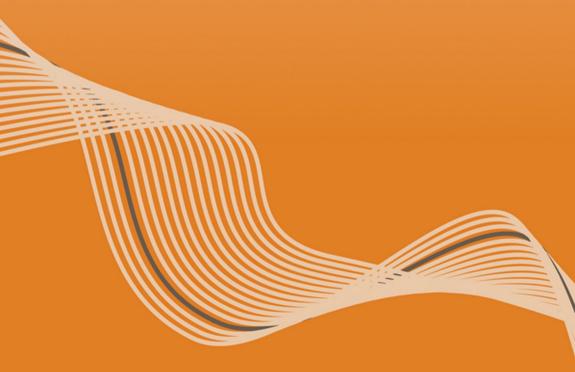# Ageing, Dementia and the Social Mind

Edited by

Paul Higgs and Chris Gilleard

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Ageing, Dementia and the Social Mind

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Contents

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1

Ageing, dementia and the social mind: past, present and future perspectives

Paul Higgs and Chris Gilleard

The sociology of dementia has been a relatively neglected topic in studies of health and illness despite dementia becoming of increasing significance to most 'ageing societies'. For this reason alone an overview of developments and directions in the sociology of dementia seems both necessary and apposite. Worldwide, it has been estimated that there will be over 80 million people living with dementia by 2040 (Prince and Jackson 2013). The significance of this condition, we would argue, goes much further than its epidemiological significance. The effects of this 'major neurocognitive disorder' as it is described in the latest edition of the Diagnostic and Statistical Manual (DSM-5; Sachdev *et al.* 2014) are not confined simply to the numbers affected by the condition. It must also include the considerable impact that the condition has on the lives of patients and carers as well as the consequences for the health and social care professionals involved in providing support and care. Dementia is responsible for over half of all admissions to residential long-term care; it impacts more heavily upon families and carers than nearly all other medical conditions and it represents one of, if not the most feared aspects of growing older (Cantegreil-Kallen and Pin 2012, Luppa *et al.* 2010, Torti *et al.* 2004). Equally, the costs associated with providing care are constantly projected to grow with Alzheimer's Disease International (ADI) estimating that the worldwide combined cost of dementia care in 2015 was US$818 billion and that this figure is likely to rise to over US$ 1 Trillion by 2030 (Martin 2015). Alongside this has to be considered that the biomedical project to find a 'cure' for dementia which could potentially alleviate these costs has foundered (Lock 2013). While the latter decades of the twentieth century were marked by the concerted effort from the pharmaceutical industry to develop and market effective 'anti-dementia' drugs, since the beginning of the twenty-first century such efforts seem to have fallen by the wayside. Attention is turning toward 'pre-clinical' risk profiling and the public health implementation of 'dementia prevention' strategies (Imtiaz *et al.* 2014). All of this has complicated and extended the significance of dementia to researchers in the sociology of health and illness.

Dementia consequently has become identified as being at the heart of the 'problem' of ageing societies as many of the above features are rolled into the idea of 'apocalyptic demography' first advanced by Ann Robertson in 1990 and still going strong in many different contexts (Lundgren and Ljuslinder 2011, Martin *et al.* 2009). Furthermore, the increasing frequency of dementia as a topical news item in the media has meant that it has a growing influence on the social representations of old age as the messages about its effects spread more widely among the general population (Hunter and Doyle 2014). Such media exposure

generates fears relating to the anticipated progressive loss of capacity of individuals who develop dementia. This fear of losing one's mind, and losing one's place in the adult world, has led to dementia being framed as a form of 'social death' (Sweeting and Gilhooly 1997). Despite the efforts of advocacy groups representing families facing the challenges of dementia and the articulation of the sufferer's voice in personal accounts of dementia, such fears have not diminished and may have prompted calls and means for voluntary euthanasia (Draper *et al*. 2010, Volicer 2016). This process appears to have occurred in parallel with what has been described as the 'Alzheimerisation of ageing' (Adelman 1995, Gilleard and Higgs 2000). Reinforced by media reports of 'institutional abuse' in nursing homes (Lloyd *et al*. 2014), the intensified search for 'a cure', and dire predictions of demographic apocalypse, the Alzheimerisation of ageing seems to contribute to the propagation of an associated and potentially negative 'neuro-culture' spread across the whole of society (Williams *et al*. 2012). In so doing the various contexts of dementia are re-setting the coordinates of what ageing and old age mean in contemporary societies. The increases in life expectancy and the improvement of health at later ages has shifted our understanding of what constitutes normal ageing (Jones and Higgs 2010) as well as creating a much more 'densified' and frail 'fourth age' (Gilleard and Higgs 2011). This transformation has been much discussed and debated within social gerontology but has not had as much attention within medical sociology (Higgs 2013).

This monograph then comes at an important time to take stock of the societal impact of dementia and its relation to health. The papers in it address several themes that exist at the intersection of dementia with a number of important concerns within the sociology of age, health and illness. The selection exemplifies our concern to further develop a critical but constructive sociology of dementia; one that is both critical in highlighting the social processes involved in dementia and dementia care as well as taking full account of the cultural and social representations of dementia that are present in everyday life. We do so to facilitate constructive engagement in the formulation of a range of potential responses to this condition. When first proposing this monograph, we drew heavily on our own understanding of the role of dementia in positioning a 'social imaginary' of the fourth age (Gilleard and Higgs 2010, Higgs and Gilleard 2015). We used the term social imaginary in order to project the idea that the fourth age has as much impact on those who are not enveloped by its corporeality as on those who by their dementia and frailty already are. We argued that using the term allows for a much greater recognition of the way in which social representations play a key role in understanding the dilemmas posed by dementia and how this may differ for those occupying the multiplicity of professional and social locations operating in this arena. This has led us to become interested in such key concepts as personhood, care work and the ethical and moral frameworks in which these practices are situated (Higgs and Gilleard 2016). These concerns are, we believe, brought out in this collection.

The volume covers four broad themes. While they are by no means exhaustive of the range of present and future possibilities for a sociology of dementia, they do serve as a sound basis from which to build one. The first theme concerns the importance of the construction of personhood in relation to dementia. This has been a key area for the development of social science thinking about what the condition of dementia means for those with the diagnosis as well as those dealing with it as both a family and a professional concern. A key point of departure has been the usefulness (or otherwise) of Kitwood's (1997) location of the 'problem' of dementia as the product of a 'malignant' social psychology. The tendency he observed for services to discount the concerns, feelings and interests of those with the condition led him to advocate a more 'person-centred' form of care as a way of recognising and supporting the 'personhood' of the individual concerned. For Kitwood, personhood was not 'dependent'

on a Kantian assumption of individual rationality but on the relatedness of persons. This approach has been very influential and a number of the contributions to this volume explicitly discuss and defend that legacy. Kontos, Miller and Kontos in their paper 'Relational citizenship: Supporting embodied selfhood and relationality in dementia care' develop this line of thinking by explicitly arguing for a notion of 'embodied selfhood'. However the debate on personhood as developed, cannot help but overlap with discussions of citizenship given that many commentators have seen the issues of personhood better understood not as ones of 'personal capacity' or even 'personal relationships' but as ones that speak to the denial of citizenship rights (Bartlett and O'Connor 2007). Here an often implicit connection is made to the activism of the disability rights movement. This is brought out in Birt *et al.*'s paper 'Shifting dementia discourses from deficit to active citizenship' which seeks to consider the advantages to be gained from adopting a disability perspective to this area of practice and research, while recognising how profound cognitive disability may pose particular difficulties for this perspective.

The second theme concerns the issue of care. This topic interrelates with issues of personhood as shown in Tolhurst *et al.*'s paper 'Narrative collisions, sociocultural pressures and dementia: the relational basis of personhood reconsidered' and in Scales *et al.*'s paper 'Power, empowerment, and person-centred care: Using ethnography to examine the everyday practice of unregistered dementia care'. What these papers illustrate is the complexity of the care relationship within dementia and, as Andrews's paper 'Institutionalising senile dementia in 19th-century Britain' shows us, how these relations are historically contextualised within both medical discourses and institutional practices.

The third theme of the monograph addresses the social representations of dementia and in particular the way in which its presence has been inserted into contemporary culture. Work by Beard (2016), Beard and Neary (2013) and Lock (2013) has started to address this process. McParland *et al.*'s paper 'Dichotomising dementia: is there another way?' shows that as the title suggests, it would be a mistake to view living with dementia purely as a failure. They advocate accepting the condition as something more fluid and paradoxical in terms of the possibilities for continuing social inclusion. Brittan *et al.*'s paper 'When walking becomes wandering: representing the fear of the fourth age' describes aspects of the social imaginary of the fourth age that many working in the field are aware of and which represent symbolic processes as much as practical concerns. In a similar fashion, Goldman's paper 'Re-imagining dementia in the fourth age: the ironic actions of Alice Munro' examines the fictional representation of dementia. It reminds us also that the social imaginary of the fourth age operates at many different levels of cultural practice not just in bio-medical, nursing and social care discourses.

The fourth theme addresses what we would term the social contextualisation of dementia. Jones's paper 'Social class, dementia and the fourth age' offers an overview of the social determinants of dementia and dementia care, both in terms of their 'equalising' nature as well as those arenas where inequalities emerge. This is complemented by the paper by Grenier *et al.* entitled 'Precarity in late life: Rethinking dementia as a 'frailed' *old age'* which sees the many issues surrounding the fourth age as being better understood when viewed through the lens of contemporary work on 'precariousness' and the 'precariat' (Standing 2011). Such a conceptualisation places dementia and the fourth age within the broader context of statuses and positions that are less and less secured in present-day society. Among the many effects of this growing precariousness, they argue, is its role in deepening the social divisions of later life.

It is this wider contextualisation for which we are advocating; seeing the sociological problem of dementia within the broader context of family life, the social imaginary institutions of

old age, the expansion of care work within the service sector of the economy, and the particular consequences of what Beck and Beck-Gernsheim (2002) have called the 'institutionalised individualism of second modernity' for those whose lives are made ever more difficult by the promulgation of an individualised reflexivity in contemporary culture. This focus continues into the care home where the issues of personhood and competence promote forms of 'third person agency' and 'proxy consumerism' (Vabø 2006).

What is perhaps one of the lacunae in this collection is the role that Alzheimer's plays within the domain of 'science, technology and society'. There has been research on the categories used in the development of the science and the development of categories within it (see, for example, Hedgecoe 2006, Moreira *et al*. 2009, Whitehouse and Moody 2006). The social representation of dementia extends beyond demographic fears, beyond considerations of the nature of autonomy in society and the related nature of care and the cultures of care. It is realised in and through media accounts and professional claims for dementia as a significant scientific and technological problem confronting society. If brain and consciousness represent one of the last 'frontiers' to be 'conquered' by science – the failure of researchers, of the pharmaceutical industry and of medicine to 'solve' the problem of dementia questions the limits of our scientific reach and of the modernist project itself.

Such concerns are raised whenever news of a breakthrough is followed by a period of media silence broken only when a new and often unrelated line of inquiry is opened. While, in the latter decades of the twentieth century, the work of the pharmaceutical industry was relatively successful in re-positioning 'dementia' from its status as part of the normative ageing process and expectations of decline from people as they reach ever greater ages, the re-branding of dementia as 'Alzheimer's and related disorders' has had minimal effect on society, beyond the evident increase in research funding associated with the condition. Cynically one might speculate that the most long lasting effect of the Alzheimerisation of old age has been to increase public anxiety and channel medical research toward a drive for a variety of cures and away from the previous concerns for improving care provision that dominated research before the era of the 'cholinergic' and the 'amyloidogenesis' hypotheses.

What then might constitute the most helpful directions of travel for research in dementia within the fields of medical sociology and the sociology of ageing? Does there need to be further research into 'the problems of care' or into the institutional practices of care? What scope is there for developing a social disability model of dementia? Or one based upon notions of 'justice' and 'citizens' rights'? Does the emergence of the social category of the 'precariat' offer a focus of resistance against the gradual erosion of services and reduction in public resources for those least able to navigate their way through what has been described by Post (2000) as a hyper-cognitive society? Are the issues surrounding dementia similar to the ones identified in the health inequalities literature and are the solutions broadly the same? What scope is there to support greater recognition – materially and socially – of the demanding and difficult work that is regularly performed by those in the care sector (Johnson 2015)? What of the challenges and points of resistance being created by an increasingly sophisticated range of technology designed to provide digital electronic support for this work?

What are the risks that can easily turn such systems of support into more oppressive forms of surveillance (Berridge 2016)? All of these are important questions that need to be developed and debated. The answers provided may reflect many different approaches but hopefully they will collectively take the field of social science dementia research forward so that it can fruitfully engage with policy and practice.

As we have pointed out earlier, as editors we have a definite approach to the questions posed by dementia and we have a clear idea of the concepts useful in answering them. Other than framing the call for papers we have not tried to endorse our views in this volume. The

papers reflect a wide spectrum of opinion and we are grateful for that. We hope that this collection will help to draw wider attention to the debates and research occurring in an area that has not commanded the attention it deserves within the wider community of researchers working in the field of the sociology of health and illness. The debates and issues present inevitably reflect our own concerns but the multiplicity of the authors' approaches indicate that there are many ways of viewing the topic. While we believe that these papers focus on those areas and social relations where the social imaginary exerts its strongest influence, specifically on those caught up with the moral imperative of care and what is sometimes known as the 'reproductive labour' of care (Yeates 2012), it is also the case that all the papers share a desire to ensure that the social relations of dementia provide conceptual and empirical resources for establishing better ways of caring and of continuing to care.

Acknowledgements

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2

Relational citizenship: supporting embodied selfhood and relationality in dementia care
Pia Kontos, Karen-Lee Miller and Alexis P. Kontos

Introduction

In the dominant discourse of dementia there is a presumed existential erosion of selfhood 'until there is nothing left' (Davis 2004: 375). This discourse is a legacy of the 17th century rise of the 'modern self' in which the self and brain became consubstantial (Vidal 2009), implicitly relegating corporeality to a subordinate role. This introduces a belief in the body's fundamental passivity because it treats the brain as the organ responsible for the functions with which the self is identified (Whitehouse 2008). The perceived loss of self is, in turn, accompanied by assumptions of loss of agency, as well as citizenship status. An individual's status as citizen, which denotes an entitled connection to a community and country with rights and responsibilities as a community member and freedom from discrimination (Bartlett and O'Connor 2007), is seen as fundamentally and irrevocably eroded by dementia because communicative competence and intellectual capacities are inextricably linked to the practice and status of citizenship.

To redress the social and structural disadvantages of people with dementia, particularly those who are severely cognitively impaired, we advocate the need for a new model of citizenship – what we term 'relational citizenship' – that fully supports their contributions to social life and what they may expect as citizens in return. It is a model that is premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care (Dupuis *et al.* 2009, Nolan *et al.* 2002). Another foundational tenet of the model is that the capacities, senses, and socio-cultural dispositions of the body are central to self-expression, interdependence, and the reciprocal nature of engagement (Kontos 2006, 2012a, 2012b). As such, relational citizenship is a model that stands to advance the discourse on citizenship by offering an important rethinking of notions of selfhood, entitlement, and reciprocity, which are central to a sociology of dementia.

We begin by tracing and critiquing the traditional paradigm of clinical and social care of individuals with dementia in order to contextualise key counter-paradigms, including citizenship and person-centred and relationship-centred approaches to care. We highlight important limitations of these paradigms, which we argue can be redressed with our relational model of citizenship (Miller and Kontos 2016, Kontos *et al.* 2016). To illustrate how relational citizenship can be supported, or undermined, at the micro level of direct care, we utilise empirical evidence from a study we conducted which explored the interactions between elder-clowns and persons with dementia residing in a long-term care facility.