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About the Social Care Workforce Research Unit

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Introduction

What is dementia? Given the high – and still rising – profile of dementia, you would expect an unequivocal answer, but there is none. There are strong, sometimes conflicting, opinions about what dementia is among public, professional and research communities, and within communities and families. Medical understanding of dementia has evolved over a hundred years, since the time of Dr Alois Alzheimer’s first scientific description of the condition, but Alzheimer’s medical approach has been challenged by researchers who have developed social interpretations of dementia, the most prominent being Tom Kitwood (Kitwood, 1990). Over the following decades other social scientists have also critiqued biomedical models of dementia (eg Innes, Kelly and McCabe, 2012), arguing that, when seen in a wider social context, dementia may fit better within a social model of disability than within a disease-based medical model.

Despite dementia’s better fit with a social model of disability, underlying assumptions about what practical support is needed by people with dementia and their carers are clinically orientated. Policy and practice tend to be set within a mental illness framework that emphasises the distressing psychological and behavioural symptoms of dementia, making old age psychiatry the medical discipline ‘responsible’ for dementia in the United Kingdom (UK). In other countries neurologists take this role, reflecting the fact that they see dementia as primarily an organic brain disorder with psychological and behavioural features. Dementia can further be viewed as a disorder of later life, a long-term condition, or as one dimension of a broader state of frailty, placing it in the territory of medicine for older people (Gilleard and Higgs, 2014).

Society’s understanding of dementia derives from multiple sources reflecting different interests and perspectives. This prompted Harding and Palfry (1997) to comment that the outcome is ‘confused professionals’ who do not necessarily understand the full implications of dementia or the best way to make and implement health and care policies. Professional education about ways to respond to symptoms or to strengthen the support available to people with dementia (and their carers) does not always have multi-disciplinary content (including input from people with dementia themselves and carers – see Mayrhofer et al., 2014) and so loses the contribution that different perspectives can offer. There are few efforts to integrate understanding of the different theoretical approaches that underpin policy and practice, a situation which we hope to remedy in this report.

We build on Bender’s (2003: 55-79) analysis of why the biomedical model of dementia is so persistent, despite its evident weaknesses (which we review below). Bender attributed the strength of the biomedical model of dementia to six factors. The first is changing demography and the expectations that costs of care will rise. The second is fear of dementia and the desire for a cure that this fear promotes. The third is the resource needs of ‘Cinderella’ disciplines like old-age psychiatry and geriatric medicine, while the fourth is the shift towards organic, ‘brain disease’ explanatory models within wider psychiatry. The fifth factor is the interest of universities in framing problems in particular ways so that they can then solve them, and the sixth is the profit-seeking ethos of the pharmaceutical industry. Although we draw on knowledge from many countries, the main focus of this report is on how dementia is understood, spoken about and managed as a problem in England.

Why dialectics?

A dialectical analysis may be helpful in clarifying the positions taken by those with an interest in dementia, the reasons why they these are adopted, as well as the consequences for people with dementia, and for carers and services. This report explores the dialectics of dementia by setting out four theses. For each thesis there is a counter-thesis, and a synthesis that attempts to resolve the polarity
between thesis and counter-thesis. For each thesis we ask: What is the counter-thesis? Who adopts a stance for thesis or counter-thesis, and for what purposes? Which voices are either not heard or not so vocal in any part of the argument? And what emerges from the clash of thesis and counter-thesis?

The four theses are:

1. Dementia is a big and expensive problem and something must be done about it.
2. Dementia is a disease process that deserves a medical solution.
3. The medical solution is undermined by failure to recognise dementia, which must be put right.
4. The care of people with dementia is primarily an individual or family responsibility.

We use the term ‘dialectics’ as a method of argument or investigation that explores the resolution (synthesis) of a clash between a particular thesis and its counter-thesis. This seems to us particularly appropriate at a time when public awareness of dementia is increasing and yet it is experienced as an individual and family problem. As Wright Mills (2000) observed, social scientists can help ‘translate private troubles into public issues’ by linking individual experiences with wider social structures. Our understanding of dialectics is somewhat different from the meaning of the dialectic approach taken by Kitwood (1990) (see below) and by Downs, Clare and Mackenzie (2006), who (following Kitwood) see it as one explanatory model of dementia among others.

Over 25 years ago Kitwood (1990: 177) identified a ‘dialectical interplay between neurological and social-psychological factors, with special emphasis on aspects of the latter which deprive a neurologically impaired individual of his or her personhood’. In this seminal article, Kitwood crystallised his thinking, arguing that an understanding of dementia needed to be ‘more comprehensive and less deterministic than those which are based on the simpler versions of a ‘medical model’ (ibid: 77). While he argued that this proposition opens up the way for a ‘more personal and optimistic view of caregiving’ (ibid), his interpretation of the polarities of medical and social models of dementia has had a stronger influence on professional thinking than have his views on caregiving.

For many readers of his work (or summaries of it), Kitwood’s insistence on the importance of ‘seeing’ the person with dementia suggested that he embraced the social rather than medical model and even, to some extent, considered them opposed. Gildeard (1992: 154) contrasted the social and medical models when he argued that ‘a psychosocial model of dementia cannot be predicated on a view that … the inner decay of mind is socially constructed; it can however assert that the place of that mind, the external significance of that person is indeed the product of the external, social response to the person’. On the other hand, Dewing (2008) implicitly argued that Kitwood’s own position was not dialectical, in that he was committed to recognising neuro-pathology as well as social influences.

Given the insights of epidemiology and neuroscience, we take a different view. Taking neuropathology and social circumstances as examples of seemingly opposed phenomena, we now know that neuropathology can be influenced by social circumstances, and vice versa. In effect, what appear to be opposites are interwoven in neuroplasticity, the malleability of a nervous system in contact with the outer environment (Lock, 2013: 235–6). We discuss this further later on in the report.

**Terminology**

First, a note on terminology. We use the word dementia to reflect current UK usages of it in policy and practice, acknowledging that current policy and practice opt at times to differentiate between different ‘sub-types’ of dementia – vascular, Alzheimer’s disease and so forth – but that they also live comfortably with Alzheimer’s Disease as an umbrella term. Indeed, the national Alzheimer’s Societies and the umbrella organisation Alzheimer’s Disease International (ADI) cover all types of dementia, while commonly using ‘dementia’ as an over-arching term.

Dementia is a syndrome (a collection of symptoms) not a disease; it cannot be diagnosed, only recognised. The conventional definition of dementia syndrome was a loss of memory plus one other change in cognitive function, sufficient to cause impairment in everyday life. The different sub-types of dementia, such as Alzheimer’s disease or Lewy Body dementia, are diagnosable as diseases because they appear to have different manifestations in the brain (although, as we shall see, this distinction is less clear than usually presented). All forms of dementia are ‘progressive’
in the sense that deterioration is inevitable and death from dementia is the outcome, unless other conditions (like heart disease, kidney failure, cancer, frailty) cause death.

The fifth edition of the widely used Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association: 2013) replaced the term ‘dementia’ by the terms major neurocognitive disorder and mild neurocognitive disorder. Another syndrome was also added to the medical taxonomy in DSM-5: Mild Cognitive Impairment (MCI), a hypothesised low-impact precursor to dementia, in which cognitive impairment is observable but does not cause major impairment in everyday life. Nonetheless, dementia services and the public appear to be using ‘dementia’ as in the earlier versions of the DSM and we continue to use it here.

We also use the phrase ‘people/person with dementia’ unless directly quoting a source where other terms are used, and we use the term ‘carer’ to refer to family and friends providing care and support. In other countries the term caregiver is often used. We differentiate these individuals from paid staff, to whom we refer by their job or professional title. When we discuss therapies for dementia we use three categories: symptom-modifying therapies, which do not alter the progress of dementia but do relieve its symptoms, at least for some people, some of the time; disease-modifying therapy, which alters the course of a specific dementia sub-type; and curative therapies, which might one day prevent the progression of dementia in the same way that chemotherapy and radiotherapy can ‘cure’ cancer.
Dementia is associated with ageing, so in ageing societies the provision of care for people with dementia has become a policy problem of growing importance to citizens (who provide the bulk of care and are aware it might affect them or their family) and governments (which fund public services used by people with dementia and count the cost of carers leaving employment and so on). The actual increase in the numbers of people developing dementia in some countries may have been over-estimated, probably unintentionally (see below). Nevertheless, dementia is a big problem. The World Alzheimer’s Report 2009 estimated that there were 36 million people worldwide with dementia, and that this number would increase to nearly 66 million by 2030, with the biggest increases occurring in low- and middle-income countries (ADI, 2009: 2).

Dementia is an expensive problem. Dementia care consumes more resources than cancer care. The total economic cost of dementia for the 15 European countries that were members of the EU before 2004 was estimated at €189 billion, compared with €117 billion for cancer. Although healthcare costs for cancer were almost five times higher than those for dementia, the ‘burden’ on unpaid carers of individuals with dementia far outweighed that for cancer (€129 billion versus €22 billion) (Luengo-Fernandez et al., 2013).

The annual cost of dementia in the UK was estimated at approximately £21 billion (at 2012/13 price levels) (Knapp et al., 2014a). More than a third of this total was the (imputed) cost of unpaid care provided by family and other carers. The total divided into 20% health care costs, 45% social care costs (publicly and privately funded) and 35% unpaid care costs. We estimate that about half of the social care costs are borne by people with dementia and their families, although this will vary geographically and by the choice of definitions of social care.

The public discourse about dementia primarily focuses on rising numbers, a dementia crisis, and a sense of being overwhelmed. Mitchell et al. (2013: 4) observed that the ‘Dementia Discourse’ features imagery of disaster, with words such as tsunami, epidemic and rising tide, leading to ‘debilitating, demeaning and despairing fears of Alzheimer’s Disease and related dementias’. As a consequence, the tragedy and fear of the disease precede compassion and empathy (ibid). Dementia – experienced as loss of mind and loss of place – contributes powerfully to the collective fear about ageing (Gilleard and Higgs, 2010).

Gilleard and Higgs further argued that fear of losing one’s mind (as in the pre-modern meaning of dementia) appears to outweigh the fear of losing one’s place (as in the loss of status associated with dependency). They therefore suggest that efforts to retain the mind may be more relevant than efforts to maintain independence (Gilleard and Higgs, 2014).

The problem of dementia is so big that it has overwhelmed the pharmaceutical industry, which now calls for public subsidies for research. Although the value of the market for medication to treat Alzheimer’s Disease stood at more than $3.7bn (£2.4bn) in 2013, the pharmaceutical industry seems to be losing enthusiasm for researching new treatments (BBC, 2015) because so much expensive research on promising drugs has failed to yield effective products. Pharmafile (2015) reported that some experts believed that investments from the public and private sectors were desperately needed because pharmaceutical
companies were experiencing ‘funding fatigue’ after a ‘history of failures’. A ‘massive step change in research funding’ was urged to prompt the pharmaceutical industry to drive the development of new treatments. However, the potential for earning profits from ‘nutraceuticals’ (dietary supplements) for dementia prevention was also recently noted by the industry (Thompson, 2014). In response to this industrial pessimism, the UK government announced that it would invest £300m in research and medical innovations in dementia, as part of the ‘Prime Minister’s challenge on Dementia 2020’ (Prime Minister’s Office, 2015).

Counter-thesis one: Dementia is a big and expensive problem, but need not be as big and as expensive as portrayed

It can be difficult to measure the incidence and prevalence of dementia exactly, partly because it is a syndrome – a set of symptoms that appear connected – characterised by memory loss plus one other limitation in cognitive abilities, and is therefore difficult to define precisely.

However, there is some evidence that its incidence may be falling in England (see Mathews et al., 2013; Jagger et al., 2016). In 2002 the first wave of the longitudinal Cognitive Function and Ageing Study (CFAS1) predicted that the prevalence of dementia among the population aged 65 years and over would reach 8.3% by 2011. The second wave of CFAS2 in 2011 found a prevalence of 6.5%.

The ADI’s 2014 report noted falls in incidence and/or prevalence in other countries. In the Framingham study, which was carried out in the United States (US), an even clearer trend emerged over three five-year waves: in the first wave there was a 17% reduction in dementia prevalence, followed by a 32% reduction in the second wave, and 42% in the third (ibid). The largest German sickness fund, the Allegemeine Orts Krankenkasse (AOK), reported a 26% fall in incidence between 2004/7 and 2007/10. A large decline (of 43%) in prevalence in men was reported from Spain (ibid). Not all countries – for example, Sweden and the Netherlands – show a statistically significant decline in incidence and prevalence (Wu et al., 2015), but nevertheless the trend appears widespread.

A decline in the incidence and prevalence of dementia may have economic, policy and practice implications. Rational planning of services for people with dementia benefits from accurate data, so some of the sense of being overwhelmed may dissipate. Those providing services and bidding for more resources, however, may be discomforted by dementia being a (somewhat) smaller problem than they had claimed. We will explore this potential discomfort among professionals (such as old-age psychiatrists), third-sector organisations (with the Alzheimer’s Society as the example), politicians and researchers in the section on factors driving up costs, below. First we need to consider the difficulties that contemporary medical science finds itself in with dementia.

Science and dementia

The failure of the pharmaceutical industry to develop effective treatments for dementia is a reflection of our limited knowledge about the causes of the syndrome. A group of four symptom-modifying medicines (cholinesterase inhibitors and Memantine) became available in the UK in 1997, but there have been no new pharmacological symptom modifiers for a generation. There have been many attempts to produce disease-modifying medication, but none have been successful. Failure to develop disease-modifying drugs suggests that medical science does not know the pathological processes that cause dementia, and much research effort has been invested with very limited gain by following a simplistic and monolithic ‘one pathology, one disease, one cure’ model. As Selkoe (a scientific optimist) put it: ‘Gnawing controversies and important gaps in our knowledge seem to cast additional doubt on the ability of the field to move forward effectively’ (Selkoe 2011: 1,060).

Research into the pathologies underlying dementia syndrome has concentrated on the abnormal folding of protein molecules and the deposition of toxic chemical products (amyloid beta and tau) within brain cells, as ‘neurofibrillary tangles’, and between brain cells, as ‘amyloid plaques’. The amyloid beta/tau pathological processes do not necessarily explain all dementia, because it is possible to have amyloid plaques and neurofibrillary tangles without dementia, and to have dementia but few or no plaques or tangles (Lock, 2013). De Strooper and Karran (2016: 603) put this more bluntly: ‘The amyloid hypothesis for Alzheimer’s disease (AD) posits a neuron-centric, linear cascade initiated by A (amyloid beta) and leading to dementia. This direct causality is incompatible with clinical observations’. 
Factors that drive up costs: Despite the current diversion of resources toward dementia research and diagnostic services, some clinicians argue that people with dementia remain ‘an inherently low status and thus usually neglected group’ (Hilton and Arie, 2011: 2) and those who work with them may also have subaltern status. Hilton and Arie (2011: 11) maintained that the 1970s’ job description for an old-age psychiatrist remained relevant today: ‘occasional militancy to gain for the elderly a fair share of scant resources, to put them to best use, to make do with too little while wheeling, dealing, and fighting for more’. Wheeling, dealing and fighting for more may be more difficult if the scale of the problem to be managed with scant resources decreases.

The Alzheimer’s Society merged 240 local branches into 49 regional centres in 2010 as part of a change programme to help it win more contracts to deliver dementia services in an increasingly marketised health economy, and since then its ability to provide services contracted out by NHS commissioners has increased. Like Old Age Psychiatry, the Alzheimer’s Society is a provider interest in the dementia economy. Members of the Alzheimer’s Society, ourselves included, are now in the potentially contradictory position described for cancer care by oncologists Stevens and Glatstein (1996: iv) two decades ago: ‘We must not be seen as yet another special interest come to drink at the well of public spending, but as advocates for the public good’.

Age significantly impacts on the choices that voters make at elections, and there is some evidence that ageing may be associated with a gradual drift towards preserving the status quo, as well as an increased likelihood to vote (Tilley and Evans, 2014). This makes dementia a politically sensitive topic, to which politicians must respond. However, encouraging research and service development for dementia runs a risk of under-resourcing other aspects of care for older people, distorting research and development priorities through the ‘Alzheimerization’ of ageing (Adelman, 1998). Politicians may also need to maintain the over-estimated scale of the dementia problem in order to justify their earlier prioritisation of it.

Dementia is evolving its own burgeoning research industry. We have now passed a turning point in research interest in dementia as different research disciplines and professions (for example, sociologists, social gerontologists, old-age psychiatrists, ethicists and health services researchers) have not only claimed that they have an important contribution to make alongside the basic medical scientists, but also foresee the risks of over-research. As van der Steen and Goodman (2015) observed, the burgeoning of qualitative research on the experience of becoming a person with dementia is a vivid example of how a research question that is recognised as important can inadvertently lead to avoidable duplication of research efforts, without clear evidence of benefit to those coping with the condition.

**Synthesis one**

The investment in preventing heart disease, over decades, may be having a beneficial effect on brain health too, and this may be one factor underlying the apparent decline in the incidence and prevalence of dementia. We have touched on this already, when considering the lack of coherent pathological models of dementia, and it indicates that there are grounds for being optimistic about the tractability of dementia as a problem.

If the solution to the problem of dementia (framed as a disease) lies in providing more memory clinics, more scans and more medication, then dementia certainly is an expensive problem. However, given the failure of the pharmaceutical industry (see above), it can be argued that further investment in pharmaceutical research needs to be justified by a scientific (rather than political) assessment of likely benefit.

On the other hand, where dementia is approached as a disability as understood from a social model, then Whitehouse (2014) was right to state that efforts to retain the mind become the response of choice. When these responses are built into the interactions of people who are not expensive professionals, but perhaps third-sector volunteers, dementia as a problem looks less costly. And, if loss of mind is the main concern of an ageing population, then Whitehouse’s ecopsychosociological approaches, applied in the here and now – for example, by fostering intergenerational environments – seem a better response than medication that is not yet in existence.
Thesis two: Dementia is the consequence of disease processes that warrant medical solutions

Current political discourse frames dementia as a disease with an organic basis that will, in time, become treatable, even curable. A recent review of knowledge and uncertainties about dementia (Kenigsberg et al., 2016) asserted that Alzheimer’s and related neurodegenerative diseases can be ‘clearly distinguished’ from normal ageing, motor disorders (like Parkinson’s disease) and non-degenerative brain diseases (such as epilepsy), causing changes in mental state. Alzheimer’s disease is described as a structural problem of brain atrophy, with loss of synaptic connections in specific regions. Although there are no biological markers for any dementia sub-type, and no disease-modifying treatments, Kenigsberg and colleagues (2016) concluded that early diagnosis and early interventions must be priorities. This biomedical model of dementia is already dominant in the policy agenda. For example, the UK Prime Minister’s Challenge on Dementia 2020 (Prime Minister’s Office, 2015) anticipated that cures or disease-modifying therapies will be ‘on track to exist’ by 2025.

Counter-thesis two: Dementia is not a disease but a syndrome with multiple causes that may be more tractable by social means than by medical treatments

It now seems that there are multiple pathological processes at work over long periods of time, interacting with multiple protective factors to create (or not) the symptoms and behaviour patterns we call dementia. Dementia appears to be the outcome of accumulating exposures to harms or benefits over decades (Drew, 2014). Harms may include sleeping too much or too little in midlife (Devore et al., 2014), having Helicobacter infection in stomach ulcers (Huang et al., 2014; Adriani et al., 2014), experiencing early parental death, having short leg length, having limited education, and working in low-status jobs (ADI, 2014).

Put simply, brain cell death causes dementia, many things kill brain cells and some things protect them. For example, the scale of brain functions (termed ‘Cognitive Reserve’), which is determined in part by education, matters because it has a protective effect against dementia (Andrade-Moraes et al., 2013). This is why Drew argued that dementia may become less common in the future: ‘Modern life, with its constant multimedia inputs, may be much more stimulating than it was 50 years ago’ (Drew, 2014: 34). Drew anticipated that a more cognitively demanding environment will, in the future, make dementia less likely, by increasing cognitive reserve. Other changes in living conditions and life experiences – such as the amelioration of poverty – already seem to be having such an effect (Wu et al., 2015).

Causal pathways in dementia

Several causal pathways may exist that promote or prevent the symptom patterns that we call dementia. For example, the behaviours that seem to foster healthy ageing – regular physical activity, not smoking, a low-fat diet, limited alcohol – may have protective effects against dementia because they increase Repressor Element1-Silencing Transcription factor (REST), which is present in normal brain ageing but lost in mild cognitive impairment (MCI) and Alzheimer’s disease. REST switches off genes promoting cell death and switches on genes protecting against stress (Lu et al., 2014). REST has other protective effects on brain cells, including reducing the toxic effects of amyloid and tau. The healthy ageing characteristics that reduce inflammatory process and atherosclerosis also promote REST activity. Prevention of dementia may be the opposite side of the coin that promotes healthy ageing. Figure 1 shows the possible relationships between different drivers of or protectors against brain cell death, and of cognitive impairment. The REST mechanisms are shown on the left of the figure; amyloid and tau are shown at the top of the pathway and cognitive reserve on the lower right. Plus signs denote a positive effect, minus signs denote a negative effect,
on the factors pointed at. Other cellular level factors (not shown in Figure 1) may protect against dementia, even when pathological brain changes are further advanced. For example, social support and activities increase levels of brain-derived neurotrophic factor (BDNF), which reduces the risks of developing dementia or having a stroke (Kuehn, 2015). BDNF is also associated with slower cognitive decline, even in the presence of brain pathology. Vascular endothelial growth factor (VEGF), implicated in reducing heart disease risk, also promotes brain development and is associated with healthier brain ageing in those with amyloid or tau changes (ibid).

Cure would seemingly do away with the problematicas of care, but there is no prospect of a cure in sight, given the multiple possible causes of dementia. As Mangialasche and colleagues (2010: 702) put it: ‘... we need to acknowledge that a single cure for Alzheimer's disease is unlikely to be found and that the approach to drug development for this disorder needs to be reconsidered’. Alzheimer’s Research UK (ARUK) recently declared that 99.6 per cent of clinical trials in Alzheimer’s disease over the last decade had failed, but nonetheless concluded that ‘with political attention and a significant increase in investment in translational research and drug development, dementia research is in the most promising position for years’ (Alzheimer’s Research UK (ARUK) 2016, p6). The policy priorities should therefore be to prevent dementia where possible and optimise care where not. As Drew (2014) put it, ‘dementia is tractable’. The current state of our knowledge about the effectiveness of approaches to reducing the scale and impact of dementia suggests that prevention (see below) will yield the most benefit (Wu et al., 2015).

**Fighting dementia**

In England, dementia policy does not generally take this long-term view. The Prime Minister’s Challenge on Dementia 2020 (Prime Minister’s Office, 2015) treated dementia as a looming and dangerous entity that must be fought, using the ‘war on cancer’ as an exemplar. The fight against dementia requires resources, like increased research funding, mobilisation of potential combatants through education of professionals and the
public, and creation of new types of combatants, like dementia advisers. These processes can be described numerically and presented as evidence of progress even if the outcomes for people with dementia and their families are unknown. This fight has patriotic overtones, as David Cameron said: ‘By 2020 I want England to be the best country in the world for dementia care and support and for people with dementia, their carers and families ... and the best place in the world to undertake research into dementia and other neurodegenerative diseases’ (Prime Minister’s Office, 2015).

Dementia, when framed this way as a ‘defeatable’ condition, encourages a wartime economy to develop. Expensive expertise needs to be applied to identify people with dementia, clinics need to be staffed, scanning machinery needs to be bought (or reassigned to a new user group), and training of professionals requires trainers and takes time and money. As in any war, it is wiser to over-estimate the opponent than under-estimate it, which may be why dying from dementia and dying with dementia are conflated in arguments for greater funding of end of life care, and why challenges to current policy are vigorously rebuffed. When LeCouteur and colleagues (2013) suggested in the British Medical Journal that the political drive to screen for pre-dementia was not evidence-based and ignored the possible harms of diagnosis, outrage was vigorously organised into a rebuttal signed by many doctors, and across disciplines, that defended their clinical and research activities (Burns et al., 2013).

A campaigning approach to dementia has attractions. Infectious diseases can be contained (like Ebola) or eradicated (like Smallpox) by tightly focussed, well-resourced and highly organised campaigns. Of course dementia is not like Ebola or Smallpox; it can neither be contained nor cured, but as a disability it can be assimilated into everyday life and accommodated. Containment and cure are outcomes of the medical approach; assimilation and accommodation are consequences of a social disability model of dementia. Medical care is highly organised and extremely well resourced compared with social care and public health, and so, even if its organisational model is scientifically flawed and arguably less relevant to the problems of people with dementia, it may be likely to win the argument over which approach to take.

**Medicalisation of dementia**

The biomedical model of dementia is not robust, as we have shown, but it is successful. In part this is because it offers a vigorous response to a problem, in the shape of ‘medicalisation’. Medicalisation – the expansion of medical jurisdiction, authority and practices into new realms – was first noted by Zola (1973). It had a strong impact on the care of older people in the UK (Ebrahim, 2002), and this is ongoing (Pereira Gray et al., 2016). North American sociologists hypothesise that medicalisation will only intensify as new technologies are applied to medicine (Clarke et al., 2003). ‘Biomedicalisation’ constructs later life as a process of incremental physical decline and brings it within the domain and control of biomedicine (Estes and Binney, 1989), fitting perfectly with truly neurodegenerative disorders like dementia.

Medicalisation of dementia makes use of expertise – both practitioner and lay – in the construction of a ‘diseased self’ based on a forgetful, muddled individual. Foucault described such expertise as part of a technology of self (Foucault, 1982), which others have later described as being able to ‘mobilise and be mobilised within political argument in distinctive ways, producing a new relationship between knowledge and government. Expertise comes to be accorded a particular role in the formulation of programs of government and in the technologies that seek to give them effect’ (Rose, 1996: 156).

An alternative way to think of medicalisation is in terms of ‘biopower’, the set of mechanisms through which the basic biological features of the human species become the object of a political strategy (Foucault, 2007). Biopower focuses on living not dying, developing strategies for the governing of life (Rabinow and Rose, 2006). For example, the Alzheimer’s Society’s magazine uses as its title the strapline ‘Living well with dementia’.

Nonetheless, medical experts can influence government to ensure that ageism and age discrimination are eradicated from health and social care policy and practice, especially ageism directed at people with dementia who receive systematically less support than younger people or those without dementia (Oliver, 2013).
Catastrophising

Another mechanism that drives medicalisation is the description of dementia in catastrophic terms. Bond et al. (2004) and Peel (2014) pointed out that the cultural representations of people with dementia are essentially negative. They called for further investigation of contemporary media representations of dementia and the salience (or not) of media coverage to those caring for people with dementia. Peel’s qualitative study of 350 recent UK national newspaper articles identified a ‘panic-blame’ theme in the newspaper coverage, which represented dementia in catastrophic terms (a ‘tsunami’, ‘worse than death’), while promoting individualistic lifestyle changes to ‘stave off’ the condition.

A range of emotionally charged metaphors about dementia pervades the popular imagination, and these are found in newspaper accounts, political speeches, literature, television and films (Zeilig, 2014). Most representations refer to crisis, epidemic, dread, inescapable loss, and death, which, at first sight, create an unlikely fertile ground for a medical approach to dementia. The apparent incongruence disappears, however, when we think of medicine as a route to potential salvation, with ‘promissory science’ (Brown and Beynon-Jones, 2012) as its source of power.

Medicine as salvation

There are several aspects to science and medicine as a source of salvation. According to Hauerwas (2012), technological medicine is obsessed with the elimination of suffering and the fetishisation of health. As religion fails to help many people to come to terms with their lives, some will seek salvation through medicine, even though medicine (being more bodily than spiritual) cannot actually deliver it.

Dresser’s (2001) work ‘When Science offers Salvation’ connects the desire for salvation to the activities of advocacy groups. Dresser argued that advocacy processes become highly political and often fragmented, as different groups of activists, and the non-activist majority, diverge or achieve consensus on what can be achieved. Such activism can lead to unfair attention being paid to particular interests, at the expense of others, even as it legitimises scientific research by offering both pragmatic solutions (understanding what ‘better’ is for those receiving treatments) and idealistic solutions (for example, public involvement is inherently good). Activism works because scientific research priorities rarely follow intellectual imperatives alone (going wherever experiment and theory lead), but are also shaped by funding, political, commercial – and now activist – imperatives. As Beard (2004: 805) suggested: ‘The role of cutting-edge scientific discoveries, new pharmaceutical treatments, a population that is ageing, a variegated group of diagnosed individuals, and the relatively new phenomenon of including the perspectives of people with dementia, all contribute to the dynamic environment embedding AD (Alzheimer’s disease).’

Brown and Beynon-Jones (2014) observed how base fear can be turned into the gold of salvation. Dementia triggers a range of persistent, almost reflex policy-making responses, including: a largely uncritical susceptibility of policy communities to promissory scientific claims made by key entrepreneurial scientific stakeholders; a perceived policy need to react rapidly to often unchallenged claims about imminent benefit; and an institutionalised historical amnesia which prevents policy communities from critically reflecting on hype and disappointment. This explains why ‘breakthrough’ stories about promising new treatments are commonplace (see Box 1, over page, for examples).
Box 1: Illustrative newspaper headlines about promising treatments for dementia

Daily Express, 22 April 2015
The Guardian, 30 June 2015
The Independent, 5 Sept 2015
Mirror, 12 February 2016
The Times, 28 July 2016
Daily Mail Online, 28 July 2016
The Independent, 1 September 2016

Synthesis two

All is not lost for biomedical research, because more complex models of the underlying causes of cognitive failure are being developed, as we hint at in Figure 1. Basic medical research is now shifting towards a range of molecular-level explanations (distinct from the study of brain structure abnormalities) for the neurodegeneration that causes both dementia and movement disorders. In addition to Alzheimer’s and vascular types, dementia variants are now being categorised as Tauopathies (frontotemporal dementia, progressive supranuclear palsy, Pick’s disease), synucleinopathies (Parkinson’s disease with dementia, dementia with Lewy bodies), trinucleotide repeat disorders (Huntington’s disease, Friedreich’s ataxia) and prion disorders (variants of Creutzfeldt-Jakob disease).

This change in focus from the organ and cellular levels of investigation to the molecular level may make the clinical term ‘dementia’ obsolete. As we noted above, the fifth edition of the Diagnostic System of Medicine (DSM-5), has already replaced ‘dementia’ as a category with ‘Major Neurocognitive Disorder’ (Ganguli et al., 2011), partly to avoid dementia’s negative connotations but also to distinguish more clearly between disorders that have cognitive impairment as their primary feature (like Alzheimer’s disease) and those that do not (like Parkinson’s disease).

If dementia were to be framed as a tractable consequence of accumulated damage, policy and practice might take a different shape. Initiatives promoting healthy ageing might be given more resources, for example, while methods of reducing the disability that people with dementia experience could be more consistently explored and evaluated. An example of the former would be the promotion of intergenerational relationships and innovative learning organisations promoted by Peter Whitehouse (2013). An example of the latter would be a focus on the complexities of a commonplace problem like helping a person with dementia to dress (Mahoney et al., 2015). In Mahoney et al.’s argument, a would-be helper could protect
the sense of self and dignity of the person with
dementia by maintaining usual routines and
absorbing blame for difficulties. But, in the process
of dressing, ‘battles’ may occur and without
support the helper will have to learn – by trial and
error – how best to manage them. Crossing child-
adult-gender boundaries can cause distress to both
parties and escalate discomfort. When demands are
unrelenting, the focus moves towards maintaining
the helper’s health. Some counselling or practical
advice to shorten the ‘trial and error’ phase may
help, as could more knowledgeable supporters
and better design of attractive and easy-to-put-on
clothing.

Responding to stigma

Some work on stigma (ADI, 2012) has drawn
on sociological theory to argue that attention
needs to be focused on this area. Goffman (1963)
conceived of stigma as ‘spoiled identity’, by which
a stigmatised person is disqualified from full social
acceptance. Link and Phelan (2001: 367) suggested
stigma only exists if ‘labelling, stereotyping,
separation, status loss, and discrimination co-occur
in a power situation that allows the components of
stigma to unfold.’ The 12th Alzheimer’s Disease
International report (ADI, 2012: 8) called Link
and Phelan’s categories ‘an excellent description
of the experience of people with dementia in their
encounters with their carers, healthcare workers,
the media, governments, and wider society’.

Everyone acting against stigma will have
to address the plethora of images that surround
dementia (beyond the military metaphors noted
above) such as the depictions of it as ‘criminal’
(stealing and taking away) or of it as ‘contagious’
or depicting ‘otherness’ (see Gordon, 2014). Social
marketing approaches highlight the importance of
providing realistic and credible images of people
with dementia to the general public and the
importance of not instilling fear of the condition
(Devlin et al., 2007).
Dementia is allegedly under-diagnosed, and correcting this has become a policy priority internationally (ADI, 2014). We do not know why under-diagnosis occurs, and why there is so much geographical variation in diagnosis, but it is assumed in the English Prime Minister’s Challenge on Dementia (Prime Minister’s Office 2015) that under-diagnosis is a problem that needs solving. Systematic identification of people with dementia has been forcefully promoted in British general practice for those with risk factors for dementia, even though we do not know (beyond anecdotes) the benefits and harms of doing so (LeCouteur et al., 2013).

Counter-thesis three: Screening for dementia is not justified, the benefits of earlier recognition are unproven, and dementia is poorly understood.

Population screening for dementia is not justifiable (or ethical) based on the current criteria for screenable conditions, so it is interesting to see how the UK National Health Service (NHS) has evaded its own screening rules (essentially that there should be no screening for conditions that cannot be treated) by rebadging it as ‘case finding’. In line with the increasing efforts to render decision making in UK healthcare rational and defensible, and to counter fears of pervasive surveillance, there are four broad criteria for screening, as shown in Box 2 (derived from the UK National Screening Programme, 2015).

Box 2: Criteria for screening

1. The condition must be important, with detectable risk factors and disease markers, a recognisable latent or early symptomatic stage and a clearly understood natural course. All cost-effective primary prevention interventions should have been implemented as far as practicable.

2. There must be a simple, safe, precise and validated screening test that is acceptable to the population. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result.

3. There should be an effective treatment for patients identified through early detection, with evidence of early rather than late treatment leading to better outcomes. This evidence should come from high-quality randomised controlled trials showing that the screening programme is effective in reducing morbidity. The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment). All other options for managing the condition should have been considered (eg improving treatment, providing other services), to ensure that no more cost-effective intervention could be introduced with the resources available.

4. The opportunity cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (ie value for money). Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme.
For social and political scientists, the questions are how is dementia being framed to fit with UK screening criteria and how is the guidance provided by rational, bureaucratic regimes – like the UK National Screening Committee – being modified or subverted by powerful claims-makers? We examine each of the four main features of effective and ethical screening below.

Important, detectable with a clearly understood natural course. Dementia is certainly important, and there are many risk factors for it. As yet there are no disease markers, like blood tests, available for general population screening. ‘Mild Cognitive Impairment’ (MCI), the presumed prodromal or precursor state of dementia syndrome, is problematic because a significant proportion of those with it revert to ‘normal’ cognitive function, so there is no definitely recognisable latent or early symptomatic stage. Nevertheless the MCI idea has in some places been reified into a real diagnostic ‘thing’. Such expansion of diagnostic categories can occur almost unnoticed as part of regular medical practice; while at the same time expanding the realm of medicalisation in significant ways (Conrad 2008). In community studies the adjusted annual conversion rate from a standard definition of MCI to dementia, Alzheimer’s Disease and Vascular Dementia is 4.9%, 6.8% and 1.6% respectively (Mitchell & Shiri-Feshki 2009). Taking symptoms alone (but not MCI), approximately 2.3% of older people with subjective memory complaints will progress to dementia per year (Mitchell et al., 2014). In terms of the value of a diagnostic method, subjective memory complaints are ‘poor’ value for ruling in a diagnosis of dementia but ‘good’ value for ruling out a diagnosis (Mitchell, 2008). Overall, the natural course of dementia syndrome is not clearly understood, its symptoms vary in type and intensity, and accurate prediction of individual life expectancy is very difficult, although often desired by family carers.

For social and political scientists, the questions are how is dementia being framed to fit with UK screening criteria and how is the guidance provided by rational, bureaucratic regimes – like the UK National Screening Committee – being modified or subverted by powerful claims-makers? We examine each of the four main features of effective and ethical screening below.

A simple, safe, precise, acceptable and validated screening test

A recent systematic review (Lin et al., 2013) concluded that there are few brief cognitive
function tests with good performance available for use in primary care, the exception being the Mini Mental State Examination (MMSE), which takes the longest and is not free for public use. Most brief instruments have been validated in only one community-based study. Memory clinics vary in their activities but a voluntary accreditation scheme in England seems likely to have had some effect on standardising the diagnostic processes. However, the charge still stands that widespread development of memory clinics was not based on robust evidence of their benefit (LeCouteur et al., 2013). Bender, a long-time critic of memory clinics, argued that they originated as treatment platforms for testing new drugs and so promote a restricted, drug-based, approach to therapy. In his view, memory clinics are in the wrong place to provide help to people with dementia and they are based on a narrow conception of what dementia is, which implicitly denies the worth of people with dementia (Bender, 2003: 80–87). The deployment of specialists towards diagnosis may result in the emergence of an ‘inverse care law’ – those with the greatest need receive the least resources (Tudor Hart, 1971) – if people with distressing or behavioural and psychological symptoms of dementia (such as aggression, agitation, ‘wandering’, sleeplessness, apathy) receive less attention.

**Effective treatment for patients with evidence of better outcomes**

There is no substantial evidence available to suggest that screening affects clinician, patient (person with dementia) or family decision-making in a beneficial way overall. The trials required to justify screening have simply not been carried out, and potential harms of screening have been discussed (Iliffe & Manthorpe, 2004) but not measured as outcomes in trials. The currently available medical treatments (the cholinesterase inhibitors and Memantine) produce changes (usually small but sometimes substantial) in mood and behaviour in some people with dementia, but at the population level their clinical benefits are probably negligible (Lin et al., 2013).

**Any screening programme should give value for money**

No independent economic evaluations of dementia screening in actual practice have been conducted (at the time of writing), but an economic modelling study (Dixon et al., 2015) suggested that screening could, in principle, be cost-effective, especially as psychosocial interventions are becoming more effective (for example, cognitive stimulation therapy or carer education) and assuming that diagnosis by other methods remains low or occurs later than is optimal. The authors warned that their modelling was, however, limited by available evidence and that a range of quality-of-life benefits, cost savings and potential harms could not be quantified. It was also beyond the scope of their modelling study to consider dynamic factors such as repeat screening, mortality, disease trajectories or trends in the numbers of people with dementia. Despite the lack of convincing economic evidence of benefit, early diagnostic activities are now incentivised in UK general practice as part of the Quality & Outcomes Framework, although this has been vigorously resisted by some General Practitioners, and others (Brunet et al., 2014). In England there has been substantial investment in memory clinics to further diagnostic investigations, even though there is little evidence to support this form of service organisation (LeCouteur et al., 2013), other than self-evaluations of pioneering clinics.

Nevertheless, screening for dementia is seductive. It appeals to a common-sense belief that catching conditions early is good medicine, even though there are only a few examples where this adage is true. It helps to bring ‘the aged body under medical scrutiny’ (Davis, 2004: 371) and adds another wave to the ‘colonisation of the life-world’ by science, as described by Habermas (1984), in which the life-world is ‘a storehouse of unquestioned cultural givens from which those participating in communication draw agreed-upon patterns of interpretation for use in their interpretive efforts’ (Habermas, 1990: 135). The system world of the UK NHS (steered by power) and the health economy (steered by money) set their own imperatives over those of the ‘life-world’. Colonisation of the life-world, as an idea, is reminiscent of Gramsci’s concept of hegemony, whereby everyday practices are impregnated with the logic of the dominant ideology (Fleming and Spicer, 2008). It imposes its own instrumental logic on the illness stories of people with a neurodegenerative disorder, and modernises them (Hagen et al., 2012), in the sense of Bauman’s understanding of modernity as a ‘quest for order’, a fight of determination against ambiguity, and
of semantic precision against ambivalence and fuzziness (Bauman, 1991). In relation to dementia, Mitchell and colleagues (2013: 5) suggested that: ‘Alarmingly, the medical colonization has seeped into the social and personal fabrics of contemporary society’.

**The consequences of colonisation**

Two particular aspects of dementia stand out in discussions among those who work with people affected by it. One is the emphasis placed on memory loss, which is the only definite symptom that makes up the syndrome of dementia. The second is the tendency to categorise dementia as a long-term condition. The value of memory loss as an early symptom is limited, since self-reported memory loss is common among older people, is weakly associated with later dementia, but also with depression and anxiety, hearing impairment, illiteracy, age, and gender (Benito-Leon et al., 2010). If used as a first-stage screening test, subjective memory loss identifies only one-fifth of those who will develop dementia (Palmer et al., 2002), with false negatives attributable to individuals who do not think their memory is worsening, even when it is, and others for whom other changes, in mood or behaviour, are more prominent. False positives can also occur.

It is not new knowledge that up to 60% of older people report forgetfulness that hinders them significantly in their everyday life. Of those with memory loss symptoms, 70% are very worried about them (Commissaris et al., 1998). People reporting subjective memory loss are not the ‘worried well’. Their quality of life is poor, and their use of health services – including memory clinics, we suspect – is relatively high. Focusing attention on memory, for this group, represents the ‘problematization of the normal’ which is at the heart of ‘surveillance medicine’ (Armstrong, 1995: 393) and which may lead to the ‘Alzheimerisation’ of forgetfulness in old age (Binstock, 2003).

Most people working with people with dementia, whether from care homes, community nursing or voluntary groups, see dementia as a long-term condition, despite the apparent short life expectancy from symptom onset (median 4.5 years) (Xie et al., 2008), and from diagnosis (3.5 years) (Rait et al., 2010). This dissonance comes, in part, from the age of most people with dementia (in their late seventies or eighties) and the experiences and memories of caring for a person with dementia, sometimes for many years. Most people with dementia are aged 80 or over, have multiple disabilities and disorders, and qualify for the description of frailty; their memory losses may be among the least of their problems when their illness stories are heard (Hagen et al., 2012). People with dementia die from the same conditions that lead to death in those without dementia, but this ‘co-morbidity’ may be overshadowed by the failing brain. Other body systems fail too, so people with dementia may also have failing immune systems, weakening muscles, declining capacity to remain mobile, worsening balance and other features of frailty (Clegg et al., 2013). The mind-body dichotomy certainly seems to cast a long shadow in the context of dementia.

**Synthesis three**

In our view, instead of trying to reach targets for dementia diagnosis, General Practitioners (GPs) could be encouraged to enhance their clinical skills, aiming to recognise the features of dementia syndrome as it emerges in individual patients, and acquire the repertoire of responses that serve the best interests of their patients, and of family carers. The challenge is to minimise misattribution of cognitive or behavioural changes to ageing or personality, and to respond in a timely way to the concerns of people with dementia symptoms, and of their families. ‘Timely’ here means when symptoms are causing concern or distress, for some member of the family or within the individual’s social network. Critics of timeliness may, of course, point out that misattribution of symptoms is common within families and delays help-seeking (Feldman et al., 2015), but since screening is ineffectual and inappropriate, it will not necessarily change this situation. The approach we are suggesting includes some difficult tasks which may challenge some GPs, but they do not reduce the practitioner to a screening technician operating a potentially flawed mechanism.

While earlier recognition of dementia might turn out to be an important and achievable policy goal in the future, it may still carry risks. These include risks to the individual who receives the diagnosis earlier than would have happened in the past; risks to the family and friends of the person with dementia; and risks to services prompted to pursue earlier diagnoses of dementia (Iliffe and Manthorpe, 2004). For the individual, the potential hazards of earlier diagnosis include restriction of
activities, preoccupation with the diagnosis, and over-protection by family carers (Bamford et al., 2004).

As discussed above, dementia is a stigmatising condition that can jeopardise existing social relationships, or prompt well-meaning but over-protective measures that infantilise the older person, placing them on a rising escalator into disability from which it is difficult to escape. If behaviours, emotions or changes in thinking or memory are automatically attributed to dementia, there is potential for over-shadowing of conditions like depression which share features with dementia. Not all the symptoms suggestive of dementia are due to dementia syndrome and, as we have argued elsewhere, a false positive diagnosis may cause distress and reduce trust in professionals (Iliffe and Manthorpe, 2004).

There is ample potential for uncertainty and confusion, if only because it may be difficult to distinguish the (adverse) consequences of receiving the diagnosis of dementia from the problems that occur while living with dementia. People with dementia may be more aware of their diagnosis than is suspected and a major recent cultural shift is that older people and the public are now better informed about dementia and its symptoms than previously. Media campaigns alerting older people to contact their family doctor if they are worried about their memory may be making it more common for people to seek help at an early stage (Heward, Palfreman-Kay and Innes, 2015).

A psychosocial alternative to the biomedical approach is to adopt a ‘strengths’ perspective (Healy, 2005). By focusing on an individual’s capabilities and potentialities, people with dementia are encouraged to express and implement their hopes for the future, rather than seeking to remedy past or present problems. Healy (2005: 157-8) noted that the strengths perspective arose in mental health practice in North America in the 1990s, challenging a service culture that saw people in terms of needs, pathology, deficits and problems. She pointed to the multiple origins of this approach in theorising about social labelling and stigma and in the development of the concept of resilience.

Work with people with early dementia can draw on such perspectives by recognising that people have strengths, abilities and resources; that they are able to determine what is best for them; and that partnerships between practitioners and people with dementia can reinforce and build up individuals’ (people with dementia and carers’) strengths. Practical implementation of these ideas (for example in terms of ‘dementia friendly communities’) by local government and its partners (Office for Public Management, 2012) might answer the question ‘What can be done about the colonisation of the life-world?’ We cannot ignore the application of medical science, because it has important functions. However, it may be possible to insert life-world values, caring behaviours, ethical concerns and principles into the system and so resist and reverse colonisation (Fleming and Spicer, 2008).
Thesis four: The care of people with dementia is primarily an individual or family responsibility

Care of the person with dementia is seen by researchers, policy makers and practitioners alike as very much the role of family members, and so takes place within existing relationships (Innes, 2002; Cameron, 2006; Downs, 2014). As Levitsky (2014) reported, in respect of the US, the ideology of it being the family’s responsibility to care is almost taken for granted. The independence of the person with dementia (meaning their living at home and not in long-term care facilities), and in particular their ability to continue living in a home that is assumed to be familiar, comforting and secure, are emphasised by policy as morally virtuous and economically good. Page and colleagues (2007: 10) had earlier observed:

‘It is one of the paradoxes of dementia care that the family carer is at one and the same time the greater provider and user of community support services. By far the greatest contribution to maintaining people with dementia in their own homes comes from “the family of the person”, a responsibility which increased following the closure of the “asylums” and the development of “community care”.

They went on to say:

‘While services provided by the family may be played down as simply a natural or normal extension of the family relationship, they have become essential to maintaining people with dementia in the community and are highly influential in terms of outcomes … those people with spouse or daughter, acting as carer, are significantly less likely to enter institutional care than those with other or no carers’ (ibid).

This contribution of labour by families, particularly women, is of great economic significance. By the end of the last century some two million carers in Great Britain devoted at least 50 hours per week to care of individuals with dementia (Office for National Statistics, 1995). The value of services provided by unpaid family carers in the UK is estimated to be about £11.7 billion per annum (Prince et al., 2014).

Family carers or ‘props’, as they have been referred to by some professionals (Manthorpe, 2014), may need support in their caring role because it is often emotionally and physically difficult. Health and social care services can provide that support (according to the official version of dementia care), but the work of caring communities, dementia friends and peer support provides a third way of supporting people with dementia and their families. This stresses their citizenship and the individual’s contribution to society (newly part of the Care Act 2014’s definition of wellbeing [Part 1.1.2.i]). It confirms politicians’ views of family responsibilities to care for their members: ‘It’s no longer about what the Government can do for older people. It’s what they can do for themselves, and what we as a society can do together’ (Cameron, 2006).

Counter-thesis four: care for people with dementia is idealised

How does the policy rhetoric on supporting carers fit with our claim that the biomedical model of dementia colonises the everyday life of family caring? The distribution of resources reveals the difference between psychosocial model rhetoric and biomedical realities. The reductions of social
care funding from local authorities in England (see Knapp et al., 2014b) and market pressures affecting and affected by care homes (Burns et al., 2016a; 2016b) contrast with the significant resources made available for diagnostic services. One perverse effect of cuts in local authority funding is that the preventive role of home care or day services may be undermined by its arriving too late (and in insufficient quantity) so that relocation of the person with dementia to a care home becomes the only feasible option for stressed carers or for people living alone.

The other is that the effects of poorly resourced care become seen as a moral failure on behalf of family carers who may be accused of being abusive or neglectful of the person with dementia. The risk is that the carer is thought uncaring or worse. This may be articulated through the architecture of professional vigilance about safeguarding vulnerable people from harm. The consequence of the emphasis on early diagnosis may be that less priority is given to finding out how to respond to challenging or distressing behaviour without using drugs (which have side effects and may not work) or to helping people with dementia at end of life. Both leave families to manage as best they can. The lack of specific goals and resources in the National Dementia Strategy (Department of Health, 2009) around family support, in contrast to goals for early diagnosis, is striking. In his foreword to the Strategy, the Secretary of State, Alan Johnson, noted that ‘[T]he pace of implementation will inevitably vary, depending on local circumstances and the level and development of services within each NHS and local authority area’ (Department of Health, 2009: 4).

The four scenarios used by Knapp et al. (2014a) for economic modelling of dementia care included improved symptom relief (with existing medication), extension of access to cognitive stimulation therapy (CST) to all people with dementia, professional case management for people with dementia, and teaching carers coping strategies. All but the CST scenario increase the costs of unpaid work by carers, while reducing health and social care costs. Interestingly, theories of ‘familism’, the subjugation of the self’s interests in favour of that of the family unit, have been considered in dementia care, but to date generally only in respect of contrasts between ethnic groups (Kim et al., 2007), or in the US, where there is less public welfare coverage (Livitsky, 2014).

Calls for ‘support’ for carers may be a way of transferring responsibility to them and enrolling them in the ‘production’ of care and its emotional labour. Some have drawn attention to the way in which they have felt put under pressure to care, and to the non-arrival or withdrawal of practical help for them. Two decades ago, researchers Twigg and Atkin (1994) pointed to the determined enlistment of family carers as ‘care workers’, being involved in the co-production of care with professionals. Support for carers may be a matter of providing them with skills and confidence to take on care tasks, as substitutes for professionals such as community nurses and home care workers. The extension of personal budgets (cash for care) to family carers and others who wish to be proxies (Laybourne et al., 2015; Jepson et al., 2015) has been a further way of enmeshing family carers in support – sometimes willingly, to counter poor-quality care or lack of continuity of care provided by professionals – but bringing their relationship and its activities under the gaze of professional monitoring.

The transfer of this responsibility for care may not allow for ‘guiltless grieving’ by family members who become unable to manage the deterioration of the person with dementia (Davis, 2004). Nor does it acknowledge the ambiguous loss and boundary ambiguities that can occur in caring for an individual with dementia (Lloyd and Stirling, 2011). Ambiguous loss denotes a loss that is unclear, as occurs when the person with dementia remains physically present but seems psychologically absent. Boundary ambiguity is a cognitive response to ambiguous loss; interactions within the carer-person with dementia dyad may become distressingly incoherent, breaking taken-for-granted systems of cognitive classification or everyday relationships. Carers may feel a guilty ambivalence towards the person with dementia, dreading his or her death while longing for the closure that the person’s death would bring. Trapped in a state of cumulative ambiguity and or invalidated grief, carers can become overwhelmed, perceiving themselves as powerless to make decisions that could lead to positive change in their daily lives (Lloyd and Stirling, 2011).

Many carers have referred to the way in which support for them seems to be a matter of ‘propping them up’ to continue caring, and the toll that this places on their own health and wellbeing. It may be tempting to see carers and people with dementia as facing the same social pressures, but some researchers have pointed to ‘relational dialectics’
Golden, 2010) as reflective of the different persona and interests of the person with dementia and their carer. At one extreme of this might be the state of ‘married widowhood’ that Baxter et al. (2002) saw as relevant to the situation of some older spouse carers whose partner was ‘socially dead’ in their eyes. In terms of support services, the Care Act 2014 (Section 1(3) f) casts this in less adversarial ways by recognising ‘the importance of achieving a balance between the individual’s well-being and that of any friends or relatives who are involved in caring for the individual’.

We can conceptualise this reliance on the family as an expression of the neoliberal turn in the political economy, with its three components of individualism, privatisation plus deregulation, and decentralisation (McGregor, 2001). The transfer of responsibility for the person with advanced dementia from the state health care system (in the UK, from the asylums or long-stay hospitals) to the family was certainly a form of decentralisation, although it began before the political period we associate with neoliberalism (the Conservative government of 1979). Responsibilities are transferred to families, not to the individual with dementia, and the social care system that is available to them currently is largely either commercialised or based on voluntary organisations, both often needing family contributions to survive. As we have described above, regulation is, if anything, greater than it was in the asylum period, and state intervention is powerful and is still enlarging, through the campaigns for earlier diagnosis and the growth of memory clinics, performance targets, and the financial levers of incentives.

**Synthesis four**

Carers need advice, support and help in varying amounts at different points on the dementia trajectory. The roles of dementia advisers (generally a non-professional but paid adviser or team of advisers who support people with dementia and carers to access information, advice and support – based in the NHS or third-sector), support workers, navigators or sign-posters have been created to try and match variable need to appropriate resources (IPPOS Mori, 2016). Dementia advisers may do more than point individuals and families in the direction of practical help, as they may also run support and education groups. There is some evidence that they reach people with dementia living alone, but there has been limited uptake of adviser services and few referrals from GPs (Alzheimer’s Society, undated). An early evaluation of dementia adviser services (Clarke et al., 2013: 8) concluded that: ‘There is no one definitive model on which to base future service development and attention is needed to local solutions to achieve sustainability within the local health and social care economy’. The impact of these initiatives is as yet unclear. Further independent evaluation of dementia adviser services is needed to establish the scope and scale of benefits they provide for people with dementia and their families, and their costs.

What is becoming clear is that market mechanisms are not solving the care problems posed by dementia, especially dementia co-existing with frailty. Since the early 1990s both home-based care and care homes have been largely provided by commercial organisations (with some charities and other not-for-profit providers). The scale of this industry is huge (see Burns et al., 2016a). It has three times as many beds as the NHS, with 90% owned and operated by commercial chains, owner-managers and not-for-profit organisations (Care Quality Commission, 2014). According to Demos (2014) the care home sector is profitable for some providers but not others, and much of it suffers from low skill levels, high staff turnover, low pay, variable quality care, and a poor image as the residence of last resort.

There are costed plans to remedy the underlying failure of investment. The Barker Report (Barker et al., 2014) rejected an unplanned and under-resourced social care market and proposed a decade-long, staged, taxation-funded reform of social care in England. It advocated free personal care for people with substantial and critical needs, like in the NHS. This would require an additional £3 billion per year initially, rising to £14 billion per year by 2025. Population ageing (not simply dementia), it predicted, will make additional funding necessary, to come from new wealth and property taxes, and enforcement of the inheritance tax. The Report called for a single ring-fenced budget derived from the NHS, local authority social care funding, and care-related benefits. We would add to this the need to explore the introduction of an NHS franchise option to support care homes by reducing their trading risks, enhancing staff pay, terms and conditions, and offering training and management support (Iliffe and Manthorpe, 2015).
In this dialectical analysis we have attempted to clarify the different positions taken by those with an interest in dementia, the reasons why they adopted them, their relation to both medical and social science, and their consequences for people with dementia, and also for carers and services.

We have argued that dementia is a specific example of the myth that an ageing population causes health costs to rise. As the authors of ‘Apocalypse No!’ demonstrated (Evans et al., 2001), it is not just ageing that inflates costs, but the actions of professionals and the costs of improved technology. Bender’s (2003) six explanations for the dominance of the medical model seem as relevant to the current state of dementia care as when he proposed them, except, perhaps, for the pharmaceutical industry’s problems with profitability in this field. The growth of memory clinics and the introduction of dementia screening into general practice in England are changes brought about by political and professional interests, not by evidence-based policy making.

Medical science does not understand enough about what dementia is to produce effective therapies and the basic medical scientists are well known and immediate. Popular culture still contains a catastrophising message about dementia, and the fear generated by this naturally leads to a desire for cure – a cure that may not be realistic given what we do know about dementia’s causes.

Despite Selkoe’s (2011: 1060) acknowledgment of ‘gnawing controversies and important gaps in our knowledge’, there are positive developments. Prevention of dementia does seem possible, up to a point. Healthy ageing appears to give some protection against dementia, but healthy ageing is more than attention to individual lifestyle factors like diet, exercise and the avoidance of health hazards like smoking or excess alcohol. A dialectical view of healthy ageing encompasses social relationships, education and poverty as factors influencing both the risks of dementia and the experiences of it, alongside lifestyle factors and choices. Prevention may mean making big changes in economies, and in society.

We should not underestimate the difficulties of changing the ways in which people think about dementia and the powerful metaphors, stories and imagery that construct these thought processes. But it could be possible to move from the rhetoric of catastrophic thinking about dementia and hopes for a cure to ordinary conversations with diverse individuals about concrete problems. This looks feasible in the medium term, given the experiences acquired by the dementia adviser services in solving problems (Clarke et al., 2013).

The immediate task for government and the NHS is to strengthen social support for people with dementia, and their families. This includes long-term post-diagnostic support. Ending the financial incentives to achieve dementia diagnosis targets, and converting memory clinics into (probably smaller) specialist clinics for difficult diagnoses and the management of distressing or challenging behaviour, would potentially release some funds. This is unlikely to be enough; the Barker Report’s plans to fund free social care also need an implementation plan. To date, most current scenarios for funding services for people with dementia involve either the transfer of labour to unpaid family carers or the expectation that other people, usually women, will do this work.

We believe that there is potential to convert the dialectical syntheses that we have presented in this report into practical policy, making the most of sociological insights to link private troubles to the public sphere. The National Dementia Strategy, launched in 2009 in England, needs refreshing and its least useful components need to be replaced with plans that are more realistic, more psychosocial than biomedical, and more engaging.
Dementia strategy 2.0? Restoring the balance

Thinking of dementia as a disability enables us to emphasise reducing poverty and enhancing educational opportunities, while reducing risks of developing dementia by promoting increasing habitual physical activity in midlife rather than later life, encouraging smokers to stop, reducing high blood pressure in midlife, and reducing heart disease (ADI, 2014).

A disability approach would not blame doctors for not recognising dementia, or families for not wanting to care. It would halt politically mandated medicine that allows politicians to ‘colonise’ or determine what goes on in consultations with health professionals (which overshadows what goes on within families and communities). It would, however, disinvest in screening for dementia, carefully consider maintaining memory clinics in their present form, and challenge vested interests that conflate their own advantage with the public good.

Dementia Strategy 2.0 would invest as a priority in the acquisition of relational skills needed to support carers through the complexity of their tasks, in changes in the language used about dementia to reduce stigma, and in the normalisation of dementia through promotion of intergenerational initiatives (Whitehouse, 2013) and dementia-friendly communities.

While carers’ needs are well understood, and in many instances require no further exploration (only delivery), psychosocial therapies like cognitive stimulation therapy to improve cognition and mood and memory training are worth promoting (Martin, 2011).

These psychosocial interventions have as much a foundation in evidence as current medical approaches to dementia, but have the added value of being mainly relational rather than technical. In the relational world, people with dementia, their family carers and all those who support them can work out, in concrete ways that are relevant to individuals and families, how to respond to dementia and its symptoms. There will be further need to acknowledge the interrelationship between dementia and physical disabilities, and how to foster social relationships that support wellbeing among people with dementia and wider social networks.

Surprisingly, practitioners have little to draw on from research of the impact of socioeconomic status and deprivation, including housing and the environment, despite the growing investment in dementia research. The effects of migration and written and spoken languages on dementia, perceptions of accessibility and appropriateness of professionals and services, and cultural attitudes to dementia are receiving attention both in debates on ageing and dementia more broadly, suggesting that the separate streams of thought that sometimes characterise ageing research from dementia research may be converging. Not before time.


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