

No substitute for human touch? Towards a critically posthumanist approach to dementia care

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ABSTRACT

This paper develops a sociological critique of the pre-eminence of humanism in dementia care policy and practice. Throughout the centuries, humanism has served as something of a double-edged sword in relation to the care and treatment of people living with progressive neurocognitive conditions. On the one hand, humanism has provided an intellectual vehicle for recognising people with dementia as sentient beings with inalienable human rights. On the other hand, humanist approaches have relied upon and re-enforced normative understandings of what it means to be human; understandings that serve to position people with dementia as deficient. Two posthumanist approaches to dementia care policy and practice are explored in this paper: *transhumanism* and *critical posthumanism*. The former seeks, primarily, to use advances in 21st-century technologies to *eradicate* dementia. The latter seeks to de-centre anthropomorphic interpretations of what it means to be a person (with dementia), so as to create space for more diverse human–non-human relationships to emerge. The paper concludes with some tentative suggestions as to what a critically posthumanist approach to dementia care policy and practice might look like, as we move closer towards the middle of the 21st century.

KEY WORDS – Alzheimer’s disease, assistive technology, humanism, transhumanism, social citizenship, symbionts, symbiosis.

Introduction: dementia in the 21st century

According to Alzheimer’s Disease International, there are approximately 46.8 million people living with dementia in the world. In line with an ageing global population, this figure is expected to almost triple to 131.5 million by the year 2050 (Alzheimer’s Disease International 2015). Addressing the economic, social and personal costs associated with dementia is increasingly constructed, within policy circles, as an international priority requiring multi-state solutions. Pan-European dementia strategies are

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starting to be formulated, following Alzheimer Europe's (2014) *Glasgow Declaration*. At the G8 Summit on Dementia in 2013, the world's richest nations committed themselves to working together to identify a cure or disease-modifying therapy by the year 2025 (G8UK 2013). Parallel to the search for cures, developments in the use and sophistication of assistive technology (AT) in dementia care are expanding rapidly (Gibson *et al.* 2014). According to the British Assistive Technology Association (2012), the term assistive technology may refer to 'any product or service that maintains or improves the ability of individuals with disabilities or impairments to communicate, learn and live independent, fulfilling and productive lives'. Several benefits have been associated with the use of AT in dementia, including improvements in quality of life, personalisation of support services and delays in the need for residential care (Bharucha *et al.* 2009). The rise of AT in dementia care has been assisted by rapid advances in the sophistication of the digital world. Developments such as Web 2.0, the Internet of Things, Big Data and Ubiquitous Computing have made it increasingly possible to deliver complex care and support interventions via digital platforms.

With the growing sophistication in digital technologies has come an emerging aspiration that machines will be able to offer not just practical services to people with dementia, such as administering medications and locating people using Global Positioning Systems software, but emotional support and companionship as well. The Japan-based company PARO (<http://www.parorobots.com/>), for example, was one of the first to pilot the use of robots in dementia care settings. PARO robots are digital devices designed to imitate baby seals and used to simulate the benefits of animal therapy. Studies suggest these robots can significantly lower blood pressure amongst older people in care environments (Robinson, MacDonald and Broadbent 2015). Following on from these initial explorations into the use of robotic companions in dementia, we are now starting to see the emergence of more sophisticated forms of artificial intelligence in care settings. Pan-European projects such as CompanionAble and Mobiserv, for example, have sought to create robots for use within residential care settings that are capable of 'inspiring interaction, and addressing more user needs in a trusted manner' (Huijnen *et al.* 2011: 325). Such developments have led to concerns that increasing automation may lead to a loss of quality and, more specifically, *humanity* within caring relationships. This underlying sentiment was exemplified by Caroline Abrahams, Director of the charity Age UK, when she stated that however sophisticated digital technologies may become in the years and decades ahead, there remains 'no substitute for the human touch' (Hudson 2013).

In dementia care policy and practice, the term *humanist* has become synonymous with a broad range of socially progressive, person-centred

approaches to caring for people with progressive neurocognitive disorders in late-modern societies (Brooker 2003). Humanist-inspired theorists of care, such as Rogers ([1967] 2004), Kitwood (1997) and Sabat and Harré (1992), are widely credited as some of the early pioneers of this approach to dementia. Their work, in particular, is credited with destabilising biomedical assumptions that dementia is a disease of *social death* (see e.g. Sweeting and Gilhooly 1997). Indeed, their success has been such that, since the late 1990s, the task of recognising the humanity of people with dementia has moved centre-stage within the policy landscapes, to the extent that failing to acknowledge the ‘standing or status’ (Kitwood 1997) of people with dementia as unique individuals with inalienable human rights would today be virtually un-thinkable. This paper, however, offers a critical discussion of the pre-eminence given to the role of *humans* and *humanity* in dementia care. Humanism, it is argued, has proved to be something of a double-edged sword when it comes to the care of people living with progressive neurocognitive conditions; on the one hand, recognising people with dementia as beings with inherent value whilst, on the other hand, retaining normative understandings of what it means to *be* human that serve to perpetuate discrimination against people living with neurocognitive disease.

Humanism and dementia: a double-edged sword

Whilst associated predominantly with late twentieth-century frameworks, humanism has been the *modus operandi* for conceptualising dementia since the term ‘dementia’ was first *anchored* (Moscovici 1984) within the psychiatric community by alienists such as Philippe Pinel (1745–1826). Published just two years after the death of one of the founding fathers of rational humanism, Immanuel Kant, Pinel’s *A Treatise on Insanity* offered the first nosology of dementia, the symptoms of which he described thus:

In dementia, there is no judgement either true or false. The ideas appear to be insulated and to rise one after the other without connection, the faculty of association being destroyed. (Pinel 1806: 164)

This, arguably, is one of the first scientific representations of dementia as *social death*, in that it defines dementia as the very absence of what Aristotle (384–322 BCE) and Descartes (1596–1650) viewed as the primary attribute of the human condition, namely reason. Whilst Pinel’s approach may be seen as the intellectual keystone of what Kitwood (1997) referred to as the *standard paradigm* in dementia, it is an approach created very much from *within* the humanist tradition. Pinel was, after all, a pioneer of the *moral treatment* school of psychiatry, which emphasised the importance

of compassion, sanctuary and asylum for people living with mental disorders (see e.g. Scull 1979). This practice that Pinel helped to establish – of promoting socially progressive approaches to the care of people with dementia whilst, at the same time, retaining normative assumptions to what it means to be human – has characterised humanist approaches to dementia ever since. We can see it, for example, in the development of one of the principle frameworks currently underpinning dementia care policy in the United Kingdom (UK) – the *Social Citizenship* approach.

Developed, in part, in response to the *Personhood* framework, the social citizenship model is anchored less in humanist metaphysical philosophy and more within the language of human rights, as it emerged across Europe during the latter stages of the Second World War (see e.g. Bartlett and O'Connor 2007, 2010). In essence, the concept of social citizenship is based on the belief that, in addition to legal and political rights, citizens must be acknowledged as having *social rights*. Social rights were first articulated by the welfare theorist T. H. Marshall thus:

By the social element I mean the whole range from the right to a modicum of economic welfare and security, to the right to share to the full in the social heritage and to live the civilised life according to the standards prevailing in society. (Marshall [1950] 2009: 149)

Since the end of the Second World War, the rights of *all* citizens to be involved – as full and equal participants – in social, economic and cultural life has become enshrined in several international human rights declarations, most notably the Universal Declaration of Human Rights (United Nations 1948), the International Covenant on Economic, Social and Cultural Rights (United Nations 1966) and the Convention on the Rights of Persons with Disabilities (United Nations 2006). These declarations have proved pivotal in shaping contemporary dementia policy in the UK; through, for example, the Charter of Rights for People with Dementia and Their Carers in Scotland (Cross-Party Group on Alzheimer's 2009). Yet, if we go back to the original post-war formulations of social rights, we can see that notions of social rights were frequently accompanied by normative beliefs as to what constitutes a *desirable* citizen. Although it is not widely recognised in debates around social citizenship, several of the early advocates of social rights, including those who pioneered universal welfare provision in the UK, were members of the Eugenics Society¹ who advocated the compulsory sterilisation of members of society who found themselves in need of State protection. As Sir William Beveridge, author of the now seminal Beveridge Report in the UK argued:

those men who through general defects are unable to fill such a whole place in industry are to be recognized as unemployable. They must become the acknowledged

dependents of the state ... but with complete and permanent loss of all citizen rights including not only the franchise, but civil freedom and fatherhood. (Beveridge 1906, cited in Lund 2002: 80)

Citizenship approaches to social justice, in short, reflect something of a mixed history, as advocates of universalism frequently viewed this approach as compatible with the expectation that less-desirable humans should be, in the words of Richard Titmuss, 'relieved of the burden of their fertility' (Titmuss 1944: 57). Indeed – and as Bartlett and O'Connor (2010) acknowledge – there remain tensions within the application of citizenship-based thinking to contemporary dementia care policy and practice, such as how notions of social rights sit alongside companion concepts, like civic responsibility, when applied to people with progressive neurocognitive conditions.

There are reasons why humanist approaches to dementia have fallen into this intellectual trap, the principal of which is that advocates of humanism in dementia have largely failed to recognise the distinction, at the conceptual level, between humanism as a *paradigm* (Kuhn 1962) and humanism as part of the modern *episteme* (Foucault 1970). Whilst the former represents a conscious and unstable body of thought, prone to overt questioning and de-stabilisation, the latter exists at the level of sub-conscious thought and has proved remarkably resilient to change. As episteme, humanism may be understood as a central element within *modern* thinking, with its origins dating back to the Renaissance period of 14th-century Europe and to the premise that *Man*, as opposed to God, is the fulcrum of knowledge (Foucault 1970). Thus, to understand humanism in dementia as pertaining solely to the work of latter-day theorists such as Kitwood (1997) and Rodgers ([1967] 2004) obscures and leaves unchallenged a set of ontological principles (that humans exist objectively and possess essential properties), the validity of which is neither pre-determined nor self-evident. To paraphrase Moscovici (1984: 13), when it comes to the human, the dementia care community has become 'like the artist, who bows down before the statue he has sculpted and worships it as a God'.

Emphasising the distinction between humanism as a *paradigm* and humanism as a part of the modern *episteme* is not an exercise in academic pedantry – although I appreciate it may seem so. Rather, it is essential to understanding how socially progressive approaches to caring for people with dementia have, inadvertently, fallen into the trap of perpetuating social inequality. By appealing to normative concepts such as the *human*, these approaches serve to re-enforce a hierarchical system of classification in which sentient beings are ordered according to the extent to which they do, or do not, approximate to the human ideal. As Wolfe argues:

[M]ost of us would probably agree that ... people with disabilities deserve to be treated with respect and equality. But ... the philosophical and theoretical frameworks used by humanism to try and make good on those commitments reproduce the very kind of normative subjectivity – a specific concept of the human – that grounds discrimination against ... the disabled in the first place. (2010: xvi–xvii)

In short, humanism in dementia is not – as is often presented – a *magic bullet* capable of addressing any-and-all instances of oppression and discrimination that people with dementia encounter on a daily basis. Rather, concepts such as the *human*, the *individual* and the *citizen* are highly normative and, as such, are ‘instrumental to practices of exclusion and discrimination’ (Braidotti 2013: 26). If we are to avoid perpetuating discrimination in the name of social inclusion, there is a need to move *beyond humanism* as the sole framework for conceptualising care.

Beyond humanism: transhumanist and critically posthumanist frameworks

Posthumanism in social science can be broadly divided into two camps: transhumanism and critical posthumanism; although authors such as Ferrando (2013) advocate for a more multi-faceted nomenclature (*transhumanism*, *posthumanism*, *antihumanism*, *metahumanism* and *new materialisms*). In essence, *transhumanism* seeks to use developments in 21st-century technology, in particular advances in computing, genetics and nanotechnology, as vehicles for self-directed evolution. Critical posthumanism, in contrast, draws on developments in 21st-century technologies to question and destabilise systems of classification that are based on the binary distinction between human and non-human. This section reviews both approaches and considers their relevance to contemporary dementia care policy and practice.

Transhumanism, as defined by Bostrom (2005: 3), is ‘an interdisciplinary approach to understanding and evaluating the opportunities for enhancing the human condition and the human organism opened up by the advancement of technology’. From this perspective, Bostrom argues, the human is a work in progress rather than an essential or unchangeable entity. Through developments in technology, humans will eventually be able to transcend the limitations of their organic bodies, thus rendering human suffering, ageing and even death itself obsolete. Whilst this may sound like the stuff of science fiction, contemporary developments in digital–neural interfacing are making it increasingly possible to realise transhumanist values within the everyday world. Cochlear implants, for example – digital devices designed to replace damaged parts of the inner ear by transmitting digital signals directly to the brain – are used by over 324,000 people globally (National

Institute of Deafness and Other Communication Disorders 2015). In 2003, biomedical engineer Theadore Berger developed the world's first brain prosthesis: a computer chip designed to replace cognitive functions executed by the hippocampus, which is an area of the brain where memory, mood and self-awareness are all understood to reside (Berger *et al.* 2011). According to Hughes (2004), these emerging technological capabilities are provoking a fundamental reconfiguration of human societies. The ability to download and recover memories, for example, will, Hughes argues, make conventional ethical, legal and philosophical frameworks of Personhood untenable. Would, for example, a recovered set of memories downloaded into a new material body constitute a new or a pre-existing person? How would associated frameworks, such as citizenship and individual identity, be applied to this (new) person? As Hughes argues:

When we get to the point where neurological functions can be controlled, designed, cloned, shared, sold and turned on and off, the fact that the continuous, autonomous self is an illusion will become more obvious. (2004: 85)

Arguments such as these represent a clear and present threat to established (humanist) frameworks for dementia care, which espouse respect for autonomy and individuality as some of highest ethical principles underpinning caring relationships (*see e.g.* Brooker 2007). Transhumanist visions of a *dementia-free* posthuman age are controversial to say the least, and the transhumanist project has been described by writers such as Fukuyama (2003, 2004) as one of the world's most dangerous ideas. And yet, as I have argued previously (*see* Jenkins 2014), questioning the essential truth of the individual, autonomous self enjoys a rich history within social theory. As Geertz (1975) observed, the notion of the *individual* as a single, discrete, autonomous entity is somewhat peculiar to Western societies and is not lionised to the same extent in other, majority world cultures. In this respect, the fact that new technological affordances may be prompting us to revisit hitherto accepted notions of what it means to be human can simply be seen as an extension of a longer intellectual tradition. Whilst this is the case, concerns that transhumanism, if realised, will lead to the development of new social hierarchies (*e.g.* *sub-humans*, *humans*, *transhumans* and *humans* +²), has led to calls from within the humanities and social sciences for a new *counter-science* to transhumanism rooted in humanist philosophy (*see e.g.* Habermas 2003; Kompridis 2009). Rather than being a radical departure from the humanist tradition, however, transhumanism is rooted in rational humanism. As Bostrom (2005) argues, the idea of using science to aid human progress dates back to the writings of key humanists such as Julien Offray de La Mettrie (1709–1751) and Friedrich Nietzsche (1844–1900), amongst others. Hence, *returning* to humanism as a counter-science to the

social, moral and philosophical challenges posed by the transhumanist project seems a curious, and ultimately ill-fated, enterprise for dementia policy. For an effective *counter-science* to transhumanism to be developed, it must originate from *within* the posthuman tradition.

The second theoretical perspective then (critical posthumanism), represents a solid foundation upon which to build a more socially inclusive approach to dementia as well as a counter-science to transhumanism. According to Badmington (2000) and Braidotti (2013), critical posthumanism can be understood as a broad intellectual tradition characterised by its critical exploration of *Man* as a socially constructed entity. This draws on several intellectual perspectives including Marxism, psychoanalysis, post-structuralism and postmodernism, where the unifying goal involves critiquing normative assumptions and regulatory frameworks that exist within humanist modes of thought. In this respect, and as Miah argues:

[T]he ‘post’ of posthumanism need not imply the absence of humanity or moving beyond it in some biological or evolutionary manner. Rather, the starting point should be an attempt to understand what has been omitted from an anthropocentric worldview, which includes coming to terms with how the Enlightenment centring of humanity has been revealed as inadequate. (2007: 72)

One of the vehicles through which critical posthumanism has sought to *de-centre* the human (and humanity) is through the development of new ways of conceptualising what it means to be a person; ways in which hierarchical orderings based on binary distinctions (*man–woman*, *natural–artificial*, *human–non-human*) are rendered obsolete. As Hayles (1999) argues, one of the most successful of such imaginaries is that of the *cyborg*. The concept of the cyborg (cybernetic organism) was first developed in the early 1960s by Manfred Clynes and Nathan Kline, as a thought experiment intended to advance space exploration, whereby humans could endure prolonged periods in space through reliance on computer-based technologies (Clarke 2003). Whilst the concept has undergone many variations since the 1960s, the basic notion that a cyborg is as a person consisting of both organic and non-organic matter remains. In what is now widely regarded as a seminal text, Haraway ([1991] 2007) draws on the concept of the cyborg in a deliberately provocative way to outline a socialist feminist manifesto for social change. She argues that, rather than thinking of ourselves as discrete, unified, organic human beings, ‘we are all chimeras, theorised and fabricated hybrids of machine and organism’ (Haraway [1991] 2007: 34). Embracing this hybridity, Haraway argues, can lead us to a world in which ‘people are not afraid of their joint kinship with animals and machines, not afraid of permanently partial identities and contradictory standpoints’ (Haraway [1991] 2007: 38).

Whilst the cyborg is, for Haraway, a means of dissolving binary distinctions that serve to perpetuate inequality and social division, it is an approach to personhood that is unlikely to take hold within policy and practice-based dementia care communities. This is due primarily to its association with notions of automata and depersonalisation. An alternative, yet equally liberating representation of personhood – and one more appropriate for dementia care settings – is that of the *symbiont*.

From the Greek *συμβίωσις*, symbiosis in its most elementary sense means living together. The concept was first used, within biology, to describe a union between organisms based on mutual benefit, yet the notion of sustained existence through mutual interdependence was developed during the 17th century to describe productive patterns of community life (*Online Etymology Dictionary* 2015). Through the work of social theorists such as Proudhon ([1890] 1970) and Kropotkin ([1902] 1972), the concept of symbiosis became positioned as one of the key ingredients for social life. As a person then, a symbiont is a being that has achieved a state of mutually beneficial co-existence with other entities, including entities that may be classified as beyond human. Symbionts, by definition, are not autonomous individuals but are defined *through* their mutual interdependence with other organic and non-organic beings. For symbionts, mutualism (as opposed to individualism) is the key principle upon which person-centred models of care are to be based. Symbionts thrive on direct democracy, voluntary engagement and the sharing of resources within communities.

Where symbiosis takes on a distinctly posthuman element in contemporary dementia care is the inclusion of mechanised agents within patterns of mutual co-existence. The notion of human–machine symbiosis was first proposed by Licklider (1960: 6), who predicted that ‘the contributions of human operators and equipment will blend together so completely in many operations that it will be difficult to separate them neatly in analysis’. In other words, in the near future it will become increasingly difficult to distinguish between the agency of humans and the agency of machines. Over half a century on from Licklider’s prediction, rapid developments in Big Data and the ability of machines to learn through trial-and-error-based algorithms, are indeed, according to some authors, increasingly blurring the lines between human and non-human forms of agency (Knox 2014).

Towards a critically posthumanist approach to dementia care

Moore’s law predicts that computing power will double every 18 months to two years, leading Vinge (1993) to hypothesise a point in the 21st century,

known as the Singularity, when humans will possess inferior levels of intelligence to that of machines. According to Ray Kurzweil, Director of Engineering at the internet giant Google, this historical tipping point could be as near as the year 2045 (Kurzweil 2005); in other words, five years before the global prevalence of dementia is expected to have tripled from current estimates. How then, in an era of rapid technological change, might dementia care adapt so as to embrace, as opposed to resist, this new technological era?

We are perhaps decades away from realising the kinds of machine–human symbiosis that were first hypothesised by Licklider (1960). Yet, the incorporation of machine intelligence within caring relationships is likely to require more than technological innovation. It will require a willingness to question and problematise the underlying assumptions upon which contemporary models of care are based. ‘No substitute for human touch’ implies that, however sophisticated machines become, they will never be able to replicate the types of caring relationships that are produced through human–human interactions. Yet appealing to *humanity* is a dangerous position, as it tends to reflect implicit, normative assumptions of what it means to *be* human; assumptions that serve to position people with dementia as deficient to begin with. If we are to realise fully the potential of 21st-century technologies to promote social inclusion, there needs to be recognition that *humanism* is not the answer to all deficiencies in the care and treatment of people with neurocognitive impairments. Indeed, in some respects, humans and humanism are, themselves, part of the problem. As recent studies have helped to highlight, the abuse and neglect of older people is alarmingly widespread throughout the UK and is a phenomenon perpetuated entirely by humans (Alzheimer’s Society 2011; Biggs *et al.* 2009), as, indeed, is the global problem of stigma in dementia (Alzheimer’s Disease International 2012). Socially progressive approaches to dementia – be it the moral psychiatry of the 19th century or the social citizenship of the early 21st century – fail to address deep-seated social inequalities when they retain the conceptual bifurcation of persons deemed to be with mind (*cum mentia*) and without mind (*dementia*). These divisions remain rooted in our language structures and our unconscious thought, despite the proliferation of policy documents espousing the human rights of people with dementia to live with dignity, respect, social inclusion and equal protection under the law.

How then, can we develop an alternative to humanist-inspired frameworks for dementia care? The first step, following Miah (2007), involves de-centring the human within the care assemblage. Anthropocentric notions, like putting the *individual* at the centre of care, need to be replaced with representations of personhood that enable a greater diversity of

thought and practice to emerge. One approach, as highlighted in the previous section, is to replace the concept of the *individual* in dementia with that of the *symbiont*. Contrary to existing models of care, which reflect the belief that there is no substitute for human touch, the idea that symbionts living with progressive neurocognitive disorders can and should form productive, meaningful and mutually beneficial relationships with machines (as well as other non-human beings) is central to the co-production of high-quality caring relationships. Hence, rather than something to be feared, the development of robotic prototypes, such as those developed through the *Mobiserv* and *CompanionAble* projects, are providing some of the earliest insights into what a critically posthumanist approach to dementia care might look like. In science fiction also, we are starting to imagine a world in which machines can build friendships and aid decision-making in dementia; as illustrated, for example, in the 2013 film *Robert and Frank*. This trend in re-imagining is only likely to increase in the years and decades ahead, as we approach the middle of the 21st century and when the Digitally Native (Prensky 2001) generations start entering the third and fourth stages of the lifecourse. As this happens, there will be an increasing need to revisit some of the assumptions currently made about people with dementia's understanding of, skills in and use of digital technologies. The idea, for example, of placing Power of Attorney in the hands of an algorithm, however sophisticated it may be, is likely to be an idea that would fill many contemporary commentators with fear, suspicion and derision. Yet, how many Digital Natives may be perfectly happy to draw on the support of a mechanised companion in later life is a question yet to be fully formulated, let alone explored empirically.

Summary remarks

Moving beyond humanist approaches to dementia will require more than technological innovation. It will require significant changes in the underlying ways in which we think about personhood and neurocognitive disease. Rather than seeking to eradicate dementia through technologically driven, self-directed evolution (an aspect of transhumanist thought), critical posthumanism seeks to develop new ways of thinking about persons and personhood in ways that address humanism's in-built tendencies to order sentient beings hierarchically, according to their approximation to the human ideal. In this respect, critical posthumanism as a branch of contemporary social theory has much to offer dementia care. To realise this potential, however, we need to first problematise some of the unquestioned

'truths' that surround this area of practice; in particular, the implicit and unquestioned assumption that there is *no substitute for human touch*.

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NOTES

- 1 An organisation established by Sir Francis Galton with the stated aim of improving the human race through natural selection.
- 2 This typology is based on the science fiction writer David Simpson's posthuman series.

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