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THE CONTEXT OF DEMENTIA STUDIES: POLITICAL, ECONOMIC AND SOCIAL ISSUES

■ ■ Chapter summary ■

- This chapter provides an overview of the global political, economic and social issues surrounding the study of dementia. Building on the previous chapter's exploration of what is known about dementia, this approach is developed to address the question of 'how we know what we know' about dementia. It achieves this by looking at the politicization of dementia, the economic costs of providing care and the social context of dementia that has received attention at individual, family, community and societal levels. By considering such contextual factors this chapter presents a stepping stone to then move forward to consider care principles and policies, the concern of Chapter 3.
- First then, this chapter considers the 'numbers' issue of dementia, which reflects demographic changes and the growing politicization of dementia, in particular Alzheimer's disease. Next, the chapter considers economic concerns relating to the financial costs of providing care, while remembering the personal costs of care provision borne by family and paid carers. The social context of dementia, including the institutionalization of people with dementia, the stigma relating to dementia and the marginalized position people with dementia and their families may occupy, is then outlined. This chapter therefore provides a contextual overview of the study of dementia required to explore the numerous challenges faced by those providing care to people with dementia and support for their carers.

The politicization of dementia: the concern with numbers

Worldwide it is estimated that there are 18 million people with dementia and this is expected to double to 37 million by 2025 (World Health Organization, 2006). There are differences in estimates of prevalence according to whether a country is classified as developed

or developing, with developing countries estimated to have lower prevalence of dementia; this may be due to lower rates of survival with dementia, environmental factors, as well as higher levels of mortality earlier in life (Ferri et al., 2005). However, Hendrie (2006: 487) predicts that by 2050, 70 per cent of people with dementia worldwide will be living in developing countries. It is also predicted that social care needs will increase in developing countries due to social, medical and economic factors, leading to less availability of care through traditional family caregiving (Chandra, 1998). Although current and future figures about the number of people with dementia vary – for example across all European countries the estimates for the number of people living with a form of dementia vary between 5.3 and 5.8 million people (Alzheimer Europe, 2007) – it is widely accepted that the number of people with dementia is expected to increase by the middle of the twenty-first century (Knapp et al., 2007b).

It is important to contextualize the study of dementia within issues relating to prevalence and demography as they shape the cost of dementia care and the services that can be delivered within finite monetary constraints. Knapp et al. (2007a) have explored such issues in relation to countries classified as ‘high-income’. They demonstrate that for the eighteen countries examined, the ratio of people aged 65 and over to people aged 15 to 64 will increase. The prevalence of dementia also increases with age, thus the authors estimate that there will be significant increases in the number of people with dementia by the middle of the twenty-first century, for example in the UK alone, there is a projected 28 per cent increase by 2021 and 154 per cent increase by 2051 (Knapp et al., 2007b).

The UK provides an example of what appears to be a worldwide trend in increasing numbers of people with dementia, with corresponding increases in the financial burden of providing care to people with dementia and support for family and paid carers. The Alzheimer’s Society in the UK commissioned a report into the prevalence and cost of dementia in the UK (Knapp et al., 2007b). The projected burgeoning numbers of people with dementia are used to great effect on the front page of this UK report, where it states that ‘by 2025 one million people in the UK will have dementia’, followed by ‘dementia costs the UK over £17 billion per year’. This is a stark image of both the number of people affected by

dementia and the substantial economic costs of this condition. Estimating the number of people with dementia has been difficult due to differences in epidemiological studies. The UK report attempts to rectify prior difficulties through the use of a consensus Delphi exercise where age (including younger people with dementia) and gender were considered, as was where people lived, in care homes and the community, enabling the authors to estimate the economic costs of dementia (Knapp et al., 2007b: 8). Key points from this report are that:

- The prevalence for dementia was higher for men for the 50–65 age range but higher for women for the over-65 age bands.
- Around 2.2 per cent of those with dementia are classed as younger people with dementia (age 50–65).
- Around two-thirds (63.5 per cent) of people with dementia live in the community and one-third in care homes (36.5 per cent).
- The proportion of people with dementia living in care homes rises with age, from 26.6 per cent for the 65–74 age range to 60.8 per cent of those 90 or over.
- The cost of providing care in the community increases with the severity of dementia but is still cheaper than providing care in care homes.

The projected increase in numbers gives rise to emotive language, such as ‘the dementia epidemic’ (Wilson and Fearnley, 2007), and calls for making dementia a national priority (Knapp et al., 2007b). This is in a sense a return to images promoted in the 1980s of a ‘rising tide’ of people with dementia (Ineichen, 1988), and could be interpreted as a ploy adopted by lobbyists to bring attention to dementia and in turn the need for funding and resources for research and care services; a ploy that has reported success elsewhere, for example in North America (Holstein, 2000).

The concern with growing numbers, and the resultant concern with how to provide care for the person with dementia and support to their carers may explain why dementia, in particular Alzheimer’s disease, is viewed as the ‘most publicized health problem in old age’ (Robertson, 1990: 430).

Manthorpe and Adams (2003: 35) use three themes to discuss dementia care policy, suggesting as ways to chart the developments in policy making over time; the place of people with dementia; dementia and decision making; dementia at the frontier:

- Where people with dementia should be cared for and the negative labelling applied to people with dementia, demonstrates the lowly status bestowed on people with dementia and the concerns of those wishing to influence policy to create more humane environments for people with dementia to live. The developments within community care policy locate people with dementia within their family network, again influencing particular policy developments.
- Dementia and decision making reflect a move towards looking at the individual with dementia and the legal and ethical debates surrounding their care and decisions made about their capacity or incapacity; this could be seen to reflect the theoretical developments calling for seeing the person with dementia.
- Dementia at the frontier reflects the move of countries to call for more attention, resources and interest in the condition and the development of standards of care to meet such objectives. (Manthorpe and Adams, 2003).

This 'legacies of the past' (Cantley, 2001: 202–3) approach to dementia care policy demonstrates the interplay between policies concerned not only with dementia, but also with older people, mental health and community care issues. As such, much dementia care policy can be seen to reflect long-standing policy issues of the role of the family and the state, how to control costs of care, particularly in institutions; managing health and social care boundaries; and concerns about equity and eligibility for service provision (Cantley, 2001: 219).

The growing convergence of dementia care policies across countries is demonstrated through developments in European Union countries. Despite the diverse political origins and cultural perspectives, as well as differences in economic developments, Alzheimer's disease movements across Europe are calling for similar care principles, namely, that people with dementia should be able to stay at home for as long as possible; carers need support to achieve this; people with dementia should have control over the support they receive; services should be coordinated at a local level; and institutional care should be as homely as possible (Warner and Furnish, 2002).

Longley and Warner (2002: 11) suggest that there are two driving forces behind different countries coming to broadly similar policy positions on dementia care; politico-economic and humanitarian. The politico-economic position reflects the growing number of older people, the prevalence of dementia in older people and the associated increased costs of providing care to more people with dementia. The humanitarian driving force reflects theoretical work, arguing for a

focus on the person with dementia, and the maintenance of the self and personhood of individuals through the provision of quality care, discussed in Chapter 1. The growth in legislative frameworks promoting individual rights (the decision making issues discussed by Manthorpe and Adams, 2003) can all be seen to contribute to legal and policy frameworks promoting standards of care which arguably have an ethical (Gove, 2002) or moral position shaping their development and resulting policy frameworks.

The applied nature of much research on dementia has resulted in a plethora of recommendations for policy makers and practitioners, reflecting wider social concerns. Recommendations for care delivery are made because of the projections about the rising number of people with dementia. For example, based on international comparisons of 18 wealthy countries, similar issues requiring policy and practice consideration were evident, such as:

- A shortage of skilled staff in long-stay care working in poor conditions.
- Quality of care being questioned and a cause for concern.
- A shift in state provision of care to more voluntary and private sector care provision.
- Public sector bodies being largely responsible for coordinating and commissioning care services.
- Inter-agency working as a preferred option.
- High-level policy initiatives in individual countries being evident, bringing dementia to the fore as an issue requiring national attention. (Knapp et al., 2007a: 15–16).

An Organization for Economic Cooperation and Development (OECD) report (Moise et al., 2004) based on a study of nine countries, Australia, Canada, England, Wales, France, Japan, Spain, Sweden and the United States, all with diverse welfare and health care systems, provides broad objectives that those formulating dementia policies should consider. Thus, despite differences in the approach to health and social care provision, it was possible for the authors to arrive at common objectives in relation to dementia care provision. The need for common objectives is contextualized within the demographics of an ageing population where increased longevity is linked to projected increases in the number of people with dementia who will require health and social care. Resources and skilled staff will be required to meet these care needs. The advice of the OECD (Moise et al., 2004: 62–3) is for:

- The needs of older people over 75 to be targeted within dementia policies.
- Measures to be put in place to enable early detection and diagnosis of dementia.
- Education, including counselling for carers of people with dementia.
- The use of anti-dementia drugs to be encouraged.
- People with dementia to remain in the community for as long as possible.
- Coordination of services to be given due consideration to enable agreement about responsibilities to be reached amongst the multiple service providers.
- More evidence about the benefits of dementia-specific services.

Two ways to support dementia caregivers are advanced (Moise et al., 2004: 63):

- A financial support package for carers to compensate for the loss of earnings and pension contributions which may help enable carers to continue caring for longer.
- The promotion of respite care.

By focusing on dementia as an individual pathology, policies focus on micro-level issues relating to the individual, for example there is a focus on service development and service needs. This occurs – when service solutions are designed to be acceptable to policy makers and care professionals, rather than addressing issues at the structural level – where the way disease and older people are conceptualized can be challenged (Robertson, 1990: 438–9). This would in turn enable policies to be formulated, which would address, for example, economic challenges of growing numbers of older people and social challenges of providing care in a way that is acceptable to older people and their families. However, the first challenge to policy influencers has been to bring the condition to the attention of the respective governments who require data on the numbers of people with the condition. Thus early diagnosis is often perceived as the first issue requiring attention, to ensure that people can receive early medical interventions (Rimmer et al., 2005), as well as be counted in the numbers presented to governments setting out the need for government attention.

To achieve early diagnosis requires health professionals to recognize the signs of dementia and also for the general public to avoid accepting the early symptoms of dementia as part of old age and thus not requiring attention or resource. Yet physicians have been found to routinely under-diagnose dementia even when cognitive impairments have been documented (Callahan et al., 1995). By recognizing and diagnosing dementia early on, it is suggested that cost-effective

therapies can be offered promptly and thus perhaps prevent the need for more costly interventions at a later date (Geldmacher, 2002). It is evident that public health concerns and the influence of such concerns for policy making actively engage with economic issues, mainly how to finance dementia care and how to be cost effective in this process. We will now move on to consider economic issues that shape knowledge and understanding about dementia and dementia care practices.

Economic issues

Three aspects to economic concerns surrounding dementia and dementia care have been identified (Keen, 1993): the impact on national economies; the impact on individual finances; and the costs and benefits of different types of care. The first issue, impact on national economies, relates to the impact on government spending in particular and national economies in general. The concern with the growing number of people with dementia is thus related to economic concerns: what is the cost of dementia and how can society pay for dementia and dementia care? To estimate costs accurately it is important to know the expected prevalence and incidence of dementia; prevalence being the rate at which a condition occurs within a given population and incidence the number of new people with a particular condition within a given population within a given time frame. Thus, the political concerns discussed above giving rise to talk of a 'dementia epidemic' (Wilson and Fearnley, 2007) based on a projected worldwide increase in the number of people who will be affected by dementia (Knapp et al., 2007a) lead to concerns about how much the condition will cost and how it will be paid for.

The cost to society of the predicted increase in the number of people with dementia is hard to predict and the OECD recommends that better models for predicting costs be developed (Moise et al., 2004: 64). The exact cost of dementia is difficult to estimate, however, as Bloom et al. (2003) demonstrate, the estimated costs of Alzheimer's disease are hugely variable, making it difficult to work out the 'real' costs of the disease. Reasons for the difficulty in comparing costs relate to the variation in the resource items, for example staff costs, included in individual studies as well as differences in the approach, for example retrospective studies or studies which follow individuals prospectively (Jonsson and Berr, 2005). Compared with other conditions, Alzheimer's

disease appears to be more expensive than stroke, heart disease and cancer (Lowin et al., 2001), with reported costs for dementia care higher than costs for caring for those who do not have dementia (Husaini et al., 2003), and institutionalization appearing to use up the highest amount of resources available for the care of people with dementia (Wolstenholme et al., 2002).

Given that economic considerations influence policy drives, and the use of numbers of people and the predicted costs by lobbying groups, it is at first glance surprising that the exact costs of dementia are not known. However, when the unpaid care provided by families is taken into account, alongside the variation in services offered and the way in which such services are financed, it is less surprising that it is difficult to estimate economic costs (Knapp et al., 2007a). Also, it appears that a universal finding is that costs increase along with the increased severity of the dementia (Jonsson and Berr, 2005: 51), with more hours of informal care required as the dementia advances (Langa et al., 2001) and institutional care costing more than care in the community, no matter what the degree of severity of the dementia (Knapp et al., 2007b). What is clear, however, is that the costs have been reported to be 'very high across European countries' (Jonsson and Berr, 2005: 52) and are expected to increase, given the projected increase in the number of older people with dementia and the expected decline in the ability of family members to provide 'free' care. However, difficulties in estimating costs due to demographic and economic factors have led to notes of caution against making 'apocalyptic judgments regarding the effects of ageing in general and dementia in particular on health-care expenditure' (McNamee et al., 2001: 265), but there is increasing pressure to define the costs of dementia to help improve resource allocation in the future (O'Shea and O'Reilly, 2000).

The second area of economic concern identified by Keen (1993) related to the costs of dementia is the impact of dementia on individual finances—this may be the finances of the person with dementia or their family members. Although it is often assumed that informal dementia care is cheaper than institutional care, one study has found that this is not necessarily the case, as the costs of informal care could be underestimated by 25 per cent for people living alone and 40 per cent for people with a co-resident carer (Schneider et al., 2003: 321). The same study also found that a high level of formal care inputs equated with high levels of informal care inputs, thus

formal care supplemented rather than substituted for informal caregiving (Schneider et al., 2003).

The unpaid costs of caring are also considerable, with one study estimating that unpaid caring labour accounted for 71 per cent of the total cost of providing care to a person with dementia at home (Stommel et al., 1994). Although it is widely known and accepted that family members make great efforts to care for people with dementia, the total cost to society of family members' formal and informal work is unknown (Winblad et al., 1996). The model used by Wanless (2006: 283) suggests that informal carers account for half the required care input of older people. The impact on the well-being of carers as well as their finances is likely to be substantial. Although this model is about older people generally, rather than people with dementia per se, it is likely that there is a similar pattern of care provision for people with dementia. Further, the OECD (Moise et al., 2004: 64) predicts that there may be an under-supply of family carers in the future which will in turn put a strain on other resources. Although family care may be seen as 'free' it is important that some monetary value is attached to family caregiving to ensure that the hidden costs of caring can be included in overall estimates of the cost of dementia to society (O'Shea and O'Reilly, 2000), be it through the public or private purse.

The third area of economic concern relates to the economics of service delivery (Keen, 1993: 375). This means looking at the relationship between the costs of the services that an individual may require, and the anticipated benefits of such services. The World Health Report, *Global Burden of Disease* (Lopez et al., 2006) estimates that dementia contributed more years lived with a disability for those over 60 years than many other conditions; 11.2 per cent for dementia compared to, for example, 2.4 per cent for cancer and 9.5 per cent for stroke. Thus, the impact of dementia for individuals is considerable, the number of individuals who are likely to experience dementia is projected to increase, in turn increasing the projected economic costs society will bear. It is expected that the combination of increase in prevalence of dementia will put stress on health care systems in all countries, developed and developing (Wimo et al., 2006). How these costs are met varies from country to country with a mix of financing arrangements often used but broad finance arrangements have been grouped into four types:

- 'User charges' paid by the service user or their family.
- Private insurance.
- Tax-based support from direct and/or indirect taxes.
- Social insurance linked to employment. (Knapp et al., 2007a).

How care should be financed has been widely debated, for example in the UK, Wanless et al. (2006) recommended that there should be increased finance for long-term care for older people and that there should be a non-means-tested entitlement to social care. In Scotland, free personal care has been introduced and appears to be having early success in its implementation, with fears that there would be an explosion in the number receiving care proving unfounded (Bell and Bowes, 2006; Bowes and Bell, 2007). However, different countries have different financing arrangements and crucially, as Wanless notes, 'the choice of funding arrangement affects who receives care, how much care they receive and what they pay' (2006: 287). Thus, debates about funding and decisions reached will have a direct impact on the lives of people with dementia and is therefore an important factor in the study of dementia.

The cost of providing care to a projected increasing number of people with dementia will incur a variety of costs. For example, the cost of providing care through staff costs is recognised by Wanless (2006: 282), who states that 'the pay rates needed to secure a suitable workforce are also a major factor'. The demand for long-term care in England alone is expected to increase by 88 per cent between 2002 and 2031, thus costs of providing long-term care services are predicted to be considerable in the future (Comas-Herrera et al., 2007). Yet, as Townsend (2007) notes, the conflicting messages in reports and the lack of obligation to implement recommendations means that the impact of such commissioned work is highly variable, a case in point being the implementation of free personal care in Scotland but not the rest of the UK after the Sutherland Report. A Swedish study found that providing care to someone with dementia in long-term institutional care involved more time costs than caring for someone in the same setting who does not have dementia, with more time required for increased severity of dementia (Nordberg et al., 2007). Thus, not only the presence of dementia but the severity of the condition impact on the time costs required to care for a person with dementia in long-stay care.

Long-stay care can be provided by the private or the public purse (O'Shea, 2004) so models of funding care provision are an important

consideration in policy developments designed to respond to projected increase in demand for services. However, the debate, transcending national boundaries, on who should pay for long-term care, the relative contribution between public and private funds, whether family carers should receive any form of payment and whether public funds should be targeted at specific individuals is long running (Tester, 1999), with no real end in sight, despite recent proposals for radical shifts in financing arrangements of care provision (Wanless, 2006). A US study demonstrates that the value of the costs incurred for dementia care vary, depending on the perspective of different payers, the groups whose perspectives are explored are medical insurers, family carers or the service user themselves, and society (Murman et al., 2007). This study therefore demonstrates that different stakeholders will define need and costs differently and thus consensus on cost-effectiveness is difficult to determine.

Barriers to early diagnosis and treatment relate to the financial resources available within specific countries' health care systems (Waldemar et al., 2007), but also reflect differences in the availability and use of drug treatments and differences in physicians' ability to make the diagnosis. Thus, the economic context surrounding the study of dementia has some consensus, for example the need to estimate the costs of dementia and the cost-effectiveness of interventions and treatments. But there is also a lack of overall coherence in recommendations for policy makers – for example what treatments and interventions should be funded and how they should be financed – as how to pay for care and the choice of what care to provide is based on value judgements reflecting social discourse surrounding dementia and dementia care.

Social context of dementia

Policy developments and economic decisions about, for example, the funding of long-term care reflect individual countries' views and expectations about caregiving: for example whether care is provided by health or social care sectors; whether long-stay care is financed by the state or individuals; and the availability of informal carers and the expectation that they can provide care for 'free' (Wittenberg et al., 2007). Thus, policy and economic decisions will reflect social norms and expectations, and it is to the social context of dementia and

dementia care that we will now give some attention and which will be developed in later chapters. Yet, dementia and dementia care have historically occupied a low position on the political agenda, with little specific government policy on caring for people with dementia (Sassi and McDaid, 1999). The underlying explanations for such a 'laissez-faire' approach can be explored by contextualizing the study of dementia within socially constructed marginalized positions, particularly relevant for the study of dementia care, old age and mental health and for dementia care and the gender of the care worker.

The social context surrounding the study of dementia is one where there are numerous socially-constructed categories where individuals may be placed. For example, race, gender, class, age, are socially constructed groupings, all of which will influence understandings about the experience of dementia. However, as Dressel et al. (1997) note, such categories are not mutually exclusive, and attempts to look at the connections between such groupings can be problematic. Attempts to be more inclusive incorporate a range of approaches that have limited success:

- 'Add and stir': where previously excluded groups are added to existing models or ways of thinking and knowing which may lead to a-theoretical understandings of the very topics to be included in the analysis.
- Tokenism: when a group identified as being on the margins is selected as a special case to be studied.
- Looking at the social reality from the vantage point of those traditionally at the margins.

To do this requires acknowledgement of historical power differentials and questioning the taken-for-granted assumptions that underpin social organization and social policy (Dressel et al., 1997: 580–3). To understand the social discourse surrounding dementia and dementia care involves looking at how older people are perceived:

Perhaps ultimately, our pervasive concern with the meaning of Alzheimer's disease reflects our society's efforts to grapple with the nature of the relationship between those who are already old and the wider community of people who will yet become old in the future. (Herskovitz, 1995: 148)

Thus, studying dementia is a fraught process requiring an engagement with issues that may be uncomfortable to acknowledge.

The move towards a more inclusive viewpoint of dementia where those with dementia and their carers' experiences are actively sought

(explored in Chapter 5) has itself a social context where user views movements have become more vocal and strive to counteract the negativity and stigma surrounding old age and mental health.

Dementia: negativity and stigma

Attitudes towards dementia can be seen to reflect negative views of old age and stigma surrounding mental health. For example, study of six European countries (Bond et al., 2005) found that although policy makers recognized Alzheimer's as a serious condition but did not necessarily prioritize it as a serious condition as it did not affect the most productive members of society. The same study also found that there was variance in the way countries diagnosed dementia and then recommended treatments (Wilkinson et al., 2005); there was also a widely held view by carers that governments were not investing enough in Alzheimer's disease. The variance in time from symptoms to diagnosis across the countries, from 10 months in Germany to 32 months in the UK (Wilkinson et al., 2005: 28). While such variations can be explained according to cultural norms and expectations in treatment, the question arises about accuracy of diagnosis and the early availability of information and treatment offered to people with dementia and their families.

It is argued that to change practice, professionals must recognize and reflect on their own attitudes to mental health and old age for challenges to the status quo of service delivery to occur (Wilkinson et al., 2005: 27). Using the example of Ireland, O'Shea (2004) argues that in the absence of government support through investment in community care services the health of informal carers suffers. This arguably applies to countries worldwide where dementia care falls predominantly on family members for at least some time in the trajectory of the illness. Personal accounts of the desire to keep a relative with dementia at home, but being unable to do so due to a lack of support and personal exhaustion (Pointon and Keady, 2005) demonstrate a lack of care and support for family caregivers to enable them to care in the way they would prefer and a resulting institutionalization of the person with dementia, not through choice but out of necessity.

Although not specifically referring to dementia or dementia care, Dressel et al. (1997) analysis of the interlocking categorizations individuals may be placed in is a sharp reminder that people with dementia are

not a homogenous group but may experience multiple interlocking oppressions (or privileges). However, people with dementia have tended to be lumped together into a socially convenient grouping where decisions about care and treatment rely initially on the diagnosis of dementia. The issue of stigma is one we return to in Chapter 4.

Caring for people with dementia

There are two primary arenas where dementia care takes place, within the community in the person with dementia's own home, or the home of a family member, or in a form of institutional care, be it hospital, residential, nursing or care home. Where people with dementia live is of interest in two ways: first, where people live will have a marked impact on their experience of dementia; and, second, how society chooses to provide care reflects values and beliefs about caregiving, as well as political preferences and economic constraints and resources available for caregiving.

Informal caregiving

The majority of people with dementia today live within the community and are cared for by family members. This trend has remained relatively constant over time (Nolan et al., 1996). Understandings about caregiving resonate with stereotypical views about gender and what it means to care, with care being constructed as an issue for women (Dalley, 1988). However, the experience of caring has been reported as quite different for men and women, with women reporting greater stress and strain than male caregivers (Morris et al., 1991). The problems, burden and stress that accompany family or informal caregiving have been well documented (Black and Almeida, 2004), highlighting the human costs of caring for a person with dementia. The satisfactions that can accompany family caregiving have also received attention (Hellstrom et al., 2005) and demonstrate the importance of maintaining a relationship between the person with dementia and the caregiver. Thus reinforcing and developing Kitwood's (1997) assertion that being in relationships was crucial to the person with dementia and that attempts to evaluate the quality of life of people with dementia must include reference to the importance of maintaining a relationship with the carer.

The ability to maintain relationships at the onset of dementia is of course called into question if a model of understanding where decline and loss are used. However, if a social-psychological approach is adopted where the personhood and self of the person with dementia remain, then it is possible to advocate relationship-centred care rather than stressing the burden of caregiving. Thus, beliefs and attitudes towards dementia caregiving reflect discourses surrounding what it means to have dementia and the impact this will have for the person and their life and the lives of those close to them. In Chapter 3, the discourse of informal caregiving is discussed further in relation to dementia caregiving, and for the purpose of this social context setting, the important message is that the majority of people with dementia are cared for at home rather than in an institution. Carers may experience stress and strain as well as satisfaction, and most importantly, the role of caregivers is vital in providing care and shaping the experience of living with dementia.

Paid care

There are interesting connotations attached to paid care work, with the assumption that women will enjoy paid care work and that they can do this fairly naturally and easily, as they extend their domestic duties into the public sphere of work (Lee-Treweek, 1997: 48). However, care work is demanding, emotionally and physically, and may not be carried out through choice but from economic necessity. The remuneration for providing paid care is low, with policy-driven reports not seeking to challenge this status quo position (The Royal Commission on Long-Term Care, 1999) through lobbying for higher than minimum wage payments for caring for members of society who require care, although the need for payment to reflect the requirements of the work has been more recently highlighted (Wanless, 2006).

A further example of the social context surrounding dementia care is long-stay care provision for people with dementia and the changes over time in the way care is provided, but also some similarities in that people with dementia continue to be excluded from society and placed in institutions staffed by workers who are themselves often on the margins of society or at best their work is seen to be of low value. Ideas about dementia care today are shaped and influenced by the historic images of institutional care. The common perception of the old

culture of care may be that described by Townsend (1962) where residents were dressed alike, with similar haircuts and housed in shared dormitories. The effects on old people living in residential homes, such as loss of occupation, loss of privacy, isolation from the community and loss of powers of self-determination (Townsend, 1962: 338–55) may be factors associated with residential home life. The ‘new culture’ of care espoused by Kitwood (1997) demands a recognition of the individual, and movements such as the Eden Project (Thomas, 1996) tried to go forward from such negative images of institutional care by changing the physical environment where people lived and also the way in which they spent their time engaged in meaningful activities supported by caregivers who were expected to uphold individuality and meet individual needs.

The clash of private space and public working life creates an interesting dynamic for those living and working in institutional care. Following on from Goffman’s (1961) seminal work on asylums, studies focusing on institutional care for older people remind us of the complex relationships that exist within institutions. For example, Tellis-Nayak and Tellis-Nayak (1989: 312) describe the care situation as one where residents and nursing aides come together as ‘two parties, both powerless, little respected and hardly recognized by society’. While McColgan (2004: 169) reminds us that the labelling of people with dementia can occur merely by their presence in a setting designated as a setting where people with dementia live.

Although care staff may be perceived as powerless within the care setting, they can exert power over those in receipt of care, and the ways in which they do so will impact on the lived experiences of people with dementia (Vittoria, 1998). The world of paid carers and those living with dementia reflects an interest and recognition that care homes have a culture worth investigating (Henderson and Vesperi, 1995), and is explored further in Chapter 4. For the purposes of this chapter, where the context of the study of dementia is being reviewed, it is enough for now to acknowledge that the social world of care settings is a complex interplay of macro-level social factors where paid care is relatively undervalued as are those who receive care: two groups on the margins of society in some way coexisting in a socially constructed physical space designed to ‘provide care’ to those who can no longer remain in their own homes.

The closure of long-stay geriatric wards, the rise of voluntary and private sector care provision in residential and nursing homes and the

emergence of care in the community (which includes residential and nursing homes) has contributed to a rise in the profile of both dementia and dementia care. Almost simultaneously, it would appear, there have been conceptual shifts in the discourse around dementia and care provision for those labelled with the condition 'dementia'.

Moving on to look at the finance of long-stay care for older people across Europe and the US, Wittenberg et al. (2007) suggest that the social contract surrounding the finance of such care proceeds from an assumption that society will pay (through taxes) for care for those who are most in need, with alternative financing arrangements for those who can afford to pay. Thus, a general expectation that society will look after those most in need is evident across the Western countries included in the analysis. However, the standards of care that might be expected and where care may be provided may reflect popular beliefs, fears and expectations about dementia often formed through very little knowledge about dementia. In addition, those paid to provide care for people with dementia may also begin this task from a position of relative ignorance about what dementia is and what dementia care should involve and be offered very little practical support or monetary recognition for the difficult work they perform.

Conclusions

The key issues from the political, economic and social issues and concerns which contextualize the study of dementia demonstrate that;

- Dementia is on the increase.
- Costs will rise.
- Informal care and institutional care provide, and are expected to continue to provide, the bedrock of care provision in the future.

Thus, any theoretical work (reviewed in Chapter 1) will be influenced by the context of a particular moment in time, as will policy and practice frameworks shaping the provision of care to people with dementia and support for those who provide care (discussed in Chapter 3).

To study dementia requires an understanding of the complexities and interconnections between theory, context and frameworks for care delivery, as the links between these factors shape the discourse

surrounding dementia and dementia care and will impact on the experiences of individuals with dementia. Douthit (2006) argues that political and economic will is required to develop knowledge of dementia beyond medical agendas. While Lechner notes the wider macro level of care may appear to be at odds with the concern of practitioners who seek to provide individuals with quality care level (2003: 132); however, to understand the micro level of care experiences, whether they be conceptualized as quality of life or quality of care issues, demands an engagement with macro-level issues which shape the discourse of dementia care, which include political, social and economic issues.

For people with dementia and their carers to be recognized, however, 'will require a revolution in our thinking and practices' (Callahan, 1991: 142). To truly appreciate the position people with dementia occupy requires an exploration of historical and contemporary movements where social values link with policy developments and economic considerations. Thus, what has been termed the 'political and moral economy of growing old' (Minkler and Estes, 1991) aptly describes the processes underpinning interpretations of dementia and dementia care and the resultant beliefs and attitudes those with dementia and their carers may encounter, shaping their experience of this condition, which is debilitating no matter what the theoretical approach adopted, biomedical or social. Although biomedical approaches will stress disease and decline aspects, social approaches uncover oppressions and prejudice. Taken together, a rather negative climate to exist with dementia prevails.

■ ■ Further reading ■

Cantley (2001) gives a useful overview of the policy context of dementia care. Knapp et al. (2007a) provide an international comparison of key issues shaping the context of dementia care. Wanless (2006) discusses the future of care of older people in the UK – the issues, however, are relevant to other countries in the Western world.