

## ARTICLE

# Bridging the gap between clinical and critical sociological perspectives in dementia

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## SUMMARY

There is a widening gap between the medical model of dementia and critical sociological perspectives of the condition. Given the relative failure of reductionism in dementia and its rising prevalence, consideration of the utility of these critical viewpoints is warranted. This article considers how these ideas, which challenge some prevailing assumptions about dementia, can be meaningfully applied in conjunction, rather than in competition, with conventional clinical ideas. To illustrate this, current perspectives on selfhood, biopolitics, citizenship and post-humanism are discussed. This article may also help to articulate sociologically oriented approaches already used by some clinicians and legitimise the time and attention needed to explore and deliver these. We support the view that dementia is an episteme in the making and that different traditions and dispositions can fruitfully collide to enliven interdisciplinary conversations about dementia and dementia care.

## KEYWORDS

Critical psychiatry; sociology; gerontology; dementia; citizenship.

## LEARNING OBJECTIVES

After reading this article you will be able to:

- explain how different models of the self in dementia suggest its resilience and may help in diagnostic counselling
- explain how citizenship is influenced by everyday activities and material objects
- consider dementia from a post-humanist perspective, offering some clinical initiatives, but also the possibility of iatrogenic harm.

The rising prevalence of dementia (from 57.4 million worldwide in 2019 to a predicted 152.8 million in 2050) due to population ageing poses a wide range of social and health challenges (Nichols 2022). Increasing dissatisfaction with the medical model's inability to account for the wide variation

in the individual experience of dementia has led to a proliferation of alternative theories of dementia arising from sociological and critical theory viewpoints. Some have accused the medical model of dehumanising people with dementia and failing to deliver treatments with substantive clinical effects (Fletcher 2023). In this article we consider how some of these perspectives, which challenge many prevailing medical assumptions about dementia, can be used alongside more traditional clinical ideas to improve the experience of diagnosis and post-diagnostic care for people with dementia. Although the use of 'dementia' as a singular umbrella term is almost as nonsensical as 'cancer' (given the multitude of aetiologies and varied individual experiences that it subsumes), it is used here for heuristic purposes. This article is most pertinent to late-onset early- to mid-stage dementia and may have less applicability to the challenges faced by younger people with the condition or those in more advanced or terminal phases of the condition. Finally, we introduce clinicians to some conceptual and practical implications of contemporary social science. This is valuable but, nonetheless, we must remember that most dementia care is 'informal', provided by family members and taking place beyond the clinic.

## Acknowledging current limitations

### *The unstable nosology of dementia*

Ever since a group of influential German physicians (Alzheimer, Pick, Kraepelin *et al*) reframed senility as a neurodegenerative disease over a century ago, the neurocognitive positioning of dementia has been contentious (Herrup 2021). This relates, in part, to the long-standing pathophysiological, cognitive and epidemiological challenges of differentiating the pathological and the normal to define a categorical dementia syndrome (Brayne 2007). The nosology of dementia remains unstable, with blurred and dynamic distinctions between aetiological subtypes (Morris 2000) and ever-changing diagnostic criteria, with limbic-predominant age-associated TDP-43 encephalopathy (LATE), vascular

dementia and frontotemporal dementias (FTD) being notable examples. Despite advances in imaging and plasma biomarkers, these continue to have a number of clinical limitations and dementia remains a clinical diagnosis in the absence of a single gold-standard radiological or laboratory test (Jordan 2017).

### *Current therapeutic limitations*

Biogenic hypotheses have had a limited therapeutic impact, and there have been several false dawns in the search for disease-modifying agents. The most recent and notable examples have been the trials of monoclonal antibodies (such as aducanumab and lecanemab) to cleanse the brain of beta-amyloid, the posited pathognomonic agent in late-onset Alzheimer's disease. Although these treatments based on the amyloid hypothesis do appear to reduce levels of plaque and other proteins in the brain, real-world results with representative populations remain disappointing (Tampi 2021). This may be due to the weak correlation between plaque load and cognition (Brayne 2007), suggesting that amyloid deposition may be more related to ageing than to disease. Given the questionable validity of brain amyloid burden as a surrogate end-point, there will be various associated challenges if any of these anti-amyloid agents enter routine clinical practice. This will include exacting conversations between clinician and patient about the rationale for treatment, potential side-effects (particularly cerebral oedema and micro-haemorrhages) and the costs and availability of the drug and required monitoring by positron emission tomography or 'PET' imaging (Tampi 2021). This would be further complicated if these agents were licensed for use in mild cognitive impairment, which remains difficult to define and where the risk–benefit balance may be even less favourable (Ebell 2022). The relative failure of pharmaceutical treatments for dementia extends beyond disease-modifying agents. Overall, evidence-based medicine has been more successful in determining which drugs are harmful (antipsychotics) or ineffective (antidepressants) rather than which are helpful, not that harmfulness always precludes use (Jordan 2017). Even cognitive enhancers, the only real pharmacotherapeutic advance in dementia care in the past 20 years, are modest treatments at best, and prescribing guidelines for non-cognitive symptoms have become more equivocal and qualified year by year (Jordan 2017).

Despite these unresolved clinical controversies, the political, economic and social imperatives to pursue dementia as a collection of neurodegenerative diseases necessitating biotechnological cures are strong. Although it may intuitively appear

paradoxical, biotechnological failure can provide a rationale for further efforts, based on beliefs that scientific progress is built on initial failures. Such convictions are evident in a range of media appeals for research funding for a magic bullet for dementia. This is often a powerful projection between patient and doctor in the memory clinic (Jordan 2017). However, once current therapeutic limitations are accepted by both parties, clinic time can then focus on constructive dialogue, such as how to adjust to the diagnosis, maintain a sense of agency and self-worth and live as well as possible with the condition (Xanthopoulos 2019). Arguably, the most important therapeutic developments in dementia have related to care, rather than cure, and have been informed by social scientific research. These include strategies to support the maintenance of selfhood and everyday citizenship. Given that these are rarely mentioned in medical texts and curriculums, some clinicians may be unsure of the theoretical rationale for these approaches and their applicability to practice, which we aim to clarify here. The time is apt for such clarification because some key social scientific responses to dementia are arguably diverging further from traditional medical commitments. Whereas earlier social dementia scholarship attended explicitly to care provision, for example person-centred care, the focus has gradually shifted towards more diverse and theoretically complex subject matter, such as postmodern citizenship, which appears at first glance to be less intuitively suited to clinical implementations (as outlined below). This article responds to this widening gap.

### **Medicalisation and personhood**

From the late 1980s, a tradition of social dementia research has critiqued mainstream thinking on dementia and posited alternatives. Scholars in this field began by criticising medicalisation and the medical model (Lyman 1989) inspired by a tradition of medical sociology from the 1970s (Zola 1972). By 'medicalisation' they referred to the treatment of later-life cognitive impairment, which had historically often been normalised as senility (Fox 1989), as a medical condition resulting from disease and therefore warranting medical intervention. For critics, the major problem with medicalisation was the dehumanisation of people with dementia, who were subject to various interpersonal insults (e.g. being infantilised, ignored or feared) or institutional impositions (e.g. involuntary confinement to care homes, an undermining of legal rights and being covertly medicated). At worst, this broad mistreatment constituted the worst aspects of the experience of dementia, with consequences more deleterious to

### BOX 1 Comparing personhood and selfhood

The word 'personhood' comes from social psychology, but Kitwood added ethical and religious attributes to it. Psychologically, self-esteem depends on one's relationships with social groups and one's corresponding roles, alongside one's own sense of self-coherence. Ethically, Kitwood rearticulated Kant's argument that the social world is only intelligible if people have intrinsic irrefutable value. Kitwood also suggested that human life is revered as sacred almost universally across religions. Hence, personhood is simultaneously religious, ethical and social psychological, defined as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood 1997: p. 8).

Sabat's notion of 'selfhood' is more distinctly rooted in the philosophical psychology of Rom

Harré. Selfhood is a composite, composed of three manifestations: Self 1, Self 2 and Self 3 (Sabat 1992). Self 1 is akin to personal identity, articulated via coherent personal narratives and pronouns. Self 2 is made up of one's distinctive mental and physical attributes. Self 3 encompasses the roles and personas that we fulfill in relation to others.

Selfhood and personhood are often conflated when people discuss ideas about the self in relation to dementia. Strictly speaking, these are distinct concepts, and it is the Self 3 manifestation of 'selfhood' and the social psychological portion of 'personhood' that overlap significantly. Ultimately, both concepts lead to a similar end – the recognition that the unique and special status of a human being is partially dependent on the complicity of other people.

well-being than the associated neurocognitive degeneration (Kitwood 1997). A related criticism of medicalisation has been that it disaggregates the sociological concepts of 'disease' and 'illness'. 'Disease' is the clinical, and increasingly biomarker-based, definition of a condition, whereas 'illness' is the person's experience of that condition – for example dementia could be defined from a disease perspective as neuron-killing proteinopathy or from an illness perspective as disabling forgetfulness. By leaning into technical disease definitions, medicalisation can alienate ill people from their conditions and devalue their experiential expertise.

In response, researchers rejected the medical model of dementia as neurocognitive degeneration in favour of more humanistic sensibilities. Early iterations of this approach focused on encouraging carers to re-evaluate their personal interactions with people with dementia. For example, Tom Kitwood proposed that carers often acted towards them based on medicalised assumptions about dementia, leading to problematic interactions that undermined personhood (Kitwood 1997). Kitwood defined personhood as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (p. 8). For him, the medical model of dementia could inspire interactions devoid of recognition, respect and trust, so that the status was not bestowed, because the carer acts towards a diseased mind rather than a human being. The solution, popularised as person-centred

care, is to act towards people with dementia with the same respect we accord to others, treating them as full humans participating in equal interactions in order to counter threats to personhood (Kitwood 1997). Practically, this can entail basic things like not ignoring, talking over or down to people, engaging with their concerns and taking their requests seriously. A congruent tradition has developed around Steven Sabat's work on selfhood (Box 1), which is similarly semi-contingent on relationships and can therefore be undermined when people are treated as lesser than other humans (Sabat 2001).

Following Kitwood's work, the notion of using person-centred care to support the personhood of people with dementia grew steadily in popularity. Through the early 21st century, person-centred dementia care became integral to related policy and embedded in practice guidelines, educational courses and many other aspects of the dementia care landscape (Brooker 2015). Often, these appeals to 'person-centredness' have translated into policy commitments to individualism, independence and autonomy, clinical practices such as name badges and life-story books and a broader consumer aesthetic (Fletcher 2020). Some of these initiatives, while often well-meaning, are far removed from Kitwood's original focus on relationships and value. Nonetheless, the ideas underpinning person-centred care retain the potential to inform effective clinical practice owing to their emphasis on using care relationships to support people with dementia existentially.

### Supporting selfhood

The fear that as we lose our memories, we stop being who we are is a nihilistic primal fear at the heart of dementia (Jordan 2017). Medicine has tended to collude with this idea as the life course has become increasingly medicalised and pathological changes in the brain have dominated medical thinking (Leibing 2008). The medical concept of self can be easily conflated with measurable quantities such as cognition, and then presumed to decline in a simple linear fashion with a declining Mini-Mental State Examination (MMSE) score (Jordan 2017). Although most people would agree that memories are an integral part of who we are, the ways that the self and memory interact are more complicated than they initially appear (Rapaport 1942; Conway 2000). Relaying these key messages (described in Box 2) in the memory clinic can help the clinician's efforts to challenge widespread views that memory loss equates with a loss of self. This idea, on its own, can offer reassurance to people newly diagnosed with dementia, who may

### BOX 2 The relationship between memory and selfhood

The idea that the self is just a passive accumulation of autobiographical memories was disputed over 80 years ago by Rapaport (Rapaport 1942). He argued that specific memories were stored and retrieved in a particular manner to maintain an individual's sense of self. More recently, Conway proposed a 'dynamic self-memory system' whereby a variety of intra-psychic methods actively operate to keep our memories coherent with our concept of self (Conway 2000).

be vulnerable to popular notions of Alzheimer's disease as a living death (Leibing 2008).

Understanding that selfhood can be conceptualised in different ways is key to understanding its resilience in the face of dementia. Several authors attempt comprehensive reviews of these models. Caddell & Clare's meta-analysis acknowledges that although there is considerable heterogeneity in these studies, particularly in how the self is defined, there is some degree of evidence arguing for the persistence of the self in all stages of the disease, using empirically derived models (Caddell 2010). These include 'Self 1' and 'Self 2' selfhood, embodied selfhood and the transcendence of enforced biological continuity (Sabat 1992; Kontos 2004; Haeusermann 2019) (Box 3). Introducing these ideas in the memory clinic, which speak to the resilience of some form of self (irrespective of cognitive decline), has the potential to neutralise the fear that dementia is inevitably dehumanising.

An awareness of the above models may also challenge the subdominant nihilistic narrative in dementia diagnostic counselling. This may make the process easier for both parties by instilling hope in what might otherwise be an avoidant conversation dominated by fear of relaying a bad prognosis (Jordan 2017). Similarly, the promotion of the lived experience of people with dementia may also help reduce fear of the condition. These individuals are experts on navigating the condition, telling stories of resilience, humour and fortitude rather than inevitable decay and despair. This might ultimately result in a re-appropriation of the D word (and its associated euphemisms and metaphors) in a similar way to cancer, described by Susan Sontag 50 years ago (Jordan 2017). However, there is little written on the potential value of explicit discussions of personhood and lived experience in the memory clinic. Although there is a lack of guidance on best practice in diagnostic counselling in dementia more generally, recent qualitative research argues that the diagnostic process should be tailored

### BOX 3 Models of selfhood that suggest resilience in dementia

Sabat's 'selfhood' suggests that Self 1 (personal identity) and Self 2 (physical and mental attributes) are relatively resistant to change in people with dementia (Sabat 1992). Self 3 (roles and personas), however, is manifest in relations with other people and is therefore more reliant on those other people to help sustain it. Crucially, none of these three manifestations of selfhood are dependent on cognitive abilities *per se*.

Kontos's 'embodied selfhood' combines social philosophies regarding mannerisms and socialisation to argue that our physical bodies can both interpret and display meaning (Kontos 2004). Through living our lives in social contexts, we unconsciously internalise culturally determined actions and pre-reflexively enact these back into the world. For instance, Kontos observed that even people with advanced impairments could still act in distinctive manners that displayed phenomena such as social class, for example when blowing their noses or combing their hair, and could respond to others through gestures, expressions, etc. Again, these embodied forms of selfhood seem to persist independently of cognitive abilities.

Haeusermann challenges the 'particular vision of personhood based on [our] past selves' and believes that forcing the person to remain the person they were previously is a form of 'forced continuity'. Instead, he encourages caregivers and broader society to 'make allowances for new narratives that emerge in old age' (Haeusermann 2019).

to the beliefs and expectations of the individual and involve a collaborative and iterative approach to disclosure rather than a one-off event (Yates 2021). In this extended post-diagnostic conversation, concepts such as personhood can be introduced and, if appropriate, models that argue for its resilience in dementia can be discussed.

### Biopolitics

Although much social dementia research and associated clinical developments have arisen as a response to the medical model of dementia, more recent scholarship has shifted its focus towards biopolitics (Box 4). Through the 2000s, medical sociologists questioned traditional medicalisation critiques, particularly regarding claims that medical authority was unduly extended over previously normal aspects of life (Rose 2007). They have challenged the extent to which real-world dementia is dominated by a medical model, arguing that beyond diagnosis, it is mostly addressed through family care. They also argue that if individual medical encounters are dehumanising, those interactions are typically constrained by institutional circumstances (e.g. consultation

#### BOX 4 Comparing medicalisation and biopolitics

The following definition typifies the concept of a medical model that has underpinned much critique in social dementia research:

'The medical model of dementia states that dementia is (a) pathological and individual, (b) organic in etiology (caused by progressive deterioration of those parts of the brain that control cognitive and behavioral functioning), and (c) treated and managed according to medical authority' (Spector 2010).

Some scholars have contested the nature of the 'medical model', arguing that it is often used in an overly simplistic and unitary manner that is not really evident in practice. They have instead posited that the conceptual model underpinning much clinical practice is more accurately understood as biopolitical. Partly overlapping, but with important distinctions, neurocognitive biopolitics treats dementia as:

'a syndrome of cognitive decline caused by discrete neuro-pathologies that are distinct from ageing, and not enough people are aware of this. Furthermore, because dementia is caused by disease, and biomedical sciences have cured some diseases, dementia is a technoscientific challenge that will be solved through technoscientific endeavours' (Fletcher 2021).

Key differences include less emphasis on professional medicine and behavioural symptoms, and a stronger focus on differentiating normal ageing, intervening in public thought and generating research capital.

times, staffing levels, resource availability) rather than being a direct consequence of the prevailing 'model' of medical thought. Instead of scrutinising the medical model, critical scholars have attended to the biopolitics of dementia. Here, mainstream understandings of dementia are influenced by a collection of non-medical stakeholders, such as charities, research institutions, governments and biotech companies. These policy actors have typically promoted notions of dementia as biogenic, distinct from normal ageing and detrimentally misunderstood by the public. This biopolitics supports speculative resource allocation to develop biotechnical interventions which are then marketed to older consumers as responsible lifestyle choices to enhance brain health (Fletcher 2022). A biopolitical perspective recognises that ageing (and by extension dementia) is not just a biological process, but is modulated by political, economic and social structures.

#### Citizenship

In line with the recognition of dementia as a political entity, social research has developed alternative

understandings of the positioning of people with dementia, beyond concerns with personhood, selfhood and person-centredness. Chief among these is the work on citizenship, which critiques psychosocial dementia research for disempowering people with dementia by making their status contingent on others and for attributing responsibility to individual carers without attending to the wider circumstances that constitute care relationships. Where personhood work is concerned with interpersonal interactions, citizenship is interested in the sociopolitics of dementia, encompassing the effects of welfare regimes on care institutions, the gender dynamics that influence care work and the resistive actions of people with dementia (Bartlett 2010). Human rights work has also been influential in this space, offering resistance against some of the political, ethical and legal challenges faced by people with dementia, such as capacity-based legal discrimination or involuntary institutionalisation (Cahill 2018). Collectively, these politically minded approaches to dementia are referred to as 'critical' because of their indebtedness to critical theory, a tradition of social theory that advocates for challenging oppressive norms through active political transformation.

#### *The clinical is political*

The major insight offered by critical approaches to dementia is that the clinical is political. The interpersonal dynamics that have long been recognised as undermining personhood (e.g. ignoring, withholding, objectification) are themselves constrained by the political and economic conditions within which they occur (e.g. social care de-resourcing, COVID-19 restrictions, lax drug regulation). In practice, a personhood approach might encourage a nurse to take the time to be attentive to a person with dementia, whereas a citizenship approach might challenge a care provider to develop policies that enable nurses to deliver person-centred care. From this perspective, attempts to educate front-line staff on how to develop better interpersonal skills and interactions are at best misguided, and at worst actively harmful, if they result in inadequate institutions transferring their obligations to individual carers. Hence, effective therapeutic practice must attend to the sociopolitical context. One practical example of a critical approach is the involvement of people with dementia in decision-making regarding their care and associated systems, democratising institutions of care and enfranchising those who fall within their remit. Another example is the extension of disability schemes, such as accessible parking, to people with 'hidden' cognitive impairments. Ultimately, the critical tradition requires the

clinician to engage with dementia beyond the immediate interpersonal encounter and to redirect some effort toward systemic change.

### *Material citizenship*

Critical theory can speak to the sociopolitics of dementia across several levels and instances. Not everything is a traditional campaign for rights, etc. Infringements on the agency of people with dementia can emerge from a confluence of institutional concerns (e.g. liability, insurance) and personal prejudices (e.g. that people with dementia are inherently incapable) that collectively undermine their citizenship. The micropolitics of everyday life are similarly important, and this is perhaps no more evident than in contemporary work on material and everyday citizenship. Material citizenship argues that mundane material objects are important in affording citizenship to people by facilitating the realisation of their agency, yet the rights of people with dementia to engage in this materiality are often restricted (Lee 2021). For instance, personal possessions are often lost during hospital transfers or can be actively removed from people because of institutional risk aversion, for example not allowing a resident with dementia to use an iron. Inattentive removal of

material items can have negative effects such as the emergence and worsening of behavioural and psychological symptoms of dementia (BPSD). The corollary of this also holds, and the restitution of cherished personal items, such as clothing, can sometimes produce dramatic therapeutic effects (as in the case study described in Box 5). If a material possession such as a walking stick poses a specific risk to others, then creative substitutions and approaches may be needed.

### *Everyday citizenship*

Everyday citizenship anchors the concept of citizenship in everyday aspects of human life and gives importance to the ordinary. The model emphasises that everyday citizenship is dynamic and requires maintenance through regular social activities and transactions. It also highlights that, although people with dementia may lose some agency in some aspects of life, it can be reasserted in others, through micro-gestures and embodied communications. Everyday mannerisms often manifest our characters – even blowing one's nose or slurping a cup of tea can be done in a recognisably distinct manner, expressing some individual quality (e.g. see 'embodied selfhood' in Box 3).

## **BOX 5 Case study: 'The gentleman and the hat'<sup>a</sup>**

### **Presenting problem**

A 92-year-old man, Bill, who had a history of severe Alzheimer's disease, was referred to a local older adult community mental health team because of persistent screaming in his nursing home. The clinical psychologist with the team conducted an extended assessment of his presenting problem over 6 hours, in collaboration with his son and using a formulation-based approach.

### **Background history**

Bill moved to the nursing home 5 years after being diagnosed with dementia. In addition to his cognitive impairment, he was legally blind and had significant hearing loss. He would speak some English and Italian, but otherwise did not often spontaneously communicate verbally.

### **Personal history**

Bill was born in Italy into a large family. He worked as a tailor and later for the Italian Embassy in the UK. He was well-travelled and multilingual and married an Irish woman in middle age, having two sons. He stopped working because of his visual impairment and decided to remain in the UK, rather than return to Italy. His hobbies and likes included cooking and gardening. He was always a smart dresser and collected a number of hats over his

lifetime. He enjoyed his 'rummage box', which included a number of fabrics he was familiar with in his prior occupation. His premorbid personality was described as 'independent, strong-willed, meticulous and particular'. It was also noted that in every single picture of him over his life, he was wearing a hat or some other form of head covering.

### **Medical history**

This included a prior episode of severe sinusitis, during which he wrapped his head in a blanket and woolly hat for comfort. Acute medical contributors to his screaming were ruled out and he remained in good constitutional health during his assessment.

### **Problematic behaviour**

His screaming was mainly when he was in the open lounge and dining room. This was sometimes accompanied by distress, anger and frustration. Although his room was furnished with old photographs and some past possessions and clothing, it was noted that he did not have access to any of his old hats.

### **Unmet need**

Bill's identified needs included control and order, alternate periods of stimulation and calm, and a source of comfort. It was hypothesised that hats had

been a vital source of his identity throughout his life and also a source of comfort, such as during his bout of severe sinusitis.

### **The intervention**

A plan was made with his son to retrieve several of Bill's old hats from home and also to buy several new woolly hats so that he could wear a hat all the time during waking hours. Once this had been put in place, his daytime screaming stopped immediately. This observed improvement was sustained during several months of follow-up contact with his son and the nursing home.

a. This anonymised case study was presented by Noel Collins and Gillian Neinaber, Clinical Psychologist, at 'What's happening now? Psychological and psychosocial aspects of dementia and dementia care', a joint meeting of the British Psychological Society in association with the Alzheimer's Society and the Royal College of Psychiatrists at the British Psychological Society, London, UK (9 October 2013). Verbal consent from the guardian was witnessed and formally recorded.

Everyday citizenship can be meaningfully included in many areas of clinical practice, for example brokering support to enable an established and valued everyday habit of walking a dog or collecting a newspaper. Here, a friendly newsagent could form part of a weekly activity schedule designed to maintain mood, agency, a sense of self and, ultimately, citizenship. It could also add to conversations about proportionate risk management and reorient support packages that otherwise may be centred purely on what is needed to maintain basic activities of daily living and reduce environmental risks. Similarly, it could legitimise the use of a clinician's time in attending to person-centred nuances, in addition to more clinical domains such as symptom profiles, phenomenology and mental state examination. It is difficult to overstate the importance of the everyday to someone with dementia (Nedlund 2019).

### *Attending to the everyday*

Making the everyday the provenance of clinicians routinely involved in dementia care could enhance clinical capacities for supporting citizenship, even if interventions may appear trivial to others. There can be a number of challenges to pursuing citizenship in a residential care home setting when everyday activities are typically dichotomised as either therapy or risk (Nedlund 2019). However, clinicians visiting people with dementia in nursing homes may find some strategies valuable. For instance, they might advocate for access to personal items, particularly for those experiencing BPSD who have been suddenly moved into or between nursing homes. Viewing the maintenance of citizenship as a micro (as well as a macro) concern justifies the time needed for a detailed inquiry into the personal histories and inventories of the lives of people with dementia. Attending to the everyday need not displace more traditional clinical conversations (such as the risk–benefit analysis of a donepezil trial), if the time needed to listen to and properly engage with a person with dementia is understood and valued by service commissioners so that clinicians have enough time to attend to these holistic needs. The provision of sufficient time is fundamentally an institutional and political-economic consideration, again highlighting the complexity of citizenship as simultaneously influenced by both micro and macro phenomena.

### **Post-humanism**

In recent years, social dementia research has again turned its critique back on itself to question the core tenets of work regarding citizenship and human rights. Chief among these critiques has been work

inspired by post-humanism. Post-humanism has traditionally questioned the status of humans generally as somehow exceptional or superior beings. From the 17th century, humanism has predicated this exceptionalism on notions of individual intellectual capabilities, a value system that inherently disadvantages those with cognitive impairments who have reason to draw on care (Quinn 2020). In response, post-humanist scholars have argued against humanism and related commitments to human exceptionalism, instead emphasising the embeddedness of people in relation to other living and non-living things (Jenkins 2017). Post-humanism represents an intriguing turn because, as noted, most social dementia research to date has been concerned with resisting the dehumanisation of people with dementia and developing strategies for supporting their humanity, be that personhood, selfhood, citizenship or human rights. Post-humanism comes at dementia from the opposite perspective, effectively advocating for an existential equality by dehumanising everybody, with or without dementia. The ultimate effect is that it is not the nature of the individual's cognition that matters so much as the quality of people's diverse relationships with places, technologies, animals and the environment.

### *Animal therapies*

The most obvious area of post-humanist clinical practice to date has been the development of animal therapies. These types of intervention have been around for some time, independently of any post-humanist sensibilities, with animals being introduced into care institutions as a means of improving the experiences of those living and working within them. There are long-standing debates regarding the value of animal-based initiatives in care. A Cochrane review found no evidence of substantive therapeutic benefits in dementia (Lai 2019), whereas another systematic review reported positive effects across measures of social behaviour, physical activity, diet, agitation, aggression and quality of life (Yakimicki 2019). However, such appraisal may be misguided. From a post-humanist perspective, if a human and a dog are mutually enriched by playing together, this is broadly therapeutic. Indeed, the aim is not so much to improve some metric of the person with dementia, but rather to cultivate vibrant encounters and generate new enlivening relations between things. Closely related to animal-based initiatives has been the advent of horticultural schemes, supporting people with dementia to become involved in gardening and fostering new relationships with other gardeners, plants, animals, tools and their wider environments (Noone 2017).

### *The role of technology*

Another clinically relevant area of post-humanism is technological enhancement. Just as post-humanist research situates people within a web of relations with other things, it similarly approaches the person as being made up of relations between many things – gut microbiota, tattoos, etc. Hence, many humans are already cognitive cyborgs, encompassing an assemblage of objects that collectively enhance cognition, such as glasses, hearing aids and dentures. Digital technologies have also become increasingly cognitively important, for example Google Maps aiding wayfinding or Alexa smart speaker reminders. Beyond these familiar technologies, cognition-enhancing neural implants have been under development for several decades. The first neural implant, for treating essential tremor, received US Food and Drug Administration (FDA) approval in 1997 and by 2020 over 150 000 people worldwide had undergone an implant (Iorio-Morin 2020). Memory enhancing implants have been successfully implemented in non-human animals (Berger 2011). From walking canes to neural implants, a post-humanist therapeutic disposition can conceive of cognition as something that occurs in the relations between a series of component parts that collectively make up people.

Everyday dementia care is unlikely to entail neural implants and more invasive cyborg-esque technological interventions. However, the relatively mundane technologies of glasses and hearing aids have obvious implications for clinical practice. When conceived of as an amalgam of cognition-supporting components, the post-human being is opened up to various forms of tinkering to enhance cognition. Interventions such as ensuring that hearing aids are functioning or setting personal mobile devices to accessibility modes take on a new meaning. These are not additional considerations – they are the stuff of cognition. Moreover, with glasses, phones and other assistive technologies there are notable affinities between post-humanist and material citizenship commitments to enriching people's lives via things, even if the relative stances towards the status of the person (and hence the envisaged 'outcome') differ.

### **Iatrogenic harm**

Reductionist thinking, to the exclusion of all other considerations, has historically been a dangerous position in psychiatric practice. This critique has typically been leveraged against biological interventions, such as the use of antipsychotics for BPSD, which sadly appears to have increased during and following the COVID-19 pandemic. Hence, it is typically the

more physically invasive clinical practices that have been subject to interrogation as potentially harmful. Exclusivist thinking is clearly problematic, but it is equally exclusivist to solely approach traditional medical interventions as risky. It is worth considering whether the adoption of approaches inspired by critical scholarship could also lead to iatrogenic harm. Philosophical shifts in psychiatry, and related changes in policy and practice, are often the subject of debate and commentary, in both medical and sociological texts. However, little is written on the potential harms of applied critical sociological theory from a clinical perspective.

Intuitively, it may seem unlikely that theory-informed practice would lead to iatrogenic harm. However, there are certainly some appreciable risks that warrant reflection. First, dementia-related social theory has a regrettable heritage of promising approaches being reified into policy frameworks that end up contradicting their initial aims. The original relationality and interdependence of person-centredness have repeatedly been misinterpreted as a call for personalisation, autonomy and independence, too often whittled down to name cards above ward beds. At worst, the focus on care interactions has placed blame on staff for not interacting correctly, as discussed above. There is a similar danger that everyday citizenship is transformed into the responsibility of individuals who are to blame for not nurturing the conditions of citizenship. Is it fair to expect an underpaid and overworked nurse to agitate for institutional change? Or a precariously employed care worker to resist the citizenship-impeditive protocols of a care agency? The citizenship of people with dementia, those caring for them and the public generally are intertwined – their struggle is everybody's struggle. Hence, any turn to critical theory must always be mindful of how ideas mutate as they translate into policies and practices.

There may also be risks from social theory that is more authentically implemented. For instance, material citizenship rightly emphasises the importance of access to everyday material objects to support citizenship. However, many objects facilitate our agency through their capacities for risk. Perhaps the most obvious example is the car. The loss of a driving licence can be a distressing part of the dementia experience, undermining citizenship in several ways. However, few would suggest that allowing all people with dementia to continue to drive as they wish is desirable. Cars are an extreme example, but items such as cigarettes, hair straighteners and knives all have associated risks. More liberal approaches to material citizenship could hence entail real harms, to both people with dementia and others around them.



## MCQ answers

1 d 2 c 3 b 4 e 5 e

Similarly, post-humanist scholarship supports more-than-human relationships and technological enhancements, neither of which are without risk. There are obvious risks of injury and infection that come from close proximity with animals. As well as those immediate dangers, there are also practical implications, such as the use of staff time to care for the animals. An already overstretched healthcare assistant may understandably be exasperated by having to clean up after a dog or search for a runaway cat. Turning to technology, there are risks regarding inequalities of access, particularly with high-end gadgets. Moreover, digital technologies are vulnerable to abuse. A hacker might hold a person's smart home to ransom, and bad actors in this space already target older people and those with cognitive impairments. We are being somewhat alarmist here, of course. That said, it is important to emphasise that iatrogenic harm is not limited to medical interventions.

### Conclusions

The introduction of critical approaches presents psychiatrists with a wider range of strategies that can be tweaked and blended in response to specific circumstances. Rather than seeing social theory as something that must be translated in a watered-down form to fit service constraints, we hope that this article has emphasised the potential for a dialogical approach. This is not a linear model of research informing practice, but rather a more creative two-way process of regeneration. Clinical practice can hence be understood as a site of radical praxis, whereby academic concepts are brought into collision with real-world phenomena, manipulated and combined in various iterations to meet the requirements of the particular situation. Importantly, the clinical encounter is freed of much of the structure of the academy. Here, distinct (and sometimes competing) traditions can be skilfully woven together in response to dementia, wherein a post-humanist everyday citizenship stance towards a person's possessions might work to support their embodied selfhood. The core focus on improving the situation of someone with dementia can act as a catalyst for the blending of such approaches, with almost immediate empirical feedback in a manner that is difficult to emulate in social research.

Leibing observes that dementia is 'an episteme in the making' and that new conceptualisations are not intended to replace the old with the new, but to add more established knowledge (Leibing 2015). For instance, work on embodiment, citizenship, materialities and post-humanism has developed distinctly, and often in mutual tension, but as we have shown, they can be blended to useful effect both

theoretically and practically. Such is the making of the new dementia episteme. We hope this article helps support a broader translation of concepts from critical social science, especially dementia studies and gerontology, into practice as part of a broader interventionist effort to construct a rich and helpful foundation of dementia theory and related practices. We hope that this article, co-authored by psychiatrist and a sociologist, demonstrates how different traditions and dispositions can fruitfully collide to enliven interdisciplinary conversations about dementia and dementia care.

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N.C. and J.F. contributed equally to the writing of this article.

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### Declaration of interest

None.

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### MCQs

Select the single best answer for each question stem.

#### 1 Personhood:

- a focuses on maintaining independence and autonomy
- b is fulfilled by using name cards in clinical settings
- c declines according to MMSE scores
- d is a psychosocial, religious and ethical relational status
- e is made up of 'Self 1' (personal identity), 'Self 2' (mental and physical attributes) and 'Self 3' (relational roles and personas).

#### 2 Kontos's concept of 'embodied selfhood':

- a suggests that selfhood is maintained during earlier stages of dementia
- b suggests that the body can exhibit signs of a person's life story and selfhood
- c suggests that forms of selfhood seem to persist independently of cognitive abilities
- d relates to physical expression through dance
- e is independent of other people.

#### 3 Material citizenship:

- a in the UK is granted by the Home Office
- b suggests that everyday possessions can support agency
- c requires clinicians to protest against legal discrimination
- d is manifest in personal mannerisms
- e focuses on maintaining independence and autonomy.

#### 4 Post-humanism:

- a is a risk-free approach to providing therapy
- b focuses on maintaining independence and autonomy
- c suggests that humans are superior to animals
- d emphasises advanced technologies
- e views people as both composite and components.

#### 5 Dementia can be considered as a:

- a neurocognitive disorder
- b social experience
- c episteme in the making
- d none of the above
- e all of the above.