Atkin 1998) and class (Hughes 1990). A recent review by Atkin (1998) argues that British literature on ageing virtually ignores the experience of ethnic minorities. Only limited attention has been

* Department of Applied Social Science, University of Stirling.

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press

paid to health and social care provision for these groups and to how the social meaning of ageing may differ between ethnic groups (Blakemore and Boneham 1994). While research is under way, little is known about the extent of disability and chronic illness in ethnic minorities in Britain, in particular for conditions such as dementia (Atkin 1998; Patel *et al.* 1998).

The growing interest in the socio-cultural context of dementia resonates with the social model of disability developed by disabled theorists and writers (Oliver 1990). This model argues that disability is caused not by the person's impairment but by physical and 'social barriers' or circumstances which restrict people's opportunities fully to engage in society (Thomas 1999). This socio-cultural definition of disability, while originally developed with reference to people with physical disabilities, was later broadened to include sensory and intellectual impairments. Recent criticisms of the social model of disability have argued that social and physical barriers are not experienced uniformly by all disabled people but will differ depending on one's ethnicity, class and gender (Thomas 1999).

As people with dementia are a heterogeneous group with respect to their social, economic, ethnic/racial and cultural circumstances, it is important to examine the extent to which socio-cultural factors influence the manifestation and response to dementia (Holstein 1998; Ineichen 1998; Pollitt 1996; Lyman 1989; Yeo and Gallagher-Thompson 1996; Robertson 1991).

A useful starting point is the acknowledgement that not all cultures view dementia as a disease. In fact the disease model of dementia is a relatively recent one within Western culture and is not universally held (Fox 1989, 2000; Holstein 2000). In the early part of this century older people with mental frailties were considered to be demented as a natural result of the ageing process, senility. Thus, senile dementia was the term used. It was Alois Alzheimer's case reports of dementia in patients below the age of 65 (amongst them that of Auguste D) which led Kraepelin to name this pre-senile condition, Alzheimer's disease. It was not until the mid 1970s, in a landmark editorial by Katzman (1976), that this term was applied to older people with dementia. Thus the idea that dementia of old age (senile dementia) may be the result of disease (Alzheimer's disease) was introduced. Dementia was no longer seen as a normal part of ageing but was viewed as the result of a disease process.

Despite the widespread use of Alzheimer's disease as an explanatory model of confusion in old age, it has not been fully accepted within social (Gubrium 1986) or medical science (Huppert *et al.* 1994). It is

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press

still cause for debate whether dementia is a normal part of neural ageing or a disease of aged neurones (Huppert *et al.* 1994).

Huppert *et al.* (1994) review multi-disciplinary research evidence for and against the 'continuum' and 'disease' models of ageing. They conclude that most of the evidence favours the continuity theory of dementia which argues that normal ageing and dementia form a continuum (Huppert and Brayne 1994). This argument is supported by the finding that almost all people over 65, regardless of cognitive impairment, have some of the 'characteristic neuropathology' of Alzheimer's disease – neuritic plaques and neurofibrillary tangles – although their location and density may differ. For example, the case report in the recently published 'nun study' suggests that one can be relatively cognitively capable while alive, yet have the 'characteristic neuropathology' of Alzheimer's disease at autopsy (Snowdon 1997).

The 'postmodern' view of dementia suggests that cultural meanings of changed mental abilities deserve as much attention as the objective counts of the incidence or prevalence of such a condition (Whitehouse 2000; Whitehouse and Deal 1995). It is assumed that these meanings will affect both the subjective experience of dementia and the response to dementia by families and the broader community. For example, the meaning given to cognitive impairment in any society affects the status afforded the person with dementia. Post (1995, forthcoming) argues that Western society, being 'hyper-cognitive' in its orientation, places little value on people with cognitive impairments. Lyman's research in residential care suggests that people with dementia are keenly aware of their reduced status in society's eyes and are less concerned with their cognitive impairment than with the negative value assigned to such impairment by those around them (Lyman 1998).

While we know relatively little about how dementia is perceived or understood in non-Western societies (Pollitt 1996; Ineichen 1998), we do know that there is no universal agreement about the meaning of dementia (Pollitt 1996). In some societies it is viewed as a normal part of ageing while in others it is viewed as abnormal, brought about by a range of causes including disease states or spirits. For example, in Chinese-American families, memory problems and associated behaviours are either considered part of normal ageing, in which case services are not sought, or they are viewed as a kind of mental disorder (Elliott *et al.* 1996). In the latter circumstance, because of the stigma and shame associated with mental illness in Chinese culture, these families will do what they can to hide the person and the problem from outside services.

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press

In addition, little attention has been paid to variations within cultures, including Western cultures, along lines of gender, class and ethnicity, in the interpretation and meaning given to cognitive impairment (Pollitt 1996). We do know, however, that even within Britain where dementia of old age is predominantly viewed as a disease, some families see it as a normal part of ageing and, therefore, do not seek medical help (Pollitt 1994).

Universally, most people with dementia (however conceptualised) live with their family[1] in the community (Twigg 1998; Whitlach 1998). Cultural values and beliefs will affect whether families consider themselves to be 'caring' for their relative (Pollitt 1994). In cultures where dementia is viewed as a disease, family members come to be called 'carers' and looking after someone is regarded as inevitably associated with 'burden'. As such, much of the literature from both the United States and Britain has focused on describing the burden of caring and its physical and mental health correlates (see Schulz *et al.* 1995 for a review).

Within this 'burden' literature, however, there has been a recognition of the heterogeneity of burden by gender, class, culture, rural/urban differences and ethnic differences (Whitlach 1998). For example, Smith (1996) reviews literature that suggests that African-American carers report less burden than Caucasians. Dilworth-Anderson and Gibson describe the extended family-centred culture of the African-American community which includes non-kin members and values interdependence, sharing resources within communities and holds a belief that one's life is in God's control (Dilworth-Anderson and Gibson 1999). The homogeneity of any one culture's response, however, has been questioned and there is now a growing recognition of important differences within cultural groups (Whitlach 1998).

The cultural context in which care is provided will influence who cares and whether services are used (Dilworth-Anderson and Gibson 1999). Cultures differ with respect to the degree to which caring is viewed as consistent with filial respect and duty (Smith 1996). While this may serve as an ameliorating effect on feelings of burden, it has been suggested that where such filial duty is combined with dementia being a stigmatised condition, for example in Japan, the burden will be greater for carers (Smith 1996).

Further research on how the subjective experience of dementia differs within and between Western and non-Western societies will help inform us as to the contexts which promote quality of life. Research on within-cultural differences in dementia along the lines of class, gender, and ethnicity is long overdue. Such research can rely on both qualitative and quantitative approaches to examine the lived ex-

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press

perience and identify social correlates of quality of life throughout the experience of dementia. There is a clear need for longitudinal research that charts the experience of people with dementia living in a variety of contexts. In addition, comparative ethnographic studies about the lived experience of dementia and the families' response to their relative with dementia will provide richer detail about differences and similarities of living with this disability.

There is a clear need for increased comparative and intra-cultural research on dementia with implications for policy developments in dementia care. In such research, as much attention needs to be paid to the differences within cultures as between them (Whitlach 1998). Clearly, broader socio-cultural circumstances influence the family's ability to provide the necessary support to their relative with dementia. In Britain, the National Health Service has emphasised institutional-based support for people with dementia and their families. Despite the fact that most people with dementia live at home with their families, community-based and home-based supports are relatively under-developed (Johansson 1998). Research on the provision and uptake of supports for people with dementia and their families will usefully combine intra-cultural and comparative approaches.

It is important in policy development and service provision that attention is paid to the socio-cultural context of the person and their family (Dilworth-Anderson and Gibson forthcoming). The meaning of dementia, the family care structure and broader service provision affect the response to people with this condition. There is, therefore, a pressing need to learn about the role of socio-cultural factors in the experience and response to dementia.

Acknowledgements

Thanks to Ms Ailsa Cook for help retrieving material included in this review. Thanks to Prof Mary Marshall, Dr Scott Geron, Ms Cathy Murray and Dr Kirsten Stalker for feedback on earlier drafts. Thanks to Prof Peter Whitehouse and Ms Julia Rajcan for making available chapter proofs of the forthcoming edited collection by Whitehouse and colleagues.

NOTE

1 The term 'family' here refers to partners and close friends with whom the person lives.

References

Arber, S. and Ginn, J. 1995. *Connecting Gender and Ageing: A Sociological Approach*. Open University Press, Buckingham.

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press

Atkin, K. 1998. Ageing in a multi-racial Britain: demography, policy and practice. In Bernard, M. and Phillips, J. (eds), *The Social Policy of Old Age*. Centre for Policy on Ageing, London.

Binney, E. A. and Swan, J. 1991. The political economy of mental health care for the elderly. In Minkler, M. and Estes, C. (eds), *Critical Perspectives on Ageing: the Political and Moral Economy of Growing Old*. Baywood Publishing, San Francisco.

Blakemore, K. and Boneham, M. 1994. *Age, Race and Ethnicity*. Open University Press, Buckingham.

Bond, J. 1992. The medicalization of dementia *Journal of Ageing Studies*, **6**, 397–403.

Bond, J. 1999. Quality of life for people with dementia: approaches to the challenge of measurement. *Ageing and Society*, **19**, 561–79.

Dilworth-Anderson, P. and Gibson, B. E. 1999. Ethnic minority perspectives on dementia, family caregiving and interventions. *Generations, Journal of the American Society on Ageing*, **23**, 40–45.

Elliott, K. S., Di-Minno, M., Lam, D. and Tu, A. M. 1996. Working with Chinese families in the context of dementia. In Yeo, G. and Gallagher-Thompson, D . (eds), *Ethnicity and the Dementias*. Taylor and Francis, Washington, DC.

Estes, C. L., Gerard, L., Zones, J. S. and Swan, J. 1984. *Political Economy, Health and Ageing*. Little Brown, Boston.

Fox, P. 1989. From senility to Alzheimer's disease: the rise of the Alzheimer's disease movement. *Millbank Quarterly*, **67**, 58–102.

Fox, P. forthcoming. The role of the concept of Alzheimer's disease in the development of the Alzheimer's Association in the United States. In Whitehouse, P. J., Maurer, K. and Ballenger, M. A. (eds), *Concepts of Alzheimer's Disease: Biological, Clinical and Cultural Perspectives*. Johns Hopkins University Press, London.

Gubrium, J. 1986. *Oldtimers and Alzheimer's: The Descriptive Organisation of Senility*. JAI Press, London.

Harding, N. and Palfry, C. 1997. *The Social Construction of Dementia: Confused Professionals?* Jessica Kingsley, London.

Holstein, M. 1998. Ethics and Alzheimer's disease: widening the lens. *Journal of Clinical Ethics*, **9**, 13–22.

Holstein, M. 2000. Aging, culture and the framing of Alzheimer's disease. In Whitehouse, P. J., Maurer, K. and Ballenger, M. A. (eds), *Concepts of Alzheimer's Disease: Biological, Clinical and Cultural Perspectives*. Johns Hopkins University Press, London.

Hughes, B. 1990. Quality of life. In Peace, S. M. (ed), *Researching Social Gerontology: Concepts, Methods and Issues*. Sage, London.

Huppert, F. A. and Brayne, C. 1994. What is the relationship between dementia and normal ageing? In Huppert, F. A., Brayne, C. and O'Connor, D. W. (eds), *Dementia and Normal Ageing*. Cambridge University Press, Cambridge.

Huppert, F. A., Brayne, C. and O'Connor, D. W. 1994. *Dementia and Normal Ageing*. Cambridge University Press, Cambridge.

Ineichen, B. 1998. Cultural concepts of care for the demented. In Wimo, A., Jonsson, B., Karlsson, G. and Winblad, B. (eds), *Health Economics of Dementia*. Wiley, New York.

Johansson, L. 1998. Care options and service innovations in dementia care. In Wimo, A., Jonsson, B., Karlsson, G. and Winblad, B. (eds), *Health Ecomonics of Dementia*. Wiley, New York.

Katzman, R. 1976. The prevalence and malignancy of Alzheimer disease. *Archives of Neurology*, **33**, 217–18.

Kitwood, T. 1998. *Dementia Reconsidered: the Person Comes First*. Open University Press, Buckingham.

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press

Lyman, K. 1989. Bringing the social back in: a critique of the biomedicalisation of dementia. *The Gerontologist*, **29**, 597–605.
Lyman, K. 1998. Living with Alzheimer's disease: the creation of meaning among persons with dementia. *Journal of Clinical Ethics*, **9**, 49–57.
Oliver, M. 1990. *The Politics of Disablement*. Macmillan, Basingstoke.
Patel, N., Mirza, N. R., Lindblad, P., Amstrup, K. and Samaoli, O. 1998. *Dementia and Minority Ethnic Older People*. Russel House, London.
Pollitt, P. A. 1994. The meaning of dementia to those involved as carers. In Huppert, F. A., Brayne, C. and O'Connor, D. W. (eds), *Dementia and Normal Ageing*. Cambridge University Press, Cambridge.
Pollitt, P. A. 1996. Dementia in old age: an anthropological perspective. *Psychological Medicine*, **26**, 1061–74.
Post, S. 1995. *The Moral Challenge of Alzheimer's Disease*. Johns Hopkins University Press, London.
Robertson, A. 1991. The politics of Alzheimer's disease: a case study in apocalyptic demography. In Minkler, M. and Estes, C. (eds), *Critical Perspectives on Ageing: the Political and Moral Economy of Growing Old*. Baywood Publishing, San Francisco.
Schulz, R., O'Brien, A. T., Bookwala, J. and Fleissner, K. 1995. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. *The Gerontologist*, **35**, 771–91.
Smith, A. 1996. Cross-cultural research on Alzheimer's disease: a critical review. *Transcultural Psychiatric Research Review*, **33**, 247–76.
Snowdon, D. A. 1997. Ageing and Alzheimer's disease: lessons from the Nun Study. *The Gerontologist*, **37**, 150–6.
Thomas, C. 1999. *Female Forms: Experiencing and Understanding Disability*. Open University Press, Buckingham.
Twigg, J. 1998. Informal care of older people. In Bernard, M. and Phillips, J. (eds), *The Social Policy of Old Age*. Centre for Policy on Ageing, London.
Whitehouse, P. J. 2000. History and the future of Alzheimer's disease. In Whitehouse, P. J., Maurer, K. and Ballenger, M. A. (eds), *Concepts of Alzheimer's Disease: Biological, Clinical and Cultural Perspectives*. Johns Hopkins University Press, London.
Whitehouse, P. J. and Deal, W. E. 1995. Situated beyond modernity: lessons for Alzheimer's disease research. *Journal of the American Geriatrics Society*, **43**, 1314–15.
Whitehouse, P. J., Maurer, K. and Ballenger, M. A. 2000. *Concepts of Alzheimer's Disease: Biological, Clinical and Cultural Perspectives*. Johns Hopkins University Press, London.
Whitlach, C. 1998. Distress and burden for family caregivers. In Wimo, A., Jonsson, B., Karlsson, G. and Winblad, B. (eds), *Health Economics of Dementia*. Wiley, New York.
Yeo, G. and Gallagher-Thompson, D. 1996. *Ethnicity and the Dementias*. Taylor and Francis, Washington, DC.

Accepted 11 November 1999

Address for correspondence:
Murna Downs, Bradford Dementia Group, School of Health Studies, University of Bradford, Bradford BD5 0BB
e-mail: Murna.Downs@Bradford.ac.uk

https://doi.org/10.1017/S0144686X99007758 Published online by Cambridge University Press