

The neuropsychiatric biopolitics of dementia and its ethnicity problem

The Sociological Review

2022, Vol. 70(5) 1005–1024

© The Author(s) 2021



Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/00380261211059920

journals.sagepub.com/home/sor**James Rupert Fletcher**

Department of Sociology, University of Manchester, UK

Maria Zubair

Department of Health Sciences, University of Leicester, UK

Moïse Roche

Division of Psychiatry, University College London, UK

Abstract

Sociological analyses of dementia have long drawn on critiques of medicalisation and the medical model. This approach fails to account for late 20th/early 21st century expansion of neuropsychiatric biopolitics, wherein a more subtle and pervasive (self-)governance of health, illness, and life itself is at stake. Since the 1970s, new neuropsychiatric imaginings of dementia have been promoted, as evident in government, third sector and research trajectories. From the 2000s, engagements with ethnicity have played an increasingly important role in these trajectories. Minority ethnic (ME) populations have emerged as a new type of dementia problem. Observations about diagnosis rates and timings, medication and nursing support (including care home admission) are normatively appraised to associate minority ethnicity with poor dementia outcomes. These outcomes are then attributed to purported cultural shortcomings of these populations. The emergence of (minority) ethnicity as a problem supports a neuropsychiatric biopolitics of dementia, wherein citizens must govern their conduct accordingly so as not to become like the imagined ‘ethnic’ antagonist. Ultimately, dementia’s newfound ethnicity problem may not serve the interests of people affected by dementia so much as researchers in the field, who should therefore reflect on their own contributions.

Keywords

Alzheimer’s, awareness, BAME, governmentality, inequality, medicalisation, race, racism

Corresponding author:

James Rupert Fletcher, Department of Sociology, University of Manchester, Floor 3, Arthur Lewis Building, Oxford Road, Manchester, M13 9PL, UK.

Email: james.fletcher@manchester.ac.uk

Introduction

Our article contributes to emerging critical scholarship on ethnicity-focused dementia research. It progresses current analyses by examining how uses of ethnicity support neuropsychiatric imaginings of dementia. Our argument is tripartite. First, we show that sociological analyses of dementia, couched in critiques of medicalisation, can be reframed within a broader post-1970s neuropsychiatric creep into human life and relations of meaning. Second, we discuss how ethnicity is fashioned into a problem within the dementia movement, through normative appraisals of ‘bad’ outcomes and the attribution of that badness to minority ethnic (ME) populations, exemplifying the mad studies observation that *madness* is readily moralised into *badness* (McWade, 2016). Finally, we consider how this new ethnicity problem perpetuates neuropsychiatric imaginings of dementia. This is not a comprehensive account, nor a systematic review of ethnicity- and dementia-related materials. Instead, we offer a critical analysis of a contemporary socio-cultural trajectory based on notable examples from various sources – research literature, public-facing literature from government bodies and third sector organisations, and traditional and social media. This echoes Moser’s (2008) analysis of how dementia is made to matter via international patient movements, medical textbooks, laboratory research, everyday care, medication advertisements, parliamentary politics and dementia conferences. Such breadth speaks to the widespread and multifaceted transformation of dementia’s meanings affecting several levels of society, which warrants greater sociological attention.

Dementia in our neuropsychiatric present

We begin by situating dementia within the broader contemporary biopolitics of neuropsychiatry and psychiatric disorder (Rose, 2007, 2009, 2019). Reframing dementia within post-1970s neuropsychiatric biopolitics diverges from traditional critiques of the ‘(bio) medical model’ that have dominated social dementia studies since the late 20th century (e.g. Bond, 1992; Kitwood, 1990; Lyman, 1989). Dementia scholars have repeatedly used traditional anti-medicalisation sociology to critique contemporary disease-based understandings of dementia. This scholarship argues that the (bio)medical model (1) pathologises a previously normal human experience (Fletcher, 2020a; Whitehouse & George, 2008), (2) obscures complex psychosocial components (Fletcher, 2018; Harris, 2010), (3) dehumanises people with dementia (Camp, 2019; Wigg, 2010) and (4) legitimises institutional control over those affected (Bond et al., 2002; Ronch, 2004). Critiquing the (bio) medical model is a crucial strand of social dementia research, having stimulated the tradition itself. It reminds us that there is more to dementia, and those diagnosed, than degeneration and a ‘loss of humanity’ (Jenkins, 2017). We acknowledge the foundational value of these critiques and adapt them to contemporary circumstances.

There are limits to (bio)medical model critiques. The (bio)medical model is too often conflated with medical professionals. In practice, it is unfair to claim that geriatricians or psychiatrists view people with dementia as degenerating brains and incapacitated minds (see Gawande, 2014). This conflation also obscures the role of various stakeholders and mediums (discussed below) that contribute to imaginings of dementia. Critiques of the

(bio)medical model are often not dealing with medicine's core conceptual schema, but rather the compromised realisation of that schema in real-world resource-constrained contexts. Herein, it is not a model per se that dehumanises patients, but rather institutions and practitioners forced to limit holism, thoroughness and intimacy in the interests of efficiency. Relatedly, the (bio)medical model is often caricatured as staunchly curative, disregarding its substantive supportive, rehabilitative and palliative components. There is also a general lack of medical involvement in dementia beyond diagnosis, meaning that most dementias are addressed by families, away from formal medical intervention (Fletcher, 2019a). As Moser (2008) argues, dementia's post-1970s profile has been driven by diverse actors outside medical science, producing a composite dementia beyond any single model. This distance from institutional medicine is echoed in common depictions of dementia (discussed below) as a moral, economic and technoscientific challenge rather than a strictly medical issue. Critiques of the (bio)medical model fall short of articulating the political moralisation of dementia as a public tragedy that should be insured against through 'proper' personal action (i.e. brain training, seeking diagnosis) and managed by families.

Countering the (bio)medical model, scholars have pursued various social models of disability as contextual and value-laden (Shakespeare, 2014). The Nordic relative model rejects health–illness dichotomies and focuses on people's capacities within environment–impairment nexuses. The North American social model is grounded in the civil rights movement, advocating emancipatory political transformation. The UK social model treats disability as a construct wherein perceived differences are labelled to justify unequal treatment (Owens, 2015). Each critiques the (bio)medical model for pathologising human differences and begetting structural restrictions, emphasising the distinctness of impairment as an attribute which may or may not be disabling in relation to extrinsic factors (e.g. a wheelchair user is *disabled* by relations between *impairment*, e.g. an amputated limb, and environment, e.g. a staircase). Regarding dementia, social models have typically focused on psychosocial and sociopolitical concerns. The former (Kitwood, 1997; Sabat, 2001) examine pathological interpersonal relations that degrade people with dementia. The latter (Bartlett & O'Connor, 2010; Cahill, 2018) explore the sociopolitical disablement of people with dementia via institutional and cultural disempowerment. For both, social forces – including the (bio)medical model – exacerbate cognitive impairment and cast it in an overly detrimental light, promoting negative interpretations of cognitive diversity and justifying structural oppression, e.g. the removal of rights under capacity legislation.

In comparison to conventional (bio)medical framings (as demarcated by social critiques), we argue that neuropsychiatric imaginings exert power over dementia and those affected by generating parameters for human experience and relationships (Fletcher, 2019b). Core neuropsychiatric imaginings of dementia are that it is a syndrome of progressive cognitive decline caused by discrete neuropathologies which are not part of normal ageing, but are commonly misconceived as such by the public. Here, dementia is a fundamentally molecular problem that will be overcome through technoscientific advances given sufficient research efforts (and resources). This imaginary is not simply an extension of medicine into illegitimate territory as much anti-medicalisation scholarship claims (indeed, following Rose, we find it unhelpful to appraise medicalisation as

'il/legitimate', etc.), but is the assemblage of new forms of life, generating intellectual tools with which all citizens can govern their own conduct and become the *right* kinds of people living the *right* kinds of lives (Rose, 2007, 2009). In this biopolitics, 'we are all asymptotically, presymptomatically ill – and perhaps all suitable cases for treatment' (Rose, 2009, p. 73).

A critical neuropsychiatric approach advances our attentions beyond traditional medicalisation arguments regarding institutionalised misunderstanding and mistreatment of people with dementia. It illuminates the sociocultural transformation of our relations with ourselves, our minds and our brains, recasting how we understand our lives. Rose (2007, p. 701) argues that 'medicalisation, implying the extension of medical authority beyond a legitimate boundary, is not much help in understanding how, why, or with what consequences these mutations have occurred'. Similarly, Williams et al. (2011, p. 231) note that moving 'beyond medicalisation challenges us to find new ways to critically understand the ideas about life and health as they travel, translate or migrate from (neuro) scientific and clinical spheres to cultural life'. This article takes such observations as its starting point for progressing a sociology of dementia that aims to 'understand the remaking – biological and clinical, economic and political, public and phenomenological – of the senile dementias today' (Cohen, 2006, p. 1). We are interested in the uses of ethnicity within this remaking of dementia, which represent an increasingly influential but under-critiqued biopolitical machinery.

Biopolitical disability scholarship reveals the conceptual, historical and biological malleability of publics and individuals, reimaging (bio)medical concerns under neoliberalism, particularly regarding responsabilisation and normative imprinting of diverse people and bodies (Mitchell & Snyder, 2015). This personal/public malleability/responsibility extends beyond traditional (bio)medical concerns with normalisation toward enhancement, explicitly seeking to improve publics (Goodley, 2018). For instance, Scotland's latest 'Brain Health' (n.d.) strategy promotes life-long neurocognitive enhancement. Zhang's (2018) biopolitical analysis of Chinese dementia models reveals how (bio)medical models are assimilated to serve particular politics – e.g. dementia was linked to capitalism under Mao. For Schillmeier (2015), dementia's transition from a problem of old age to a problem of ageing societies underpins its contemporary biopolitics. Here, dementia catalyses an alarmist politics of ageing equating demographic change with economic crisis, and by extension societal collapse. These observations trace a biopolitics of dementia that draws on (bio)medical themes but contains much more than medicalisation alone. Of course, there is no single biopolitical perspective. Important issues such as the nature of 'neoliberalism' and 'cognition' remain uncertain, exceeding the scope of this article. Instead, we apply this vibrant tradition to ethnicity and dementia to stimulate critical attention. One academic shortcoming we do address is the whiteness of much biopolitical scholarship, wherein raceless power affects raceless publics (Howell & Richter-Montpetit, 2019), overlooking longstanding racialised biopolitics of mental hygiene (Howell, 2018).

Our argument sits within the context of late 20th/early 21st century psychiatric disorders, wherein post-1970s neuropsychiatric imaginings of various human mental phenomena have proliferated beyond (bio)medical professions and entered wider public life. Be it sadness, worry, joy or forgetfulness, publics increasingly interpret and articulate

psychogenic experiences in relation to notions of health, illness and disease, often in reference to the brain (Rose, 2019; Williams et al., 2012). While much sociology of mental health focuses on classifications such as depression, anxiety and schizophrenia (Manning, 2019; Rose, 2019), dementia is also part of this neuropsychiatric story. During the late 20th century, dementia progressed from a low-priority state of later life forgetfulness to an infamous neurocognitive disorder and pressing global health concern (Chaufan et al., 2012; Fox, 1989). The recent history of dementia therefore resembles various neuropsychiatric disorders.

This newfound neuro-enthusiasm exemplifies Rosenberg's (2002) observation that the validity of diagnoses has become contingent on pathophysiologic aetiology. Indeed, the recent history of dementia is characterised by a struggle for legitimacy that remains heavily reliant upon appeals to the diseased brain. The 1970s reimagining of Alzheimer's as the 'fourth or fifth most common cause of death' (Katzman, 1976, p. 217) was predicated on novel uses of microscope technologies to attribute dementia to neurodegenerative proteinopathies rather than old age (Fox, 1989). Today, the foundational status of neuropathology remains central to the promotion of neuropsychiatric dementia. Alzheimer's Research UK (ARUK) claim: 'Dementia is *not* a natural part of ageing. It's caused by physical diseases' (ARUK, 2019a, emphasis original). Similarly, Alzheimer's Disease International note: 'There are a large number of underlying conditions which cause the symptoms of dementia, as a result of changes that happen in the brain' (ADI, 2020). In such assertions, dementia is part of a wider post-1970s neuropsychiatric 'creep' into human life that continues to reimagine our psychic experiences, our brains, and the relations between them (Moser, 2008; Rose, 2019).

'Awareness' is central to the contemporary promotion of neuropsychiatric imaginings. Mental health awareness is now a major public health phenomenon, with various celebrities publicly disclosing their illnesses and encouraging us to be equally open (Rose, 2019). Examples include a BBC documentary with singer Jesy Nelson discussing her mental health problems (BBC, 2019), and a Public Health England mental health awareness film featuring Premier League footballers and Prince William (Gov.UK, 2020). Again, dementia echoes the trend. Awareness campaigns are now a key public health response to dementia, with organisations and celebrities publicising personal experiences, encouraging those affected to disclose and seek help, and the public to be understanding and sympathetic (Fletcher, 2019c). Reflecting on a recent celebrity-fronted awareness campaign, ARUK's (2019b) Chief Executive noted: 'Samuel L. Jackson's role in our #ShareTheOrange campaign will put a global spotlight on the seriousness of dementia and the huge impact it has on society . . . We're calling on the public to #ShareTheOrange, turn fatalism into hope.' Similarly, Oscar-nominated actress and Alzheimer's Society (n.d.) ambassador, Carey Mulligan, has claimed: 'I want every person in every corner of the world to be dementia aware' and 'we need to change the way people think, act and talk about the condition'.

The transformation of public interpretations of mental life has inspired a congruent tradition of work to define and measure those interpretations. Since the 1990s, research on the dementia 'awareness' of different populations has expanded dramatically. Figure 1 shows the rise in both the overall proportion of dementia-specific research publications and those citing 'dementia "awareness"', "literacy", "understanding" and "knowledge"

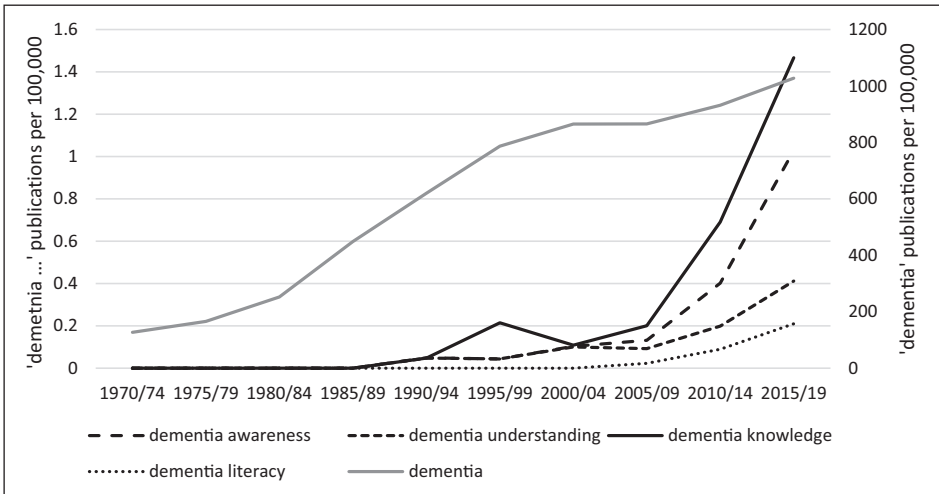


Figure 1. Research publications citing ‘dementia awareness/literacy/understanding/knowledge’ by five-year period between 1970 and 2020, plotted against the first y-axis (left). Data are normalised per 100,000 citations to avoid influence of general increases in publication/archiving. Proportion of overall ‘dementia’ publications per 100,000 citations are also shown for comparison, plotted against the second y-axis (right). Normalised data collected 8 July 2020 from <https://esperr.github.io/pubmed-by-year/>.

between 1970 and 2020, as registered by PubMed on 8 July 2020. Especially evident is the rapid recent growth of awareness literature. Today, this encompasses research on awareness among people with dementia (Lee et al., 2016; Willis et al., 2020), family carers (Andrews et al., 2017; Graham et al., 1997; Hinton et al., 2005), healthcare professionals (Fessey, 2007; Pathak & Montgomery, 2015; Turner et al., 2005) and the general public, both nationally (Cahill et al., 2015; Glynn et al., 2017; McParland et al., 2012; Smith et al., 2014) and internationally (Cations et al., 2018; van Patten & Tremont, 2020). Such research underpins the awareness economy because it allows stakeholders to establish a need for their work and prove its efficacy.

Dementia’s new ethnicity problem

Within the trend toward research on how people conceptualise dementia, a notable sub-genre deals with populations classified via ethnicity (Fletcher, 2020b). Adding ‘ethnicity’ to the search terms in Figure 1 reveals a similar acceleration of publications during the 21st century. While such figures are crude reflections of actual output, they indicate the scale and recency of growth in ethnicity-focused dementia research, and the emergence of ethnicity as a conventional tool within a broader expansion of dementia research. This turn to ethnicity as a means of classification is evident across several strands of dementia research, including under-diagnosis (Nielsen et al., 2011; Schrauf & Iris, 2012), low service engagement (Haralambous et al., 2014; Low et al., 2011; Sun et al., 2014), the development of education programmes (Lam & Woo, 2018; Morano & King, 2010);

Valle et al., 2006) and under-representation in research (Gallagher-Thompson et al., 2003; Hinton et al., 2000). These studies share a conviction that (minority) ethnicity is a problem in dementia, tied to various bad outcomes (discussed below), necessitating empirical scrutiny to inform solutions.

The turn to ethnicity is typically justified via appeals to access inequalities. Many ethnicity-focused dementia research papers begin by noting the existence of pronounced inequalities in service-use among people affected by dementia from different ethnic groups (e.g. Hossain & Khan, 2020; Nielsen et al., 2020; Parveen et al., 2017). Similarly, charitable organisations justify ethnicity-focused work with reference to service inequalities. The Alzheimer's Society (2019) argues that its recent promotion of 'BAME research' is necessary because 'research suggests BAME communities often face delays in dementia diagnosis and barriers in accessing services'. Some evidence supports these claims. A systematic review of 33 studies found that ME groups were diagnosed later and were less likely to move into residential care, participate in research and receive medication compared with the majority ethnic population (Cooper et al., 2010).

The framing of diagnosis, service and treatment inequalities to problematise ethnicity requires greater critical attention. Under-diagnosis is repeatedly flagged as problematic because diagnosis facilitates access to treatments, services and support, and enables families to plan. However, diagnosis can be unreliable and distressing, treatments and services can be poor, and prognostic variability undermines planning (Fox et al., 2013; Milne, 2010; Samsi & Manthorpe, 2014). Robust long-term harm–benefit evaluations of dementia diagnosis are lacking, so claims for and against are ultimately grounded in argument and convention rather than evidence (Fox et al., 2013; Watson et al., 2018). Some scholars frame low rates of residential care admission as a bad outcome (e.g. Mausbach et al., 2004; Napoles et al., 2010), yet research has found that 70% of UK adults fear care home entry with dementia (Alzheimer's Society, 2013). A systematic review of studies comparing domiciliary and institutional care for older people found that health outcomes were similar, but that people generally preferred domiciliary care (Boland et al., 2017). Finally, low medication receipt is also cited as a negative outcome. However, dementia medications have low efficacy, severe side effects and increased mortality risk (Maust et al., 2015; Vaci et al., 2020; Valenzuela et al., 2019). Ultimately, the outcomes of diagnosis, residential care admission and medication are subject to ongoing debate and should not be taken for granted. However, the problematisation of ethnicity-based inequalities is predicated upon normative evaluations of the desirability of these outcomes. It is also notable that such evaluations are typically made on behalf of ME populations, irrespective of their preferences.

The problematisation of (minority) ethnicity in dementia extends beyond the evaluation of outcomes to understanding their causes. Once ethnicity-differentiated outcomes are framed as detrimental for the minority group, the blame for this disadvantage is then often attributed to their 'culture' rather than institutions and services responsible for providing support. The ill-suitedness of services to different populations is cast as poor help-seeking by ME populations, while under-diagnosis is blamed on poor understanding (e.g. Low et al., 2019). The Social Care Institute for Excellence (SCIE, n.d.) advice for professionals working with ME carers illustrates this:

There is evidence that minority ethnic carers are more likely to be isolated from mainstream services. Some may view using a service as a source of shame. In Islam, Hinduism and Sikhism the duty of care is apparent or is regarded as a 'test from God'. There is stigma around dementia in some cultures; it may be regarded as a punishment for past misdemeanours or a family member with dementia may damage the marriage prospects of a young relative.

There's evidence that people from BME communities are not sure where or how to find information about dementia. This is exacerbated by language barriers or when people have lost cognitive skills, or if online information is not available in community languages. People may confuse the symptoms of dementia with 'normal ageing' and not seek the support that is available.

Here, 'isolation from mainstream services' is primarily attributed to minority cultures, which are thus rendered problematic. This homogenising account of ME persons' cultural differences is accompanied with only a brief acknowledgement that information should be made available in various languages. The root of the problem is hence identified as the ways of being of those affected. The risk is that dementia's purported ethnicity problem is partially sustained by normative evaluations of certain outcomes as problematic, without robust evidence and on behalf of those populations, and the subsequent shifting of blame from institutions onto the populations being spoken for.

In 2004, Iliffe and Manthorpe questioned uses of ethnicity in dementia research. They reiterated longstanding category fallacy critiques of ethnicity, wherein ethnic categories are crude proxies concealing other important phenomena, e.g. educational and socio-economic inequalities. They suggested that intra-ethnic differences in experiences of dementia were at least as pronounced as inter-ethnic differences. This observation passed largely unheeded, as heterogeneous classifications of ethnicity within dementia research have since proliferated. British studies have used: Asian (Jolley et al., 2009), South Asian (Uppal & Bonas, 2014), South Asian (Indian) (Purandare et al., 2007), British Indian (Parveen et al., 2017), Hindi and Punjabi South Asian (La Fontaine, 2007) and Sikh (Uppal & Bonas, 2014). There is little standardisation across categories that use country, (sub)continent, religion and/or skin colour to delineate types of people, with scant consideration of what such categories contain, exclude, reveal and conceal.

Noting these unreflective approaches to ethnicity in dementia research, Roche and colleagues (2021) interrogate the continued use of ethnic classifications. While useful in highlighting broad commonalities and differences, the vast diversity that is contained within common categories means that these analyses forfeit much cultural nuance. Hence, such research may not be substantively applicable to the individuals it claims to represent. Roche et al. (2021) also note widespread ethnic discordance between researchers and participants in such scholarship, with research about ME groups dominated by majority ethnicity researchers. This could partially explain the common attribution of blame to, and calls for intervening in, populations rather than services. Ultimately, Roche et al. (2021) ask researchers to reflect on whether they are racialising data that capture the difficulties experienced by various people facing different political, cultural and socio-economic constraints. This recognition has been forwarded elsewhere (e.g. Fletcher, 2020b, 2021; Forbat, 2003; MacKenzie, 2006; O'Connor et al., 2010), albeit infrequently. It is a concern to which we will return when considering what aspects of dementia are revealed by the newfound ethnicity problem, and what is concealed.

Taking a different approach, Fletcher (2020b) has questioned the problematisation of minority ethnicity populations in dementia research on awareness. This analysis reveals that a growing body of research measures the ‘awareness’ of crudely categorised ME populations against poorly justified neuropsychiatric knowledge claims; finds these populations to be culturally deficient in knowledge and awareness; and advocates interventions to improve these populations. For example, Jang et al. (2010, p. 426) asked Korean Americans whether the following statement was true or false to measure knowledge: ‘All humans if they live long enough, will probably develop Alzheimer’s disease.’ It is unclear how anybody could evaluate the validity of this statement, yet awareness tests often involve these kinds of questions and admonish participants’ ethnic groups when their answers are deemed incorrect. Rather than engaging with diversity, much ethnicity-focused awareness research judges ME groups to have insufficient knowledge and to therefore require re-education in superior ways of knowing and being. Such approaches implicitly equate ‘poor’ outcomes with cultural deficiencies.

These critiques sit within wider scholarship on racism and psychiatric disorder. Pickens (2019) argues that blackness and madness are historically and culturally entangled as ‘hauntological’ presences, each defining the other as we argue (below) that ethnicity is used to support neuropsychiatric imaginings of dementia. Such entanglements litter history. Slaves in the 18th–19th century US were widely deemed predisposed to madness, as were Jews in Nazi Germany (Gilman, 1985). This history shapes contemporary neuropsychiatric engagements with ethnicity, e.g. African Americans are four times more likely than white Americans to be diagnosed with schizophrenia (Metzl, 2010). Institutional racism in the British mental health system has long been recognised, from historic conceptualisations of non-Europeans as psychosocially primitive, to the contemporary IQ movement and the disproportionate detention of ME people under psychiatric legislation (Fernando, 2010). Echoing our concerns, Fernando (2010) has critiqued the universalisation of psychiatry over diverse cultures, wherein ethnicity-associated differences are normatively appraised against white Western values.

The concordant problematisation of ME mental health ‘access’ inequalities has received critical attention. Contra explanations of poor help-seeking and poor understanding, racist attitudes can prevent people from accessing services and worsen the experiences of those who do (Faulkner, 2014). As a stark example of racialised access/barrier beliefs underpinning support services, Burman et al. (2004) have shown that services often exclude ME victims of domestic violence by overlooking, even excusing, such abuse for ‘cultural reasons’. Services are often ill-equipped to engage with, and at worst actively refute, people’s own appreciations of psychiatric disorder, including influences of racism (Kalathil, 2011). Even well-intentioned interventions can serve problematic imaginings of ethnicity. Gunaratnam (2008) has argued that the contemporary rise of ‘cultural competence’ therapeutic approaches essentialises culture and obscures sociopolitical facets of the health and illness experiences of ME people. Insufficient funding for dedicated ME services exacerbates these issues, with mainstream services tailored toward majority ethnic populations amidst resource pressures. Such settings offer little scope for users to share experiences of racism. This opens possibilities for non-compliance with neuropsychiatric imaginaries as anti-racist resistance. Gardner (2020) has observed that the illness narratives of Bangladeshi migrants living in London can contain

veiled protests against mainstream health services that migrants perceive to have failed them. Echoing these wider scholarships on ethnicity and mental health, an emerging critical sociology of dementia aims to question the problematisation of ethnicity (e.g. Fletcher, 2020b, 2021; Roche et al., 2021). At its heart is the observation that the recent turn to ethnicity in dementia's neuropsychiatric development is contingent upon suspect claims, racialised assumptions, and positioning (minority) ethnicity as a new type of problem in relation to dementia. This sociology traces how ethnicity has become a conventional domain within the dementia movement. However, this emerging scholarship is yet to consider how neuropsychiatric imaginings of dementia are aided by problematic uses of ethnicity. It is to this issue that we now turn.

A useful problem?

In this final section, we will document two major ways in which the ethnicity problem furthers specific imaginings of dementia. First, ethnicity provides a means of asserting a normative neuropsychiatric system of meaning that governs public conduct. Ethnicity becomes an example of how we ought not to be. Second, the problematisation of ethnicity provides a basis for legitimising action, and more specifically, the righteous accrual and mobilisation of resources, often in a manner that perpetuates the ethnicity problem. Ultimately, we show how the propagation of an ethnicity problem supports broader neuropsychiatric imaginings of dementia.

Beginning with normative neuropsychiatric meanings, Cohen (2006) notes that dementia is a powerful manifestation of the foundational problem of geriatrics – disentangling pathology and old age. In the early 20th century, Nascher, the founding father of geriatrics, noted that physicians overlooked the complexities of ageing and agedness because they could not distinguish the normal from the pathological in older patients. This problem remains central to dementia (Fletcher, 2020a). How is one to objectively distinguish normal age-related cognitive decline from dementia given longstanding discrepancies in observations of neuropathology and symptomology? Since the 1970s, various numerical scales have been designed to distinguish dementia from age-related cognitive decline (Wilson, 2014). The current iteration of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) has gone so far as to reclassify dementia as cognition at least two standard deviations below an age group's mean cognition (Sachdev et al., 2014). This quantification echoes the wider post-1970s proliferation of psychiatric statistics as governments sought more sophisticated modelling of mental health welfare expenditure (Orr, 2010). Quantification is hence a major component of biopolitics generally.

This reliance on numerical differentiation between the normal and the pathological in contemporary neuropsychiatric imaginings of dementia exemplifies Canguilhem's (1998) modern concept of disease within a quantified normality–abnormality spectrum. Here, pathology is an extreme variation of a physiological range, deviating from a healthy average. Canguilhem contended that the medical promotion of a quantified notion of disease is an attempt to claim value-neutrality. Using statistics as an alternative to normative judgement is flawed, however, because deeming any human condition (*ab normal*) cannot be neutral. Indeed, efforts to distinguish pathology are driven by desires

to derive therapeutics that can transform undesirable states into preferable states. This is an inherently value-laden endeavour, distinguishing desirable states from those which require intervention.

Much discussion of dementia's ethnicity problem centres on neuropsychiatric appraisals of the normal and the pathological. SCIE (n.d.) claims that ME groups 'may confuse the symptoms of dementia with "normal ageing" and not seek the support that is available'. The All-Party Parliamentary Group on Dementia (2013, p. 27) suggests that ME groups 'are unlikely to recognise the early symptoms of the condition or perceive them as a health problem' and that 'the lack of a concept of cognitive impairment or dementia can make it difficult to provide a coherent account of symptoms'. Such claims also pervade research literature. Moriarty (2015, pp. 88–89) posits that 'people from ethnic and cultural backgrounds¹ who view dementia as a "normal" part of ageing may be less likely to request support for family members with dementia until a crisis point is reached, because they do not think they have an illness'. Similarly, Gray and colleagues (2009, pp. 925–926) note that 'ethnic minority families may lack the necessary information or hold culturally influenced beliefs about dementias that can delay necessary help seeking. Unfortunately, the increased understandings of dementia resulting from medical/scientific advances are not commonly held among members of various ethnic minority groups.' Within such claims, notions of normality/pathology enable negative moral assessments of ME families.

The latter example is particularly revealing of how (minority) ethnicity is problematised to support neuropsychiatric imaginings of dementia, explicitly targeting failure to engage with 'increased understandings of dementia resulting from medical/scientific advances' (Gray et al., 2009, p. 926). Discussions of ethnicity often reassert the righteous conceptualisation of dementia as a cognitive syndrome caused by discrete neuropathologies that are distinct from ageing. The 'ethnic' failure is explicated as a failure to know the truth. However, despite stakeholders' assertions, the neuropsychiatric account of dementia remains hypothetical, with several longstanding inconsistencies (Fletcher, 2020a). The observation that some people with symptoms do not have the associated pathology, while some people with pathology do not experience symptoms, is among the most perplexing neuropsychiatric problems (Lock, 2013). Moreover, clinical trials based on dominant molecular hypotheses have failed to produce effective treatments or even worsened outcomes (Cummings, 2018; Fletcher & Birk, 2019). Hence, appeals to dementia as an established neuropsychiatric entity are themselves undermined by scientific evidence, yet ME groups are repeatedly measured and derided in reference to these appeals.

Similarly suspect are claims that dementia is not normal ageing, which are repeatedly used to discredit ME groups (Fletcher, 2020b). Much critical gerontology scholarship cautions against prescriptions of 'normal' ageing because ageing is a driver of heterogeneity. Indeed, cultural gerontology has revealed the marked diversity of ageing (Rajan-Rankin, 2018). Appeals to 'normal ageing' have traditionally been used to apply authors' values to older people, and have been criticised as problematically universalist and normative (Holstein & Minkler, 2003; Martinson & Berridge, 2014). References to 'normal' in articulations of ethnicity as a problem in dementia hence exemplify long-critiqued political practices. In appealing to 'normal ageing' as a benchmark for other

states of later life, commentators make claims about what later life should be, cloaking those judgements in a façade of incontrovertibility and universality. Those claims typically originate from researchers of a different ethnicity to the populations on whose behalf the claims are presented (Roche et al., 2021).

Considering core molecular and cognitive uncertainties, coupled with normative claims, reveals that neuropsychiatric imaginings of dementia are vulnerable to critique and therefore require sustained support. The supportive effort is evident in high-profile campaigns such as ARUK's (2019a) #ShareTheOrange productions or the Alzheimer's Society's (2017) Dementia Friends initiative, which explicitly seek to convert the public to neuropsychiatric imaginings (Fletcher, 2019c, 2020b). Contemporary representations of ME groups as insufficiently compliant offer another means of support by casting those populations as neuropsychiatric antagonists. The implication is that people should not be like those uninformed ethnic 'others' whose non-compliance causes worse outcomes. Hence, neuropsychiatric compliance becomes a means of not being like the ethnic antagonist. Ethnicity functions as a cautionary tale that reiterates a neuropsychiatric ethic of self-governance, guiding the 'continuous work of modulation of the self in relation to an ideal' (Rose, 2009, p. 80). A new form of life is prescribed, part of a broader biopolitics of attaining the right kinds of later life in relation to dementia (Latimer, 2018).

The positioning of minority ethnicity as an existential cautionary tale in dementia exemplifies several features of governmentality. 'Government' here is taken in the broad sense of controlling people's conduct, and is combined with 'mentality' to denote control over thought. Ultimately, this governmentality facilitates conduct of conduct, making people into self-governing subjects, conducting themselves according to the parameters of said rationality. Positionings of ethnicity in dementia contribute to this governmentality, manifesting a symbolic binary of right (neuropsychiatric) and wrong (ME) conduct. This governmentality uses longstanding racist depictions of mental disorder to substantiate neuropsychiatric imaginings. Beliefs that minority ways of being are somehow inferior and problematic furnish a pre-existing intellectual foundation against which the opposed – and thus superior and unproblematic – way of being can be drawn in starker contrast (Rajan-Rankin, 2018). That said, while the positioning of ME groups in relation to dementia contributes to governmentality, it also extends beyond it. Li (2007) has charted the limits of governmentality in the context of colonialism, wherein more forceful forms of racist control are also imposed. Thus, governmentality is a useful concept for analysing racialised governance, but it is not always sufficient, and one must be mindful of more aggressive racist aspects of the ethnicity problem in dementia.

Conclusion

We have sought to outline how recent uses of ethnicity in the dementia movement have created an ethnicity problem. We have contextualised its emergence in relation to dementia within the broader late 20th/early 21st century creep of neuropsychiatric imaginings into public life and human relations of meaning. Doing so reveals how new representations of ethnicity and ME groups as a problem contribute to a wider neuropsychiatric symbolism through which we increasingly understand and govern our lives. This

problematization of ethnicity supports neuropsychiatric imaginings of dementia through reasserting core meanings and concealing tensions. Appeals to an ethnicity problem are particularly potent because they catalyse several panics. Longstanding alarm regarding blackness and madness aligns with newer terrors of demographic ageing and welfare burden. Hence, the topic of ME dementia manifests existential perils that extend far beyond dementia, ultimately threatening population decay and proliferating disorder. A biopolitical analysis highlights this amalgamation of historic concerns to a greater extent than anti-medicalisation scholarship has been able to.

Taking a biopolitical approach draws attention toward moral and political facets of a neuropsychiatric dementia that, while drawing on a (bio)medical model, goes further in its truth claims and prescribed interventions. Whereas (bio)medical models cast medicine as the instrument of normalisation, neuropsychiatric imaginings of dementia venerate promissory technoscience, personal responsibility and outright enhancement. This has major implications for the public, because while the (bio)medical model requires that they accept expert intervention, the neuropsychiatric imaginary requires correct personal conduct. Moreover, dementia is made into a universal public concern, a longitudinal risk that we must all, irrespective of our age and cognition, guard against through self-governance and preventative effort (Leibing & Schickanz, 2021). This extension of personal responsibility may have important implications for social care because the need for later life care manifests life-long failings of self-care, undermining the moral case for public support. However, this is complicated by the repeated admonishment of ME people affected by dementia for failing to engage with services, thereby casting formal care in a pro-neuropsychiatric/non-ethnic light. Such tensions warrant further research. A biopolitical view also alerts us to the dynamism of neuropsychiatric imaginaries, with the ethnicity problem emerging relatively recently and rapidly. The phenomena described herein exemplify Rabinow and Rose's (2006) tripartite conception of biopower: (1) vital truth claims (e.g. the dementia/ageing dichotomy), (2) intervention strategies (e.g. awareness campaigns), (3) subjectification (e.g. re-education). Such component identification creates potential for more dedicated scholarly attention to these issues.

Stakeholders in dementia's ethnicity problem might reflect on their engagements with ethnicity, especially regarding how they articulate certain problems and whose interests are served by such articulations. Rajan-Rankin (2018, p. 36) argues: 'de-colonizing the western canon requires us to not only question these knowledge claims, but also being mindful of not reproducing them'. We are not suggesting intentionality, but rather emphasise the Weberian heritage of sociological work on biopolitics, noting that social action typically entails unforeseen, sometimes perverse, consequences (Ecks, 2020). The ethnicity problem was likely never intended in its current form, but nonetheless, it now exists. Researchers must consider whether they perpetuate or challenge it.

Declaration of conflicting interests

The author have declared no conflicting interests.

Funding

Moïse Roche is funded by Alzheimer's Society UK, grant number 404 AS-PhD-17b-007.

Note

1. Phrasing is indicative of a tendency to imply that only ME groups have ethnicity and culture, casting white people as ethnicity-less.

References

- All-Party Parliamentary Group on Dementia. (2013). *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*. House of Commons.
- Alzheimer's Disease International. (2020). *Types of dementia*. www.alz.co.uk/info/types-of-dementia (accessed 23 March 2020).
- Alzheimer's Society. (n.d.). UK Global Dementia Friends Ambassador Carey Mulligan. www.alzheimers.org.uk/about-us/policy-and-influencing/global-dementia-friendly-movement/global-dementia-friends-ambassador-carey-mulligan (accessed 24 March 2020).
- Alzheimer's Society. (2013). *Low expectations: Attitudes on choice, care and community for people with dementia in care homes*.
- Alzheimer's Society. (2017). *Dementia Friends*. www.dementiafriends.org.uk/ (accessed 31 March 2020).
- Alzheimer's Society. (2019). *Black, Asian and minority ethnic communities and dementia research*. www.alzheimers.org.uk/for-researchers/black-asian-and-minority-ethnic-communities-and-dementia-research (accessed 28 March 2020).
- Alzheimer's Research UK. (2019a). *#ShareTheOrange*. www.alzheimersresearchuk.org/orange/ (accessed 23 March 2020).
- Alzheimer's Research UK. (2019b). Samuel L. Jackson stars in powerful dementia campaign to challenge misunderstanding of condition. www.alzheimersresearchuk.org/samuel-l-jackson-share-the-orange/ (accessed 24 March 2020).
- Andrews, S., McInerney, F., Toye, C., Parkinson, C. A., & Robinson, A. (2017). Knowledge of dementia: Do family members understand dementia as a terminal condition? *Dementia, 16*(5), 556–575.
- Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Policy Press.
- BBC. (2019). *Jesy Nelson: 'Odd one out'*. www.bbc.co.uk/iplayer/episode/p07lrs4d/jesy-nelson-odd-one-out (accessed 24 March 2020).
- Boland, L., Légaré, F., Perez, M. M. B., Menear, M., Garvelink, M. M., McIsaac, D. I., Guérard, G. P., Emond, J., Brière, N., & Stacey, D. (2017). Impact of home care versus alternative locations of care on elder health outcomes: An overview of systematic reviews. *BMC Geriatrics, 17*(1), 20.
- Bond, J. (1992). The medicalization of dementia. *Journal of Aging Studies, 6*(4), 397–403.
- Bond, J., Corner, L., Lilley, A., & Ellwood, C. (2002). Medicalization of insight and caregivers' responses to risk in dementia. *Dementia, 1*(3), 313–328.
- Brain Health (n.d.). www.brainhealth.scot/ (last accessed 2 November 2021).
- Burman, E., Smailes, S. L., & Chantler, K. (2004). 'Culture' as a barrier to service provision and delivery: Domestic violence services for minoritized women. *Critical Social Policy, 24*(3), 332–357.
- Cahill, S. (2018). *Dementia and human rights*. Policy Press.
- Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Disease & Associated Disorders, 29*(3), 255–275.
- Camp, C. J. (2019). Denial of human rights: We must change the paradigm of dementia care. *Clinical Gerontologist, 42*(3), 221–223.

- Canguilhem, G. (1998). *The normal and the pathological*. Zone Books.
- Cations, M., Radisic, G., Crotty, M., & Laver, K. E. (2018). What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys. *PLoS One*, *13*(4), e0196085.
- Chaufan, C., Hollister, B., Nazareno, J., & Fox, P. (2012). Medical ideology as a double-edged sword: The politics of cure and care in the making of Alzheimer's disease. *Social Science & Medicine*, *74*(5), 788–795.
- Cohen, L. (2006). Introduction. In L. Leibing & L. Cohen (Eds.), *Thinking about dementia: Culture, loss, and the anthropology of senility* (pp. 1–20). Rutgers University Press.
- Cooper, C., Tandy, A. R., Balamurali, T. B., & Livingston, G. (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *The American Journal of Geriatric Psychiatry*, *18*(3), 193–203.
- Cummings, J. (2018). Lessons learned from Alzheimer disease: Clinical trials with negative outcomes. *Clinical and Translational Science*, *11*(2), 147–152.
- Ecks, S. (2020). Coronashock capitalism: The unintended consequences of radical biopolitics. *Medical Anthropology Quarterly Rapid Response Blog Series*. <http://medanthroquarterly.org/2020/04/06/coronashock-capitalism-the-unintended-consequences-of-radical-biopolitics/> (accessed 6 April 2020).
- Faulkner, A. (2014). *Ethnic inequalities in mental health: Promoting lasting positive change a consultation with black and minority ethnic mental health service users*. National Survivor User Network.
- Fernando, S. (2010). *Mental health, race and culture* (3rd ed.). Palgrave.
- Fessey, V. (2007). Patients who present with dementia: Exploring the knowledge of hospital nurses. *Nursing Older People*, *19*(10), 29–33.
- Fletcher, J. R. (2018). A symbolic interactionism of dementia: A tangle in 'The Alzheimer Conundrum'. *Social Theory & Health*, *16*(2), 172–187.
- Fletcher, J. R. (2019a). *A problem shared: The interacted experience of dementia within care*. King's College London.
- Fletcher, J. R. (2019b). Distributed selves: Shifting inequities of impression management in couples living with dementia. *Symbolic Interaction*, *43*(3), 405–427.
- Fletcher, J. R. (2019c). Destigmatising dementia: The dangers of felt stigma and benevolent othering. *Dementia*, *20*(2), 417–426.
- Fletcher, J. R. (2020a). Mythical dementia and Alzheimerised senility: Discrepant and intersecting understandings of cognitive decline in later life. *Social Theory & Health*, *18*(1), 50–65.
- Fletcher, J. R. (2020b). Positioning ethnicity in dementia awareness research: The use of senility to ascribe cultural inadequacy. *Sociology of Health & Illness*, *42*(4), 705–723.
- Fletcher, J. R. (2021). Black knowledges matter: How the suppression of non-white understandings of dementia harms us all and how we can combat it. *Sociology of Health & Illness*. Advance online publication. <https://doi.org/10.1111/1467-9566.13280>
- Fletcher, J. R., & Birk, R. H. (2019). Circularity, biomarkers and biosocial pathways: The operationalisation of Alzheimer's and stress in research. *Social Science & Medicine*, *239*(1), 112553.
- Forbat, L. (2003). Concepts and understandings of dementia by 'gatekeepers' and minority ethnic service users. *Journal of Health Psychology*, *8*(5), 645–655.
- Fox, P. (1989). From senility to Alzheimer's disease: The rise of the Alzheimer's disease movement. *The Milbank Quarterly*, *67*(1), 58–102.
- Fox, C., Lafortune, L., Boustani, M., & Brayne, C. (2013). The pros and cons of early diagnosis in dementia. *British Journal of General Practice*, *63*(612), e510–e512.

- Gallagher-Thompson, D., Solano, N., Coon, D., & Arian, P. (2003). Recruitment and retention of Latino dementia family caregivers in intervention research: Issues to face, lessons to learn. *The Gerontologist*, 43(1), 45–51.
- Gardner, K. (2020). *Age, narrative and migration: The life course and life histories of Bengali elders in London*. Routledge.
- Gawande, A. (2014). *Being mortal: Illness, medicine, and what matters in the end*. Profile Books.
- Gilman, S. L. (1985). *Difference and pathology: Stereotypes of sexuality, race, and madness*. Cornell University Press.
- Glynn, R. W., Shelley, E., & Lawlor, B. A. (2017). Public knowledge and understanding of dementia: Evidence from a national survey in Ireland. *Age and Ageing*, 46(5), 865–869.
- Goodley, D. (2018). Understanding disability: Biopsychology, biopolitics, and an in-between-all politics. *Adapted Physical Activity Quarterly*, 35(3), 308–319.
- Gov.UK. (2020). *HRH Duke of Cambridge and football legends champion mental health*. www.gov.uk/government/news/hrh-duke-of-cambridge-and-football-legends-champion-mental-health (accessed 24 March 2020).
- Graham, C., Ballard, C., & Sham, P. (1997). Carers' knowledge of dementia and their expressed concerns. *International Journal of Geriatric Psychiatry*, 12(4), 470–473.
- Gray, H. L., Jimenez, D. E., Cucciare, M. A., Tong, H. Q., & Gallagher-Thompson, D. (2009). Ethnic differences in beliefs regarding Alzheimer disease among dementia family caregivers. *The American Journal of Geriatric Psychiatry*, 17(11), 925–933.
- Gunaratnam, Y. (2008). From competence to vulnerability: Care, ethics, and elders from racialized minorities. *Mortality*, 13(1), 24–41.
- Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., Lee, S. M., Vratsidis, F., Lautenschlager, N., & LoGiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. *Journal of Cross-Cultural Gerontology*, 29(1), 69–86.
- Harris, P. B. (2010). Dementia and dementia care: The contributions of a psychosocial perspective. *Sociology Compass*, 4(4), 249–262.
- Hinton, L., Franz, C. E., Yeo, G., & Levkoff, S. E. (2005). Conceptions of dementia in a multiethnic sample of family caregivers. *Journal of the American Geriatrics Society*, 53(8), 1405–1410.
- Hinton, L., Guo, Z., Hillygus, J., & Levkoff, S. (2000). Working with culture: A qualitative analysis of barriers to the recruitment of Chinese-American family caregivers for dementia research. *Journal of Cross-Cultural Gerontology*, 15(2), 119–137.
- Holstein, M. B., & Minkler, M. (2003). Self, society, and the 'new gerontology'. *The Gerontologist*, 43(6), 787–796.
- Hossain, M. Z., & Khan, H. T. (2020). Barriers to access and ways to improve dementia services for a minority ethnic group in England. *Journal of Evaluation in Clinical Practice*, 25(6), 1629–1637.
- Howell, A. (2018). Forget 'militarization': Race, disability and the 'martial politics' of the police and of the university. *International Feminist Journal of Politics*, 20(2), 117–136.
- Howell, A., & Richter-Montpetit, M. (2019). Racism in Foucauldian security studies: Biopolitics, liberal war, and the whitewashing of colonial and racial violence. *International Political Sociology*, 13(1), 2–19.
- Illiffe, S., & Manthorpe, J. (2004). The debate on ethnicity and dementia: From category fallacy to person-centred care? *Aging & Mental Health*, 8(4), 283–292.
- Jang, Y., Kim, G., & Chiriboga, D. (2010). Knowledge of Alzheimer's disease, feelings of shame, and awareness of services among Korean American elders. *Journal of Aging and Health*, 22(4), 419–433.

- Jenkins, N. (2017). No substitute for human touch? Towards a critically posthumanist approach to dementia care. *Ageing & Society*, 37(7), 1484–1498.
- Jolley, D., Moreland, N., Read, K., Kaur, H., Jutla, K., & Clark, M. (2009). The ‘Twice a Child’ projects: Learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services. *Ethnicity and Inequalities in Health and Social Care*, 2(4), 4–9.
- Kalathil, J. (2011). *Recovery and resilience: African, African-Caribbean and South Asian women’s narratives of recovering from mental distress*. Mental Health Foundation.
- Katzman, R. (1976). The prevalence and malignancy of Alzheimer disease: A major killer. *Archives of Neurology*, 33(4), 217–218.
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer’s disease. *Ageing & Society*, 10(2), 177–196.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S., & Oyeboode, J. R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing*, 60(6), 605–614.
- Lam, N. H., & Woo, B. K. (2018). Exploring the role of YouTube in delivering dementia education to older Chinese. *Asian Journal of Psychiatry*, 31, 25–26.
- Latimer, J. (2018). Repelling neoliberal world-making? How the ageing–dementia relation is reassembling the social. *The Sociological Review*, 66(4), 832–856.
- Lee, J. Y., Park, S., Kim, K. W., Kwon, J. E., Park, J. H., Kim, M. D., Kim, B. J., Kim, J. L., Moon, S. W., Bae, J. N., & Ryu, S. H. (2016). Differences in knowledge of dementia among older adults with normal cognition, mild cognitive impairment, and dementia: A representative nationwide sample of Korean elders. *Archives of Gerontology and Geriatrics*, 66, 82–88.
- Leibing, A., & Schickel, S. (2021). *Preventing dementia? Critical perspectives on a new paradigm of preparing for old age*. Berghahn.
- Li, T. M. (2007). Governmentality. *Anthropologica*, 49(2), 275–281.
- Lock, M. (2013). *The Alzheimer conundrum: Entanglements of dementia and ageing*. Princeton University Press.
- Low, L. F., Anstey, K. J., Lackersteen, S. M., & Camit, M. (2011). Help-seeking and service use for dementia in Italian, Greek and Chinese Australians. *Ageing & Mental Health*, 15(3), 397–404.
- Low, L. F., Barcenilla-Wong, A. L., & Brijnath, B. (2019). Including ethnic and cultural diversity in dementia research. *The Medical Journal of Australia*, 211(8), 345–346.
- Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, 29(5), 597–605.
- MacKenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia*, 5, 233–247.
- Manning, N. (2019). Sociology, biology and mechanisms in urban mental health. *Social Theory & Health*, 17(1), 1–22.
- Martinson, M., & Berridge, C. (2014). Successful aging and its discontents: A systematic review of the social gerontology literature. *The Gerontologist*, 55(1), 58–69.
- Mausbach, B. T., Coon, D. W., Depp, C., Rabinowitz, Y. G., Wilson-Arias, E., Kraemer, H. C., Thompson, L. W., Lane, G., & Gallagher-Thompson, D. (2004). Ethnicity and time to institutionalization of dementia patients: A comparison of Latina and Caucasian female family caregivers. *Journal of the American Geriatrics Society*, 52(7), 1077–1084.
- Maust, D. T., Kim, H. M., Seyfried, L. S., Chiang, C., Kavanagh, J., Schneider, L. S., & Kales, H. C. (2015). Antipsychotics, other psychotropics, and the risk of death in patients with dementia: number needed to harm. *JAMA Psychiatry*, 72(5), 438–445.

- McParland, P., Devine, P., Innes, A., & Gayle, V. (2012). Dementia knowledge and attitudes of the general public in Northern Ireland: An analysis of national survey data. *International Psychogeriatrics*, 24(10), 1600–1613.
- McWade, B. (2016). Recovery-as-policy as a form of neoliberal state making. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, 5(3), 62–81.
- Metzl, J. M. (2010). *The protest psychosis: How schizophrenia became a black disease*. Beacon Press.
- Milne, A. (2010). Dementia screening and early diagnosis: The case for and against. *Health, Risk & Society*, 12(1), 65–76.
- Mitchell, D. T., & Snyder, S. L. (2015). *The biopolitics of disability: Neoliberalism, ablenationalism and peripheral embodiment*. University of Michigan Press.
- Morano, C. L., & King, M. D. (2010). Lessons learned from implementing a psycho-educational intervention for African American dementia caregivers. *Dementia*, 9(4), 558–568.
- Moriarty, J. (2015). Accessing support and services. In J. Botsford & K. H. Dening (Eds.), *Dementia, culture and ethnicity: Issues for all* (pp. 85–104). Jessica Kingsley Publishing.
- Moser, I. (2008). Making Alzheimer's disease matter: Enacting, interfering and doing politics of nature. *Geoforum*, 39(1), 98–110.
- Napoles, A. M., Chaduha, L., Eversley, R., & Moreno-John, G. (2010). Reviews: Developing culturally sensitive dementia caregiver interventions: are we there yet? *American Journal of Alzheimer's Disease & Other Dementias*, 25(5), 389–406.
- Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2020). Barriers to post-diagnostic care and support in minority ethnic communities: A survey of Danish primary care dementia coordinators. *Dementia*, 19(8), 2702–2713.
- Nielsen, T. R., Vogel, A., Phung, T. K. T., Gade, A., & Waldemar, G. (2011). Over-and under-diagnosis of dementia in ethnic minorities: A nationwide register-based study. *International Journal of Geriatric Psychiatry*, 26(11), 1128–1135.
- O'Connor, D., Phinney, A., & Hulko, W. (2010). Dementia at the intersections: A unique case study exploring social location. *Journal of Aging Studies*, 24(1), 30–39.
- Orr, J. (2010). Psychiatry and the informatics of diagnosis: Governing mentalities. In A. E. Clarke, L. Mamo, J. R. Fosket, J. R. Fishman, & J. K. Shim (Eds.), *Biomedicalization: Technoscience, health, and illness in the US* (pp. 353–379). Duke University Press.
- Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health & Illness*, 37(3), 385–403.
- Parveen, S., Peltier, C., & Oyeboode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: A scoping exercise. *Health & Social Care in the Community*, 25(2), 734–742.
- Pathak, K. P., & Montgomery, A. (2015). General practitioners' knowledge, practices, and obstacles in the diagnosis and management of dementia. *Aging & Mental Health*, 19(10), 912–920.
- Pickens, T. A. (2019). *Black madness: Mad blackness*. Duke University Press.
- Purandare, N., Luthra, V., Swarbrick, C., & Burns, A. (2007). Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. *International Journal of Geriatric Psychiatry*, 22(8), 777–781.
- Rabinow, P., & Rose, N. (2006). Biopower today. *BioSocieties*, 1(2), 195–217.
- Rajan-Rankin, S. (2018). Race, embodiment and later life: Re-animating aging bodies of color. *Journal of Aging Studies*, 45, 32–38.
- Roche, M., Higgs, P., Aworinde, J., & Cooper, C. (2021). A review of qualitative research of perception and experiences of dementia among adults from Black, African, and Caribbean background: What and whom are we researching? *The Gerontologist*, 61(5), e195–e208.

- Ronch, J. L. (2004). Changing institutional culture: Can we re-value the nursing home? *Journal of Gerontological Social Work*, 43(1), 61–82.
- Rose, N. (2007). Beyond medicalisation. *The Lancet*, 369(9562), 700–702.
- Rose, N. (2009). Normality and pathology in a biomedical age. *The Sociological Review*, 57(2), 66–83.
- Rose, N. (2019). *Our psychiatric future*. Polity.
- Rosenberg, C. E. (2002). The tyranny of diagnosis: Specific entities and individual experience. *The Milbank Quarterly*, 80(2), 237–260.
- Sabat, S. R. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Blackwell.
- Sachdev, P. S., Blacker, D., Blazer, D. G., Ganguli, M., Jeste, D. V., Paulsen, J. S., & Petersen, R. C. (2014). Classifying neurocognitive disorders: The DSM-5 approach. *Nature Reviews Neurology*, 10(11), 634–642.
- Samsi, K., & Manthorpe, J. (2014). Care pathways for dementia: Current perspectives. *Clinical Interventions in Aging*, 9, 2055–2063.
- Schillmeier, M. (2015). *Eventful bodies: The cosmopolitics of illness*. Ashgate.
- Schrauf, R. W., & Iris, M. (2012). Very long pathways to diagnosis among African Americans and Hispanics with memory and behavioral problems associated with dementia. *Dementia*, 11(6), 743–763.
- Shakespeare, T. (2014). *Disability rights and wrongs revisited* (2nd ed.). Routledge.
- Smith, B. J., Ali, S., & Quach, H. (2014). Public knowledge and beliefs about dementia risk reduction: A national survey of Australians. *BMC Public Health*, 14(1), 1–10.
- Social Care Institute for Excellence. (n.d.). Black and minority ethnic (BME) communities and dementia. www.scie.org.uk/dementia/living-with-dementia/bme/ (accessed 28 March 2020).
- Sun, F., Mutlu, A., & Coon, D. (2014). Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. *Clinical Gerontologist*, 37(2), 120–138.
- Turner, S., Christie, A., & Haworth, E. (2005). South Asian and white older people and dementia: A qualitative study of knowledge and attitudes. *Diversity in Health & Social Care*, 2(3), 197–209.
- Uppal, G., & Bonas, S. (2014). Constructions of dementia in the South Asian community: A systematic literature review. *Mental Health, Religion & Culture*, 17(2), 143–160.
- Vaci, N., Koychev, I., Kim, C. H., Kormilitzin, A., Liu, Q., Lucas, C., Dehghan, A., Nenadic, G., & Nevado-Holgado, A. (2020). Real-world effectiveness, its predictors and onset of action of cholinesterase inhibitors and memantine in dementia: A retrospective health record study of 7400 individuals using the UK CRIS platform. *The British Journal of Psychiatry*. Advance online publication. doi: 10.1192/bjp.2020.136.
- Valenzuela, M., Sachdev, P., & Brodaty, H. (2019). Concerns about cholinesterase inhibitor recommendations. *Neurology*. <https://n.neurology.org/content/concerns-about-cholinesterase-inhibitor-recommendations> (accessed 27 March 2020).
- Valle, R., Yamada, A. M., & Matiella, A. C. (2006). Fotonovelas: A health literacy tool for educating Latino older adults about dementia. *Clinical Gerontologist*, 30(1), 71–88.
- Van Patten, R., & Tremont, G. (2020). Public knowledge of late-life cognitive decline and dementia in an international sample. *Dementia*, 19(6), 1758–1776.
- Watson, R., Bryant, J., Sanson-Fisher, R., Mansfield, E., & Evans, T. J. (2018). What is a ‘timely’ diagnosis? Exploring the preferences of Australian health service consumers regarding when a diagnosis of dementia should be disclosed. *BMC Health Services Research*, 18(612), 1–9.
- Whitehouse, P. J., & George, D. (2008). *The myth of Alzheimer's: What you aren't being told about today's most dreaded diagnosis*. St Martin's Griffin.

- Wigg, J. M. (2010). Liberating the wanderers: Using technology to unlock doors for those living with dementia. *Sociology of Health & Illness*, 32(2), 288–303.
- Williams, S. J., Higgs, P., & Katz, S. (2012). Neuroculture, active ageing and the ‘older brain’: Problems, promises and prospects. *Sociology of Health & Illness*, 34(1), 64–78.
- Williams, S. J., Katz, S., & Martin, P. (2011). Neuroscience and medicalisation: Sociological reflections on memory, medicine and the brain. In M. Pickersgill & I. Van Keulen (Eds.), *Sociological Reflections on the Neurosciences* (pp. 231–254). Emerald Group Publishing.
- Willis, R., Zaidi, A., Balouch, S., & Farina, N. (2020). Experiences of people with dementia in Pakistan: Help-seeking, understanding, stigma, and religion. *The Gerontologist*, 60(1), 145–154.
- Wilson, D. (2014). Quantifying the quiet epidemic: Diagnosing dementia in late 20th-century Britain. *History of the Human Sciences*, 27(5), 126–146.
- Zhang, Y. (2018). Governing dementia: A historical investigation of the power of states and professionals in the conceptualization of dementia in China. *Culture, Medicine, and Psychiatry*, 42(4), 862–892.