Routledge Advances in Sociology

AGEING, DIVERSITY AND EQUALITY: SOCIAL JUSTICE PERSPECTIVES

Edited by
Sue Westwood

Ageing, Diversity and Equality: Social Justice Perspectives

Current understandings of ageing and diversity are impoverished in three main ways. Firstly, with regards to thinking about what inequalities operate in later life there has been an excessive preoccupation with economic resources. On the other hand, less attention has been paid to cultural norms and values, other resources, wider social processes, political participation and community engagement. Secondly, in terms of thinking about the 'who' of inequality, this has so far been limited to a very narrow range of minority populations. Finally, when considering the 'how' of inequality, social gerontology's theoretical analyses remain under-developed. The overall effect of these issues is that social gerontology remains deeply embedded in normative assumptions which serve to exclude a wide range of older people.

Ageing, Diversity and Equality: Social Justice Perspectives aims to challenge and provoke the above described normativity and offer an alternative approach which highlights the heterogeneity and diversity of ageing, associated inequalities and their intersections, in relation to:

- Gender and sexualities
- Culture, ethnicity and religion
- Ageing with disabilities and/or long-term health conditions
- Care
- Ageing spatialities.

Multidisciplinary in nature with contributions from leading UK and international authors, this edited collection utilises a framework of a social justice perspective in order to analyse inequalities of resources, recognition and representation. It will appeal to students and researchers interested in fields such as Social Studies, Gerontology and Socio-Legal Studies.

Dr Sue Westwood is a socio-legal and social gerontological scholar working as a consultant academic and as Lecturer in Law, York Law School, University of York, UK.

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This book is dedicated to my dear aunt,

Dorothy Felton née Calverley (1920–2017)

Dorothy is a shining example of a life well-lived.

She died as she had lived, full of gratitude, love and acceptance, with little bursts of wisdom, generosity, kindness and humour.

She has left behind a wealth of people who loved her, who were blessed to have been loved by her, and whose lives were better for having known her.

A life well-lived indeed.

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Contributors

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Robin A. Hadley's PhD (Keele, 2015) examined the experiences of involuntarily childless older men. He is a founding member of the campaign group Ageing Without Children. Recently, he collaborated in research projects on dementia technology, health monitoring technology and fathers' influence on infant feeding. Previous careers include counsellor, scientific photographer and kitchen assistant. Robin's counselling and own experience of childlessness led him to self-fund his MA and MSc (University of Manchester, 2008; 2009) on the desire for fatherhood and the levels of desire for parenthood in childless people and parents. He was born in Manchester, the seventh of eight children.

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Sue Westwood is a socio-legal and social gerontological scholar, working as a consultant academic and as Lecturer in Law, York Law School, University of York, UK. Her book *Ageing, Gender and Sexuality: Equality in Later Life*, published by Routledge in 2016, won the Socio Legal Studies Association Early Career Book Prize for 2017. Her second book, co-edited with Elizabeth Price, *Lesbian, Gay, Bisexual and Trans* (LGBT*) Individuals Living with Dementia: Concepts, Practice and Rights*, was also published by Routledge in 2016. A further collection, *Older Lesbian, Gay, Bisexual and Trans People: Minding the Knowledge Gaps*, co-edited with Andrew King, Kathryn Almack and Yiu-Tung Suen, was published by Routledge in 2018.

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Sue Westwood

1 Introduction

Sue Westwood

Ageing, diversity and equality

As Daatland and Biggs (2006, 1) observed over a decade ago, 'to understand contemporary societal ageing, there is a need to recognise its diversity'. However, social gerontology continues to approach ageing from homogenous, normative perspectives (Martinson and Berridge, 2014) with insufficient attention paid to diversity:

> There is a staggering lack of evidence for some groups and certain aspects of inequalities. We have ignored or overlooked the diversity of our ageing population, arguably through focusing primarily on the differences between young and old.
>
> (Centre for Ageing Better, 2017, 12)

There is a long-standing body of literature on ageing, gender and class (Arber and Ginn, 1991; Arber, Davidson and Ginn, 2003; Calasanti and Slevin, 2013). However, this has very often failed to connect with other social divisions, and sites of inequality. While lesbian, gay, bisexual and trans (LGBT) ageing is also beginning to be addressed within research (Rosenfeld 2003, 2010; Ward, River and Sutherland, 2012; Hoy-Ellis and Fredriksen-Goldsen, 2017), diversity among older LGBT people is less well recognised (Blood and Bamford 2010; Westwood, 2016; Westwood and Price, 2016). Furthermore, heterosexual ageing remains a taken-for-granted norm, informing much of mainstream gerontological research in an under-interrogated way (Cronin, 2006). While research is now also addressing culture, ethnicity and ageing (Torres, 2015; Ute and Torres, 2015) and religion, spirituality and ageing (Mackinlay, 2015), the subtleties, complexities, nuances and intersections in these areas are also not yet well addressed (Zubair and Norris, 2015).

Similarly, while there is a growing body of literature on older people and social care (Vlachantoni et al., 2015; Daly and Westwood, 2017) it mostly refers to the needs of older people with age-acquired disabilities and health conditions, rather than those ageing *with* them. Indeed, the trope of 'successful ageing' is predicated upon the assumption of their absence. Issues affecting older people

with learning/intellectual disabilities are particularly under-addressed (Ward, 2015). Moreover, while there is growing academic interest in spatiality as a dimension of inequality, ageing spatialities, beyond the urban/rural dichotomy (Buffel, Phillipson and Scharf, 2012; Burholt and Dobbs, 2012) remain under-explored (Schwanen, Hardill and Lucas, 2012), particularly workplace ageing and ageing in hidden contexts, such as prisons (O'Hara et al., 2015).

In addition to the 'who' and the 'where' of ageing, diversity and inequality, the 'what' (Baker et al., 2016) has also been considered along relatively narrow lines. Social gerontologists have considered inequalities in terms of social and economic contexts (Angel and Settersten, 2013) including at their intersection with 'class' (Formosa and Higgs, 2015), and the 'interplay of health disparities, economic resources, and public policies' (Crystal, 2017, 205). These have been analysed at local, national and comparative international and global levels (Hyde and Higgs 2016; OECD, 2017). In his recent review of critical gerontology, and the theoretical/philosophical concepts underpinning it, Jan Baars (2017) has observed that social inequality in terms of material reproduction has been prioritised over social inequality in terms of cultural reproduction. His analysis highlights not only the privileging of materiality but also the binary ways in which inequality is approached, i.e. the material and/or the cultural.

In terms of the 'how' (Baker et al., 2016) of ageing and inequality, this has been addressed, to a greater or lesser extent, by the main theories in social gerontology, i.e. '(1) social constructionist, (2) social exchange, (3) life course, (4) feminist, (5) age stratification (age and society), (6) political economy of aging, and (7) critical theory' (Bengtson, Burgess and Parrott, 1997, S72). Social constructionist theories of ageing emphasise how older age(s) are socially constituted positions, which change according to cultural, temporal and spatial contexts. More recently, they have pointed to 'increasing diversity within age categories and cohorts that is accompanied by cumulative inequalities across all phases of life' (Mortimer, Jeylan and Moen, 2016, 111). Life course theories (Shanahan, Mortimer and Johnson, 2016) have emphasised in particular the significance of cumulative dis/advantage across a lifetime (Dannefer, 2003; DiPrete and Eirich, 2006). However, notions that lifetimes follow a particular 'course' are imbued with assumptions about how lives are lived, predicated on heterosexist reproductive norms (Carpenter, 2010). Feminist theories (Arber and Ginn, 1991; Calasanti and Slevin, 2013) have focused on the centrality of gender as an organising principle in life and in ageing, the comparative socio-economic disadvantages of older women compared with older men and 'how the dominant social institutions render older women vulnerable and dependent throughout their life course' (Estes, 2017, 81). While social constructionist, life course and feminist theories have much to offer to an analysis of wider ageing diversity and inequality, they have not been applied to this as much as they might have been.

Critical gerontology is 'an interdisciplinary sub-field consisting mostly of humanities and social science scholars who challenge the assumptions of

mainstream gerontology and biomedical models of ageing' (Katz, 2015, 29). It has focused on three main conceptual areas:

> Firstly, political economy '. . . postulates that aging and old age are directly related to the nature of the society in which they occur and, therefore, cannot be considered or analyzed in isolation from other societal forces and characteristics'. . . . Secondly, moral economy studies aging and old age through '. . . norms, beliefs and values in a given context'. . . . Finally, humanistic gerontology focuses on larger questions of meaning in the lives of the older people.
>
> (Paris, 2016)

These theories are themselves restrictive, continuing as they do to focus on socio-economic issues. Moreover, even critical gerontology has, with a few notable exceptions (e.g. Daatland and Biggs, 2006), not considered ageing and diversity in any great depth.

> Researchers interested in aging have relentlessly collected mountains of data, often driven by narrowly defined, problem-based questions and with little attention to basic assumptions or larger theoretical issues . . . the lack of attention to theory has meant that research questions have often been informed by an uncritical reliance on images and assumptions about aging drawn from popular culture or from traditions and paradigms of theory that are considered outdated within the broader discourses of behavioral and social theory.
>
> (Baars et al., 2017, 1)

This 'uncritical reliance' has often led to homogenising narratives which make generalisations about ageing based on research which has often not included questions of diversity in its parameters, has not included representative populations (i.e. included people from minorities) and has not incorporated issues of diversity and/or inequality in its analysis. This means that at best associated narratives only apply to majority populations and at worst, they are grossly inaccurate, because they are based only on data from, and analyses of, part of the ageing population.

There is growing recognition of the significance of intersectionality in the social sciences. Intersectionality refers to 'the mutually constructed nature of social division and the ways these are experienced, reproduced and resisted in everyday life' (Taylor, 2009, 190). Intersectional analyses 'look at forms of inequality which are routed through one another, and which cannot be untangled to reveal a single cause' (Grabham et al., 2009, 1). Intersectionality is generally understood to be significant for ageing.

> Multiple factors combine and overlap to influence individual and group experiences of later life. Intersectionality describes the simultaneous impact

> of characteristics, such as gender, poverty and disadvantage and sexual orientation. It considers the many personal identities and power hierarchies and systems that contribute to discrimination and disadvantage. Intersectionality offers a holistic account of people's experiences of disadvantage and discrimination in later life and has the potential to offer solutions that are better suited to our increasingly diverse older population.
>
> (Centre for Ageing Better, 2017, 12)

However, while intersectionality has been considered in relation to particular ageing minorities (Cronin and King, 2010), it has not been considered in relation to ageing as a whole. Indeed, much of social gerontology continues with narratives of homogeneity, privileging majority populations. Where minoritised groups are considered, it is often only as an add-on, as a politically correct nod to 'difference' without any critical interrogation of the broader normative assumptions which inform social gerontological discourse. Minoritised older people are at best considered in terms of the exotic 'Other', rather than being integrated into mainstream theorising. Those working to make the experiences of marginalised older people more visible, and indeed more thinkable, have tended to advocate on behalf of particular groups, e.g. people from minority ethnic backgrounds, or LGBT older people. In order to render their arguments more distinct, they have, inevitable drawn upon the strategic use of identity categories (Bernstein, 2009) to demonstrate comparative inequalities. While understandable, this has, inevitably, led to narratives of ageing and diversity existing in silos, without making (potentially illuminating) connections between uneven outcomes in later life. These silos have then led to diminished power in the voices of those seeking to highlight the heterogeneity of ageing, and associated inequalities.

So, understandings of ageing diversity are currently impoverished in three main ways. Firstly, in terms of thinking about the 'what' of inequality, i.e. what inequalities operate in later life. There has been an excessive preoccupation with economic resources, and to a lesser extent, cultural norms and values, and an under-attention to other resources, wider social processes, and to political participation and community engagement. Secondly, in terms of thinking about the 'who' of inequality, this has so far been limited to 'race', culture and ethnicity, and LGBT issues, with insufficient attention given to diversity within and among these populations and in relation to other areas of diversity. Thirdly, in terms of thinking about the 'how' of inequality, social gerontology's theoretical analyses remain under-developed. The overall effect of this is that social gerontology remains deeply embedded in normative assumptions which serve to marginalise increasingly relevant minority populations.

This edited collection aims to challenge and provoke this normativity, and offer an alternative approach which highlights the heterogeneity and diversity of ageing. It also aims to explore and critically interrogate the (in)equalities associated with ageing and diversity. The overarching framework of this collection is that of a social justice perspective, engaging with the work of Nancy

Fraser (2013) who approaches social justice from three interrelated dimensions: resources (economic), recognition (social status, cultural visibility and cultural worth) and representation (social and political participation and access to justice). Several authors (Lynch et al., 2016; Westwood, 2016) have expanded Fraser's concept of resources from economic to include affective resources (love, care and affection), social resources (social support) and formal care provision, and this collection will also do so.

The collection is multidisciplinary, with contributions from both UK and international authors (many of whom are leaders in their fields) from a wide range of backgrounds: cultural studies, demography, economics, ethics, social gerontology, health sciences, history, law, migration studies, psychiatry, psychology, psychotherapy, social justice, social policy, social work, sociology, socio-legal studies, statistics. Several activists are also co-contributors, combining academic perspectives with lived experiences. This wide variety of perspectives is unified by each chapter being framed around the same theoretical structure, i.e. Fraser's social justice model.

Social justice framework

Nancy Fraser (1996, 1997, 1998, 2000, 2007, 2008a, 2008b, 2013) initially theorised about social justice in relation to both (Marxist) economics and also issues of recognition (Honneth, 1992, 1995). Nancy Fraser originally argued for the need to think about social justice in terms of *both* resource distribution and cultural recognition.

> Today, claims for social justice seem to divide into two types: claims for the redistribution of resources and claims for the recognition of cultural difference. Increasingly, these two kinds of claims are polarized against one another. As a result, we are asked to choose between class politics and identity politics, social democracy and multiculturalism, redistribution and recognition. These, however, are false antitheses. Justice today requires both redistribution and recognition. Neither alone is sufficient.
>
> (Fraser, 1998, 1)

In her analysis of resources, Fraser placed emphasis on the traditional issue of the (re-)distribution of economic resources. However, other resources are also of importance, especially in later life.

> Health, physical and cognitive functioning (Glaser, Price, Willis, Stuchbury & Nicholls, 2009), access to 'love, care and solidarity' (Lynch, Baker & Lyons, 2009), safe housing (Barnes, 2012), social networks and informal social and instrumental support ('social capital', Cronin & King, 2014) all have direct impact upon well-being in late life (Bond & Cabrero, 2007; Fredriksen-Goldsen et al., 2013). Differential access to these can produce profound affective inequalities (Lynch, Baker & Lyons, 2009) and engage

> with issues of inequalities of care from the perspectives of feminist care ethics (Tronto, 1993; Kittay, 1999; Sevenhuijsen, 2003; Held, 2006; Lynch, 2007, 2010).
>
> (Westwood, 2016, 8)

Equality of recognition involves 'social status, cultural visibility and cultural worth' (Westwood, 2016, 8). As Fraser (1998, 5) explains, in terms of the politics of recognition, 'Here the goal, in its most plausible form, is a difference-friendly world, where assimilation to majority or dominant cultural norms is no longer the price of equal respect'. Fraser describes a lack of recognition or 'misrecognition' as 'status injury whose locus is social relations' (6). She goes on to explore how both resource distribution and cultural recognition are central to social justice, using gender as an example,

> Gender, in sum, is a two-sided category. It contains both an economic face that brings it within the ambit of redistribution and also a cultural face that brings it simultaneously within the ambit of recognition. It is an open question whether the two faces are of equal weight. But redressing gender injustice, in any case, requires changing both the economic structure and the status order of contemporary society.
>
> (6)

Inevitably Fraser's thinking has evolved across time. She initially created waves by asserting that lesbian, gay and bisexual inequalities were purely a matter of recognition:

> Fraser controversially asserted in 1996 that lesbian, gay and bisexual equality was a problem of recognition, not redistribution (Fraser, 1996, pp. 13–14). This, not surprisingly, aroused considerable debate (Olson, 2008) particularly with Judith Butler (1997) and Iris Marion Young (1998). Butler, in her paper 'Merely Cultural', emphasised the interrelatedness of 'the reproduction of goods as well as the social reproduction of persons' (Butler, 1997, p. 40) and Iris Marion Young conceptualised cultural recognition not as an end in itself but as 'a means to economic and political justice' (Young, 1998, p. 148). Fraser did acknowledge in a footnote in a paper in 2007 'even sexuality, which looks at first sight like the paradigm of pure recognition, has an undeniable economic dimension' (Fraser, 2007, p. 27, footnote 3) indicating that she had somewhat shifted her position in response to these criticisms.
>
> (Westwood, 2016, 8)

Fraser refers to resources and recognition as a '"bivalent" conception of justice' (10), each informing the other. In her 1998 paper she suggests that both, in turn, inform 'parity of participation . . . social arrangements that permit all

(adult) members of society to interact with one another as peers' (10). However, she subsequently developed this third area into a category of its own, representation, which involves 'social and political participation and access to justice' (Westwood, 2016, 9). Individuals can enjoy equal distribution of resources and equality of recognition, and yet still not enjoy parity of participation. Indeed, Fraser has subsequently asserted that 'there can be no redistribution or recognition without representation' (2008a, 282). In order for there to be social justice, individuals must have equality of resources, recognition *and* representation.

If we apply Fraser's approach to ageing, diversity and inequality, we can see immediately that it affords wider opportunities for analysis in several ways. Firstly, it offers three dimensions of inequality (resources, recognition, and representation) which go beyond the traditional economic/cultural binaries of analysis. Secondly, the modified application of Fraser's theory incorporates a much broader analysis of resources, beyond the economic/material, to also think also about the resources of health, love, care and support (both informal and formal). Thirdly, Fraser's concept of recognition offers a more nuanced analysis beyond the simply 'cultural'. And lastly, by including representation, Fraser highlights a domain which is often under-recognised in discourse about ageing and inequality, i.e. community engagement and political voice.

Chapter outlines

This book is divided into five sections.

Part I: Gender

Five chapters comprise this section, which explores ageing and social justice through the lens of gender, and intersections with it.

In **Chapter 2**, Athina Vlachantoni addresses the later life economic implications of women's greater likelihood of providing informal care for children and older parents, and in particular, the links to higher poverty risk among older women. She explores the gender differentials in socio-economic resources in later life, in the UK and also the broader European context, discussing the interaction between women's atypical life courses compared to men's, considering the role of pension system and associated policy challenges. She argues that increasing the recognition and representation of informal carers could potentially lead to policies which would appropriately reward the place of informal care provision in society and improve women's economic status, including in later life.

In **Chapter 3**, Laura Hurd Clarke considers ageing, gender and social justice through the lens of embodiment, specifically the physicalities of growing older. She examines how ageism and healthism combine with idealised masculinity and femininity to culturally devalue the recognition of older bodies

in gendered ways. She argues for increased enquiry into the corporeality of ageing and inequality in relation to resources, recognition and representation, calling for more research in particular on the role of the body in the exclusion of marginalised older adults.

In **Chapter 4**, Chris Gilleard and Paul Higgs offer a highly theoretical essay, building on their previous work which has explored distinctions between the 'third' and 'fourth' ages, and which has suggested that the privileging (recognition and representation) of the former has led to the disadvantaging (recognition, representation and resourcing) of the latter. They highlight that while physical and cognitive 'frailties' of the fourth age have been explored, the significance of gender for the fourth age has not yet been given sufficient attention, even though it is primarily occupied by women. They consider this through the lens of Castoriadis' interpretation of the collective representations of the social world juxtaposed against Fraser's model of social justice. Gilleard and Higgs explore in particular the abjection of the fourth age in the 'social imaginary' (recognition), and argue for better representation and increased resourcing of 'deep' old age.

In **Chapter 5**, Robin A. Hadley considers the under-addressed issue of older people ageing without children, a population growing in number. He explains that the experiences and meanings of ageing and childlessness are not yet well understood, especially in relation to men, and that these gaps in knowledge are a key feature of the under-representation/misrepresentation of older childless people. Hadley proposes that much more needs to be understood about the resource implications of entering old age without children (i.e. in terms of accrual of material resources), and the resource implications of being older without children (i.e. in terms of two-way flows of material and social support). Central to Hadley's argument is that pronatalist and heteronormative ideals are obscuring the recognition and representation of older people ageing without children, and that this in turn leads to older age policies and provisions which are not equipped to meet their needs.

In **Chapter 6**, Jenny-Anne Bishop and Sue Westwood consider the inequalities associated with ageing as a trans(gender)/gender diverse (trans/g-d) person, i.e. someone who is transsexual, transvestite, gender queer, gender fluid, non-binary, genderless, agender, non-gendered, third gender and bi-gender. They utilise Fraser's social justice model to explore how older trans/g-d people explore significant inequalities in relation to resources, recognition and representation. Following a lifetime of social marginalisation, many have fewer material resources than cisgender older people (those who identify with the (sole) gender they were assigned at birth), while at the same time also being more vulnerable to physical and mental health problems. They argue that recognition is a key issue for trans/g-d people, particularly in terms of the pains and penalties of mis-recognition. They suggest that increasing recognition and representation of older trans/g-d people are offering opportunities to re-vision both gender and ageing.

Part II: Sexualities

This section is composed of four chapters that address lesbian, gay, bisexual and heterosexual ageing, respectively.

In **Chapter 7**, Jane Traies considers the under-representation of older lesbians' lives and experiences in the growing body of literature on lesbian, gay, bisexual and trans (LGBT) ageing, which she argues leads to unequal resource distribution, particularly in relation to advocacy, housing, health and social care provision, and informal support. She highlights the significance of the intersection of ageing (and ageism) with gender (and sexism) in informing older lesbians' experiences of ageing. These in turn intersect with sexual identity (and heterosexism), Traies argues, to ultimately deprive older lesbians of appropriate representation, recognition and resources. She concludes by advocating for ongoing challenging of social assumptions (recognition) about sexuality and ageing; by gaining a 'more contextualised understanding' of the lives of older LGBT people, and by promoting and reinforcing non-discriminatory practice among service providers.

In **Chapter 8**, Mark Hughes and Peter Robinson consider the challenges which older gay men continue to face in relation to material inequality, a lack of cultural recognition and deficits/complications in political representation. They highlight how ageism shapes not only how older gay men are perceived by others, but also how they view themselves as older/old men. Even so, older gay men now are ageing during times of political and social transformation, with increasing legal protections for gay rights. However, the extent to which current cohorts of older gay men are themselves reflecting and/or are reflected by these transformations, is highly contingent upon the context(s) within which they are ageing. Hughes and Robinson conclude by resisting the categories of 'older' and 'gay men' suggesting that the experiences of ageing as a gay man is much more nuanced than convenient typologies might suggest.

In **Chapter 9**, Sarah Jen provides an overview of research on bisexual ageing, considering why bisexual populations are under-represented in ageing research. She argues that older bisexual individuals are under-resourced, under-recognised and under-represented both in comparison with older heterosexual people and older lesbian and gay people, and proposes that increased visibility and voice are needed before improvements in resource distribution can be achieved. She advocates for increased research on bisexual ageing (particularly in relation to health disparities among older bisexual individuals) in relation to bisexual individuals specifically, older LGBT populations more broadly, and ageing individuals in general. Jen suggests that recognition is a central issue, in that bisexual erasure and bisexual-specific stigma inform a lack of representation in research, practice, and political spheres. Increasing recognition, she concludes, is essential to increasing resources and representation for bisexual older people.

In **Chapter 10**, Sue Westwood critically examines heterosexuality as the taken-for-granted norm in gerontological discourse. She argues that the many

social gerontological studies which do not include non-heterosexual ageing are inevitably only giving partial accounts of the ageing experience. Moreover, how heterosexuality itself informs the ageing experience goes un-interrogated. She suggests a research agenda for exploring the place of heterosexuality in ageing, which should include (a) asking how heterosexuality as an identity practice and as a sexual practice informs access to resources, recognition and representation in older age and (b) asking how gerontological research and discourse can become disengaged from their heterosexist and heteronormative underpinnings.

Part III: Culture, ethnicity and religion

This section is made up of four chapters.

In **Chapter 11**, Sandra Torres draws upon a scoping literature review of scholarship on health and social care, old age/ageing and ethnicity/race to critically interrogate why it is not informed by the social justice framework. She argues that this is because much of the literature takes an essentialist, rather than a social constructionist, approach to understandings of ethnicity/race, which makes it 'injustice-oblivious'. She argues that a shift from the former to the latter is needed in order to address the socially located and positioned inequalities associated with ethnicity/race and ageing. Torres concludes that if ethnogerontologists want to take onboard issues of social justice, they need to shift their attention from the needs and identities of older people from ethnic minorities (recognition) and focus instead on what practitioners and policymakers can do to address (resource) their needs.

In **Chapter 12**, Shereen Hussein considers the experience of migrants growing older in host communities, focusing on social networks as a key resource in older migrants' lives. Drawing on data from research with older Turkish migrants living in the UK, Hussein considers cultural visibility and social status (recognition) and participation within and outside the 'community' (representation). She argues that although strong social networks among ageing migrants can be sources of resources, recognition and representation, they can also exacerbate social marginalisation (and decreased access to resources, recognition and representation) among the wider community.

In **Chapter 13**, Alistair Hunter considers 'transnational ageing', exploring diversity both between *and* within groups of older migrants. He argues for the importance of this approach in order to move beyond stereotypes, such as 'vulnerable' former labour migrants ageing in place and 'privileged' older lifestyle migrants. Hunter argues that privilege and disadvantage among ageing migrants is more complex, nuanced and context-contingent than has been previously understood. He argues for increased inclusion of older migrants in social gerontological research and in particular for greater attention to the diversity not only *between* but also *within* groups of older migrants.

In **Chapter 14**, Peter Kevern considers the place of religious beliefs, institutions and practices in relation to later life inequalities. His discussion is based

on the six main religions (Christianity, Judaism, Islam, Hinduism, Sikhism and Buddhism) in the UK. Kevern argues that the traditional rhetoric of the valoration of, and support for, older people among religious institutions does not take into account how this is nuanced by institutional responses to (privileged) normative and (less privileged) non-normative identities. Kevern concludes that religious institutions, rather than mitigate age-related inequalities may serve to reinforce them in relation to some aspects of diversity and ageing.

Part IV: Disabilities, long-term conditions and care

This section includes four chapters: the first three explore inequalities associated with ageing with, as opposed to into, disability and chronic health conditions; the fourth explores rights and inequality issues associated with residential care provision for older people.

In **Chapter 15**, Sue Westwood and Nicola Carey explore issues of inequality in relation to the increasing numbers of people who are growing older with pre-existing physical disabilities and/or physical or mental health related long-term conditions. These individuals are more likely to have experienced inequalities of resources, recognition and a representation prior to ageing, which are then further compounded at their intersection with older age itself. They argue that models of 'successful ageing', predicated on an active, healthy, disability-free lifestyle, by definition exclude those older people ageing with chronic health problems and/or disabilities. They propose that increasing the recognition of people ageing with, as well as into, disabilities and long-term conditions has the potential to create more inclusive constructions of ageing successfully.

In **Chapter 16**, Karen Watchman explores the intersection between ageing and intellectual disability, highlighting gaps in knowledge, understanding and service provision for the older people with intellectual disabilities who are at high risk of developing a number of age-related health problems prematurely, including dementia. She considers the need for improved health and social care resources, suggesting this will be achieved in three main ways. Firstly, through increasing the recognition and representation of older people among intellectual disability services. Secondly, through increasing the recognition and representation of people with intellectual abilities among ageing services and dementia services. Thirdly, through more joined up working between the respective services and increasing the recognition of the intersection of ageing and intellectual disability.

In **Chapter 17**, Dana Rosenfeld, Damien Ridge and Jose Catalan apply Fraser's inequalities framework to our UK-based HIV and Later Life (HALL) study. They argue that Fraser's framework is 'imperfect' in capturing the factors which inform disadvantages experienced by older people living with HIV. They argue that these disadvantages cohere around under-funded HIV-specific supports (resources) which were created to compensate for under-resourcing from mainstream provision (underpinned by issues of mis-recognition) and that these both inform and are informed by under-representation. They conclude

that inequalities associated with ageing with HIV are primarily issues of (mis-) representation. However, they mobilise the concept of representation differently from Fraser's (and the editor's) analysis.

In **Chapter 18**, Jonathan Herring explores the problem of abuse within care home settings, considering the difficulties of responding to such abuse through the lens of Fraser's framework of resources, recognition and representation. Herring questions whether applying and/or implementing further legislation will address the problem, suggesting that it is located in issues of recognition (specifically ageism and age-related social exclusion) and legal representation which focuses on minimum, rather than optimum, care standards. Herring proposes that residential care resources can only be improved by addressing recognition, and in particular the interpersonal relationship of staff and residents in residential care homes.

Part V: Spatiality

This section is composed of four chapters that explore spatiality and ageing in global and local contexts and in two contrasting locations: the workplace and prison.

In **Chapter 19**, Martin Hyde considers both the growing numbers of, and increasing diversity among, older people, in global contexts, reflecting upon the importance of space for understandings of ageing and later life. He critically explores the spatial patterning of redistribution/maldistribution, recognition/mis-recognition, and representation/misrepresentation, and the extent to which they help to understand ageing in the context of globalisation. He concludes that drawing upon Fraser's model highlights the persistence of economic, cultural and political inequalities for many older people around the world. However, Hyde refutes Fraser's assertions that such inequalities are linked to globalisation per se, however he suggests that more research is needed to investigate 'the ways in which global political actors are framing discourses about ageing and later life'.

In **Chapter 20**, Vanessa Burholt, Paula Foscarini-Craggs and Bethan Winter draw on data from the ESRC funded research programme *Grey and Pleasant Land? An Interdisciplinary Exploration of the Connectivity of Older People in Rural Civic Society (GaPL)* in this chapter to examine ageing and inequality in rural areas of the United Kingdom. They explore the intersectionality of rural areas with age, gender, marital status, health, and socio-economic status in relation to distribution of resources, recognition, and representation of rural older people. They observe that participants living in the most remote and deprived areas had 'fewer material resources, greater levels of poverty, lower levels of social participation and resources, and lower levels of civic participation and trust in local officials, but more local concerns than those in the more affluent and accessible areas'. They conclude that the most rural and remote areas are mis-recognised and misrepresented in the media and social policy.

In **Chapter 21**, Annette Cox explores older people's participation in employment. She considers how personal resources (skills, health, income levels) shape access to work, which is itself a resource (offering income, social contact and purpose). She highlights how both inclusion in the workplace and age-related workplace adjustments are contingent upon not only employer constraints but also whether and how older people are recognised by employers and potential employers. In terms of representation, Cox suggests that older people's workplace participation is, in part, shaped by the opportunities made available to them, and that similarly the extent to which their voices are expressed, heard and acted on are contingent on organisational strategy and context. She concludes by proposing that demographic pressures will promote a non-discriminatory economy in which older people can continue to participate meaningfully in employment.

In **Chapter 22**, Helen Codd considers the needs and experiences of the growing numbers of people ageing in prison, reflecting in particular on the tensions between criminal justice and social justice in this context. Older people in prison are comparatively under-resourced and under-recognised, compared with younger people in prison and older people living in the community. Codd focuses on parity of participation, arguing that all prisoners are excluded from a range of forms of civic engagement, but that older prisoners are additional excluded, due to age-related disabilities, from active participation in prison life. She argues that this raises issues of social justice within and outside of prison, and she advocates a rebalancing of the principles of criminal justice and social justice, particularly in relation to older prisoners.

Resources, recognition and representation

Resources

As outlined earlier, this edited collection is using an expanded notion of resources, beyond Fraser's material/economic definitions, to include such things as love, care and support. The authors of each chapter have, in turn, offered their own interpretations and/or explanations of resources, with some interesting commonalities and differences. The significance of economic resources (i.e. pensions, savings, material assets) for later life has been highlighted in particular by:

- **Vlachantoni** (particularly in relation to gender and earnings across the life course);
- **Hurd Clarke** (also in relation to gender and the ability to 'consume' health-promoting resources);
- **Hadley** (in terms of the economic consequences of ageing without children);
- **Traies**, **Hughes and Robinson**, and **Jen** respectively (in terms of the constraints upon earning opportunities for across the life course for older people with minoritised sexualities);

- **Torres** and **Hussein** (who considered the relatively lower economic capital of older people from minority ethnic groups);
- **Hunter** (who considered the implications of global and local divisions of labour for ageing migrant populations) and **Hyde** (who considered global spatial inequalities of economic resource distribution);
- **Westwood and Carey**; **Watchman**; and **Rosenfeld, Ridge and Catalan** (in relation to the comparative economic disadvantages of ageing with a disability and/or long-term health condition);
- **Burholt, Foscarini-Craggs and Winter** (in relation to rural poverty); and
- **Cox** (who explores the economic 'value' of older people).

Other significant resources which were highlighted by the authors include:

- Health and well-being (**Gilleard and Higgs**; **Westwood and Carey**; **Watchman**; **Rosenfeld, Ridge and Catalan**)
- Informal social support (**Hadley**, **Torres**, **Hussein**, **Traies**, **Hughes and Robinson** and **Jen**)
- Community connections (**Hussein**; **Kevern**; **Traies**; **Hughes and Robinson**; **Jen**; **Burholt, Foscarini-Craggs and Winter**)
- Appropriate and good-quality formal health and social care provision (**Gilleard and Higgs**; **Herring**; **Codd**; **Rosenfeld, Ridge and Catalan**)
- Culturally attuned (**Torres** and **Hussein**) and sexual identity-sensitive (**Traies**, **Hughes and Robinson**, and **Jen**) health and social care provision
- Access to employment for those who wish, and are able, to work (**Cox**)
- Autonomy, choice and control (**Gilleard and Higgs**, **Herring**, **Codd**, **Traies**, **Hughes and Robinson**, **Jen**)
- Freedom from incarceration (**Codd**)

The chapters also highlighted the interconnections between resources. As **Codd** demonstrated, incarceration often results in poorer health and social care provision. While, as **Gilleard and Higgs** and **Herring** have highlighted, older people with increasing disabilities (who are most likely to be women) are particularly vulnerable to the vagaries of health and social care provision. Moreover, those with the resources of informal care and support are less likely to turn to formal care provision and/or to do so later than those without such resources, or diminished ones (**Hadley**, **Torres**, **Hussein**, **Traies**, **Hughes and Robinson**, and **Jen**). Those with the greatest economic resources are more likely to be able to fund (and therefore have greater choice and control over) their formal care and support (**Vlachantoni**), highlighting the cumulative effects (Dannefer, 2003) of advantage and disadvantage in later life.

Recognition

Recognition was a key concern for many of the authors. **Cox** highlighted how the stigma of ageing can restrict workplace opportunities. Several authors considered the interconnections of stigmatised ageing identities with gender (**Hurd Clarke**, **Gilleard and Higgs**, **Bishop and Westwood**) and in turn with other stigmatised identities. These include older lesbians (**Traies**), gay (**Hughes and Robinson**) and bisexual (**Jen**) people located at the intersection of ageism, sexism and heterosexism; those older people from marginalised minority ethnic backgrounds located at the intersection of ageism, sexism and racism (**Torres**, **Hussein**); older people ageing with and/or into disability and long-term health conditions located at the intersection of ageism, sexism, disablism and 'healthism' (**Westwood and Carey**, **Watchman**, **Gilleard and Higgs**); older people ageing in prison, at the intersection of ageism, sexism and the stigma of imprisonment (**Codd**).

Recognition also plays a key part in access to resources. As the chapters have highlighted, historically stigmatised/culturally devalued identities tend to be linked to a reduced accrual of economic and material resources in later life. They are also linked to reduced physical and mental health in older age, and increased reliance on formal health and social care provision. However, those same stigmatised identities make it likely that such provision will be, at best, under-prepared to meet the needs of older people who do not have majority identities and, at worst, sites of prejudice and discrimination.

While most of the chapters' authors found Fraser's framework helpful in analysing inequalities and social injustices in relation to ageing and diversity, two did not. **Gilleard and Higgs** found the approach restrictive in their analysis of the social imaginary of the fourth age constraining, preferring instead to draw more upon the work of Castoriadis (1987) and his 'interpretation of the collective representations of the social world'. They use the term 'representation(s)' when considering stigmatised ageing identities, especially in regard to the oldest old, who are often cognitively and/or physically disabled. Fraser (and this editor) would understand this issue not as one of representation (political voice) but rather one of recognition. The words recognition and representation are in a sense being used synonymously by Gilleard and Higgs. Nevertheless, the overarching message remains the same, i.e. those in the fourth age are socially located in terms of 'abjection, frailty and loss'.

The other authors who found Fraser's framework less amenable to their analysis were **Rosenfeld, Ridge and Catalan**, who in particular struggled with the concept of representation. They, like **Gilleard and Higgs** have used 'representation' to refer to what Fraser would categorise as recognition. However, they have gone one step further to argue that both resources (cuts to funding in the HIV sector) and recognition (the cultural invisibility of older people ageing with HIV beyond the HIV sector) should come under the 'representation' category. Whereas the editor's understanding, in accord with Fraser's, is

that these issues of resources and recognition both inform and are informed by misrepresentation but are not issues of representation themselves.

Representation

Representation was identified by many of the authors as a major issue in relation to ageing diversity and inequality, in terms of:

- Older women's lack of representation, or political voice (**Hurd Clarke**)
- The limited representations of the voices of those in 'deep' old age and/or those advocating on their behalf (**Gilleard and Higgs**) and associated human rights implications (**Herring**)
- The under-representation of childless older people in research, advocacy and social policy (**Hadley**)
- The challenges of accessing full citizenship for older trans(gender)/gender diverse people, and the need to include them more in research (**Bishop and Westwood**)
- The under-representation (in terms of visual and political representation) of older lesbians (**Traies**)
- The socio-political and contextual contingencies attached to political representation and older gay men (**Hughes and Robinson**)
- The under-inclusion of bisexual people in LGBT research (**Jen**)
- The over-inclusion of heterosexual people in ageing research, and in ageing advocacy (**Westwood**)
- The under-inclusion of older ethnic minorities in ageing research (**Torres**)
- The risk that their tight minority ethnic communities may be sites of both political representation and political exclusion (**Hussein**)
- That the potential to act politically is dependent on the locus of citizenship (**Hunter**) and spatial contexts, globally (**Hyde**), locally (**Burholt, Foscarini-Craggs and Winter**; **Cox**) and in terms of whether one is permitted to participate in democratic processes (**Codd**)
- The issue of *whose* ageing interests are represented by (normative) religious organisations (**Kevern**)
- The exclusionary processes of politicised 'successful ageing' in relation to those ageing with disabilities and/or long-term conditions (**Westwood and Carey**; **Watchman**; **Rosenfeld, Ridge and Catalan**)

Conclusion: still thinking in silos?

At the outset of this chapter, one of the critiques I levelled at scholars and activists who address particular aspects of ageing and diversity, is that they tend to operate in silos. By this I mean that they tend to think only about one particular domain of diversity (and inequality) and not its intersections with others. This risks a number of things, not least of which are competitions and tensions over who is the most disadvantaged. It also risks a failure to take into account the

structures which inform intersecting inequalities, and the ways in which they may influence each other. Going back to the origins, for example, early theorists such as Kimberle Crenshaw opposed the additive approach to understanding discrimination, arguing that Black women experience sexism differently from White women, and racism differently from Black men, not because they are Black plus women, but because of the intersection of the two, which cannot be disaggregated.

Despite the aim of this book to encourage intersectional thinking, and exhortations to the authors to think beyond their particular diversity boxes, this has not occurred as much as I had hoped. The section on gender pays only passing attention to sexuality/sexual identity, for example, while several of the chapters on sexuality pay little heed to issues of gender. Neither pay much attention at all to issues of culture, ethnicity or religion. Discourse about ageing in the workplace and rural ageing is scant apart from the respective chapters which address each. Ageing prisoners are not considered anywhere outside of the chapter about them. Often (sometimes at my editorial urging), qualifiers have been added in about the lack of research on older BAME or LGBT people, for example. However, they have often been tokenistic nods to broader equality and diversity issues.

This is not, I hasten to add, the fault of the authors. In many ways, it is mine. Practical difficulties getting this collection off the ground meant that a planned e-roundtable had to be abandoned. Several authors joined later than others. So, the dialogue I had hoped to facilitate did not take place. Moreover, each of these authors are experts in their respective fields, necessitating intense focus on their particular area of expertise. When it is in relation to a marginalised group, they are trying to carve out a specific identity/social location, in order to distinguish between majority privilege and minority disadvantage. To add qualifiers, i.e. other intersections, can weaken intellectual and/or strategic positions.

Nevertheless, the completion of this book has left me with a strong sense of the need for disadvantaged older minorities to come together, locally, nationally and internationally, in ways which can give greater voice (and power) to their respective concerns.[1] It seems to me that social gerontology should be at the fore of such an initiative, not lagging behind.

This edited collection has, however, succeeded in its aims to challenge and provoke social gerontology's normativity. It has highlighted a wide range of ageing inequalities not previously considered, in terms of specific populations, locations and social positions. In doing so it offers an invitation to social gerontology to include these wider aspects of diversity in its research and its discourse about ageing. The collection has also demonstrated the usefulness of Fraser's framework in approaching ageing, diversity and inequality, echoing Fraser's own arguments that both distribution and cultural recognition are essential for social justice, while at the same time broadening definitions of each. It has also highlighted the significance of representation for ageing and equality: older people not only need access to a wide range of resources in later life, and to be recognised and valued as equal members of society, but

they also need parity of participation, i.e. social connectedness, social engagement, community involvement, political voice, advocacy (where required) and inclusion in research. Only when all three dimensions of equality are attained for all older people, across the diversity spectrum, will social justice in later life have been achieved.

Note

1 See, for example, the Diverse Elders Coalition in the USA: www.diverseelders.org/

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Part I

Gender

Sue Westwood

Introduction to Part I

This section addresses the intersection of ageing and gender. In Chapter 2, Athina Vlachantoni examines the higher poverty risk among older women compared to older men in the United Kingdom and Europe. She explores women's atypical life courses compared to men's through the framework of resources, recognition and representation, arguing that socio-economic inequalities across the life course and older age must be addressed in order to promote the well-being of future ageing cohorts. In Chapter 3, Laura Hurd Clarke considers ageing, gender and social justice through the lens of embodiment. She explores the gendered devaluation of older bodies within youth-, health-, and able-bodied privileging cultures, and how this informs unequal access to recognition, representation and resources in later life. In Chapter 4, Chris Gilleard and Paul Higgs consider the 'third' and 'fourth' ages and that the privileging (recognition and representation) of the former, has led to the disadvantaging (recognition, representation and resourcing) of the latter. They highlight that while physical and cognitive 'frailties' of the fourth age have been explored, the significance of gender for the fourth age has not yet been given sufficient attention, even though it is primarily occupied by women. In Chapter 5, Robin A. Hadley explores the increasing significance of ageing without children, which is magnified through the lens of gender. He argues that current gaps in knowledge are leading to under-informed social policy which leads in turn to inadequate social care support for older people, and that there is a need for greater representation of childless older people, especially men, in research, advocacy and social policy. In Chapter 6, Jenny-Anne Bishop and Sue Westwood explore inequalities associated with trans(gender) gender-variant (trans/g-v) ageing. They argue that issues of recognition, mis-recognition, representation and misrepresentation are central to understanding the cumulative material and social disadvantages experienced by older trans/g-v people. They propose that improved recognition and representation will lead to an improvement in resources, especially in relation to health and social care provision.

All five chapters address the enduring theme of the gendering of older age and its associated inequalities. Vlachantoni gives an up-to-date account of

women's socio-economic disadvantages in later life, while Hurd Clarke considers embodied cultural devaluation associated with both age and gender, and Gilleard and Higgs highlight the gendering of the fourth age which is predominantly occupied by women. In this way these three chapters make an important contribution to the long tradition of social gerontological enquiry into the ageing disadvantages experienced by older women compared with older men. The other two chapters serve to broaden this field of enquiry. Hadley considers the gendered implications of ageing without children, highlighting the differences for women and men in relation to resources, recognition and representation. Notably, he argues that ageing childless men are less well researched than ageing childless women. Bishop and Westwood offer a further area of expanded enquiry through critically interrogating ageing in relation to trans(gender) and gender-diverse (trans/g-v) individuals. They flag the potential for trans/g-v ageing to deconstruct many aspects of gendered ageing.

2 Socio-economic inequalities in later life

The role of gender

Athina Vlachantoni

Introduction

In her *Tanner Lecture on Human Values*, Fraser noted that 'gender contains both an economic face that brings it within the ambit of redistribution and a cultural face that brings it simultaneously within the ambit of recognition' (Fraser, 1996, 17). Gender's place in the 'politics of recognition' and the 'politics of redistribution' is nowhere better illustrated than when exploring gender inequalities across the life course and in later life in terms of socio-economic resources and the risk of experiencing poverty (Falkingham, Evandrou and Vlachantoni, 2010). Such risk is the culmination of gender differences manifested at various stages of the life course, including women's greater likelihood to provide informal care (Jenson, 1997; Dahlberg, Demack and Bambra, 2007; Lewis, Campbell and Huerta, 2008; Evandrou et al., 2016), women's increased risk of having interrupted employment records in order to provide such care (Ginn, Street and Arber, 2001; Evandrou and Glaser, 2003; Carmichael, Charles and Hulme, 2010; Lee and Tang, 2015; Proulx and Le Bourdais, 2014; Gomez-Leon et al., 2017) and women's higher likelihood of retiring with non-existent or inadequate pension arrangements in place (Ginn and Arber, 1998). The impact of such accumulation of risk over the life course can be further exacerbated as a result of pension systems which do little to recognise diversity in individuals' working lives (Street and Ginn, 2001;Vlachantoni, 2012).

Drawing on Fraser's analysis of individuals' differential resources in society, and the resultant effect on individuals' socio-economic status, this chapter uses empirical evidence from the UK and beyond, in order to explore, firstly, the interaction of paid work and unpaid care on the one hand; and secondly, gender differentials in the way pension systems operate. The chapter critically discusses Fraser's suggestion that resources, recognition and redistribution are all required in order to achieve social justice, and explores the ways in which the interaction of men's and women's life courses and the design of pension systems result in gender differentials in terms of income in later life, which are discussed in Section IV. The final section returns to the principles of resources, recognition and redistribution as fundamental cornerstones of a pension system designed for modern societies which values diversity in individuals' life courses and offers an adequate valorisation of informal care provision.

Gender differentials and the interaction of paid work and unpaid care provision

The literature evidencing gender differentials in employment patterns across the developed world is abundant. In spite of the increase in women's formal labour market participation since the 1970s, gender gaps both in the volume of work and the nature of work (i.e. occupational sector) have remained (Ginn, Street and Arber, 2001). Although some research shows that during the recent financial crisis, the gender gap in employment narrowed (Jaba et al., 2015), women are still less likely than men to enter the labour market. Men are almost universally more likely than women to be working full-time, as well as continuously during their working life, whereas women are more likely to interrupt their careers in order to provide informal care (World Bank, 2012). Where such interruptions in women's working lives do not occur, for example among younger cohorts of women juggling the roles of paid work and unpaid care provision is increasingly becoming a norm (Berecki-Gisolf et al., 2008). Such juggling is highly dependent on the generosity and structure of welfare systems, and the extent to which parental and other types of leave are embedded both in national legislation and cultural practices (Lewis, Campbell and Huerta, 2008; Ray, Gornick and Schmitt, 2010). In addition, a gender wage gap averaging around 15% remains in most developed countries, although such gap has been shown to narrow over time (ILO, 2017). The gender wage gap is the result of the interaction of a number of complex factors, such as women's greater likelihood of working part-time, and their greater likelihood of working in occupations which pay less well (e.g. shop salespersons and demonstrators, domestic cleaners, personal carers, administrative professionals) (European Communities, 2009).

Gender differentials in terms of unpaid care provision are also well documented in the academic literature. Throughout their life course, women in heterosexual partnerships are more likely than men to provide informal care within or outside the household; and when providing such care, they are more likely to be providing intense care (i.e. more than 20 hours per week), and to be caring for more than one individual (Vlachantoni, 2010). Research among heterosexual couples has shown that such gender differences reverse in later life (i.e. above the age of 70 or so), when men are more likely to care for their female spouses (Del Bono, Sala and Hancock, 2009; Robards et al., 2015). Academic literature has also emphasised the impact of informal care provision on paid work over the life course, and by extension on women's pension incomes in later life, as well as other types of resources (e.g. health, emotional). For example, Young, Grundy and Jitlal (2006) have highlighted the complexity in analysing patterns of informal care provision and their impact on health and socio-economic resources over a period of time, while Evandrou and Glaser have shown that female carers are less likely to be entitled to the Basic State Pension than male carers (Evandrou and Glaser, 2003). More recently, Gomez-Leon et al. (2017) showed that the provision of informal care in mid-life towards

one's parents or parents-in-law can have more adverse consequences for women's employment patterns compared to men's. Specifically, mid-life women were found to be more likely than mid-life men to increase the intensity of care provided towards their parents/ parents-in-law, and to exit employment altogether as a result (rather than reduce their hours of work). Such a finding could be pointing to the fact that mid-life women may have already changed their working patterns long before reaching that stage of their life course.

Such empirical evidence challenges the perception that paid and unpaid work is recognised or valued equally in modern societies. Moreover, the gender division of labour (both paid and unpaid) implies that, on average, women are more likely to be un-recognised or under-valued than men in terms of their contribution to society. Such evidence seems to leave no doubt that gender is, as Fraser puts it, a 'bivalent mode of collectivity', which 'contains both an economic face that brings within it the ambit of redistribution and a cultural face that brings it simultaneously within the ambit of recognition' (Fraser, 1996, 17). Following this line of thought, women represent a bivalent collectivity, or a group of persons who are experiencing injustice both in terms of recognition and in terms of redistribution. In turn, such experiences are likely to result in women's disadvantage in terms of acquiring financial resources across the life course. An important caveat of such an approach is that every group of individuals in society which is characterised by a specific feature (in this case gender) also includes diversity in terms of a range of other features (e.g. living arrangements and partnerships status, participation in the labour market, provision of unpaid care, pension arrangements in place). As such, women's likelihood to have atypical labour market patterns, and to provide informal care provision at most stages of their life course, can also be measured on a continuum. That is, not all women engage in part-time work to start with; and among those who do, not all women work part-time as a result of informal care obligations, just as not all men work full-time and are free of caring obligations.

At the same time, the interaction of individuals' characteristics can result in an intersectionality of disadvantage, for example where one's gender and ethnic origin intersect to accentuate an existing gap in resources. For instance, taking ethnic diversity into account, among women of working age, it is the Polish (79%) followed by the White British (74%) groups that are the most likely to be in paid work, while Pakistani and Bangladeshi women are significantly less likely to be in paid work (both 30%) (Vlachantoni et al., 2015). Indeed, Pakistani and Bangladeshi women have been shown to be consistently disadvantaged compared to women (and men) in other minority ethnic groups, and the most adverse impact of the interaction of individual characteristics is evident in later life, in terms of one's eligibility for different types of pensions. Vlachantoni et al. (2017) showed that Pakistani and Bangladeshi women aged 60 and over are the least likely across all (female and male) ethnic groups to be in receipt of a state or occupational pension; and the most likely to be in receipt of the (means-tested) Pension Credit. In terms of sexual orientation, the scarce evidence base shows that LGBT persons are either as likely or slightly more

likely to be in paid work than heterosexual persons (Powdthavee and Wooden, 2014), however any initial differences disappear once education is controlled for (Li, Devine and Heath, 2008). Similarly, not all men or women have childcare, grandchild care or other family care obligations during their life course, and even those who do are a diverse group in terms of how such care obligations affect their employment patterns. The Office for National Statistics showed recently that mothers with a child between three and four years old have the lowest employment rate of all adults with or without children and are the most likely group to work part-time; but at the same time, mothers aged under 50 are less likely to be in employment than women under 50 without dependent children whereas the opposite is true for men (ONS, 2017). Acknowledging such diversity within the women's population is important when exploring the nature and extent of inequalities arising from gender differentials in paid and unpaid work patterns.

However, men's and women's life courses are one side of the story, and in the case of socio-economic resources in later life, the other side of the story is the design of pension systems, and the extent to which they can ameliorate or accentuate gender differences in socio-economic terms.

The impact of gender in pension systems

Long after Lord Beveridge in the UK imagined a society of 'full employment' and Chancellor Bismarck in Germany structured welfare around one's formal occupation, modern pension systems continue to be designed with men's typical employment patterns in mind (Bonoli, 1997). That is, the calculation of one's pension in later life is largely based on continuous patterns of work, during which one's salary and position within the occupational social structure both increase over time (Myles, 1984). As a result, gender differences in the division of paid work and unpaid care provision, far from being ameliorated over time, are rather accumulated over the life course with a resulting disadvantage for women (see for example the analysis by Ginn, 2001; Sefton et al., 2011). The ability of modern pension systems to recognise and value diversity in terms of employment patterns has not improved over time, although differences between welfare states and so-called pension regimes exist (see for example Luckhaus, 1997; Moehring, 2017). Indeed, much of the literature in this area has argued that the use of typical male working patterns as a way of calculating pensions over the life course continues to be problematic from a gender perspective (Luckhaus and Ward, 1997; Sefton, Evandrou and Falkingham, 2010). Such a problem can be conceptualised both in terms of the symbolic recognition of an 'accumulated disadvantage' for women across the life course (Rake, 1999) and in terms of the distribution of resources which is reflected in the way the pension calculation formulae can affect gender differences.

Pension systems can increase or decrease the 'gender penalty' on pensions through the balance of redistributive elements within the pension entitlement structure (Leitner, 2001; Moehring, 2017). Indeed, the concept of redistribution

is fundamental in the study of pension outcomes, and research comparing different pension systems has shown the important effect of redistribution in real terms. For instance, the closer the link between earnings and the final pension income, the higher the penalty for women with atypical working lives, which tend to be shorter, with more gaps compared to men, and often in less well-paid occupations (Falkingham, Evandrou and Vlachantoni, 2010). Research by Sefton et al. (2011) compared women's employment histories in the UK, US and West Germany, and found that the number of years in employment and the type of employment (full or part-time) had a greater effect on older women's income in Germany and the US compared to the UK, where only full-time employment during one's life made a significant difference in the amount of income received from public pensions in later life. A similar penalty has been evidenced in terms of private pension arrangements, including occupational pensions. In their seminal research, Bardasi and Jenkins (2004) noted that contributing to occupational pensions could make the difference between experiencing a poverty risk in later life or not.

A smaller body of research has investigated the effect of taking periods of informal care provision into account in the calculation of the state pension. Such research is important in highlighting the recognition of informal care as a valuable activity affecting an increasing proportion of individuals in society. For example, Moehring (2017) analysed life history data from the Survey of Health, Ageing and Retirement in Europe (SHARELIFE) for women aged between 60 and 75 in 13 European countries, and found that the lower income among mothers is mainly a result of fewer years of paid work and lower-paid jobs during their working life, while care credits do not fully compensate women for such disadvantage. Such empirical findings show that the symbolic or cultural recognition of unpaid care provision over the life course as part of the pension calculation is as important as the adequate valorisation of caring activities, in order to achieve income compensation for older women.

Gender inequalities in income in later life

The way pension systems interact with individuals' life courses can have a direct impact on gender inequalities in income in later life. Empirical data has continued to confirm women's higher risk of experiencing poverty compared to men, and such data emanates both from the academic and the policy realm. For example, Barcena-Martin and Moro-Egido (2013) analysed European data and showed that structural elements in women's environments, such as the welfare state, were more important than individuals' characteristics in perpetuating gender differences in socio-economic status, and eventually feeding gender inequalities in this respect. The latest data from Eurostat (2016) shows that across EU-28, about 16.5% of men and 17.8% of women are at risk of poverty, whereas for the population aged 65 and over, women are 6.9% more likely than their male counterparts to face the risk of poverty in later life. The European Institute for Gender Equality (2016) emphasised that routes into and out of

poverty differ for men and women, and that women are more likely than men to face poverty throughout their life course. Although women's higher poverty risk is widely acknowledged, nevertheless the ways in which the public and private spheres interact in each country in order to mitigate such risk have been debated to a lesser extent. Southern European countries, where redistributive elements in the welfare state are the least developed, maintain a strong tradition of family support which can mitigate to some extent the poverty experienced by individuals (Boehnke, 2008). In addition, individuals in Southern Europe may be better able to access housing wealth than in other parts of Europe, as the prevalence of home ownership as a means of intergenerational support is higher in Southern Europe. Indeed, research by Faye, Nolan and Maitre (2004) has shown significant differences between Northern and Southern Europe in this respect, with housing wealth often providing an important 'buffer' against poverty, especially in later life.

Gender inequalities in income in later life, and the associated gendered gap in the risk of being in poverty, are manifestations both of a lack of redistribution of resources between the two genders and a lack of recognition of women's position in modern society. In the first instance, the lack of redistribution of different types of resources, such as finances and time, is evident throughout the life course, particularly during individuals' working age. If the division of paid and unpaid labour was not permeated by gender differences for typical couples in developed societies, then the distribution of resources would be more equitable between men and women. The ability of societies to redistribute resources, primarily through formal mechanisms such as the welfare state, but also informally through embedded cultures of promoting and sustaining gender equality, is then the focus of attempts to rebalance inequalities and achieve greater social justice. However, as evidenced earlier and argued in academic literature, the efforts of welfare states to introduce redistributive elements in their modus operandi also sit on a continuum, and some countries are more effective than others in this respect.

The second type of manifestation, that of a lack of recognition of women's position in society, is closely linked to the lack of redistribution. Indeed, as Freeman notes, 'the need for this sort of two-pronged approach becomes more pressing . . . as soon as one ceases to consider [redistribution and recognition] together as mutually intersecting' (Fraser, 1996, 22). Even when pension systems introduce the valorisation of unpaid care provision into the formula for calculating the final pension, research shows that such efforts do not go far enough in terms of compensating women for time spent outside the labour market (see for example Buckner and Yeandle, 2011; Mentzakis, Ryan and McNamee, 2011). Such reduced compensation reflects both a perpetuated culture in modern societies of under-valuing care provision and the continued inability of pension systems to recognise women's typical contribution to society in a way which does not penalise them for being outside the labour market. The additional layer of complexity introduced when focusing on economically developing contexts, where the prevalence of unregulated or so-called grey labour

among women and men is high (World Bank, 2012), is equally important but beyond the scope of this chapter.

Towards pension systems which recognise diversity

Gender inequalities in socio-economic resources in later life are the result of the accumulation of inequalities throughout the life course, and the combined effect of diversity in women's paid/unpaid labour patterns and the way such diversity is treated in their country context. Although the reduction of the poverty risk is an explicit goal for both national governments and supra-national institutions, nevertheless the evidence points to a continued gender gap in this respect which has tended to disadvantage women. To some extent, such gap is expected to narrow, both as a result of conscious efforts by welfare states to introduce more redistributive elements in the way they calculate the final pension income, and as a result of younger cohorts of women combining paid work with childcare, or postponing fertility to later years. Still, the challenge of designing modern pension systems which recognise diversity and deliver social justice on some level, is still present.

Fraser maintains that 'justice today requires both redistribution and recognition, as neither alone is sufficient. As soon as one embraces this thesis, however, the question of how to combine them becomes paramount' (Fraser, 1996, 5). Modern pension systems are faced with the combined challenge of delivering redistribution, fair access to resources and recognition through innovative ways of ensuring that women's greater tendency to provide informal care for the majority of their life course is not penalised vis-a-vis their male counterparts. To that end, a broader conceptual understanding of redistribution of (financial and other) resources and the recognition of individuals' multi-layered contribution to society, is needed in order to design responsive pension systems for the future. Fraser asks herself a question and responds: 'Can existing theories of recognition adequately subsume problems of distribution? Here, too, I contend the answer is no' (Fraser, 1996, 28). Such rejection of existing theoretical tools at our disposal requires careful consideration, and poses an even greater challenge for welfare state scholars and policymakers alike.

In the context of gender inequalities in income across the life course and especially in later life, Ingrid Robeyns' suggestion that the capability approach developed by Amartya Sen (1982) could be an even more appropriate framework for incorporating redistribution and recognition for men and women seems plausible. More specifically, Robeyns makes the point that the capability approach, which is focused on enabling individuals to function at different levels, is useful in critically examining the constraints faced by women (and men) in their choices at the start. She argues that 'in the capability approach, preference formation, socialisation, subtle forms of discrimination and the impact of social and moral norms are not taken for granted or assumed away, but analysed upfront' (Robeyns, 2003, 15). Such approach ensures that 'power relations within collectivities such as the household need to be taken into account' (ibid., 16).

In the words of Martha Nussbaum, such an approach is also concerned with 'entrenched social injustice and inequality' (Nussbaum, 2011, 19).

The critical examination of what individuals can and cannot do at different stages of their life course, is a powerful way of understanding inequalities between men and women which eventually lead to a gender gap in terms of income and the risk of experiencing poverty. The capability approach is of paramount importance in allowing us to dissect constraints faced by women, especially during that part of their life course when juggling paid work and the provision of informal care seems inevitable. However, the concepts of access to resources, redistribution and recognition are still essential ingredients not only in the design of modern pension systems but also in the continuous monitoring of pension outcomes. Fraser's contribution to our understanding of the tension between an ideal society where social justice prevails, and the real world where institutional structures and embedded norms are much harder to shift, remains distinctly relevant to the study of gender inequalities in socio-economic resources, both across the life course and in later life.

From a policy perspective, efforts to ensure that men and women are afforded an equal and fair access to mechanisms for the accumulation of financial resources across the life course, require at least three elements. Firstly, the provision of informal care throughout the life course should continue to be recognised for the purpose of pension contributions, offering both substantive and symbolic compensation to women (and men) of working age who reduce their working hours, or stop work altogether, in order to provide care. A second requirement, which is more difficult to incorporate in exercises of 'crediting' periods of informal care provision to the pension calculation, is the symbolic recognition of career *progression* during the period when the informal carer has been out of the formal labour market, which in turn informs the final pension entitlement. This different kind of recognition would further narrow the disadvantage faced typically by women returning to work following a period of childrearing. The final tool at the disposal of policymakers is the continued support of informal carers, male and female, in recognition of the importance of the activity they are undertaking. In the UK, such support builds on the Carers' Strategy introduced in 2008 and revisited in 2010, and focuses on the carers' well-being, opportunities to combine informal care provision with paid employment where appropriate, and a personalised focus on carers' circumstances and needs. The combination of such policy tools can further enhance the concept of informal care provision in modern societies, and offer both men and women greater recognition in their roles within and outside the household.

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3 Gender, (in)equality and the body in later life

Laura Hurd Clarke

Introduction

The body is central to the experience of ageing and inequality as changes to older adults' appearances, health and physical abilities are at the heart of their social exclusion in later life (Laws, 1995; Slevin, 2006). Since Western culture privileges youthfulness, health and independence, having an older body is perilous to an individual's social status and inclusion (Calasanti and Slevin, 2001; Hurd Clarke, 2011). Moreover, the taken-for-granted norms regarding later life and older bodies influence older adults' body image and embodied experiences, delimiting their resources, expectations, and sense of well-being. In this chapter, I draw on Fraser's (2007) work concerning social justice and her conceptualisation of recognition, representation and resources to discuss how older adults' experiences of ageing and injustice are grounded in corporeality. Fraser contends that injustice results from the inequitable distribution of resources combined with the unequal political representation of particular groups or identities and the differential recognition, or assigned social status and cultural value, of some groups relative to others. In this way, Fraser affords important insights into the mechanisms by which older adults' lives are simultaneously shaped and constrained by social structures and cultural constructions. Centring my consideration of inequality and injustice on the body, I focus my lens on the ways that social norms and locations, particularly gender, combine to render older bodies (some more than others) progressively more devalued and excluded.

Recognition in later life: social norms and the older body

The social status (e.g. recognition (Fraser, 2007)) of older bodies is shaped and constrained by deeply entrenched social norms and organising principles concerning later life. Ageism, or 'the systematic stereotyping and discrimination against older adults because they are old' (Butler, 1975, 12) delimits older adults' representation, recognition and resources in everyday life. Defined as a 'set of oppressive social relations' (Laws, 1995, 112), age-based discrimination enables the 'not old' to acquire and retain power over the 'old' (Calasanti and Slevin,

2001; Hurd, 1999). Consequently, older adults are systematically marginalised and denied resources and opportunities (Bytheway and Johnson, 1990) in the workplace (Harris et al., 2018; Stypinska and Turek, 2017), the health care system (Ben-Harush et al., 2016; Chrisler, Barney and Palatino, 2016; Robb, Chen and Haley, 2002) and in everyday interactions (Hurd Clarke and Korotchenko, 2016; Vincent, 2015).

Underlying the prejudicial treatment and exclusion of older adults are deeply entrenched stereotypes about aged bodies. Associated with asexuality, dependence, frailty, senility, poor health, unattractiveness and loss of productivity, older bodies are assumed to be flawed, deviant, objectionable and unruly (Cuddy, Norton and Fiske, 2005; Nelson, 2002; Nussbaum et al., 2005; Palmore, 1999). Rather than being perceived as an accomplishment or the outcome of good fortune, the accumulation of corporeal mileage is increasingly positioned as undesirable if not dangerous. Older bodies are constructed as less than ideal, as they are linked with decreasing attractiveness, loss of health, functional dependence and declining social currency (Hurd, 1999).

At the same time, ageist stereotypes, especially those concerning the body, are gendered and position older men and women in distinctly different ways (Krekula, Nikander and Wilinska, 2018). Sontag (1997) has argued that the double standard of ageing means that older men who are wealthy and powerful are often considered sexy and distinguished in later life irrespective of their ageing appearances. In contrast, signs of ageing in older women are thought to be unfortunate, if not unappealing, as female beauty is primarily associated with youthful, toned, slim, voluptuous and wrinkle-free bodies (Bordo, 2003; Calasanti and Slevin, 2001; Hurd Clarke, 2011). The different reading of older men's and women's bodies reflects masculinity and femininity ideals. Men are primarily valued for what they do with their bodies, as idealised masculinity is associated with accomplishment, dominance, economic and political power, and hyper sexuality (Calasanti, 2004; Marshall, 2006; Meadows and Davidson, 2006). Women's social value is closely tied to their appearances, specifically their ability to be aesthetically pleasing and capture the male gaze (Bordo, 2003). Thus, while looking older may augment a man's status as an experienced, powerful leader (Hurd Clarke, Bennett and Liu, 2014; McGann et al., 2016; Thompson, 2006), having an ageing appearance diminishes a woman's erotic capital (Hakim, 2011; Sontag, 1997).

The negative framing of older bodies is further strengthened by healthism, which Crawford (1980, 2006) has defined as the cultural positioning of health as both a personal responsibility and a product of individual effort. Constructing poor health as the result of moral laxity, healthism diverts attention away from the impact of accumulated health and social inequities over the life course (Crawford, 1980, 2006; Dworkin and Wachs, 2009; Hurd Clarke and Bennett, 2013b). This understanding of health is deeply entrenched in Rowe and Kahn's (1997) concept of successful ageing, which they have defined as low probability of disease and disability, high functioning and active life engagement, and similarly argued is attainable 'through individual choice and effort' (Rowe and

Kahn, 1998, 37). To avoid poor health and 'failing' at ageing, individuals are thus increasingly expected to actively engage in an ever-widening array of bodily practices to ensure the optimisation of their bodies (Higgs et al., 2009). Self-care regimens encompassing everything from healthy lifestyles to appearance management are promoted as a means of disciplining the body, fighting the physical realities of growing older, and demonstrating one's morality (Carter, 2016; Lefkowich et al., 2017). In other words, health has become a commodity that individuals are expected to purchase through active personal investment and engagement with consumer culture (Crawford, 1980, 2006; Leontowitsch et al., 2010). Despite the inevitability of physical changes over time and the fact that the ability to consume health promotion is limited by one's socio-economic status, healthism has thus resulted in the blaming of individuals, as poor health and disability have been redefined as evidence of an individual's moral failure resulting from a lack of proper care for the body (Becker, 1986; Galvin, 2002; Katz, 2005).

Ageing into oblivion: the cultural invisibility of older bodies

Older adults' unequal access to resources, representation and recognition are additionally reflected in and constituted by the ways that their corporeality is given meaning through symbolic signification (Ylänne, 2012). Indeed, cultural portrayals of later life and older bodies 'create expectations of what it is to be a person of a particular age' (Bytheway, 2011, 80). To date, these expectations have been largely negative, as media messages concerning later life have 'depicted old bodies as problems, in decline and miserable' (Calasanti, Sorensen and King, 2012, 20). In particular, portrayals of old age have reproduced and reinforced associations between ageing and loss of attractiveness, health, independence and cultural value, as well as assumptions that later life is a time of social and political disengagement (Bytheway, 2011; Nelson, 2002; Rozanova, 2010). Notably, older women have been depicted more negatively than their male counterparts, as women in later life have been portrayed in ways that suggest that they have 'lost their utility as their youth and sexual appeal have faded' (Sink and Mastro, 2017, 18; Lauzen and Dozier, 2005; Lemish and Muhlbauer, 2012; Vares, 2009). As such, these images mirror and reinforce older women's lack of representation, or political voice (Fraser, 2007), in a cultural landscape where they are increasingly denied citizenship.

At the same time, older adults have been largely under-represented across various forms of media, including advertising (Calasanti, Sorensen and King, 2012; Lee, Carpenter and Meyers, 2007), television (Dolan and Tincknell, 2013; Kessler, Rakoczy and Staudinger, 2004; Sink and Mastro, 2017), mainstream newspapers (Fealy et al., 2012; Rozanova, 2010; Wada, Hurd Clarke and Rozanova, 2015), popular magazines (Hurd Clarke et al., 2014; Lewis, Medvedev and Seponski, 2011; Wada, Clarke and Rozanova, 2015) and Hollywood movies (Bazzini et al., 1997; Chivers, 2011; Robinson et al., 2007). This

lack of a cultural presence has been attributed to the devaluation of later life and the assumption that advanced age is not a marketable commodity (Calasanti, 2007). The cultural invisibility of older adults and ageing bodies is even more pronounced when considering intersecting forms of oppression such as age, disability, ethnicity, race, sexual orientation and social class (Calasanti and Slevin, 2001; Slevin, 2006). In particular, depictions of ageing are underscored by ableism, classism, heterosexism, racism and sexism, as the limited numbers of portrayals of older bodies are primarily of White, heterosexual, middle-class and upper-class men (Deliovsky, 2008; Gross, 2012). As such, portrayals of cultural diversity, disability, LGTBQ ageing and women are particularly scarce, reflecting their social exclusion and oppressed status in society more generally.

That said, more recent research indicates that although limited, media depictions of older adults, especially those of older, heterosexual, White men, are becoming more positive as older men are often portrayed as happy, healthy, distinguished, powerful and sexy (Chivers, 2011; Hurd Clarke et al., 2014; Spector-Mersel, 2006; Williams et al., 2010; Zhang et al., 2006). These portrayals increasingly suggest the possibility of 'growing older without aging' (Katz, 2005, 188) as they position ageing, like health, as a choice made possible by consumption and attention to lifestyle. The changing depiction of ageing is reflective of a powerful social imaginary in which good ageing is juxtaposed against bad ageing, particularly in advertising and celebrity culture (Lemish and Muhlbauer, 2012; Marshall and Rahman, 2015). Positive portrayals draw upon Third Age imagery which points to 'an aging youth culture' (Higgs and McGowan, 2013, 22) and is characterised by health, independence, leisure, consumption, and social engagement (Gilleard and Higgs, 2005). The third age is contrasted with the dreaded fourth age (Gilleard and Higgs, 2000, 2010), which is understood and represented as the 'era of final dependence, decrepitude and death' (Laslett, 1996, 4). The fourth age is the embodiment of ageist stereotypes and the realisation of societal fears related to growing older and end of life. Given the inevitability of decline and death as well as the ways in which socioeconomic status determines one's consumption ability, third age older bodies constitute an aspirational way of ageing that is increasingly elusive with the passage of time and only attainable by a limited segment of the older population.

The body as diminishing resource: subjective perceptions and experiences

As ageism undermines the recognition of older bodies, and media depictions of later life reflect an increasingly unachievable ideal, older adults' perceptions and experiences of their bodies as resources are invariably challenged. The body image research sheds light on the personal meanings and values that older adults ascribe to their bodies in their everyday lives. Defined as individuals' thoughts, feelings, and perceptions of their bodies (Grogan, 2016), body image reflects how individuals evaluate their physical selves relative to age norms and gender ideals as well as the resultant investments they make to enhance or preserve

their appearances and body functionality. While the number of published studies continues to be limited, the body image research concerning older men reveals that their corporeal evaluations are strongly influenced by masculinity ideals which emphasise the importance of having an athletic, physically imposing, strong, youthful and virile body (Connell, 1987, 1995; Kimmel, 2005; Ridgeway and Tylka, 2005). Thus, older men report body dissatisfaction primarily in relation to reduced muscularity, changes in health status and declining physical abilities (Hurd Clarke, Griffin and The PACC Research Team, 2008; Kaminski and Hayslip, 2006; Liechty et al., 2014; Tiggemann, 2004). In an effort to redress changing body functionality, older men have been found to turn to exercise, sport, and the use of pharmaceuticals such as Viagra and Cialis (Calasanti et al., 2013; Marshall, 2010). In contrast, older women tend to express dissatisfaction with their appearance, directing their discontent towards their wrinkles, sagging skin, weight gain, and grey hair (Baker and Gringart, 2009; Hurd Clarke, 2011; Slevin, 2010; Tiggeman, 2004; Ward and Holland, 2011). Consequently, older women often use make-up, hair dye, non-surgical and surgical procedures or fashion to mask their chronological age and more closely approximate the youthful, feminine beauty ideal (Brooks, 2010; Hurd Clarke and Griffin, 2008; Hurd Clarke, Griffin and Maliha, 2009; Muise and Desmarais, 2010; Slevin, 2010; Smirnova, 2012).

A growing literature explores body image among diverse older populations, revealing important similarities to and differences from studies with predominantly heterosexual, White sample participants. For example, older gay and bisexual men have been found to have heightened body image dissatisfaction relative to their heterosexual counterparts which has been attributed to their internalisation of sub-cultural norms that privilege youthful and muscular appearances (Brennan, Craig and Thompson, 2012; Drummond, 2006; Slevin and Linneman, 2010). The research that has included or focused on older lesbians and bisexual women offers some conflicting insights. On the one hand, a few studies suggest that lesbians may be protected from the body discontent that is prevalent among heterosexual women as a result of their freedom from the male gaze and differing appearance norms in lesbian communities (Bergeron and Senn, 1998; Clarke and Turner, 2007; Winterich, 2007). However, other research suggests that gender socialisation is a stronger determinant of body image as lesbians internalise feminine beauty ideals, which in turn leads to body image dissatisfaction comparable to heterosexual women (Huxley, Clarke and Halliwell, 2014; Kelly, 2007; Peplau et al., 2009; Slevin, 2006). The limited research that has explored the impact of culture and race on body image in later life has found that non-White, older men and women report higher body satisfaction than individuals of European descent (Cachelin et al., 2002; Dunkel, Davidson and Qurashi, 2010; Reboussin et al., 2000), although acculturation and the effects of globalisation often negatively impact individuals' body perceptions (Sussman, Truong and Lim, 2007).

At the same time, the research suggests that the importance of appearance for both men and women declines over time as body functionality becomes

more salient (Baker and Gringart, 2009; Hurd, 2000; Jankowski et al., 2016; Reboussin et al., 2000; Reddy, 2013; Tiggemann, 2004). The shifting of priorities may reflect alterations in individuals' embodiment or their 'experiences in and through the body' (Hurd Clarke and Korotchenko, 2011, 496). In particular, changing health and concomitant physical abilities may disrupt older adults' embodied identities and personal narratives (Bury, 1982). In this way, bodily changes may result in biographical disruption, as awareness of the body is heightened and taken-for-granted assumptions about physical abilities and future possibilities are renegotiated (Bury, 1982). Biographical disruption is a gendered process, as men and women make sense of their altered corporeal realities in light of masculine and feminine ideals (Charmaz, 1994; Hurd Clarke and Bennett, 2013a; Hurd Clarke, Griffin and The PACC Research Team, 2008; Oliffe, 2009). While men experience the body as a diminished or failing resource in terms of their declining abilities to be autonomous, strong leaders, women express dismay over their changing appearances as well as their decreased abilities to perform femininity through nurturing and/or caregiving roles (Hurd Clarke and Bennett, 2013a). To date, the literature concerning biographical disruption and gender in later life has not explored the impact of culture, race or sexuality on older adults' perceptions and experiences and thus constitutes an area of scholarship much in need of exploration.

Concluding comments

In this chapter, I have drawn upon Fraser's (2007) conceptualisation of recognition, representation and resources to survey the literature and consider how older adults' experiences of inequality and exclusion are related to and mediated by the body. In particular, I have examined how older bodies are devalued as a result of ageism and healthism, how later life is culturally represented in ways that reproduce ageist and sexist stereotypes and establish increasingly elusive ideals, and finally how older adults internalise age and gender norms to the detriment of their body image and embodied experience. I have further explored how the recognition, representation and resourcing of the older body is gendered and shaped by intersecting multiple oppressions. I join Fraser (2007) in the call to consider the complex ways that social structures combine with cultural constructions and result in injustice, understood in the context of this chapter in relation to ageing corporeality. In a world where youth, health and independence are increasingly valorised and privileged, ageing, and having an older body, disadvantages individuals who become ever more invisible and excluded.

Future research will need to continue to track the impact of third age imagery on older adults' exclusion, personal evaluations of their bodies and expectations about and experiences in later life. Additionally, more research is needed to understand the role of the body in the exclusion of marginalised older adults. For example, to date, there is no research that has explored the bodily perceptions and experiences of ageing trans individuals and very few

studies have examined the body image and embodied experiences of culturally diverse older adults. Given the centrality of the body to social exclusion in later life, these avenues of future scholarship will invariably shed important light on how corporeality underlies the systematic oppression of older adults in taken-for-granted yet insidious ways.

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4 Gender and the social imaginary of the fourth age

Chris Gilleard and Paul Higgs

Introduction

Later life is not what it once was, neither for women nor for men. Shifts in the nature of the post-war economy, generational cleavages of the 'cultural revolution' and the progressive individualisation of citizenship and society have all contributed to this change. This has been variously represented by some as a 'new' age of ageing; by others as a shift toward active, healthy or productive ageing; and by still others as the emergence of third age cultures (Bass, 2000; Carr and Komp, 2011; Gergen and Gergen, 2001; Gilleard and Higgs, 2005). Such narratives embody a positive, optimistic view that we – adults of the world's developed economies – are realising a richer more rewarding retirement based upon higher incomes; greater wealth; better education, health and housing; and increasing opportunities for freedom, leisure and pleasure (Higgs and Gilleard, 2015a). Alongside such celebratory, even emancipatory accounts runs a counter-narrative that offers a much darker background against which the cultures of the third age stand defined. This, it has been argued, can be understood as the social imaginary of the fourth age, a stage of life or state of being that is represented within the collective consciousness as one bereft of agency, autonomy and desire; dominated by frailty and failure; constituting part of a new 'abject' class whose social realisation is enacted by the institutions of welfare and welfare rationing (Gilleard and Higgs, 2010; Higgs and Gilleard, 2015b).

In this chapter we aim to illustrate the gendering of this social imaginary – that is its social representation as both a cultural figure and a social status that is occupied largely by old women. If the third age is open to social realisation and representation across the gender spectrum, albeit differently, the fourth age, we shall argue is not. It is a social imaginary institution whose history is that of imagined old women, usually poor, often pitiful, but once also considered threatening or even predatory. Our aim in exploring this theme is not so much to demonstrate the comparative material circumstances of older men and women, nor to consider the evidence for or against their growing equality or persistent inequality, as citizens or as consumers. Instead we focus upon social representations of old age, their mediation through the lens of gender and the consequences such representations have for the political recognition and

resourcing of later life under conditions of ill health and infirmity. It is in this sense that we engage with the broader debate associated with Nancy Fraser's writings on recognition and redistribution (Fraser, 1995, 2000, 2007). How if at all is it possible to escape from the social imaginary of a feared old age that is socially realised in the hidden corners of society but which, as an imaginary, pervades the expanding space that is later life?

Fraser has argued that 'claims for redistribution and claims for recognition cannot be insulated from each other' such that there can be 'no redistribution without recognition' (Fraser, 2007, 33). But what constitutes the appropriate 'recognition' (or representation) of old age and how might particular representations call forth or constrain the resources for any redistribution of resources? Is there not a tension in eliciting resources between on the one hand portraying old age as frail and pitiful and, on the other, emphasising its opportunities? In thinking about these matters, how far is gender imbricated in this imaginary? How far do images of frail old women (as impoverished widows, for example) frame old age as a category of social need, those deserving of either charity or welfare? Such questions are particularly difficult to answer when what is being represented is framed not just by age and gender but also by judgements of frailty and suffering.

The call for more resources for social care, for example, is too often and too easily framed by reference to an 'apocalyptic demography' with a more or less totalising threat that, while all are at risk of failing and hence all should be concerned in cushioning that fall, nevertheless it is women who are deemed frail and it is women who are also deemed those providing care. While we would be loath to see old age – or better, later life – through such a singular lens, our concern in this chapter is with the representation of 'deep' old age and its representations as a gendered frailty, rather than, say, as an issue concerning economic inequality. Hence our implicit focus upon policy and the resourcing of social care, rather than on policies related to pension provision, home ownership, fuel poverty and the gendered nature of these and other structural inequalities.

In dealing with the issue of recognition and representation, we have chosen to problematise these processes through the concept of social imaginaries, those collective representations of society and social relations that form part of already instituted society. Consequently, we have derived our understanding of 'social representation' through this term 'social imaginary' by drawing upon the work of the French political philosopher, Cornelius Castoriadis and his interpretation of the collective representations of the social world (Castoriadis, 1987). Rather than assume an ideological coherence to any socially represented identity or institution, his term 'social imaginary' or 'social imaginary significations' is, we consider, more productive in encapsulating the complex, polysemous symbolisations of age and the life course that permeate Western culture.[1] So we turn first to a brief outline of Castoriadis' work and particularly his formulation of social imaginary significations as society's 'fantastically complex' edifice of meanings, whereby society and the social individual are constructed, or rendered sensible 'for themselves' (Castoriadis, 1991, 42–43).

In this sense, the existence of binary identities – women/men, old/young, heterosexual/homosexual etc. – is to be interpreted by Castoriadis not merely as matters of contingency, nor of already instituted society's symbolic order, but arise within an imaginary of social and cultural networks of meaning that forever exceed the uses to which such identities can be put. Though the gendered nature of 'deep' old age – the 'fourth age' – captures part of that multiplicity of referents, it is not fully boundaried by such terms. Some are more central than others. Thus, deep old age can be framed as an 'asexual' position devoid of subjective desire – a suffering without subjectivity where gender is more salient than sexuality (or racial identity). Hence the fourth age body can be framed by its very antithesis to desire, longing and movement – as frail, weak and withered. In that sense there is an ordering of identities within its social imaginary, an implicit organisation that operates through past and present imaginaries of gender, health and vitality and the dialectic of subject and object.

Castoriadis' concept of a social imaginary

Castoriadis' use of the term 'social imaginary' can be thought as another form of what Durkheim called 'collective representations' – the ways in which 'society' or a culture thinks about and gives meaning to the social relations, practices and institutions by which it is constituted (Durkheim, 1898). Castoriadis argued that society institutes itself through a process of representations, affect and intentions (Castoriadis, 1991, 158) – what he called its 'instituting power'. These processes are 'neither locatable nor formalizable' since everyone, as social beings, acts as the co-author in sustaining and reproducing these meanings, shaping the intentions and experiencing the affects that are attached to them (Castoriadis, 1991, 166). For Castoriadis, in so far as an 'anonymous collectivity' realises the meanings given to the social, there is a necessary diffuseness to the social imaginary institutions of society – whether they concern 'language, work, sexual reproduction, the raising of new generations, religion, mores . . . [or] "culture" in the narrow sense' (Castoriadis, 1991, 158).

When he comes to consider the relationship between these social imaginary institutions – the network of meanings by which society is instituted – he is at pains to avoid making, or implying a distinction between the significations and the 'things' that are being signified. Thus he argues that 'the world of significations instituted in each case is obviously neither a copy nor a tracing (reflection) of a 'real' world nor [*he adds*] is it without any relation to a certain 'being thus' of nature (Castoriadis, 1987, 354). It represents what he calls 'a leaning on' to certain aspects of the 'first natural stratum', which is itself inevitably altered by this leaning on – in effect rendered part of the very social-historical understandings of the world into which successive generations are realised as social beings. The 'radical' imaginary of the collective anonymity, as he once called it, implies that every society has an almost unlimited capacity to draw on, re-form and re-produce social institutions, social understandings of the world and hence social practices that no purely symbolic organisation – no set of laws or rules – can contain. The potential surplus of significations – drawn equally

from the radical imaginary of society (the anonymous collectivity) and the radical imaginary potential each individual possesses (the 'almost total plasticity' of the psyche to acquire the totality of social representations realised across time and cultures) – means that, however realised, each and every social imaginary will possess contradictory and contestable meanings, affects and intentions (Castoriadis, 1991, 152).

These three features of the social imaginary – its multiplicity of meanings, its socio-historical reproduction in the creation of successive generations and its capacity to 'drive' and 'shape' people's social relations with the world in both its 'natural' and its 'social' aspects – together give it a centrality in the constitution of society. This is not dissimilar to what Durkheim claimed for collective representations, namely that they constitute the social facts that make society an observable phenomenon (Durkheim, 1898, 19). The question arises, of course, of what cannot be regarded as a potential social imaginary, what cannot constitute a social representation? Castoriadis argued that social imaginaries constitute 'a mode of being which is primary, originary, irreducible'. They 'cannot be reduced to actual individual representations or to their "common" "average" or "typical part"'. If individuals are likened to actors in a play, he argues, it remains unclear whether or not one can also treat the play itself as the product of any of the roles of its actors (Castoriadis, 1987, 366). The imaginary realises the roles and not the other way around, just as it is impossible to discern the play without the actors, whilst recognising that none of the actors are its authors.

This paradox was something that Durkheim had already recognised in his account of individual versus collective representations. It is easier, in a sense to contrast one with the other, without resolving what the other is, apart from its contrast with the more definable other that constitutes 'individual' social representations. Thus, Castoriadis is at pains to avoid categorising social imaginary significations as any one 'thing' – not even as a representation. Instead he insists upon there being an 'indefinite and essentially open multitude of individuals, acts, objects, functions, institutions . . . which in each case constitutes a society' (Castoriadis, 1987, 369). Whilst this may seem an unsatisfactory conclusion that renders the term of limited operational utility, it helps to distinguish, for our purposes, exploring the social imaginary of 'real' old age that involves neither treating old age as a distinct social category or investigating attitudes or beliefs about old age as 'ideology' (e.g. through such terms as 'ageism'). While the former implies that old age exists as a countable object in society and the latter implies that a normative set of beliefs can be identified and measured by a series of attitudinal scales, 'real' old age understood as a social imaginary remains an open terrain, represented in the meanings attached to various acts, affects, functions, institutions and practices. It is to this terrain we next turn.

The fourth age as a social imaginary

Despite its familiarity as a term, old age has often been represented as something 'other' – a 'foreign' country which is alien' to the experiences of most members of society (Lowenthal, 1985). This 'otherness' surrounding old age relates not

just to its corporeal otherness, the physical differences between old and young bodies, but to the chronological distance that seems to separate its 'inhabitants' from the contemporary concerns of those who embody the present and who orient themselves to the future. This idea has been well expressed by the poet and novelist, May Sarton in her book *As We Are Now*. She wrote 'The trouble is, old age is not interesting until one gets there. It's a foreign country with an unknown language to the young and even to the middle-aged' (Sarton, 1983, 15). Similar sentiments are evident in the opening lines of L P Hartley's *The Go-Between*: 'The past is a foreign country: they do things differently there' (Hartley, 1953, 1). While the former stresses the otherness of being old, the latter emphasises the otherness of agedness – the strangeness of old age and the old as strangers. These quotes illustrate one of the central features of what we have called the social imaginary of the fourth age, its otherness (Higgs and Gilleard, 2014). A number of authors have explored the historical roots of this trope when old age is represented not as a conscious identity of an individual social being but as an attribute of others. To that extent old age has shared the same kind of 'not me/us' identity that other 'not me' identities possessed, like 'the disabled', 'women' or 'homosexuals'. These various representations of otherness involve several interrelated qualities – a negative evaluation, a process of objectification and a subordinate or limited status contrasted with the positive identity of the implicit 'us' who form the implicit authors of such 'othering' narratives.

Of course, much progress has been made in calling out and critiquing these processes, queering the implicit binaries by which such representations are presented, but certainly in the case of age, the challenge to old age's 'otherness' has seen a new divide established. As consumer culture has helped create new post-working later lifestyles there has been a shift in focus upon what has been called 'ageless ageing', effectively pushing away the association of a particular chronological age with images and ideas of infirmity and dependency (Dychtwald, 1999). At the same time, this separation of chronology from corporeality has thrown into stark relief a newly residualised, 'deep' old age, a 'real' old age whose representation now fashions what we have called the social imaginary of the fourth age (Degnen, 2007). Unlike the effects of ageism, this re-imagining of old age makes it not so much a status or social category but a state of being, whose ontology is framed by frailty, abjection, need and the associated indignities associated with a deeper old age (Gilleard and Higgs, 2010). It is this discursively revised othering of 'real' old age that plays a key role in situating the social imaginary of the fourth age. But even as it does so, it still draws upon many of those old shared assumptions about the course and nature of old age that long surrounded it well before it became an ordered part of the 'institutionalised' life course of classical modernity.

This interconnectedness of vulnerability with frailty is fundamental to contemporary processes of othering old age. As Higgs and Gilleard (2015b) have pointed out, frailty has become one of the key boundary issues articulating the fourth age as a social imaginary. Frailty (or infirmity, to use an old-fashioned term) has become the epi-centre of an increasingly 'densified' old

age where corporeality and morbidity demarcates an 'us' from a 'them' more so than chronological age per se (Degnen, 2007). Within the discourses of health and social care, frailty functions as a way of alerting concerned institutions to recognise the imminent collapse of agency and personal identity of an individual older person. When mental frailty is added to the discourse of physical frailty a further deepening of the social imaginary occurs, in terms of what some have called the 'social death' of the subject (Sweeting and Gilhooly, 1997). Dementia represents a state of 'unbecoming' as it (or those processes constituting the variously diagnosed dementias) strips the individual of the forms of agency expressed by choice, autonomy, self-expression and pleasure. Social responses to the condition often amplify this 'ageing without agency' replacing first person narratives with those of the third person – the other as object of professional and familial concern and decision making. Decisions about the point at which institutional care is necessary further demonstrate this particular form of distributed agency and the way in which it becomes a normalised discourse about ageing and old age. Feared incapacity becomes part and parcel of 'going into care', and constitutes a core aspect of the social imaginary of the fourth age.

What makes this particular representation of old age especially powerful in contemporary society is the seeming lack of social determinacy that is associated with 'being placed in care'. During earlier points in the process of industrialisation the fear of ending up in the workhouse was associated with poverty and low social position. In contemporary society such associations are largely absent. The position of those subject to the social imaginary of the fourth age is no longer determined by the structured social disadvantage that the poor once suffered nor by the internalisation of social prejudice against which it was possible to rally. Old age and the old age institutions of the past were once the evident last resting places of the poor; their intolerability formed a clear target for the improved social welfare that was established in the post-war welfare state. In place of the 'classed' position of poor old age is a more diffusely 'corporealised' old age, whose fate seems determined not by a lack of cultural, economic or social resources but by the body's own betrayal (Lakdawalla and Philipson, 2002; Luppa, Luck, Wyerer et al., 2010). The moral imperative of care has not vanished but now it depends not upon socio-economic divisions and inequalities but the categorical assessment of an older person's 'objectified' and 'abject' future – whose 'agedness and infirmity' constitute, in Julia Kristeva's phrase, the 'contamination of life by death' (Kristeva, 1982, 149).

This 'othering' of old age and its abject state cannot easily be represented as the ideological othering of an abject class or as the exercise of a ruling class' dispossession of its dominated inferiors in the way that Georges Bataille originally contended membership of the 'abject classes' (Bataille, 1999). It is an othering of a more totalising but yet less specified risk that leaves no fixed position from which to offer opposition or frame an effective counter-imagery: an othering incapable of articulation or transgression, of claiming a subject position demanding recognition. If the social imaginary is realised as a 'relation' or 'oscillation' between a set of triggers and their activation, the suppression of

its imaginary cannot be realised nor can an alternative imaginary be 'induced' without denying or ignoring the salience of agedness itself, in effect asserting what the cultures of the third age seek to achieve, an all-embracing agelessness. The fourth age is called on each time someone voices the thought that 'something needs to be done'; each time resources are called on to protect an older person from an imminent corporeal betrayal. The very limitations that prevent the person from representing themselves, from constructing a social representation of themselves as a civic or social agent or that might constitute a position of transgression constitute the conditions for their necessary representation by others, as frail and failing; in short the necessity to be recognised as 'an aged other', othered as it were from the opportunities of contemporary later life, at the same time as being another for whom something has to be done.

Representing gender within the fourth age imaginary

Thus far, we have emphasised the idea that the fourth age can be understood as a social imaginary of old age; that abjection, frailty and the limited exercise of social agency and self-representation constitute key elements in that imaginary; and that the collective recognition of a need for care create the conditions for its institutional realisation within the framework of health and social care services. How then does gender mediatise such representations? That is the central concern for the rest of this chapter. To address this question, we shall take several points of reference – first through various historically over-determined tropes concerning old age as embodied by old women (represented in such terms as the crone, the hag, and the vetula);[2] secondly through the relative invisibility of old women as citizens of concern, and their subjugation under the male breadwinner model that dominated modern welfare; thirdly through the dominance of women in epidemiological representations of agedness and infirmity – that deep old age is more often women's experience and women's terrain; and finally through the recent discourses of consumer culture and the positioning of gender within those discourses and practices that constitute the cultures of the third age.[3]

Of these various sources, the socio-historical arguably exercises the more pervasive influence. The representation of old women in Greek and Roman satirical literature, for example, was dominated by images of repulsive undesirable bodies, desiring but disgusting, who evoke in the (invariably male) playwrights and poets 'the most intense expressions of fear and disgust along with a sense that they constitute a sort of uncanny other' (Richlin, 1984, 71). Although old age is represented in classical literature in negative terms, irrespective of gender, there is more often some attempt at advancing some compensatory narrative regarding the position of older men (Falkner, 1995; Falkner and De Luce, 1989). In the courtly literature of the middle ages, the old woman reappears in a not dissimilar position, where 'the metamorphosis of firm young feminine flesh into the wrinkled skin and sagging body parts of the old woman is a horrifying signifier of mortality and death' (Sidhu, 2006, 46). Much the

same has been said of early medieval Anglo-Saxon literature where a tradition of depicting 'the monstrous regiment of hags, viragos and villainesses' was later 'swollen by a further cohort of older or elderly women either given to the bottle or to bawdry or to both' in the early modern period (Shaw, 1990, 7). There is throughout the pre-modern period, a remarkable degree of consistency that seems to exclude any obviously sympathetic presentation of older women as loving mothers or faithful friends and partners – in short of the portrayal of older women as embedded within a family network. While grandmotherhood has been offered as 'the only positive stereotype for older women' (Westwood, 2016) it features scarcely at all in pre-modern writings.

Turning to painting, similar conclusions may be reached – the relative invisibility of portraits of older women and the generally unflattering nature when they were portrayed. Campbell has noted that when Italian renaissance artists portrayed old women they did so to illustrate the 'unenduring' beauty of women, with an implicit contrast drawn to the enduring beauty of man at every age (Campbell, 2006, 167). Arguably such notions were necessary conceits, given that the commissioning of much portraiture was occasioned by elite 'senior' men, whose presumed grandeur the male artists would be expected to reflect. Some have argued that during the course of the eighteenth century old age underwent a change in its cultural representation, with 'a literary and artistic turn from comic derision . . . to greater respect and sentimentality' (Troyansky, 2005, 175).

Not only was there a persistent representation of old women as ugly and undesirable – as irredeemably other – within pre-modern art and literature, at the same time there was an underlying sense that despite or because of this, old women retained a kind of 'crone' power that threatened the social order of patriarchy (Roberts, 2003, 119). This power was vividly represented in the image of the older woman as sorceress, witch or 'vetula'. Such imagery was present in the literature of the classical world but it reached a particularly virulent level during the early modern period when witches became the targets of intense investigation by the state (Roper, 2004; Rowland, 2001). It was argued, for example, 'that older women were "by reason of their sex inconstant and uncertain faith, and by their age not sufficiently settled in their minds", and were thus "much more subject to the devil's deceits"' (Rowlands, 2001, 52). Whether or not there was any truth in such claims is not the point: rather it was the weight of assumptions that older, solitary women exercised a fearful presence within the community, being tied neither to the role of maiden or matron, but 'roaming' loose that perhaps made her the more likely victim of accusations at a time when religious conflict was at its height. As Roper notes, 'time and again, the themes of the witch trials turned on birth, fertility and the dangerous wishes of old women' reflecting a common 'hatred' of elderly unfecund women, cultural imaginaries 'linked to fantasies which clustered around the human body itself . . . concerning mothers and wombs . . . [and] sterile sex' (Roper, 2004, 178).

With the advent of modernity, these stereotypical portraits of old women held less sway. Fear and ridicule were slowly replaced by respect; or if not

respect a degree of recognition concerning the hardships of old age.[4] From the nineteenth century onwards, the physical appearance of agedness competed with a more socially framed concern with old age as a symbol of poverty. While the economic consequences of ageing in an era dominated by wage labour applied especially to older men, the plight of older women was equally imbued with the perils of pauperisation. Nineteenth-century censuses indicate how common older men and women ended up as either indoor or outdoor paupers; this was a time when old age was very much split between two nations – each living at a considerable remove from the other. The middle classes offered a representation of old age as genteel, respectable and even severe – with the old mother as nurse or matron, and the old father as wise and masterly; in contrast, old age among the working classes was a neutered picture of hardship, hunger and limited opportunities to earn a living or keep a house. Although there are many examples of ageing diarists ruefully recording the physical decline of their bodies, such personal concerns were less often the topics of cultural examination or of public concern. The body aged privately: what was public were the signs of poverty or prosperity written on the aged body – man or woman. Though they were not forgotten, those earlier cultural representations of ugly, disgusting and threatening old women were increasingly confined to the fairy stories of Victorian gothic fiction. Still, the cultural devaluation of older women has not disappeared (Gott, 2005). What has disappeared is the pre-modern link to 'other worldly' powers that once qualified the disparagement implied by these terms – a power that arguably has been disconnected and transformed, in both site and gender, to that of 'Dr Alzheimer'.

The second arena where gender is embedded within the social imaginary of the fourth age is through the social securitisation of the life course instituted during the course of modernity and most fully realised during the second half of the twentieth century (Kohli, 2007). This model of ensuring financial support before and after working life was not confined to men, but it was presaged upon the idea of the married male breadwinner whose earnings during his working life were seen as serving to ensure support for his children as they grew up and later to guarantee support in his and his wife's old age. As men's earnings grew in the course of the post-war decades, and consequently as the impact of cumulative pension/social insurance contributions built up, poverty in old age declined. This effect was staggered, appearing most clearly in the latter decades of the century. Not only did old age poverty decline at this point, but its 'age gradient' began to lessen, such that the poverty of the oldest old – those aged 80 or more – which had once been most acute, fell to the point that wealth and income became more or less equivalised from early to late old age, at least in the more developed economies of Western Europe (Oris et al., 2017). Because old women were more often than not married when they reached age 65, their income and wealth benefitted, first from their status as wives but secondly – and increasingly – from their own contributions as more working-age women joined the labour force from the 1970s onwards. Single women have always been more likely to have worked for pay during their adult lives.

Their income status in old age has improved during the second half of the twentieth century, as a result both of reductions in gender-segregated employment and the progressive equalisation of pay. Still, compared with married women, lone women remain at higher risk of enduring poverty in old age in most of the world's developed economies, compared with both older lone men and with older married women (Goldberg, 2010, 292).

Because women's working life has been more often disrupted (typically by childbirth and family caregiving), it yields a weaker cumulative growth in lifetime earnings and contributions, while historical inequalities in men's and women's earnings ensured a further limitation, such that women reaching age 65 who were single, divorced or widowed were more likely to remain poor in old age, despite the post-war expansion of welfare benefits. Women benefitted less because of the assumptions underlying the institution of retirement and its foundation upon women's later life being secured principally by their husband's earnings. This 'feminisation' of old age poverty was the focus of much writing on the political economy of ageing during the 1970s and 1980s (Minkler and Stone, 1985). Even at the turn of the twenty-first century, older women's personal income has remained well below that of older men's. Only by considering 'average household income' (in effect averaging older men and women's incomes) do married men and women seem 'equal', while women living alone remain the poorer group (Arber, 2006, 66–68). In contrast, lesbian women's lifetime earnings have been found to be 10% to 15% higher than those of heterosexual women, largely it would seem as a result of their more often avoiding the financial penalties of family and childcare (Black et al., 2003; Klawitter, 2015).

The third vector through which gender permeates the fourth age imaginary concerns the expansion of public health and its epidemiological gaze. The statistical examination of society during the nineteenth century provided the backdrop to later developments in social policy and the role of the state as guarantor of the health of the body politic – that is of 'its' population (Randeraad, 2010). At first the paternalistic concern of rulers, planners and the governing elite, over time this became of increasing interest to the population itself. The transformation wrought by what Foucault termed the systems of governance associated with this new 'bio-politics' saw responsibility for securing the population's well-being transfer from the business of the state (its ministers, civil servants, local and national officials and those closely concerned with such business) to matters of concern to the general public. Self-governance became the state's preferred route as the least costly means of ensuring population health and well-being (see Lemke, 2001, 201–204; Miller and Rose, 1990). The opening out of the welfare state (some would call it retrenchment) after the fiscal crisis of the mid-1970s has seen a steady rise in media accounts of the health, wealth and well-being of the population and the emergence of international 'league tables' on health happiness and well-being. Alongside such accounts in the media have been the public dissemination of academic (expert) analyses of those factors thought to contribute to such health, wealth

and well-being, in effect confirming the possibilities that a long and healthy life can be realised as much through individual lifestyle as through social policy and institutional practice. This 'freedom to age' of course ignores the many constraints that limit the capacity of many marginalised groups of women to realise such choices. Unsurprising then that social marginalisation seems to contribute so much to the failure of health and loss of well-being in old age (Fredriksen-Goldsen et al., 2017).

Out of the perspectives of epidemiology and public health, has appeared an apocalyptic demography (Robertson, 1990, 1997). This literature which so pervades geriatric and gerontological studies and so often now permeates the public media focuses relentlessly upon the perils of an ageing population, the ever-rising health problems arising from such ageing and the threat that these pose to the economic and social well-being of our 'ageing' societies. Such reports are not the work of pure fabrication; they are the hard-fought products of sincere research conducted by sincere academics in fields such as demography, economics, epidemiology, public health and sociology. What they do however is support and sustain the idea of a feared old age, increasingly associated with the mental decline of dementia, which has become one of the most feared aspects of growing ever older in recent decades (Cantegreil-Kallen and Pin, 2012; Kessler et al., 2012). The consequence of such reports has been to stabilise a gendered representation of 'deep' or 'real' old age for, as Martha Holstein has observed, 'deep old age is predominantly a woman's experience' (Holstein, 2015, 129). It is especially the corporeality of old age that is aligned with and represented by old women and their associated economic, moral and social dependency, their frailty and infirmity. Thus demographic and epidemiologic data from the developed economies indicate that, compared with old men, old women are (a) more likely to be found among the oldest age categories – those aged 80 or more; (b) more likely to live alone, whether as unmarried, unpartnered or as widows; (c) more likely to report difficulties carrying out the activities of daily living unaided; (d) more likely to suffer from dementia;[5] and (e) more likely to end their lives in institutional settings such as nursing homes (Del Bono et al., 2007; Vlachantoni et al., 2015; von Heideken Wågert et al., 2006). At the same time, measures indicative of psychosocial status – such as happiness, loneliness, or well-being – do not indicate any consistent gender differences. The paradox of such epidemiological research is that, despite older men being fitter, stronger and less impaired mentally and physically than older women, they are nevertheless less likely to live on into the oldest ages (Oksuzyan et al., 2008). Such selective attrition implies that those older men who reach their 80s and 90s show evidence of ageing more successfully than older women, despite older women succeeding more often to reach these oldest ages. The 'failings' of older men to survive however are invisible, as frail men die quickly, while older women's failure to age well is all too visible and their frailty lasts longer (Borrat-Besson, Ryser and Wernli, 2014).

The fourth vector through which gender is imbricated within the social imaginary of the fourth age concerns issues of contemporary consumerism and

the gendered representations of third age culture. If women navigate much of their adult lives through conditions of relative disadvantage and oppression, it is perhaps unsurprising that the cumulative consequence of such experiences is not just to enfeeble their old age but also arguably to sensitise them much more to the possibilities of failure – and perhaps render them more resilient in the face of such frailty. A paradox is present, in that survival into later life despite a lifetime of relative disadvantage may enable women to navigate through the failings of old age better than men faced with but less prepared for similar failings in later life. If successful ageing is the anticipated ideal for older men – cashing in their accumulated life's capital as it were – surviving despite it all may be more often women's experience when survival itself through old age – alone or as a family – may count as a success.

In the eyes of the world – and in the framework of the gerontological enterprise – such 'success' may be little cause for celebration. Old men running marathons, climbing up mountains, paragliding over clifftops, lifting hundreds of kilos, staying on top of corporate empires or surviving in positions of power provide the celebratory foregrounding of much successful ageing. Old women dancing, dressing up or otherwise 'performing age' offer but a pale shadow of these accomplishments; a performance that is always subject to the potential for betrayal, revealing the 'real' person behind the persona, the real agedness of the age denying actor. A similar risk frames anti-ageing cosmetic surgery, where the prospect of failure resides both in success (the outcome being claimed too 'artificial' or 'unreal') and in failure (where haematomas, paralysis or scarring arise 'in place of' age). Of course, the rise of anti-ageing/age-denying lifestyles has not been confined to one gender, but both its 'artificiality' and its 'performativity' are evoked more often in relation to older women, as if echoing pre-modern male disgust once expressed towards older women for dyeing their hair, using make-up and wearing fashions deemed more suited to younger 'marriageable' women.[6]

Placed against either set of images are the representations of 'real' old age – those imaginaries of a fourth age that are captured by abject old women in nursing homes, whose secret abuse is displayed in some undercover TV documentary. These scenes convince in no uncertain terms the fit from ever contemplating that such an ending might serve as a satisfactory conclusion to their lives.

Resources and representations: the moral imperative of care

The abject nature of agedness and infirmity is not easily transcended, not even within the domestic sphere, where care most commonly takes place (Abellan et al., 2017). Although women are more often than men the providers of care within the household (i.e. when they act as informal carers), this is much less the case after the age of 65 (Del Bono, Sala and Hancock, 2009). Late life gender differences in marital status, household composition and overall degree of

disability account for much of the variability in giving and receiving informal care but the point is that the gendered nature of care is much less evident in care giving than it is in the receipt of care. As already noted, women are more likely to report difficulties with daily living, more likely to not have a partner to provide informal care and more likely to receive care from others – and most notably, spend their last months residing and being cared for in an institutional care setting (Del Bono et al., 2007;Vlachantoni et al., 2015).

Most developed economies are facing 'the problem of long term care' – that is the problem of funding care, ensuring its quality and the equitable distribution of care to those most in need in times of 'continuing constraints on public expenditure' (Gori, Fernández and Wittenberg, 2016, 294). This confrontation between rising demand for and limited supply of 'care' is seen as a looming crisis that metaphorically hangs like a shadow over virtually all of the developed economies, threatening to consume society's welfare resources – in other words, its capacity to care. Given such formulation, does the gendered nature of the fourth age imaginary serve to orient those social practices and policies aimed at addressing the problem? Is it, in some sense, treated as another 'women's issue' which, though it cannot be ignored, nevertheless ranks well below the top priorities facing the governing elites of the developed world – such as employment, economic growth, immigration and terrorism?

Three factors warrant consideration – the extent of need, the nature of entitlements and the accessibility of extra household services. Representations of the client – the trend toward such framing of care recipients reflects the growing 'consumer orientation' of long-term care evident across the EU (Riedel, Kraus and Mayer, 2016) – are gendered; LTC clients are commonly imagined as aged, infirm women living alone. Their status as clients is rendered akin to that of the female customer, whose needs are ministered to by paternalistic service commissioners and providers. Entitlements are treated as those derived from the care recipient as a needy householder, rather than, say derived from the person's position as a former worker or breadwinner. Access is given on the basis of their present needs more than their past contributions – and hence the trade-off is to 'up' the criteria to ensure that those deepest into agedness and infirmity get first call to whatever services are included under the social care arrangements of a given country, region or local authority.

In short, the gendered representation of older care recipients reinforces their position as needy but frail consumers, offered services that are available from packages that have been constructed through pre-determined practices of domiciliary or institutional care; 'demand' is not a subjectively held position but a construction of need determined more by the authorities than by the desires of the care recipients. The care sector, though an increasing part of most national economies, is rarely seen as a 'small or medium enterprise' in need of infrastructure investment or an industry of the future. It is represented more as a drag, rather than a driver of the economy, that is realised by paying minimum wages to a largely unorganised, female-dominated workforce encouraged to perceive their work as 'quasi' familial, reproductive labour (Rodriquez, 2014).

Although the beginnings of an insurgent interest into the technological possibilities of care giving can be discerned, the economy of care remains dominated by the gendered representations of this fourth age moral imperative.

Conclusion

Our argument in this chapter has been sketched out; much of the detail to support it requires further exploration both in contemporary and in historical sources. Our intention has been to offer a summary of our account of the social imaginary of the fourth age and its embeddedness within a gendered perspective. While the representations and realisations of third age cultures incorporate gendered perspectives, the third age as a term encompasses the narratives and practices of older men and women particularly in relation to consumption, leisure and lifestyle, patterned on established gendered distinctions. By contrast, the fourth age, we suggest, is less a cultural set of gendered narratives or practices than a social imaginary – the collective representation of a feared old age. Within this collective representation, abjection, frailty and loss dominate; care practices and policies actualise and institutionalise its social imaginary. The nursing home serves as its iconic image – the fate that awaits those who fail to negotiate an active, healthy, successful later life. That fate – the fate of a frailed old age – is profoundly associated with the female. But while past images of old women as crones, hags or vetulas possessed a transgressive power, alongside their belittlement and denigration, the contemporary imaginary is largely shorn of that power. While some older feminists have sought to recover the concept of the crone or the virago as a transgressive position against which to resist the social exclusion and cultural invisibility of older women, the problem is that such attributes have largely been stripped from the contemporary social imaginary of the fourth age – stripped because they imply both desire and the power to disrupt the social order, that are antithetical to the contemporary imaginary of 'real' old age.

The site of conflict, we suggest, is not culture, not even issues of voice and choice and consumer representation, but over the provision of an adequately resourced long-term care service. Although social representations of age and gender play their part in rendering social care the subject of a less visible politics, improving the material conditions affecting the adequate provision of social care must remain the more immediate goal. Combatting 'ageist' ideology may be more difficult and less effective – because of the very pervasiveness and power of the social imaginary of the fourth age – than pressing for improved infrastructure and better terms and conditions of care labour. The past casts long shadows – not just in terms of the images of the workhouse, its inmates and its infirmaries, but of the old practices and the marginality of the pauper nurses and wards maids employed there. Staff working in the long-term care sector remain marginalised and deserve better. It is important that the nursing home becomes a site of innovation, not a structure inherited from the past. There is a need to make long-term care work a skilled, respected and challenging practice,

with opportunities for specialisation and career advancement: a workforce for the future, not an echo of the past. In terms of Nancy Fraser's 'feminist politics', what is required is a 'non-identititarian account of recognition capable of synergizing with redistribution' (Fraser, 2007, 23). Given such a perspective, it is not a matter of calling for 'anti-ageist' social welfare policies to 'combat' the malign influence of the fourth age imaginary: change needs to take place elsewhere, within the productive economy of long-term care and in the performances of long-term care work.

Notes

1 The polysemous nature of the social imaginary refers to Castoriadis' belief that the combination of human and collective creativity ensures that ideas about society – the ways that society understands itself – cannot be pinned down to positions within or statements about a purely symbolic order. The social imaginary is more diffuse – fuzzier – than the purely lexical, relying upon analogy, metaphor and the complexities and contradictions of social [collective] narratives (Castoriadis, 2007).
2 Each of these invariably derogatory terms for 'old woman' can be traced back to their early Dutch/German ('hag/hagatusjon'), French ('crone/carogne') or Latin ('vetula') origins, entering the English language at some point during the late middle ages (source: www.oed.com/, 2017).
3 While a fifth dimension could be considered in the obvious discrepancies of power and influence between men and women, this pervades all aspects of the life course and arguably constitutes a less distinctive feature of the gendered representation of old age/later life, with which this chapter is concerned.
4 Roper states that 'by the century's end [i.e. the end of the seventeenth century] the image of the death-dealing old crone-witch was gradually loosening its grip on the popular imagination' (Roper, 2004, 181).
5 At least amongst those aged 80 and over: data on younger onset dementias – those occurring before age 70 – do not show such gender disparities (Miech et al., 2002).
6 See for example Erasmus' Praise of Folly 1511/2008, p. 39.

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5 Ageing without children, gender and social justice

Robin A. Hadley

Introduction

This chapter takes Nancy Fraser's (2000) three domains of social justice – resource distribution, recognition and representation – and applies them to people who are ageing without children. This is a relatively new area of research, with very little literature preceding the past couple of decades (Kreager and Schröder-Butterfill, 2004; Dykstra, 2009; Ivanova and Dykstra, 2015; Kreyenfeld and Konietzka, 2017a). The growth of interest reflects an increase in childless older adults in many parts of the world, which has raised questions about the factors which influence the significance, or not, of the absence of children and grandchildren for later life (Dykstra and Hagestad, 2007). Notably, studies of childlessness, as with studies on parenthood, have so far tended to focus far more on women than on men, with considerable gaps in knowledge about men's experiences at all ages, including in later life (Schick et al., 2016). In considering these issues I will draw on my auto/biographical research into the life experiences of male 'involuntary' 'childlessness' (Hadley, 2015, 2018; Hadley and Hanley, 2011), as well as wider authorship on ageing with/without children.

Definitions

'Childlessness is a shifting identity within various storylines across time and circumstances' (Allen and Wiles, 2013, 208). The term itself has been criticised for being a deficit identity:

> The childless are generally defined in terms of the category to which they do *not* belong: they are not parents and they do not have children. This conception of the childless as a noncategory has influenced the kind of research that has been done on the consequences of childlessness. Much of the research has focused on establishing what the childless do not have and what they are lacking.
>
> (Dykstra, 2009, 682)

One of the reasons for this deficit approach has been its embeddedness in an unreflective acceptance of two sets of norms: pronatalist norms (which idealise and promote

human reproduction); and heteronormativity (the assumption that heterosexuality and biological family forms are the norm) (Zamora, 2017; Westwood, 2018). These frame the construction of parenthood as natural, unconscious, and spontaneous, serving to 'Other' those who are not parents, particularly women. The idealisation of motherhood in particular 'places women who do not conform to pronatalist norms of stereotypical femininity because they have no children, at risk of stigmatisation and social exclusion' (Turnbull, Graham and Taket, 2017, 333).

It is, however, difficult to distinguish between parents and non-parents without somehow using the language of 'lack'. Even the term 'childfree' can be exclusionary, denying the experiences of those who are involuntarily childless and feel little sense of freedom, but rather loss (Letherby, 2016). Moreover, the binary distinction between parenthood and non-parenthood is misleading:

> There is no straightforward distinction between being or not being a parent: a person can become a parent as the result of having a natural child (with or without the help of assisted reproduction technologies), but also by adopting a child or becoming a stepparent of a partner's child. Thus, people can have children through different routes and at different points in their life course. A person can also cease to be a parent. The most obvious case in which this occurs is when a parent has survived his/her children. But there are also parents who, due to life events such as a divorce or an intense family conflict, have lost track of their children and no longer have contact with them. Other parents have children who live very far away. . . . Thus, we conceptualise parenthood and childlessness not as two fully separate conditions, but as a continuum of parental statuses.
>
> (Albertini and Kohli, 2017, 354–355)

While recognising, and agreeing with, this continuum, for the purposes of this chapter, childlessness in older age is understood as a state experienced by older people who do not have living biological or social (foster, adoptive and/or step-) children.

Demographics

According to the Pew Research Center in the US, in 2017, 'Nearly one-in-five American women ends her childbearing years without having borne a child, compared with one-in-ten in the 1970s'.[1] This is matched by similar trends in Australia,[2] New Zealand,[3] Canada[4] and Europe,[5] with increases in childlessness also reported in China[6] and Hong Kong[7] and among some, but not all, socio-economic groups in some countries on the African continent, for example among higher educated Black and White women in South Africa.[8] By contrast,

> In most of the less developed countries the percentage of childless women in their late 40s is typically under 10 percent. And in some populous nations, such India, Indonesia, Pakistan, South Africa and Turkey, the proportion of women remaining childless by their late 40s is below 5 percent.[9]

The HIV/AIDS epidemic in Africa and other countries has also created its own form of childlessness, with many older people being both without support from their adult children (who may be ill, or have died) and responsible for the care of their grandchildren and/or foster grandchildren (Seeley et al., 2009; Kautz et al., 2010). These grandchildren may then in turn provide care for their 'childless' grandparents when they are older (Kasedde et al., 2014).

The causes for the increase in childlessness are framed within competing ideological narratives:

> Some commenters have characterized increasing childlessness as an outgrowth of an individualistic and ego-centric society . . . or have blamed childless women for the rapid aging of the population and for the looming decay of social security. . . . Meanwhile, commenters on the other side of this debate have called for a 'childfree lifestyle' and have recommended 'bypassing' parenthood. . . . From a feminist perspective, the decision to remain childless has been described as an expression of a self-determined life, as in previous generations a woman's life had been constructed around the roles of wife and mother.
>
> (Kreyenfeld and Konietzka, 2017b, 3)

Data on childlessness rates are patchy, due to both how such information is recorded, and how it is searched for and retrieved; moreover, what data there is primarily focuses on women rather than men (Dykstra, 2009; Hadley, 2018). Exact figures for those who experience 'involuntary childlessness' are difficult to calculate because people who do not seek medical advice concerning their 'childlessness' are not recorded (Greil, Slauson-Blevins and McQuillan, 2010). The overall level of 'childlessness' in the United Kingdom is around 20% (Berrington, 2015, 2017). The UK, like the vast majority of countries, bases their figures on the collection of a women's fertility history at the registration of a birth (Berrington, 2004; Hadley, 2018; Kreyenfeld and Konietzka, 2017). The lack of available data on men's fertility is partly down to the historical attitude that fertility and family formation are relevant only to women, combined with the view that men's data may be unreliable and/or difficult to access (Berrington, 2004).

> Most studies on the impact of childlessness have therefore examined the effects on women only, and have overlooked or simply neglected men. . . . Recent studies which have investigated the extent to which men's lives are affected by remaining childless have concluded that the implications of childlessness are no less significant for men than for women, but that the effects may be different.
>
> (Keizer and Ivanova, 2017, 313–314)

This is further nuanced by sexuality/sexual identity: older lesbian, gay and bisexual (LGB) individuals are less likely to have children than older heterosexual

individuals, with older lesbians and bisexual women more likely to have children and grandchildren then older gay and bisexual men (Guasp, 2011; Choi and Meyer, 2016; Westwood, 2016).

Resources

The considerable knowledge gaps about childlessness in later life, especially among men, means that the resource implications are not yet well understood. While the earlier literature had suggested that childlessness had a detrimental effect in life, recent empirical evidence does not support the assumption that childless older people have lower levels of economic, psychological or social well-being than their counterparts who have children (Hank and Wagner, 2013). In many areas the resource implications of childlessness remain contested.

Material resources

In terms of material resources,

> According to an influential theory of the modern transition to low fertility, one of the main reasons why people had children in the past was because the children were expected to provide social and economic support when the parents became old and frail and were no longer able to be self-sufficient . . . whereas today older people no longer depend on the support of their descendants in old age because they can now rely on pensions, health care, and social services provided by the welfare state. . . . Some authors have argued that such old-age security motives for having children – ensuring material support and care in old age – still apply today, not just in low-welfare developing societies, but to some extent also in affluent societies with extensive welfare states . . . this controversy has yet to be resolved.
>
> (Albertini and Kohli, 2017, 353)

While the material implications of childlessness for men are not yet fully understood, it does appear that they do have some significance for women. Average women's earnings continue to be less than those of average men's (see Vlachantoni, this collection). This is due not only to the enduring gender pay gap, but also to women being more likely to work part-time (due to informal care commitments) and in low-paid care work. This in turn impacts upon their ability to accrue capital in later life. However, childless women are less likely to be affected in this way (Mika and Czaplicki, 2017).

Health and well-being

In terms of health and well-being, again, some research has suggested that older people ageing without children were more likely than older parents to suffer from

greater and earlier physical and mental health problems, and to die comparatively sooner (Modig et al., 2017). However, other research has contradicted this:

> There has been a tendency to view childless older adults as a problem group, but findings show they are not more prone to poor psychological well-being and social isolation than older parents.
>
> (Dykstra, 2015, 671)

A key factor affecting well-being would appear to be the reasons for childlessness, the adjustments made to it and the particular circumstances of an individual. In other words, '*How* someone ends up with no children may be more important than not having a child *per se*' (Albertini and Kohli, 2017, 352). Chosen childlessness is less likely to cause psychological distress than involuntary childlessness. However, even among those who are involuntarily childless and/or who have suffered the death of a child, adjustments and accommodations can be reached in later life, 'ranging from a wistful regret to acceptance' (among men, according to Hadley and Hanley, 2011, 63) and from 'solo-loneliness' to 'meaningful futures' (among single women, according to Hafford-Letchfield et al., 2017, 321). Well-being among childless older people is nuanced by gender. In a recent review of the literature, Keizer and Ivanova (2017) observed,

> The impact of childlessness among men is conditioned to a much larger extent by partner status than it is among women. . . . For example, Kendig et al. (2007) showed that never-married and formerly married childless men were more likely than married childless men to report being in poor physical health, whereas among women there were no significant differences in self-reported health among childless women based on partner status. Other studies have shown that the life outcomes of never-married childless women are much more favourable than those of their married counterparts (Koropeckyj-Cox and Call, 2007). Taken together, these findings suggest that the presence of a partner is more important to the wellbeing of childless men than of childless women.
>
> (314)

There is a need for further research in order to better understand the consequences of childlessness upon the health and well-being of older people, especially older men.

Social networks

Earlier research focused on childlessness as a deficit:

> In previous research on childlessness, a recurring theme has been the consequences for an individual's risk of social isolation and insufficient informal support, particularly in later life. . . . From the perspective of public policy, childless elderly people are usually seen as a problem group . . . it

> is generally assumed that compared to adults who have children, childless adults are at higher risk of lacking the social and emotional support they will need when they become frail and dependent.
>
> (Albertini and Kohli, 2017, 351)

However, drawing upon their study of older people in 11 European countries, Albertini and Kohli suggest that there are two main reasons for these assumptions to be flawed:

> First, childless elderly people are not only on the receiving end of support; they also give to their families and to society at large by establishing strong linkages with next-of-kin relatives, investing in non-family networks, and participating in voluntary and charitable activities. Taking these transfers and activities into account, we have found that the differences in the support exchange behaviours between parents and childless adults are small (Albertini and Kohli, 2009). Second, childless elderly people are not a homogenous group. . . . The social consequences of being childless in later life depend on the specific paths into childlessness (Dykstra and Hagestad, 2007; Keizer et al., 2010; Mynarska et al., 2015), and they may also depend on the specific family and kinship constellations of each childless individual.
>
> (351–352)

In terms of intergenerational support, Pesando's (2018) analysis of the study of ageing in Europe suggested that childless middle age and older adults may provide more upward intergenerational support (i.e. to people older than themselves) – in the form of financial, practical and emotional transfers – than middle age and older parents. This was echoed in my own research. For example, George (60) and his wife were seen as 'available-to-care' for her ageing parents, 'We are supporting my wife's family [parents] now. We're the main support and we don't have children. My wife's brothers, have children' (Hadley, 2015, 225).

In terms of personal support networks, 'the childless have more friends and extended kin, and they are more likely to consider them as potential supporters, than parents' (Schnettler and Wöhler, 2016, 1339). Indeed, 'some childless people not only successfully substitute friends and collateral kin for children and lineal kin, but also seem to have ties that are more efficient in providing them with support' (Klaus and Schnettler, 2016, 95). However, these support networks may be insufficient in relation to complex and/or personal care needs (Deindl and Brandt, 2017).

Care needs

With an ageing population – i.e. there are more people living for longer and into older old age – there is also a growing demand for care in later life. At the same time there has been a reduction in formal care provision in many parts of the world, including the UK, with an increasing emphasis on (dwindling) informal social support (Daly and Westwood, 2017). Most unpaid care for older

people is provided 'either by their children or by their spouses or partners' (Pickard, 2015, 97). However, as Pickard has shown, there is now a growing 'care gap', with supply no longer able to meet demand. Among childless older people these issues arise sooner and disproportionately:

> On average, 10 per cent of older Europeans today have no children. Sporadic informal support for these elders is often taken over by the extended family, friends and neighbours, and thus the lack of children is compensated within the social network. Intense care tasks, however, are more likely provided by professional providers, especially in the case of childless older people. In countries with low social service provision, childless elders are therefore likely to experience a lack of (formal) support, especially when depending on vital care.
>
> (Deindl and Brandt, 2017, 1543)

This means, according to Dykstra (2009) that 'in countries with few formal care arrangements available, frail childless elderly are particularly vulnerable' (683). However, such 'vulnerability' is highly contingent upon personal circumstances and context:

> Identifying vulnerable older people and understanding the causes and consequences of their vulnerability is of human concern and an essential task of social policy. To date, vulnerability in old age has mainly been approached by identifying high risk groups, like the poor, childless, frail or isolated. Yet vulnerability is the outcome of complex interactions of discrete risks, namely of being exposed to a threat, of a threat materialising, and of lacking the defences or resources to deal with a threat.
>
> (Schröder-Butterfill and Marianti, 2006, 9)

Nonetheless, in many countries single childless adults are more likely to spend the last years of their lives in receipt of formal care provision, and to be disproportionately represented in older age residential care facilities (Dykstra, 2009; Koropeckyj-Cox and Call, 2007). In the Netherlands, van der Pers, Kibele and Mulder (2015) found that older people with children living nearby were less likely to enter residential care than those with children living further away. This highlights that functional or *de facto* childlessness (Kreager and Schröder-Butterfill, 2004) may be as significant as actual childlessness.

Recognition

Social status and visibility

In the majority of societies, biological parenthood provides the surest way to a positively valued social identity within normative understandings of the life course. All the main religions promote the childbearing ideal as a

'blessing' and not conceiving as 'barrenness'. Moreover, the 'childless' are socially disenfranchised through the absence of any positive cultural narratives recognising their status. Indeed, people ageing without children are misrecognised almost to the point of invisibility because childlessness counters the structurally embedded pronatalist and heterosexist normative. In older age, the statuses of parenthood and grandparenthood can mitigate some of the negative stereotyping associated with ageism and sexism (Calasanti and Slevin, 2013), with grandparenthood in particular being a positive status identity for older people (Timonen and Arber, 2012; Tarrant, 2012). Grandparenthood can be a form of social currency from which non-grandparents cannot benefit:

> Colin (59). 'The only time I ever think about what I might have missed out on is when I see people putting comments or pictures of their grandchildren on Facebook.'
>
> (Hadley, 2015, 223)

Childless older people not only do not benefit from the 'protective' identity of grandparentood but may also be Othered by their childlessness. Their 'outsiderness' (Hadley, 2018, 1) is informed, for older men, by their failure to comply with the 'virility-proved by-fertility' normative (Hadley, 2018, 8). Whereas,

> Old women who are childfree violate heterosexual life-course norms, indeed 'women without children' can be understood as 'a contradiction in terms' (Hird and Abshoff, 2000, p. 347).
>
> (Westwood, 2016, 101)

For the childless older men in my research, there were particular anxieties in relation to being perceived in negative sexual terms:

> All the men expressed a fear of being viewed a paedophile; the widowers and single men expressed this most strongly. The negative portrayal of older people is well established with lone older men particularly viewed as 'dirty old men' and sexual predators.
>
> (Hadley, 2018, 8–9)

For example, when Harry's partner was alive the local children would ask to see and play with their dogs. However, following her death Harry (64) was concerned about how he would be (mis)recognised:

> Some of the [neighbours] kids like to come in and play with the dogs. And you have to say, 'No! Look go and get your Dad!' I'd hate someone to look saying, 'Watch that old man, always got kids round him.' I don't want anyone looking at me thinking that.
>
> (Hadley, 2015, 169)

Harry's concerns reflect ageist stereotypes whereby lone older men are frequently viewed as 'dirty old men' and sexual predators (Walz, 2002; Gutmann, 2009). In other words, the men in my study were concerned about issues of mis-recognition in that their childlessness, rather than make them *less* visible, made them *more* visible, but in risky and inaccurate ways.

In Westwood's (2016) study of older lesbian, gay, bisexual and non-labelling (LGBN) individuals, she reported that older lesbians also experienced issues in relation to non-grandparenthood and identity, in ways which were both similar to, and yet different from, the men in my study. Many of her participants also felt 'Othered' by their childlessness.

In May's interview, for example, she attributes this to her sense of difference when she tried to join the Women's Institute (WI):

> I think you do stand out of the crowd more because you're not like everyone else. So I tried to join the WI. And I was different. I don't have a man to talk about. And everyone was going on about their grandchildren and their bloody husbands, and I get a bit bored by that. What is there to talk about? Very empty. People made me welcome, chatting away, but I didn't feel part of it. I didn't go back. I've got nothing in common with them (May, aged 64).
>
> (Westwood, 2016, 100)

Other lesbian participants in Westwood's study, unlike the men in my study, felt they were made less, not more, visible by the grandparent stereotype:

> And there's the assumption because I am an older woman that I must be heterosexual, that I must have children and grandchildren.
>
> (Diana, aged 69)

> As a single older woman, you immediately fall into that stereotype of 'a granny'. And 'a granny' is heterosexual by default. And people are always asking me about my bloody grandchildren. I don't have any grandchildren, lesbians didn't have children in my day (Audrey, aged 67).
>
> (Westwood, 2016, 100)

Comparing my own findings with those of Westwood (2016), suggests that gender *and* sexuality play a role in the mis-recognition of childless older men and women. For the childless older men in my study, it involved Othering, and the potential mis-recognition as sexual predators. For the childless older lesbians in Westwood's study (unlike the older lesbian parents), non-grandparenthood was also understood as a source of Othering, but also as a lack of visibility, rather than an unsafe visibility. Childless older men (both heterosexual and gay), it would seem, are concerned about being mis-recognised through a deviant sexual lens, whereas childless older lesbians are concerned about not being recognised at all.

Social policy

Social welfare policies in many parts of the world are predicated upon notions of 'the family' (i.e. children) as the first tier of support for older people (Daly and Westwood, 2017). These do not take into account those childless individuals for whom such support is not available (Westwood, 2018). In Mediterranean parts of Europe, such as Italy, where the norm is for family-care for older people, childless older people face a deficit due to the absence of primary intergenerational support:

> Childlessness is an increasingly common condition in many European societies. The consequences that this demographic phenomenon might have on welfare systems – and long-term care policies in particular – are widespread. This is particularly the case for the familistic welfare states of Southern Europe . . . in Italy elderly nonparents . . . are likely to miss those forms of support that are most needed in the case of bad health. [They] are more likely to be helped by nonrelatives and not-for-profit organizations and to a lesser extent by the welfare system.
>
> (Albertini and Mencarini, 2014, 331)

By contrast, in Northern Europe, with less familistic welfare policies, and greater expectations of state support in older age (Haberkern, Schmid and Szydlik, 2015; Albertini and Pavolini, 2017) this is less of an issue. There is then a need for social care policies which take into account the needs of the growing population of older people ageing without children.

Representation

Older childless people are under-represented in three ways: in research; in advocacy; and in social policy.

Research

There is a need for more research on the life trajectories of older people ageing without children:

> Pathways and meanings of childlessness vary so much that it is unwise to assume that people have similar experiences of nonparenthood, especially in later life.
>
> (Allen and Wiles, 2013, 206)

In terms of this variety, much more needs to be understood about ageing childless men:

> Research on childless older adults has suffered from historical myopia, a neglect of men and a disregard for the diversity among the childless.
>
> (Dykstra, 2009, 671)

Additionally, there is a need to better understand not only the positive adaptive styles of older childless people, but also the extent to which, and how, they may form alternative intergenerational relationship ties:

> The paucity of research on intergenerational friendship reflects the focus of existing research on homophily, and consequently friendships among older *or* younger adults; and that this in turn reflects a social construction of older adults as unsuited to friendship with younger adults. Investigations of intergenerational friendship can help challenge the images and models of ageing and older adults that both research and societies currently operate with, and are constrained by.
>
> (O'Dare, Timonen and Conlon, 2017, 1)

Other intergenerational ties, beyond friendship ties, involve godparenting, and this may also be an important source of two-way support, and in particular a care resource for older childless people in later life (Westwood, 2016). This too requires further research, as well as other forms of 'fictive kinship' which are sources of support and resilience for childless people in older age (Jordan-Marsh and Taylor Harden, 2005).

Advocacy

In the UK the organisation which represents childless older people is Ageing Without Children (AWOC) [10]. It is a grassroots organisation founded in 2015 by four people (including myself) who wanted to raise awareness among governments, academics, health and care institutions and charities. The AWOC report *'Our Voices'* (The Beth Johnson Foundation [BJF] and AWOC, 2016, 3) asks the critical question *'How will and should older adults without children approach their later years?'* The report outlines AWOC's fourfold aims (5) which are:

- To carry out more research into the issues associated with ageing without children, to inform policy, practice and planning
- To develop a network of local groups for people ageing without children
- To campaign for issues affecting people ageing without children to be included in mainstream thinking and planning on ageing, and to challenge the judgements made about them
- To work with other organisations to develop solutions to some of the difficulties faced by people ageing without children.

The report highlights how relevant organisations, policymakers and stakeholders need to recognise the increase in the population of people ageing without children and for planning, policy and services for older people to reflect these societal changes. This group receives no funding support. While many age-related issues such as isolation, loneliness and dementia have recently gathered

extensive attention (and funding) people ageing without children is a subject that remains unreported, under-researched and under-represented at all levels.

Policy inclusion

As Pesando (2018: 1) observed, 'policy makers should take into more consideration not only what childless people receive or need in old age, but also what they provide as middle-aged adults'. AWOC has developed a range of policy recommendation (BJF and AWOC, 2016, 31–32), which include:

- Ensure that central government planning on ageing takes into account that increasing numbers of people will get old without family support.
- Require local authorities to identify how many people in their area are likely to age without children and incorporate this into their strategies on ageing.
- Enable GPs, hospitals and social care services to identify people without family, to provide support or care at an early stage and to guarantee involvement of other services to ensure they are not left without support.
- Invest in intergenerational programmes and activities so that people ageing without children still have the possibility of engaging with other generations.
- Develop a national strategy for people ageing without children that brings together individual people and Ageing Without Children, along with national and local government, the NHS, housing providers and key bodies from civil society.

Conclusion

As this chapter has demonstrated, there is a pressing need for a deeper understanding of the experiences of the growing numbers of childless older people, especially men. The contingencies which determine health and well-being in later life and the nature of support networks, particularly in relation to intense care needs, need further research. The diverse experiences of older childless people no doubt span the spectrum of potential later life outcomes. However, it is important to know more, for them to become more visible, and for social policy to be better informed, so that the needs of childless older people are not overlooked.

Notes

1 Livingston and Cohn, 2010.
2 Corsetti, 2017.
3 "Childless couples and empty-nesters the future for NZ." October 28, 2017. www.stuff.co.nz/life-style/parenting/family-life/98325547/childless-couples-and-emptynesters-the-future-for-nz.
4 Grenier, 2017.

5 Kreyenfeld and Konietzka, 2017a.
6 Feng, 2018.
7 Tam, 2017.
8 Masebe and Ramosebudi, 2016.
9 Chamie and Mirkin, 2012.
10 Ageing Without Children. For a Positive Later Life Without Children. https://awoc.org/

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6 Trans(gender)/ gender-diverse ageing

Jenny-Anne Bishop OBE *and Sue Westwood*

Introduction

In this chapter we will examine the equality and social justice issues relating to trans(gender)/gender diverse (trans/g-d) people and ageing. As Persson has observed, 'transgender elders are both underserved and understudied. Neither the aetiology nor prevalence of transgender is well understood' (Persson, 2009, 633). It has been estimated that 1% to 2% of the population are trans/g-d (GIRES, 2011), although this is generally considered to be a conservative estimate. With growing legal and social recognition of trans/g-d people (Hines, 2007), it is likely that their visibility, and this estimate, will increase. In this chapter we argue that increased recognition and representation of older trans/g-d people has significant emancipatory potential for not only older trans/g-d people themselves but also for a broader understanding of embodied, gendered, ageing.

We use the term trans(gender)/gender-diverse (trans/g-d) as a broad umbrella collective to describe individuals who are transgender, and including all those who are transsexual, transvestite, gender queer, gender fluid, non-binary, genderless, agender, non-gendered, third gender and bi-gender people. The term transgender/trans has had different meanings in different times and societies, and in some contexts, is used to include all of these gender diversities.[1] However not everyone is comfortable being described as transgender/trans and so here we are using the broader category trans/g-d in order to be more inclusive.

We shall use the term 'transgender' to describe individuals who have transitioned in any way from the gender they were assigned at birth to the gender they identify as. Transmen have transitioned from being assigned female to self-identifying as male. Transwomen have transitioned from being assigned male to self-identifying as female. Some will have had chemical and/or surgical interventions to support their transitioning, some will not. Some will have legally changed their gender, in those countries in which they are able to do so, some will not. Some will be living in countries where their rights are recognised, some will not (Human Rights Watch, 2018). We explore the issues affecting older trans/g-d people from a social justice perspective, drawing upon Nancy Fraser's (1997) model of social justice. Fraser has argued that inequality includes

but also goes beyond resources, to also include recognition (social and cultural value, status and worth) and representation (political voice). All three mutually inform each other, and combine to produce greater inequalities. All three must be addressed, Fraser argues, for inequalities to be remedied. While Fraser understood resources in terms of the material, and financial, we consider other resources to also be of significance, particularly in older age. These include access to housing, health and social care and support (Westwood, 2016). We believe Fraser's model is extremely helpful in understanding the intersecting domains of inequality and we have previously used it to consider the inequalities associated with dementia experienced by trans(gender)/gender-diverse people (Hunter, Bishop and Westwood, 2016).

In this chapter we consider how older trans/g-d people are affected by the intersection (Hines, 2010) of resources, recognition and representation to produce later life disadvantage, and how these are informed by cumulative disadvantage, nuanced by their trans/g-d identities across the lifespan. We identify ways in which such disadvantages need to be addressed by policymakers, services providers and advocacy organisations. Through identifying the key issues for trans/g-d individuals, this chapter also offers insights into how normative and non-normative gender identification and attribution informs the ageing process and associated (in)equality issues.

Resources

Material resources

It might not seem at first glance that there is any reason why trans/g-d individuals should be differently positioned in terms of access to material resources, compared with cisgender[2] women and men. However, this is to not understand the impact of being gender non-conforming on a person's in/exclusion and positioning in the world of work and social networking, and in turn, a trans/g-d person's accrual of resources, e.g. pensions, property, savings (Whittle et al., 2007; Auldridge et al., 2012). Some transwomen and transmen have concealed their identities for many years, with only some eventually transitioning.[3] For many of these individuals the consequences for their mental health and well-being have been harsh, with many suffering from mental health problems, particularly depression (Hoy-Ellis and Fredriksen-Goldsen, 2017). Many have also been affected by substance use issues and have been at increased risk of ending their lives (Fredriksen-Goldsen et al., 2013).

Some trans/g-d people have been gender non-conforming all their lives, i.e. their gender identity and presentation has never aligned with the gender others perceive them to be. This non-normativity has resulted in bullying at school, prejudice and discrimination in the workplace and being subject to transphobic[4] attacks in everyday life (Whittle et al., 2007; Grant et al., 2011). Some trans/g-d people have also been subject to domestic abuse related to being trans/g-d (Cook-Daniels and Munson, 2010). Many trans/g-d people have also

experienced profound workplace prejudice and discrimination (McFadden and Crowley-Henry, 2016). These risks are partially mediated by the extent to which a trans/g-d person can 'pass' (which is known as 'passing privilege'), i.e. comply with culturally acceptable binary gender norms. This includes both transsexual people who have not yet transitioned and those who have (Bailey, 2012).

These challenges and exclusions impact upon a trans/g-d individual's employment, both whether they are able to work, the kind of work they choose to do, their increased risk of workplace discrimination, and associated reduced job security promotion prospects (Grant et al., 2011). This in turn has implications for their associated relatively diminished accrual of financial capital, pensions and property: trans/g-d people are more likely than cisgender people to be living below the poverty level (Crissman et al., 2017).

These material disadvantages are further compounded by ageing, in several ways. The relative economic disadvantage of gender non-conforming people means that in older age, they are more likely to be on lower incomes, and more reliant on state welfare and/or charitable support to sustain their daily living needs. At the same time, they may be more reluctant to seek such support because of ongoing fears about transphobic and cisnormative[5] prejudice and discrimination (Fredriksen-Goldsen et al., 2014). Further, this minority population is more likely to be living in housing which is inappropriate for their needs (Johnston and Meyer, 2017; Wathern and Green, 2017). This is in two main ways. Firstly, they may be living in housing which is not age appropriate, where they may or may not be subject to transphobia and/or cisnormativity. Alternatively, they may be living in housing which is age appropriate, but where they are subject to such prejudice and discrimination, too often from their peers as well as their care providers.

These associated and accumulated material disadvantages also have profound implications for older trans/g-d individuals' health and well-being and their ability to maintain themselves.

Health and well-being

Health issues affecting older trans/g-d people in general and older transwomen and transmen in particular is an emerging area of study. As Age UK (2017, 11) has observed:

> Knowledge is improving as trans(gender)/gender diverse people age but there are still unanswered questions about what later life and health will be like for trans(gender)/gender diverse people. . . . We are only now seeing the first generation of trans(gender)/gender diverse people in their 60s and over who have taken hormone therapy for 30 years or more, many of whom are living with gender reassignment[6] surgeries performed using the very different techniques of the 1960s and 70s.

We do already know, however, that trans/g-d people of all ages experience significant physical and mental health inequalities which are compounded in/by older age (Auldridge et al., 2012; Cook-Daniels, 2015). Trans/g-d people experience high levels of victimisation and discrimination (see Whittle et al., 2007; Grant et al., 2011) as well as reduced levels of social support from social networks, including family, friends, neighbours, work colleagues, and mainstream religious organisations. This in turn leads to being at increased risk of associated mental health problems, especially depression, with trans/g-d people being at increased risk of ending their lives (Fredriksen-Goldsen et al., 2013; McNeil et al., 2012).

These health inequalities are further compounded by ageing. Older trans/g-d people are more likely to suffer from a range of mental health problems associated with a lifetime of discrimination, marginalisation and social exclusion (Auldridge et al., 2012; Fredriksen-Goldsen et al., 2013; Hoy-Ellis and Fredriksen-Goldsen, 2017). Older trans/g-d people who are able to create supportive networks and/or construct positive self-images may experience greater resilience in ageing (Witten, 2014a). Transwomen and transmen who transition in later life may find their levels of depression become lower post-transitioning (Bailey, 2012). However, transitioning itself can be associated with significant family losses, even in older age (Witten, 2009; Riggs and Kentlyn, 2014). For those transwomen and transmen who do not have compensatory social support networks (see the following section) depression and the risk of ending their lives is a major concern.

Trans/g-d people may be particularly vulnerable to domestic abuse, due at least in part to their social marginalisation (Barrett and Sheridan, 2017). This can be heightened for older trans/g-d people (Cook-Daniels and Munson, 2010) whose vulnerability to such abuse may be compounded by physical and/or mental frailties and/or heightened dependence upon others for care and support. This, in turn, may be even further compounded by unequal access to and provision of services by domestic violence programmes which are rarely set up to include trans/g-d and/or LGB[7] people (Harvey et al., 2014; Seelman, 2015; Rogers, 2016).

Older trans/g-d individuals also face unique and/or specific physical health challenges (Fredriksen-Goldsen et al., 2013). Particular issues can affect older transwomen and older transmen respectively. For older transwomen, these issues may include (Age UK, 2017, 11–12) the long-term effects of oestrogen replacement therapy; oestrogen, testosterone and prolactin (hormone) levels; prostate health (the prostate is not removed even with lower surgery); abdominal aortic aneurysm (AAA) screening; breast screening; dilation and douching advice if a transwoman has had plastic surgery to create a neo-vagina (vaginoplasty); and the state of silicone breast implants.

For older transmen, the particular issues which may concern them include (Age UK, 2017, 11) osteoporosis risk; side effects associated with testosterone therapy; vaginal health (if the transman still has a vagina); whether or not to

undergo a hysterectomy; the need for cervical smear tests if he has not had a full hysterectomy; risk of urethral stones if he has had genital reconstruction; breast screening (even when breasts are removed, not all potentially cancerous glands are removed); the state of silicone testicular implants and/or penile prosthetics.

Care and support

Informal care and support

While some older trans/g-d people enjoy supportive family and friendship networks (Witten, 2014a), many do not:

> For many trans(gender)/gender diverse and gender-nonconforming older adults, family and social support relationships are either fraught with difficulty or non-existent.
>
> (Finkenauer et al., 2012, 318)

Many older trans/g-d people have experienced a lifetime of transphobic rejection from family, friends and in the workplace. Transwomen and transmen often encounter further rejection when they transition. Riggs and Kentlyn describe the narrative of KrysAnne, featured in the USA *GenSilent* documentary,[8] a 59-year-old transwoman who transitioned in her 50s – 'cured the depression', she said, laughing, in the film – and who was subsequently diagnosed with lung cancer. A war veteran, previously heterosexually married, with children and grandchildren, she was rejected by her entire family post-transitioning.

> Most people that transition expect losses, sometimes a great many losses, but I didn't expect [to lose] everyone. I haven't heard from them since. For two years I desperately tried to connect with my family. And some of [the letters] weren't even opened. [The letters were returned saying] 'this person is dead' [images of letters with name struck out saying 'no such person!' and 'deceased']. It was horrible. It was vile.
>
> (KrysAnne, quoted in Riggs and Kentlyn, 224)

When she became ill, and was, eventually, dying, KrysAnne had no informal social support. As Riggs and Kentlyn observed (225),

> Not only has her family's reaction to her transition left her at a loss for social contact and caring relationships, but it has also left her at risk in terms of her physical health and wellbeing.

Although KrysAnne was eventually supported by an older LGBT★[9] support network, as Riggs and Kentlyn describe (228),

> KrysAnne, talking in the form of a video diary, shares the absolute loneliness of her illness, left with a body that no longer functions in ways that allow her to live a full life, and with no one in her life with whom she has established connections . . . [she spent] her final days at home alone and in distress.

Formal care and support

Access to formal health care is severely constrained, especially in those countries where trans/g-d rights are not respected. As Winter et al. have written,

> Many transgender people live on the margins of society, facing stigma, discrimination, exclusion, violence, and poor health. They often experience difficulties accessing appropriate health care, whether specific to their gender needs or more general in nature. Some governments are taking steps to address human rights issues and provide better legal protection for transgender people, but this action is by no means universal.
>
> (Winter et al., 2016, 390)

This is then further compounded in older age. Many trans/g-d people, especially older trans/g-d people, will have experienced a lifetime of unhelpful and/or transphobic responses from the health care system, which has pathologised their gender identity issues. In many countries this still endures. As the UK Equality and Human Rights Commission (EHRC) has observed,

> Experiences of discrimination in the health sector include inappropriate diagnoses, denial of treatment, humiliation, and trans(gender)/gender diverse status being raised when seeking treatment for entirely unrelated health concerns. The latter has been described as 'trans(gender)/gender diverse cold syndrome', where a clinician views gender history as more important than the presenting medical complaint.
>
> (EHRC, 2015, 1)

This is often compounded at its intersection with other social divisions, e.g. trans/g-d people who identify as lesbian, gay and bisexual; people from Black, Asian and Minority Ethnic (BAME) backgrounds; people living with HIV/AIDS; sex workers; and those from other marginalised social positions.

Moreover, medical practitioners may be uneasy, underprepared and uncomfortable in responding to trans/g-d patients (Snelgrove et al., 2012). Many trans/g-d people, especially older trans/g-d people are extremely wary of engaging with health care providers because of their negative experiences. This can result in a lack of health screening and/or delayed diagnosis of, and treatment for illnesses, particularly for those transwomen and transmen with parts

of the body they have not assimilated and which may not be associated with their acquired gender.

> It seems than many transgender persons simply live with untreated or under-treated chronic conditions such as hypertension or diabetes. Furthermore, fear of revealing their transgender status may prevent adequate health screenings, such as for breast or prostate cancers. Treatable health conditions may increase in severity unnecessarily, due to the reluctance of transgender people, young and old, to either put themselves in further abusive situations or be forced to confront prejudice in the health care system. . . . This may be particularly true for transgender elders who were part of a generation that was raised to passively accept the authority of medical professionals.
>
> (Williams and Freeman, 2007, 97)

Even in those countries which are more trans(gender)/gender-diverse- inclusive, specific gender identity health care is often limited (Auldridge et al., 2012) or not available at all. Many gender diverse people face barriers to accessing gender confirming health care, particularly genital reconstruction/confirmation surgery. This can be, in part, due to unresponsive and/or unhelpful (medical practitioner) gatekeepers as well as very long waiting lists and/or lack of funding (White Hughto et al., 2017). Although difficulties/delays in accessing gender confirming treatments are deeply painful and pose significant challenges to many gender diverse people, such barriers are particularly stressful for those who are older and have only a limited amount of time available for them to realise and fully express their true gender identities.

Formal social care is also problematic. There are significant concerns that social care providers (of home care, day care and residential care) are at best under-prepared to meet the needs of older trans/g-d people and at worst sites of prejudice and discrimination towards them (Ansara, 2015; Fredriksen-Goldsen et al., 2014; Siverskog, 2014; Jones and Willis, 2016; Porter et al., 2016). Writing in Canada, for example, Marshall, Cooper and Rudnick (2015) have described how a nursing home struggled to care for Jamie, a transwoman with dementia. The staff were unable to deal with her gender confusion (after the home stopped her hormone treatment), the other residents' transphobia and her daughter's refusal to accept her gender identity. As a result, Jamie died 'confused, frightened, and alone' (Westwood, 2016, 28). Many trans/g-d people are fearful of needing care and support in later life and of being vulnerable to such inadequate and/or inappropriate care (Witten, 2014b, 2016).

There is now a growing number of policy initiatives and good practice guidance in some parts of the world, i.e. Australia, Canada, the US and the UK (e.g. Fredriksen-Goldsen et al., 2014; Westwood et al., 2015; Jones and Willis, 2016; Porter et al., 2016). However, there would appear to be a long way to go before practice and service provision reaches appropriate standards even in these more enlightened parts of the world. Moreover, in the other parts of the world where

gender non-conforming people's rights are even less well respected and/or protected such aspirations are even further away.

Recognition

Trans/g-d people and recognition

Recognition is a central issue for trans/g-d people of all ages, but especially in later life (Kennedy, 2012). Many campaigners are arguing for increased visibility for older trans/g-d people who share with all older people the embodied politics of social exclusion, further complicated by gender variance/diversity (Siverskog, 2015; Miller et al., 2017). However, not all older trans/g-d people identify as such. For them being associated with the trans/g-d movement – even with a well-meaning emancipatory agenda – would be another form of misrecognition. By contrast, for some older trans/g-d people, positive recognition – i.e. recognition that is respectful, validating and supportive – is important in achieving trans/g-d rights, particularly in relation to health and social care provision, and issues relating to death and dying. Some trans/g-d people fear that family members may not respect their true gender at their funerals, and will insist on using their birth assigned gender. Some trans/g-d people seek to ensure that this is prevented through legal means, via advance planning. However more need to be encouraged to do so (Kcomt and Gorey, 2017).

Many gender-diverse people have felt mis-recognised pre-transitioning, i.e. recognised for the gender which they were assigned at birth and not for the gender they identify as. For those who have transitioned, a central concern is being able to present themselves according to their true gender identity and being recognised and/or accepted as such. For those who have transitioned but have not had surgical and/or hormone treatment – and some trans/g-d people cannot for a variety of health reasons, especially in older age – their bodies may not be congruent with their gender identities and presentation. This can pose particular challenges in terms of receiving care, especially close personal care, in later life.

> My partner and I are both male-to-female trannies [transsexuals]. Neither of us could afford the genital realignment surgery we both so desperately desire. My deepest fear is how the world will see us when we come to a point where we need assisted living care or when one of us dies. God forbid they put together that our lesbian relationship is between two women who have penises.
>
> (quoted in Witten, 2016, 1157)

Dementia is another particular concern for older trans/g-d people.

> I worry that I will become incapacitated and not be able to communicate my history as a trans* person (medical, surgical history) before requiring care. I worry that caregivers will not be experienced in dealing with trans*

> bodies and health issues and I will at best not get the care I need and at worst be ridiculed, mocked or ignored because of the state of my body.
>
> (Witten, 2016, 115)

> Will I be treated with dignity? Will I be respected? Will I be in a defenceless situation at the mercy of those that do not or are unwilling to understand me being trans?
>
> (Witten, 2016, 116)

In each of the preceding quotes, these trans/g-d individuals are concerned about how their bodies will be recognised, about issues of misunderstanding and misrepresentation, about stigma, prejudice and mis-treatment. Some trans/g-d people may seek to mask their non-congruent bodies, but in terms of personal care this may not be possible:

> How and when people express their gender identity is an extremely personal choice . . . transgender people may not have complete control over who knows their gender identity. If they choose to live as their preferred gender, some people may have physical features they cannot change (or afford to change). So when a transgender person needs a physical exam from a physician, or needs help with bathing or dressing in an acute care or residential care setting, there is a risk of being found out, with the potential for subsequent discrimination or outright abuse. . . . Transgender older adults may delay or avoid seeking assistance or services because they are concerned about detection and its consequences.
>
> (Witten and Carpenter, 2015, 1)

There is an urgent need to address stigma in the mis-recognition of trans/g-d people in general and older trans/g-d people in particular, especially in relation to health and social care. As Fredriksen-Goldsen et al. (2013) have observed from their research:

> [There are] important modifiable factors (stigma, victimization, health-related behaviors, and social support) associated with health among transgender older adults. Reducing stigma and victimization and including gender identity in nondiscrimination and hate crime statutes are important steps to reduce health risks. Attention to bolstering individual and community-level social support must be considered when developing tailored interventions to address transgender older adults' distinct health and aging needs.
>
> (488)

Ageing bodies

Trans/g-d ageing is not all doom and gloom (Witten, 2014a), however. It also offers significant emancipatory potential, not only for older trans/g-d people specifically, but for all older people. Trans/g-d politics, and ageing trans/g-d

politics in particular, make a unique and significant contribution to the understandings of embodied ageing. The growing number of trans/g-d individuals who consider gender transitioning in later life, having reached a place of freedom to transition, throws new light on the concept of 'successful ageing' (Fabbre, 2014) and on (hetero-)normative constructs of the life course (Bailey, 2012).

> Perspectives on ageing trans bodies destabilize previous notions of failure in relation to timing during the life-course. This could be a flaccid penis, softened muscles, menopause, etc. However, for transgender-identified people, these expected bodily changes can actually mean that one's previous failure becomes something more normalized. To have a flaccid penis or to lack menstruation can be a failure when it is 'off time' earlier in the life-course, but could actually be perceived as being 'on time' if it occurs in later life, even though it may be surrounded by ageist discourses.
>
> (Siverskog, 2015, 16)

Although there is currently a 'striking lack'[10] of visual representations of older trans/g-d people, with increasing legal and social recognition of trans/g-d people this is changing. Such changes pose interesting challenges to the norms and normativities of 'successful ageing' (Fabbre, 2014). One of the key criticisms of 'successful ageing' is that it privileges those who are able to remain fit and active and fully engaged in society, while further marginalising those who – due to physical and/or cognitive disabilities – are unable to do so. These individuals are then seen as having 'failed' to age successfully (see Chapter 15 by Westwood and Carey in this collection). Stigmatised (ageing) bodies play a significant part in this so-called failure and associated social exclusion (this is also explored in the subsequent section on representation). Trans/g-d people and trans politics challenge the notions of 'normal' bodies and offer a vehicle to conceptualise and validate diversity and worth in non-normative ageing bodies (Sandberg, 2008).

Increasing the recognition of trans/g-d people in general, and trans/g-d older people in particular – i.e. reducing stigma, increasing acceptance and validation, and indeed making them more visible – will be of significant benefit to their health and well-being. It will also be an important step in achieving social justice for trans/g-d people. Most importantly, it opens up avenues to reconsider what we mean when investigating 'successful ageing' and how we need to take into account the diversity and changeability of ageing (gendered) bodies when we do so. Achieving improved recognition for older trans/g-d people is inter-implication in achieving increased representation of and by them as well, as the next section demonstrates.

Representation

Citizenship

Representation involves, in Fraser's model, being actively engaged in society and having a political voice at both the local and national level. Many gender

diverse people of all ages 'remain on the margins of citizenship' (Hines, 2007, 8.1). This is further compounded by the exclusions and marginalisations associated with ageing. With the notable exception of some specialist organisations,[11] trans/g-d ageing issues, and the voices of older trans/g-d people, are under-represented in ageing services (Age UK, 2017). Furthermore, the voices of trans/g-d people are often conflated with those of lesbian, gay and bisexual people (only some of whom may also be trans/g-d) while the voices of older people are generally already under-represented in LGBT advocacy. Thus, the voices of older trans/g-d people are marginalised because of both their age and their trans/g-d status. Additionally, diversity within and among the (older) gender non-conforming community is also under-represented:

> Rather than thinking of a unified trans* community, it is more useful to understand different groups of trans* people as constituting a collection of sub-communities, with some shared characteristics but with many and significant differences, including a variety of different socio-political and medical aims.
>
> (Hunter, Bishop and Westwood, 2016, 125)

Because many older trans/g-d people are marginalised and socially excluded, they may be unable and/or unwilling to fully participate in society, one of the prerequisites of 'successful ageing'. As Riggs and Kentlyn have observed,

> There are significant social and personal factors that impact upon transgender women's capacity to live a life that adheres to the norm of 'successful ageing.' This is not to say that many transgender women do not age extremely well, despite the negative social and personal contexts they live in. Rather, it is to say, well-founded critiques of the neo-liberalism of the concept of 'successful ageing' aside . . . transgender women continue to face significant barriers to active participation in the world around them.
>
> (Riggs and Kentlyn, 2014, 231)

This marginalisation – linked to both trans/g-d status and to ageing – also applies not only to transwomen but also transmen, and gender non-conforming individuals. Breaking down barriers to participation is key to improving representation of older gender diverse people and moving towards increased social justice for them.

Research

Representation also involves – and this is particularly important for people from minority groups – inclusion in research. For without a presence in knowledge production, the needs, issues and concerns of individuals remain invisible and unheard. This in turn informs their mis-recognition and/or non-recognition,

which also informs the lack of tailored policies and provision (resources) to meet their needs. While there are emerging specialist research projects,[12] older trans/g-d people are, as yet, under-represented in research,

> Little is known about transgender elders. The need to make broad assumptions about the size of this population underscores one of the major problems in understanding the needs of this group. Transgender elders are not only underserved, they are also understudied. There is a need for continued efforts in the areas of research, education, service, and advocacy. Transsexuals, cross-dressers, intersex, and other persons whose gender expression or identification is other than traditional represent an invisible minority within the worldwide elderly population.
>
> (Persson, 2009, 642)

Without sufficient research, the needs, issues and concerns of older trans/g-d people are under-represented, under-recognised and under-resourced. Only increased knowledge production can remedy this.

> A lack of knowledge regarding the needs and experiences of trans and gender-nonconforming older adults contributes to and perpetuates the experiences of marginalization associated with being trans. Mitigating the conditions of marginalization – including those that are compounded by age – requires the production of trans aging knowledge.
>
> (Finkenauer et al., 2012, 311)

Addressing the marginalisation of older trans/g-d people in relation to knowledge production, is best tackled by increasing their presence in both mainstream and specialist research and is key to improving their representation and increasing social justice for them.

Conclusion

In this chapter we have highlighted some of the inequalities, particularly those associated with resources, recognition and representation, in the lives of older trans/g-d people. As Fraser herself acknowledged, these three dimensions of social justice do not stand alone but intersect and mutually inform each other. For example, increased representation will lead to increased (positive) recognition and social inclusion, which will in turn lead to improved resources. In this way the social justice model has much to offer both in terms of understanding sites of inequality experienced by (older) trans/g-d people and pathways to remedy them.

Increased recognition and representation of older trans/g-d people, particularly through research and awareness-raising, has the potential to reframe conceptualisations of embodied, gendered ageing. In particular, gender diversity inclusion and acceptance has the potential to create new avenues for all older

people whose bodies do not comply with the stereotypical cultural expectations associated with successful ageing. Trans/g-d inclusion thus offers a pathway not only to increased social justice for older trans/g-d people but for all people, as we age in embodied ways.

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Notes

1 In some contexts, the term transgender/trans includes all these gender diversities. See, for examples: www.gires.org.uk/resources/terminology/ and www.apa.org/topics/lgbt/transgender.aspx
2 Cisgender describes someone who identifies with the (sole) gender they were assigned at birth.
3 Transitioning describes the process whereby an individual moves from the gender they were assigned at birth – with which they did not identify – to the gender with which they do identify.
4 Transphobia describes negative attitudes, feelings and/or or actions towards trans(gender)/gender-diverse people.
5 Cisnormativity refers to the assumption that a cisgender identity is the norm, and also involves the privileging of cisgender people.
6 We prefer the terms Genital Reconstruction Surgery (GRS) or Gender Confirmation Surgery (GCS).
7 Lesbian, gay and bisexual.
8 http://gensilent.com/
9 This acronym uses another variant of the term trans.
10 Kellaway. 2015.
11 E.g. the Transgender Aging Network (USA), http://forge-forward.org/aging/; and SAGE USA, www.sageusa.org/issues/transgender.cfm
12 E.g. Trans Ageing and Care (TrAC) project: http://trans-ageing.swan.ac.uk/

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Part II

Sexualities

Sue Westwood

Introduction to Part II

This section addresses ageing, sexualities and in/equality. In Chapter 7, Jane Traies considers the under-representation of older lesbians' lives and experiences in the growing body of literature on lesbian, gay, bisexual and trans (LGBT) ageing, which she argues leads to uneven resource provision for them. She highlights the significance of the intersection of ageing (and ageism) with gender (and sexism) in informing older lesbians' experiences of ageing. These in turn intersect with sexual identity, Traies argues, to deprive older lesbians of representation, recognition and resources. In Chapter 8, Mark Hughes and Peter Robinson consider the challenges which older gay men continue to face in relation to material inequality, a lack of cultural recognition, and deficits/complications in political representation. They highlight the enduring significance of ageism for how older gay men are perceived both by others and by themselves, and that this needs to be addressed before greater equality can be achieved. In Chapter 9, Sarah Jen provides an overview of research on bisexual ageing considering why bisexual populations are under-represented in ageing research. She argues that older bisexual individuals are under-resourced, under-recognised and under-represented both in comparison with older heterosexual people and older lesbian and gay people, and proposes that increased visibility and voice are needed before improvements in resource distribution can be achieved. In Chapter 10, Sue Westwood critically examines heterosexuality as the taken-for-granted norm in gerontological discourse. She argues that studies which do not include non-heterosexual ageing are inevitably only giving partial accounts of the ageing experience. Moreover, how heterosexuality itself informs the ageing experience thereby also remains un-interrogated. She suggests a research agenda for exploring the place of heterosexuality in ageing.

All four chapters demonstrate the significance of sexuality for ageing, and the diversity among ageing sexualities. Importantly, they disaggregate the L, the G and the B, from 'LGB ageing'. In doing so, they highlight the importance of recognising diversity among and between older LGB people and identifying both similarities and differences in their ageing in/equalities in relation to resources, recognition and representation. By emphasising the 'B' (bisexuality)

in particular, this section aims to address and redress the 'disappearing B' in LGB ageing research (Jones, 2010). By contrast, the chapter on heterosexuality is included with the aim of removing its taken-for-grantedness in social gerontology and repositioning it as an (ageing) sexual identity category which must be considered equally alongside all others.[1]

Note

1 Jones, Rebecca L. 2010. "Troubles with bisexuality in health and social care." In *LGBT issues: Looking beyond categories. Policy and practice in health and social care*, edited by Rebecca L. Jones and Richard Ward, 42–55. Edinburgh: Dunedin Academic Press.

7 Older lesbians, ageing and equality

Jane Traies

Introduction

The first part of this chapter takes as its framework Nancy Fraser's (2000) use of the concepts of *representation, recognition* and *access to resources* as tools for analysing the ways in which social justice and injustice are reproduced for groups within a society. Fraser has argued (2000) that justice can be understood in two separate but interrelated ways: distributive justice (the equitable distribution of resources) and the justice of recognition (the equal recognition of different identities or groups within a society). As a consequence, she identifies two corresponding forms of injustice or inequality: maldistribution and misrecognition (Fraser et al., 2004).

In relation to the lives of older women, and in particular of older lesbians, there is a piquancy to Fraser's subsequent arguments, since she has also asserted (Avendaño, 2009) that the liberation movements of the 1960s and 1970s, in challenging the injustice of mis-recognition and fighting for recognition on the basis of identity, lost sight of the need to challenge the growing injustice of maldistribution. More recently, she has stated that a focus on identity politics has diverted attention from the destructive effects of neoliberal capitalism and from the increasing economic inequality that now characterises many societies (Fraser, 2013; Fraser, Hernandez and Navarro, 2016). Most lesbians born before 1950 were, and still are, passionate feminists; many were active in the Women's Liberation Movement and other contemporary social justice campaigns; as a group, they subscribe to a strong politics of identity, both as women and as lesbians. As this chapter shows, I favour an interpretation which sees misrecognition and lack of representation as the root *causes* of maldistribution, rather than as distractions from it.

The database

My arguments in this chapter are based on three sets of data from my research (Traies, 2016): a questionnaire survey of self-identified lesbians over 60 in the UK, carried out in 2010–2011 and completed by nearly 400 women; a collection of some 50 life histories of lesbian-identified women born between

1919 and 1950, gathered between 2009 and 2016; and a focus group discussion convened in the summer of 2016 to explore older lesbians' experiences of inequality, consisting of eight (White, lesbian or bisexual) women between the ages of 60 and 75.

Although the data is therefore drawn from a large sample, it still cannot claim to be fully representative of all older lesbians. However, the groups just described were certainly sufficiently broadly based to reflect the diversity of that population. Older lesbians can be found in every place and in every walk of life, and differ from each other in class, race, religion, socio-economic status and education. Such diversity might call into question the very category 'older lesbian': how meaningful is it to speak collectively about them in terms of an identity category based simply on sexual orientation, when a variety of other intersecting social processes have rendered their lives so various? Nonetheless, older lesbians themselves tend to have a strong sense of unity and of a common identity that is able to transcend these differences (Traies, 2016); it is rooted in the shared experience of stigma and discrimination across the life course. In other words, the experience of inequality is the cement that binds the older lesbian community together.

Representation

Fraser uses the word 'representation' in its political sense (that of participation in a representative democracy). In this chapter I use the word in its cultural studies sense, that is to say as 'the process by which meaning is produced and exchanged between members of a culture, through the use of language, signs and images which stand for or represent things' (Hall, 1997). If older lesbians are viewed through this lens, one aspect of their inequality becomes immediately obvious: compared to other social groups, they lack cultural representation to a remarkable degree (Traies, 2009).

There are no reliable statistics for the number of older lesbians in the UK. The number of lesbian, gay and bisexual people in Britain over the age of 55 has been estimated to be in the region of a million (Stonewall, 2011; Knocker, 2012); at least half of those will be lesbians or bisexual women. There might, then, be as many as half a million older lesbians in the population; but no one reading a newspaper or watching television is likely to be made aware of the fact. Shugart (2003) has suggested that media representations of gay men create privilege for them; lesbians, whose presence disrupts rather than supports the patriarchal norm, have been less often (and less kindly) represented in the media, especially on television (Cowan and Valentine, 2006). This issue was raised in the focus group when Nuala (born 1952) remarked on the scarcity of 'out' lesbian television celebrities:

> NUALA: You just have to look at the media! Even Graham Norton, a gay guy, quite a camp gay man – [but] there has never been, to my knowledge, a woman in that kind of high status position.

SANDRA: Sandi Toksvig, now?

NUALA: But even she hasn't got a mainstream programme on Saturday evenings!

Dominant culture tends to promote selective images of ageing individuals (Grossman, 1997; Brotman et al., 2015) and representations of older lesbians hardly exist (Traies, 2009). This combination of ageism and sexism means that older lesbians rarely see women like themselves represented in the media. Nuala concluded, 'We are desperate for any role models at all, whether we identify with them or not'. Challenging the dominant cultural assumptions that render older lesbians invisible is therefore a necessary political and ethical act, because if the way we are 'seen' determines the way we are treated (Dyer, 2002), then those who are not seen will be treated as if they do not exist.

As in the media and popular culture, so in research; in the growing literature on lesbian, gay, bisexual and trans (LGBT) ageing, older lesbians have been consistently under-represented, even though there are significant ways in which lesbian ageing is unique. A comprehensive review of recent research into the lives of LGBT older adults in the US (Orel and Fruhauf, 2015) contains only a handful of references to specifically lesbian data. In the UK, a major report by the lobbying group Stonewall (2011) surveyed a sample of 1,036 lesbian, gay and bisexual people over the age of 55 across Britain, but this sample comprised more than twice as many men as women. Only 17% of the sample were women over 60 and 1% women over 70. This means that research findings presented as descriptive of all 'older lesbians, gay men and bisexuals' were predominantly based on the responses of gay men and women in their 50s: a characteristic example of the way in which older women who identify as lesbians are denied cultural representation and, hence, cultural recognition.

(Mis)recognition

When I asked the focus group where, if at all, they felt their identity *was* recognised, Pat (born 1948) immediately replied, 'In the company of other women who are exactly the same!' Her comment was greeted with approval and recognition by the rest of the group. Ruth (born 1956), referring to a women's co-housing development group of which she is a member, said:

> That's the motivation for the project – wanting to be that evident tribe that supports each other. Where there is no experience of that invisibility, that denial, that becoming more and more invisible as you get older, and assumptions made, so that you have to keep on coming out, and out.

Brenda (born 1948) then described a new next-door neighbour who, when introduced to Brenda's partner, 'just walked away', refusing to acknowledge their relationship. By contrast Sarah (born 1944) said how affirming it had been to work in a college where the principal and vice principal were gay: 'I was very lucky . . . that

was great'. These comments strongly suggested that, even today, older lesbians feel they still need to be with people like themselves in order to be 'seen'.

There are many benefits to recognising the existence and particular characteristics of older lesbians beside this individual sense of affirmation. They include the added dimension that lesbian sexualities bring to a more general discourse about women and ageing, and the understanding of their needs in terms of age-related resources (Westwood, 2013). But in order to 'see' older lesbians it is necessary to challenge the cultural assumptions that make them invisible. I have written at length elsewhere (Traies, 2012) about the discourses which underpin older lesbians' cultural invisibility; for the purpose of the present discussion, these can be seen as a form of mis-recognition. Prevailing heterosexist assumptions mean that an old woman who has been married or is a mother will usually be assumed to have led an unrelievedly heterosexual life; one who has been neither is likely to invoke dismissive cultural stereotypes of the 'old maid'.

Several of my life history interviewees had experienced the effects of this cultural blindness, when crude stereotypes of gay people contributed to disguising the sexual identity of anyone who, in interviewee Catherine's words, doesn't 'look like one'. Catherine (born 1939) was always 'in the closet' at work and in public life, but enjoyed socialising with a group of lesbian friends:

> We were in the Spotted Dog one night, and a woman from my work and her husband came in. So everybody sort of pushed me down under the table and sort of sat on me. They didn't stay very long.
>
> The next day she came into the office and said, 'You'll never guess where I went last night! We went to a gay pub.' And she said, 'And all these men in makeup, drinking cocktails, and all these ladies in collars and ties, drinking pints of beer.'
>
> And it wasn't like that at all!
>
> And then she said to me once, 'You wouldn't understand this, but if a lesbian walked into this room, I would know!'
>
> So I said, 'Hazel! How?'
>
> She said, 'I don't know, but if somebody walked over there, I would know!'
>
> I said, 'Gosh, isn't that strange?'
>
> That's one advantage of not looking like one. You get some very funny remarks made to you.

Another interviewee, Marion (born 1942), had similar experiences:

> You hear a lot more than if you're really obvious, and it used to freak me out, what people really thought. [Butch colleague] might walk in and out of the office, and people would talk about her afterwards, and I'd be sitting there thinking, 'Shit.'

Unlike Catherine, Marion was unhappy about what she felt to be her lack of courage in not being honest about her identity:

> It was one of those parties where everyone's lounging about, smoking, . . . quite a nice atmosphere and stuff, . . . and some guy walked in and said, 'Oh god, I just got propositioned by some faggot!'
>
> And the woman who was next to me . . . said, 'Oh God, I hate that, I really, really hate that! But it's the same for us women. If someone walked in here and they were – ' (I can't remember what word she used, 'queer' I think it was) 'and they were queer, I'd know it straight away!'
>
> And she turned to me and went, 'Wouldn't you, Mal?'
>
> And it was a perfect time for me to say something, and I couldn't. I chickened out.

These two examples also demonstrate the complexity of the processes behind mis-recognition, and highlight the fact that, historically, many lesbians and gay men have contributed to their own invisibility by concealing their sexual identities. Even in the present, those who have decided to stop hiding do not make themselves visible on all occasions. Interviewee Maureen (born 1945) discussed the extent to which she was open about her lesbian relationship:

> How open am I? I'm as open as I . . . I'm very situational. . . . Yes, it depends. If I feel – not exactly threatened, but – if somebody's making unthinking assumptions which harm the nature of our interaction, then I have to say something. But if I'm out buying a pound of walnuts, or getting a lift, and somebody says, 'Oh, what about your' whatever (nobody's yet said 'mother', or 'daughter' – I'm seven years older than [partner]!) I let a lot of things go.

Maureen and her partner had recently retired to a quiet seaside town, and she thought that such attitudes had a geographical dimension, too:

> Down here people tend to assume you're 'Mrs', and when the doctor said 'Mrs – oh, I'm so sorry!' I said, 'It's fine.' . . . It's not worth . . . you have to decide what is worth taking on, and is really important, and what's just 'Let it flow, let it go . . .' In London, I think it's a completely different planet. Down here, people are much the same as they were forty years ago. . . . but the downside is that it can be fuddy-duddy, and people totally make assumptions about you being a 'Mrs'. And the grandchildren thing, of course! I'm surrounded by people with grandchildren.

As a result of the mis-recognition implicated in these cultural absences, the particular needs of older lesbians – emotional, physical and social – can go unrecognised, resulting in an imbalance in resource provision. To use Fraser's terms, mis-recognition can lead to maldistribution.

Intersecting inequalities

It is never simple, however, to tease out a set of typical 'older lesbian' experiences. This is because each woman has also suffered from inequalities other than those associated with a minority sexual identity, and might (or might not) have a range of privileges to set against those. A striking example of this occurred in the focus group. My first question was, 'Have you ever felt a sense of inequality in the way you've been treated, because of any aspect of your identity?' Immediately, the women started to talk, with much feeling, about their schooldays. They all belonged to the generations for whom the 11-plus examination determined their secondary education: they spoke of the inequities embedded in that system, and the loss of self-esteem associated with it. Pat failed her 11-plus; she took it again, but 'knew I wasn't going to fit in, and knew I was going to fail again – and I failed again. Twice. And I thought, that fits in with who I am'. For Sandra (born 1948), who did pass the exam, inequality was represented by 'going to grammar school, and yet feeling very much like lower class citizens, in the lower stream. . . . if you weren't in the top stream, you were rubbish and riff-raff . . .'. Sarah (born 1944), who also passed her 11-plus, simply refused to go to grammar school, because she didn't feel it reflected herself or her family:

> My father was out of work, . . . my mother worked in a sweatshop, and I knew I would not be able to fit in, because of the uniform, because of everything . . . I knew my family wouldn't be able to afford that. And it would have taken me away from my family and from my family values. . . . I didn't want to be different.

Her father wanted her to go, because 'although we were very working-class, there was aspiration'. Sandra recognised that aspiration as 'a Jewish thing', but Nuala remembered that her Irish family also aspired to 'education – and shoes'. For Pat the poverty of her Irish Catholic childhood had meant outsider status and exclusion. Sarah commented:

> The Irish and the Jews lived together – but we were very, very separate. . . . 'The Cohens and the Kellys' they used to call it.

As these comments show, when asked to think about inequality, these older lesbians did not immediately talk about sexuality. Although all the women in the group defined as lesbian or bisexual, and knew that the research I was engaged in was about older lesbian experience, their initial responses were all about the intersections of class, money and religious/ethnic identity. Two group members talked about the shame and confusion of not conforming to gender norms, but their sense of difference was always intertwined with these other struggles.

When I prompted the group by asking them to think about ways in which they had experienced inequality in their adult lives, they talked first about

the miseries of institutionalised sexism they had experienced throughout their lives:

> 'men thought they could touch you on the arse, they could touch you on the tits, they could do whatever they wanted to do to you, and it would be ok. And nobody would ever say, 'No you can't do that, how dare you?' . . . The only way to get on, was to let these bastards do this to you.
>
> (Brenda)

Those who were still at work thought things had not changed much over the years. Ruth said she was paid less than her male colleagues; Nuala described an incompetent man being appointed to a position of power over competent (lesbian) women: 'A combination of sexism and homophobia, in my view'.

The life stories I collected also offer a forceful reminder that the experience of stigma and discrimination is always gendered. For the women who told me those stories, the pressures of homophobia had been inextricably intertwined with the pressures of everyday sexism. Lesbians born in the first half of the twentieth century – women who are now in their 70s, 80s and 90s – faced all the barriers to equality shared by their heterosexual sisters. As late as the 1970s, women were economically and socially disadvantaged in ways which are easily forgotten today: equal pay and equal opportunities were not enshrined in law and there was no redress against unfair dismissal from a job either on the grounds of gender or of sexual orientation. Until 1975, it was legal to pay women less than men for doing the same job. Women could not obtain mortgages or take out hire purchase agreements. Married women's incomes were still taxed as if they were their husbands' property. So for those who identified as lesbians, the struggle against institutionalised homophobia went hand in hand with this struggle against institutionalised sexism. A woman without a man was at a serious social and economic disadvantage, but that disadvantage was doubled for lesbian couples, where both partners shared the female fate of low incomes and limited job prospects, as well as the fear of reprisal should their sexual orientation be discovered (a lesbian was, among other things, considered an unfit mother and many lost custody of their children). Such past experiences continue to shape the identities and behaviour of older lesbians in the present.

Although changes in social attitudes and in the laws of the UK have brought about some lessening of the pressures of sexism and homophobic discrimination, these women have now become prey to a third oppression: ageism. Fifty per cent of my survey respondents reported that they had experienced discrimination against on the grounds of age (23% reported such discrimination within the lesbian community). Of course, it will affect some more than others. Three decades ago Monika Kehoe's (1986) use of the phrase 'triply invisible' to describe older lesbians importantly highlighted exactly this combination of oppressions (ageism, sexism and heterosexism) – but with hindsight it can also be seen to imply that all older lesbians will suffer similar levels of marginalisation

and disempowerment. Cronin and King (2010) rightly point out that this 'additive' approach to oppressions ignores the ways power relations and social divisions interact to affect the lives of individuals, and so may unwittingly re-inscribe inequalities by obscuring differences. Not only age, gender, and sexuality, but also ethnicity, class, health status, social networks, geography and many other influences (Valentine, 1996; Heaphy, Yip and Thompson, 2004; Hunt and Fish, 2008) will characterise the life of any individual older lesbian.

Since Crenshaw (1991) first drew attention to the oppressions at the intersection of race and gender, scholars such as Skeggs (1997, 2004) and Taylor (2007, 2009) have explored the relationship between class, gender and sexuality, while Ward et al. (2008) and Cronin and King (2010) have investigated the interplay of sexuality, gender and ageing. However, in spite of the increased use of this intersectional approach in the social sciences over last 20 years, Calasanti and King (2015) have observed that it is still comparatively rare in ageing studies. Since policymakers and service providers are now beginning to acknowledge the historical mis-recognition or misrepresentation of older lesbian, gay and bisexual service users, there is an urgent need for research to reflect more accurately the 'complex and multifarious' experiences of this diverse group. As Cronin and King (2010, 877) observe, 'older LGB adults are positioned at the intersection of multiple identifications, the effects of which will change depending on context' and 'intersectionality enables a more fine-grained analysis of difference'. An intersectional approach is therefore essential in exploring the relations between the multiple inequalities and privileges of individual lives.

Focus group member Ruth observed that:

> There's a huge issue about inequality in the distribution of resources, in all sorts of ways. Women's needs – our needs, as older lesbians – just don't seem to signify in terms of priorities in . . . housing, in health, in welfare.

Her comment suggests that the needs of older lesbians are both shared with other women and also distinct from them. My data also indicate that older women who are lesbians have been subject to specific experiences and pressures which can produce profound inequalities; and that older lesbians, as well as sharing many experiences of inequality with other women, face particular forms of misrepresentation and mis-recognition which put them at risk of the injustice of maldistribution. There are some clear differences (of degree, if not always of kind) between older lesbians and older heterosexual women.

First, older lesbians are more likely to live alone. Older lesbian, gay and bisexual people generally are more likely to live alone than their heterosexual contemporaries (Ward, River and Fenge, 2008; Almack, Seymour and Bellamy, 2010) and this was true of my respondents. Half the women in the survey (49%) lived alone: almost double the proportion of older heterosexual people (28%) living alone in the UK (Stonewall, 2011). Second, older lesbians are more likely to be childless. (Nearly 58% of respondents had never had children.) Third, older lesbians are likely to be economically disadvantaged in later life. Even

those who never married and who had 'male-pattern' working lives will have earned less than their male counterparts over their life time. A fifth (19%) of my survey respondents were living on less than £10,000 per annum.

Access to resources

All these factors put older lesbians disporortionately into the category of those who are likely to need support from external agencies in older age. Women in the UK tend to live longer than men (and therefore to make greater use of health and social care services) so, as Archibald (2010) points out, older lesbians' chances of requiring long-stay care are greater than those of gay men. Archibald also suggests that older lesbians will approach health and care services 'in ways that differ from younger lesbian women and from their heterosexual peers' (41); and they appear from my research to be deeply distrustful of what they see as the heteronormative assumptions and attitudes of services for the elderly. For example, 42% of my survey respondents said their GP did not know they were a lesbian; 59% said that they did not feel able to discuss sexual matters with health professionals; almost half (49%) of the respondents who were social service users (including all of those over 80) said they were not out to any of these services. My interview data suggest that – as Ward et al. (2008) have also observed – this distrust of health and social services professionals can be attributed to long-standing experience of institutionalised discrimination, but can also be reinforced by unsympathetic practice by professionals.

I interviewed Jackie (born 1935) shortly after her 80th birthday, and she told a distressing story about being marginalised by health and care services. In her early 70s, she had begun a relationship with Naomi, who was a few years older than herself. After about five years, Naomi began to show symptoms of Alzheimer's disease. The two women did not live together, but Jackie said,

> I used to visit her a lot. She has no family. But she has a nephew. Not a real nephew, but the nephew of her partner [now dead], with whom she wasn't in any civil partnership, because there weren't such things.

Eventually Naomi's dementia worsened and she had to go into care.

> And I absolutely fought to have her near me. And they [the nephew and his wife] overruled that. And they have her near them, which is an hour and three quarters [drive] . . . and I go and see her every week.
>
> I'm the person closest to her in the world. And the wife of the nephew, she accepts that. But she didn't support me.
>
> I used a solicitor. I went to Age UK about it, and they arranged an appointment for me with a solicitor in relation to my rights, and my rights in relation to knowing about Ruth's health and welfare, because of course there was no Power of Attorney. There is a financial Power of Attorney, but not health and welfare. Well, now, had I been clued up, I would have

> taken that out when she was well enough. . . . But the solicitors fought for me. They advised me that I should take further advice – and so, I've spent thousands on this, because I just think it was terribly important to fight it.

Eventually, after much dispute, the care home agreed that if Naomi was ill or had an accident, Jackie should be phoned at the same time as the nephew and his wife. However, the home then changed hands, and the new managers would not agree to do that. Just before I interviewed Jackie, she had fallen and broken her leg, and had not been able to drive to see Naomi for more than two months. She was bitterly angry that, when it came to a choice between people, none of whom were Ruth's biological kin, the heterosexual couple had been privileged over the lesbian lover. Such experiences can help to explain why some older lesbians might be reluctant to share their problems, and illustrates the way in which the cycle of invisibility and mis-recognition can lead to older lesbians being denied access to the resources they need.

It is also important to remember that resources are not always tangible. Access to social capital – the 'ability of actors to secure benefits by virtue of membership in social networks or other social structures' (Portes, 1998, 6) – and, as a result, to improved mental and emotional well-being – is still an issue for some older LGBT people. Fokkema and Kuyper (2009) found that LGB elders in the Netherlands were significantly lonelier and less socially embedded than heterosexual elders, and there is some evidence (Hughes and Kentlyn, 2014) that LGBT people's experiences of psychological distress and loneliness are higher than might be expected in a sample from the general population. Beal (2006) found that more women than men report feeling lonely. Although older lesbians often have access to 'bonding' social capital through social networks and communities, which can have a protective quality on health and well-being, this does not always include 'bridging' social capital which would connect the group to the outside world. The fact that so many older lesbians have supportive partners and/or friendship networks should not be allowed to obscure the existence of an extremely isolated minority. Although changing social attitudes have encouraged many older LGBT people to 'come out', 2% of women in my survey said none of their friends knew they were lesbian. Six per cent said that none of their family knew. Three per cent saw their closest friends 'rarely'. Eleven per cent described themselves as 'unhappy'. Women in all these categories were less likely to be in a relationship, more likely to be without family contact and to rate their own emotional health as 'poor'. They are the most likely to need mental health and social care in the future, but the least likely to be 'out' to health and care professionals, thus intensifying both their isolation and their disadvantage.

Conclusion

Older lesbians continue to be culturally under-represented, their existence obscured by homophobic/misogynist stereotypes and conventional

assumptions. That lack of representation is mirrored in academic research; in the growing literature on LGBT ageing, the specific experiences of older lesbians remain under-examined. This inequality is exacerbated by the fact that many older lesbians are still unwilling to be open about their sexual identities, finding security and recognition only among others like themselves. Older lesbians' formative experiences of inequality across the life course have been the result of numerous intersecting oppressions, and in large part those experiences have been shared with heterosexual women, as sexism has been a major cause of inequality in their lives. However, older lesbians also face their own particular pressures and inequalities, which means that as a group they might in future make disproportionate demands on health and social care services and services for older people. At the same time those experiences have made some of them reluctant to engage with the services they need. Overcoming this reluctance and allaying their fears of discrimination are therefore urgent priorities for providers of services to old people. Care services which are truly inclusive are still, unfortunately, rare (Almack and Simpson, 2014), and there is still a need to build professional practice which allows every individual to feel valued, knowing that her relationships and lifestyle are validated by those who care for her. As I have suggested elsewhere (Traies, 2012), this can only be done by challenging social assumptions about both sexuality and ageing; by gaining a more contextualised understanding of the lives of older LGBT people, taking into account their personal and community histories and the long years of oppression and concealment that many have experienced; and by reinforcing non-discriminatory practice.

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8 Gay men and ageing

Mark Hughes and Peter Robinson

Introduction

Research indicates that public acceptance of homosexuality is improving in an increasing majority of countries and that younger generations tend to hold more favourable attitudes than older generations (Smith, Son and Kim, 2014). Despite these positive developments, gay men continue to face social injustices across the life course in relation to material inequality, lack of cultural recognition and limited or problematic representation in the political domain. These experiences are intersected by other dimensions of advantage and disadvantage – not least gender and age – that play out differently in different contexts.

In this chapter we draw on Fraser's (2008) tripartite conceptualisation of social justice, which comprises economic, cultural and political dimensions. Thus, we explore the economic and material (resources) disadvantage faced by older gay men in comparison with other population groups. We examine the extent to which older gay men are culturally recognised – including how their gender is positioned in relation to an idealised masculinity – and how ageing is depicted for gay men, both within gay male communities and wider society. We also investigate the representation of older gay men's voices in the public domain, including in policy and service delivery contexts. We conclude with a reflection on the transformative activities older gay men are engaged in and that are linked to a wider politics of redistribution, recognition and representation. One note concerning language: while in this chapter we use the term or category 'older gay men', we resist the idea that such a category is stable and unambiguous.

Data

This chapter draws on Robinson's (2017) research into gay men's experience of ageing, work and retirement, using a reduced sample of 55 gay men aged 19 to 82. The men were interviewed about their own experience of ageing and their attitudes towards older gay men. Recruited from six large cities from northern and southern hemispheres – Auckland, London, Manchester, Mumbai, New

York and Sydney – all were English speakers. The sample included a significant number of non-White, non-middle-class men.

The original sample was recruited in order to satisfy two principal aims, which were to collect the ageing experience of gay men first, from Anglophone countries and secondly, across at least two age cohorts. The data used here have not been reported in previous publications (Robinson, 2013, 2017) but were analysed similarly, that is, interview transcripts were examined for common themes that were then used to select and organise data. Once arranged by prominent themes or narratives, the data were then re-examined and organised by secondary themes or narratives where appropriate.

The principal narratives revealed by the data were most relevant to discussions in the sections on recognition and representation and less so for the section on resources. The principal narratives related to how the men understood themselves to be regarded by straight society and then by other gay men. On the whole, their accounts suggested a strong belief that others, straight and gay, regarded them negatively or at best neutrally as unseen or indistinguishable from the general population of older people. It was in the gay world the men reported the most discriminatory views of themselves as old people in ways that supported the findings of other research, that is, as invisible, pitied, or avoided (King, 2016, 74).

Resources

Fraser (1996, 13) argued that homosexuals are found across the socio-economic spectrum, and thus one might expect older gay men to have the same access to economic and material resources as the rest of the population. Indeed, there is a common discourse that gay men are advantaged economically because they are more likely than heterosexual men not to have children and thus not be burdened by the economic responsibilities of family life (Matthews and Besemer, 2015, 96). Yet the television stereotype of White, sophisticated gay men with high disposable incomes is patently false for the majority of people (DeFilippis, 2016, 147). In fact, numerous studies have demonstrated that gay men earn less than their heterosexual counterparts (DeFilippis, 2016, 151). For example, a systematic review by Badgett et al. (2007) indicated that in the United States gay men earn 10% to 32% less than equivalently qualified heterosexual men.

Throughout their lifespan, gay men have been susceptible to employment discrimination (Badgett et al., 2007) and workplace harassment (Sears and Mallory, 2011), which can lead to more frequent job changes, absenteeism and reduced opportunity for promotion. An analysis of the large Household, Income and Labour Dynamics in Australia study revealed that gay men were 15.6% less likely to be employed than their heterosexual counterparts and faced up to a 25% earnings penalty due to negative employment periods and lower wages (Sabia and Wooden, 2015). While more research is needed, it is likely that these factors impact negatively on financial preparedness for retirement including

reduced asset accumulation, interruption to superannuation contributions, and lower rates of home ownership (Jepsen and Jepsen, 2009). Research by Hughes and Kentlyn (2014, 16) noted older gay men's concerns about secure housing:

> My accommodation is substandard but if I rented something better it would chew up all of my income. I am concerned as I grow older that accommodation options will become less and less affordable and it might mean moving into a boarding house or similar. That scenario is really depressing.
> (Steve, gay man, aged 62)

A further factor is the impact of health conditions that make older gay men vulnerable to financial insecurity in later life. Across all regions of the world, gay men are significantly more likely to contract HIV than the general adult population (Beyrer et al., 2012) and gay men living with HIV in Western countries are more likely to be living below the poverty line (e.g. Grierson, Pitts and Koelmeyer, 2013). In particular, the AIDS crisis of the 1980s and 1990s meant that a generation of HIV+ men were unprepared for reaching older age and thus have inadequate retirement savings, superannuation, health insurance, home ownership and other material resources to support them in later life (Solomon et al., 2014). Gay men, including older gay men, also experience rates of psychological distress, anxiety and depression that are significantly higher than for heterosexual men and the general population (Wallace et al., 2011). In the general population, these conditions are associated with poverty indicators such as unemployment and this is born out in research on gay men as well (Leonard, Lyons and Bariola, 2015).

There is some indication in the United States that, when other factors are controlled for (e.g. education rates), men in same-sex relationships are more likely to be poor than those in different-sex relationships. For example, an analysis of the American Community Survey 2010 revealed that the poverty rate was 20.1% for male couples compared to 18.8% for different-sex couples – although, significantly, the rate was 33.0% for female couples (Badgett, Durso and Schneebaum, 2013). The authors suggest that the legal inequalities faced by same-sex couples may partly account for these disparities.

The material needs of older gay men are in the main no different from those of the rest of the population (Robinson, 2016, 6–7, 2017, 163). Like everyone else, any form of material deprivation would affect their quality of life in old age. And older gay men too look for financial and personal security as they age and like others, where practicable, continuing independence or, if necessary, a limited dependence on others (Robinson, 2017, 164–165). Where research suggests older gay men experience a greater form of social isolation than others (and this included lesbian and bisexual older people) is their greater tendency not to be in a relationship and to live alone (Fredriksen-Goldsen et al., 2013).

For older people, being single and living alone are both associated with poverty, in part due to the fixed costs of running a household (Australian Council of Social Service, 2016; Phillipson, 2013, 99). Research by Goldsen et al. (2017)

suggested that single gay men fared much worse economically than their partnered or married gay male counterparts, and that they were less likely to own their own home and have health insurance. In other words, as Simpson (2015, 97, 114, 117–118), Phillipson (2013) and Westwood (2017, 115–116, 157) argue, class affects how individuals experience old age, and this is as true for gay men and lesbians as it is for their heterosexual neighbours and relatives. And in the case of gay men, relationship status it could be argued acts as a catalyst and can intensify class disadvantage for those who are single.

Recognition

Just as Fraser (1996, 2007) argued that women suffer from injustices based on gender and class that are both independent of each other and interconnected, we argue that gay people experience social injustice based on their sexuality and class. While this account has been widely debated (e.g. Butler, 1997), there is little doubt that mis-recognition (i.e. low cultural status) and non-recognition (i.e. cultural invisibility) remain central to the injustices gay men experience and especially, as we argue later in the chapter, older gay men. In this section, we consider the cultural recognition of older gay men from the standpoint of society, in general, and gay men, specifically. We point to the ongoing significance of stereotypes, but also recognise the ways these are being challenged in both private and public spaces.

Recognition by society

For many commentators, older gay men are perceived as being invisible in society – not so much being mis-recognised as just not being noticed (Heaphy, 2007). Leo (aged 31, Sydney) in Robinson's study said, 'old gay men are not particularly visible to the community', just as older people are not in society generally. For some older gay men – particularly those who grew up and came out in the pre-gay liberation era – invisibility was a necessary means of protection. Without it they were humiliated, sometimes physically attacked or beaten, incarcerated and chemically castrated. The latter was the punishment meted out to British scientist Alan Turing who, after being found guilty of the 'gross indecency' of having consensual sex with another man, was given the choice of imprisonment or chemical castration. Turing chose the latter (Tatchell, 2014). By creating private spaces – often within public settings (such as parks, beaches and public toilets) – gay men were socialised into gay culture and formed both fleeting and lifelong friendships and relationships (Chauncey, 1995; Kong, 2012). Even when homosexuality – and in most English-speaking jurisdictions this was male homosexuality – was decriminalised, the argument that all adults had an equal right to privacy and a private life took time to gain widespread acceptance.

In more recent times, the invisibility and non-recognition of older gay men arises not so much from society needing to be shielded from what might be

going on behind closed doors, but from a pervasive heteronormativity or the assumption that heterosexuality is the norm and is normal (King, 2016, 111, 160–161). This is particularly the case for older people, where 'people do not see old people as being anything but old heterosexuals really' (Godfrey, aged 81, Sydney). This is evident in a range of contexts, including in the delivery of health, social care and housing services. For example, in a study of care homes in Wales, Willis et al. (2016) argued that despite sexually charged encounters between residents and between residents and staff, and frequent discussion of heterosexual partners and children, lesbian, gay and bisexual lives were almost completely invisible. Further, the heteronormativity that Godfrey noted and scholars such as Simpson (2015, 180) and Westwood (2017, 76, 96) have observed is reinforced by persistent ageism whereby older people are seen as asexual and so sexual differences between older people, and in particular sexual minorities, go unrecognised.

In addition to non-recognition, there are also indicators that older gay men are mis-recognised within society. For older gay men, the effects of heteronormativity and ageism are reinforced by sexism where denigrated forms of masculinity (such as those arising due to homosexuality and old age) are associated with femininity (Calasanti, 2004, Connell and Messerschmidt, 2005). According to Edmund (aged 44, Mumbai), in Robinson's research, a 'misconception [is] that most gay men are effeminate . . . they always confuse being gay and transgender [and that] gay men are impotent'. All men, but particularly gay men, are acutely aware of their position on the hierarchy of masculinity, their ability to perform masculinity in different contexts and their experience of being ascribed feminine attributes (Tyler et al., 2016). These tensions remained through the period of the gay liberation movement even though there appeared some loosening of gay men's reflexive engagement with gender norms:

> Gay liberation . . . produced two entirely contradictory images of the gay body. On the one hand, the license (sic) afforded by the growing climate of tolerance and permissiveness ushered many gay men into a whole new era of self-pampering . . . [on] the other hand, gay liberation gave men the confidence they needed to wage war against effeminate stereotypes and to assert themselves in exaggeratedly masculine ways, cultivating an implausibly studied machismo intended to counteract the traditional image of the limp-wristed swish.
>
> (Harris, 1996, 112)

Perhaps even worse is the cultural mis-recognition of older gay men as deviant – typically sexual predators or outcasts: 'in the general heterosexual *Daily Mail*[1]-reading population [there is the thought] that older gay men equates to paedophile, corrupters of youth' (Alfie, aged 63, Manchester, Robinson's research). This image of the older gay man as paedophile is found in both Western and non-Western cultures (Zingsheim et al., 2017). Also prevalent has been the image of the lonely, bitter old queer, which, for Knauer (2011), acted

as a cautionary tale for the pre-Stonewall generation. Allen, in a pro-homosexual booklet, stated that 'Whatever the causes the homosexual often tends to end up lonely and sometimes boring others in a rooming house' (Allen, 1961, 95). Yet one of Robinson's participants asked,

> Do people generally see older gay men as very lonely and bereft of proper family – the lonely old queen who is now paying the price of a lifetime of fecklessness and promiscuity? But people are perhaps beginning to appreciate this as a rather inaccurate stereotype.
>
> (Ben, aged 52, Manchester)

It was not surprising then that gay and lesbian gerontology in the 1980s and 1990s (e.g. Friend, 1980) sought to dispel this negative stereotype by emphasising – and probably overemphasising (Hughes, 2006) – older gay men's successful ageing and the development of crisis competence in the face of adversity.

Despite the apparent non-recognition and mis-recognition of older gay men by society, there is a suggestion of change in the status order of older gay men (Simpson, 2015, 9–10; Westwood, 2017, 91, 94–95). Not only have jurisdictions in the Anglophone world (e.g. the UK, Australia, New Zealand) introduced legislation to prohibit discrimination on the grounds of sexuality and to allow same-sex adoptions but they have also begun pardoning or expunging the criminal records of gay men accused of 'gross indecency' or similar crimes, including that of Alan Turing. In 2017, the Canadian Prime Minister issued a public apology to those who were prosecuted or forced out of public service due to their sexuality or gender diversity. A decision by the British Supreme Court in favour of gay asylum seekers was noted by one of Robinson's participants as,

> a really important judgement . . . [because the judges said] these people are gay . . . have a right to be gay [and] the fact that those white, middle aged, very middle class, and heterosexual men were prepared to say [so].
>
> (Bryce, aged 63, Manchester)

In a similar way, the effect of the introduction of same-sex marriage in an increasing number of countries increases the likelihood of gay men (including older gay men) being accorded recognition that would have been previously unthought of. And so, as advanced Western democracies extend rights to marry, to adopt children, to workplaces free of sexual discrimination, the likelihood increases of greater recognition for sexual minorities and with this, greater recognition of older people among those sexual minorities.

In advanced Western societies where acceptance and recognition of same-sex attracted people has gradually increased over the last two or three decades, older gay men are becoming more visible in the planning and delivery of health and social care services (King, 2016, 159–160). In Britain, for example, local government and non-government organisations have developed strategies

addressing the needs of LGBT seniors, and in Australia a range of initiatives were developed following the establishment of a National LGBTI Ageing and Aged Care Strategy (Hughes, 2016b). Strategies to provide more responsive health and aged care services include the development of sensitivity training, culture change within organisations, promotion of legal rights (e.g. advance care planning), and appropriate facilitation of identity narratives in interviews with service providers and in advocacy and policy consultation activities (Hughes, 2016a). One initiative, which has gained attention internationally, has been the 'Rainbow Tick', which is an accreditation framework that assesses services against six standards to help them demonstrate LGBTI inclusive practice and service delivery (GLHV@ARCSHS, La Trobe University, 2016).

The lingering concern, though, is that only certain types of older gay men will be accorded cultural recognition by society and perhaps only in some contexts. According to Hughes (2006, 56) 'we need to keep a critical eye on which identities and sexualities are being valued and which remain disparaged, private and invisible'. Care homes may, for example, become more accommodating of 'presentable' older gay men in long-term stable relationships, but may be challenged by those who are into the leather scene, who have open relationships, or who attend cruising grounds for sex, intimacy and friendships.

Further, given the diverse range of social spheres or contexts that give value to different practices, what is culturally recognised in one sphere may not necessarily be recognised in another (Armstrong and Thompson, 2009). In Australia, for example, same-sex marriage was recognised in the political sphere when, in December 2017, the Commonwealth parliament passed a bill to amend the *Marriage Act, 1961* so as to change the definition of marriage to a union 'between two people'. However, this change remains contentious in the religious sphere where it is not recognised by many mainstream Christian, Jewish or Muslim institutions on the grounds that the government of Australia has a responsibility to protect 'religious adherents and their organisations when they have a conscientious objection to same-sex marriage' (Walsh, 2016, 108). In the view of same-sex activists and many gay people, therefore, this, together with the fact that governments in Australia have previously passed legislation to allow religious organisations to discriminate against employing same-sex attracted and gender diverse people (Walsh, 2014), represents a form of misrecognition of sexual diversity in the religious sphere.

Recognition by other gay men

Older gay men are subject to forms of non-recognition and mis-recognition from other gay men that can be more brutal and diminishing compared to what they experience from wider society. For example, the image of the predatory older gay man is present in the discourses of gay men across the life course (Goltz, 2014) and in both online and offline environments, such as commercial gay venues. Mobile dating apps, such as Grindr, provide the option for men to indicate their preferences with a high degree of anonymity, revealing,

according to one user who resisted this option, 'ageism, fat shaming, racism' (Shield, 2017, 255). Such practices, if widespread, would suggest a negative, competitive dimension to gay men's collectivities (Tyler et al., 2016), which can be surprising to non-LGBTI people and to those who have recently come out as gay. Thus, cultural recognition – and mis-recognition – of older gay men by other gay men (both older themselves and younger) is often characterised by a focus on the body, particularly a youthful, active and physically desirable body. One man in Hughes and Kentlyn's (2014) study said,

> I've always had some difficulty identifying with the gay community, despite having made many friends and having enjoyed many gay activities, but in recent years I have been finding it harder and harder to feel that I have anything in common with the 'community' as represented by the free gay press.
>
> (Grayson, gay man, aged 60)

In spite of these challenges, older gay men also report that strong social networks support and validate their identities and attributes and that friendships and inter-generational relationships are valuable sources of these. There is an indication, for example, that as gay men grow older they place more value on their friendships, which may extend to ex-partners: a study by Lyons, Pitts and Grierson (2013) of 422 gay identified men aged 40 and over revealed the significance of social support, particularly from close friends, for gay men's mental health. In a related study, the authors found that provision of tangible support to middle-aged and older gay men may reduce internalised homonegativity (Lyons and Pepping, 2017). And while the social connections between gay men of different generations have been disparaged culturally, there remains hope of stronger intergenerational ties that reject tropes such as the 'dirty old man' and 'asexual grandfather' and that exist beyond gay culture and its emphasis on sex (Goltz, 2014; Robinson, 2017, 162–165, 171, 189, 194). Robinson's (2017, 181–185) research suggests that middle-aged gay men were most concerned about social isolation in old age and that it related to a fear of being alone because they would not have children to look after them or because their partner predeceased them. And that, in line with the work of Phillipson (2013), class accentuated these fears.

The suggestion here is that older gay men (and younger ones too) are as acutely aware of *homo*normative practices as they are of heteronormative ones. Homonormativity refers to the presentation of an acceptable homosexuality, which can be easily assimilated into heteronormative structures such as gender conformity, youth obsession and consumerism (Rosenfeld, 2009). Yet homonormative practices are not simply accepted by ageing gay men, they are engaged with reflexively and sometimes challenged or transformed (Simpson, 2013, 28–29, 55–57, 110–112, 121–122).

Three examples from different parts of the world illustrate this reflexivity. In Australia, Waite and Gorman-Murray (2007) reported on the experiences

of an older gay father in a regional city – here he felt comfortable in his '"in-between" or "hybrid" status as both parent and gay man' (575) in a way that he could not if he lived in the homonormative space of Oxford Street in Sydney and the 'apparent invisibility of older and fatter bodies' (576). In Hong Kong, Kong (2012) described the homonormativity, classism and ageism of gay saunas, bars and clubs, which, since the decriminalisation of homosexuality in 1990, replaced the less regulated public spaces (e.g. public toilets) as sites of same-sex intimacy. Even in the face of such challenges, the older gay men in his study still found 'their "ways of operating", through sex tourism, *tongzhi* [LGBT] volunteer work, and immersing with their close friends' (910). And in his account of middle aged men in the gay heart of Manchester, UK, Simpson (2013) examined the use of 'ageing capital' – comprising 'emotional strength, self-acceptance, age-appropriate bodily display/performance and awareness of the relations constitutive of gay culture (and wider society)' – to challenge ageist and homonormative practices in nightclubs (286).

Representation

The third dimension of social justice Fraser (2008) articulates is political representation, which she argues is 'rooted in the political constitution of society, whose associated injustice is *misrepresentation* or political voicelessness' (403). To what extent and how do older gay men enjoy equal representation compared with other older people and/or younger gay men? In Western countries they are not barred from voting, they are able to stand for election, and they can be appointed to senior government and judicial positions; and so it could be argued that their sexuality is no longer the hindrance it once was. Indeed, there are examples of older gay men who have high profile in the political realm. In the UK, an example is Peter Mandelson, aged 64 at the time of writing, who has held senior positions in both the British and European parliaments. An Australian example is former High Court Justice Michael Kirby, aged 78 at the time of writing, who takes a prominent place in national political discourse, particularly on human rights matters, and was voted a National Living Treasure in 1997. While each example could be seen as an exception to what other gay men their age can achieve by way of representation, the fact that they achieved what they did suggests a level of real change in acceptance of gay people in advanced Western societies.

Political representation operates not only on the national stage, but also at state, local and community levels. This can include local governance, but it may also extend to policy development and the planning and delivery of services by non-government and private sector organisations. At this level, it is clear that for many years older gay men – like their other same-sex attracted and gender diverse compatriots – have been excluded from full representation. In Australia, for example, Harrison (2004) documented the almost complete absence of LGBTI people and issues within gerontology – including in clinical practice, service delivery, training, research and policy development.

As with their cultural non-recognition, a key dimension of older gay men's experience in the political realm has been one of being invisible. Pugh (2002, 162) pondered that along with older lesbians, this absence of older gay men in public life seems 'analogous to a science fiction tale in which everybody over a certain age suddenly vanishes as if to avoid tarnishing young people'. This invisibility is evident in a wide range of public policy areas including housing, transport and social security, all of which have the potential to impact negatively on older gay men's life circumstances. Arguably, of most concern has been the invisibility of older gay men – and thus their lack of political representation – in the arenas of health and social care, for example, in the UK, their absence in the development of person-centred care policies and in strategic planning and commissioning (Concannon, 2009). Although there are signs of improvement. Willis et al. (2016) reported in their survey of 121 residential aged care staff in Wales that care staff and managers generally held positive attitudes towards lesbian, gay and bisexual identities and relationships. Nevertheless, what was lacking was knowledge about sexuality in later life and LGB histories. The policy and advocacy stakeholders involved in their study identified the need for residential care staff to stand up to homophobic practices and for managers, in particular, to ensure compliance with human rights obligations and promote organisational culture change.

The tension emanating from emerging political representation of older gay men in the context of ageing, as with increased cultural recognition, is between homonormative representations of them, their relationships and 'lifestyles', and more transgressive representations. Older gay men who are to some extent gender diverse or who have a transgender history may be concerned that their needs will not be as well recognised as those who are more obviously cisgender. Those who are single may worry that their circumstances will not be as well accommodated as those who are in relationships. And those who are polyamorous or who do not support same-sex marriage – for some this is seen as part of a conservative, patriarchal social agenda – may fear that services and policies will ascribe more status to those who are married than those who are not. So while the development of services targeting older gay men is clearly positive, caution is needed to ensure that homonormative representations of older gay men – and other sexually and gender diverse people – do not dominate. Unfortunately, the downside of having such services funded by government is that there is a greater risk of convergence with the dominant values – including valued identities and 'lifestyles' – expressed by government (Hughes, 2016b).

The increasing political representation of older gay men in areas such as health and social care has emerged not simply because policymakers, service providers and academics have decided that this group is now deserving of recognition. It has emerged from – and continues to be transformed by – the activism of gay men, as well as their other same-sex attracted and gender diverse compatriots. In Western societies, the political experiences of many older gay men – and many of those moving into older age – were shaped by the AIDS epidemic of the 1980s and 1990s and the devastating impact

that had on their relationships, communities and expectations for their own futures. Between 1981 and 2000, nearly 450,000 people died of AIDS in the United States, with male-to-male sex the most common means of HIV contraction (Centers for Disease Control and Prevention, 2001). A study of gay men aged 44 to 75 years in California in 2012 identified that over 20% had lost 15 or more close friends or relatives to HIV/AIDS (Wight et al., 2012). Yet in the face of this adversity, gay men and their supporters mobilised to support each other, gave their time and labour, and, in some countries such as Australia, worked with governments to develop HIV prevention strategies (Robinson, 2013, 60–62, 2017, 88–92). Eventually some of the support and activist groups (e.g. AIDS Council of New South Wales) became formalised non-government organisations that would, in time, provide the infrastructure for LGBTI health and ageing programmes in the 2010s. According to Hilton (aged 53, New York), in Robinson's study,

> Older gay men – whether they were HIV positive or not – almost by definition had to be the most resourceful and adaptable people in general because they have had so many challenges and barriers to survive. Now I don't think that most straight people have that level of sophistication or appreciation or understanding and . . . unless an older gay man is publicly distinguished in some way [they still have] a stereotypical view [of him] as just some old freak.

Transformation

The action orientation of Fraser's (2008) theory of social justice can be articulated at two levels: the superficial level and the deep level (Armstrong and Thompson, 2009). At the superficial level, action tends towards affirmative strategies, of enabling the maligned group to have the same equal access to resources, cultural recognition and fair representation that any other group within society would have. The aim is to 'correct inequitable outcomes' (Fraser and Honneth, 2003, 74). At the deep level, the focus is more transformative – to tackle to root causes and disrupt underlying structures of society. With respect to older gay men, the former is associated with assimilation politics whereby certain types of older gay men would have their identities and relationships affirmed. The latter is associated more with the transformative queer agenda, which is about disrupting existing identities and boundaries resulting in 'a shifting field of multiple differences' (Fraser and Honneth, 2003, 76).

While not all older gay men align themselves with a queer agenda – indeed many reject any association with that maligned term – there is evidence of a wide range of older gay men engaging in transformative practices. Many middle aged and older gay men are actively resisting both heteronormative and homonormative trends, particularly in their ageist assumptions (e.g. Simpson, 2013, 81–88, 133–142). For example, in the domestic arena, a gay man's decision to maintain a private home life does not have to represent a succumbing to

neoliberalism and conservatism, as some (e.g. Duggan, 2002) have argued, but instead the creation of an environment for comfort and safety. Nor must it be seen as an unusual choice in a gay world where open relationships, communal living and families of choice are seen as normal or *de rigeur* (Gorman-Murray, 2017).

Beyond the home, networks of support are often mobilised from among friends, partners, ex-partners and others (Tester and Wright, 2017) in what has been typified as a transformation of intimacy (e.g. Giddens, 1992), although as King (2016, 113–114) argues it is important not to overly simplify or idealise these relationships. At the community level, new physical and social spaces are being created to enable older gay men (often alongside other sexually and gender diverse people) to support each other, challenge normative practices and re-create communities (e.g. Goltz, 2014, Radicioni and Weicht, 2018).

Conclusion

In this chapter we have used the term or category 'older gay men' but we resist the idea that such a category is stable and unambiguous. It has become apparent that each of the concepts that make up the category – older, gay and men – are contested in everyday lives. Some, perhaps many, older gay men question what it means to be older and resist those assumptions, for example by remaining physically active (Tyler et al., 2016); some interrogate what it means to be gay particularly in the context of the commercial 'scene' (Robinson, 2008); and some challenge hegemonic masculinity and the implied sexism in associating a disparaged masculinity with femininity (Robinson, 2017, 68).

Research on the resources available to older gay men suggest a multi-layered reality in advanced Western societies. Where it was their experience, discrimination in the workplace contributed to fragmented careers, which in turn meant older gay men were materially less well prepared for old age (Robinson, 2017, 58–70). Those now aged 60 and older belong to that age cohort that was most affected by the first wave of the HIV-AIDS epidemic in the West. Many of these men did not think they would survive into later life and did not prepare for it 20 years ago. Such men now face an impoverished old age because of inadequate retirement savings, superannuation, home ownership (Solomon et al., 2014). Further, it is likely that single older gay men who live alone run the risk of living out their life in impoverishment given that poverty rates are higher among those who live alone and are not in a relationship (Australian Council of Social Service, 2016; Phillipson, 2013).

Experience of recognition for the age cohort aged 60 and older in 2018 compares poorly with that of younger gay men. Many lived closeted lives and silently and stoically endured the taunts and prejudice of society in the 1950s and 1960s (Chauncey, 1995; Kong, 2012; Tatchell, 2014). Sadly, their reports of acceptance as older men in the gay world are not positive. If anything, because of the valorisation of youthfulness, everyday ageism is amplified (Robinson, 2008). Evidence from recent research suggested older gay men therefore experienced

mis-recognition, as part of the generality of older people, indistinguishable because all old people look the same, and non-recognition because they were most notably invisible in the eyes of younger gay men, sometimes scorned, most often ignored. And yet, there is research (Simpson, 2015, 198–201; Westwood, 2017, 164–166) to show older gay men resisting or being aware of the importance of resisting social obsolescence in the gay world and elsewhere.

Representation for older gay men we argued was difficult to assess or quantify. While it is true, sexuality has never been a bar to enfranchisement, and while it is true also that eminent gay men who have publicly acknowledged their sexuality in Western society are no longer silent, the representation of issues affecting older gay men have only slowly been included in public policy. Its most dramatic occurrence was in the 1980s and 1990s in countries like Australia, Britain and France where gay men lobbied and pressed governments and conservative professions like medicine and science to include social understandings of disease prevention and gay representatives in their efforts to curtail the spread of HIV-AIDS among gay men and other at-risk communities. More recently, growing awareness of and attention to the special ageing needs of gay men and other sexual minorities represent the fruit of decades of research and lobbying by LGBTI scholars and bureaucrats.

In many ways, older gay men are living examples of transformation. Many lived through a time when to be a homosexual was to risk imprisonment, loss of family, career, and then later when HIV-AIDS laid waste emerging communities of creative social possibilities and thence to 2018 when they may now marry. As Robinson's research (2013) showed, not all old gay men supported or understood the push for same-sex marriage. Some harboured more radical notions of relationship while others were more traditional in their intimate and social lives. For, as Simpson (2013) argued, there are older gay men too who resist both heteronormative and homonormative impulses and practices.

The significance of being older, gay and a man varies, we would argue, according to context, and intersects with other social and personal characteristics, such as class, ethnicity, ability, geographical location. An appreciation of what it means to be a particular older gay man is therefore inevitably contextual. While older gay men appear to be gaining more cultural recognition and political representation, it is important not to avoid stereotypes and to challenge depictions of them that are convenient cultural tropes or easier to manage politically.

Note

1 The *Daily Mail* is a tabloid newspaper published in London. Its political sympathies are with the conservative side of British politics. One of its more controversial stands was to condemn British judges in 2016 as 'enemies of the people' for upholding the rights of the British Parliament; see www.independent.co.uk/news/media/daily-mail-nazi-propaganda-front-page-ipso-complaints-brexit-eu-enemies-of-the-people-a7409836.html (accessed 2 February 2018).

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9 Bisexuality and ageing

Striving for social justice

Sarah Jen

Introduction

The goal of this chapter is to analyse issues of inequality within the context of bisexual ageing. I begin by providing an overview of the research landscape around bisexual ageing, accounting for what is known and what limitations and gaps in knowledge remain. Nancy Fraser's (2000, 2007) concepts of representation, recognition, and resource access are then applied to illuminate the different forms of inequity facing older bisexual individuals from a social justice perspective. For it is through these dynamics of power that older bisexual individuals are rendered and largely remain invisible, devalued, underserved and under-resourced, spanning both the socially constructed and material realities of later life. While Fraser (2007) has argued that identity politics draw attention away from the harsh consequences of unjust resource allocation and increasing economic inequality, an analysis of representation and recognition are necessary precursors to any meaningful understanding of resource distribution in the lives of older bisexuals. From this starting point, we might imagine the next steps that would support the most positive possible future for bisexual individuals as they age.

Defining bisexuality

As theorisations of sexuality have changed, conceptualisations of bisexuality have followed, expanding over time to accommodate more nuance and complexity in the various dimensions of one's sexual experience over time (Halperin, 2009; Jones, 2010). Although scholars have rightfully described bisexuality as a 'complicated or troublesome' category of analysis (Jones, 2010, 4), the complexity and nuance of bisexuality is also one of its strengths, the result of decades of theorising to which bisexual individuals themselves have contributed.

In the early 1900s, Freudian theory cast bisexuality as common, but also incomplete or transitional (Eisner, 2013). Alfred Kinsey et al. (1948; Alfred Kinsey et al., 1953) would also claim bisexuality as a common orientation when he developed the Kinsey scale, a 7-point scale ranging from 'exclusively heterosexual' (0) to 'exclusively homosexual' (6) with a gradation of bisexual

attractions in between. He presented sexual attraction as a continuum for the first time, blurring the harsh lines around homosexuality and heterosexuality. Forty years later, Fritz Klein would present case studies of the 'healthy bisexual' in *The Bisexual Option* (1993). He also created the Klein Sexual Orientation Grid (KSOG), in which sexual identity is rated on a 7-point scale on multiple dimensions (e.g. attraction, behaviour, fantasy, etc.) as well as over time, illustrating the importance of fluidity and complexity.

More recently, Rebecca Jones (2000) suggested a model specific to bisexuality in which individuals could locate themselves in terms of their bisexual feelings or attractions, behaviors and identity. This model remains useful for scholars and service providers who wish to understand the complexities of a bisexual population that might be defined in various ways based on these three overlapping spheres of experience. Jones (2000) and Paula Rodriguez-Rust (1993, 2000) have also defined bisexuality as a social or cultural construction, the meaning and cultural interpretations of bisexuality as an identity are constantly changing and will vary by societal context across time and space.

There are many factors that might influence one's choice to identify with bisexuality, as evidenced by the narratives of older adults with a history of bisexual behaviors (Jones, Almack and Scicluna, 2016). Some see sexuality as too fluid to map onto any sexual identity label. Others opt for alternative labels such as 'queer' or 'pansexual' or to use no label at all. These findings highlight the continued variation in how and why bisexual populations self-identify. It is also particularly important to account for variation in attraction, behaviour, relationships, and identity in the lives of older bisexual individuals as they may have long and varied histories that reveal the fluid and complex nature of their sexual experience over time (Jones, 2019). With this in mind and for the purpose of this discussion, the defining characteristic that unifies bisexual individuals is their capacity to be attracted to or pursue emotional or sexual relationships with individuals of more than one sex and/or gender, although those attractions may vary in type, timing and degree (Ochs and Rowley, 2009). This broad definition offers the benefit of accounting for various dimensions of sexuality by which a bisexual population might be identified, thereby including a larger population of interest, and acknowledging the ongoing fluidity and complexity that sexuality is increasingly understood to encompass.

Current research on bisexuality and ageing

Recent estimates indicate that bisexual-identified men and women make up a larger proportion of the adult population than gay men and lesbians combined, constituting about 3.5% of the US population age 18 and older, while up to 11% report attractions to multiple genders (Gates, 2011). While there are no current estimates of the size of the older bisexual population, recent studies suggest there are about three million LGBT adults age 50 or 55 and older in the US, a number that is expected to double by 2050 (Espinoza, 2014; Fredriksen-Goldsen and Kim, 2017). Despite the size of the population, research focused

on bisexual populations or bisexual-specific experiences are rare. Common themes include comparisons of demographic patterns and health outcomes between bisexuals and lesbians, gay men or heterosexual adults, analyses that reveal possible causal factors related to bisexual-specific health disparities, and a small collection of qualitative studies that explore specific individual or social issues in greater detail.

When bisexual adults are studied as a separate population, they often report differences in life sequences and disparities in health compared to lesbians and gay men. Several studies have found that women are more likely to identify as bisexual or express bisexual attractions compared to men (Gates, 2011). Compared to lesbians and gay men, bisexuals also report lower socio-economic status (Fredriksen-Goldsen et al., 2016). In terms of health outcomes, bisexual adults report greater prevalence of depression, anxiety, substance use issues, suicidal ideation, negative affect and lower levels of social well-being compared to lesbian, gay and heterosexual adults (Fredriksen-Goldsen et al., 2011).

There are many possible reasons for these observed disparities in health. The stability, reality, or definition of identities outside of accepted binary social categories (e.g. bisexual, multiracial, gender queer) are often questioned, challenged or socially imposed as they threaten to disrupt the normalised social order, contributing to identity confusion or ambivalence, lack of identity cohesion or valence, higher rates of internalised stigma and struggles to maintain an internal sense of identity among these populations (Hartman-Linck, 2014). Beyond the individual, anti-bisexual sentiment, termed 'biphobia' (Jones, 2010) or 'binegativity' (Eliason, 2000), also contributes to experiences of discrimination and negative social interactions both inside and outside of LGBTQ communities (McLean, 2008). Because of these experiences, many bisexuals choose to conceal their sexual orientation and may not engage in queer environments, creating a lack of support from and connections with LGBTQ individuals and communities (McLean, 2008), adding to their relative invisibility.

Bisexual older adults

Although bisexuality has become increasingly common and accepted among young people in many Western countries, researchers note the continued invisibility of the history, lives and experiences of older bisexual people (Westwood and Lowe, 2017; Jones, 2019). The exclusion of bisexuals as a relevant subgroup within LGBTQ research is even more pronounced in ageing-related scholarship. In a recent review of empirical LGBTQ ageing literature, less than one-third of articles included bisexuals in their study sample and none focused solely on bisexual ageing (Fredriksen-Goldsen and Muraco, 2010). This gap renders bisexuals invisible among an already understudied and underserved population and limits knowledge development specific to bisexuality and the ageing process (Scherrer, 2017).

Although less information is available regarding the health of older bisexual adults, preliminary findings identify similar health disparities relative to younger

adults. Older bisexuals report poorer physical and mental health compared to gay men, lesbians and heterosexuals (Fredriksen-Goldsen et al., 2013, 2017). Similar risk and protective factors are also relevant in the context of bisexual ageing, contributing negative health impacts that might be minimised (risks) and positive influences that might ameliorate the impact of negative experiences and contribute to resilience (protective factors; Fredriksen-Goldsen et al., 2013). In terms of risk factors, older bisexual individuals report higher levels of internalised stigma and more concealment of their sexual identity, which are associated with higher rates of depressive symptomology and disability. Older bisexuals also report having smaller social networks, lower levels of social support, and fewer feelings of belonging in LGBTQ communities, all of which can be protective for older sexual minorities in terms of health (Fredriksen-Goldsen et al., 2017).

Of particular concern for bisexual men, HIV-related issues can add complexity to health care and social concerns in later life as nearly one-fifth of older bisexual men are living with HIV (Fredriksen-Goldsen et al., 2011). Among gay and bisexual men living with HIV, the number of comorbid conditions individuals experience and instances of victimisation over the life course are associated with poorer physical and mental health-related quality of life (Emlet, Fredriksen-Goldsen and Kim, 2013). Gay and bisexual men are also less likely to be married or partnered or to have children compared to lesbian and bisexual women, making them particularly vulnerable to loneliness and a lack of social support (Kuyper and Fokkema, 2010).

There remains almost no research that addresses the experiences of trans or gender non-conforming folks who also identify as bisexual. In one international study of bisexual transgender older adults, more than half subjectively reported that they were ageing successfully (Witten, 2016). However, many worried they may not have access to needed health care and ageing services at the end-of-life due to discrimination or financial strain and nearly one-third did not know who would provide their informal care if needed in the future. When asked what factors contributed to their ageing-related concerns, most focused on the potential negative impact of their trans identity, while only one mentioned their bisexual identity as a factor. These findings offer nuance to the combined influences of living with both marginalised identities. However, in order to further build on this small area of study, researchers must take care to thoroughly conceptualise and operationalise the intersections of gender and sexual identity categories in later life (Fredriksen-Goldsen and Muraco, 2010).

As Jones (in press) has noted, the life course perspective is particularly pertinent to the experiences of older bisexual individuals. This perspective makes up a key theoretical paradigm in social gerontology literature from which to theorise how individual lives interact with historical context and how the timing of individual lives come to influence the ageing process. When considering the timing and sequence of life events, bisexuals, and particularly bisexual women, often recognise their same-sex attractions later in life compared to gay men and lesbians and their coming out milestones are also spread over more years

of development (Koh and Ross, 2006; Rust, 1993). Older cohorts of bisexuals also report different patterns of partnership, such as being more likely to experience an opposite-sex marriage, separation, divorce or widowhood (Fredriksen-Goldsen et al., 2017).

Several qualitative studies have included older bisexual individuals, but were not driven solely by their experiences nor were they focused on bisexuality, focusing instead on experiences with LGBTQ living environments (Sullivan, 2014), home care services (Grigorovich, 2015, 2016), caregiving (Muraco and Fredriksen-Goldsen, 2014) and HIV-related stigma (Haile, Padilla and Parker, 2011) among older sexual minority women or men or LGBT adults. These studies indicate that older LGBT individuals feel embarrassment or frustration at becoming a burden to informal caregivers (Muraco and Fredriksen-Goldsen, 2014) or may lack caregivers altogether due to strained relationships with family or a lack of biological children (Grigorovich, 2015). Most would prefer to live in an LGBTQ-specific retirement community where they feel acceptance, comfort and safety (Sullivan, 2014). They conceptualise quality of care as providing competent, non-judgemental care while being sensitive to the possible historical sources of victimisation and oppression that care recipients have experienced (Grigorovich, 2016). One study of 20 older Black gay and bisexual men living with HIV in New York City revealed the complex interrelated impacts of multiple sources of stigma. Participants reported that HIV-related stigma marked them as dehumanised bodies in the context of social and medical institutions, while their experiences of poverty, illness and race made them vulnerable to economic and health-related crises (Haile, Padilla and Parker, 2011).

Qualitative studies also reveal the agency and resilience of bisexual participants. By asking bisexual individuals to create images of their own imagined ageing futures, Jones (2011) revealed how bisexuals enact agency through imagining and idealising non-normative ageing futures outside the bounds of normative expectations. Additionally, in the *Looking Both Ways* study, Jones, Almack and Scicluna (2016) gathered the life course histories of 12 bisexual individuals age 51 to 83 that illustrated the diversity of paths that older adults have taken to reach a bisexual identity as well as reasons individuals who might be behaviourally bisexual choose not to identify as such. This limited qualitative work illustrates the possibilities for exploring issues of social influence, agency and diverse life stories through qualitative analytic methods.

This overview of the current definitions of bisexuality and the state of research provides a backdrop for understanding issues related to bisexuality and ageing. I now turn to a deeper examination of particular aspects of inequality experienced by older bisexual individuals, framed by Fraser's concepts of recognition, representation and resource access.

Recognition

According to Fraser (2007), successfully achieving recognition in cultural visibility, cultural worth and social status entails not only creating and maintaining

'a positive relation to oneself' (30) but also being seen as an equal social participant. Being able to positively relate to oneself is a particular struggle for older bisexual individuals, informed by the limited cultural and historical narratives available to them and their devalued cultural and social worth. These experiences are shaped by the intersections of ageism, heterosexism and biphobia.

As bisexuality has become more common, it has also been imbued with certain cultural meanings, stereotypes and possible narratives. One possible script, depicted by the idea of a 'lesbian-until-graduation' is that of the young woman experimenting with her attractions to women for a transitional period of time, after which she will return to dating men exclusively and go on to live a heteronormative, and therefore privileged, lifestyle (Eisner, 2013). Another common bisexual-specific storyline often depicted in literature and film, is that of the bisexual predator who takes on a near sociopathic role, seducing and disrupting the lives of people of various genders and leaving a trail of jealously and heartbreak behind them (Ochs and Rowley, 2009). While both scripts contribute to the negative image of bisexual individuals as promiscuous or untrustworthy as sexual partners and allies, they are also limited to younger individuals. In fact, one would be very hard-pressed to find any representation of older bisexual characters in film or fiction texts. This lack reflects the relative lack of attention to the sexuality of older adults in general, making issues of sexual identity appear less relevant in later life as well as the assumed heterosexuality in most cultural representations. The non-existence of older bisexual models in cultural representations limits bisexual individual's opportunities to envision or plan for their own ageing futures (Jones, 2011).

In addition to cultural silence, Klein (1993) demonstrated the erasure of many historical figures who were known to have bisexual relationships but were later portrayed by history as gay or lesbian, such as Alexander the Great and Oscar Wilde among many others. In recent history, the influence of many bisexual activists is also forgotten or unacknowledged, such as Brenda Howard, who organised the first Pride march in New York City to commemorate the Stonewall riots (San Francisco Human Rights Commission, 2012). While a lack of popular media figures limits the cultural influence and visibility of bisexual older adults, the erasure of bisexual figures from history further suggests that their past experiences and contributions do not matter, particularly in the context of the modern gay rights movement (Eisner, 2013).

The absence of bisexual figures from the cultural imaginary and retelling of history can be tied to multiple sources. The continued misunderstanding, denial, and degradation of bisexual identities and resulting stigma continue to discourage individuals from choosing the identity for themselves or from forming a collective that might be seen as a coherent and proud community (Jones, 2019). Additionally, within LGBTQ communities, there is a troubled history between bisexual individuals and gay and lesbian communities. In 1970s, feminism drove a wedge between lesbian separatists and bisexual women who were considered traitors for their continued relationships with men and associated privilege through patriarchy. In the anthology *Bi Lives* (Orndorff, 2012), Lani

Ka'ahumanu describes the political resonance of a bisexual identity in this context:

> It was a badge of honor, coming out as lesbian . . . I always felt strong and proud when I said I was a dyke or lesbian. When I said I was bisexual it was not empowering; it didn't feel good.
>
> (105)

The lack of positive resonance around bisexual identities is likely associated with the relative frequency of ambivalence that bisexuals report in relation to their sexual identity (Rust, 1993). The stereotype of the bisexual traitor or untrustworthy sexual partner was deepened through the social and medical discourses surrounding the HIV/AIDS epidemic, portraying bisexual men as an 'infection bridge', connecting otherwise separate heterosexual and homosexual circles of sexual contact (Kaestle and Ivory, 2012). Because of these fractures, the bisexual-specific community and movement are still relatively new and immature in development. The 1990s would also see the beginnings of a bisexual-specific political movement in the US, evidenced by the establishment of national organisations (e.g. BiNet USA established in 1990),[1] events (e.g. Bisexual Pride Day established in 1990), magazines (e.g. *Anything that Moves* established1991) and anthologies (e.g. *Bi Any Other Name: Bisexual People Speak Out*, Ka'ahumanu and Hutchins, 1991). However, the bisexual portion of LGBTQ communities has not yet found a voice as unified and directive as other aspects of LGBTQ rights activism.

While this history may not impact younger generations of bisexual individuals to the same degree, historical tensions continue to cast shadows over the dynamics between older members of LGBTQ community dynamics today. Unfortunately, older bisexuals have access to fewer positive associations or community connections to outweigh these negative experiences and remain isolated from the broader society. Thus, finding no cultural models, little recognition for their political contributions, and lacking a positive sense of their own identity or community, there are few positive sources of recognition available to older bisexual individuals.

Representation

In terms of representation, Fraser emphasises access to political participation and voice (2007). In the lives of older bisexual individuals, it is also crucial to account for their lack of representation in research and service provision, which are factors that in turn limit access to political representation.

Research and practice

To date, the fields of gerontology and LGBTQ research have been characterised by under-representation of bisexual ageing at best and complete silence at worst

(Scherrer, 2017). In addressing the 'disappearing B' in LGBTQ research, Jones (2010) has cited multiple examples of LGBTQ reports and studies that, while including the 'B' or bisexuals in their name, fail to report on findings specific to bisexuals, allowing these experiences to go unknown. When bisexual individuals are included in empirical research, they are often combined with other sexual minorities (e.g. sexual minority women, SMW; men who have sex with men, MSM, etc.) or enveloped into acronyms such as 'LGB'. Another common practice is to combine bisexual individuals of multiple gender identities into a single category, effectively collapsing the bisexual experience and ignoring differences between bisexual men, women, and gender non-conforming individuals (Fredriksen-Goldsen and Muraco, 2010). While these practices are common in research, Keppel and Firestein (2007) have noted that they are also present in practice settings:

> It is startling to realize how little attention is being directed toward older bisexual men and women by organizations focused on LGBT ageing that nominally include bisexuals in the titles of their organizations and in their mission statements.
>
> (168)

Many service providers assume that bisexual clients will find culturally competent and responsive services in LGBTQ-specific organisations (Johnston, 2016). In contrast, bisexual older adults may feel even less welcome or safe accessing services in these organisations due to the historical tensions between sexual minority groups and ongoing bi-erasure in queer political movements (Johnston, 2016; Fredriksen-Goldsen et al., 2011). The exclusion of bisexual representation in research and practice reveals the relative marginalisation of bisexual populations from both LGBTQ communities and the broader population (Brewster and Moradi, 2010; Kaestle and Ivory, 2012), echoing issues of recognition. However, this lack of representation also has implications for political voice.

When the needs of a population are not captured through research, they fail to become political priorities. As one pertinent example, practices of the US Census as well as other large-scale and population-based studies, allow for bisexual lives to be obscured by collecting data on the gender or sex of one's partner or spouse, but not according to sexual identity. While these studies offer useful information on how relationships of various sexual or gender compositions differ, they also render bisexuals invisible as they may fall on either side of this dividing line, obscuring their experiences. This practice is particularly impactful for older bisexual individuals who have likely experienced varied relationships in terms of gender over the course of their lives (Jones, in press). Further, the outright exclusion of older LGBTQ individuals from surveys that are used to determine the health-related patterns, needs, and the allocation of ageing-related services, such as the Older Americans Act Survey, is an extreme example of devaluing their lives to the point where they are considered unworthy of examination or political relevance (SAGE, 2016).

When older bisexuals are not represented in practice, they cannot advocate for their specific health-related or social needs. Although marriage equality has been legalised in multiple nations, the global landscape of marital rights afforded to LGBTQ couples remains inconsistent. When a couple lacks legal representation, the possible impacts are numerous, including lacking legal authority in health care decisions, estate planning, and public financial or health care programmes that serve older adults (Movement Advancement Project and SAGE, 2017). While scholars and organisations have frequently emphasised the need for LGBTQ elders to be aware of and advocate for the legal protections they require, this will not be possible until they can feel comfortable accessing the services they need and disclosing their identities and relationships to service providers. This remains a key issue for older bisexuals, who are less likely than lesbians or gay men to disclose their sexual identity to their health care providers (Fredriksen-Goldsen et al., 2011). Therefore, the limited ability of older bisexuals to be seen, counted, and have their needs acknowledged in research and practice in turn limits their potential to form a collective political voice or take action as individual advocates.

Resources: the overlooked materiality of life

In addition to economic resources, I include other personal resources of interest to older adults. These resources include health and physical functioning, social resources, access to care, and housing needs, all of which are interrelated aspects of resource distribution.

Health and physical functioning

Disparities in physical and mental health are among the most established and consistent empirical findings in research on bisexuality and ageing (Jorm et al., 2002; Fredriksen-Goldsen et al., 2013 and 2017) and issues related to health and functioning put strain on other aspects of resource access in later life. As many scholars have noted, being in worse health and developing health-related issues at an earlier age, due to experiences of stress, stigma, victimisation, discrimination or complex health issues such as HIV, means that LGBTQ older adults disproportionately require formal and informal care that may not be accessible, affordable or safe (Fredriksen-Goldsen et al., 2011; Grigorovich, 2013; Witten, 2016). Therefore, health and functioning can act as a protective factor or strain on other resource areas in later life.

Economic resources

Among LGBT older adults, the highest rates of poverty are observed among the oldest cohorts (Fredriksen-Goldsen, Kim et al., 2014), bisexual men and women (Fredriksen-Goldsen et al., 2013) and transgender older adults (Fredriksen-Goldsen, Cook-Daniels et al., 2014). A recent analysis comparing

older bisexual men and women to gay men and lesbians revealed that having a lower socio-economic status (measured through income and education level) was one of the strongest predictors associated with disparities in physical and mental health outcomes found among the bisexual participants (Fredriksen-Goldsen et al., 2016). Socio-economic status was also found to indirectly impact health by contributing to lower levels of social support, smaller social network sizes and higher internalised stigma connected to bisexual identity. Therefore, while economic access continues to be a strong predictor of health in later life, it also has the potential to impact access to social support and psychological processes.

Social resources

When compared to lesbians and gay men, older bisexuals report smaller social networks, lower overall levels of social support and a weaker sense of belonging in LGBTQ communities (Fredriksen-Goldsen et al., 2016). Combined with their relatively marginalised social standing inside and outside LGBTQ communities, older bisexuals have little access to social capital in addition to economic resources. In addition to their possible lack of children and strained relationships with biological family (Grigorovich, 2015), gay men and lesbian individuals have also stated that they are less likely to provide caregiving support to a bisexual person than another gay or lesbian person (Grossman, D'Augelli and Dragowski, 2007). This lack of informal care support puts added strain on individuals when health care systems are designed to place the primary responsibility for care on the family with public programmes offering only enough support to supplement these informal sources of care (Grigorovich, 2013). All of these factors limit one's ability to access care when needed outside of formal care settings, which may be intimidating or unwelcoming.

Formal care services

Older LGB-identified individuals often report avoiding or delaying accessing health care due to fears of discrimination, past negative experiences and discomfort with non-LGBTQ-specific services (Fredriksen-Goldsen et al., 2011), which can lead to isolation, self-neglect and worse health (Grigorovich, 2013). Many have been denied care or provided with inferior health care due to sexual or gender identity as well (Fredriksen-Goldsen et al., 2011), which contributes to avoidant patterns. Additionally, while 15% of LGBTQ older adults report fear of accessing health care *outside* of LGBTQ communities, 16% of bisexual women report fear of accessing health care *inside* the community, indicating that even LGBTQ-specific services may not improve the likelihood that bisexuals would access competent or welcoming care. Negative care dynamics or unmet need, whether they be formal or informal, are especially likely to impact the ageing of women who tend to live longer and have greater need for care services over longer periods of time (Grigorovich, 2013). Compared to gay men and lesbian, older bisexual men and women are also less likely to disclose their

sexual identity to their health care professionals (Fredriksen-Goldsen et al., 2011), which can put individuals at risk for misdiagnosis and prevent relevant health care discussions.

Housing access

Historically, there has been little access to LGBTQ-specific housing communities or cultural competency trainings in mainstream residences. However, housing access is beginning to improve and a recent report noted the locations of 20 LGBT-inclusive housing projects that were established or under-development across the US as of June of 2016 (Movement Advancement Project and SAGE, 2017). While qualitative studies of 'LGBT' older adults indicate that this would be a preferred setting (Sullivan, 2014), the rift between bisexuals and the rest of the community may indicate that this solution will not be as preferred, effective or welcoming for older bisexuals as for others.

Implications for inequality

Applying the lens of Fraser's (2000, 2007) perspective, issues of recognition reveal the lack of cultural references for the ageing bisexual while the elimination of bisexuals from history implies that their stories are not worth telling. These dynamics contribute to and maintain the invisibility and socially marginalised status of older bisexuals, thereby limiting their own sense of identity or community. Because of their misunderstood or devalued social and cultural location, older bisexuals are also not afforded equal or equitable representation in research and practice. This erasure in turn limits their access to an influential political voice, either at the population level or individually in care and service settings. While Fraser (2007) argued to move beyond these issues toward an analysis of material distribution, tackling issues of representation and recognition are necessary precursors to revealing inequality related to distribution in the lives of older bisexuals. In other words, our tendency to under-represent or misrepresent bisexual older adults and our failures to recognise their contributions, experiences, and identities as distinctive and worthwhile contribute to the challenge of understanding or improving the material reality of their lives. For while bisexuals are not recognised for their social value, their needs will not gain visibility or influence and until bisexuals are represented in research and practice, their needs in terms of service and material allocation will not be accurately documented or understood. Therefore, a consideration of all three concepts is needed to more fully address issues of distribution for this marginalised and often invisible ageing population.

While older bisexuals face many challenges in terms of recognition, representation, and resource access, these varied aspects of inequality stem from similar issues including bisexual-specific stigma, the lack of a positive bisexual-specific identity or sense of community, and a lack of data on varied aspects of bisexual ageing.

With the goal of addressing bisexual-specific stigma, the continued theorising of bisexuality will help to solidify the accepted reality and value, not only of bisexuality, but also of other sexual identities that are characterised by fluidity and complexity. This theoretical work will also allow us to acknowledge the cultural value of bisexuality as an identity that challenges our thinking around sexuality more broadly (Halperin, 2009). Being able to theorise bisexuality more clearly also allows scholars to understand how to best study and document sexuality in research in order to capture the broadest possible bisexual population and to acknowledge fluid sexual histories, particularly among bisexual older adults (Jones, in press). In practice settings, bisexual-specific cultural competency trainings are necessary to improve service provision to older bisexuals, both in mainstream and LGBTQ-specific services (Johnston, 2016). Even when ageing-related services do not seem to be influenced by the client's sexuality, it is still crucial for bisexual clients to know that they are accessing a safe space where they can feel comfortable and at ease, strengthening the provider/client relationship and allowing providers to ensure their services are relevant to the client's needs (Johnston, 2016). Breaking down stigma around bisexuality, both inside and outside of LGBTQ communities, is also a key step toward creating the potential for positive bisexual identities and a sense of community (Eisner, 2013), both of which are severely lacking (McLean, 2008; Eliason, 2000). This will also help to ease the tension between bisexual older adults and their families, possible caregivers and other lacking dimensions of social support.

In terms of research, there is plenty of evidence to suggest that the experiences, life sequence and health of older bisexuals differ significantly from those of other older adult populations. Therefore, it is necessary that the experiences of ageing bisexuals be considered in their own right and for their own unique contributions to the literature. We also must begin accounting for sexual identities in more complexity to better understand how older bisexual populations based on identity, behaviour, attraction and relationship history might differ from one another as well as accounting for subgroup differences across gender, age, race and other relevant intersectional identities. Applying qualitative and life course-centred methodologies will help to ensure that sexual variation over time and within specific subgroups is addressed in this research (Jones, 2010). Although we now know that older bisexuals are at risk for poor health outcomes and lack some specific resources, little research has yet explored the factors which might explain these issues or what forms of prevention and intervention might be most successful with this population. While documenting these issues will serve practitioners who wish to better serve older bisexual clients, the acknowledgement of older bisexuals in large-scale research is also a necessary step toward creating a unified political voice and space for advocacy for this marginalised population (SAGE, 2016) that will also inform the creation of inclusion policies (Westwood et al., 2015).

Conclusion

This chapter provides an overview of the current literature on bisexual ageing, revealing the limitations of current research approaches and areas for further development. While there is evidence to support the recognition of health disparities among older bisexual individuals, researchers might shed more light on how these disparities are shaped over the life course and how they might be addressed in intervention and prevention efforts. An analysis using Fraser's concepts of recognition, representation, and resource access further reveals issues of particular relevance for addressing issues of inequality among this marginalised and often invisible population. The common sources of these inequalities can be traced back to bisexual erasure, bisexual-specific stigma and a lack of representation in research, practice and political spheres, which serve as useful next steps for scholars, practitioners and policymakers who hope to address issues of inequity in the context of bisexual ageing.

Note

1 BiNet USA, "A brief history of the bisexual movement." http://www.binetusa.org/bi-history

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10 Heterosexual ageing

Interrogating the taken-for-granted norm

Sue Westwood

Introduction

This chapter explores heterosexual ageing, utilising Nancy Fraser's (1997, 2000) social justice framework to consider inequalities of resources, recognition and representation. As the editor of this collection, I attempted to commission a variety of potential authors to write this chapter. I was disappointed to find that no one was willing to do so. Academics interested in heterosexuality were not, on the whole, comfortable addressing ageing issues; while those who *were* interested in ageing sexualities were less comfortable considering heterosexuality beyond sexual practices. Lesbian, gay and bisexual (LGB) ageing scholars felt it had all been said already, in terms of the well-documented comparative disadvantages experienced by older LGB people compared with older heterosexual people (e.g. Cronin and King, 2010; Fredriksen-Goldsen and Muraco, 2010; Westwood, 2016a).

Having failed to recruit anyone to write the chapter, I was left with two options: either leave it out, or write it myself. I was keen for the section on ageing sexualities to be not only about lesbian, gay and bisexual (LGB) people, serving to reinforce their 'Othering', while heterosexual ageing remained lurking in the shadows. So, in the absence of anyone else to do it, I decided to write the chapter myself. My aim is threefold: to raise critical questions about heterosexual ageing, to outline knowledge gaps and to propose a potential future research agenda.

Definition

Heterosexuality is the taken-for-granted assumed norm in everyday discourse (Wilkinson and Kitzinger, 1993; Ingraham, 1996; Richardson, 1996; Katz, 2007). It 'is an institution, so embedded in the ways we think and act that it is almost invisible, unless you try to escape it' (Weeks, 2007, 12). It is both about sex, and also much more than sex:

> Heterosexuality is, by definition, a gender relationship, ordering not only sexual life but also domestic and extra-domestic divisions of labour and

> resources. . . . Thus heterosexuality, while depending on the exclusion or marginalization of other sexualities for its legitimacy, is not precisely coterminous with heterosexual sexuality. Heteronormativity defines not only a normative sexual practice but also a normal way of life.
>
> (Jackson, 2006, 107)

Normative heterosexuality 'establishes a heterosexual/homosexual hierarchy' (Seidman, 2005, 40) which also 'privileges monogamous coupledom' (Jackson, 2006, 110) via regulatory frameworks which reinforce biological family and family forms based on the different-sex couple and the nuclear family (Westwood, 2013, 2016a, 2016b and 2017). For example, there is a heterosexist bias in social welfare policy frameworks in many countries, which are predicated upon, and benefit, these particular relationship/family forms while penalising and stigmatising others (Lind, 2004; Harding, 2010). In terms of relationship recognition, heterosexual acts between consenting adults have always been legal; marriage (both religious and civil) has always been available to heterosexual couples of the age of consent; different-sex couples have always been able to adopt and to receive whatever fertility treatment has been available at the time. Section 28 of the Local Government Act 1988, the Conservative ban on promoting homosexuality in schools (which was repealed in 2000 in Scotland and 2003 in England and Wales), referred to non-heterosexual families as 'pretended' family relationships. Now-ageing heterosexual couples were not only immune to this discrimination, they were privileged by it, while being mostly unaware of this privileging.

Despite the binary discourse of heterosexuality and non-heterosexuality, which excludes bisexualities, non-binary and genderqueer lives, in reality there is considerable overlap between the hetero- and the homo- (Kinsey et al., 1948, 1953; Richardson, 1996, 2000; Barker et al., 2012) particularly among women (Kitzinger, 1987; Diamond, 2008; Traies, 2016; Westwood, 2016a). As Adrienne Rich (1980) demonstrated in her landmark paper written over 30 years ago, women (and men) have been compelled into 'compulsory heterosexuality' with the alternatives being rendered unthinkable. While alternatives are now becoming more thinkable, heterosexuality still prevails as the primary, privileged, default identity in mainstream society (Weeks, 2010).

Recognition in older age: heterosexuality as a (gendered) identity practice

Recognition involves cultural visibility and social status (Young, 1990; Fraser, 1996; Nussbaum, 2010). Recognition is a crucial issue in relation to ageing and social justice. Indeed, Mario Paris and colleagues have argued that the struggle for recognition in older age is the 'next stage' in critical gerontology (Paris, Garon and Beaulieu, 2013; Paris, 2016). Heterosexuality in older age is unique in that it is always recognised and yet never acknowledged:

> Heterosexuality in representations of mid-to-later life is, as always, notable by its unremarkability. It is the sexuality which never needs to be noted or declared as such.
>
> (Marshall, 2017, 6)

Visibility and worth

Older heterosexual people are subject, as are all older people, to the processes of ageism and sexism (Calasanti and Slevin, 2007). They are both buffered by heterosexism – in that their ageing is 'ordinary' – and also constrained by it – in that they are required to comply with 'successful ageing' within which '"success" is equated with enactments of normative, gendered heterosexuality' (Marshall, 2017, 1) and the promise of 'heterohappiness' (Marshall, 2017, 1). Older heterosexual people are more likely to have experienced, and have had validated, the 'transitions that exist in the normative life course based on heterosexuality' (Fredriksen-Goldsen and Muraco, 2010, 11), i.e. marriage, parenthood and grandparenthood. Their family forms and later life support networks are most likely to be recognised in older age, with social policies predicated upon the notion of intergenerational biological family support. Health and social care providers are more likely to assume that an older person is heterosexual (Fish, 2006; Jones, 2010), and to engage with them about their lives, life histories and significant relationships accordingly (Simpson, Almack and Walthery, 2016). In this way, people who identify as heterosexual enjoy *automatic* recognition as having lived 'normal' lives, i.e. lives which have complied with the privileged heterosexual norm. Their visibility is also less likely to be 'risky' compared with older LGB people (Westwood, 2016a, 2016b) whose identity, if made visible, maintains the same risk of opprobrium as in their youth.

Sexuality

There has been a shift in thinking about older people in relation to sexual desire and sexual activity (Gott and Hinchliff, 2003). From previous constructions of older people as asexual, there is a growing appreciation that sex remains significant for older people, and has become closely linked to notions of successful ageing. However, the sex privileged in this discourse is heterosexual:

> Sexuality has increasingly been associated with positive and active ageing, and to be continuously sexually active is understood as a way of resisting growing old while ageing. . . . However . . . it is not primarily sex as such that is celebrated as part of the good later life, but rather heterosexual intimacy. . . . By intimacy, I mean something both sexual and non-sexual, a cluster of touch, sensuality, disclosure, and feelings of love and commitment that hold particular significance to the heterosexual culture . . . [this]

> intimacy is in turn understood as the 'vision of the good life,' and this is increasingly salient also to later life.
>
> (Sandberg, 2015, 26)

Similarly, the majority of research on ageing sexualities has focused on older heterosexual people (Hinchliff and Gott, 2008; Hughes, 2011; Fileborn et al., 2017) in normative (i.e. monogamous) relationships. Interestingly, far less attention has been given to less normative heterosexual activities involving 'older swingers' (Dukers-Muijrers et al., 2010), sexual fluidity among older people (Bouman and Kleinplatz, 2015) and those older people (predominantly older women) who had previously identified as heterosexual but, quite late in life, no longer do so (Westwood, 2016a; Traies, 2016).

In my own research, for example, with older LGBNL (LGB and non-labelling) people in the UK, one of the participants, Ellen, formed a sexual relationship with a close friend (later her civil partner, now her wife) after 40 years of heterosexual marriage. She had had no prior inkling of any sexual attraction to women:

> I mean since I realised that I love Tessa, and love a woman, no one could be more shocked than me, I can tell you. I've never fancied a woman in my life. . . . I don't know if I am a lesbian, I really don't know. Am I a lesbian? All I know is I love Tessa, I love her to death and there's a very broad spectrum, isn't there? Because I lived as a heterosexual all my life, I didn't know as a child I was different, I didn't know as a young adult, middle adult, listening to lesbians talking, there's always been an innate knowledge, a recognition, even if it was denied. I've never had that recognition.
>
> (Ellen, aged 64, quoted in Westwood, 2016a, 57)

Ellen reflected on the potential for other women to discover the possibilities of same-sex relationships,

> I am amazed at how many people we have met, and in [local lesbian group] who said they had been married – I thought I was the only one who was married, you know. [It's] fabulous, absolutely fabulous. And then it makes me think, well how many more are out there? Come on out girls! Let's get them out! Away from the kitchen, get out!
>
> (Ellen, aged 64, quoted in Westwood, 2016a, 198)

There is, then, a need for research which: (a) explores with heterosexual-identifying older women, how heterosexuality has shaped and informed their lives; and (b) explores with heterosexuality ambivalent older women how this ambivalence has been experienced and has shaped their ageing experience. Moreover, research about ageing sexualities must encompass the full spectrum of sexualities, not only heterosexualities, in order to locate heterosexuality in its full context (and challenge what may well prove to be false boundaries).

Heterosexual compliance: the potential pains of mis-recognition

One of the frequent narratives about older heterosexual people is that that they are less likely than older LGB people to have mental health problems in later life due to the absence of sexual minority stress. In other words, being socially marginalised and socially positioned as inferior, even to themselves, damages LGB people psychologically. This damage accumulates with age (Fredriksen-Goldsen et al., 2013) in ways which do not affect older heterosexual people. However, an area that has not yet been explored is the effects on an individual who has positioned themselves as heterosexual all their lives, when this positioning may not accord with their desires and/or identification. Many older people who have formed same-sex relationships in later life talk about the pain of hiding themselves when in heterosexual relationships and the relief to be free from that hiding (Westwood, 2016a). What we do not yet know is what it is like for those individuals who remain in hiding, never forming a same-sex relationship, or only doing so in clandestine ways. In other words, we need to better understand the penalties as well as privileges of adopting a heterosexual identity/lifestyle with which one is not fully in accord.

The constraints of (ageing) heterosexual compliance

While much has been written about heterosexual privilege, less well explored are the disadvantages of heterosexuality. There is a growing interest in how heteronormative masculinities constrain the possibilities for being and for self-expression among heterosexual men (Lodge and Umberson, 2013). This has particular implications for older age, where older heterosexual men face the prospects of cultural devaluation if they are unable in older age to successfully comply with the gendered, sexualised ideals associated with '"doing" masculinity' (Fileborn et al., 2017, 2097). Similarly, in terms of those women for whom non-heterosexuality has been an 'unthinkable' due to compulsory heterosexuality (Rich, 1980) but who might have been open to same sex sexual intimacies option, we do not yet understand how compliance with heterosexism and heteronormativity has constrained their opportunities for sexual fulfilment and/or self-expression. Moreover, in considering the gendered inequalities of ageing (see Part One of this collection), there is much to be understood about the place of heteronormativity, compliance with hetero-gender norms, and the enduring significance of patriarchy, in shaping those inequalities.

Resources in older age: heterosexuality, material, personal and social capital

In her analysis of resources, Fraser was primarily considering economic resources. However, there is a growing appreciation of the importance of other kinds of resources for equality and social justice, especially the affective resources

(Lynch, 2010; Lynch et al., 2016) of social networks, health and well-being, and care. These take on particular significance in later life (see Herring, Chapter 18).

Employment and access to material/financial capital

The UK Stonewall-commissioned YouGov survey (Guasp, 2011) compared the ageing experiences, issues and concerns of 1,050 heterosexual and 1,036 LGB people over the age of 55. The study reported that heterosexual people over 55 are less likely to be in paid employment than older LGB people (Guasp, 2011, 6): half of those surveyed aged between 55 and 59 were in full- or part-time paid employment (compared with two-thirds of LGB people in the same age bracket); 93% of heterosexual respondents aged 70 and over were retired, compared with 81% of older LGB people. There are two possibilities for this: either older heterosexual people are less able to obtain work in older age than older LGB people (which does not seem likely) or they have less need to do so, i.e. they have access to relatively greater financial resources (which seems more likely). There is considerable evidence now of historical heterosexual privilege in employment, which means that heterosexual individuals, particularly those who are now ageing, were more likely (than LGB individuals) to have greater choice in their career-type, to establish themselves within a particular career pathway and to achieve promotion into higher paid roles (van Loo and Rocco, 2009).

However, this analysis is nuanced by gender and by parenthood/non-parenthood status. It is now well-recognised that older women are, overall, poorer than older men (see Vlachantoni, Chapter 2). This is partly due to pay inequalities between women and men, and to the gendering of lower-paid care work (more often performed by women). It is also due to women being more likely to work part-time, due to their informal care commitments, particularly women with children and grandchildren. This in turn impacts upon their ability to accrue material and financial resources in later life.

Childless women are not similarly affected, and are more likely to accrue greater capital by the time they reach older age than women who are parents (Mika and Czaplicki, 2017). Given that older heterosexual women are more likely to have children than older LGB women (see further on in this chapter, and also Hadley, Chapter 5) there is then an argument to be made that they are more likely to suffer from the associated financial disadvantages of the 'motherhood penalty' (although they reap the patriarchal dividend of a husband). A number of authors have argued that this may disproportionately affect lower-skilled low-income women (e.g. Killewald and Bearak, 2014), while others have argued that they disproportionately affect highly skilled, higher-paid women (e.g. England et al., 2016). However the 'motherhood penalty' needs to be understood in its wider context, as married women/widows are often well provided for by their husbands, at least relatively more so than their lesbian counterparts. Moreover, in later life children can add social and financial support, not enjoyed by those ageing without children.

There is a need for far greater understanding of the implications of the motherhood (and fatherhood) penalty in later life, across the sexualities spectrum, nuanced not only by class but also other significant socio-economic positions such as culture, race and ethnicity (Bowleg et al., 2013; Harris, 2014).

Relationships

The Stonewall survey (Guasp, 2011) also found significant differences in the social networks of older heterosexual and older LGB. See Table 10.1 for a summary of the findings in relation to relationships.

As Table 10.1 demonstrates, older heterosexual people are more likely to be in couples than older LGB people, less likely to live alone, more likely to have children and more likely to see biological family members on a regular basis. Although friendships are important to older heterosexual people (Gray, 2009), as Table 10.1 shows they were less important to those in the survey than to their LGB counterparts (Guasp, 2011, 9). Moreover, as Table 10.1 shows, older heterosexual people are half as likely as older LGB people to expect to rely on formal social care provision in older age (Guasp, 2011, 20). As older people develop age-related care needs, particularly personal care needs, they tend to turn to their spouses/partners and/or children for support rather than friends (Pickard, 2015). Older people with strong *intra*generational friendship networks, whether heterosexual or LGB, may find that they are less likely to be able to support one another, if they are all developing age-related care needs at a similar time (Westwood, 2016a).

Older heterosexual people are more likely than LGB people to comply with the assumed heteronormative identities of grandparents and enjoy the associated positive status and its connections to successful ageing.

> [the] associations between hetero-happiness and successful aging through the widely disseminated imagery of heterosexual coupledom . . . Success is

Table 10.1 Summary of Stonewall survey's findings about relationships

People aged 55+	*Heterosexual*	*LGB*
Single	15%	40%
Live alone	28%	41%
Have children	90%	Women: 50% Men: 25%
See biological family at least once a week	50%	25%
'View their friends as family'	Women: 60% Men: 48%	Women: 81% Men: 69%
Likely to turn to a friend for practical help if ill	Women: 19% Men: 14%	Women: 52% Men: 42%

Source: Guasp, 2011

> not just illustrated through coupledom, but also portrayed through happy intimacies with grandchildren, pointing to (hetero)kinship as that which makes later life meaningful and positive.
>
> (Sandberg and Marshall, 2017, 3)

Grandmotherhood and grandfatherhood are still very much framed as heterosexual identities (Arber and Timonen, 2012; Tarrant, 2013), although this is likely to change in those countries where successive cohorts of same-sex couples are now having children (Traies, 2016; Westwood, 2017). Importantly, heterosexual people with children and grandchildren avoid the ostracising experiences of older people ageing without them (Hafford-Letchfield et al., 2017; Hadley, this collection). In this way, access to children and grandchildren is important *both* as a site of recognition and as a (care) resource in later life.

Health and well-being

Fredriksen-Goldsen et al. (2013) conducted a comparative study on the health of heterosexual and LGB people over 50 in the US. They reported that heterosexual older adults had comparatively lower risks for disability, cardiovascular disease and obesity, poor mental health, smoking, and excessive drinking than older LGB people. This suggests that older heterosexual people are privileged compared with older LGB people when it comes to the body as an 'ageing resource' (see Hurd Clarke, Chapter 3). They also observed that older heterosexual and LGB people have different later-life support networks, with older heterosexual people relying more on partners, spouses and children. They proposed that 'future research needs to investigate how differing types of social networks, support, and family structures influence health and aging experiences' (71).

According to the Stonewall survey, older heterosexual people reported that they drank alcohol less often than older LGB people (31%, compared with 45%) (Guasp, 2011, 3). They were also less likely to take drugs: only 1 in 50 reporting that they had taken drugs in the past year, compared with 1 in 11 LGB older people.

Over a third of heterosexual respondents reported worrying about their mental health, although this was less than older LGB people. Older heterosexual women were less likely to have ever been diagnosed with anxiety (26%) or depression (33%) than lesbian and bisexual women (33% and 40%, respectively) (Guasp, 2011, 19). The differences between older heterosexual men and older gay and bisexual men were even more marked. Older heterosexual men were much less likely to have ever been diagnosed with anxiety (13%) or depression (17%) than gay and bisexual men (29 and 34%, respectively) (Guasp, 2011, 19). This would suggest that heterosexuality involves reduced risk of exposure to certain factors associated with anxiety and depression, and/or acts as a buffer to their occurrence.

This is further nuanced by gender. Older heterosexual women reported higher rates of anxiety and depression (26% and 33%, respectively) than older heterosexual men (13% and 17%, respectively). However, although older lesbians and bisexual women also reported higher rates of anxiety and depression (33% and 40%, respectively) to older gay and bisexual men (29% and 34%, respectively), the gap between the two is far narrower. Such insights could potentially offer important contributions to the debate about the place of heterosexuality in gender differences, anxiety and depression in later life (Sjöberg et al., 2017).

Other later-life issues affecting older women more than older men (irrespective of sexuality) are: the challenges of 'very old' old age (as older women live longer than older men – see Gilleard and Higgs, Chapter 4); ageing into disability (although women live longer than men, they do so with higher levels of disability, Chatterji et al., 2015); and ageing and dementia (women are more likely to have dementia than men) (Erol, Brooker and Peel, 2015). How gender informs these events – for both heterosexual and non-heterosexual women – requires further exploration.

Care concerns

Older heterosexual and older LGB people share many similar concerns about ageing. In the Stonewall survey, just under half of older heterosexual (47%) and older LGB (45%) people reported feeling positive about getting older (Guasp, 2011, 6). Their concerns about ageing (see Figure 10.1) cohered around the following key themes: needing care; independence; mobility; health; housing; and mental health.

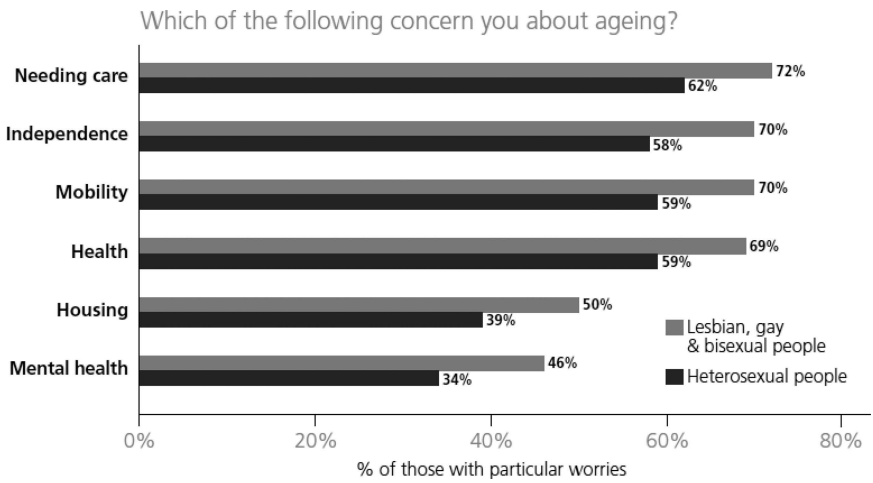

Figure 10.1 Older heterosexual and LGB people's concerns about ageing

Source: Guasp, 2011, 7

Although older LGB people see formal care provision as a heterosexualising process (Westwood, 2016b), older heterosexual people nevertheless share many of their concerns about care. According to the Stonewall survey, 51% of older heterosexual people were not confident that social care and support services would be able to understand and meet their needs; 51% of older heterosexual people were not confident that housing services would be able to understand and meet their needs; and 33% of older heterosexual people were not confident that mental health services would be able to understand and meet their needs. In terms of residential care provision, a striking 71% of older heterosexual people in the survey said that they were not confident that 'they would be treated with dignity and respect in a care home setting' (Guasp, 2011, 28). Furthermore, 61% of older heterosexual people reported being concerned that they would not be able to 'be themselves' if living in a care home and 52% felt they would have to hide things about themselves. They were also concerned about the expression of sexual intimacy in care homes: 43% of older heterosexual people said they would not feel able to be affectionate with their partners and 45% felt they would not be able to maintain a sexual relationship (Guasp, 2011, 27–28).

Older heterosexual people (as well as older LGB people) are affected by (a) issues relating to poor quality home care and residential/nursing home care (Equality and Human Rights Commission, 2011; Care Quality Commission (CQC), 2016); (b) issues relating to sexual citizenship in residential/nursing home care (Mahieu and Gastmans, 2015; Simpson et al., 2015) and (c) the monitoring and surveillance of older age sexualities in those spaces (Bauer et al., 2014). However, their heterosexual sexualities will be policed less severely than those of older LGB people (Ward et al., 2005; Willis et al., 2014). This is, of course, *unless* older people who have lived heterosexual lives and identities then show an interest in same-gender sexualities while living in formal care spaces. They may then find themselves additionally positioned within and among the exclusionary processes affecting older LGB people and the inhibition of sexual/sexuality expression in care homes (Furlotte et al., 2016).

These issues are of particular significance to older women, who, because they live longer than older men, but with greater disability, are disproportionately affected by shortcomings in the formal care system:

> Despite this gendered pattern of ageing, older women's sexuality is conspicuously absent from social policies and much of the extant research and theorizing. Reflecting this absence, institutionalised ageism and sexism operating within health care systems, social services, such as aged care, and culture more broadly continue to limit older women's ability to enjoy pleasurable and safe sexual experiences.
>
> (Hurd Clarke, Fileborn and Thorpe, 2017, 29)

There is then a need for research which considers the care concerns shared by both older heterosexual people and older LGB people. The specificities of those

concerns include not only sexuality but also gender, class, culture and ethnicity (see Torres, Chapter 11, and Hussein, Chapter 12).

Representation in older age: heterosexuality and ageing politics

Representation involves, according to Fraser's theorising, social and political participation and access to justice. It also involves knowledge production, both in terms of research and in the dissemination of that research.

Gerontological discourse

Despite increasing recognition of (sexual) diversity among older women and men, heterosexuality has long been the default narrative in social gerontology (Cronin, 2006; Jones, 2011, 2012). Indeed, particularly in the United Kingdom, social gerontology, and gerontology more broadly, remain 'resolutely heterosexist' (Clarke et al., 2010, 216). For example, the *Sage Handbook on Social Gerontology* (Dannefer and Phillipson, 2010) makes no specific reference to heterosexual ageing whatsoever, and while it has a chapter on LGBT ageing (Rosenfeld, 2010), this is the only place non-heterosexuality or heterosexuality are referred to in the entire volume. More recently, several articles on ageing sexualities were published, based on the English Longitudinal Study on Ageing (ELSA) (Hinchliff et al., 2017; Lee et al., 2016). Yet the ELSA's participants' self-reported sexual experiences were 'entirely/mostly with opposite sex' (95% women; 96% men) and self-reported sexual desires which were 'entirely/mostly with opposite sex' (94% women; 96% men) (Hinchliff et al., 2017, 4). This kind of reporting, which fails to give a more nuanced analysis, perpetuates the privileging of heterosexuality and the obscuring of marginalised non-heterosexualities.

There is, then, a need to further understand the privileging of heterosexuality in gerontological discourse, and to what extent and how it distorts narratives of ageing lives. Authors, educators, editors, commentators, all need to address and correct the default heterosexual narrative in gerontological discourse. They must ensure that when older people are being described, considered and addressed, such analyses *always* encompass people across the sexualities spectrum. This is not simply to avoid excluding older LGB people and/or the lack of critique of the place of heterosexuality in framing the ageing experience. It is also to avoid social policymakers relying upon misleading narratives that are not representative of the ageing experience as a whole.

Research

Many studies about older people are based on samples which either do not ask about sexuality and/or assume heterosexuality. As in the previous example, those samples which do ask about sexuality tend to comprise a predominance of heterosexual participants. In some ways this privileges heterosexuality.

However, in some ways it also obscures heterosexuality, because heterosexuality is itself not critically interrogated. Even in those studies which are explicitly about older heterosexual people, the place of heterosexuality itself in the shaping of their ageing is rarely examined. There is then a need for research which always considers sexuality and sexual identity both as a demographic feature and as a component of analysis. In other words, researchers need to ensure their participants include a cross-section of society. Research funders could make this a condition of their grants and journal editors could make this a condition of publication.

Ageing advocacy

Advocacy with and/or on behalf of older people and those with age-related conditions (e.g. dementia) assumes a heterosexual default. This is not made explicit; indeed, heterosexuality itself is not even referred to by organisations such as Age UK or the Alzheimer's Society. However, it is evident in the way there are specialist materials for LGBT people provided by each organisation, serving to 'Other' them in their non-heterosexuality, e.g. Age UK's *Meeting the Needs of Older LGBT People*[1] and the Alzheimer's Society's *LGBT People and Dementia*.[2] The only ageing activists who do address sexuality are LGBT activists,[3] when they are seeking to highlight comparative disadvantage compared with heterosexual and/or cisgender people. The resounding silence on heterosexuality, heterosexism and heteronormativity among mainstream ageing activists is telling in and of itself. While LGB ageing activists are seeking to resist the norms and normativities associated with heterosexuality, the work of mainstream ageing activists, in overlooking heteronormativity, serves to reinforce them.

Social participation

There is widespread recognition that prejudice and discrimination associated with ageing informs the social exclusions experienced by many older people. Less well recognised, apart from on the margins of critical gerontological discourse, is the place of heteronormativity and heterosexism in a) buffering the social exclusions which are associated with both ageing and sexuality and/or b) contributing to the shaping of them.

Conclusion

As this chapter has highlighted, much more needs to be understood about how heterosexuality frames and informs the experiences and perceptions of ageing. Specifically, the following questions need to be addressed:

1 How does heterosexuality as an identity practice inform access to resources, recognition and representation in older age?
2 How do heterosexuality, heterosexism and heteronormativity inform the gendering of older age disadvantages? How can they be remedied?

3 How has heterosexuality as a sexual practice operated in the lives of individuals across adulthood and into older age? To what extent has heterosexuality been a stable identity construct and/or practice?
4 What does the phenomenon of purportedly heterosexual people, especially women, engaging in same sex sexual practices in later life say about the contingencies and constructions of a heterosexual identity?
5 How can gerontological research and discourse become disengaged from its heterosexist and heteronormative underpinnings?

As Fredriksen-Goldsen and Muraco (2010) have observed, studies which include the experiences of *both* older heterosexual people *and* older LGB people 'would expand our knowledge about the adjustment to aging as another life transition to be navigated' (11). Without such studies, we are only ever getting partial perspectives on the intersecting ways in which ageing, gender and sexuality inform later life.

Much of the literature on LGBT ageing is framed in relation to comparisons with heterosexual ageing. Somewhat inevitably this chapter has also taken a similar approach. It is to be hoped that in the future ageing sexualities can be explored not in opposition to one another but as an integrated whole. Increasingly, for younger generations, rigid sexual identity boundaries are loosening and becoming more fluid. The distinction between heterosexual and non-heterosexual may become less relevant in time, with naming such categories increasingly obsolete. For now, however, for current cohorts of older people, ageing continues to be navigated through and against the dominant frame of heterosexuality. Because of this, we must better understand its place in ageing.

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Notes

1 Age UK. 2017 "Meeting the needs of older LGBT people." www.ageuk.org.uk/latest-news/articles/2017/november/meeting-needs-of-older-lgbt/
2 Alzheimer's Society. "LGBT: Living with dementia." www.alzheimers.org.uk/info/20029/daily_living/1190/lgbt_living_with_dementia
3 See, for example, the US "National Resource Center on LGBT Aging" (www.lgbtagingcenter.org/); and the UK's "Opening Doors London" (http://openingdoorslondon.org.uk/)

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Part III

Culture, ethnicity and religion

Sue Westwood

Introduction to Part III

This section addresses a range of issues relating to ageing, culture, ethnicity and religion. In Chapter 11, Sandra Torres draws upon a scoping literature review of scholarship on old age/ageing and ethnicity/race to critically interrogate why such scholarship is not informed by a social justice framework. She argues that this is because much of the literature takes an essentialist, rather than a social constructionist, approach to understandings of ethnicity/race. She proposes that a shift from the former to the latter is needed in order to address the socially located and positioned inequalities associated with ethnicity/race and ageing. In Chapter 12, Shereen Hussein considers the experience of migrants growing older in host communities, focusing on ageing Turkish migrants in the UK, and on social networks as a key resource in migrants' life course. She also considers cultural visibility and social status (recognition), participation within and outside the 'community' (representation). Hussein argues that strong social networks among ageing migrants can be both sources of resources, recognition and representation, and yet can also exacerbate social marginalisation from the wider community. In Chapter 13, Alistair Hunter considers 'transnational ageing' exploring diversity both between *and* within groups of older migrants. He argues for the importance of using this approach in order to move beyond stereotypes, such as 'vulnerable' former labour migrants ageing in place and 'privileged' older lifestyle migrants. Hunter argues that privilege and disadvantages among ageing migrants is more complex, nuanced and context-contingent than has previously been understood. In Chapter 14, Peter Kevern considers the place of religious beliefs, institutions and practices in relation to later life inequalities. His discussion is based on the six main religions (Christianity, Judaism, Islam, Hinduism, Sikhism and Buddhism) in the UK. Kevern argues that the traditional rhetoric of the valoration of, and support for, older people among religious institutions does not take into account assumptions of homogeneity. They may also be sites of exclusion for some among more heterogeneous populations.

All four chapters highlight the importance of understanding cultural, ethnic and religious diversity as socially constructed and socially located positions. Thus, issues of recognition are key to conceptualising diversity in the first place.

Additionally, there is a need to understand diversity within and among minoritised populations including those known as migrants, in order to appreciate sites of both privilege and disadvantage, inclusion and exclusion, according to context. As Hussein has argued in particular, under some circumstances certain resources can be both sites of inclusion (e.g. a sense of local community belonging among migrant populations) and exclusion (from the wider community) at the same time. These in/exclusions are also sites of interaction between resources, recognition and representation.

11 Ethnicity, race and care in older age

What can a social justice framework offer?

Sandra Torres

Introduction

Sometimes invitations to join a book project come with very clear expectations. The invitation to join this edited collection was that way. The editor asked if I could contribute to an edited collection on ageing, diversity and equality with a chapter on ageing, ethnicity and equality. Accepting her invitation seemed easy at first since the intersection between old age and ethnicity has been one of my research interests for decades. In addition, the timing of her request could have not been more appropriate since I had just finished working on two publications which addressed three of the pieces of the puzzle that her request touched upon (i.e. ageing, diversity and ethnicity; e.g. Torres, 2015a, b) and was in the very midst of working on a new book about what characterises studies at the intersection of ethnicity and old age (e.g. Torres, 2019). Thinking about ageing, ethnicity and equality was, in other words, at the very core of the intellectual quests I was engaged in when her invitation first arrived.

Once I had agreed to contribute to this edited collection, the editor asked if I could draw on Nancy Fraser's social justice framework. At first, I thought that this was an impossible task since I could not recall that a single one of the 300+ articles I was in the very midst of reviewing for the book on old age and ethnicity that I was working on had employed Fraser's framework. Scholarship on old age and ethnicity – which I often refer to as ethno-gerontology – is not, in other words, informed by the perspective of social justice that the editor of this collection was asking me to employ. The more I pondered on her request, the more I realised, however, that this was, in fact, an opportunity to critically ask the two questions that became this chapter's aim: How is it possible that scholarship on old age and ethnicity – which sheds light on the inequalities that older ethnic minorities face – is not informed by the social justice framework? And what, if anything, can this perspective offer to ethno-gerontology?

Fraser's framework and what it suggests about research on old age and ethnicity

Before I begin to formulate the answer to the questions that this chapter will answer, it seems necessary to give an abridged introduction to Fraser's (1996

and 1997) framework. Fraser was originally interested in bridging the intellectual gaps that were created when scholarship on social justice shifted its attention from thinking of justice claims in redistributive terms to thinking of them in terms of recognition. Part of Fraser's argument is that the former focus on more just distribution of resources while the later are about the creation of a diversity-friendly world, and that it is our inability to combine these perspectives that has led to the stagnation of the academic debate on social justice. According to Fraser (1997), social justice theorists that stress the importance of the 'politics of redistribution' tend to focus on economic structures and regard exploitation, marginalisation and deprivation as the ways through which injustices occur. Social justice theorists who focus on the 'politics of recognition' instead are mostly concerned with bringing attention to the ways in which social patterns of representation, interpretation and communication create cultural injustices.

In the book Fraser published in 2008 she added 'the politics of representation' to her framework since she realised that participation (which is always understood as political in all its shapes and forms in her work) is also one of the ways through which injustices can be combated. This new concept – which she originally launched by alluding to it as the principle of parity of participation (Fraser, 2007) – encompasses both the 'straightforward sense of political voice and democratic accountability' (Fraser, 2009, 147) as well as 'the salient questions about the (in)justice of boundaries and frames' (ibid.). At this metal-level, this dimension of justice calls attention not only to the question of who is included (and excluded) 'from the circle of those entitled to participate' (ibid.) but also to the question of how the 'political injustices of misframing' (ibid.) actually operate. It is because of this that Fraser defines representation as concerning 'the intersection of symbolic framing and democratic voice' (ibid.).

In relation to older people from ethnic minority groups specifically, it must be stated that if social justice theorists that focus on redistribution were to study this group they would regard their lower economic capital (as well as the disadvantageous working lives that they sometimes have led) as an important angle of investigation. Social justice theorists who focus on the politics of recognition would instead bring attention to the ways in which these older minorities are misinterpreted in different spheres (the welfare institutions that cater to their needs being one of them). Whereas social justice theorists who focus on the politics of representation would bring attention to the ways in which their voices may be relegated to the periphery of a debate because they are not deemed to be obvious members of the 'circle of those entitled to participate' (Fraser, 2009, 147). Phrased differently, one could say that while redistribution-minded theorists would see economic restructuring as the remedy for the injustices that older people from ethnic minorities tend to experience, and recognition-minded theorists would most likely regard cultural and symbolic change as the way forward, the representation-minded theorist would see the question of voice as central to how we move forward. Fraser's theoretical framework urges us to combine all three dimensions of justice.

Worth noting before I conclude this section is that the two social justice perspectives which Fraser's original framework was concerned with (i.e. redistribution and recognition) regard group differences in very different ways: redistribution-minded theorists envision a world where differences can be abolished whereas recognition-minded theorists think that differences (irrespective of whether or not they are regarded as pre-existing or not) need to be recognised. The problem for them is not, in other words, that differences exist but rather than we have come to interpret them in a value-hierarchical way. This is something we need to keep in mind as we critically appraise ethno-gerontological scholarship since the establishment of difference is so central to this scholarship's raison d'être.

Ethno-gerontological scholarship: the literature on the health and social care as an example

The reason why I have chosen health and social care as the starting point of this chapter is twofold. First, once I had decided to use the review of literature on old age and ethnicity that I had just conducted for a book on this very topic (i.e. Torres, 2019), I had to find a way to narrow the scope of literature to be used here. The review comprises namely the 300+ articles in peer-reviewed journals[1] that focus on ethnicity/race and ageing/old age between the years of 1999 and 2017, so basing a single chapter on such a vast number of articles was not possible. Narrowing down the literature to be used in this chapter was therefore a must. The review had identified the three topics that scholarship on old age and ethnicity has mostly focused on (i.e. health and health inequalities, health and social care and intergenerational and social relationships) so I decided to pick one topic and since injustices happen within specific contexts, I deemed the health and social care theme to be the most propitious for the task at hand. The fact that most of the work on health and social care in old age that uses ethnicity as a lens comes from gerontological journals is most likely the reason why the sections that follow focus on the angles they focus on; these are namely the angles that have received the most attention in this literature.

Access and usage in health and social care

Most of the research on access and usage states that there are racial and ethnic differences in the types of services that older people use and that those from minorities' access and usage can best be described in terms of inequality (Torres and Ute, 2016). Some of this literature also draws attention to the fact that these inequalities cannot always be explained in terms of socio-economic variables. These minorities use fewer services than what one would expect considering their health situation. Thus, it is not uncommon for articles on health and social care to summarise their findings with statements such as 'for reasons that are unrelated to financial assets, Blacks remain vulnerable in their ability to access services' (White-Means, 2000, 76) or 'results provide evidence that

racial/ethnic disparities in utilization of drugs used to treat dementia exist and are not accounted for by differences in demographic, economic, health status, or health utilization' (Zuckerman et al., 2008, 328).

Worth noting also is that this literature is almost exclusively based on quantitative studies with data collected in the US focusing on older ethnic minorities as recipients of health and social care. The data comes most often from large-scale projects that tap into a huge array of variables. As such, this is not data that has been generated by asking members of different older ethnic minority groups for their opinions on access and usage but rather data that has been used to shed light on access and usage patterns because it is already available through different registry, large-scale or longitudinal studies. Also worth noting that the vast majority of these studies bring attention to African Americans/Blacks and compare their access and usage to that of their White counterparts (e.g. Coleman and Feuer, 2001; Bradley et al., 2004). The few articles on access and usage that bring attention to other ethnic groups focus on Hispanics but never solely since comparisons between them and Whites and/or Blacks are almost always the starting point (e.g. Calderón-Rosado et al., 2002; Zuckerman et al., 2008; Bowen and González, 2008; Miller et al., 2014). Thus, it is not only that this literature mixes-up ethnicity and race (which is why the word race is used in this chapter's title), but also that comparisons are almost always at stake in these studies. From Fraser's standpoint one could therefore say that the literature is very much characterised by an insatiable curiosity to see how racial minorities flare in comparison to the racial majority. As such, this scholarship seems oblivious to the fact that 'being subjected to patterns of interpretation . . . that are associated with another culture and are alien and/or hostile to one's own' (Fraser, 1996, 7) – which is what cultural domination is all about – is one of the ways through which injustices can be reproduced. Thus, by failing to address the variety of ethnic backgrounds from which access and usage can be discussed (which is what recognition is about), and by failing to give a voice to the older ethnic minorities that these studies focus on (which reminds of Fraser's politics of representation), this literature fails to recognise a central concern. This is that half of the battle if one wants to remedy injustices involves appreciating that the diversity that characterises our societies these days is far greater than what the literature recognises and that diversity can only be addressed if minorities' are allowed to join in 'the circle of those entitled to participate' (Fraser, 2009, 147).

Most of the articles on access and usage also draw attention to the different care arrangements that older people from minorities make and/or the types of care services that they use or fail to use (e.g. Choi, 1999; Wallace et al., 1999). In addition, some of these studies address the mediating effects that family structure and social class can have on access and usage (e.g. Cagney and Agree, 1999), the importance of economics in determining access (e.g. Dunlop et al., 2002) and the impact that social norms concerning family caregiving can have on these issues (e.g. Bradley et al., 2004). Taken as a whole, however, it is puzzling to note – even if the quotes in the beginning may have suggested

otherwise – that remarkably few articles explore the implications that income or wealth can have on the access and usage angle that they explore. From Fraser's standpoint, this literature seems, in other words, to be oblivious to the fact that injustices cannot be addressed if 'redistribution politics' are not part of the agenda. Thus, although cognisant that disparities exist in how different older ethnic minority groups access and use health and social care services, this body of work does not really say much about how injustices in these respects can be remedied.

Attitudes, preferences and experiences of relevance to health and social care

Just as was the case with the previous theme, most of literature on health and social care that scholarship on old age and ethnicity has generated and which brings attention to the angle that attitudes, preferences and experiences offers, comes from American studies. In this theme, however, there are studies from other parts of the world as well; even if these are still in a minority. Thus, once again we are dealing with a body of work that barely scratches the surface of what ethnic diversity actually entails. It cannot therefore, as a whole, offer much as far as giving us an idea of what different health and social care settings actually offer the diverse populations of older people to which they cater and/or what diversity means to how people regard and experience the services that are available. Worth noting also is that, in this theme, there were more studies using qualitative methods and also studies that approach their research aims by giving a voice to care providers so the approaches utilised in studies in this theme seems more purposeful than the ones used in the previous theme. In other words, this theme tends to be explored not necessarily because there is large-scale, registry or longitudinal data to be used, but rather because studies are specifically designed to address the question of older ethnic minorities' attitudes, preferences and experiences as far as health and social care are concerned.

The articles that originate from the US focus primarily (though not exclusively) on African Americans in comparison to Whites even though fewer studies in this theme rely on comparisons. Amongst the American studies found, there were studies about: how older African Americans and Whites regard adult care homes and family care (Sudha and Mutran, 1999); how satisfied both groups are with such facilities (Mutran et al., 2001); the similarities and differences of these groups' preferences for mental health care (Dupree, Ann Watson and Schneider, 2005); how African Americans' enrolled in an Alzheimer's research programme regard brain donation (Lambe et al., 2011); and how Blacks and Whites regard cremation (Glass and Samuel, 2011). Also coming from the US are articles that bring attention to Asian minorities: one of them on the health-seeking behaviours that Chinese Americans prefer (Pang et al., 2003); and another focusing on Chinese American women's views on health and cancer screening (Liang et al., 2004).

In terms of the articles that come from other parts of the world it seems interesting to note that these are mostly about the ways in which ethnic minorities

experience the services that the health and social care sector offers and/or the ways in which formal care providers deliver care across linguistic and ethno-cultural boundaries. One of the articles from Canada focuses, for example, on how older ethnic minorities and their families (as well as health and multicultural service providers) regard access to care and the numerous barriers to care that ethnic minorities experience (Koehn, 2009). Another, also from Canada, brings attention to the communication challenges that staff and residents in ethno-culturally and linguistically diverse long-term care facilities face (Small et al., 2015). There are also two articles from Sweden both of which focus on the Finnish minority albeit in different ways: one of them brings attention to the elderly care preferences that elderly Finns have (Heikkilä and Ekman, 2003); the other focuses on how nursing staff experience the challenges that caring for people with these backgrounds can entail (Söderman and Rosendahl, 2016). Last, but not least, we have the few articles from the UK that focus on experiences; one of them brings attention to both older people who had recently experienced a hospital stay and people who had an older relative who had been hospitalised (e.g. Ellins and Glasby, 2016). Another study brings attention to the ways in which older ethnic minorities experience local health and social care services (e.g. Manthorpe et al., 2009).

Thus, some of this literature seems to be wanting to explore *why* it is that access and usage is limited amongst older ethnic minorities. Conclusions suggesting that the reason for this may lie in ethno-cultural values and preferences are therefore not uncommon. One can, for example, read assertions such as 'results suggest that the cultural preference for family care often attributed to ethnic differences is also partly determined by dislike for institutionalized care' (Sudha and Mutran, 1999, 570) and 'the identified differences in end-of-life decision-making preference and practice suggest that clinical care and policy should recognize the variety of values and preferences found among diverse racial and ethnic groups' (Kwak and Haley, 2005, 634) in the articles about this theme.

From Fraser's (1996 and 2009) standpoint, and using both the politics of recognition and the politics of representation as our starting point, one could therefore say that the literature on this theme fares a bit better since it is trying to give older people from ethnic minorities a voice. It also seems cognisant of the fact that understanding them on their own terms is a must if we are to address the disparities in health and social care that the literature as a whole highlights.

The suitability of different programmes/interventions/services

One of the interesting things to note about the literature on health and social care that focuses explicitly on assessing the suitability of existing programmes, interventions and services is that most of this literature is based on newly designed programmes that cater to the specific needs that older ethnic minorities are expected to have (e.g. Dornelas et al., 2007; Parker et al., 2002;

Pope et al., 2013). This means that – even though some of the articles alluded to in the previous section do give voice to people's experiences with existing services – very few of the articles that are specifically about assessing the suitability of services are based on studies that assess whether they are suitable for the increasing number of people from ethnic minorities that are now using them. This is despite the fact that there is ample evidence suggesting that the services available are not being used by older ethnic minorities to the extent that one may expect considering that their health condition is often poorer than their ethnic majority counterparts. From this it follows that (taken as a whole) this literature does not seem to be aware that without redistribution and representation efforts, the programmes that are available cannot be improved. In addition, it is interesting to note that this literature does not recognise the diversity that characterises ethnic (and racial) minorities from the politics of recognition standpoint either, so there is much to be done here as well.

Making sense of ethnicity: what scholarship on ethnicity knows and scholarship on old age could learn

In the introduction to this chapter I explained how the invitation to contribute to this book lead me to pose a question I have been pondering upon ever since: how is it possible that scholarship on old age and ethnicity – which sheds light on the inequalities that older people from ethnic minorities face – is not informed by the social justice framework? In this section I will suggest that one of the reasons why this is the case is that ethno-gerontologists' understandings of ethnicity seem to be stuck in a time warp. This is a fact that I have argued elsewhere (e.g. Torres, 2015b) but which I think has some bearing on why the injustice lens has yet to inform ethno-gerontological scholarship in general, and the literature on health and social care in particular. The reason why I state this is that one of the many analyses I have performed for the book I am working on at the moment entails assessing which approach to ethnicity this literature relies on. I have found that the vast majority of the literature relies on either the essentialist, the structuralist or a combination of these understandings.

A few words about what this means are therefore necessary. The first thing that needs to be mentioned is that if one wants to grasp how understandings of ethnicity have developed over time one needs to look back at the eighteenth-century Enlightenment's search for order. It is namely this search that started the mode of thought that is essentialism. Isaac's (1975) work on ethnicity is often deemed to be one of the most coherent examples of how essentialism flourished within the social sciences in the mid-nineteenth century. He believed that we are conditioned by the characteristics we share before we can choose: such as our phenotypical traits; the geographic and topographic features of the place where we were born; the history and origins of the group into which we were born; our nationality and first language as the religion and culture into which we were born. This is why essentialist understandings of ethnicity, such as Isaac's, regard it as a background that defines us.

Cornell and Hartmann (1998) have argued that although the essentialist understanding of ethnicity is still influential today, a new understanding of ethnicity was born out of a mode of thought that is structuralism. The structuralist understanding of ethnicity poses that ethnic backgrounds are important not necessarily because they tell us something about who we are, but because they give us insight into the resources that different backgrounds give us access to (or hinder us from acquiring). This understanding of ethnicity places importance on the circumstances that determine the meaning that ethnicity takes on. Ethnic backgrounds are, in other words, interesting because of the advantages and disadvantages that these backgrounds can entail in different contexts and the resources that are made available (or not) through them. According to Cornell and Hartmann (1998), 'common to circumstantialist approaches . . . is the idea that ethnic groups are largely the products of concrete social and historical situations that – for a variety of reasons – heighten or reduce the salience and/or utility of ethnic and racial identities' (60). Thus, central to the structuralist understanding of ethnicity is not only that ethnic backgrounds can make different resources available to people but also the notion that people can choose to accentuate and/or undermine the importance of their own (and others) ethnic backgrounds depending on the context in which they find themselves.

The latest understanding of ethnicity that scholarship has launched is inspired by the mode of thought that is constructionism. From this perspective, social interaction is crucial to the meanings we attach to people's ethnic backgrounds. Barth's (1969) idea that the ethnicity others ascribe to us, and the ethnicity we claim for ourselves, need not always coincide is one of the key ideas associated with the social constructionist understanding of ethnicity. Understood this way, ethnicity is assumed to be one of the parameters that we use in order to draw boundaries. However, because ethnic boundaries are almost always fluid, the 'we' that we invoke when we describe 'them' is always just as fluid as the 'them' that we describe when 'we' try to separate ourselves from 'the Other'. The boundaries between ethnic and cultural groups are thus permeable precisely because they are situational (cf. Jenkins, 1997).

Ethnicity scholars have gone, in other words, from (a) thinking about ethnicity as a background that determines who we *are* (which is what the essentialist understanding of ethnicity is all about) to (b) thinking of it as a background that can determine what we *have* (*or lack*) (which is what the structuralist understanding of ethnicity wishes to bring attention to) to (c) arguing that ethnicity is best understood if we think of it in terms of what we *do* (which is what the social constructionist understanding of ethnicity urges us to focus on). The understandings of ethnicity that inform scholarship on old age have not, however, evolved this way since this field still relies most often on understandings of ethnicity 'as a fixed, static, invariant characteristic of individuals in homogenous social groups' (Kramer and Barker, 1994, 412). Koehn et al. (2013) have argued that this is so because 'theoretical perspectives that incorporate race/ethnicity/culture are not well-developed in the ageing literature' (ibid., 439). They blame gerontologists' focus on single categories and their reliance

on methodologies that cannot address 'the inherent complexity of the inter-relationships between markers of differences like ethnicity, socio-economic status, gender and immigration status' (ibid., 456) for the under-developed understandings of ethnicity that tends to be characteristic of gerontological scholarship. Although I agree with their assessment, I have elsewhere argued (Torres, 2015b) – based on a literature review of articles published in a limited number of gerontology journals – that part of the reason for this is that scholars in this field tend to rely on essentialist and structuralist understandings of ethnicity instead of the more nuanced understanding of ethnicity that social constructionism offers. The main focus of the research alluded to in the previous section is indicative of this very fact.

Regarding ethnicity in the social constructionist way means shifting focus from *what* ethnicity is to *how* ethnicity is made into something significant, and *when* and *how* it is allowed to play a determinative role in our lives. The social constructionist take on ethnicity proposes namely that ethnic backgrounds are important not only because we sometimes insist on assuming that these backgrounds matter, but also because belonging to an ethnic group and/or being assigned to one by others can open opportunities in some occasions and close them in others. Thus, the social constructionist approach to ethnicity – which is the approach that informs most ethnicity scholars' inquiries these days – accepts that essentialist understandings are still influential to how ethnic minorities regard themselves and how others regard them. It focuses instead on either how these minorities make sense of their backgrounds and/ or how different circumstances assign importance to their backgrounds even when they themselves may not. As such, this approach to ethnicity is not too concerned with what ethnicity is (or what it can mean in terms of what we have) but rather how ethnicity is accomplished in interaction; how ethnicity is done and why it is done in certain ways within different settings.

Conclusion

In alluding to what the literature on health and social care that scholarship on old age and ethnicity has focused on, and what the social justice framework would suggest to be characteristic of this literature, this chapter has claimed not only that injustice is not part of this literature's vernacular at this point in time but also that the social justice lens has not yet been applied to the implicit study of inequalities that this literature could be claimed to focus on. The bulk of articles alluded to in a previous section seem mostly concerned with either *comparing* minorities with their majority counterparts and *stating* that there are inequalities in access and usages or with *shedding light* on the attitudes and preferences that older ethnic minorities uphold in relation to various health and social care services and *stating* that these differ from the ones that characterise what could be considered to be typical of either 'Whites' or the ethnic majority to which these groups are being compared.

This literature focuses, in other words, on bringing attention to older minorities as 'ethnic Others' whose realities we can only grasp if we use the lens that is offered by the ethnic majority. From this it follows that this literature reminds us of the kind of cultural domination to which Fraser's notion of 'the politics of recognition' brings attention. This literature does not namely seem to be too concerned with explaining *why* older ethnic minorities' access, usage, attitudes and preferences as far as health and social care are concerned are different nor does it seem to want to shed light how these populations are 'Othered' by the health and social care institutions that are meant to cater to their needs. The fact that this literature, as a result of this, does not seem to be interested in suggesting what can be done to address the injustices that these differences end up entailing is therefore perhaps understandable. This is namely not what lies at the core of this literature's interests. My contention is therefore that because inquiries into old age and ethnicity are often launched from either an essentialist and/or structuralist perspective, the literature on health and social care seems to be exclusively interested in stating that inequalities exist and not in exploring *how* the injustices that these inequalities entail are de facto created or maintained. As such, this literature seems content to just shed light on the status quo as opposed to want to challenge how things are.

The implicit message that this literature sends is therefore that ethnicity is a background that determines who older ethnic minorities are, and that this is, as such, a background that shapes how these older people regard the health and social care services that are available to them. Thus, one of the reasons why this literature seems to be stuck on stating over and over again that inequalities are at stake as opposed to showing us how they are created and maintained and what we can do to remedy the injustices that these inequalities ultimately entail, is that this literature has yet to regard ethnicity as the 'sets of social relations, characterised by power, that are fundamental structures or organising features of social life' (McMullin, 2000, 525). And since this literature as a whole does not seem to grasp this very fact it does not seem able to move 'beyond the view that these are individual characteristics that create difference' (ibid.; see also Torres, 2019 where these issues are addressed at length).

In the introduction to this chapter I stated that the reason why I wanted to answer the question of how it was possible to study inequalities in the seemingly injustice-unaware way that is characteristic of ethno-gerontology was that I wanted to see if there was something that this field could learn from the social justice framework. One of the conclusions I have drawn is that studying inequalities in the injustice-unaware way that is characteristic of this scholarship makes it possible to shed light on inequalities without holding anybody responsible for them. In approaching inequalities in this manner, this scholarship seems to remain oblivious to the fact that injustices are at stake.

If ethno-gerontologists were to want to expand their imagination in a social justice-informed way, they would need to abandon what seems to be their main interest (i.e. what differentiates these older people from their ethnic majority counterparts) in favour of inquiries into how the so called 'difference'

of older ethnic minorities is accomplished by themselves and others in interaction. The key to being able to remedy the injustices that some of these older people experience lies namely in moving beyond stating the obvious (i.e. that 'belonging' to a minority group increases a person's chances of experiencing inequalities of different kinds) to exploring how inequalities are created and maintained in spite of us knowing that they lead to injustices. A social-justice-informed agenda for ethno-gerontology needs namely to shift this scholarship's focus from who these older ethnic minorities are, and what they need, to what practitioners and policymakers can do to address these older people's needs. And the question all of this raises is, of course, ultimately, what are we as scholars prepared to do in order to design research (and report on findings) in ways that can assist us all in combating the array of injustices that older ethnic minorities face and that we seem content with documenting over and over again.

Note

1 Two databases (i.e. ASSIA & Web of Science: Core Collection) known for indexing a large number of journals in gerontology and ethnicity/migration studies were used (n = 65 journals). In addition, the articles fitting the sampling criteria were searched for in the *Journal of Cross-cultural Gerontology* since this journal is not indexed in the databases used but was deemed important as a dissemination outlet for research at the intersection of old age/ageing and ethnicity race. The keywords used in the search were: ethnicity, minority, race, diversity and/or a label alluding to specific ethnic groups (such as, for example, African Americans). Worth noting is also that only articles that explicitly allude (either in their titles, abstracts and/or keywords) to making a contribution to our understanding of the intersection between old age/ageing and ethnicity/race met the inclusion criteria for the review. This means that articles that were, for example, about older migrants and/or migrant care workers that were not aiming to contribute to our understanding of this intersection were not included in the review.

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12 Migration, ageing and social inclusion

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Introduction

In this chapter, I consider the experience of migrants growing older in a 'new', host community focusing on the roles of migration trajectories, social networks and culture in shaping the experience of social inclusion among older migrants. I draw on data obtained from life history interviews with 66 older Turkish migrants, aged 65 years or more collected in 2012–2013 and 30 interviews with community workers and care workers supporting Turkish older people (see Hussein and Öglak, 2014; Hussein, forthcoming). While Turkish migrants are not as large a proportion of the UK migrant population as they are in other European countries such as Germany, they are a sizeable part of some migrant communities, especially in London.

The analysis is based on Nancy Fraser's trilogy of interrelated factors of social justice: resources, recognition and representation (Fraser, 2007). Fraser's original analysis focused on the re/distribution of economic resources. In my analysis I will focus on social networks as a key resource in migrants' life course. The concept of social networks is used here as a key element of 'resources' within Fraser's trilogy of social justice. It reflects the availability and quality of resources and information in order to achieve certain goals (Fawcett, 1989). The configurations of social networks and their linkages with a selected group, wider community in the host country or country of birth become of paramount importance in understanding their structure and impact on the levels of social inclusion of people as they grow older in the host country (Savage, Bagnal and Longhurst, 2005; Boccagni, 2012).

For recognition, I will discuss the cultural visibility and social status of this particular group of migrants and how these interact with wider recognition of 'migrants' and 'older people' as integrated groups within the wider society. In relation to representation, Fraser (2007) focused on social and political participation and access to justice; here, I will include participation within and outside the 'community' and draw attention to the vexed impact of 'strong social networks' and solidarity in creating support as well as potential of social inclusion. Here, I consider social inclusion of older people as a key component of the social justice discourse (Artiles et al., 2010).

Ageing and migration in context

Ageing might appear as a well-known concept, it simply means 'growing older', yet defining what constitute ageing and how it manifests itself is far from simple. Ageing has diverse definitions and meanings; not only across different cultures but also between various groups within the same society, including between men and women (Vincent, 2003). The meaning of ageing is very much dependent on the context of discussion and debate where it can be a symbol of wisdom and experience or an image of dependency and burden. The simple statement of 'growing older' thus brings both connotations of experiences and disadvantages. Notwithstanding the various definitions of ageing, most societies are organised in a patterned fashion corresponding to various 'stages' in our lives from children, to working adults to older people.

The interaction of culture and ageing can be viewed from different perspectives, likely to be centred on the definition of 'old age' and affected by the cultural norms of a community. Further, the identity of older people from different cultures is shaped by a long and intertwined processes and structures. Generally speaking, studies on ageing and migration tend to link older migrants with notions of 'double' and 'triple' jeopardy, and cumulative advantage/disadvantage (Phillipson, 2015). However, double and triple jeopardy theories have been criticised because of their failure to capture the heterogeneity and inequalities within ethnic groups. Torres (2006) in her study of Iranian immigrants in Sweden argues that these models have resulted in problematising and labelling ethnic minority older adults as a homogenised social category of 'older migrants'; resulting in a narrow focus of attention given by governments, social policy and academics. Within Fraser's framework, older migrants' experience of social (in)justice is shaped by resources, or lack of them, (mis) recognition and how they participate and interact within and outside their closed community. Some of the variability in these core three elements could be explained in part by migrants' histories during their working-age including the types and structures of their engagements in the host countries as well as the extent of their culture and social networks and the processes of accumulating human and social capital (Mutchler and Burr, 2011). At the same time, ethnic and racial backgrounds are important on how 'others' view them and consequently how such perceptions of the others can open or close opportunities within their own communities and the wider host society (Cornell and Hartmann, 1998; Torres, 2013).

The multiple experiences of migration and gender are situated within a complex array of assumptions, practice and environments that are viewed within specific perspectives among different groups within the same place. Such dynamics present further challenges to the meaning of ageing? How does ageing manifest itself within families, communities and states? And what are the implications of the differences observed on individuals and societies? Are all important questions to understand the experience of different groups of older people and attempt to reduce inequalities at old age that are associated with race, gender and cultural backgrounds.

Data

The interviews with older Turkish migrants took place in Turkish culture centres (n = 19); day centres or residential care homes (n = 23); participants own homes (n = 17) and in public places such as coffee shops (n = 7). All interviews were conducted by a Turkish-speaking researcher, recorded with permission, transcribed and then professionally translated to English. Participants had an almost equal gender split, 34 women and 32 men and had a mean age of 72.3 years. The majority of participants originally arrived to the UK to seek paid work (n = 28) or accompanying other family members (n = 13), but a large group of 24 arrived to the UK as refugees. The majority lived with their spouses either on their own or with their adult children. Data collection was through life histories and individual biographies' approach (Denzin and Lincoln, 2000). This was achieved through face-to-face interviews guided by an interview guide focusing on each individual 'story', using prompts when needed to trigger further conversations. We have intentionally avoided constructing a formal process of interviewing, composing the discussion as 'a chat about your life' as a tool of empowering participants and reducing the public/private divide within the research process (Zubair and Victor, 2015).

Migration and resources while growing older

Older migrants are by no means homogenous and many did not necessarily follow difficult migratory paths and trajectories. Some migrant groups including transnational professionals, return or retirement migrants might experience ageing differently in their new countries of destinations (Warnes and Williams, 2006). Yet, the majority of First-generation Turkish migrants to the UK were directly or indirectly recruited into low-paying jobs, in most cases to work within Turkish speaking communities, working as tailors or in shops. This work formed an important part of their social networks' structure and the development of their 'new' social identity as migrants. They joined the UK at a time when immigration policies targeted low-skilled migrant workers. This was triggered, as in the majority of Europe, by the Second World War and consequent severe labour shortages. However, unlike other European countries, the UK did not develop large-scale 'guestworker' programmes to recruit migrants. Instead, most immigration to the UK was spontaneous and, in large, initiated by migrants themselves and was supported by strong social networks spanning between host and home countries. Evren's case (following) represents a typical story of many of the participants in our study.

> My husband had a business in Istanbul. But he went bankrupt and we were stuck in a difficult situation. I had heard from my friend that the tailors earn good money in London. But I was illiterate; I had never gone to primary school however I learnt it [making dresses] by myself. Moreover I do not know English. My friend suggested to come here and to work here. And I took my little daughter and came to London. Next day I began to

> work in a garment workshop. I did not have to speak English because everyone there spoke Turkish. My friend had arranged a room for us. I worked hard and in tough conditions but without any formalities and I worked largely as pieceworker.
>
> (Evren, 72 years, Turkish woman)

This process of migration highlights the crucial role of social networks both at home and in the UK at all stages of the migratory process and post migratory experience. This expanded from the early stages of identifying an opportunity in relation to the migratory destination, then in facilitating the migratory action through continued practical support in finding work and accommodation. The strong social network of the Turkish community in the UK redistributed various resources including practical and emotional support to the then new migrants in many ways. They facilitated the initial act of migration by providing accommodation and connections to a large group of earlier migrants, access to paid work, and knowledge albeit limited and specific to the day-to-day needs of migrants. Ageing for many was not an issue that they reflected upon or considered at their younger ages, it was rather a process that took place in relative silence, only surfacing with the onset of health conditions or the cessation of work. In most cases, there was little awareness of what they could do once their informal employment ceased to exist.

There is paucity of research investigating the social life of older migrants and its relationship with the wider community and environment. The vast majority of participants in this study were regular visitors to their local culture centres, indicating great potential for such centres to play key roles in promoting well-being and reducing social isolation at old age. Here, the 'community' and the environment of the Turkish culture centre acted as facilitator for social activities and as a great resource. However, the type of activities was not gender neutral and the nature of 'engagement' was still very confined to almost the same group of Turkish older migrants, prohibiting the development of new social networks. During the interviews some older women felt particularly excluded because of limited language proficiency as well as their gender when the community centre failed to provide specific activities for women.

> Men go the Turkish Cafe or Turkish Community Centre but we [women] are not included in any Centre.
>
> (Ayşe, 62 years, Cypriot woman)

Accessing the wider community, whether for care needs or social and well-being support, was more restricted. The analysis shows that language and communication issues were evident barriers acting on at least three levels. Such challenges were presented pre, during and post communications in all life aspects and in particularly in relation to accessing health and social care support. Language barriers were evident in approaching outside support as well as during receiving support, where many felt limited ability to communicate their needs and preferences and ended up accepting their own assumptions

as facts. Then among those who experienced receiving support from outside the Turkish community some felt they were being mistreated, misunderstood, or in some cases humiliated. It was difficult to establish if these incidents of mistreatment were genuine or were simply perceived due to lack of their ability to effectively communicate their own feelings and needs.

Migration and recognition at old age

Older migrants' biographical stories involved the acceptance of losses, as of the work role and importance within the Turkish community and in many cases indicated a mismatch between hopes and reality. Many of our participants came from depressed rural areas and had relatively little education and few formal or technical job skills.

For many migrants there was a preference to receive support from their close family members or at least from Turkish workers. Many were in receipt of social care benefits such as personal budgets, which forms a corner stone of the personalisation agenda of the English social care system (Boxall, Dowson and Beresford, 2009), and used such benefits to facilitate receiving care from their close social network. Older Turkish migrants perceived these arrangements as the most desirable options to addressing their care needs, which would minimise potential conflicts related to cultural and language preferences. By maintaining care exchange within the same network they have effectively extending their reliance, although more formally, on their close social network particularly their family. However, it was clear that other options of care provision were not usually explored or weighted up against the opportunity of continuing this emotional exchange within their closest social network. Indeed, the narratives from this study included examples where this type of reliance did not seem to be the best option, and in some cases appeared to pose some further risks of neglect or abuse. More generally, retaining the interaction within the same social network into old age posed certain challenges in relation to feelings of isolation and social exclusion at old age

The interviews with Turkish community support workers indicated some misassumptions about Turkish older people, particularly in relation to the availability, willingness and quality of their social capital and their role in older people's well-being.

> They [the Government] think that our elderly people stay with us but we use some social care services at home such as home help, meals on wheels, from Council or Government.
>
> (Turkish Care Co-ordinator)

There was also an expressed lack of recognition among the participants of how older people in general, and migrant older people in particular, were treated by the wider public. For example, many participants related to 'bad stories' they have heard concerning older people who receive formal long-term care including incidents of mistreatment and neglect. They used such stories to justify their lack

of acceptance of help and support from outside their closed community. The latter highlights the power of closed social networks in exchanging information and their limitations in reflecting the wider experience of other older people who have more positive experiences. Thus, a combined effect of communication difficulties and lack of awareness of suitable activities and support, through a selective pool of experiences, made many older Turkish migrants prefer to stay within the comfort zone of the Turkish community, both formally and informally, regardless of whether this was best meeting their needs or not.

However, some older Turkish migrants also questioned the assumptions of filial obligations, where the wider community assumes they will be looked after and treated with respect by their offspring and family members (Valk and Schans, 2008). Furthermore, older women strongly felt that duties towards their husbands' care and their children and grandchildren come first, and in many situations they expressed a strong feeling of marginalisation.

> They [my family] don't give me any respect and as a person, I feel very alone in my home. Never go out, always at home and in front of TV.
>
> (Frieda, 83 years, Turkish woman)

In Frieda's case there seemed to be signs of emotional abuse and neglect and her experience highlights the complexity of family relations that could be observed in all cultures and cautioned from simplistic assumptions related to family care and concepts of filial obligations (Cylwik, 2002; Nauck, 2005).

Generally, Alevi community tends to keep to itself, particularly through membership of associations, which (though not exclusively) are likely to have a strong political engagement. Therefore, the 'England Alevi Cultural Centre & Cemevi (IAKMC)' was established in 1993, with the aims of preserving their cultural and religious identities and providing social support. The IAKMC also aimed to have a 'social mission' to address economical, and social problems, offering consultancy services with culturally oriented activities (Wahlbeck, 2002). IAKMC has membership of over three thousand, forming one of the biggest non-governmental organisations with Turkish origin in England. It was no surprise that for most Alevi/Kurdish older people in the sample. The IAKMC was very important and many participated regularly within this community.

Migration and representation at old age

The representation of migrants in the British public space is both problematic and yet over simplified. The discourse of public image of migrants in Britain has continued to take a central stage in various domestic debates from economic participation/pressure to national threats and terrorism (Duffy and Frere-Smith, 2014). The representation of migrants is, in general, focused disproportionately on 'illegal' immigration and asylum seekers/refugees with very little coverage of the significant contribution of migrants in the labour market and the UK higher

education system (Blinder and Allen, 2016). The negative coverage of illegal migrants and asylum seekers is usually generalised to include all 'migrants' fuelling anti-immigration and racial sentiments (Threadgold, 2009; Balch and Balabanova, 2016). Despite some recognition of the growing populations of 'migrant' older people in the UK and Europe, the representation of older migrants, let alone older migrant women, is almost absent in the media and policy debates (Cela and Fokkema, 2017). The limited body of research focusing on older migrants in Europe portrays negative health and social experiences of higher rates of isolation and unmet needs. Part of such (mis)representation is the tendency to consider labour migration as a 'temporary' phenomenon, such perception is not only present among policymakers but among migrant groups themselves.

Another reason for the absence of older migrants from the public debate is their current age profile, with fewer numbers currently considered 'older' than the general population. While this might be the current state, there is general agreement that there will be more migrant older people in the UK, simply because people from all communities are living longer. It is projected that by 2051 the ethnic groups with the highest proportions of people aged 50 and over will be 'other White', Chinese, 'other Asian', White British, Indian, 'other' and White Irish (Lievesley, 2010).

Research highlights a wish among various groups of older migrants in Europe to return to their home countries at one point, however, such 'wish' remains as such due to practical and family commitments (Warnes and Williams, 2006). During the interviews with Turkish older migrants, they were prompted to talk about their preferred place to grow older. The majority appreciated being in the UK with only five participants said they were actively considering returning back to Turkey to spend their later years of life. Their reasons for wishing to return 'home' were explained in relation to cultural issues, to be better understood by the wider community and the availability of larger social network in Turkey and general nostalgia to better weather and a familiar place from their childhood and youth memories.

The vast majority of participants (n = 61) were certain that they will continue living in the UK, some highlighting the better care services offered to older people in the UK when compared to Turkey while the majority explained that most of their social networks including immediate families were already in the UK and thus they felt a sense of belonging to the UK; '*here is my real homeland*'. The social construct of their identities seemed to be fluid with time and circumstances. While they tended to identify their belonging to the UK as older people in need of care and support they were in fact referring to their strong socially constructed networks rather than the wider British society. Further, many of the participants were more influenced by their own perception of ageing as young adults when migrated from Turkey than becoming an older 'British' citizen, thus reflecting a perception of ageing that related to a different place (Turkey) but that might have also related to a different generation (how their own grandparents have aged for example).

Social participation of this particular group of older Turkish migrants seemed to revolve around family obligations, such as grand-parenting and looking after spouses for women, and heavy involvement in the cultural centres and their activities among men. The culture centres offered access to Turkish movies, TV and music as well as food and old games. They offered a safe place where older men can speak in Turkish with other people who share similar histories.

Lütfi, a 66-year-old man who arrived to the UK 30 years prior to our interview, has made a clear effort to access wider activities. He originally came looking for work but had never 'formally' worked but managed to provide paid 'help' to friends. He brought his wife and had four children who all lived near by his home in London. Lütfi was one of the most active participants despite his poor command of the English language; he had a gym membership through his local council and swam regularly, at least twice a week. When we asked him where he would prefer to spend the next ten years of his life, he quickly said '*in the UK*', when prompt why, he said '*this is my 'homeland' now, here is my wife and children and I am happy here*'. The gender influence in Lütfi's case should not be ignored as none of the women we interviewed referred to participating in activities involving the wider British society not the least sporting activities such as swimming. Lütfi's grown up children were also important in shaping his outlook to life, they have actively encouraged him to join the local gym and lived geographically close to him providing support when needed. They have thus acted as a bridge to a wider set of networks.

Discussion

It is important to note the limitation of this sample of older Turkish migrants and their representation to the wider older Turkish community in the UK. The interviews were based in North London, where many of the older Turkish migrant communities initially settled. The group who remained geographically immobile since arrival may not fully represent other Turkish migrants who had moved to other parts of the UK due to employment, family or other reasons. I have also used the culture centres to initiate participants' recruitment process; the sample thus may over represent those who make use of the culture centres more regularly. This sample lived in some of the most deprived urban areas in the UK and previous research (Scharf, Phillipson, Smith, 2005) has shown that older people in deprived urban areas have longer length of residency and tend to age in place more than others. Older people within these settings tend to suffer from multiple exclusions due to a set of disadvantages including limited social relations, low working-life income and long residency in low-status neighbourhood (Scharf, Phillipson, Smith, 2002; Scharf, Phillipson, Smith, 2005).

The experiences of older Turkish migrants presented in this analysis highlight the importance of the intersectionality of migrants' background in their experience of ageing and over all levels of social inclusion (Dannefer and Settersten, 2010). Following Fraser's concept as a framework of understanding the experience of older migrants, we find their core resources to be their social networks

which shaped most of the processes associated with accumulation of human and social capital, work and employment trajectories and cultural ties (Mutchler and Burr, 2011) emphasising the importance of considering migrants' identity, in part, as a social construct of what group identity means at old age. Here the level of involvement of various actors, such as family and friends, in the migration process is likely to impact on individual migrants' post migration wider choices and decisions. These decisions may include maintaining and formulating old and new networks and interacting with various layers of the 'new' society as well as the continuity and strength of transnational ties and connections with the country of birth (Castles, 2010). Within such context, the composition of social networks consists of a multiplicity of social actors and groups.

The migration journeys of all participants in our study were highly influenced and initiated by self and closest networks including family and friends in Turkey and the UK. Where such networks formed a key resource for a considerable part of their lives. Their biographies indicate a process of a social network building that involved interchanging support and reliance on a specific social group that unintentionally comes with a long process of isolation from the wider communities of the host society (the UK) through informal working, limited opportunities to acquire transferable skills including language and dependency on information exchanged within a closed network. Thus, while the resources they had were essential to complete their migratory goals 'successfully', to the contrary to Fraser's theory, this particular type of resource did not provide a basic component in their experience of social inclusion, and potential social justice in the host country. In this context, thus, resources in the form of strong elective social networks did not enhance the social inclusion of older migrants but perhaps facilitated a sense of ambivalence of own belonging as older people within the wider British society (Grillo, 2007). What was clear from the analysis is that older migrants lacked the type of 'resources' necessary for facilitating a path to social inclusion and social justice within the wider British society.

Recognition is a key component in people and group's levels of social inclusion and (in)justice. Honneth (2006) argues that experiences of mis-recognition are the fuel of contemporary social and political struggles, and mutual recognition is the most relevant criterion of justice. Not only how a group recognises itself is important, but how various groups are recognised and understood by the wider community is even more important. The path to older age for most participating migrant older people was formed through the identification with an 'elective belonging', referring to the way in which 'place biographies' have become less important than their personal biographies and identities (Phillipson, 2007; Buffel, 2017). The discrepancies between the preferred and actual place of ageing resulted in a high degree of feelings of social exclusion at later age and a sense of marginalisation from the wider community, which had been observed among other groups of migrants in previous studies (Buffel, 2017). These feelings formulated how they recognise themselves and how they feel they are recognised by the wider society. Older migrants with certain political background, such as Alevi or Kurdish, established a further political identity

through creating a diaspora as a notion of self-portrayal and political mobilisation (Wahlbeck, 2002). Here, cultural centres played an important role in identity recognition and support mechanisms. A body of literature points to the interplay between the notion of diaspora and feelings of marginalisation, disadvantages and the continued struggle for recognition (Brubaker, 2005), yet they remain regarded as the 'dangerous enemy within' or as 'agents of change' (Kleist, 2008). The empirical data reflect a greater sense of belonging to a certain identity among the group who arrived as refugees with Alevi/Kurdish background, where there appeared to be a greater resistance among this group to interact with the wider community.

The findings indicate a general feeling of lack of recognition among older Turkish migrants; these were manifested in some cases as a constant perception of being mistreated and misunderstood. The perceived assumptions by the wider British public of the availability and willingness to provide for 'their' older people are equally questioned and added to lack of recognition of the needs of older migrants. Fraser emphasises the need for both redistribution of resources and recognition as key requirement for social justice (Fraser, 1996). The way to incorporate both, she argues, is through a comprehensive framework where differences are recognised, through a norm of participatory parity, and fair redistribution of resources.

To capture the level of social participation, rather than political participation, I considered how older migrants actively participated within and outside of their 'communities'. As a pivotal point, the analysis shows that the majority of migrants did not anticipate growing older in their destination country with significant implications not only for their planning towards old age but also for their acceptance of being 'older people' within the British society. The representation and social participation of older migrants were shaped by the continued connections with the social networks formed during the migratory journey as well as their political identity as the case with Alevi/Kurdish older migrants (Öglak and Hussein, 2016). Only a handful of migrants interviewed made a clear effort to create and maintain connections with the wider British community. Almost all of this group were men and the processes were, in the majority facilitated, by their grown-up offspring, who were well educated and were able to facilitate some form of participation. Thus, working with second-generation migrants and addressing gender differences could prove fruitful in facilitating meaningful social, and potentially civic, participation and representation of older migrants.

The findings of this study have wider implications as they resonate to a large extent with the experience of other older Black and minority ethnic communities in the UK (Victor, Martin and Zubair, 2012). For Turkish older migrants, social networks were key resource that provided them with significant safety nets at crucial times in their lives. However, the same 'resource' created unintentional isolating bubbles from the wider society for prolonged periods of time, which had negative implications on the way they felt they are recognised and on how they actively sought representation. Turkish culture centres play a crucial part in providing safe places for communication and social activities,

which could be utilised to extend migrants' own social networks. These centres can also act as a starting point for information sharing and support, including awareness-raising of individuals' own rights and to enhance their broader representations.

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13 Older migrants

Inequalities of ageing from a transnational perspective

Alistair Hunter

Introduction

In many parts of the world, the population of older migrants is increasing. Relatively wealthy individuals from Northern Europe, North America and Australasia move in later life to retirement destinations in South America, South-East Asia and the Mediterranean region, for reasons of climate, affordability and other 'lifestyle' factors (King, Warnes and Williams, 2000; Hayes, 2014; Botterill, 2017).[1] Conversely, young workers from the Global South who responded to the demand for migrant labour in the Global North following World War II have now settled and aged in place. Statistical projections in Austria, Britain,[2] France, New Zealand and the United States point to rapid increases in the numbers of older foreign-born residents (Rallu, 2017).

Mainstream gerontology has been slow to grasp the significance of migration-related diversity within the older population, and of the inequalities which map onto this diversity in intersecting ways. This chapter seeks to build on the insights of the small body of work which has addressed migration-related diversity within gerontology (e.g. Samaoli, 1999; Blakemore, 1999; Burholt, 2004; Warnes et al., 2004; Torres, 2006; Victor, Burholt and Martin, 2012), by paying special attention to inequalities. I argue that these inequalities can be better grasped by adopting a *transnational comparative lens* which is sensitive to older migrants' 'duality of references', encompassing both countries of origin and destination (Bolzman, Fibbi and Vial, 2006, 1361). For the purposes of this chapter, migration is taken to mean international migration, that is to say a change in a person's habitual place of residence by moving across an international border. The qualifier *habitual* serves to indicate that such a change in residence is relatively durable, typically defined as lasting one year or more. The chapter's focus on migration likewise serves to differentiate it from a longer established literature on ageing and ethnicity (Dowd and Bengtson, 1978). Indeed, research in this area has tended to conflate migration background with ethnicity (cf. Heisig, Lancee and Radl, 2017). In prioritising migration background, I do not mean to imply that migrants' ethnicity is irrelevant in struggles for equality – quite the contrary, as Sandra Torres' contribution to this volume ably shows. Rather I wish to highlight the importance of analysing ethnicity

and migrant status as separate (but often interacting) variables. This task will only become more important in the decades to come as we see increasing numbers of older ethnic minority individuals in the Global North who are *not* migrants but rather the children of migrants who settled.

Like the other contributions to this volume, this chapter takes a social justice approach to inequality, drawing on Nancy Fraser's three-dimensional model of social justice as *resources*, *recognition* and *representation*. I will show that the disjuncture of international migration has potentially far-reaching consequences across all three domains. Some older lifestyle migrants move in order to maximise their standard of living in old age by relocating to a country where their retirement income goes further. Such late-in-life mobility challenges gerontological models which prioritise personal and social continuity as the basis for successful ageing (Torres, 2006). Conversely, for many older migrants who have aged in place in the Global North, the systemic employment disadvantages which they faced during working life lead to inequalities in their access to financial and social resources in later life. Parity of access to such resources may also be hindered by lack of recognition of language needs and cultural and religious practices, for example in health and social care. In response, some migrants seek access to institutions of political and legal representation, in order to further such demands for recognition when faced with resistance. Yet many older migrants face exclusion from political and legal institutions, both those ageing in place in the Global North and lifestyle migrants who move abroad following retirement. A transnational comparative analysis of such inequalities *both in places of origin and destination* offers a more nuanced understanding of the complex accumulation of circumstances which older migrants negotiate, showing that while they may face disadvantage relative to non-migrant peers in one setting, they may be comparatively well-off in the other setting.

International migration, ageing and inequalities: an analytical framework

Insofar as later life is usually characterised by greater reliance on social protection, international borders – and the degree to which social protection is portable across them – may be especially salient for older people (Böcker and Hunter, 2017). International borders constitute what Michael Bommes called 'thresholds of inequality' between countries with differing welfare regimes (Bommes, 2000, 91). Bommes is one of the few scholars to consider questions of migration, inequality and the role of the welfare state. Indeed, research on migration has been critiqued for neglecting the multifaceted relationship between migration and inequality (Faist, 2016). When this relationship is discussed, the focus is usually limited to inequalities in income distribution, with individuals motivated to move to where wages are higher and where their labour yields greater reward (Galbraith, 1979; Faist, 2016).

To confine the discussion of migration and inequalities to economic resources is overly narrow. In older age, social resources become important, such as access

to care and informal support. This is an insight developed by Nancy Fraser in her later work on social justice. Furthermore, as Fraser contends, justice is not only about the *redistribution* of resources but also about *recognition* of marginalised identities and groups which have historically faced disadvantage and discrimination in direct or indirect ways, for example due to gender, ethnicity and sexual identity (Fraser, 2007). Indeed, Fraser's analysis of the feminist movement since the emergence of neoliberal ideology in the 1980s highlights that struggles for redistribution have increasingly become subsumed to identity politics. The third dimension of Fraser's framework, *representation*, relates to the political realm of inclusion in governance structures and decision-making procedures (Fraser et al., 2004).

Following the other contributions to this edited collection, this chapter's analysis will be structured according to the three dimensions of resources, recognition and representation. The next section will briefly review the literature on older migrants and outline how Fraser's framework of resources, recognition and representation can be adapted to offer a transnational comparative lens on inequality.

Older migrants: a topic of surging interest

The academic literature on older migrants has grown considerably in a short space of time. With rare exceptions, academic interest in older migrants did not materialise until the late 1990s (Blakemore, 1999; Samaoli, 1999; King et al., 2000). However, recent years have witnessed a veritable surge of interest, including several edited collections (Horn and Schweppe, 2016; Karl and Torres, 2016; Walsh and Näre, 2016) and journal special issues (Ciobanu and Hunter, 2017; Ciobanu, Fokkema and Nedelcu, 2017). From the outset, this body of work has been cognisant of the diversity of older migrants, comprising some of the most advantaged in society as well as some of the least endowed, be that in terms of wealth, health, human capital or rights of residence. Warnes et al. (2004) point to this diversity in categorising older individuals who migrate into three groups: relatively affluent older people who move based on considerations such as higher standard of living, better climate or attractive scenery (amenity-seeking or 'lifestyle' migration); individuals who move to join adult children who emigrated previously (family-joining migration); and those who return to their places of origin after having spent their working lives abroad (retirement return migration).

In terms of the relative attention given to these different categories, lifestyle migration has generated a considerable body of literature (e.g. King et al., 2000; Hayes, 2014; Botterill, 2017). Less attention has been paid to retirement return (Baykara-Krumme and Platt, 2016; Hunter, 2018) and family-joining migration in later life (Nedelcu, 2009), an indication that these forms of late-in-mobility are both less common and less readily observable compared with lifestyle migrants, who tend to congregate in particular destination regions. As regards

retirement return, the available quantitative data suggest that definitive return is a minority preference, with most migrant workers ageing 'in place' (Attias-Donfut, Tessier and Wolff, 2005; Bolzman, Kaeser and Christe, 2017).

Increasingly, however, the distinction between ageing in place and definitive return fails to capture the reality of 'transnational ageing', namely the complex and multi-sited living arrangements which many older migrants adopt.[3] In particular, patterns of back-and-forth mobility between countries of destination and origin are increasingly in evidence among older migrants (Attias-Donfut, Tessier and Wolff, 2005; Bolzman, Kaeser and Christe, 2017; Hunter, 2018).[4] Warnes (2009, 359–360) speaks of 'transnational patterns of residence' by which 'older people can exploit, maintain and continue to develop residential opportunities, social networks and welfare entitlements in more than one country', facilitated by cheaper international travel and advances in communications technology. This 'bi-residence' option may be a means to experience the 'best of both worlds', maximising the benefit of having a 'duality of resources and references' (Bolzman, Kaeser and Christe, 2006, 1361). Yet it may also engender feelings of 'double absence' (Sayad, 1999), of being marginal both in the place of origin and the destination country. While most studies examining these residence patterns have drawn upon research with older people who migrated in early adulthood for (often low-skilled) work, it is important to acknowledge that other categories of older people engage in transnational ageing, including lifestyle migrants and family-joiners (Horn and Schweppe, 2016).

As transnational ageing becomes more and more practicable for an increasing number of people, it seems imperative to consider older migrants' dual resources and references when thinking through questions of equality which touch this population. The key analytical point I wish to underline in this chapter, therefore, is the importance of viewing inequalities experienced by migrants in a transnational comparative perspective. To seize the significance of dual references and resources (Bolzman, Kaeser and Christe, 2006) requires us to focus on inequalities between older migrants and non-migrant older people, both at the places of destination and departure. This call is echoed by Thomas Faist (2016, 331), who alludes to 'the often disparate social positions of migrants in immigration and emigration countries'. Such inequalities may be observed in standardised measures and survey instruments, as well as subjectively perceived by migrants themselves.

A further advantage of adopting a transnational comparative lens is that it disrupts the homogenising narratives which the above categorisations sometimes reinforce, such as 'vulnerable' former guestworkers ageing in place, or as 'privileged' globe-trotting lifestyle migrants. As a number of recent contributions underline, it is important to grasp the diversity of lived experiences *within* these socially constructed categories (Ciobanu, Fokkema and Nedelcu, 2017). To give some empirical underpinning to this comparative transnational application of Fraser's framework, I will now give some applied examples for each category – resources, recognition and representation.

Resources: inequalities flowing from the division of labour, globally and locally

Economic resources and access to health care or informal support are among the most important components of quality of life for older people (Moriarty and Butt, 2004; Motel-Klingebiel, 2006). The prominence of such economic and social resources in the literature is reflected in the weight accorded to resources in this chapter, as compared to the somewhat shorter sections on recognition and representation.

Economic resources

The value of applying a transnational lens to older migrants' experience of inequalities in older age is evident when considering economic resources. Migrant workers may have low socio-economic status in the destination country, but experience considerable social mobility vis-à-vis peers in the place of origin (Faist, 2016). Similarly, lifestyle migrants may have a high standard of living abroad, yet their decision to emigrate may have been made in part to avoid hardship in old age in a context of diminished retirement security and welfare retrenchment in the Global North (Hayes, 2014). In both cases, for migrant workers and lifestyle migrants alike, these comparative advantages are predicated on

> the global division of labour which has benefited workers whose labour was located in the Global North over those in the Global South . . . [Through] transnational mobility . . . privileges gained at higher latitudes of the global division of labour can be cashed out at lower latitudes.
>
> (Hayes, 2014, 1966)

The capacity to engage in transnational mobility to capitalise on these global disparities is subject to constraints, however. Older lifestyle migrants may be vulnerable to policy shifts and changes in the wider economy which leave them in a more precarious position, such as unfavourable currency exchange rates and lack of affordable state-provided health care, necessitating very expensive private health insurance (Botterill, 2017).[5] Likewise, many former labour migrants face barriers to transnational mobility due to work-related poor health, and are thus obliged to spend most of their time in the Global North where they are more likely to experience poverty compared to non-migrants (Heisig, Lancee and Radl, 2017). Research in different European countries has shown that migrant-origin populations are less likely to have sufficient contributory pension funds and therefore more likely to rely on the minimum subsistence level afforded by means-tested income support (Ginn and Arber, 2001; Kaeser, 2015; Böcker and Hunter, 2017). The smaller pensions drawn by migrants are in part due to systemic disadvantage, a consequence of their later entry to the labour market (and thus shorter period amassing a pension

fund) compared with non-migrants. This trend is observed in many European countries (Bommes, 2000; Ginn and Arber, 2001; Harrysson, Montesino and Werner, 2016; Heisig, Lancee and Radl, 2017).

Intersecting with migration background is the crucial variable of gender, which reveals wide disparities in income after retirement in various European countries, particularly for foreign-born populations (Ginn and Arber, 2001; Heisig, Lancee and Radl, 2017). These differences are largely due to labour market participation and are explained by motivations for emigration, with older males having largely moved for work while family reasons were the most common motivation among older heterosexual women, i.e. to join a male partner already abroad in the context of family formation or reunification (Gallou, 2006). Within migrant populations major differences by origin can be observed in the labour market participation of women, with females from Pakistan and Bangladesh having very low labour market participation in Britain (Ginn and Arber, 2001). In later life, such patterns translate into very low or non-existent pension funds for women compared with men. Given women's longer life expectancy, the prospect of poverty for many migrant women in later life is very real, to which must be added increased likelihood of dementia and loneliness in widowhood (Gallou, 2006).

Despite the economic disadvantages often faced in destination countries, older migrants hold favourable views of their social mobility (Kaeser, 2015), being more positive in their evaluations of social mobility than their non-migrant contemporaries (Attias-Donfut, Tessier and Wolff, 2005). Although counter-intuitive at first glance, this perception of social mobility is explained by the fact that older migrants make such judgements with reference to the lives they would have led in countries of origin, had they not emigrated (Kaeser, 2015). And for many migrants ageing in place, the standard of living they enjoy in older age is higher than their peers 'back home' (Baykara-Krumme and Platt, 2016), bolstered by pensions and other forms of social protection which are rare or non-existent in countries of origin. Furthermore, pensions are often exportable to countries of origin with minimal financial penalties and, thanks to favourable differences in costs of living, are worth much more there than in the country where the pension was accumulated (Hunter, 2018). Thus, while relatively deprived in the destination country, in home countries older migrants may be rather well-off vis-à-vis their 'left-behind' relatives and friends, with whom many continue to maintain links. These transnational connections are nourished through regular transfers of money by migrants, creating new inequalities between remittance-receiving households and those without a member abroad (Bracking and Sachikonye, 2010). A transnational perspective on ageing and inequality brings into relief these dynamics.

Social resources

Maintaining physical and psychological health, and accessing appropriate care and support when health diminishes, constitutes the most important component

of quality of life in older age (Motel-Klingebiel, 2006). In Europe, the proportion of older people declaring to be in poor health is higher amongst migrants than non-migrant older people (Lanari and Bussini, 2012; Hjelm and Albin, 2014; Kaeser, 2015). These differences can be attributed in part to migrants' greater exposure to fatiguing work conditions and work accidents (Moriarty and Butt, 2004; Kaeser, 2015; Hunter, 2018), as well as lack of access to or familiarity with health care systems, thereby over time negating the 'healthy migrant' effect which is widely held to determine who migrates in the first place (Lanari and Bussini, 2012). Older migrants also report poorer mental health than non-migrant elders. A study by Lanari and Bussini (2012) analysing the first wave of data from the pan-European 'Survey on Health, Ageing and Retirement in Europe' (SHARE) found that 45% of foreign-born respondents aged over 50 experienced depressive symptoms, compared with 35% for those not born abroad.

The act of migrating, at least in the short term, imperils health insofar as migrants are cut off from their customary networks of support and care. While this may be temporary, such disruption to support networks often persists across the life course, compounded by other factors of disadvantage such as poverty. A transnational comparative perspective is yet again valuable here. With regard to migrants' countries of origin, in Ireland Barrett and Mosca (2013) analysed quantitative data and found that return migrants are more likely to be socially isolated than their age peers who had never left Ireland. In another quantitative analysis, but this time centred on a destination country (Germany), Fokkema and Naderi (2013) highlighted the higher incidence of loneliness among older adults of Turkish origin vis-à-vis their non-migrant German peers (see also Victor, Burholt and Martin, 2012). Similarly, qualitative research has drawn attention to worrying trends of depression and alcoholism among some older lifestyle migrants, particularly older men (Botterill, 2017).

These findings on loneliness and depression indicate that the level of informal support received from relatives and friends is a key factor. This is a subject of much debate in the field. Stewart et al. (2008) note that meanings and norms of support are culturally-contingent, informing either collectivist or more self-sufficient attitudes about giving and receiving care. However, prioritising 'culture' may lead service providers to make stereotyped assumptions about the needs of older migrants (Torres, Ågård and Milberg, 2016). A culturalist narrative that informal support is more common in migrant-origin communities has been regularly documented among welfare providers, who assume that there is therefore less need for their formal interventions (Willis, Price and Glaser, 2013). Whether informal support is actually received is of course a different matter, and other studies have shown that this is not always the case, with the potential for ambivalent attitudes among older migrants, caught between expectations of care and not wishing to be a burden upon one's children (Cook, 2010).

Where the possibilities for informal care are diminished due to lack of family or friendship networks, ageing migrants are likely to require greater input from

formal care providers (Hunter, 2018). Despite their greater health needs, most studies have found that older migrants make less use of health care services than non-migrant seniors (Hjelm and Albin, 2014). Furthermore, when care services are used by older migrants, surveys have found that they are less satisfied than the non-migrant majority population. In a study looking at ethnic variations in satisfaction with social care in the UK, understanding how the care system works was found to be a key determinant of satisfaction, and here again poor language proficiency was shown to be an important barrier to care (Willis, Price and Glaser, 2016). Similarly in health care settings, '[p]eople's ability to understand what was happening to them, to share important information and to participate in their care was significantly constrained – if not eliminated – where language barriers existed' (Ellins and Glasby, 2016, 59). The problem of language barriers in accessing care leads to the second strand of Fraser's framework, *recognition*.

Recognition: language, cultural competence, racism and female empowerment

Care can be straightforwardly conceptualised as a type of resource, but for older migrants it is also a question of recognition, including recognition of migrants' language needs. Cook's research with older women from Somalia and Hong Kong who migrated to the UK in later life underscores the barriers constituted by non-recognition of languages when it comes to accessing welfare services (Cook, 2010). Unfortunately, interpretation services 'are still woefully inadequate and under-funded' (ibid., 265). Those who migrate in later life tend to be less proficient in local languages, since they have had fewer opportunities to acquire fluency through, for example, labour market participation (Burholt, 2004). This is particularly the case for vulnerable recent arrivals such as older refugees. Cook (2010) documents major language barriers to accessing services, including in health care. Younger family members were not always able to assist with interpreting due to school or work commitments: when they did help, this sometimes compounded their older relatives' sense of dependency (ibid.).

However, it is not only recognition of language needs which is at stake when older migrants try to access care and support, but also cultural and religious norms, such as dietary needs (Ellins and Glasby, 2016). The latter factors have been discussed at length in the large literature which now exists on 'cultural competence' in care settings (Alizadeh and Chavan, 2016). Despite the evident popularity of cultural competence as a concept, there is a lack of empirical evidence on the efficacy of this approach (ibid.). Indeed, scholars – particularly in the field of palliative care – have critiqued the concept due to 'the essentialisation that takes place when stereotypical assumptions about patients' ethnocultural backgrounds are used as a compass to guide the care they receive' (Torres, Ågård and Milberg, 2016, 104; see also Gunaratnam, 2013).

When service providers fail in their duty to ensure parity of access to their services for different groups on the basis of cultural inferiority and cultural

stereotypes, racism is at work (Moriarty and Butt, 2004). One reason why racism has been marginalised in this research area is that much racism goes unreported and it is therefore difficult to reliably gauge its extent (ibid.). In the UK, Cook (2010) reported older Irish and Somali women's experiences of racist attitudes among officials at welfare agencies. In their mixed-methods research, Moriarty and Butt (2004) found that around a half of their minority ethnic respondents had experienced racism, either in the form of physical or verbal abuse, or unfair treatment in the workplace. Furthermore, these individuals were more likely to mention financial worries or complain of isolation: the former may be a consequence of blocked career advancement, while the latter may reflect neighbourhood dissatisfaction and fears about going out (Moriarty and Butt, 2004). In my own research in France, I encountered numerous instances of public bodies disproportionately targeting older foreign-born people when investigating social security fraud (Hunter, 2018).

Sexism is a further manifestation of mis-recognition which denies parity of participation in social life. Whether migration impedes or facilitates equality for women is a topic of considerable debate in migration studies. Once again, taking a comparative transnational view of origin and destination contexts can be instructive. Many studies have found that women who migrate, either singly or via family reunification, value the increased autonomy which they enjoy in destination countries vis-à-vis their peers 'left behind' (Böcker and Gehring, 2015). This autonomy is often mentioned as a reason why (heterosexual) women are usually less keen than their partners to return home after retirement (ibid.). Turning to countries of origin, the evidence is mixed as to whether 'left behind' women gain in autonomy during the absence of émigré fathers, brothers and husbands (see Lenoël, 2017 for overview). Interestingly, Lenoël's research in Morocco shows that the empowerment of left-behind spouses, when it occurs, is linked to lifecycle stage, with women experiencing greater autonomy later in life once their responsibilities to their husbands' parents come to an end (often following the death of the latter), enabling them to set up their own nuclear households and control how remittances are spent (ibid.).

This overview of the multiple axes of identity implicated in older migrants' (and stayers') struggles for recognition leads me to the third strand of Fraser's framework – access to institutions of political and legal representation – in order to further such demands for recognition when faced with resistance.

Representation: the potential to act politically but dependent on the locus of citizenship

A key debate among theorists of democracy pits those who espouse a more active role for citizens through pluralistic, deliberative forms of representation against those who favour a more minimal, passive role via the election of professional politicians to represent ordinary citizens. Yet as Urbinati and Warren (2008, 394) contend,

> Important though these debates about active versus passive representation were, they glossed over the glaring fact that many groups within the established democracies lacked even passive inclusion . . . particularly those based on gender, ethnicity and race.

This political exclusion certainly applies also to migrants. In European countries which encouraged labour migration after World War II, migrants who have aged in place tend to be poorly represented. Indeed, ageing migrants were for a long time invisible in public policy due to the assumption that they would return to countries of origin before reaching old age (Kaeser, 2015). The persistence of this 'myth of return' in policymakers' imaginations has led to a lack of concerted planning for the challenges of a more ethnically diverse ageing population. When older migrants do come to public consciousness, it is often in negative terms – for example in scandals around poor housing, social security fraud or social care (Hunter, 2018). In some European countries, these problems have led to the commissioning of government reports, but concrete policy measures have been slow to emerge (Böcker and Hunter, 2017).

One reason for this lack of urgency among policymakers is that many migrants ageing in Europe do not have electoral voting rights. In most European countries, only those migrants who have naturalised may vote in national elections.[6] In Austria, France, Germany and Italy the electoral exclusion of third-country nationals even applies to local elections. The same exclusions on foreign nationals also apply to electoral candidacy. In any case, setting aside migrant status for one moment, politicians of ethnic minority backgrounds are under-represented in national political systems. In the UK, 6% of members in the two Houses of Parliament were of an ethnic minority background prior to the 2017 General Election, yet ethnic minorities compose 13% of the total UK population (Audickas et al., 2016). 6% of members of the German Federal Parliament were from a migrant background as of 2013, compared with 20% for the overall population (ibid.).

Despite these statistics showing the gap which migrant and ethnic minority populations still have to overcome to attain parity in the political sphere, taking a transnational perspective on inequality does reveal a more nuanced picture. Older migrants' political perspectives are not confined to countries of residence, indeed they may be far more engaged in homeland politics. Research I carried out in France and Senegal with older Senegalese former labour migrants revealed the power and influence which they yield in their places of origin, despite their long absences (Hunter, 2018). A particularly important driver of this was their leadership of 'hometown associations', which are a means to collectively pool remittances and develop communal infrastructure such as schools, clinics and clean water supply (ibid.).

Turning lastly to older lifestyle migrants and their political participation in places of residence, this theme has been very marginal in the literature. This is perhaps unsurprising given that lifestyle migration is often framed as an

individualistic and 'rather apolitical' form of mobility (Janoschka, 2010, 270). Indeed, lifestyle migration in later life can even be considered a consequence of the political failure of collective bargaining to defend pensions in the face of neoliberal individualism, with less well-off retirees from the recession-hit Global North relocating to the Global South where their depleted retirement funds will stretch further (Hayes, 2014). Nonetheless, the stores of human, social and financial capital which lifestyle migrants often possess give them 'the potential to seriously alter political life' in their destinations, as a study of the political campaigning of Northern European migrants against local land use policies in Spain shows (Janoschka, 2010, 271). Hitherto, however, the minimal evidence available in this area indicates that such potential influence is rarely enacted.

Conclusion

Up until relatively recently, migrant older people were of marginal concern in the mainstream gerontology literature, symptomatic of a broader tendency in this field to occlude the heterogeneity of older populations and the inequalities which map onto this diversity in intersecting ways. As a number of scholars have argued, the ways in which older people respond to the disjunctures brought about by migrating are potentially a source of theoretical renewal in gerontology, bringing new insights to models which have prioritised personal and social continuity as the foundation for successful ageing (Torres, 2006). My contribution here has been to highlight the value of a transnational ageing perspective, sensitive to older migrants' 'duality of references' (Bolzman, Fibbi and Vial, 2006, 1361), with many older migrants simultaneously evaluating the success (or otherwise) of their life projects in relation to their peers both in countries of destination and in places of origin.

A further advantage of a transnational perspective is that it draws attention to the diversity not only *between* but also *within* groups of older migrants. This enables research on older migrants to move beyond certain stereotypes, such as 'vulnerable' former labour migrants ageing in place (Ciobanu, Fokkema and Nedelcu, 2017) versus 'privileged' older lifestyle migrants (Botterill, 2017). Rather, the same individual may be simultaneously disadvantaged in comparison with one reference group, but privileged in relation to another.

In terms of priority areas for future research, the structuring typology of resources, recognition and representation provides a useful template for reflection. As noted above, the lion's share of work in this area has focused on older migrants' economic and social resources. Nonetheless, a comprehensive statistical overview of the resource inequalities faced by migrants, at a Europe-wide level or even within specific countries, is lacking (Kofman et al., 2009). An effort to standardise statistical categories and indicators across different national contexts would greatly facilitate comparative analysis. In terms of recognition of marginalised identities and groups which have historically faced disadvantage, a clear research void is found at the intersection of migration background, ageing and sexual identity. There is barely any literature on the sexual lives of older migrants (one notable exception is Lulle and King, 2016). Experiences of

racism also appear to be common, although research into the implications of this for well-being in later life is lacking. Similarly, the representation of older migrants in print and broadcast media has been largely overlooked.[7]

More generally, this chapter has called attention to the analytical benefits which future research may reap by distinguishing between migration background and ethnicity. The importance of analysing ethnicity and migration background as separate (but often interacting) variables will only become more pronounced in future decades as we see increasing numbers of older ethnic minority individuals in the Global North who are *not* migrants but rather the children and grandchildren of those who first settled.

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Notes

1 Although reliable statistics are not readily available, proxy measures such as the number of people receiving their pensions in well-known lifestyle migration destinations indicates that this specific group of older migrants is expanding.
2 In Britain, ethnicity rather than country of birth is the measure used in statistics, but given that second- and third-generation descendants of immigrants are still not numerous in the older age brackets, most non-White British elders are in fact also immigrants (Moriarty and Butt, 2004). Their number will increase by 148% between 2006 and 2026, versus 55% for the population overall (Rees et al., 2012). By 2051, 20% of the UK population over 65 is projected to be of 'visible' minority background (ibid.).
3 The term transnationalism describes 'the *frequent* and *durable* participation of immigrants in the economic, political, and cultural life of their countries [of residence and origin], which requires regular and frequent contact across national borders' (Portes, Escobar and Radford, 2007, 252; emphasis added).
4 It is worth noting that transnational ageing does not necessarily imply physical mobility across borders. One example is when care arrangements for ageing parents are coordinated remotely by adult children who no longer live in the same country (Baldassar, Vellekoop Baldock and Wilding, 2007).
5 A further specificity in the case of some non-resident UK pension recipients concerns 'frozen' state pensions which are not uprated annually in line with inflation (Botterill, 2017).
6 Note that in the UK, for historical reasons, some foreign nationals have voting rights (i.e. Irish nationals and citizens of certain Commonwealth countries). An EU citizen has the right to vote and be a candidate in municipal and European Parliament elections in whichever EU country he or she resides.
7 A session on this topic was organised at the annual conference of the IMISCOE Research Network in June 2017, and a special issue of the *International Journal of Ageing and Later Life* on this topic is currently in preparation.

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14 Ageing, religion and (in)equality

Peter Kevern

Introduction

The purpose of this chapter is to explore some of the effects of religious beliefs, institutions and practices in creating (in)equality for older people. The main problem limiting the discussion is that, like 'culture', the category of 'religion' poses a dilemma for social analysis. It is used to designate a diversity of human activities, beliefs, social institutions, artefacts and practices across the world, and as such may be too vague to withstand rigorous critical scrutiny; but precisely because the term 'religion' designates such a broad and profound field of human interaction, the category is too useful to be discarded.

In order to manage this diversity and arrive at some meaningful conclusions, I will limit and 'frame' the discussion in two ways. In the first place, I will focus primarily on the UK context, and the six religions (Christianity, Judaism, Islam, Hinduism, Sikhism and Buddhism) with the strongest organisational presence there, although I will refer to research from elsewhere in the world or in relation to other religious groups where appropriate. In the second place, I will draw on Nancy Fraser's framework of *resources* (or *redistribution), recognition* and *representation* (Dahl, Stoltz and Willig, 2004; Fraser, 1998; Fraser, 2007) as a lens through which to view and sort the rather divergent and unwieldy data on the subject; and in particular on the inequalities that mark the experience of older people within religious communities, as well as beyond them.

These two strategic decisions structure the chapter, which falls naturally into three parts. In the first, I will briefly survey the available data on the current religious ecology of the UK: the demographics of religious groups, their cultural makeup and the political context within which they function. This will lead naturally to an examination of the resources, recognition and representation of older people within these groups and in relation to wider society, using Fraser's categories, which in turn will lead into a Conclusion with recommendations for further reflection. The broad direction of the argument is that both the official rhetoric of religious organisations and the undifferentiated way in which they are understood by policymakers and service providers act to obscure the real diversity of resources, experiences and opportunities available to older adherents of religious institutions.

The religious ecology of the UK

In the United Kingdom, the various regional churches 'Established' by the State (Church of England, Church of Scotland, Church in Wales[1] and Church of Ireland) have between them traditionally claimed to be the majority religious expression by a significant margin. This distorts the public perception of religion in two ways. First, these churches are disproportionately visible: their buildings are numerous, their bishops sit in the House of Lords and their chaplains lead prayers in schools, hospitals and the armed forces. But secondly, their dominance has been rapidly waning for several decades: for example, only about 20% of the adult population of England now claims to be an adherent of the Church of England. Consequently, the church buildings are often attended only by a few people and their average age is well above that of the population (Bullivant, 2017).

For the outside observer, these features combine to give the misleading impression that, in the UK, religion is in decline and predominantly the concern of older people. In fact, most other religious institutions are maintaining their numbers or growing (notably the Muslim community; but there has also been particularly rapid growth in some protestant Christian groups). The most striking change has not been in the numbers of religious people but in their environment: religious expressions are becoming more diverse, and are being conducted in a more explicitly secular context in which the majority of the population now claim to have no religious allegiance of any sort.

In the light of these reflections, what generalisations *can* be made about the role and characteristics of institutional religion in contemporary UK society? For the purposes of this chapter, three seem particularly useful and salient. In the first place, religions resist generalisation because they exhibit enormous variety, both between and within religious groups. Individuals (including older people) may engage with their religious tradition and be awarded a place within it in different ways, which may fluctuate over the life course according to circumstances (Coleman, Mills and Spreadbury, 2011). Secondly, an individual's claim to a named religious 'identity' situates them socially and politically in relation to their co-religionists and to society as a whole. In the evocative terminology of Goldenberg (2015) religious groups are 'vestigial states', functioning as alternative, past or future social orders. Finally, the emergent 'minority' status of religion generally renders it less known and more 'other' as a cultural expression (Bruce, 2014). In the construction pioneered by Wulff and developed by Duriez et al. (Duriez, Fontaine and Hutsebaut, 2000) the social context which all religious expressions have in common in western Europe is one in which no religion can claim to possess the dominant narrative: the truth of religious claims is always contestable; and the authority of all religious authorities is relativised.

This rather arcane theoretical discussion has a practical corollary. Before we can discuss the relationship between ageing and religion, we have to be able to recognise religion 'on the ground': to identify the features which are distinctively 'religious', and to name the groups or institutions that embody them.

In the light of the preceding analysis, I propose to evaluate the relationship between religion and (in)equality in ageing under three headings: individual involvement, religious identity and social context. As will become clear in the discussion that follows, these map naturally to the three domains of Fraser's model of social justice (resources, recognition and representation) which connect this account to those of other chapters within the book.

Religious involvement among older people, and their access to resources

There is an assumption shared across religious traditions that people become more religious as they get older, and some studies have found that religiosity increases with age and the proximity of death (Bengtson et al., 2015). There is a well-established correlation between religiosity and life expectancy, or in older people religiosity and mortality that, taking account of regional variations (Stavrova, 2015), appears to have cross-cultural validity and reliability (Zimmer et al. 2016). An element of this effect can be ascribed to religious activity itself (McIntosh et al., 2002, 119), but membership of a religious group has more far-reaching effects via its encouragement to healthy behaviours and the positive effect on the individual's social networks (see e.g. Rote, Hill and Ellison, 2013). Finally, the social support provided by religion may include improved access to resources in the wider society such as housing and health care (Benjamins and Brown, 2004). On the face of it, religious activity appears to address and reduce inequalities of resource allocation for older people.

As soon as such a generalisation is made, however, it must be qualified. Religious institutions take a variety of forms; and (as will be apparent from other chapters in this book) 'ageing' may be experienced in and conditioned by a diverse range of contingent circumstances. We must therefore beware of the assumption that because many religious institutions appear to confer benefits on older people these are distributed uniformly or equitably. A religious rhetoric of care for older people may conceal profound inequalities.

If religious institutions, as communities which share resources, can be sources of social capital and practical support, they can also function to increase inequality of access to resources supplied by others. Older people from some religious traditions may be slower to access certain forms of health care: for example, because of fears that the available offerings are not sensitive to their religious requirements (Ajrouch, 2016; Greenwood et al. 2015); that they may be offered religiously-unacceptable food or be attended by care staff who they consider unsuitable (Koehn, 2009). Conversely, some medical conditions may remain untreated because they are considered particularly shameful in certain religious contexts, such as alcoholism among older Sikhs (Cochrane and Bal, 1990); urinary incontinence in some Muslim communities (Sange C et al. 2008) or mental illness (Ng et al. 2011). Similarly, religious communities may have expectations about the appropriate distribution of money or assets which leave some older people relatively economically dependent (there is good evidence

that religious institutions generally reinforce inequalities of wealth. See Solt, Habel and Grant, 2011).

In summary, we may speculate on the basis of the available evidence that religious adherence has a generally positive effect on the health and well-being of older people because of its capacity to create coherent and mutually-supportive communities. In particular, the tendency of religious institutions to create bounded communities with a strong pressure towards normativity generates a context that supports individuals' access to resources. However, these same properties may in some cases work to impoverish and disempower individuals or groups by discouraging help-seeking beyond its boundaries, and on occasion by promoting social or individual practices which contribute to the financial or psychological burden on individuals. The same pressure to normativity which creates coherent and mutually-supportive religious communities may serve to increase the inequality and isolation of those who fail to conform: either actively, by intentionally excluding them from the shared pool of resources; or passively, by restricting discussion and action to a fairly narrow range of 'acceptable' situations which do not respond to the diverse needs of individual members of the community. This brings us naturally to the question of recognition, and the ways in which a religious group's expectations of ageing individuals determine their visibility.

Recognition and religious identity

It goes without saying that, within the framework provided by a religious institution, an individual's social worth and status are defined in terms of their 'religious identity'. That is to say, they are conferred and calibrated in terms of the individual's relationship with that institution. It follows that religious institutions often have an important role to play in the support of vulnerable members, both by creating a shared allegiance and by creating an expectation of mutual support (see e.g. Bei-Hung, Noonan and Tennstedt, 1998). For any given older individual, one may expect that their recognition as a member of the community and as a co-religionist will go hand in hand and consequently, religious institutions can both confer and withdraw status according to an individual's perceived value within the community.

Since any institution that persists for generations relies upon the transmission of a tradition from its older members to the younger ones, it is also self-evident that the public rhetoric of the most visible religious institutions and traditions in the UK context will be broadly positive towards older people. This translates into a normative expectation that the faithful adherent will be willing to care at least for their own older family members and potentially for older people generally. Furthermore, this generalised respect for elders is reproduced in institutional structures (where senior positions tend to be held by older men) so religion can provide status and social function for at least some older people (Coleman, Mills and Spreadbury, 2011). For example, the age of Roman Catholic Cardinals at the time of writing ranges from 50 to 98 with an average

of 77 (GCatholic, 2017), although only those under 80 are allowed to vote in the selection of a new Pope. In addition, the social interactions generated by religious belonging may provide some protection to older people at risk of abuse or neglect (Podnieks and Wilson, 2005).

However, not all older people are considered equal in the eyes of the institution. In most if not all groups the visibility of an individual will depend upon their gender; it may also be conditioned by class, caste or ethnicity and their sexuality (e.g. Woody, 2014 for LGBT African Americans); it may depend upon their marital status (with spouses and widows with children tending to have higher visibility than, for example, childless and unmarried family members; see Dhar, 2012). It is also worth noting that some of these attributes (as well as the level of engagement with the community) are open to change over time: the cultural visibility of a member of the community may rise or fall to the extent that they are perceived to exemplify its norms and ideals. For example, Manjit Jaur Nijjar recounts a literal shift in her father's visibility after his diagnosis of dementia:

> Dad had always been a religious man so I would take him to our local [Sikh] Gurudwara. The one and only time we stayed to have langar (the food served after the service) we were told to sit behind a column so the congregation wouldn't have to look at us. In the blink of an eye we had become invisible.
>
> (Watkins and Wahab, 2015, 279)

Conversely, the family of a Muslim woman with dementia interpret her behaviour in mid-stage dementia as an exemplary demonstration of faith:

> Conversations with Bayjee became difficult, as her mind was preoccupied with the past. Every recollection ended with an invocation to Allah, for forgiveness and mercy. As we encouraged her to talk about her parents and siblings, the depth of her relationship to God became clear: the unwavering faith, which had sustained her throughout her life, was her only preoccupation.
>
> (Watkins and Wahab, 2015, 288)

In the first of these, the recognition of the person concerned is dependent upon their conformity to a fairly narrow normative account of their status within the community; in the second a broader and more flexible account of religious identity is brought into play to recognise both continuity and change in the person's identity as she ages.

Finally, conflicts with religious leaders, disputes with co-religionists or arguments over doctrine may be a significant source of distress for older members (Ellison et al., 2009). In a few cases, this leads to the creation of new religious communities in response to the marginalisation of some groups by established ones, which have the potential to provide an alternative source of recognition

and social capital for their members. Thus, for example, the denial of religious legitimacy to LGBT+ Christians within mainstream churches of the UK led to the formation of alternative organisations which provided recognition, support and social capital such as the Lesbian and Gay Christian Movement; and for some a parallel religious structure in the Metropolitan Community Church (see also Porter, Ronneberg and Witten, 2013 for research among ageing transgender Christians).

To summarise this section, stable religious institutions may be expected to support and reinforce the social status and visibility of older people, as all of them transmit and preserve a broadly gerontocratic tradition in which old age is seen as imparting worth and authority. In practice, this respect for older people may be contingent upon the way in which they fulfil an 'exemplary' role, and recognition may be withdrawn as well as conferred. An older person who commands respect within the community at one stage in their life may cease to do so with increasing age. It is generally the case that people entering the 'fourth age' find themselves increasingly invisible within social institutions, but in addition religious identity, status and recognition may change dramatically as a result of imposed changes such as poverty, widowhood or the onset of dementia; or as a consequence of a decision to declare a non-normative sexual preference or religious position. As Fraser terms it, 'what is really important here is not the demand for recognition of a group's specific identity, but the demand for recognition of people's standing as full partners in social interaction, able to participate as peers with others in social life' (Fraser in Dahl, Stoltz and Willig, 2004, 377). Religious institutions are as likely to increase as to reduce inequality in ageing if the recognition they extend towards older members is withdrawn when increasing age, infirmity or nonconformity reduce status.

Representation and the politico-religious context

The role of religious beliefs, practices and institutions in addressing the inequalities of ageing must necessarily be placed within the wider context supplied by the relationships of religious institutions to a predominantly secular society. '[N]either distribution nor recognition can be properly understood without explicit reference to the problem of frame . . . redistribution and recognition must be related to representation, which allows us to problematise governance structures and decision-making procedures' (Fraser in Dahl, Stoltz and Willig, 2004, 380). There is ample evidence that many older people with a religious identity are more willing to turn to their religious representatives for help than to statutory services (Local Government Association, 2017), and one corollary of this is that a critical and constructive engagement with the former may be an essential element in any attempt to address inequalities associated with ageing.

The religious landscape of the UK is a complex one and the relationships between religious institutions and public providers of resources vary widely (Jochum, Pratten and Wilding, 2007). In principle, religious institutions might

serve as vehicles for social and political representation for the interests of their older members, and since about the beginning of the millennium there has been renewed interest in their potential role in reducing health and social inequalities in hard-to-reach groups. In practice, as noted above, such institutions might be selective about the interests and needs of their members which they are prepared to recognise and validate. But even where this is not the case, there are intrinsic difficulties in representing the interests of religiously motivated individuals and groups in the context of a secular society (Green, Barton and Johns, 2012).

Lowndes and Chapman (2007) identify three 'in principle' rationales that statutory bodies may invoke to justify collaboration with religious institutions: normative (to do with community values and identities); resources (focusing on the organisational capacity of faith groups) and governance (where faith groups represent and lead broader communities and networks). In practice, continued confusion about the validity and practicality of these rationales appears to have impeded the representation of marginalised members of religious groups within the political process. For example, Smith (2004) points out that the appropriate use of such communities as a means to deliver social goods and health outcomes has been a source of some uncertainty and debate at the level of public policy, and there has frequently been a significant gap between the public rhetoric and individual policy decisions. Contributory factors include religious communities' mistrust of official approaches which sought to appropriate resources but not acknowledge the beliefs and practices of the community on the one hand; and fear of government being seen to support proselytisation on the other (Lowndes and Chapman, 2007). In general, where religious identities are transacted with in an identifiable way, it tends to be in the terms laid down by the religious hierarchies; where these are ignored, the religious concerns of service users tend to be ignored with them.

This is true at every level, from the 'micro' politics of individual institutions to the 'macro' level of public policy. An example of the former is the experience of Marylyn, a Trinidadian Christian with dementia:

> She had never been a good sleeper. When she couldn't sleep, she prayed and sang hymns, which apparently didn't go down very well with the staff on night duty, but at least one other patient sang along with her. At one point they gave her a tranquilliser and knocked her out completely . . . my mum couldn't eat breakfast or lunch because she couldn't wake up.
>
> (Watkins and Wahab, 2015, 247–248)

Here, the needs of the individual are overridden (or at least mis-recognised) as a result of a failure to take into account her religious identity. Similarly, there are repeated complaints from religious patients that their religious practices are treated at best as an inconvenience, at worst as a pathology (Mir and Sheikh, 2010).

As an example of the latter, consider the difficulties in engaging traditional religious groups as partners to deliver welfare services to LGBT members of

the minority ethnic communities they serve (Carr, 2008). Here, the concern to engage with religious communities on their own terms leads to a secondary marginalisation and double discrimination for a subgroup with an overlapping identity. It is not difficult to see how this sort of partnership with a source of religious authority may marginalise and silence a group of older people within the community it is designed to support. Thus, the somewhat lazy assumption that 'They look after their own' (Katbamna et al., 2004), whether used for ethnic or religious communities, overlooks significant heterogeneity and inequality in access to care and resources.

It follows that any consideration of the involvement of religious communities in the representation of older people in the community must pay careful attention to the terms on which this engagement is intended to take place. To the extent that the religious organisation is used as a conduit to channel attention or support to older people within a particular community (and we have noted above the tendency to conflate religion with ethnicity) it functions as an agent for social control, and in particular control over the acceptable face of ageing. To the extent that it is ignored, the needs of older people associated with it are liable to be ignored as well.

Conclusion

The foregoing discussion began with the observation that, overall, older people who are religious live longer than those who are not. On the face of it, this result seems to imply that religious institutions reduce the inequalities associated with ageing for those who adhere to them; but these global data mask a considerable diversity in the status, social positioning and access of individuals both in comparison with their peers and over time. The role of religion is more subtle and diverse, both contributing to and addressing inequalities amongst older people who occupy different social positions, and at different times.

On the basis of the discussion above, it is possible to construct a range of accounts of the role of religious institutions and practices in relation to ageing and (in)equality. They differ profoundly in the data they take to be definitive of the experience of ageing in the context of religion, and the valences they give to each separate element.

At one end of a spectrum, religion may be understood as a positive contributor to equality in ageing because of the way in which it can enhance the visibility and agency of particular older people. According to this account, religious institutions encourage healthy behaviours and social connectedness; build respect and offer practical support for older members; and may serve as conduits through which the needs of marginalised older people (such as those from ethnic minorities and/or with little understanding of English) can access a range of statutory and voluntary services that would otherwise be closed to them. Thus, resources, recognition and representation merge seamlessly in the social and political identity conferred by membership of the religious institution and combine to strike at the roots of inequality in ageing.

The contrasting account would be one that stresses the ways in which religious institutions may distort or impede access to resources, recognition and representation by their beliefs, expectations and relations to secular society. Thus, some religious beliefs and the institutions that propagate them may impede access to resources by misdiagnosis (e.g. of mental illness as a spiritual condition) or as a result of concerns about how service provision may violate religious codes (e.g. by having a female non-relative bathe an older man). A negative account of the role of religion could also point to the tendency for recognition of the older member to be highly norm-governed, so that their status as well as their access to shared resources may be conditional upon their continued conformity to an image of 'exemplary' old age. Finally, the representation of an individual as sharing in a particular religious identity has as much potential to increase their alienation from the sources of support outside the religious community in the statutory and voluntary sectors as to enhance access.

Both of these accounts are relatively complete in themselves; in each, there is an explicit relationship between the three themes of resources, recognition and representation which combine to either address or exacerbate issues of inequality in ageing. In each case, the determining element appears to be recognition: as this is accorded or withdrawn by the religious community, so access both to the internal resources of the community and to a public voice in society follow.

Thus, if we are concerned with the ways in which religion 'on the ground' enables or impedes equality in ageing, the fundamental question must be: What is *recognised* as valid, acceptable and even exemplary ageing, and who is being marginalised by reason of their frailty, social status, self-identification or behaviour? Thus, for example, there may be a world of difference between the cultural visibility of a high-status, 'respectable' heterosexual married professional male elder with children and a low-status single older lesbian female with no children and little education. The secondary question is: What is the effect of that validation or marginalisation on the access to resources enjoyed by that individual or group? The public rhetoric of aged privilege may conceal significant heterogeneity of worth, visibility and status which has a direct effect upon an individual's ability to shape their environment or mobilise cultural assets. Finally, the question must be asked, particularly by statutory bodies developing institutional relationships with religious groups: Whose voice is not being included in this encounter because they are not considered a 'proper' representative of the religion? Although religious institutions might be expected to increase the visibility, representation and access to political power of their members, their public rhetoric around the role and status of their older members will demonstrate the same mis-recognition of 'non-exemplary' members.

Although it is beyond the scope of the present chapter to develop a detailed model of the relationships between religions, individuals and social context, it is clear from the above that at least three factors are in play: the location of the individual in relation to the institution; the normative rhetoric of the religion in question and its role in socially situating them within it; and the relationship between the religious institutions and the wider social and political context. The complexity of the possible interactions between these elements goes some

way to explain the diversity of ways in which religious beliefs, institutions and practices impact upon the inequalities encountered by older people, collectively and individually.

This chapter has intentionally taken a narrow sample of religious expressions and institutions for study, restricted as it is to a particular type of religion (embodied in the rhetorics and institutions of 'world faiths') in the single social context of the UK. As should be clear from the discussion above, even within this restricted frame of reference, there are significant divergences between the ways individuals are enabled or impeded in their access to resources, recognition and political representation by the religion with which they are identified. The main conclusion to be drawn is that there is no level of analysis at which the particularities of individuals' religious behaviour can be set aside for a general scale of values against which religious institutions may be measured to assess their contribution to (in)equality in ageing. The question of whether religions impede or promote equality for older people can only be answered be reference to particular individuals in particular social and historical contexts.

Note

1 The Church in Wales is now, technically, disestablished; but it retains control of the historic church buildings and institutions associated with Establishment.

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Part IV

Disabilities, long-term conditions and care

Sue Westwood

Introduction to Part IV

This section considers ageing in relation to people with disabilities and/or long-term health conditions, and issues of care inequalities. In Chapter 15, Sue Westwood and Nicola Carey consider issues of inequality in relation to people who are growing older *with* pre-existing physical disabilities and/or long-term health conditions, as opposed to those who acquire them as they age. They argue that the experiences of this growing population, informed by inequalities of resources, recognition and representation, are obscured by 'successful ageing' discourse, and argue for a more fully inclusive model of ageing. In Chapter 16, Karen Watchman explores the intersection between ageing and intellectual disability, highlighting gaps in service provision for the older people with intellectual disabilities. She considers the need for improved health and social care resources through increasing their recognition and representation among intellectual disability services, ageing services and dementia services. In Chapter 17, Dana Rosenfeld, Damien Ridge and Jose Catalan apply Fraser's inequalities framework to our UK-based HIV and Later Life (HALL) study. They argue that Fraser's framework is imprecise in capturing the factors which inform disadvantages experienced by older people living with HIV, proposing that HIV-specific supports (*resources*) are increasingly threatened by agents operating within Fraser's *representation* domain. In Chapter 18, Jonathan Herring explores the problem of abuse within care home settings, considering the difficulties of responding to such abuse through the lens of Fraser's framework of resources, recognition and representation. Herring argues that the problem reflects and reinforces the exclusion of older people in society.

All four chapters highlight the need for increased recognition and representation of people ageing with and/or into disabilities and long-term health conditions. Such an increase would in turn improve their current constraint access to resources. People ageing with disabilities are marginalised both by the imperative of (disability-free) successful ageing significance of spatiality for the ageing experience and by the marginalisation of older people, especially those with care needs. While Rosenfeld, Ridge and Catalan question the precision of Fraser's framework to analyse inequalities associated with ageing with HIV, they nonetheless do utilise it to show how (under-) representation informs resource constraints.

15 Ageing with physical disabilities and/or long-term health conditions

Sue Westwood and Nicola Carey

Introduction

This chapter considers ageing and diversity in relation to people who are growing older with pre-existing physical disabilities and/or physical or mental health related long-term conditions (LTCs).[1] Considerable attention has been given to older people with age-acquired health problems and/or disabilities (who 'age into disability', Molton and Yorkston, 2017, 290). However, far less consideration has been given to the implications of ageing for people with pre-existing conditions: 'social gerontology has largely focused on those ageing *into* disability rather than those ageing *with* disability' (Simcock, 2017, 1703). Yet, 'there is a significant difference in work and life experience between disabled people who have grown older with their disability and older people who have become disabled in older age' (CPA, 2016, 1). The experiences of ageing among those ageing *with*, as opposed to into, disabilities and/or LTCs, are informed both by those (socially located) conditions *and* by those socially located conditions associated with ageing. While some authors understand this in terms of one being 'superimposed' on the other (Sanai et al., 2016, 717), it is probably more accurate to think in terms of intersections and interactions between them, each influencing the other.

The World Health Organisation (2018) estimates that over a billion people (15% of the world's population) live with some form of disability, and that these rates are increasing both due to population ageing and increasing survivorship among people with disabilities and/or LTCs. Despite the increase in people ageing with disabilities and/or LTCs, research on ageing has so far focused on age-acquired health problems disabilities (e.g. Wahl et al., 2013). As a consequence,

> we know relatively little about disabled people's lives over time, and the meaning of living with a disability for many years, to grow old, and to be old.
> (Jeppsson-Grassman and Whitaker, 2013a, 1)

What literature there is, would suggest that there is a lack of understanding of the implications of ageing for people with disabilities and/or LTCs. This in turn

often means that their needs are inadequately met in older age. Moreover, their presence is often obscured within current narratives and models of 'successful ageing' (Bowling and Dieppe, 2005) upon which good health and freedom from disability is often predicated. We support the arguments in the literature that the model of successful ageing in gerontological literature and in media representations – is inherently ageist and ableist (Sandberg and Marshall, 2017). It promotes a stereotype of ageing without ill health and disabilities, thereby denying the lived experience of many older people and positioning them as having 'failed' to age successfully (Katz and Calasanti, 2014).

We consider these issues using Nancy Fraser's model of social justice (Fraser, 1997, 2000 & 2007) which approaches inequality through three intersecting domains: resource distribution; recognition (social status and cultural worth); and representation (social engagement and political voice). While Fraser considered resources in terms of economics, we use an expanded understanding of resources to also include access to informal and formal health and social care. We propose that people ageing with disabilities and/or LTCs are under-resourced both materially, due to lifelong cumulative disadvantage, and in relation to care, due to specialist and/or ageing services providers being under-prepared and ill-equipped to meet their needs. This in turn engages with issues of under-recognition of those needs, in which notions of 'successful ageing' are also implicated. This is also reflected, and further compounded, by a lack of political voice, and community engagement with/on behalf of older people ageing with disabilities and/or LTCs. We consider how these inequalities might be addressed in social policy, social gerontological discourse and research.

Ageing with physical disabilities and/or long-term physical health conditions

More people with physical disabilities and/or LTCs are living for longer and into older old age, primarily due to improvements in medical knowledge, diagnosis and pharmacological treatments (Molton and Yorkston, 2017). Some people are ageing with lifelong physical disabilities, others with disabilities caused by trauma. others with disabilities associated with the progression of LTCs.

Ageing with physical disabilities

Definitions of disability vary and are contested, particularly as it is increasingly recognised within the social model of disability (Oldman, 2002; Oliver, 2013) that the concept is socially constructed and might be better understood in terms of disabling contexts rather than inherently disabling conditions. The key physical/sensory disabilities with which people may be ageing are: blindness/visual impairment; deafness/hearing impairment; cerebral palsy, spina bifida, hydrocephalus, postpoliomyelitis syndrome, and other related conditions; traumatic spinal cord injury (SCI); loss or limited use of limbs, either from birth or due to trauma (either an accident or a war injury). In terms of prevalence,

disability in later life is often measured in relation to Activities of Daily Living (ADLs) (Katz, 1983) which comprise key elements of everyday functions.

> The ability or difficulty experienced in performing Activities of Daily Living (ADLs) are widely used as a measure of disability for older people covering personal care such as being able to bathe, dress, mobility and toileting. Instrumental Activities of Daily Living (IADL) relate to domestic tasks such as shopping, cooking and housework, and in some cases using the telephone and managing money.
>
> (DWP, 2014)

Disability is a significant feature of older age, nuanced by geographical location: those older people living in poorer parts of the world are more likely to be disabled, and more severely disabled, sooner than those in wealthier parts of the world (Barnes and Sheldon, 2010). In the United Kingdom:

> Disability, measured as Limitations on Activities of Daily Living (LADL), affects 40% of older people aged 60, and 75% of those aged 80 and above. The disability is severe for 20% of older people aged 60 and 50% of those aged 80 and above (CPA, 2016, 1). Over 20% of people of state pension age in the United Kingdom report becoming disabled before reaching the age of 50.
>
> (DWP, 2014)

There are major gaps in knowledge about ageing with, as opposed to ageing into, physical disabilities. In particular, 'little is known about what adults with childhood acquired physical disability consider central to optimal ageing' (Mudge et al., 2016, e012551). Yet, ageing is of considerable significance to people with disabilities:

> For those ageing with a disability, the complex interaction of these medical and social factors, and their timing and impact in the developmental life course, create an especially challenging environment for successful aging.
>
> (Molton and Yorkston, 2017, 291)

In terms of the limited information available so far, the picture for people ageing with blindness/visual impairments is that sight loss is significant not only for older people *when* they age but also for older people *as* they age (Thomas Pocklington Trust, 2015). According to a recent UK review of the literature on ageing with sight loss (Age UK and RNIB, 2015, 8), compared with the general older population, older people with sight loss are more likely to: have other health conditions; experience falls; have problems with mobility outside the home; to be unable to shop for every day necessities without assistance; experience chronic pain; need formal health and social care support; have difficulty accessing those services; live in poor quality housing; live in

poverty; report having poor quality social relationships and negative views of their neighbourhood.

In terms of deafness/auditory impairment, in a review of the literature on older Deaf people, Young (2014) reported:

> Older Deaf people's strengths, life experiences, preferences and characteristics are not necessarily the same as those of younger generations. . . . The consequences of the social, educational and economic circumstances in which today's older generation of Deaf people grew up and have led their adult lives create significant vulnerabilities in older years associated with health, well-being, access to resources and safety. Deaf people experience life-long inequalities in access to health, education and social care, resulting in significantly poorer health and wellbeing outcomes. These impact on the challenges of older age over and above the ageing process itself.
>
> (24)

Reflecting the paucity of the literature in general, in a recent review of the literature, Simcock (2017) reported finding 'no studies examining deafblind people's experience of ageing and old age' (1703).

In terms of cerebral palsy (CP), spina bifida, hydrocephalus, postpoliomyelitis syndrome and related disabilities, as with other forms of disability, what happens with ageing is not yet well understood. However, it is generally recognised that ageing for people with such disabilities involves both 'the "normal" effects of ageing [and] the wear and tear of ageing with these disabilities' (Spina Bifida Hydrocephalus Queensland, 2014, 84). The consequences of this can include: 'deteriorating mobility; joint issues; incontinence issues; pressure sores/skin issues; managing pain; high blood pressure; kidney issues' (84). Moreover, as SCOPE, the UK campaign organisation, has observed, for those who have lived a lifetime with a physical impairment, the effects of ageing can become apparent earlier than expected' (SCOPE, 2017), also known as 'accelerated ageing' (Verbrugge, Latham and Clarke, 2017). This might involve early onset diabetes and osteoarthritis 'as well as development and progression of "secondary conditions" like pain and fatigue, which, compared with adults without disabilities, are more severe, occur sooner, and stay elevated from midlife into older age' (Molton and Yorkston, 2017, 291). This in turn can increase the risk for those in employment of earlier retirement and associated 'poorer long-term financial and psychosocial trajectories' (291).

The literature on ageing with CP has suggested:

> That age-related physiological changes occur earlier in adults with CP, and the prevalence of secondary conditions such as pain, osteoporosis, fatigue and musculoskeletal and joint problems is higher in adults with CP compared to age-matched adults without CP. . . . Given the early and accelerated age-related changes in function, adults with CP are likely to have greater need for health services as they age.
>
> (Mudge et al., 2016, e012551)

Older people with CP and other related conditions 'are a group with few advocates and they represent a marginalised group within two already marginalised populations, older people and disabled people' (Paterson and Watson, 2013, 24). Despite the significance of ageing for people with CP and other related conditions, much of the focus of rehabilitation is on children and not older adults, creating unmet need in older age:

> Frontloading rehabilitation in childhood does not meet the long-term needs of children growing up and growing older with physical impairments. As they grow up and grow older, they lose many of the gains they achieved in rehabilitation yet they have nowhere to turn to receive rehabilitation for their aging bodies.
>
> (Moll and Cott, 2013, 1276)

In terms of limb loss, the research associated with ageing is extremely limited, however studies of US army veterans suggest that long-term outcomes are linked to successful early and lifelong rehabilitation, mental health support and pain management (Foote et al., 2015; Caddick et al., 2018).

Traumatic spinal cord injury (SCI) 'can be a life-altering event leading to long-term disability' (Jörgensen et al., 2016, 1). Increasing numbers of people with SCIs are living into older age. In Western nations, it is estimated that 30% to 40% of adults with SCI are over 65 (Molton and Yorkston, 2017). These older adults have a lower life expectancy than older people ageing without SCIs (Groah et al., 2012). In a recent review of the literature on SCI and ageing Jörgensen et al. (2016) described a number of ways in which ageing can inform SCI and SCI inform ageing:

> There is evidence of an accelerated aging of organ systems, exacerbating their disability. For people with SCI, age itself is associated more closely with increased dependence in daily activities than level and completeness of injury. SCI-related impairments and activity limitations can increase over time, and superimposed disabilities can be experienced 15 to 20 years earlier in people with SCI than in noninjured populations. Even small changes in functioning can therefore have far-reaching consequences for their performance and engagement in everyday life. There are various examples how SCI-related impairments accompanied by accelerated aging can increase the risk of developing secondary complications and lead to premature death. (667–668)

Ageing with physical LTCs

The main physical LTCs with which people are now living into older age are: arthritis; cancer; congestive obstructive pulmonary disorder (COPD) (progressive lung diseases including emphysema, chronic bronchitis, refractory (non-reversible) asthma, and some forms of bronchiectasis); diabetes; neurological disorders (e.g. multiple sclerosis (MS), motor neurone disease (MND),

Parkinson's disease (PD); and some viral diseases such as hepatitis C and HIV-AIDS (see Chapter 15 regarding the latter). In the UK, in 2012, 14% of those aged under 40 reported having an LTC, compared with 58% of those aged 60 and over (Department of Health, 2012). Many of these LTCs, as they progress, involve not only a range of physical health problems but also associated disabilities. Indeed, 'chronic illness is the most common form of disability in the Western world' (Jeppsson-Grassman, 2013, 19).

Disabilities relating to physical LTCs are many and varied and can involve: blindness/visual impairment; deafness/hearing impairment; mobility impairment; breathing and/or swallowing difficulties; speech problems; and incontinence. Many people with LTCs experience more than one set of symptoms and/or disabilities (co-morbidities/multimorbidities) (Marengoni et al., 2011, 438). Multimorbidities are associated with ageing: in the UK, 25% of those over 60 report having two or more LTCs (Department of Health, 2012). Population ageing means that this is likely to become a major public health concern (Yarnall et al., 2017, 882). A key co-morbidity relates to mental health:

> Research evidence consistently demonstrates that people with long-term conditions are two to three times more likely to experience mental health problems than the general population. Much of the evidence relates specifically to affective disorders such as depression and anxiety, though co-morbidities are also common in dementia, cognitive decline and some other conditions. There is particularly strong evidence for a close association with cardiovascular diseases, diabetes, chronic obstructive pulmonary disease (COPD) and musculoskeletal disorders.
>
> (Naylor et al., 2012, 3)

The literature is scant in relation to people ageing with long-term physical health conditions. In terms of cancer, older adult cancer survivors experience 'a greater decline in physical functioning over time compared with those without a history of cancer, especially survivors of lung, colorectal, and breast cancer' (Leach et al., 2016, 1950). This decline involves a higher prevalence of urinary incontinence, depression, functional limitations, falls, hearing difficulties, lower self-reported health, and higher rates of reliance upon others for everyday personal care (1948). However, more research is needed 'to disentangle the effects of cancer and ageing' (1952).

In terms of COPD, early onset COPD is associated with accelerated ageing in both smokers and those who have never smoked (Choudhury and MacNee, 2017). There are particular issues in relation to older people ageing with asthma:

> Some people who have had asthma all their life may find it starts affecting them in different ways as they get older. For example, they may have coughed or wheezed previously, but may notice they become more

> breathless. Older people are less likely to have periods of remission, and changes in symptom patterns and triggers may add to confusion regarding the relevance and severity of symptoms. Many older people with asthma appear to be compliant with treatment, but in reality they may feel confused or anxious about their symptoms and treatment.
>
> (Carnegie and Jones, 2013, 53)

Older people with asthma may find it is not focused on by health care professionals as compared with younger people with asthma, often being conflated instead with other COPD conditions (Jones et al., 2011). This is a particular concern given the increased risk of morbidity associated with asthma in older people.

In terms of neurological disorders, it has been reported that ageing 'intensifies' the care and support needs of people living with Parkinson's and their carers (Giles, Thomas and Lewin, 2015, 338). This is also true for people living with other long-term neurological conditions, which can be further nuanced by both age and gender (Ploughman et al., 2017, 165).

> One must understand how to distinguish normal aging phenomena from worsening MS and to identify other neurological disorders that are common in aging, but may nevertheless mimic some of the many symptoms of MS.
>
> (Sanai et al., 2016, 722)

There has been a recent growth in research in relation to ageing with MS (e.g. Solaro, 2015; Sanai et al., 2016; Silverman et al., 2017). Older people with MS are at increased risk of falls compared with younger people with MS and older people without MS (Finlayson, Peterson and Cho, 2006). By contrast, 'healthy ageing' with MS is linked to 'health care, social engagement, lifestyle and independence . . . [and] . . . financial flexibility, mental and cognitive health, resilience and social support' (Ploughman et al., 2012, 26). This is also closely linked to 'resilience' in ageing:

> Participants [with MS] found it difficult to generate a concise definition of resilience, but they generated evocative descriptions of the concept. Psychological adaptation, social connection, life meaning, planning and physical wellness emerged as facilitators of resilience. Resilience depletion, negative thoughts and feelings, social limitations, social stigma and physical fatigue emerged as barriers to resilience.
>
> (Silverman et al., 2017, 14)

Despite increasing research in relation to ageing with MS, there are gaps in knowledge about people ageing with LTCs in general 'in relation to people's lived experience of how such conditions impact on their life' (NICE, 2015, 24).

There are also gaps in knowledge in relation to ageing with specific LTCs. This is explored further in the section on representation.

Long-term mental health conditions

Many people are ageing with long-term mental health conditions, which comprise:

> Common mental health disorders, such as depression, generalised anxiety disorder, panic disorder, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and social anxiety disorder, may affect up to 15% of the population at any one time. Depression and anxiety disorders can have a lifelong course of relapse and remission. There is considerable variation in the severity of common mental health disorders, but all can be associated with significant long-term disability. For example, depression is estimated to be the second greatest contributor to disability-adjusted life years throughout the developed world. It is also associated with high levels of morbidity and mortality, and is the most common disorder contributing to suicide.
>
> (NICE, 2011, 1)

In addition, an estimated 4% of the population have some form of personality disorder (Coid et al., 2006) while 'over a lifetime, about 1% of the population will develop psychosis and schizophrenia' (NICE, 2011, 1).

The literature on ageing with a mental health condition is surprisingly sparse, with far greater attention being paid to age-acquired mental health problems, especially dementia. Despite an emerging recognition of the need to take a life course perspective on the spectrum of mental health conditions (Newton-Howes, Clark and Chanen, 2015; Cohen, Vengassery and Garcia Aracena, 2017), which includes their trajectories in later life, there is an urgent need for more research in this area. What is known is that:

> People with a severe mental illness die up to 20 years younger than their peers in the UK. . . . People with mental health conditions consume 42% of all tobacco in England . . . [and] the mortality rate among people with a severe mental illness aged 18–74 is three times higher than that of the general population.
>
> (Mental Health Strategic Partnership, 2012, 1)

There is a long-held, and long-disputed suggestion that schizophrenia, or some schizophrenias are linked to accelerated ageing, or some aspects of it (particularly in relation to cognitive function) (Kirkpatrick and Kennedy, 2017). However, psychosocial functioning among those people with schizophrenia who survive into older age 'improves with age, with diminished psychotic symptoms, reduced psychiatric relapses requiring hospitalization and better

self-management' (Jeste, Wolkowitz and Palmer, 2011, 451). People with long-term severe depressive disorders are also at risk of 'ageing-related somatic diseases such as heart disease, diabetes, obesity and cancer' (Verhoeven et al., 2014, 895). People with long-term anxiety conditions are at increased risk of 'ageing-related somatic conditions including coronary heart disease, diabetes, and disability, as well as for overall mortality' (Verhoeven et al., 2015, 371). There are also suggestions that personality disorders in older age may be linked to earlier rates of mortality, functionality and physical ill-health. For those individuals with co-morbid mental health conditions (e.g. psychoses and personality disorder) 'generally have poorer outcomes than those without co-occurring disorders, but particularly in elderly people' (Newton-Howes, Clark and Chanen, 2015, 731). Different types of personality disorders may also be affected by specific age-related issues: people with avoidant personality disorder, for example, might find residential care particularly difficult. There is a need for much more research in this area: 'The little recognition that personality disorder in later life receives might be concealing a substantial public health burden that will become increasingly important in countries with ageing populations' (Newton-Howes, Clark and Chanen, 2015, 731).

Social justice framework

Resources

The quality of life of all older people is informed by access to resources, both material resources (e.g. housing, pensions, savings, Smith et al., 2004) and social, i.e. social engagement, care and support (Zahava and Bowling, 2004; Victor et al., 2005). It is also informed by a subjective sense of well-being (Steptoe, Deaton and Stone, 2015). Older people ageing with, rather than into, disabilities and/or LTCs are under-resourced in each of these main areas (Gjonca, Tabassum and Breeze, 2009). They are known to be materially disadvantaged, both through reduced employment opportunities and earnings throughout adulthood (TUC, 2016, 2017), and also the need among those in employment to retire early due to the combined effects of ageing with specific LTCs. This material disadvantage in turn informs comparatively reduced accrual of private/occupational pensions (to supplement the state pension) and savings and access to poorer quality housing.

> People with long-term conditions and co-morbid mental health problems disproportionately live in deprived areas and have access to fewer resources of all kinds. The interaction between co-morbidities and deprivation makes a significant contribution to generating and maintaining inequalities.
>
> (Naylor et al., 2012, 2)

In terms of the resource of informal care and support, people ageing with disabilities and/or LTCs are affected by the ageing of their informal care networks.

For example, as parents and/or spouse-carers age, they may be less able to provide the same levels of support they did when they were younger, and may indeed develop their own care and support needs (Carers UK and Age UK, 2015). This, in turn, often means that people ageing with disabilities and/or LTCs may need to turn to formal care providers sooner and in disproportionately greater numbers than people not ageing with disabilities and/or LTCs. Yet at the same time, there are relatively fewer services for older people with disabilities compared with younger people with disabilities (Kane, Reinhard and Neumann, 2007). Moreover, formal services are often ill-equipped to meet their needs. This is in three main ways.

Firstly, disability organisations may not be geared up for people with ageing issues. For example, older people with MS report a range of unmet needs relating to access to care and support.

> While many of these needs might also be reported by younger individuals, we need to be aware of, and sensitive to, how older and younger individuals may differentially perceive or express these needs and how they can best be met in this population. Attempts to provide needed services must consider not only the needs of older individuals, but also service delivery options. For example, the MS Society offers a number of support groups, recreational activities, and educational programs for members. However, many are geared toward newly diagnosed individuals, or may have content more appealing to younger members. Furthermore, groups must be offered at times and locations that are convenient for older individuals. In fact, one study found people over age 65 to report no longer going to support groups, and that support groups was an unmet need in the oldest age group (65–74 years).
>
> (Finlayson, 2006)

Secondly, ageing services providers are often ill-equipped to meet the needs of people ageing with disabilities and/or LTCs. For example, ageing services may not employ staff who can use the sign language with which many Deaf people communicate (Willoughby, 2014). Older deafblind people and/or older people with dual sensory impairment living in residential care for older people often 'feel unable to reach out to others, to be aware of what is happening in their environment, or to discuss and negotiate about the care they receive' (Roets-Merken et al., 2017, 6). Those older deafblind people who are not actively engaged in the life of the residential environment have a 50% increase in mortality compared with those who do feel involved (Yamada et al., 2015).

As Michelle Putnam (2012), writing in the USA, has observed

> A challenge for gerontological social work is that individuals aging with disability are not our traditional consumers or clients. Most gerontological training focuses on older adults who are aging into disability. Thus, we tend to have a lack of familiarity with everything from the symptoms

> of early and mid-age onset diseases to philosophies and theories of disability to funding and structures of disability support and service systems. Additionally, we are often less aware of the short- and long-term effects disability-related socio-economic, health, and political disparities can have on individuals and their families. Finally, the organizations, systems, and policies that work are typically designed for adults aging into disability all of the way from mission statements to program delivery options.
>
> (93)

The third way in which formal ageing services often fail to meet the needs of people growing older with disabilities/LTCs is in relation to comorbidities and fluctuating needs. Health care systems are modelled around individual diseases rather than conditions involving multimorbidity (Barnett et al., 2012). There is often a gap in particular between physical and mental health teams:

> Care for large numbers of people with long-term conditions could be improved by better integrating mental health support with primary care and chronic disease management programmes, with closer working between mental health specialists and other professionals.
>
> (Naylor et al., 2012)

Indeed, achieving greater awareness of physical LTCs among people with mental health issues is a real concern: many are diagnosed and treated later than people without mental health issues, with consequent poorer outcomes. Additionally, health care systems are modelled on the concept of the 'compression of morbidity', i.e. that older people are supposed to experience chronic illness and/or disability only in the very final years of life (Chatterji et al., 2015). Yet a key feature of ageing for many people with disabilities/LTCs is one of early and ongoing comorbidities. LTCs in particular can also involve a complex range of symptoms which fluctuate over time.

Services for older people may lack the ability to deal with such complexities and to deliver joined up care (NICE, 2015). There can also be a reluctance to engage with end-of-life issues:

> Although patients with chronic, life-limiting, noncancer conditions experience greater symptoms and worsening quality of life as their disease progresses (even for the oldest patients), care often focuses on treatment and disease management without addressing advance care planning and decision making.
>
> (Cleary, 2016, 46)

Recognition

Recognition is closely linked to resource distribution: lower status and cultural worth of people with disabilities/LTCs, often informs their relatively

diminished access to and accumulation of, resources. Moreover, as noted above, service providers often do not recognise or meet their needs: disability and LTC services failing to recognise and meet the needs of older people; ageing services failing to recognise and meet the needs of people ageing with disabilities/LTCs. Recognition is indeed central to understanding how the experiences of people ageing with disabilities are often 'forgotten' (Zarb, 1993). This lack of recognition and/or mis-recognition occurs at the nexus of two key sites of prejudice, discrimination and social exclusion: ageism (Bytheway, 2005; Nelson, 2004) and ableism (Campbell, 2009; Goodley, 2014).

Ironically, 'for the disabilities system, ageing is a success; for the ageing network, disability is a failure' (Ansello, 2004, 4). Yet 'the inference that a significant percentage of individuals could reach advanced old age without appreciable deterioration in health or function is simply not supported by population studies' (Molton and Yorkston, 2017, 291). One of the major criticisms of 'successful ageing' (Katz and Calasanti, 2014; Martinson and Berridge, 2014) is that it is predicated upon the absence or avoidance of disease and disability. Indeed, at its core, 'successful ageing discourse simply ignores the fact that we will all physically decline, and we will all die' (Stephens, 2017, 293). This means that the image of someone who is ageing successfully inherently excludes those individuals ageing with disabilities and/or LTCs.

> Ageing successfully is, in academic accounts, explicitly or implicitly, portrayed as non-disabled, an image reinforced by a complete lack of visible impairments or tools such as wheelchairs, walkers or sticks in advertising and in media presentations of the modern, recreationally active senior citizen.
>
> (Taghizadeh Larsson, 2013, 56)

Such practices 'make it very difficult for people with a lifelong disability to aspire to successful ageing' (Bigby, 2004, 18). Those older people with such 'markers' of disability are inherently excluded from being recognised as someone who is ageing successfully. Instead they are positioned as someone who is 'failing' to age successfully (Higgs and Gilleard, 2015; Stephens, 2017) or is ageing 'unsuccessfully' (Gilleard and Higgs, 2017). Their experiences of stigmatisation are compounded caught at the intersection of ableism, 'sanism' (Poole et al., 2012) and 'compulsory able-bodiedness' (McRuer, 2010, 83) with ageism and 'compulsory youthfulness' (Gibbons, 2016). Indeed, 'acknowledging the impact of ageism is central to a proper understanding of the ways in which multiple forms of oppression impact on the lives of older disabled people' (Zarb and Oliver, 1993, 17).

Representation

Representation, according to Fraser, involves political voice, policy inclusion and community participation. While some people with disabilities remain

actively engaged in their community as they age (Paterson and Watson, 2013), others may not. Some of this may be linked to increasing levels and types of disability, but more is linked to how people ageing with disabilities and/or LTCs are positioned in society. Jeppsson-Grassman's (2013) long-term study with ageing individuals in Sweden who are blind or visually impaired, has highlighted the cumulative effects of living with a disability and how these are informed by the social policy contexts in which disability is framed. As Paterson and Watson, 2013, have observed,

> 'Active ageing' for disabled people is often impeded because of a lack of appropriate support or because of the controlling influence of others rather than the existence of age-related changes.
>
> (23)

As we have argued, older people with disabilities and/or LTCs, particularly those ageing with them, are marginalised by current understandings of successful ageing, upon which ageing policies are predicated, which does not reflect the experienced of people ageing with LTCs (Fereshtehnejad and Lökk, 2014) and which 'may undermine the value of people with disabilities' (NCA, 2006). There is then, a need for policies and strategies which increase the social inclusion and community participation of older people ageing with disabilities and/or LTCs (Raymond, Grenier and Hanley, 2014). This may necessitate taking a capabilities approach which would 'focus on the capability of all older people to achieve valued functioning, rather than being responsible for ageing "successfully"' (Stephens, 2017, 496). This issue, as Zarb and Oliver wrote a quarter of a century ago, and which remains true today is 'about genuine political citizenship which would empower older disabled people as full and equal members of society' (Zarb and Oliver, 1993, 111).

Representation also involves inclusion in knowledge production and research. There are gaps in knowledge about people ageing with disabilities and/or LTCs 'in relation to people's lived experience of how such conditions impact on their life' (NICE, 2015, 24). The literature consistently reports the need for more research on ageing with disabilities and/or LTCs in general and in relation to specific conditions (Salvador-Carulla et al., 2012, Nalder et al., 2017). Moreover, there is a need to understand the positive dimensions of ageing with a disability, particularly resilience, adaptability, self-determination and a focus on well-being in bodies which do not necessarily comply with idealised norms (Silverman et al., 2015).

Freedman (2014, S62) has identified seven major research gaps in relation to the demography of ageing with disabilities:

1. How many adults are aging with disabilities?
2. Has survival improved for individuals aging with disabilities?
3. Can the notion of active life expectancy help inform understanding of aging with disability?

4 What is the pattern of onset of secondary conditions for individuals aging with disabilities and how might such conditions be prevented and/or their debilitating effects ameliorated?
5 What role has obesity had in shaping the population of individuals aging with disability?
6 How do individuals aging with disability differ from those who develop disability later in life? and
7 What are the long-term consequences of developing disability before late life for subsequent health, functioning, and socio-economic outcomes?

A further area for consideration is the potential for technology 'to enhance independence for those ageing with a disability' (Agree, 2014, S33).

NICE (2015, 24) have recommended the following research agenda in relation to ageing with LTCs:

- the experiences of older people in the UK living with multiple long-term conditions and how their conditions affect them over time and at different stages of their life;
- how a person's multiple long-term conditions interact with each other and how this affects the person over time;
- the priorities, meanings and preferences of older people living with multiple long-term conditions.

A number of authors have highlighted the need to bridge the gaps (Nalder et al., 2017) between ageing and disabilities studies:

> There must be a strong commitment by the scientific community to support and engage in research that bridges ageing and disability and to acknowledge some flexibility in traditional and historical borders that segment ageing and disability.
>
> (Salvador-Carulla et al., 2012, 3)

It is in many ways that the ways the voices of older people are represented (or not) in disability studies and the voices of people ageing with disabilities in ageing studies, that contributes to the paucity of knowledge development in each. This in turn informs a lack of much-needed collaborative interdisciplinary research.

Conclusion

Older adults with long-term disabilities and LTCs can offer important insights on how to age 'successfully' *with* disabilities, particularly in terms of resilience (e.g. Silverman et al., 2017) and positive adaptation (Molton and Yorkston, 2017). Increasing the visual and political representations of older people across the dis/abilities spectrum open up possibilities to move away from disability-denying

'successful ageing' to disability-inclusive 'successful ageing'. This, in turn, offers the potential to increase and improve their inclusion in society, their access to associated resources (material and social) and 'changes in service delivery to improve practices that will encourage active ageing for people with disabilities in retirement' (Goods and Millsteed, 2016, 713).

Older adults ageing with LTCs may be able to offer information, guidance and support to older adults ageing with age-acquired LTCs. In this way the 'deficits' associated with ageing with LTCs could be usefully reframed as assets, in terms of the expertise from experience which they can offer older people who are new to living with chronic health conditions. Acknowledging the realities of ageing with, as well as into, disabilities and LTCs, opens up the possibilities of exploring how to live life to the full beyond the false narrative of a disability/disease-free older age.

Note

1 This chapter does not address ageing with intellectual disabilities. Please see the chapter by Karen Watchman in this collection which addresses this subject.

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16 The intersectionality of intellectual disability and ageing

Karen Watchman

Introduction

Intellectual disability is characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which cover many everyday social and practical skills reducing ability to learn new things (Department of Health, 2001). Intellectual functioning refers to mental capacity, whilst adaptive behaviour spans a range of conceptual, social and practical skills often referred to as daily living skills. Approximately 2% of the population in England have an intellectual disability although fewer than this are known to services (Public Health England, 2015). People with Down's syndrome make up between 15% and 20% of the population of people with intellectual disabilities, with around 1 in every 700 babies born affected by this chromosomal disorder (Centers for Disease Control and Prevention, 2017). There are a range of individuals who are often considered to have an intellectual disability but who do not, including persons with dyspraxia, dyslexia, attention deficit disorder, Asperger's syndrome or some individuals with autism.

Life expectancy globally is increasing for many people with an intellectual disability as a result of improved neonatal care, increased quality of life and improved access to health and social care services (NHS Scotland, 2017). For example, in 1983 a baby born with Down's syndrome often did not live beyond age 25, whereas today the average life expectancy for a person with Down's syndrome is between 50 and 60, with a small number of people living into their 70s (Down's Syndrome Association, 2018). Therefore, people with Down's syndrome of 50 years and over are typically considered as falling into the older age group of people with intellectual disabilities.

Discussion of issues relating to ageing with an intellectual disability throughout the chapter leads to consideration of one of Nancy Fraser's (1996; 2014) key questions – whether social justice requires the recognition of individuals or groups, or if recognising common humanity is sufficient. Whilst Fraser recognises the need for a pragmatic approach, what ought to be recognised depends on what is essential to ensure parity. By reframing support for people ageing with intellectual disability it is possible to argue for an extension of Fraser's social justice framework to give a particular focus on changes associated with

the early onset and progression of dementia in people with Down's syndrome. This calls for a reframing of 'ageing' among people with intellectual disability to reinforce the importance of intersectionality between intellectual disability, ageing and dementia. To do so, this chapter will firstly explore the chronological challenge through the lens of Fraser's social justice framework (1996). Beginning with Fraser's two-dimensional perspective of distribution and recognition, we then reflect on resources and (re)distribution to demonstrate how working in silos is preventing a cohesive approach to supporting people ageing with intellectual disability. Recognition (identity) highlights the lack of preparation, provision and support for people with intellectual disability in later life. We then consider representation with discussion of the extent to which the voices of older people with intellectual disability remain unheard. This takes us on to Fraser's three-dimensional, rather than two-dimensional, approach with recognition of the social injustices faced by this group that are only compounded by age and further age-related disability.

Models of ageing with an intellectual disability

Fraser did not specifically write about intellectual disability, however in the context of disability generally she focused on the social model to support a model of inclusion. As such it is not the 'player', but the unequal 'playing field' that impacts on how far a person is included (Fraser, Honneth and Wolf, 2003). Using Fraser's definition, it seems that if many people with disabilities want to participate and communicate with those in power, they will have to conform to 'ableist' norms. The distinction between impairment and (physical) disability has received much attention over the years with attempts to reorientate the debate by focusing on society rather than the individual. For example, Oliver (1997) highlighted how society further disables 'impaired' individuals through such an ableist structure, thus increasing the potential for dependency.

Older people with intellectual disabilities are a diverse group. Although chronological age is typically used as a trigger to access services and support for older people generally, this is not a useful indicator of the age-related needs of persons with an intellectual disability. Indeed, it presents the first paradox in this chapter. The standard life course model of ageing views getting older as a linear progression through stages and life events with chronological ageing as the norm. Yet, the life course for people with intellectual disability differs significantly in terms of relationships, marital and financial status, number of children, employment and physical health reinforcing the lack of a level playing field but with no option to conform to norms when age, typically 65, is the criteria used in the UK to access age or dementia related services.

When considering theoretical models, this does not make a life course approach unsuitable for people with intellectual disabilities, indeed childhood experiences are crucial as is future planning for older age, however it typically takes a different route (Krahn and Fox, 2013). Grenier, Griffin and McGrath (2016) report a similar tension among the population of people ageing with

a physical disability (see also the chapter in this collection by Westwood and Carey on ageing with physical disabilities and long-term conditions). There has been a shift in generic models of ageing with Foster and Walker (2015), for example advocating for 'active ageing' as a paradigm shift from 'successful ageing', which was derived from development of theories such as continuity, activity and disengagement. The active ageing discourse focuses on encouraging the participation of older adults in society and emphasises the competence and knowledge that older people possess. 'Active' was defined by the World Health Organisation as 'continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force' (WHO, 2002, 12). Whilst this perspective challenges negative stereotypes of older age and emphasises autonomy and participation, it highlights the schism between people with and without an intellectual disability for whom the term active ageing is rarely applied.

Nowhere is this gap more evident than when we consider dementia in people with intellectual disabilities. After age 60, about 6% of adults with intellectual disability will be affected by a type of dementia, with the percentage increasing with age (Janicki and Dalton, 2000; Zigman et al., 2004). However, this rises to 50% to 70% of adults with Down's syndrome in the same age group (National Task Group on Intellectual Disabilities and Dementia Practice, 2012) with a prevalence rate of one in three aged in 50s increasing to nearer two in three from age 60. Indeed, Hithersay et al. (2017) suggest that more than 80% of people with Down's syndrome may experience dementia by age 65 years. Such earlier onset with associated impact on parents who are often primary carers, intellectual disability services and the growing numbers of ageing adults themselves, combine to raise concerns within the health and social care agenda that are not yet reflected or represented in national dementia plans and strategies. People who have intellectual disabilities are mentioned in just 37% of the 79 available plans (Watchman et al., 2017). However, being 'mentioned' cannot be extended to being 'represented' when content is restricted to highlighting the link between Down's syndrome and dementia, rather than suggesting strategies for support in practice or in policy, or when no acknowledgement is given to the differences among this group in terms of age and life experience.

Many people with an intellectual disability experience the same age-related sensory, physical, social and mental health-related conditions as people who do not have an intellectual disability. However, this population will typically die, on average, more than 14 years younger than the population generally, and are significantly more likely to have certain conditions and diseases (e.g. coronary heart disease), some at a younger age (Hatton et al., 2016). Little is known of people with intellectual disabilities' perception of their own ageing; Burke et al. (2014) reported that 57% described their own health to be very good to excellent but had negative views of getting older. This raises the question of how far people with intellectual disability conform to ageing norms and enjoy 'active ageing' (Walker, 2015). This does not only refer to physical activity but to ongoing social engagement in the communities of which older people are

a part. Active ageing should apply to all citizens, including older people with intellectual disabilities, (Foster and Boxall, 2015).

Whilst Fraser wrote that the shift to conform to 'ableist' norms was required to facilitate inclusion (albeit of people with physical disabilities), Knight (2014) argues that such a focus on 'normalisation' is particularly unfair for cognitively and/or linguistically impaired individuals, arguing that attention to communicative diversity is also required. Even though origins of the social model were not intended as an all-encompassing theory of disability but rather a starting point for how society views disability, an over reliance on the social model of disability has been challenged in relation to people with intellectual disabilities (Oliver, 1997). Terminology also throws up a contradiction, with the term 'disabled people' recognised as consistent with the social model, yet in the field of intellectual disability the paradigm has shifted to 'people with intellectual disability'. This is more than just semantics, as it reflects a shift in ideology to a 'people first' and person-centred approach.

In order to understand more about apparent paradoxes in representation of this relatively recent group of people ageing in higher numbers with intellectual disabilities it is first necessary to explore Fraser's concepts of resources and recognition.

Resources/redistribution

Resources relevant to people with intellectual disability are usually controlled by others: accommodation setting, access to health care, social care and support – either provided by family or paid provision. As part of the redistribution of such resources, there is a pattern of viewing intellectual disability and ageing in isolation, and even more so intellectual disability and dementia, rather than seeking to understand what one field can learn from the other. Heller, Gibbons and Fisher (2015) recognised the importance of redistribution and increased partnership between the fields of ageing and intellectual disability whilst Watchman and Janicki (2017) identified the same schism between the fields of dementia and intellectual disability. This also applied at end of life with McCallion et al. (2017) calling for integrative efforts between intellectual disability and palliative care providers alongside specialist training for carers and the involvement of adults with intellectual disability themselves in their advanced care planning.

Consideration of the lack of divergence in models between ageing and intellectual disability will involve exploration of the extent to which older people with intellectual disability fare economically and how this is related to redistribution. Typically, such a focus on injustice is defined as socio-economic; poorly paid and derived from cultural norms with the remedy being recognition rather than redistribution. However, people with intellectual disabilities have a history of exclusion and marginalisation (issues of recognition) and even now their wishes or wants are not always considered in formative decision making (issues of representation). Employment remains beyond the reach of most with

an overreliance on volunteering, for example the national rate of employment for people with intellectual disabilities in the UK barely changed in the 20 years between 1990 and 2010 (Humber, 2013). As recently as 2014, it was mooted by a UK government minister (Watt and Wintour, 2014) that some disabled people could be paid less than the minimum wage to secure employment.

Redistribution cannot be considered without an understanding of where people live and sources of funding for this. Prior to the shift to 'community care' in the UK many people with intellectual disability lived in long-stay hospitals or asylums located physically and socially on the margins of society (Radford and Tipper, 1988). Even as the asylums closed and people moved into nearby communities, this experience of separation and isolation continued, a situation termed the 'asylum without walls' (Dear and Wolch, 1987, 6). Older people with intellectual disabilities are less likely to be married or to have children and those living with parents are often seen in mutually dependent relationships whereby the person with a disability is often the carers for one or more older parents (Cairns et al., 2012). Shared living arrangements are also common with an individual living with one or more peers, also with an intellectual disability, supported by paid carers, with the level of support depending on individual need. The extent of choice and control that has followed this shift to community-based support, whether informal with families or formal with paid carers, remains limited. For example, Kahlin et al. (2015) noted that both choice and control are dimensions of participation that are limited in a shared small group home (two or more people with intellectual disabilities living together supported by social care staff). In reality, participation is limited by the organisation, the environment, staff knowledge and skills.

It is important to extend previously held perceptions of the role of older people with intellectual disability and to remove the notion of being a passive recipient of care and support. We need look no further than family relationships for an example of this. Adults with an intellectual disability may also gain the status of carer, when a parent, older sibling or other person in their life is diagnosed with dementia (Blackman et al., 2014) and they become the primary carer. This will inevitably bring challenges as navigating services can be problematic, but even more so if the services do not recognise the carer's role or efforts simply because they are marginalised because of the perception of their intellectual disability by others. Such instances will become increasingly prevalent as more adults with intellectual disability are placed into primary carer roles in the absence of any other involved family members. This not only requires recognition of their role as carer, but also the need for specialised services and support to enable these roles to be undertaken.

As the person ages and, for some, health needs change significantly, barriers exist to maintaining accommodation or support services. Diagnostic overshadowing (Inglis et al., 2015) can occur when a health professional makes the assumption that a person with intellectual disabilities' behaviour is a part of their disability without exploring other factors such as biological determinants. This can also include physical conditions mistakenly attributed to mental health or

something that is inherent in the person's intellectual disability. As people with intellectual disabilities have a much higher risk of experiencing a variety of diseases and conditions, it is vital that physiological or pathological determinants in behaviour change are explored. For example, gastrointestinal cancers are approximately twice as prevalent in people with intellectual disability and coronary heart disease is the second highest cause of death (Heslop et al., 2013). In the example of people with Down's syndrome and dementia, social care staff may not recognise early signs or the significance of behavioural changes that may indicate the onset of dementia (Watchman 2016). Furthermore, many social care staff will be unfamiliar with dementia, unsure how to adapt services, lack confidence or knowledge to support the individual as dementia progresses or are hindered by financial restrictions on providing the nature of care required for persons with intellectual disability, particularly as dementia progresses (Watchman and Janicki, 2017). Referral and transfer to inappropriate services (often to nursing or residential care facilities where residents are considerably older and staff are unaware of communication strategies) may be initiated, disrupting established routines and social relationships, as well as affecting a loss of a familiar environment and compromise of meaningful relationships with family members and other long-term friendships (Jokinen et al., 2018).

Institutionalisation does not just take place historically in large out-of-area facilities (People First Canada, 2016). It occurs in any place where people are isolated, segregated, and do not have control over their day-to-day lives. Given most countries' historical policies of institutionalising both children and adults with intellectual disability (Johnson and Traustadottir, 2005), the oldest-old are more likely to have a history of institutionalisation – which has led to self-advocates with intellectual disability strongly voicing their opposition to being re-institutionalised due to ageing-related issues. Companionship for many increasingly comes from people who are paid to provide support and proactive support is required to maintain relationships. This can involve a change in the approach to support that may have previously been provided by staff or family. A consequence is that we know little about experiences from the perspective of the person with an intellectual disability and even less following a diagnosis of dementia.

Despite the social model of disability typically being lauded and advocated, we see a shift towards increased medical needs as a dementia progresses – not just dementia-related changes but in addition to the same age-related health problems as other older adults. For some individuals, sensory and mobility impairment, obesity, sleep apnoea and poor oral hygiene can contribute to health challenges. Inequality is seen in health service and inadequate health provision which does not recognise specific needs of older people with intellectual disability. In relation to mental health and well-being, loneliness has been identified as a significant predictor of age-associated physical and mental health difficulties although with very little research to investigate its impact among people with intellectual disability. Gilmore and Cuskelly (2014) proposed that societal views traditionally stigmatise people with intellectual disability and

limit opportunities for social connectivity with others. In turn, this lack of opportunity reinforces negative attitudes.

This focus on Fraser's social justice framework relating to resources and redistribution already indicates the potential for the lack of a cohesive approach when people age with an intellectual disability. The requirement to conform to 'typical' ageing resources and services are beyond both the reach and the capacity of many people with intellectual disabilities with the social model of disability failing to recognise the intersection between lifelong intellectual disability and increased disability associated with ageing, particularly for people with Down's syndrome who are at risk of early onset dementia.

Recognition

Whilst being excluded from distribution of economic resources is recognised as a threat to social justice, for people with intellectual disabilities this is a long-term exclusion with little likelihood of this changing or of having the choices that are available to other sectors of society. However, Fraser also refers to a second type of social justice – the politics of recognition which recognises and celebrates difference, noting that that both distribution and recognition are required for social justice. People who are the most vulnerable whether due to age, complexity of their disability, lack of verbal communication or a progressive condition remain the most marginalised in society. Whilst the *objective* circumstances of some people with intellectual disabilities has improved, many continue to experience discrimination. The extent of discrimination ranges from personal safety, victimisation in the community and disability hate crime, despite the United Nations Convention on the Rights of Persons with a Disability, Article 19 (2006) stating that people with disabilities have a right to a life in the community – not just a house (Beadle-Brown et al., 2014). By ignoring the contribution of individuals who have been positioned as recipients of care, and overlooking their potential to contribute socially or economically, the process of exclusion and marginalisation can only be continued. This is the ultimate 'other' of difference, previously confined to institutional living, albeit in less obvious form, in the policy of 'social inclusion'.

This is never more apparent than when needs change in the case of people with intellectual disability and dementia and raises a further issue of representativeness. Even less is known of personal preferences and experiences of this group as communication and cognition continue to change. Voices remain unheard and what is understood about people with intellectual disabilities is instead framed through the lens of carers perspectives. Whilst general dementia-related literature contains work on the perspectives of adults who are diagnosed with dementia, with reflections on experiences and reflections on what the progression of dementia may mean (Botek, 2016), most of the literature on dementia-related experiences in the intellectual disability field is drawn from the perspectives of family or staff carers (Carling-Jenkins, Bigby and Iacono, 2014; Lin et al., 2014). Limited experiential information is

available from the perspectives of adults with intellectual disability (Blackman, Thompson, Brookstein and Brooksby, 2014; Lloyd, Kalsy and Gatherer, 2007; Watchman, 2014) and almost none is available from research drawn from their personal perspectives (Watchman and Janicki, 2017) emphasising that under-representation in turn informs under-recognition.

Just as the term disability is contested so too is identity, with terminology again rearing its head when we seek to understand sense of identity. Reference to individuals with an intellectual disability and dementia as a 'hard to reach' group, for example in research, perpetuates the stereotype of not being able to communicate with, or hear the views of, people with intellectual disability and dementia. The term 'under-researched' is more appropriate by placing the onus on the researcher and practitioner to facilitate inclusion rather than assuming that, as a group already marginalised by others' perception of their intellectual disability, this is not achievable. A recurring theme in the literature is of not seeking the perspective of the person with intellectual disability with a diagnosis of dementia, not knowing how to do so, and not recognising the potential for naturally occurring activities that may facilitate conversations. Whilst this is not unique to people with intellectual disability (other marginalised groups are also often excluded from studies), it does indicate an on-going issue facing researchers in the intellectual disability field as this does not reflect the changes undergone in intellectual disability services from when historically exclusion was the norm. At the same time, people with intellectual disability do not necessarily identify themselves as 'old' or 'ageing' (Buys et al., 2008). Preference instead is identified for continuation of areas of life that were enjoyed and meaningful, rather than an age-enforced change in circumstances or 'retirement' from services.

All of this means that a contradiction is apparent. Redistribution is less likely to remedy injustice as it is historical as well as societal and cultural. Recognition has more of a cultural focus and is where most shifts have been, however although representation has become increasing positive for many people with intellectual disability, for some this stalls with increased age or co-morbidity. The question must be asked as to how injustice can be remedied in the face of a remodelling of services, reduction in choices and opportunities in day care facilities and an increase in (at times younger) people with intellectual disability placed in aged care facilities and generic care/nursing homes. This often poses dilemmas particularly for individuals with Down's syndrome who are typically considerably younger than other residents and simultaneously staff often feel, whether accurately or not, that they are ill-equipped to support someone with an intellectual disability (Cleary and Doody, 2016). Rather than a person-centred or individualised community-based service, this raises the question of a return to a culture of institutionalised style of living as people get older. However, we have noted that institutionalisation is more than just a building and limitations extend beyond environmental factors. Fraser noted that neither redistribution nor recognition alone could remedy injustice – both are needed together. Looking historically at the experiences of people ageing with

an intellectual disability and the extent to which this group experience bivalent collectively and are excluded from participation throughout the world, suggests that an increase in identity leads to increased participation, with a redistribution of resources being important from both an individual and a service perspective.

Representation

A key issue when considering representation is the extent to which the voices of older people with intellectual disability are represented, whether through self-advocacy or being represented by advocates for people with intellectual disabilities. In many societies and cultures, the person-centred movement continues to emerge and grow, as does the self-advocacy movement, which is seen in both dementia (DAI, 2017; Swaffer, 2016) and intellectual disability populations (The Arc, 2014). Recently, this has extended to consideration of dementia as a disability under the Convention for the Rights of Persons with Disabilities (Shakespeare, Zeilig and Mittler, 2017) although not with unanimous support, largely due to concern over further labelling (Whitman, 2015). Such a changing level of self-advocacy is reflected by increased inclusion of adults with dementia on planning groups, on boards of dementia organisations, and as sought-after representatives at public policy forums (DAI, 2017). This extent of self-advocacy is not yet expressed by the population of people with intellectual disability affected by dementia or their families, nor has it been evident in decision-making levels within national third sector or non-government organisations advocating on behalf of people with intellectual disabilities (Watchman et al., 2017).

The World Health Organization's (WHO 2012) report *Dementia: A Public Health Priority* called for the development and adoption of national dementia plans or strategies to guide public policy and set development goals for services, supports, advocacy and research related to dementia. There are currently 79 worldwide national or sub-national plans and national or non-governmental strategies. Their content addresses such diverse issues such as encouraging research into the causes and eventual prevention of dementia, establishing early diagnosis and treatment programmes, post-diagnostic support, education and training and supports for family carers. Although the WHO report also called upon countries to address the needs of diverse groups within the scope of these national dementia plans or strategies, just 37% of the 79 plans mentioned adults with intellectual disabilities, with most not going beyond noting the connection between Down's syndrome and dementia. Those strategies and plans that included representation from people with dementia in their development did so as members of a task force, working group, or as part of the consultation process. None referred to the inclusion or representation of people with intellectual disability.

Omission of the perspectives of individuals with intellectual disability in both policy and practice limits understanding of experiences of ageing. It leads to an overreliance on proxy reporting; which should be considered a backwards

step in person-centred work. In relation to a diagnosis of dementia, the perspectives of people with intellectual disability must be considered whenever interventions and supports are discussed. Planning is required at an earlier stage for advance directives that guide medical treatment, and for advice or support around relationships, continuity of social networks, and when securing or adapting dementia-friendly housing.

We have looked at lack of representation of older people with intellectual disabilities in a particular context, ageing with dementia. However, we are faced with a more pressing challenge of how far we can hear the voices of people with intellectual disabilities even before they reach older age, given the continued stigma and social exclusion that stems from both medical and societal pressures. Today there is an increasingly public profile of people ageing with intellectual disability with some in the public sphere providing role models for current and future generations of children and adults. Yet, at least 90% of pregnancies are still terminated when Down's syndrome is determined antenatally and each new screening test developed is lauded by the medical community. The public perception of negativity around Down's syndrome is in sharp contrast with individuals' own positive life experiences and hopes for the future. People with intellectual disabilities continue to seek representation in society, yet remain consistently impacted by the decisions made by others without such disabilities.

Conclusion

The extent and complexity of issues affecting people ageing with intellectual disabilities emphasises the importance of understanding factors that influence representation and recognition. This includes addressing the extent of an individuals' participation and choice, which is often determined by others or by an organisation and acknowledges the need for greater support for self-advocacy. It requires that attention be paid to policy or strategy frameworks that do not accurately reflect the reality for people ageing with intellectual disabilities.

Although Fraser did not write specifically about people with intellectual disability, it is clear that the distinction between redistribution of resources and recognition viewed among older people with intellectual disabilities is consistent with her framework. Furthermore, representation is not only an essential requirement, it has been shown how this should be at the centre of social justice. Economic redistribution and cultural recognition can only stem from political representation and nowhere is this more apparent that when we look in the context of getting older with intellectual disabilities and co-morbidities, including dementia. In terms of Fraser's social justice model, this points to presence of inequality and lack of justice and offers potential to extend her previously limited work on intellectual disability.

Rather than older peoples' services, intellectual disability services and dementia services working in silos, Fraser's social justice model can be extended to reframe our approach to supporting people who are ageing with an intellectual disability. Such an approach should place representation at its core, seeking to

understand individual perspectives and developing this to recognise appropriate support as health or cognition changes, and redistributing resources to reflect the reality of ageing with an intellectual disability. This would not only see an improvement in resources available for older people with intellectual disabilities, thus increasing recognition, but it would also promote recognition of the intersection of ageing and intellectual disability, and as appropriate, dementia. In order to do this, the voices and lived experiences of older people with intellectual disabilities need to be better represented to inform and shape the services made available to them. This supports an extension of Fraser's two-dimensional model to three dimensional, noting the ever-present inequality rising from stereotypes and stigma already present for people with intellectual disabilities then compounded by ageing or additional cognitive impairment due to dementia.

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17 Ageing with HIV

Dana Rosenfeld, Damien Ridge and Jose Catalan, on behalf of the HIV and Later Life (HALL) Team[1]

> You haven't had old HIV people. We're technically the guinea pigs and first generation of old HIV people . . . up till now, no one discussed it because no one thought it would happen, that we'd be old HIV people. You know, give them six months and that's them out the door.
>
> (P43, gay White man in his 60s)

Introduction

That this chapter appears in a section entitled 'Ageing with a long-term condition or disability' rather than, for example, 'End of life' speaks to the radical changes that the HIV community has undergone over the past three decades (Deeks, Lewin and Havlir, 2013). From the first reports, in 1981, of young gay men suffering from diseases typically associated with compromised immune systems (later recognised as 'the first official harbingers of AIDS' – Altman, 2011) until 1996, when effective antiretroviral medications were developed, HIV typically led to AIDS, which caused high rates of premature death from opportunistic infections. Now, assuming early diagnosis and good access and appropriate adherence to medication, people living with HIV (PLWH) can survive into later life (Nakagawa, May and Phillips, 2013) and even reach normal life expectancy (May, Gompels and Sabin, 2012). The HIV population is now experiencing good health and ageing that neither the HIV sector nor medical science could have imagined only a few decades ago.

Consequently, in the United Kingdom, almost 30,000 PLWH aged 50+ access HIV specialist care, with the median age of PLWH accessing this care rising from 39 to 45 between 2006 and 2015 (Kirwan et al., 2016). If current trends continue, over half of the UK HIV cohort will be aged 50+ by 2028 (Yin, Kall, Skingsley and Delpech, 2015). The situation is similar in the United States, where the number of older PLWH (OPLWH) 'increased from 301,647 to 428,724 – an increase of nearly 40%' between 2010 and 2014 (Harris et al., 2018, 3), and worldwide: 'For the first time since the start of the HIV epidemic', 10% of adult PLWH in low and middle-income countries are aged 50+, making the estimated OPLWH population in these countries 2.9 million, and 'in

high-income countries, approximately 30%' of adult PLWH are aged 50+ (UNAIDS, 2013, 3). OPLWH are members of the first generation to age with HIV – an historical fact introducing a mix of unique challenges, as detailed in this chapter.

In its early years, AIDS decimated the gay male community, in which it was primarily found (Halkitis, 2013; Tester, 2017). The HIV epidemic is now embedded across multiple groups and geographical regions, with, in the UK and in descending order, prevalence highest among White men who have sex with men (MSM), heterosexual men and women of Black African origin, and White heterosexual men and women. Thus, the older HIV population, like its younger counterparts, varies by gender, sexuality and ethnicity, each of which introduce their own circumstances, challenges and resources. Further bisecting these differences are age at, and time since, diagnosis. Older age at diagnosis has consequences: physical (e.g. age-related comorbidities or frailties), social (e.g. in terms of having or raising children, and romantic relationships or prospects) and economic (e.g. ability to work), both immediately and in the long term (hence time since diagnosis) as they accumulate over the life course (Willson, Shuey and Elder, 2007). Finally, both age at and time since diagnosis overlap with historical dimensions of illness: here, for example, OPLWH diagnosed pre-1996 are typically ageing after long periods of ill health, relatively high levels of stigma and un/under-employment.

Compared to their HIV-negative peers, OPLWH experience higher rates of frailty, and at younger ages (Kooij et al., 2016); higher rates of mental ill health, particularly anxiety and depression (Kall et al., 2015); and more comorbidities, again, at younger ages (Smit et al., 2015) within social support systems that, while often strong, are also disproportionately 'fragile' (Shippy and Karpiak, 2005). OPLWH are far likelier to live alone, and many, especially longer-term diagnosed MSM, are ageing in networks depleted by multiple AIDS-related deaths (Rosenfeld, Bartlam and Smith, 2012). As a result, OPLWH are lonelier than are their HIV-negative peers (Terrence Higgins Trust, 2017). Significant numbers of OPLWH depend on social networks primarily composed of friends whose own disabilities (Siegler and Brennan-Ing, 2017) and/or HIV status (Karpiak and Brennan-Ing, 2016) limit their ability to provide care.

OPLWH share HIV-related stressors with younger PLWH (e.g. stigma, challenges of disclosure, uncertainties of living with a chronic condition, impacts on romantic and sexual relationships, work and financial security and managing medical treatment). But they also face challenges that younger PLWH do not. For example, our study's participants experienced uncertainty about how HIV affects 'normal' ageing (Rosenfeld, Ridge and Von Lob, 2014), and their experience of living with HIV was shaped by ageism, the development of frailty and comorbidities with age, retirement and the availability of pensions, parenting and grandparenting, caring for older parents, approaching dating and romantic relationships as a parent and/or older person, coming to terms with the past, imagining the future as an older person and concerns over independence and long-term care (see Rosenfeld et al., 2015).

No study to date has considered these challenges through the lens of Fraser's framework of social justice, which contests the 'false antithesis' between socio-economic and cultural oppression, each of which has, in traditional models, its own solution (economic restructuring and 'cultural or symbolic change' – Fraser, 2003, 7 – respectively). Fraser (2003) 'posit[s] a type of collectivity' whose core experiences and social position are equally shaped by 'the economic structure and the status order of society' (ibid., 15), where '*neither of these injustices is an indirect effect of the other, but both are primary and co-original*' (ibid., 15, emphasis in original), and who are thus 'bivalent' (also important is that individuals are members of multiple collectivities, some dominant, others subordinate). Thus, for example, gay men and women's oppression stems from cultural biases, but these biases' consequences are partly economic, as coming out 'poses economic risks' (ibid.) that undermine this group's ability to fight homophobia. This chapter thus brings empirical knowledge about ageing with HIV into Fraser's framework for the first time. Fraser's framework does not specifically identify people living with stigmatising illnesses as bivalent collectivities, nor does she consider age, but, as this chapter shows, age and, in this instance, living with HIV are not only bivalent identities in themselves but intersect with such other collectivities as ethnicity, sex and sexuality in ways that subject OPLWH to socio-economic and cultural injustice.

Here, we draw on qualitative data gathered for our HIV and Later Life (HALL) study into OPLWH's mental health, social support and quality of life (QoL) to explore those challenges that best resonate with Fraser's three domains of inequality: *recognition* (social status, cultural visibility and cultural worth); economic, social care and support *resources*; and *representation* (social and political participation and access to justice). In our data, these intersect in ways that challenge Fraser's divisions. We argue, for example, that while social care 'belongs' in Fraser's 'resources' category, given OPLWH's cultural invisibility outside the HIV sector, and their impoverishment by recent statutory shifts regarding disability payments, social care more naturally falls into the 'representation' category, as does the defunding of HIV service organisations.

Methods

The HALL team included HIV consultants, social scientists, mental health professionals, epidemiologists and a community advisory board (CAB) of HIV activists and advocates who were living with HIV. We secured ethical approval before conducting 17 stakeholder interviews, and three focus groups, and 76 life-history, semi-structured interviews with recently and longer-term (diagnosed for <10 years or ≥ 10 years at time of interview, respectively) White MSM, Black African heterosexual men and women, and White heterosexual men and women, all aged 50+. We recruited OPLWH through two HIV clinics, one mental health clinic serving a high number of OPLWH, and HIV organisations, all in London.

At interview, OPLWH were asked about their typical day, personal histories and histories with HIV, social relations and support, QoL, ageing with HIV and hopes and concerns for the future. OPLWH whom we interviewed completed a survey combining questions on QoL, depression and anxiety, and a further 24 OPLWH completed the same survey containing supplemental questions on social relations and support, demographics, physical health and history with HIV. All interview data were transcribed ad verbatim; a researcher took notes on focus groups as they were conducted; and all data were fully anonymised. OPLWH interview data were subjected to open and closed coding before being uploaded into NVivo 10 folders, then analysed using a thematic, constant comparative approach (Glaser and Strauss, 1967; Strauss, 1987). Survey data were subjected to bivariate and multivariate analysis, specifically, step-wise multivariate linear regression, using SPSS.

Our interview and survey sample consisted of 53 MSM (50 gay, three bisexual), 12 Black African heterosexual men, 18 Black African women (17 heterosexual, one of unknown sexual orientation), nine White women (eight heterosexuals, one bisexual), and nine White heterosexual men. Their ages ranged from 50 to 87, with 94% of the sample aged 50 to 70 (median age 56.0, mean age 58.4 years). Age at diagnosis ranged from 24 to 79 years (median age 47 years, mean age 47.2 years); 23 participants were diagnosed <40 years. Years since diagnosis ranged from 1 to 32 (median 10 years, mean 11.4 years); 21 participants were diagnosed pre-1996. Fifty-nine participants lived alone, and one in three was partnered. Ninety-seven per cent of Black African and 82% of White heterosexual, versus 17% of MSM, participants were parents.

Almost half of the sample was in full- or part-time work (28%) or retired (20%); 52% was not in paid work. As a result, and in keeping with the UK's wider OPLWH population (58% of whom live before the poverty line, up from 48% in 2010, double that of the HIV-negative population, and one-third of whom rely on benefits – Terrence Higgins Trust, 2017), incomes were low (median £10,400, mean £20,430), with almost half of the sample earning <£10,000/year, and 80% earning <£31,000/year. Fifty-five per cent were in receipt of one or more welfare benefit (e.g. Disability Living Allowance, or DLA; Employment and Support Allowance, including Incapacity Allowance; Housing Benefit), with women and Black African participants over-represented (78% and 73%, respectively, versus 53% of White heterosexuals and 45% of MSM).

To ensure confidentiality, we identify OPLWH whose accounts figure here by membership in one of our core groups (MSM; Black African males and females as BAM and BAF, respectively; and White heterosexual males and female as WHM and WHF, respectively), recently or longer-term diagnosed (RD or LTD) and age by decade. We further identify focus group participants by reference to their host focus group: RD MSM, LTD and BA.

Recognition

Participants situated their social status within two broad contexts. The first was *PLWH's low cultural worth*, grounded in damaging myths about HIV's

infectiousness and its transmission, by 'deviant groups', through 'immoral' activities (specifically, sexual excess and/or impropriety, and drug use). They viewed HIV stigma as a more significant barrier to well-being than was physical ill-health ('the big burden I carry isn't a health burden, it's the stigma' – P48, LTD WHM, 50s), although several participants, especially the LTD, did suffer from poor health. Thus, participants viewed the recent equation of HIV with other chronic, manageable diseases as misguided and naive: as P70 (RD WHF, 50s) explained, HIV 'doesn't feel like diabetes. Medically it may be, but emotionally and mentally it's very, very different'. To P48 (LTD WHM, 60s), whereas 'cancer's kind of bad luck, not because you've been injecting drug users or screwing around or anything else unpleasant, HIV is "deviant behaviour"'.

This stigma was, in these accounts, grounded in enduring fears and myths about HIV's transmission (through casual contact, and through sexual promiscuity, prostitution or the abuse of drugs) and of HIV as a 'Black', 'African' or 'gay' disease. Thus P47 (LTD WHF, 60s) described the stereotype of PLWH as 'people who sleep around, people that are drug addicts', and P50 (RD MSM, 60s) knew 'how people think: people deserve it, there are African Blacks, these gays . . . it's the same as they see minority groups, whatever they are. . . . I'm very aware about prejudice on the left and on the right. That's why I decide not to tell'.

The myths' endurance was, participants said, exacerbated by the diminution of HIV health promotion messages since the early days of the AIDS epidemic. As a result, participants explained, the HIV-negative population still (mis)understood HIV through the lens of the UK government's infamous 1980s 'tombstone' public health advertisements: as a highly infectious and fatal condition:

> Years ago, way back, when it came up, they had these horrible adverts with gravestones on or whatever, and from that point, nothing . . . they need to do something to push out that it is there, and that it does affect every single age group. It would be wonderful if they did a documentary . . . on HIV.
>
> (P5, RD WHF, 50s)

The second context was these *myths' intersection with ageist attitudes* (see also Emlet, 2006); for example, P23 (RD MSM, 50s) said 'It's not only being HIV positive, but it links into other prejudices around age, around sexuality, maybe even around disability, and the older you get, those compound even more'. The most relevant ageist bias was the normative expectation that sexual activity should diminish, and self-restraint, discretion and rational decision making increase, with age. As P47 (LTD WHF, 60s) explained, HIV-negative people think 'we shouldn't be having sex anyway, because after like 30, people think you shouldn't be having sex'. This contributed to making disclosure especially difficult for OPLWH: 'As an older person, to be seen as HIV positive, alarm bells ring out from the people who you think should know better. And sometimes, because of that, people don't talk about it' (BAFG#4, LTD BAM, 50s).

Here, cultural worth is a heightened concern with real and imagined consequences. These included embarrassment: when asked how the HIV-negative

viewed OPLWH, P36 (LTD WHF, 50s) replied, 'Drugs, or maybe I was sleeping around, I don't know. So, it's a bit embarrassing'. LTD BAF, 50s, whose children know her HIV status, described 'times when I sit and wonder what's going on in their minds, that she was promiscuous after she divorced our father', adding 'but I don't ask'. But participants described the spectre of abandonment or rejection by the HIV-negative as more damaging and more likely. If discovered, participants said, their HIV status would subject them to assumptions of age-inappropriate activities and thus to even greater stigma and discrimination. P5 (RD WHF, 50s) felt that OPLWH 'would be more discriminated against. They would absolutely think you were the dregs of the earth'.

These intersecting stigmas placed participants at a disadvantage regarding social relationships. Both RD and LTD participants imagined that their existing relationships could end or become more distant, and new relationships precluded, should their HIV status become known. For P48 (LTD WHM, 50s), 'The social stigma risk is a big deal. My biggest fear in life is my family, my friends, my neighbours, the guys I work with, finding out'. Few participants had experienced rejection, largely due to disclosing their HIV status strategically, to those with whom they were particularly close[2] (or to people they knew were PLWH), but rare instances of rejection were deeply hurtful. For P72 (RD MSM, 50s), HIV remained 'a huge influence on everything I do in my life, especially when you're rejected. If you say to somebody 'Oh, by the way I'm HIV'. Luckily, I think I only get about 10% rejection, but it still is like being knifed'. After P63 (RD BAM, 60s) disclosed to his son, his son 'didn't say anything', but 'changed completely', moving out of their shared flat: 'It's two years I don't see him. I don't know where he lives. I'm asking. I don't know. As soon as he heard'.

Most single participants wanted to form a romantic relationship but considered the prospect of doing so to be complicated, even precluded, by their HIV status. After her diagnosis, P70 (RD WHF, 50s) thought 'relationship-wise, that's it now . . . it was difficult enough finding someone anyway, and I sort of resigned myself to thinking I probably won't have a sexual partner again'. P58 (RD BAF, 50s) considered herself:

> still young enough to have a boyfriend or to get married and enjoy life. But because of this HIV now, you're afraid that maybe I'll hurt myself if I find a man and this man knows and they'll leave me again. If you're lucky, they accept you, then you can start living again and have a partner, someone who'll look after you. So, you're in a dilemma. You don't know because of the age again . . . you don't know to start it or not.

When P60 (LTD MSM, 50s) disclosed to potential partners, 'they either run away or they ask questions. . . . It's hurtful because you think, "it's just an illness. I'm still the same person you thought you liked. Now you don't want to have anything to do with me and I'm not even allowed to touch you". That hurts sometimes'. For many participants, the prospect of being romantically

unattached in later life had worrying implications for support, general well-being and mental health: when asked how HIV had affected him, P45 (RD WHM, 50s) answered, 'Just the endless solitude of it, how you get a deep, meaningful relationship. The close relationship thing's clearly been directly associated with the HIV, I'd say'.

Resources

Economic resources

While some participants were financially secure, most were struggling financially due to their HIV: for example, P59 (RD WHF, 60s) 'went from being somebody that was self-supporting, earning well and so on, to someone that was left not being able to'. Three core factors placed many participants under significant financial strain: *interrupted work histories due to ill health and/or migration*, *changes and threats to DLA* and *migration status*. For participants with interrupted work histories, time spent away from working or from working in jobs for which they had originally been trained made it very difficult to re-enter the employment sector at their original level, if at all.

For Black African participants, financial hardship due to interrupted work careers was exacerbated by uncertain migration status, which limited their right to work. All had been diagnosed while visiting the UK and remained in the UK for HIV treatment that was unavailable or unaffordable in their countries of origin. LTFG#5 (LTD BAF, 60s), who was 'still waiting for my papers', 'came to the UK to attend [a family function]' but could not return 'because I became very sick'. P63 (RD BAF, 60s) was also awaiting the Home Office's decision about his migration status:

> The first application was before I was diagnosed. It was for diabetes and blood pressure. They said you can go back to Africa where you can treat diabetes. But now it's diabetes, blood pressure and this one. You see? It became difficult. In Africa the treatment's very difficult.

Many Black African participants had earned good salaries in their countries of origin as e.g. specialists in banking and finance, the media, and law, but were now unemployed, significantly underemployed and/or on benefits. P9 (LTD BAF, 50s) 'couldn't continue with the same career and the same lifestyle I had in my country. I had to go low. I started off with cleaning jobs here. I'd never done a cleaning job in my life'. P7 (RD BAF, 50s) needed financial help 'because if I was granted my status I could be working and financially I'd be all right, but now I have to wait for the vouchers. Sometimes it's hard for me to buy maize to cook my traditional meal'.

Migration's effects were psychological as well as financial: participants whose applications for indefinite leave to remain were still under consideration described being stuck in limbo. P55 (LTD BAF, 50s) did not know 'where

I'm going to be next year . . . I just want to know if I'm going to get deported, so I can deal with it'. Uncertain migration and work status also affected these participants' family lives, as most of their family members (including, in many cases, children, spouses and parents) lived in their countries of origin. P66 (RD BAM, 50s) was depressed and

> missing my wife, my children . . . to bring my wife over, I need to be earning, like, £18,000 a year . . . right now I'm feeling sick, I can't look for a job to start working, so how am I expected to bring her out?

Many LTD participants, primarily MSM, had left the workforce due to ill health pre-1996, when most PLWH were thus advised by health providers and/or social workers given PLWH's short life expectancy at the time. These participants had been placed on DLA, were ageing with limited financial capital due to lack of earnings (and therefore pensions) over time and faced draconian changes to the benefits system, whereby DLA recipients were to be reassessed and, if deemed eligible to work (based on what participants considered unfair criteria, as below), expected to apply for jobs. As MSMFG#3 (RD MSM, 60s) explained, 'There's a big move to get people back to work, including those with HIV. . . . That's coming next year. Everyone has to be re-interviewed. I've seen a draft of the questions and they're much harder. You have to be a blob of jelly in a bucket'.

These impending changes introduced financial concerns ('My main worry's losing DLA. That would leave me financially devastated' – MSMFG#1, LTD MSM, 50s) and uncertainty: MSMFG#4 (RD MSM, 50s) said, 'You can't plot a course for your life. You have this thing going on. It's constantly changing'. Being 'constantly threatened' with having his DLA revoked had caused P60 (LTD MSM, 50s) 'a lot of trauma over the years':

> If the government changes their policy they can still take them away, and it actually says that in the letter: 'The fact that you've been awarded them indefinitely does not mean you will receive them indefinitely'.

Imminent changes to DLA also introduced the spectre of having to disclose HIV status to prospective employers. Moreover, the relapsing/remitting, or 'good days/bad days' (Charmaz, 1991), nature of HIV-related symptoms made assessment of capacity to work dependent upon the randomly generated assessment date rather than on actual ability. This, alongside stigma and OPLWH's age, would, MSM participants said, limit their work opportunities:

> I'd like to go back to work but I know the situation: when you get there and have to fill out the form, you'll have to disclose, so there's no chance in hell they'll take you on over a young person.
>
> (MSMFG#4, RD MSM, 50s)

> How do you explain to your new employer that you have to go to hospital?
> (MSMFG#3, RD MSM, 60s)

> One day you feel OK, another day you feel like shit. One day you can get out of bed and feel horrible.
> (MSMFG#4, RD MSM, 50s)

> No one's going to employ you anyway if you tell the truth. . . . At our age, and our condition, we're not going to get jobs.
> (MSMFG#2, RD MSM, 60s)

> Why would they take someone 50 or 60 when they can [hire a younger person] and pay them less?
> (MSMFG#1, LTD MSM, 50s)

> As long as you're seen to go through the interview process, and they reject you, you can't say you've been discriminated against, because you've been interviewed.
> (MSMFG#1, LTD MSM, 50s)

Social support

Several participants had what Shippy and Karpiak (2005) termed 'fragile' social networks. For example, while a friend had been helping P31 (RD MSM, 70s), who lived alone and had hypertension, he was 'frightened now that she's going to have a baby. Who's going to look after me now?' Because a friend who was helping P69 (LTD BAF, 70s) had returned to Africa, 'no one's helping me'. P61 (RD WHF, 60s), who lived alone, said 'when I was ill I couldn't manage with my housework, I had to pay someone'. Others, especially MSM, were lonely because

> At a relatively young age, we lost lots of friends, which usually happens when you're older. It was almost like what happens during a war, when almost a whole generation is wiped out . . . a lot of gay people with HIV are lonely because a lot of the people they should have grown old with have gone.
> (MSMFG#3, RD MSM, 60s)

But most participants had close connections with friends and family, and, again, one in three were in supportive and fulfilling romantic partnerships. Participants valued support from HIV-negative friends and family, including children – for example, P80 (RD WHM, 60s) appreciated his daughters and friends 'preparing a meal in time for me to take my medication' – but they also contrasted this support with that provided by other PLWH who held what we term 'experiential

knowledge' of HIV's clinical, social and psychological impacts. Participants viewed support from other PLWH who were, in several participants' words, 'in the same boat', as irreplaceable (Rosenfeld and Anderson, 2018). As P47 (LTD WHF, 60s) explained, 'that's the only answer: having friends in the same situation'.

This made access to other PLWH critical for mental health, well-being and social support. In this context, *HIV organisations and support groups* provided essential practical support (e.g. guidance on managing HIV and such related challenges as medication management, housing and other benefits) and combatted isolation: LTDFG#5 (LTD BAF, 60s) said, 'we need centres to socialise, those for HIV positive people and older people. . . . Maybe do some dancing. Loneliness – I'm old, I can't do a lot of walking. But if there's a certain place I have to go to, I can do that'. HIV support groups, participants explained, provided access to other PLWH for mutual understanding, social support and solidarity – 'If I hadn't joined those groups', P63 (RD BAM, 60s) said, 'maybe I'd have died now, because it's those groups that actually told me "Look, you're not alone in this fight"'. Meeting other OPLWH was also crucial: while 'some people, when you say, "I'm HIV positive", don't expect you to live longer than five years' (P44, RD MSM, 50s), HIV groups showed participants that they could live long, healthy lives:

> When you're newly diagnosed, they say, 'Oh, that's the end of me, I'm going to die' and so on. But they're always given the support. They say, 'You see this one, you see here also, some have already spent more than even ten years being ill' and so on, so they pick up that courage.
>
> (P18, RD BAF, 60s)

Finally, HIV organisations and support groups provided a 'safe space' that stood in stark contrast to the awkwardness, hostility or misunderstanding participants expected to experience in non-HIV-dedicated spaces should their HIV be known. P78 (LTD BAM, 50s) said that the 'moral support' and opportunity to 'meet your friends, chatting, speaking the same language' offered by HIV organisations 'helps a lot. Because some places you go, you keep mum, you don't say anything, you listen. You can speak, but you feel it's not okay. There's a barrier'. P43 (LTD MSM, 60s) described entering 'a room full of HIV people' when he first attended an HIV organisation:

> You didn't worry about judgement, because when you're applying for things, you start using euphemisms for what you've had, and you don't want to tell people because it's early days. You think they judge, and you start worrying about that. Here, you were just left to breathe.

Representation

In Fraser's inequality model, representation refers to social and political participation and access to justice. In the developed West, and especially in the UK,

'access to justice' issues that had dominated the HIV sector's early years – access to medication, legal protection from discrimination in employment (although, as we have shown, still a concern) and housing, and representation in scientific research and medical policy – are now less on the radar and did not emerge in our data as core concerns. Rather, our analysis uncovered three obstacles to representation as defined by Fraser: changes to DLA, HIV-related stigma and homophobia in long-term care settings, and defunding of HIV service organisations.

Changes to DLA

Since the completion of our study, DLA has been reconfigured into Personal Independence Payments (PIP), designed to cover a long-term condition's added costs. A National AIDS Trust's (NAT) report showed that PIP's 'fundamental assessment design and criteria' (NAT 2017a, 27) significantly disadvantage PLWH: 'compared to the overall population of people claiming DLA', PLWH are 'less likely to be awarded PIP following reassessment; less likely to receive an increase in their rate of benefit when moving from DLA to PIP; [and] more likely to receive a decrease in their rate of benefit when moving from DLA to PIP' (ibid., 2). PIP's criteria and descriptors do not adequately capture PLWH's distinctive mental health (e.g. 'risk of isolation due to HIV-related anxiety'), mobility, medication management and nutritional needs, and disregard 'the support needs around managing toilet needs and incontinence which are more likely to apply to' PLWH due to immunological compromise and/or medications' side-effects. Moreover, HIV's stigmatisation is directly linked to 'the stress which the face-to-face consultation causes' PLWH (ibid., 3). Given OPLWH's (especially the LTD) disproportionate reliance on benefits, the shift to PIP clearly constitutes injustice and introduces barriers to social participation (via a diminution of support for, e.g. travel outside of the home) and political disenfranchisement.

Long-term care

Given our sample's relatively young age, few participants had considered long-term care, but those who had done so expressed concerns that care staff and other residents would hold stigmatised beliefs about HIV that would compromise the care they received. For example, P48 (LTD WHM, 50s) wondered what would happen 'if I ended up in an old folks' home when I'm 80 and on the medication and the staff in the old folks' home, there's 100 people in it and there's 99 who are negative and I'm the one positive one, what happens when word gets around? Because the nurses are going to have to dish out medication'. Similarly, P22 (RD MSM, 50s) was concerned that, eventually,

> I'm not going to be able to look after myself, which will mean that I'll need someone to look after me and tend to me. Who can I trust? Where

> am I going to be? Am I going to be having people, carers, that aren't going to want to come in to tend to me because I'm HIV positive?

Most participants who had considered long-term care were MSM who feared that homophobic attitudes, combined with HIV-related stigma, would undermine the quality of long-term care. To P81 (RD MSM, 70s), who, while visiting a gay male friend living with HIV in a nursing home, witnessed 'this patient opposite continually ma[king] snide comments – "oh, the queers are here"', concerns that all older people had regarding long-term care were 'exacerbated because of sexuality, and because of HIV'. As P43 (LTD MSM, 60s) explained, 'Care is based for heterosexuals':

> What if I can't stay in my flat, and I'd be one of these little old biddies hanging onto the stair rail saying, 'I don't want to leave'? . . . If you're a gay person in a heterosexual nursing home, where would you fit? And then they find out you're HIV, and a lot of heterosexual people don't understand HIV, so they'd be throwing their china away. So, what do you do? Have HIV ghettos?

These concerns echo those raised across the HIV sector. Relevant research, while both limited and new, shows that, while protected under the 2010 Equality Act, OPLWH in the UK fear encountering HIV-related stigma and discrimination in care settings, and are concerned about home-based and residential home care providers' lack of training in HIV-related health needs and treatments (Beer, James and Summer, 2014). Indeed, HIV-related stigma and discrimination in health care (Nöstlinger et al., 2014; NAT, 2014) are widely documented, and emerging research documents stigma, inadequate understandings of HIV, and reservations about admitting OPLWH among care-home staff (see e.g. Naudet et al., 2017). HIV-related stigma often translates to discriminatory practices (i.e. refusal to admit or care for PLWH, forced isolation within care homes – Terrence Higgins Trust, 2017). Such recognition of intersectional factors such as stigma and privilege are critical for deepening understanding of access to resources in later life – including good health and access to quality of long-term care – where hostile providers are a real threat, particularly to those with fewer resources (Westwood, 2016). Finally, apprehensions about confidentiality in LTC settings increase as OPLWH's care teams widen from health care professionals who regularly uphold confidentiality to include carers who may be less well-trained (Beer, James and Summer, 2014). As the experience of ageing with HIV within residential care settings, and in the context of home-based long-term care, remains significantly under-researched, OPLWH, and HIV organisations are still working with limited knowledge of long-term residential care for OPLWH, but concerns over justice as described earlier continue to characterise relevant discussions.

Defunding of HIV organisations

Given HIV service organisations' central role in providing OPLWH with much-needed social support, connections and solidarity, the recent defunding of HIV organisations (by an average of 28% across England between 2015–16 and 2016–17 – NAT 2017b) is a pressing concern for the HIV sector, as it was for many of our study's participants. BAFG#4 (LTD BAM, 50s), for example, said 'Unfortunately, a lot of these organisations are going out of existence, because of lack of funding, which is putting more pressure on the older generation'. Some participants' access to HIV organisations had already been curtailed by funding cuts at the time of our study, well in advance of more recent cuts. For example, P41 (LTD MSM, 70s) used to attend an HIV support group, which was 'quite nice, quite useful', before it closed due to funding cuts. Moreover, since 'HIV organisations have consistently highlighted the intensive advocacy and support needs which their clients have needed to initiate, undergo, and complete the assessment journey' related to the new PIP system (NAT 2017a, 22), these organisations' defunding intensifies injustices caused by the shift from DLA to PIP.

Conclusion

OPLWH face stressors that distinguish them from their HIV-negative peers and from younger PLWH. While some adverse effects of ageing with HIV are HIV-related (e.g. stigma, ill health, discrimination), others relate to ageing in a society that denies older people their full humanity (e.g. the denial of sexuality), or statutory policies that make it more difficult for older people, who are more likely to live with chronic and/or disabling conditions, to secure support. These same policies disadvantage PLWH and especially OPLWH, as they are even more likely than their HIV-negative peers to be disabled and/or in poor health. If we are to take Fraser's seriously notion of bivalence, whereby bivalent collectivities are composed of individuals whose social positions and experiences are independently shaped by economic structure *and* social status orders, then all PLWH are clearly (and at the very least) bivalent, with their HIV status continuing to receive economic and cultural responses that are, at base, unjust.

By the same token, each PLWH embodies other bivalent identities, as their gender, class, migration/work/parental status, ethnicity and sexuality are shaped by both economic factors and the social status order, which operate independently. These will intersect in unique ways, as when sexuality and HIV status combine to heighten fears over ageing with HIV in long-term care settings. But ageing with HIV introduces yet more characteristics that produce bivalence: age itself, and long-term survivorship. Some factors producing bivalence in this population (class, sexuality) are recognised by Fraser, while others – most notably age and health – are not. The data we explored here, we suggest, signal the need to include age and health in the index of bivalence.

Fraser's domains of inequality are useful entrees to the challenges and sources of injustice that OPLWH face because of their age/ing and HIV status. Under *recognition*, OPLWH face HIV-related stigma, intersected and exacerbated by racism, homophobia, ageism and the state's abandonment of health-promotion messages. Fraser's *resources* domain captures challenges to OPLWH's economic security (interrupted work histories, benefit changes, migration status) and to their social support (fragile social networks, defunding of essential HIV support organisations and groups), but this is where Fraser's clear divisions between her three domains begin to erode. The social supports (*resources*) put in place by the HIV sector and PLWH themselves to compensate for the difficulties and injustices emanating from the *recognition* domain and the economic resources element of the *resources* domain are threatened by agents operating within Fraser's third domain: *representation*. Thus while, in Fraser's framework, both social care and service organisations 'belong' in the *resources* category, the politicisation of these resources in the context of neoliberal policies make the domain *representation* equally relevant to them. Accessing essential resources is, thus, an issue of *representation* – a fact of increasing relevance given increases in the number and proportion of older people (and younger people living with chronic and/or disabling conditions) needing care and support on the one hand and the purposive erosion of the welfare state in the UK and the US on the other.

The issue of representation takes on added valence in the context of a significant imbalance in third-sector and governmental organisations' attention to OPLWH, and of OPLWH's own participation of activism and advocacy on their own behalf. While an effective AIDS activist movement developed in the early days of the pandemic (including the AIDS Coalition To Unleash Power, or ACTUP), demanding political action, including faster development of – and better access to – effective treatments (Morris, 2012), the introduction of effective treatments in 1996 lessened the need for activism focused on developing life-saving treatments, although access to these treatments remains uneven (see e.g. Souteyrand et al., 2008). Some notable community activism persists, e.g. to support good and equitable access to PrEP (Pre-exposure Prophylaxis) and PeP (Post-exposure Phrophylaxis) via public health systems (Brisson and Nguyen, 2017). Yet, there is also a sense that OPLWH's ability to maintain earlier levels of political activism has waned, as OPLWH, particularly long-term survivors, are exhausted by the traumatic fallout of the epidemic's early years and by the challenges of assimilating the multiple losses of those years. These days, OPLWH are not leading on activism to improve their lives as OPLWH, but rather are participating in research and/or are recipients of help. Here, the voices of OPLWH typically are being represented by researchers, the NHS and charities, rather than by OPLWH-led activism, although many OPLWH do collaborate on relevant research (see e.g. Terrence Higgins Trust, 2017), and long-term survivors provide peer support and engage in advocacy work (see e.g. the 'Let's Kick Ass' group – Anderson, 2015).

Moreover, little overlap exists between the concerns of HIV and ageing activist/advocacy organisations; there is, for example, little reference to HIV

on the Age UK website, compared with the Alzheimer's Society website which provides information on HIV-related cognitive impairment (Alzheimer's Society, 2015), and the recent (2017) Age UK resource guide for professionals designed to 'help health and care professionals meet the needs of older lesbian, gay, bisexual and trans (LGBT) people' makes no reference to HIV despite the disproportionate HIV prevalence among men who have sex with men of all ages. The HIV sector is thus far more attentive to recognising and serving the needs of OPLWH than is the ageing sector – a gap which must be bridged if OPLWH are to achieve adequate representation and, indeed, social justice.

Notes

1 Jane Anderson, Homerton University Hospital NHS Foundation Trust, London, UK; David Asboe, Chelsea and Westminster Hospital NHS Foundation Trust, London, UK; Valerie Delpech, Public Health England, London, UK.
2 Most had disclosed to family members, partners, and adult children – for issues regarding disclosure to young children and older parents – see Rosenfeld et al., 2016.

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18 Older people and deficiencies in the formal care system

Equality and rights

Jonathan Herring

Introduction

Few people look forward to spending their old age in a care home. Portrayals of the ideal old age in the media involve activity, health and independence. Common images of care home life, by contrast, are of sitting in an arm chair staring into space. The very antithesis of so-called successful ageing. Nowadays, life in the care system is commonly perceived to be at best unbelievably boring and unstimulating, and at worst abusive, neglectful and undignified. Not surprisingly, this has led to calls for tighter legal regulation to protect the rights of older people in the formal care setting. This chapter questions whether the solution to concerns over the quality of care for older people in care homes lies primarily with further legal regulation. There are three primary reasons for this scepticism. First, legal interventions inspections fail to tackle ageism, which is the root cause of the problem of care home provision. Second, legal inspections tend to promote standard approaches and formulas rather than individualised response to older people and their needs. Third, the law typically promotes minimum standards rather than seeking the highest standards.

Before going further, it is important to correct a common misperception. First, it is sometimes wrongly assumed that most people will end their days in a care home. In fact, that is rare. Only 3.2% of over 65s live in care homes and even among those over 85, 13.7% do (Office for National Statistics, 2016). However, the population is significantly gendered, with 2.8 women for every man in care homes. Further, it is particularly a feature of those with dementia. It has been estimated that around 80% of care home residents have dementia (Alzheimer's Society, 2013).

This chapter proceeds as follows. It starts by outlining the problem of abuse in care home settings. It will then briefly explain the current legal problems, before turning to the limitations of legal responses and suggestions as to other ways of improving the quality of life in care homes. During this chapter, in line with other chapters in this volume, I will utilise Nancy Fraser's typology of resources, recognition and representation.

Abuse and neglect in care homes

This section explores the nature and extent of abuse and neglect of older people in care homes. It highlights, in Fraser's typology, the issue of access to the resource of safe, good quality care.

Extent of abuse

The Royal College of Psychiatrists (2000, 6) have suggested that abuse 'is a common part of institutional life' in care homes. A Care Quality Commission (2013) report on care of people with dementia found 'more good care than poor care in the care homes and hospitals our inspectors visited, but the quality of care for people living with dementia varies greatly'. While there are too many cases of serious physical abuse and death, a more widespread problem is the general atmosphere of care homes. As one report by Royal College of Psychiatrists (2000) put it, 'the predominant culture is one of warehousing older citizens' (Royal College of Psychiatrists, 2000). It went on to claim that most of the abuse is due to 'ignorance, unthinking and ageism' rather than malicious or sadistic acts. Such attitudes may be fostered by the culture and atmosphere of many institutions, but they in fact reflect wider social attitudes towards older people.

The two main sources of nationwide data are reports by the Care Quality Commission (CQC) and from Safeguarding Adult enquiries from local authorities. The latest CQC (2017a) reports that as at 31 July 2016 of the adult social care services they had reported 71% were rated good and only 1% outstanding. Two per cent were reported as inadequate. Worryingly, of those in previous years rated as inadequate, 47% did not improve their rating and in 8% there was a deterioration in standards leading to an inadequate rating. The latest Safeguarding Adult Enquiries, launched into response that a vulnerable adult was at risk found that 39,639 risks were investigated in 2015–2016, 36% of all enquiries (NHS Digital, 2017). A BBC Radio 4 investigation (BBC, 2016) found on average two sexual assaults in care homes against residents reported each day.

Kinds of abuse

The World Health Organisation (2002, 2) has adopted the following definition of 'elder abuse':

> a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person.

The most commonly referred to are sexual abuse, financial abuse, misuse of medication, physical abuse, neglect and humiliating behaviour (House of

Commons Health Committee, 2004, 1). All of these kinds of abuse can be found in a care home setting. We will explore some of the particular issues shortly, but it worth emphasising some of the aspects of abuse in a care home which make it a particular serious matter.

First, the victim has limited chance to escape from the abuse. Older people are often both less willing and less able to complain, because of their care dependency (Ware et al., 2003). There is also little or no advocacy, especially everyday advocacy, for older people in closed care spaces, raising in Fraser's terminology an issue of representation (Anderberg and Berglund, 2010). Further, they will not be able to access alternative accommodation and accessing sources of help will be restricted. Second, abuse in a care home setting is a severe breach of trust (Herring, 2011). Entering a care home makes you physically and emotionally vulnerable. The trust placed in staff is considerable. This is not just to ensure one's physical well-being but relationships with staff can be important to the older person's sense of self and value. Abuse and neglect can, therefore, strike at the very heart of a person's identity. Third, the abuse of older people in care home reflect and reinforce ageist attitudes within society. It is therefore an issue of wider significance than simply the older individual themselves.

In the light of this, it is not surprising, but greatly saddening, to read that depression is four times more common among those in care homes than older people living in the community, running at 40% to 60% (Seitz, Purandare and Conn, 2010). I will say a little more about some of the more prevalent forms of abuse in a care home setting.

Dignity

Perhaps the most common complaint of treatment in a care home is that there is a lack of protection for the dignity and privacy of residents (Department of Health, 2006). In Fraser's typology this can be seen as a resource of being treated with dignity and an issue of recognition, i.e. being recognised (and this treated) with respect. The arrangements are designed for the ease of the staff and the well-running of the home, rather than treating and respecting each person as an individual. Dame Jo Williams, writing to introduce an inspection of hospital care captures these concerns:

> Time and time again, we found cases where patients were treated by staff in a way that stripped them of their dignity and respect. People were spoken over, and not spoken to; people were left without call bells, ignored for hours on end, or not given assistance to do the basics of life – to eat, drink, or go to the toilet.
>
> (Care Quality Commission, 2011, 5)

These incidents to some may seem minor, but it is through a series of such dehumanising incidents that an individual's self-esteem can be lost and staff can

develop demeaning attitudes towards residents. In the enclosed world of a care home minor demeaning acts can take on a huge significance.

Infantilisation

This issue of infantilisation appears to be a particularly prevalent concern. This, too, can be seen in Fraser's terminology as both an issue of resource (treatment) and recognition (as an adult). Little acts of lack of respect, although each relatively minor, together create an atmosphere which is dehumanising. John Cobett writes

> One of the things I found difficult was being treated like a child; it threatened my sense of independence. We were always told things would be nice for us. Some of the other residents felt rebellious: we didn't want things that would be 'nice' for us but things that would be a bit of a challenge sometimes The one-size-fits-all approach to the trip to Worthing (it was always bloomin' Worthing because it 'would be good for us') was not what several of us wanted. Why the heck couldn't we go somewhere else? We would have liked something different (and cheaper), like a trip to some woods to see the bluebells.
>
> (quoted in Pillemer and Moore, 1989, 16)

Neglect

Neglect is perhaps the most prevalent complaint in care homes. One report (Care Quality Commission, 2011, 7) noted the following comments from patients and their relatives:

> The patient constantly called out for help and rattled the bedrail as staff passed by. . . . We noted that 25 minutes passed before this patient received attention. When we spoke with the patient we observed that their fingernails were ragged and dirty.

What can be particularly sad is that sometimes relatively little effort would be required to provide something of great significance to resident. Ann MacFarlane, a resident, makes this comment:

> An abiding memory is of a woman who cried out each morning for her grapefruit spoon. It was her one possession from her own home and invariably it was missing from the breakfast trolley.
>
> (quoted in Help the Aged, 2008, 38)

Legal response

The legal response to abuse in care home settings will now be summarised. In Fraser's terminology this might be seen as an issue of legal recognition.

Criminal offences

The mistreatment of older people in care homes can give rise to criminal prosecutions. Of course the standard criminal law applies just as much where the victim is an older person as anyone else (Payne, 2005). So in incident of elder abuse will often amount to one of the standard criminal offences such as assault or theft or even murder. But the criminal law has gone further and introduced some specific offences that are, in part, designed to protect care home residents.

Most notable is the offence of ill treatment or neglect, found in section 20 Criminal Justice and Courts Act 2015:

> It is an offence for an individual who has the care of another individual by virtue of being a care worker to ill-treat or wilfully to neglect that individual.

Section 21 allows a care provider to be convicted if

(a) an individual who has the care of another individual by virtue of being part of the care provider's arrangements ill-treats or wilfully neglects that individual,
(b) the care provider's activities are managed or organised in a way which amounts to a gross breach of a relevant duty of care owed by the care provider to the individual who is ill-treated or neglected, and
(c) in the absence of the breach, the ill-treatment or wilful neglect would not have occurred or would have been less likely to occur.

There is also the offence of ill-treatment or neglect of a person lacking capacity in Mental Capacity Act 2005, section 44. Section 76 Serious Crime Act 2015 creates an offence of controlling or coercive behaviour. However, this only applies in a case where there is an 'intimate relationship' and it would be unlikely that a carer and resident in a care home would be said to have an 'intimate relationship' unless they became particularly close.

Tort law

Where a care home resident is harmed as a result of negligence a claim in tort law can be brought. Damages can be awarded to compensate for any loss. There would be little difficulty in showing that an employee of a care home owed a duty of care to a resident. The difficulty would be that unless the abuse caused financial loss it would be unlikely significant levels of damages would be available.

Regulation

The regulation of care homes falls on local authorities under the Care Act 2014 and the Care Quality Commission. Both of these will be briefly explained.

The Care Act 2014 has introduced a significant legal regulation of care in care homes. This is found in sections 42–46 and Sch2 of the Act and chapter 14 of the Care and Support Statutory Guidance. The broad aims of this policy are to prevent and stop abuse and neglect in a range of setting and to safeguard adults to enable them to have control over their lives. The powers are designed to protect anyone who has care and support needs and is not limited to care home or older people.

The local authority's duty is found in section 42 and is to make enquiries where there is 'reasonable cause to suspect that an adult with care and support needs is being abused or neglected or is at risk of being abused or neglected'. The enquiry should enable the local authority to determine what action is needed.

The Care Act 2014 in section 43 also requires local authorities to set up Safeguarding Adults Boards. These are designed to be multi-agency bodies bringing together knowledge and information from a range of bodies in relation to adults' abuse whom there are concerns. The Safeguarding Adults Boards have a duty to undertake a case review of there has been a serious safeguarding incident (section 44). This is designed to ensure that action is taken in response any lessons that need to be learned from the incident.

The Care Quality Commission (CQC) has the task of inspecting and regulating adult care services. Care homes and other agencies must register with the CQC and they undertake inspections that are designed ensure that the bodies comply with the relevant standards of care. Where there are failings the care home is given advice on how to respond to the issues raised. The Health and Social Care Act 2008 sections 26–32 give the CQC a number of sanctions if a care home is failing to comply with a request for action. These range from an emergency closure order to a variation of condition of registration to a fine (Furness, 2007).

The CQC (2017b, 11) has produced a list of 'fundamental standards' which it expects its inspection and regulation to achieve. They tell care home residents that these are the standards they are seeking to enforce. They include:

- Person-centred care: You must have care or treatment that is tailored to you and meets your needs and preferences.
- Dignity and respect: You must be treated with dignity and respect at all times while you're receiving care and treatment. This includes making sure:
    - You have privacy when you need and want it.
    - Everybody is treated as equals.
    - You're given any support you need to help you remain independent and involved in your local community.
- Safety: You must not be given unsafe care or treatment or be put at risk of harm that could be avoided. Providers must assess the risks to your health and safety during any care or treatment and make sure their staff have the qualifications, competence, skills and experience to keep you safe.

- Safeguarding from abuse: You must not suffer any form of abuse or improper treatment while receiving care. This includes:
    - Neglect
    - Degrading treatment
    - Unnecessary or disproportionate restraint
    - Inappropriate limits on your freedom.
- Staffing: The provider of your care must have enough suitably qualified, competent and experienced staff to make sure they can meet these standards. Their staff must be given the support, training and supervision they need to help them do their job.

Protective orders

Where concerns are raised about the care of a resident of a care home which cannot be resolved then steps can be taken to obtain court authorisation to remove someone from a care home setting. If there is abuse within a care home setting and the family or local authority wishes to remove the person from the home this is unproblematic if the individual has capacity and wishes to move. Where they lack capacity or are unwilling to move then a court order is required and there are a range of orders that could be sought (*Re DE* 2006). This could be under the Mental Capacity Act 2005 if the person lacks capacity, although moving someone to a different care setting is likely to involve the use of Deprivation of Liberty safeguards *LB Hillingdon v Steven Neary (2011)*. Even if a person has capacity it may be possible to use the inherent jurisdiction to protect vulnerable adults (*DL v A Local Authority* 2012). The Mental Health Act 1983 provides another mechanism by which a person can be 'sectioned or detained' in order to receive treatment for a mental disorder. I will not go into the details of that legislation, but it can only be used to facilitate the provision of treatment and not simply to provide alternative accommodation.

Problems with the current legal response

In this section I explore the problems with the current response. Using Fraser's framework this can be described as legal mis-recognition which results in under-protection (resource distribution) and under-representation (under-funded advocacy).

The primary direct legal interventions criminal law sanctions and order for payments under tort law. However, these legal interventions are primarily retrospective rather than forward looking. They are designed to allocate responsibility and ensure compensation is paid, rather than preventing a repeat of the harms (Quick, 2006). Direct legal actions also come with costs. They encourage secrecy and can cause emotional and financial costs for those perusing claims or defending them. Indeed, Oliver Quick (2012, 99) is adamant: 'There is no clear evidence connecting the threat of civil action with safer healthcare'.

Although, therefore there are reasons to be wary about legal intervention it would be wrong to dismiss its role in terms entirely. Direct legal intervention through the law of tort and criminal law is only rarely used, but this does not mean it lacks value. It is important to have the threat of criminal punishment of the most serious of cases to offer guidance and operate as a deterrent. Only a tiny minority of contracts get to court. That does not mean contract law is useless. It is primarily designed to deter people from breaching a contract or guide parties as to how to (extra-judicially) resolve disputes if a breach has taken place.

I now explore some of the particular problems with relying on legal regulation to improve the quality of life in a care home.

Not dealing with causes

The wide range of legal responses to situations of abuse and neglect in care home setting, but these do not deal with the underlying causes of the problem. I would argue there are two: ageism and underfunding.

Ageism

At the heart of the problems with standards of care in care homes is ageism (Herring, 2009). As the Toronto Declaration on the Global Prevention of Elder Abuse (World Health Organisation, 2002, 1) puts it:

> Ultimately elder abuse will only be successfully prevented if a culture that nurtures intergenerational solidarity and rejects violence is developed.

Ageism permeates society (Thornton, 2002). Abuse of older people in care homes reflects and is reinforced by wider attitudes in society. Tackling these must be at the heart to tackling elder abuse. It is crucial, when discussing ageism to consider it in the context of sex and race (Walker and Northmore, 2006) and indeed other forms of power within society (Ward and Bytheway, 2008), such as discrimination on the basis of sexual orientation (Kimmel, Rose and David, 2006; Westwood, 2016) or disability (Sargeant, 2011).

Older people are typically seen as a burden. The so-called care crisis played a major role in the 2017 UK elections. It reflected a common fear that older people are a growing populating of dependent and vulnerable people (Fitzgerald, 2006, 94). This, I argue, feeds into neglect of older people in care homes. To give just one example, one resident, Ms C, is reported as saying,

> It was young boys who gave us our bath. They told me they didn't have enough time, 'We have one minute per patient.' I told them you couldn't call that a proper bath. . . . They said, 'You know, you're only temporary.'
>
> (Charpentier and Soulières, 2013, 347)

This poignant example reflects and explains why inadequate treatment and neglect can be justified to care homes and their staff.

I would argue, however, that the response is not to deny the idea that some older people may be dependent for help but to reconsider whether dependency is bad (Herring, 2016). We are all, or virtually all, dependent on others; and others are dependent on us. A recognition of the significance of relationships which are central to all our lives shifts the starting point away from the autonomous individual to a person sited in inter-dependent relationships. Once, then, we accept our inherent vulnerability and dependency on others, the image of the all-powerful rights bearer falls away. Indeed, it may be that what drives ageist attitudes is the fact that old age make undeniable the lack of autonomy and need for interdependence that has always marked our lives, however much we may seek to deny it.

Society portrays older people and disabled people as lacking capacity or being of doubtful capacity. This can restrict their access to power, public spaces and their role in the community. Disablist and ageist attitudes create and reinforce attitudes among older people about themselves. The ageist notion that older people are a 'waste of space' and always complaining about things, deters victims of elder abuse from seeking help or indeed even leads them to believe that the behaviour is not abusive. Such attitudes belittle and sap the confidence of those suffering abusive relationships. Until we tackle these wider attitudes about age, care and dependency we will not be able to tackle.

Funding and organisational structures

While the law generally responds to wrong doing by individuals, it finds it difficult to allocate blame on organisations and structures. The traditional legal tools of finding an action and a state of mind work inadequately when seeking to address problems in a culture or complex organisation. The problems of abuse and neglect in care home abuse is that the difficulties often reside within a structure. It may not be possible to identify a particular carer worker who behaved badly or a particular incident of serious abuse. It may simply be that everyone was doing their best, but there are not enough care workers to help the individual. It may have been a general malaise about the unstimulating environment that cannot be limited to a particular decision at a particular time.

The abuse of older hospital patients identified in Francis Reports (2010, 2013) were seen as primarily not about the fault of individual nursing staff but rather reflected deeper problems within the trusts. These included that the trust's board had 'an insidious negative culture involving a tolerance of poor standards and a disengagement from managerial and leadership responsibilities' (Francis, 2013, 3). The inquiry (Francis, 2013, 3) summarised the issues as including follows:

> a corporate focus on process at the expense of outcomes; a failure to listen to those who have received care through proper consideration of their complaints; staff disengaged from the process of management; insufficient

> attention to the maintenance of professional standards; lack of support for staff through appraisal, supervision and professional development; a weak professional voice in management decisions; a failure to meet the challenge of the care of the elderly through provision of an adequate professional resource.

This is true of many of the problems in care homes too.

Running through these broader institutional problems is money and the fragile state of the adult social care market. CQC (2016, 12) notes:

> Our data shows the severe financial strain that local authority funded providers continue to be exposed to. Care home providers with more than half of their turnover funded by local authorities achieve, on average, 10% less fee income per bed and generate almost 28% less profit per bed, compared with all providers.

This, they argue, has led to a severe shortage in care home beds for publically funded residents and severe problems in recruiting and retaining staff. With around 7% of the adult social work force being non-British EU workers, Brexit may increase the concerns. Legal intervention is ill suited to deal with these broader political, economic and structural problems.

One size fits all

An approach based on law has the danger that it too easily take a 'snapshot' approach to a problem. Law is typically designed to deal with a particular event. A hit B on the nose. This approach works less well where the wrong is best understood in relational terms. No form of annual inspection or traditional criminal law regulation can capture the day in day out tedium or infantilisation that I discussed earlier in this chapter.

Another limitation on the effectiveness of law as a method of promotion of patient safety is that one of the foundational legal principles is the 'rule of law'. That requires the law to be sufficiently certain so that citizens can know in advance what the law requires of them. This, in part, creates the 'tick box' mentality for which the law is sometimes criticised. The law sets down in precise tests what is required so that an individual can know what the law requires.

Minimum standards

The law's enforcement mechanisms are typically aimed at preventing harmful behaviour rather than promoting good behaviour. Generally, the criminal law will not punish you for being rude, insensitive or for failing to help someone in need and will only intervene if you have actually caused someone harm. The law of tort punish those who fall below the standard of the reasonable person,

but does not require to live up to the highest standards. While therefore it may be designed to prevent the most egregious harms to patient, it sets the bar relatively low.

Regulation is the other primary legal tool and that too is problematic. There is a danger that in following the letter of a regulation care homes lose sight of the greater goal of improving the general well-being of residents. Ensuring that the electrics are in good order and there is no food poisoning does not ensure a flourishing care home life, just that a minimum standard is met. Indeed, meeting regulatory standards can skew the objectives of a care home. Christopher Newdick (2014) claims that that occurred in mid-Staffordshire where concerns about breaching waiting time targets meant that less urgent cases were dealt with before more urgent ones.

Reform

The issues that we have identified in the previous section are best dealt with not by further legal intervention. Relying on Fraser's terminology we can see three major issues. First, there is the issue of resources. Claims that tighter and better regulation is the solution to the decline in standards of care may simply be a smokescreen for the fact that care is expensive and we simply need to put more money into the system if it is to work well.

Second, in terms of recognition, regulation has a role to play but it is limited in its 'snapshot' approach and the fact it focuses on minimum standards. Indeed, there have been serious concerns about the effectiveness of the Care Quality Commission's inspection as even ensuring minimum standards are met (Royal College of Nursing, 2012). The House of Commons Public Accounts Committee (2015, 1),

> in that it is not yet an effective regulator of health and social care. Because of staff shortages it is not meeting the trajectory it set itself for completing inspections of hospitals, adult social care and primary care. There are also concerns about the consistency and accuracy of draft inspection reports, and the time the Commission takes to finalise a report after carrying out an inspection.

Third, there are issues of representation. We need to use law as a base minimum but seeking a different route to improve standards in care home. Here are some suggestions as to how that may happen.

First, we must empower patients and their families to contribute to communal life (World Health Organisation, 2013; Knight, Haslam and Haslam, 2010). Of course, it would not be appropriate to see patients as being responsible for their own safety, but part of the problem in mid-Staffs was the failure to take seriously the complaints by families of patients and not listening to the comments of patients themselves.

Second, many older people want to care and be useful (Help the Aged, 2008). One study found that even giving an older person a house plant to look after had a significant impact on well-being and even death rates (Gilbert, 2005). But there may be a host of ways of encouraging and helping older people to care for each other and feel they are being of some use. A major defect in many care home settings is the failure to encourage caring relationships that involve both give and take, and are central to human thriving. There is so much more we can do to enable older people to feel they are contributing to the common good, rather than simply being passive recipients of care.

Third, we need to encourage meaningful relationships between staff and between staff and patients. This must be seen as a major role for care home life.

Fourth, care staff need to be listened to and respected. Any promotion of quality in a care setting depends on the staff. The success of regulation depends on the co-operation of those being regulated (Healy, 2011). Working with the strong ethical code that most health professionals have is more effective than imposing an alien set of targets. It works best when it is seen as a collaborative effort involving medical professionals, patients and the regulators.

Conclusion

This chapter has explored the problems of abuse and neglect in care home settings, relying on Fraser's themes of resources, recognition and representation. As greater realisation of the problem has occurred, it is natural that people have turned to law to provide a solution. This chapter has sought to outline the current legal interventions. They are helpful, but their limitations must be realised. Indeed, there is a danger in seeing the problem of abuse as lying at the feet of law that we lose sight of the broader issues and other ways to tackles the issue.

The problems of elder abuse reflect the wider social response to older people. Their social exclusion and marginalisation in our society, reinforced by private and public expressions of ageism combine to reinforce and enable elder abuse to take place. Consider this finding of one survey. Looking at older people in a care home it found during the length of the study that 42% of residents observed spent no time at all in contact with others living in the home (Help the Aged, 2008). This revelation of the utter loneliness and isolation that those older people suffered is a reflection of their position more widely in our society. One might make a similar point about the isolation felt by care workers in the system.

The solution lies not in producing further legislation or more thorough inspection but in focusing on meaningful relationships between residents and staff, both among and between those groups. That will mean being more creative about what it means to relate to others and what is meaningful in human interaction. The importance of the gentle touch, the kind smile and the tender word cannot be underestimate. Our common humanity must underpin life in a care home.

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Part V

Spatiality

Sue Westwood

Introduction to Part V

This section addresses ageing spatialities, i.e. the different spaces within which older people navigate ageing, and associated issues of (in)equality. In Chapter 19, Martin Hyde considers the significance of space for understanding ageing lives. He highlights the international variations in the economic (resources), cultural (recognition) and political (representation) circumstances of older people, arguing that globalisation has done little to impact these inequalities. In Chapter 20, Vanessa Burholt, Paula Foscarini-Craggs and Bethan Winter examine ageing and inequality in rural areas of the United Kingdom. They observe that participants living in the most remote and deprived areas have fewer resources, lower levels of social participation and more local concerns than those in the more affluent and accessible areas. They conclude that the most rural and remote areas of the UK are mis-recognised in media and policy representations. In Chapter 21, Annette Cox explores older people's participation in employment. She identifies how personal resources shape access to work as a resource, highlighting that this is in turn dependent on recognition of their talents and skills and on employer resource constraints. She argues that demographic pressures will promote a non-discriminatory economy in which older people can continue to participate meaningfully in employment. In Chapter 22, Helen Codd considers the needs and experiences of people ageing in prison, reflecting in particular on the tensions between criminal justice and social justice in this context. She identifies a range of inequalities of resources, recognition and representation which are both common to prisoners of all ages, and specific to older prisoners. Those which are specific to older prisoners, distinguish them from both younger prisons and older people ageing outside of prison.

All four chapters highlight the significance of spatiality for the ageing experience. Hyde shows the importance of international variations in ageing, in relation to access to resources, recognition and representation. Burholt, Foscarini-Craggs and Winter highlight the differences in ageing experiences in a single country, when differentiated by rural/urban contexts. Cox and Codd both demonstrates that specific spaces and contexts inform the ageing experience, Cox in terms of workplace opportunities (and challenges) and Codd in terms

of the ways in which ageing challenges are exacerbated and compounded by imprisonment. In this way we can see that fully understanding ageing and diversity necessitates taking into account the locations, spaces and contexts in which people are ageing, which are fundamental to informing their experiences of later life.

19 Ageing and spatial equality

Martin Hyde

Introduction

There has been a resurgence of interest in the spatial relations of ageing and later life. Interest in environmental or geographical gerontology has grown apace over the past few decades. This has produced a range of work from retirement migration (King, Warnes and Williams, 2000; Warnes, King, Williams and Patterson, 1999; Warnes, 2006), residential arrangements (McHugh, 2000; McHugh and Larson-Keagy, 2005; Peace, Wahl, Mollenkopf and Oswald, 2007), the use of domestic space (Percival, 2001), place attachment (Smith, 2009) and age-friendly cities (Buffel, Handler and Phillipson, 2018). The growth and range of these topics show, firstly, that space is important for our understanding of ageing and, secondly, that there are concerns that older people are at risk of marginalisation through various spatial practices. This is illustrated well by Hazan (1994, 14) who described the historical deterioration of the status of older people through successive changes in their socio-spatial location:

> The allocation of space to the elderly at once indicates their place in the community and instructs it as to the overall structure of society and the nature of social relationships prevailing in it. . . . In biblical times, the 'elders', sages, wise men and leaders, as guardians of the community were allocated social and physical space at the gate of the town [i.e. the most prestigious position]. Today their situation is just the opposite. From the almshouse and the workhouse through community-sponsored 'old age homes' to the large denominational charities, institutional care for the aged implies marginality and isolation from the mainstream of society.

These arguments gained additional salience with the changing nature of space in the contexts of globalisation (Hyde and Higgs, 2016). Globalisation is often seen as a threat to the provision of welfare for the older population in both the Global North and the Global South. In the Global North it is seen to undermine the basis of national citizenship without providing an adequate, supra-national, alternative (Neilson, 2003; Phillipson, 2003; Wilson, 2002). Phillipson (2002) argues that there has been a fundamental reconfiguration of citizenship away from the

nation state towards global networks. In this he explicitly argues that there has been a scalar shift away from the national to the global.

> Growing old has, itself, become relocated within a trans-national context, with international organisations (such as the World Bank and International Monetary Fund) and cross-border migrations, creating new conditions and environments for older people. . . . Globalisation, it is argued, has produced a distinctive stage in the social history of ageing, with a growing tension between nation state-based solutions (and anxieties) about growing old and those formulated by global actors and institutions. Ageing can no longer be viewed as a 'national' problem or issue but one that affects trans-national agencies and communities. Local or national interpretations of ageing had some meaning in a world where states were in control of their own destiny.
>
> (Phillipson, 2002, 1)

Whilst in the Global South Polivka (2001) and Polivka and Borrayo (2002) identify globalisation as the main threat to the ageing populations through the imposition of austerity programmes and the resultant cuts in social spending.

However, despite the intuitive appeal of the argument that globalisation has affected a radical change in the spatial relations of society, eclipsing all other forms of spatial logic, e.g. the regional, the national and the local, Hyde and Higgs (2016) have shown the remarkable persistence of these other non-global spatialities. Indeed, their analyses reveal a mosaic of different, sometimes competing, sometimes co-operating, spatial logics in which the global and the national operate alongside the local and the regional. Each spatiality has its own set of logics as well as its own actors. The relations between them may continually shift, but none can be said to be reducible to the others.

Drawing on these arguments and a range of empirical data, my aim in this chapter is to critically explore the spatial patterning of the three dimensions of Fraser's theory of justice: (a) redistribution/maldistribution, (b) recognition/mis-recognition and (3) representation/misrepresentation, in the context of globalisation. In *Social justice in the age of identity politics* Fraser (1998) argues that contemporary claims to equality have become pulled in two seemingly different directions. The first of these she identifies as being 'traditionally associated with the theory of distributive justice, especially concerns pertaining to the economic structure of society and to economically defined class differentials'. In line with this, being excluded from the fair distribution of economic resources is a threat to social justice. The second set of justice claims focus on 'the institutionalised cultural patterns of interpretation and evaluation . . . [to] ensure equal opportunity for achieving social esteem' for all participants in society. These concerns emerge from the philosophy of recognition and frame situations where individuals or groups have their identify denied or denigrated as a threat to social justice. Ultimately in this paper Fraser argued that the dichotomy between issues of (economic) redistribution and (cultural) recognition was false and she sought a unified model, based on participation, to unite them. However, later and in response to her concerns about globalisation Fraser

sought to extend this model to include (political) representation (Fraser, 2005). This is particularly interesting in the context of the current chapter as many of the concerns raised by Fraser about globalisation echo those coming from within gerontology at the time. She argued that,

> Globalization is changing the way we argue about justice. Not so long ago, in the heyday of social democracy, disputes about justice presumed what I shall call a 'Keynesian-Westphalian frame'. Typically played out within modern territorial states, arguments about justice were assumed to concern relations among fellow citizens, to be subject to debate within national publics, and to contemplate redress by national states.
>
> (Fraser, 2005)

For Fraser (2005) this scalar shift away from the nation state as the key juridical-political arena for the pursuit of justice and equality claims has created new forms of politics and political representation within global networks of power. In response to this, she notes that many social and political movements, such as feminists, religious and ethnic minorities; peasants and indigenous peoples; and coalitions of human-rights activists, have sought to create new transnational networks to achieve social justice. However, issues of ageing and later life are absent from her analyses. In what follows I will aim to explore (a) the extent to which older people fare economically around the world and how this is related to globalisation (redistribution), (b) the degree to which older age is accepted or denied as a valued identity (recognition) and (c) the representation of older people in the political process around the world (representation).

Spatialities of redistribution

Perhaps unsurprisingly, given the role that work and pensions have played in the construction of later life, much of the literature on the relationship between globalisation and later life has focused on the financial situation of older people. As noted earlier, writers such as Vincent (2003) and Polivka (2001, and Polivka and Borrayo (2002) predicted that globalisation would have a deleterious impact on the economic position of older adults. They predicted that national governments would trigger a 'race to the bottom' in social spending as they sought to attract global capital. This would inevitably hit older people as spending on pensions was reduced. However, more recent analyses have failed to support this hypothesis. Using a range of international data Hyde and Higgs (2016) have shown that there are wide variations in the financial circumstances of older people around the world and in the redistributive nature of national pension systems. Moreover, there was no evidence that exposure to economic globalisation had a negative impact on the progressivity of these pension systems. Indeed, there appeared to be a weak, positive relationship suggesting that economic openness is compatible with progressive, i.e. redistributive, pensions.

However, in their analyses Hyde and Higgs (2016) did not directly look at the risk of being in poverty in later life. Instead they relied on self-reported

satisfaction with one's financial circumstances. Yet, it is possible that older people might shift their frame of reference when assessing financial satisfaction to cope with having restricted economic circumstances. Hence, poverty measures will give us a more objective measure of the spatial patterning of the possible economic marginalisation of older people. To address this I have used data from the 2015 EU-SILC study to look at the proportions in various age groups who are considered to be at risk of poverty, defined at being at 60% of the median equivalised income across 33 European countries (Table 19.1).

However, although the data presented in Table 19.1 suggest that there is a wide degree of international variation in the spatial pattering of economic

Table 19.1 At-risk-of-poverty rate before social transfers (pensions excluded from social transfers) by age group in Europe, 2015

	Less than 18 years	*18–24 years*	*25–54 years*	*55–64 years*	*65+*
Hungary	43.7	32.2	26.0	21.4	6.7
Slovakia	32.2	19.1	18.3	15.0	7.9
Netherlands	24.9	35.9	22.1	26.3	9.9
Czech Republic	23.9	16.3	15.7	19.0	10.6
France	34.1	32.6	23.7	20.4	10.9
Luxembourg	37.8	33.7	26.7	24.4	11.4
Iceland	25.6	22.3	20.6	18.0	12.8
Poland	28.2	27.8	21.8	25.8	14.4
Norway	30.9	48.6	25.0	22.7	15.4
Austria	38.9	29.2	24.5	22.6	15.4
Spain	37.5	41.6	30.7	31.6	15.7
Denmark	23.1	54.2	23.0	33.3	16.2
Italy	34.4	32.1	26.3	21.5	16.5
Greece	32.6	33.7	26.3	23.1	16.7
Germany	31.3	30.7	23.9	29.8	17.5
Macedonia, FYR	32.7	26.6	23.4	22.6	18.1
Belgium	32.8	31.9	24.4	31.5	18.6
Cyprus	30.2	29.5	24.4	23.6	19.0
Finland	30.6	46.0	24.1	27.1	19.8
Portugal	31.3	33.8	24.7	30.8	20.2
Romania	43.6	38.2	27.0	21.8	21.1
United Kingdom	43.0	37.6	24.8	24.1	23.0
Sweden	29.4	45.1	24.4	18.2	26.6
Slovenia	26.2	24.7	22.3	28.7	26.8
Lithuania	37.0	27.6	24.4	31.0	28.3
Ireland	42.3	45.4	32.4	36.9	28.7
Switzerland	31.3	27.1	21.2	21.6	28.8
Malta	30.9	17.7	18.7	24.0	30.9
Serbia	41.2	42.3	36.1	37.9	33.2
Bulgaria	37.4	29.7	23.4	24.7	33.5
Croatia	36.0	26.2	26.6	32.6	36.6
Latvia	30.7	27.2	21.4	26.9	37.4
Estonia	29.0	25.7	22.0	30.9	38.7

Source: Eurostat-http://epp.eurostat.ec

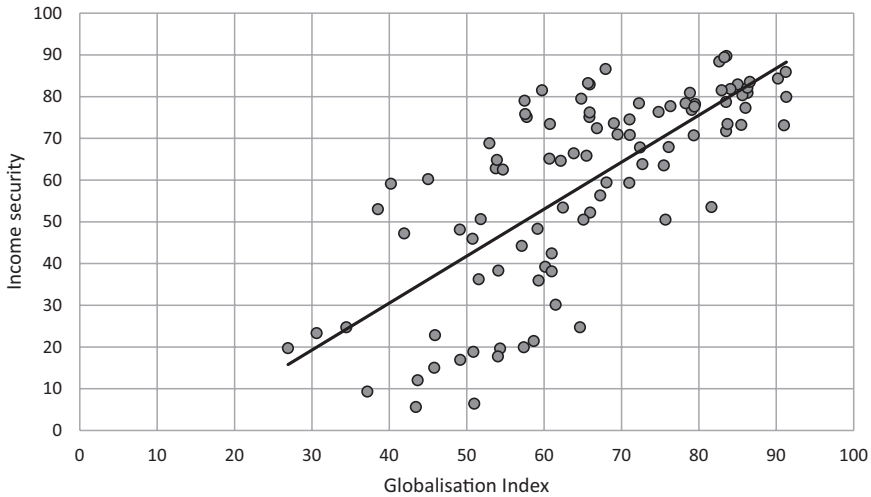

Figure 19.1 The relationship between globalisation and income security in later life, selected countries

Note: For the income security measure 0 represents the lowest level of income security and 100 represents the highest level of income security. For the globalisation measure 0 represents the absence of globalisation and 100 represents the highest level of globalisation.

marginalisation of older people throughout the world, they do not allow us to directly test Fraser's argument that the shift away from the Keynesian-Westphalian state model has had a profoundly negative impact on claims to redistributive justice. To do this I have performed a correlation between two different data sources: (a) the income security in later life sub-scale from the Global Ageing Index (GAI) and (b) the KOF index of globalisation (Dreher, 2006). I have chosen to use the GAI measure rather than continuing to use the at-risk-of-poverty indicator for two reasons. Firstly, the GAI measure is a broader, multidimensional measure of economic marginalisation and, secondly, because data are available on a wider number of countries, including those outside of Europe. This allows us to get a much more global view of this issue. As we can see from the data presented in Figure 19.1, contrary to the arguments put forth by Fraser and gerontologists such as Vincent and Polivka, not only is there no negative association between levels of globalisation and income security in later life but the relationship appears to be positive. Hence, high levels of global openness appear to be highly compatible with high levels of economic well-being in later life.

Spatialities of recognition

Whilst global economic and political actors clearly play an important role in shaping the conditions of later life it is important not to neglect potential

relationships between global socio-cultural flows and the experience and expectations of older people. One of the key arguments in the literature on globalisation is that cultural products, images and signifiers have become dislocated from their original contexts and are increasingly caught up in the vortex of global flows (Appadurai, 1996; Friedman, 1994; Lash and Lury, 2007; Lash and Urry, 1993; Robertson, 1990). As Lash and Urry (1993, 14–15) argue, in relation to the rise of globalisation and the end of organised capitalism,

> Not only does this spatio-temporal ether have to take on an abstraction so that markets can 'stretch' over national and then international space, but so also do the objects that circulate in it. And indeed these objects have become increasingly emptied out of meaning. . . . What is increasingly being produced are not material objects, but signs.

These arguments alone raise a number of important issues about the extent to which older people around the world are connected to or excluded from these cultural flows and in particular what are the dominant signifiers of ageing that are being reproduced through these global flows. Perhaps the most obvious indicator of the mis-recognition of older people is ageism. Recent analysis carried out by the World Health Organization (WHO) covering 57 countries found low respect for older adults (Officer et al., 2016). One area which has attracted a lot of attention is the circulation of negative images of older people in the media. The consensus from earlier research in this field was not only that older people are under-represented, in relation to their demographic profile within the population, but that they are also more likely to be portrayed in a negative manner (Carrigan and Szmigin, 1999). Most of the evidence for these conclusions comes from work done on the appearance of older people in magazine advertisements. A number of studies from the US and Canada in the early 1990s found that older people were less likely to appear in adverts than younger people and that they were more likely to be described negatively, in terms of poor health, mental capacity and social networks, when they did appear (Peterson, 1992; Zhou and Chen, 1992). On the basis of these and other studies Carrigan and Szmigin (2000, 217) argue that by 'either ignoring older people altogether or presenting them in caricatures or negative stereotypes' the advertising industry perpetuates ageist assumptions about older people. Moreover ageist representations of older people were found not to be restricted to advertising but prevalent in a range of media from birthday cards (Ellis and Morrison, 2005), country music lyrics (Aday and Austin, 2000) and Hollywood movies (Markson and Taylor, 2000).

However other research failed to find any evidence that older people were either under-represented or discriminated against in advertising (Bailey, Harrell and Anderson, 1993; Langmeyer, 1993). Indeed, a number of studies appear to show that there has been a noticeable change in the ways in which older people are represented in the media. Although older people are still under-represented they are increasingly portrayed in a positive manner. Contrary to

the earlier studies on advertising more recent studies did not find evidence of prevalent negative stereotypes of older people in either magazine or television adverts (Lee, Kim and Han, 2006; Miller, Miller, McKibbin and Pettys, 1999). On the basis of their study of over 2,000 television adverts broadcast on prime time British TV Simcock and Sudbury (2006, 99) conclude that 'overwhelmingly, older models are not portrayed in a negative, derogatory or stereotypical light'. Indeed, a number of studies found that older characters were generally presented in a positive manner (Robinson et al., 2007; Robinson and Umphrey, 2006). So dramatic is this shift in the representation of older people that number of writers have criticised the media for ignoring what they see as the reality of old age (Kessler, Rakoczy and Staudinger, 2004; Lucas, 2004). Rudman (2006) argues that this shift in the representation of older people is indicative of the interconnections between neo-liberal political rationality and the discursive constructions of new 'retiree' subjectivities. Similarly Bowling (2006) and Bowling and Dieppe (2005) have criticised the concepts of 'healthy ageing' and 'successful ageing' for re-medicalising later life. It is argued that these concepts represent a 'new ageism' in which the fear of ageing has been replaced by the fear of ageing with a disability. However, it has become the individual's responsibility to ensure that they remain disability free. Thus, rather than ensuring healthiness in later life, this discourse ignores socio-economic factors and ends up blaming the victim (Angus and Reeve, 2006; Minkler and Fadem, 2002). The adoption of this discourse by policymakers, at the national and international level, is seen to fit with a broader, neo-liberal assault on welfare (Asquith, 2009; Biggs, 2001).

Another indicator of mis-recognition would be the extent to which older people see their age as a key constituent of their identity. A high degree of age-identification could be seen as evidence of an acceptance amongst older people of agedness as a valued social identity and the basis of a politics of age (to which we will turn in the next section). However, previous analyses by Hyde and Jones (2013) revealed low levels of age-identification both across countries and across time. Drawing on data from 35 countries in the International Social Survey Programme it is clear to see that in very few countries do those aged 60 to 74 see their age as an important source of their identity (Figure 19.2). Only in Taiwan and Spain do a significant proportion, around one-fifth, of those in this age group see age as important. Age does appear to be a more salient aspect of identity for those aged 75 and over in a number of countries. For example, in Japan only around 6% of those aged 60 to 74 see age as important compared to 20% of those aged 75.

Spatialities of representation

In this third section, we will address the third of Fraser's dimensions of equality and look at the spatial distribution of misrepresentation of older people by exploring the extent to which are excluded from political participation throughout the world. In particular we will look at (a) the arguments that there

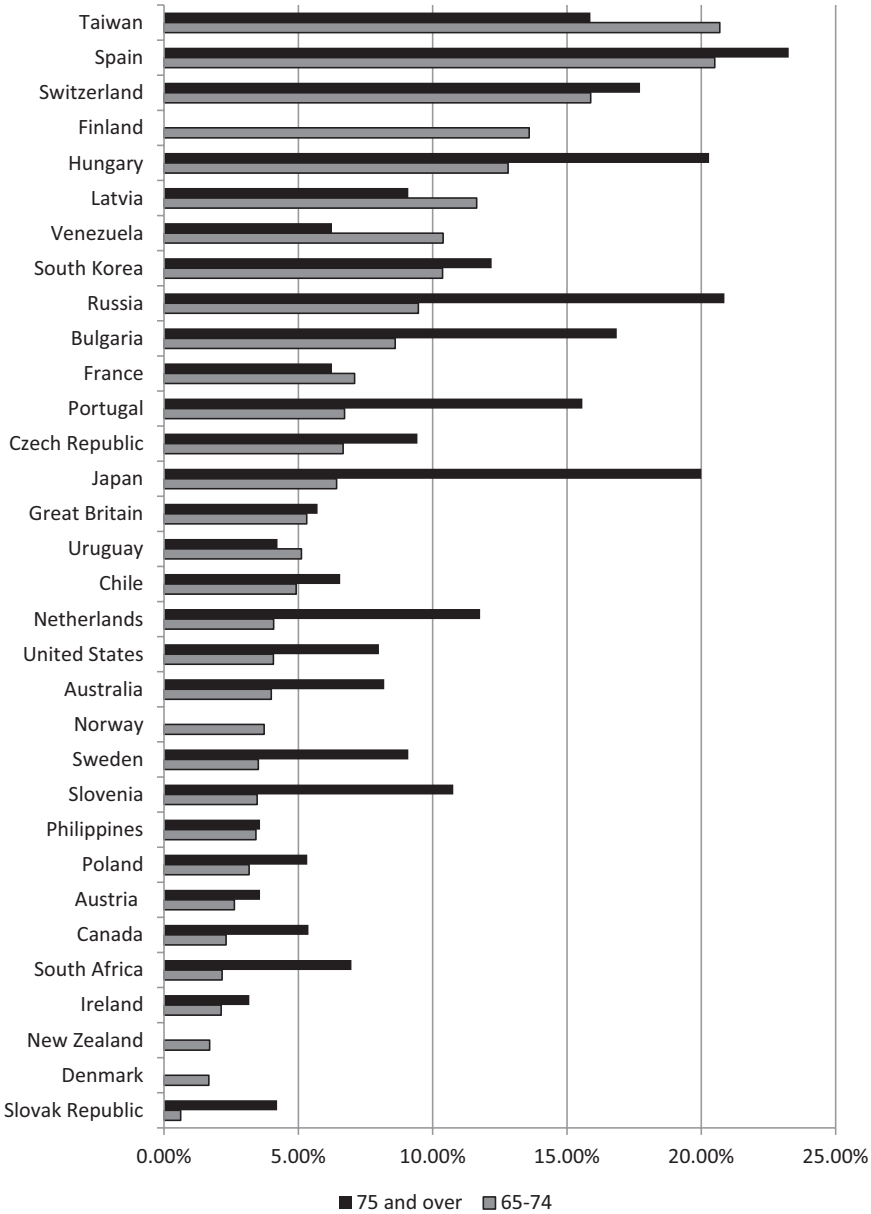

Figure 19.2 Proportion of those aged 60 and over who say that their age is the most important source for their identity

Source: ISSP, 2004

has been some form of generational capture of the political process by older people, (b) the voting patterns of older people and (c) the sense to which older people see themselves as part of a global citizenry.

Over the past few decades there has been an increased interest in treating contemporary politics through the lens of ageing and generation (Goerre and Vanhuysse, 2013). While there has been a long-established concern regarding the burdens that an ageing population would place on nation state, the past few decades have seen a much more concerted approach to put this topic within the context of relationships between generations and in particular relations between the 'baby boom' cohorts and those younger than them. While mainly an Anglo-Saxon concern the popularity of taking a generational equity position has been evidenced in a number of different countries. A number of books and articles have addressed the idea of generational inequality (Beckett, 2010; Howker and Malik, 2010; Willetts, 2010; O'Rourke, 2013, Bristow, 2015). It is interesting to note that for many in Europe and North America the issues of generational conflict were mainly associated with the student rebellions of the 1960s and the divisions creating the 'generation gap'. However, concern with generational justice first emerged during the 1980s and addressed pressures on US welfare programmes (Williamson, Watts-Roy and Kingston, 1999) and centred on the short-term interests of older people set against children's futures (Longman, 1985; Preston, 1984). Some argued that tax and welfare systems favoured older people and denied 'generational justice' to younger people (cf. Longman, 1987; Thomson, 1989). A more politicised version of this approach was introduced in the form of Kotlikoff's model of 'generational accounting', which examined present and future inter-cohort inequalities arising from taxation and welfare policies (Kotlikoff, 1992). Under conditions of welfare retrenchment Dowd (1994) argued that welfare programmes benefited 'mostly older middle- and upper-middle Americans' and placed a burden on future indebted generations (Dowd, 1994, 191). In the UK the concern was also with the older post-war groups who were set against those of working age as can be seen from the title of an edited collection called 'Workers versus Pensioners' (Johnson, Conrad and Thomson, 1989). However, the debate about inequity between the generations really began to take off much later when the baby boomers themselves began to retire. A key theme of this arena of conflict was that this group of older people represented a particularly 'selfish generation' and that they were unwilling to pass on their good fortune to younger cohorts. In Britain, particularly the baby boomers moral character was seen to be at fault. One author argued that they were set to destroy the benefits that their own parents had worked so hard to bestow upon them (Beckett, 2010, xii).

What evidence is there to support the idea that there has been generational capture of the politics of many countries, particularly in the most prosperous nations? It is important to remember that age-based politics are not a recent phenomenon. There were political movements of pensioners in the inter-war years in both America and Europe. These movements played an important role in creating the social security systems of Western societies in the immediate

post-war era (Amenta, Caren and Olasky, 2005; Macnicol and Blaikie, 1989). However, pensioner movements have failed to capitalise on their early start and have retreated from centre stage. This is also the case for political parties that aim to represent the interests of older people. So-called Pensioner's Parties or Grey Parties began to emerge throughout Europe from the late 1980s and early 1990s. The first of these to appear in Europe was the *Pensjonistpartiet* which was founded in Norway in 1985. This was followed by the *Partito dei Pensionati* in Italy, *Suomen eläkeläisten puolue* (the Finnish Pensioners' Party) and *Sveriges Pensionärers Intresseparti* (the Swedish Senior Citizen Interest Party), which were all founded in 1987. Similar parties emerged across Western Europe in Belgium, the Netherlands, Germany and Denmark through the 1990s. With the collapse of Soviet Communism these were joined by parties throughout Eastern Europe, such as the *Krajowe Porozumienia Emerytów i Rencistów Rzeczypospolitej Polskiej* (National Alliance of Pensioners and Retired Persons of the Polish Republic) and the *Demokratična stranka upokojencev Slovenije* (Democratic Party of Pensioners of Slovenia). However despite the number of these parties none of them have had any significant electoral success, often securing less than 1% of the vote, and they have remained on the periphery (Hanley, 2013). It is only in Russia that pensioner poverty has been a source of political mobilisation among pensioners themselves (Chandler, 2004; Jones, 2002). In the 2003 parliamentary elections *Rosiiskaya Partiya Pensionerov* (the Alliance of Russian Pensioners' Party) secured 3.1% of the votes. However in 2006 they merged with the Fair Russia bloc (Hanley, 2013). Hence, although attempts to raise the issue of pensioner poverty continue to be made by various age-based advocacy groups, pensioner poverty no longer defines later life, and therefore such advocates draw but muted support from the retired populations in most societies. Claims for 'a growth in political participation among older people at grassroots level' in the European Union (Walker, 1998, 33) are not, on the surface, apparent. There has been a lot of institutional investment put towards achieving such an objective such as the Federation Européenne des Retraites et Personnes Agées, which is an internal organ of the European Trade Union Confederation while new social movements associated with old age such as the American Gray Panthers have failed to develop their political agenda.

On the basis of these analyses there is little evidence of any direct representation of older people's interest through age-based political parties. However, this does not mean that older people are necessarily disconnected from the political process. Indeed, it is fairly well established that older people are generally more likely to vote in national elections than younger age groups (OECD, 2011). However much of what we know about age-related patterns of voting comes from high-income countries such as the US and the UK. We know relatively little about international variations in the rates at which older people vote in national elections, especially amongst middle- and lower-income countries. Yet, it is these middle- and lower-income countries, such as Brazil, India and China, that are experiencing some of the fastest rates of population ageing and where age politics could be an issue. In these situations, an inability or unwillingness to

engage in the political process could lead to marginalisation as well as a failure to establish policies that would benefit older people. As a consequence, the rates at which older people vote in national elections could be seen a reasonably good indication of their level of involvement in the formal political process of a particular country. As Figure 19.3 shows, there is a considerable degree of international variation in the proportions of older people who report that they vote in national elections. There are a number of countries where less than half of those aged 60 and over vote in these elections. At the other extreme, there are four countries where over 90% of those aged 60 and over report that they always vote. However, as with voting patterns more generally, there does not appear to be a clear pattern for which countries have higher or lower rates of voting amongst their older citizens.

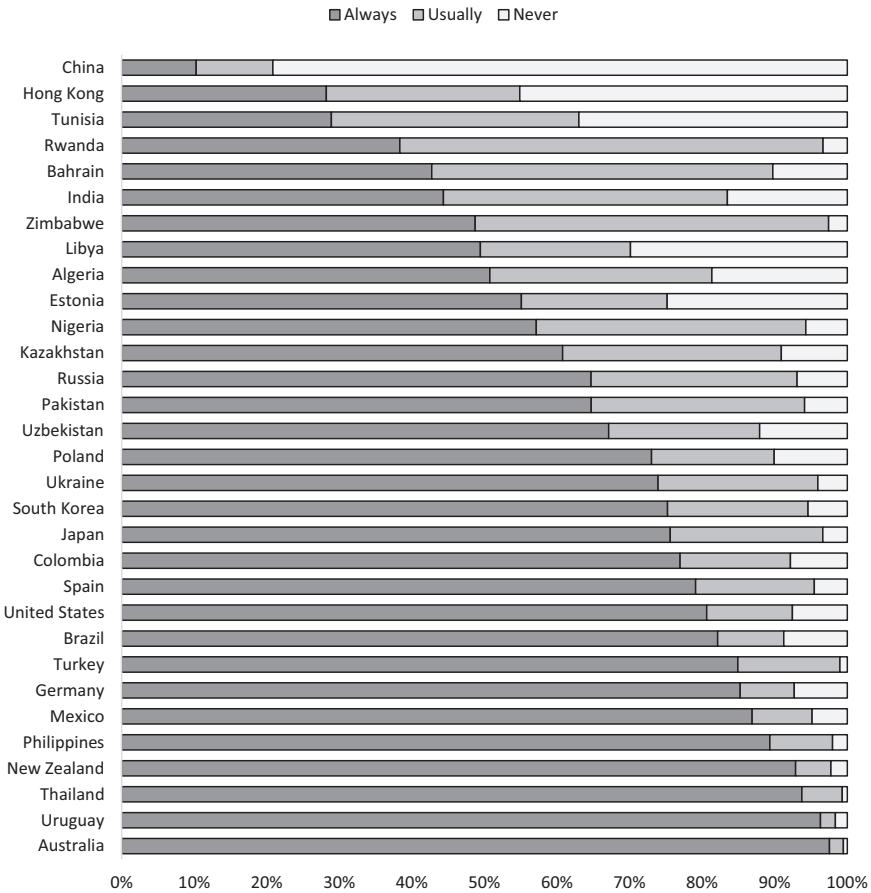

Figure 19.3 Proportion of those aged 60 and over who vote in national elections, selected countries

Source: WVS 6th Wave

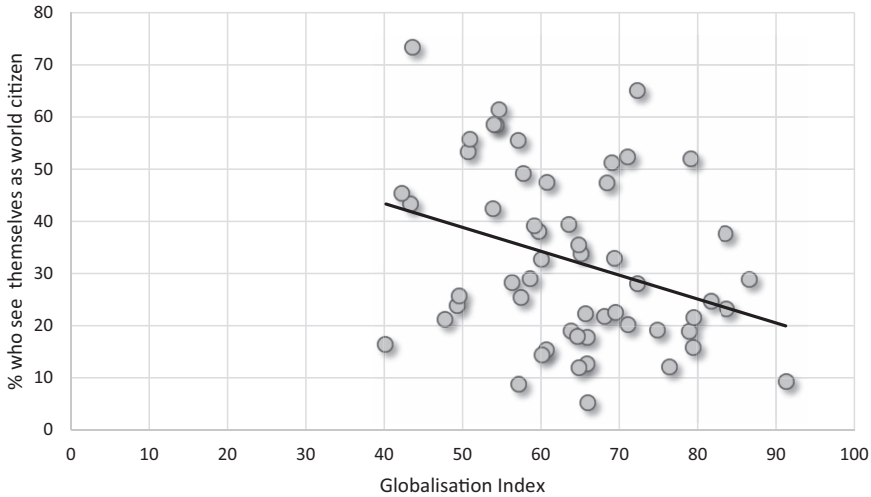

Figure 19.4 The association between globalisation and proportion who consider themselves as a world citizen, selected countries

Source: WVS 6th Wave

However, whilst the foregoing analyses are important in showing that some groups of older people are excluded from formal political processes they tell us nothing about the possible impact of globalisation. Returning to those concerns raised by both Fraser (2005) and Phillipson (2003) that globalisation has effected a scalar shift in the body politic away from the nation state to new supra-national arenas, Figure 19.4 shows the proportions of older people who strongly agreed that they saw themselves as a world citizen against the KOF globalisation index (Dreher, 2006). The distribution of the points shows that there is no clear association between the extent to which a country is connected to global economic, social and political flows and proportions of its older population who see themselves as world citizens. Overall, however, as the black line shows there is a weak negative correlation between the two measures. What this means is that as countries become more globalised there is a slight tendency for older people to be less likely to see themselves as global citizens. These results suggest that older people are being left out of these global flows.

Conclusion

In conclusion, a number of points appear to be evident. Firstly, on the basis of the empirical analyses we can see that there is a high degree of international variation in the extent to which older people are excluded from processes of redistribution, recognition and representation. In terms of Fraser's (1998, 2005) model, these data clearly point to the persistence of inequalities and a lack of justice for

groups of older people around the world. Economically, culturally and politically older people in a number of countries remain marginalised. Hence, there is still much work to be done to secure the conditions of participatory parity for older people around the world. However, the analyses also show that contrary to the expectations of both Fraser (2005) and numerous gerontologists there appears to be little evidence that globalisation per se has had a uniformly negative impact on these processes. Indeed, findings here and elsewhere (Hyde and Higgs, 2016) indicate that globalisation appears to be quite compatible with relatively generous and redistributive pension systems. However, more research is needed here to look at the ways in which global political actors are framing discourses about ageing and later life. In their book Hyde and Higgs (2016) identified a number of epistemic communities seeking to seeking to determine the direction of policies and practices around ageing and later life. How the interests of older people are framed within these communities of knowledge-based experts requires greater exploration. The fact that, as shown in Figure 19.4, older people in more globalised countries feel less like global citizens suggests that they feel that their interests are being sidelined as social action moves beyond the nation state. All of which brings us to the third observation and the question as to whether we can see evidence that these three claims to justice, redistribution, recognition and representation, are being brought together to advance the interests of older people in the contexts of globalisation. On the basis of the findings presented in this chapter this would appear not to be the case.

The debate on pensions provides us with a clear prism though which to examine this as it encapsulates all three dimensions, the economic, the cultural and the political. Yet the picture we have is one of dislocation rather than the co-ordination of justice claims along the 3Rs. In economic terms, the global picture is one of widely diverse pension issues. Although there are global campaigns for pensions, such as those by HelpAge International, these are largely focused on securing social pensions in the Global South. Indeed, the differences pension issues facing older people in the Global North, e.g. the closing of final salary pensions, rising state pension ages, and those in the Global South, e.g. the lack of any basic pension, are so great that there appears to be little basis for a global pensioner movement. This should not surprise us given the lack of political parties representing older people at the national level. As has been shown single-issue pensioner politics can still exist, but they are generally confined to the nations of post-Communist Europe. Here, the near collapse and reform of social protection schemes fell hardest on the standard of living of pensioners (Piper, 2015).

In countries that have seen the existence of formal pensioner parties such as in Holland or Italy, they have failed to engage the majority of older people and have exercised little positive influence in the conflict over pension reform (Lynch, 2006). Most large European countries do not have pensioners' parties (e.g. France, Germany, Poland and Spain) although they have a growing number of age-advocacy groups. Consequently, despite the greying of Europe, there is

little for the political representation of older people as a culturally or socially oppressed group who are deprived of a voice within society (Chris Gilleard and Higgs, 2009). As Gilleard and Higgs (2000, 2005, 2009) point out, old age is not an identity that creates any sense of solidarity nor stirs any new desire for recognition. As was shown earlier in Figure 19.4, age was not considered to be an important basis for one's identity in later life. These results lend support for Gilleard and Higgs' (2009) argument that current cohorts of older people are actively rejecting age-based labels as they enter later life and, by extension, demonstrate that 'old age' alone provides a weak basis for the formation of a global politics of later life. This is not particularly surprising given that (old) age is not a clear source of social identity possibly because of its association with a position of dependency rather than one of possible liberation. The reasons why other new social movements have not embraced ageing may lie in their own histories but also may reflect an unease with old age itself (these issues are discussed at length in Gilleard and Higgs' *Ageing, corporeality and embodiment*). Whatever the reasons for this state of affairs it is clear that in the context of global financial austerity different ways of implicating ageing and old age will be introduced into debate and provide the wellsprings for resistance and critique. It is too early to know whether this will accord with Phillipson's (2013) call for new forms of solidarity which are now called for in the context of increased longevity and transformed institutional support for older people; however, it is certainly the case that new iterations of terms such as old age, generation and fairness are likely to shape the political terrain worldwide.

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20 Rural ageing and equality

Vanessa Burholt, Paula Foscarini-Craggs and Bethan Winter

Introduction

This chapter examines ageing and inequality in rural areas of the United Kingdom. Existing research evidence is organised under four themes: rurality, resources, recognition and representation. While each topic is of interest in gerontology, the body of rural research is relatively under-developed (Burholt and Dobbs, 2012) and the intersectionality between these themes has been overlooked. An intersectional approach that simultaneously takes into account two or more dimension of oppression and/or privilege can provide a better understanding of the experience of ageing in rural areas. We draw on data from the ESRC funded research programme *Grey and Pleasant Land? An Interdisciplinary Exploration of the Connectivity of Older People in Rural Civic Society (GaPL)* to investigate the intersectionality of these themes within the rural context.

The GaPL study was concerned with later life experiences across diverse rural locations and the data lend themselves to analysis of ageing and inequality in rural areas. This is important because rural populations in many European countries are ageing (Burholt and Dobbs, 2012). Declining fertility and mortality rates have influenced the population age structure, which has become increasingly weighted towards the older age groups. Simultaneously, population mobility and urbanisation has resulted in an overall decline in the number of people living in rural areas: in Europe the rural population is expected to decline from 100 million in 2000 to around 75 million in 2030. Despite the decline in overall numbers of people living in rural areas, it is anticipated that there will be a greater proportion of older people in rural areas compared to urban areas due to the out-migration of younger people and the in-migration of retirees. This trend is reflected in the UK, where the proportion of population of older people in rural areas of England, Wales, Scotland and NI is greater than in urban areas (Stockdale, 2011).

In this chapter we examine diversity, demonstrating that older people living in rural areas are not a homogenous group. We start by describing the ways in which rural areas may be differentiated and why we may expect to find inequalities between rural communities. Next, we discuss the current knowledge concerning the distribution of individual economic resources, recognition (social status

and social participation), and representation (civic participation, trust and local concerns) of older people living in the countryside. We set out to describe how existing research identifies how each is influenced by geographic location, gender/gender identity, class, sexuality/sexual identity, disability/health and ethnicity. As not all dimensions are covered in the existing literature, we conclude the introductory section by summarising the gaps in knowledge about ageing and equality in rural areas. Furthermore, we pose some key research questions on intersectionality that are addressed through analysis of GaPL data.

Rural differentiation and inequality: community resources

There is no universally accepted definition of rurality. Within the UK there are approximately 30 definitions used in different institutions. There has been a long sociological tradition of linking the size and density of a population to the type and depth of social interaction. For example, Tönnies (1957) suggested that rural communities were typified by close relationships and strong kinship bond (*gemeinschaft*). Similarly, Frankenberg described a morphological continuum of communities from rural to urban (Frankenberg, 1966). Communities at the more 'rural' end of the continuum were assumed to have more social solidarity than those at the 'urban' end. This is supported to a certain extent by studies which have shown that rural communities are supportive, neighbourly and friendly, and that older rural people are strongly embedded in social-support networks (Burholt and Dobbs, 2012).

Post-modern scholars suggest that in the face of population change and the restructuring of rural areas the rural idyll (depicting rural areas as homogenous and more supportive than urban areas) bears little resemblance to the plurality of experiences and meanings of rural inhabitants (Bell, 2006). There is evidence of unequal access to social relationships for older people living in the countryside often related to population change (i.e. inward and outward migration) (Burholt and Sardani, 2017) and a number of rural areas are substantially materially or economically deprived in comparison to the rest of the country.

Rural areas have been differentiated in terms of material inequalities but *clusters* of variables have also been used to distinguish between locations. These clusters of associated problems such as unemployment, ill health and social disadvantage in rural areas can be exacerbated by a lack of access to services, and a poor quality of service provision. The economies of rural resource communities (e.g. mining communities) have been subject to the vagaries of political and private commercial decisions concerning profitability; disinvestment has been accompanied by economic decline and resulted in 'resource poor' communities (Skinner et al., 2014). Aspects of village life such as local shops, post offices and doctors have often either closed or moved into larger towns, rendering rural dwellers increasingly dependent on public or private transport. However, in some rural areas gentrification has had the opposite effect, boosting local economies and tailoring services and amenities to the lifestyle choices of affluent

incomers (Wood, 2016). Both processes represent an intersection of location, wealth and power.

Individual economic resources in rural areas

Research on ageing and inequalities has tended to focus on urban deprived areas (Hennessy, Means and Burholt, 2014) and exclusion, but deprivation and inequalities in distribution (or maldistribution (Fraser, 2007)) of resources among older people living in rural areas have been under-explored. While rural communities can be categorised in terms of the access to resources (levels of deprivation) the distribution of resources within communities are subject to individual differences.

Exclusion from material resources occurs where an individual lacks sufficient income to maintain an acceptable standard of living and is unable to fully participate in society. Poverty in small towns and rural areas is often overlooked or denied. Moreover, rural poverty has been contrasted with rural affluence and older people living in the countryside have been depicted as one of the most affluent groups in society. However, the 'affluence' of older people in rural areas should be treated with caution: poverty continues to be a significant problem for older people with one study reporting that over one-fifth of rural respondents were reliant on the state pension as the sole source of income (Doheny and Milbourne, 2014). While an extensive body of research has demonstrated that material inequalities in later life are related to age, gender, marital status, living arrangements, ethnicity, transitions in work status and rurality (Burholt, 2010), there is very little evidence on the intersectionality of these risks.

Recognition: social status through social roles and social participation

Social exclusion provides a useful framework to examine the recognition of older people living in rural areas. Social exclusion is the dynamic processes of being excluded from key systems and institutions that can shape the economic and social integration of people within society. If the status of older people in rural society constitutes them as less than full partners in social relations and social participation (based on geographical location, age *and* gender, disability, race and sexuality), it institutionalises 'mis-recognition' (Fraser, 2000).

There is good reason to believe that rural ageing is overlooked and older people mis-recognised. For example, older people are often portrayed as welfare recipients and their contributions to rural communities are overlooked (Walsh et al., 2014). While relationships with family and friends may provide a source of personal care, transport or financial assistance for older people living in rural areas and are instrumental in ensuring a good quality of life, older people are also providers of support. Globally, research has indicated that the informal practices of older people can improve inclusivity in rural settlements and help

address inequalities in access to formal services in some rural locations (Walsh et al., 2014).

One way of examining the recognition of older people in rural areas would be to explicitly look at discrimination. Some research in rural areas has attempted to do this and has focused on specific communities of interest (e.g. gypsies and travellers (Hennessy et al., 2014)); lesbian, gay, trans people (Rowan et al., 2013; Fenge and Jones, 2012) and older people from Black and minority ethnic groups (Manthorpe et al., 2012), but this is not prolific. Alternatively, recognition could be examined implicitly by examining the ways in which normative expectations about rural living are, or are not achieved by subgroups with different modes of power relating to age, gender, disability and class and in diverse rural settlement types.

Representation: civic participation, trust and local concerns

There is a paucity of studies exploring the civic contributions that older people make to rural community and citizenship (Burholt and Dobbs, 2012). GaPL defined civic engagement as 'individual and collective actions wherein older adults participate in activities of personal and public concern that are both individually life enriching and socially beneficial to the community' (Hennessy, Means and Burholt, 2014, 4). Reciprocity and trust are generated in rural areas through older people's engagement in local activities and local groups. In this chapter we used the term 'representation' to refer to civic participation of older people, but also the ways in which civic society, politics and policies reflect the desires and needs of older people living in rural areas in terms of addressing local concerns or generating trust in local public services.

Diversity in rural research

While gender and disability (usually operationalised as self-assessed health or functional ability) are sometimes included as dimensions of inequality in rural ageing studies, there are deficiencies in the extent to which socio-economic class, ethnicity and sexuality/sexual identity are addressed. Some rural populations are under-researched and described as 'difficult to reach' because absolute numbers are small and/or dispersed across a large geographic area. Research on ethnicity and sexuality has, on the whole, been conducted in urban areas. However, the experiences of elders living in rural areas are likely to be very different from those living in urban areas.

This chapter explores issues of equality for older people living in rural areas of England and Wales. Drawing on data from the ESRC funded *Grey and Pleasant Land* study it explores the intersectionality of rural area with age, gender, marital status, health, and socio-economic status in relation to distribution of resources, recognition and representation of rural older people. Rural areas are described in terms of their population density and nearness

to urban locations; level of deprivation; resource dependency; and population turnover/stability. The roles of rural areas (classified using these dimensions) are explored in relation to the distribution of material resources of older people. With regard to recognition, a rural ageing identity is observable in institutionalised pattern of cultural values (the rural idyll) which emphasises the bucolic and virtuous nature of community life and the extent to which subgroups achieve this idyll. Recognition through social status may be captured by the extent one can meet certain lifestyle expectations, thus we examine the relationship between rural area, and participation in the social life of communities. Representation flows from civic engagement in the community, but also the degree to which elected officials represent the voices of rural elders and is examined through trust in local officials and the strength of local concerns.

Methods

GaPL research was carried out across six different rural regions in the South West region of England and Wales. Three rural community types were classified based on social, economic, cultural and political differences. The study selected one type of rural area from each of South West England and Wales. For a complete description of the study protocol, see Hennessy, Means and Burholt (2014). A brief description of the three types of rural areas follows (see also Figure 20.1).

- Area A (North Cornwall and Ceredigion) – *remote and deprived*. This area has an 'indigenous' population with low income, some tourism and with marginal agriculture, and contains small dispersed settlements with poor road networks.
- Area B (North Dorset and Powys) – *less remote and less deprived* but still a rural area. This area is middle income, and has a more diverse economy than Area A. Settlements are not as sparse and are closer to major road networks and larger cities.
- Area C (Stroud and Monmouthshire) – *affluent and accessible*. It is considerably less rural than Areas A and B, being close to major cities and frequently individuals living in these areas commute for work.

A quantitative survey was conducted with 920 participants living in the six rural areas. Face-to-face interviews were conducted in older people's homes in the language of choice (English or Welsh). This chapter is based on the responses of 719 (78% of the total sample) participants with no missing data for any of the variables used in the analysis.

The mean age of participants in this sample was 71.47 years (SD 8.22). A majority were female (58.4%), with fewer male participants (41.6%). Most were married (72%), and just under one-fifth were widowed (18.2%). Only 3.9% of participants had never married and 5.8% were divorced or separated.

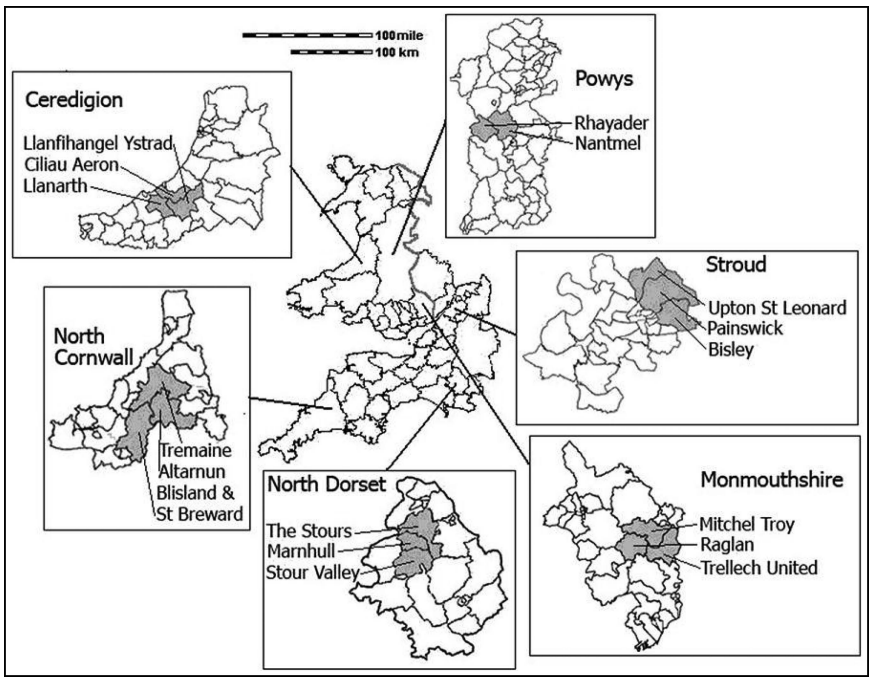

Figure 20.1 Districts and local authorities in Wales and South West England showing the location of the study sites

Source: Hennessy, Means and Burholt (2014)

The majority of participants or their spouses had a skilled occupation (93%) compared to a semi-skilled/unskilled occupation (7%).

Measures

Demographic

Self-Reported health was measured using a single item. Participants rated their health over the past four weeks, on scale from very good (1) to very poor (5). Lower scores indicated better self-reported health (M = 2.08, SD = 0.97).

Socio-economic status was assessed using a reduced version of the Standard Occupational Classification 2000 (Elias et al., 2000). Participants were asked about their and their spouse's current or previous main occupation. Occupations were coded into nine major categories: (1) managers and senior officials, (2) professional, (3) associate professional and technical, (4) administrative and secretarial, (5) skilled trades, (6) personal service, (7) sales and customer service, (8) process, plant and machine operative, and (9) elementary. These were collapsed into two categories: skilled (major categories 1–7) or semi-skilled/unskilled (major categories 8 and 9).

Access to resources

Material resources were assessed using a series of questions which captured different forms of income and resources (Burholt and Windle, 2006). Scores ranged from 0 to 5, with higher scores indicating more material resources (M = 2.48, SD = 1.19).

Poverty was assessed by asking participants if they had access to the 'necessities of daily living'. Items were: whether individuals were able to afford to make regular savings, keep the home in a decent state of decoration, replace worn out furniture and electrical goods, have a small amount of money to spend on themselves each week, and have a holiday away from home once a year. Scores ranged from 0 to 6 with lower scores indicating greater levels of poverty (M = 5.07, SD = 1.39).

Recognition

Social participation was measured through a count of the number of activities (from a list of 22) that individuals performed with others. Scores ranged from 0 to 14 with higher scores indicating that participants took part in more activities (M = 2.85, SD = 2.42).

Access to *social resources* was assessed using a modified version of the Lubben Social Network Scale (LSNS-6) (Lubben et al., 2006). Scores ranged from 0 to 36 with higher scores indicating a greater number of social resources (M = 22.26, SD = 9.02).

Representation

Civic participation was measured using a count of the number of activities (from a list of 11) individuals participated in that were organised by civic and local organisations. Scores ranged from 0 to 11 with higher scores indicating that individuals participated in more civic activities (M = 1.5, SD = 1.67).

A mean score for *local concerns* was constructed from participants' rating of how concerned they were regarding 16 issues or developments in their local community. Individuals indicated their level of concern using a scale from not concerned (1) to very concerned (3). Scores ranged from 1 to 3 with higher scores indicating a greater level of concern (M = 1.45, SD = 0.32).

Participants were asked to rate their *trust in local officials* from a list of nine roles (e.g. local government officials and police). This was measured using a 5-point scale, from very dishonest to very honest. Scores ranged from -2 to 2 with more positive scores indicating greater trust (M = 0.8, SD = 0.45).

Analysis

To explore the extent to which the independent variables influenced access to resources, recognition, and representation, seven different models were developed, with demographic variables (age, gender, health, marital status, and socio-economic status) and area type predicting each of the dependent

variables (resources: material resources, poverty; recognition: social resources, social participation; representation: civic participation, trust in local officials, and local concerns). Each model was tested using a three step hierarchical multiple regression. Demographic variables (age, marital status, health, and socio-economic status) were entered in step 1, area type was entered in step 2, and interaction variables (gender x age, marital status, health and socio-economic status) were entered in step 3. The inclusion of the interaction terms did not increase the explained variance. Therefore the models were restricted to the two-step hierarchical multiple regression.

Results

Bivariate analysis indicated that there were several differences between area types (Table 20.1). There were no differences in age, marital status, gender, or socio-economic status between the three different rural types. Overall, participants in Area A had worse self-reported health, fewer resources, lower representation and recognition. On the other hand, participants in Area C had better self-reported health, greater resources, representation and recognition.

Regression analysis

Adjusted R^2 values for all regression models were small, indicating that the models only explained a small amount of variance. However, each model had a significantly better fit to the data than the intercept only model and contained

Table 20.1 Means and standard deviations for key study variables by area type

	Area A		*Area B*		*Area C*		*Total*	
	N = 215		*N = 246*		*N = 258*		*N = 719*	
	Mean	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*
Age	70.38	7.61	71.14	8.21	71.96	8.66	71.21	8.21
Health	*2.20*	1.05	2.09	0.99	1.97	0.87	2.08	0.97
Civic participation	1.15	1.47	*1.70*	1.69	*1.60*	1.76	1.50	1.66
Social resources	21.37	8.92	21.58	9.22	*23.65*	8.78	22.26	9.02
Material resources	2.28	1.20	*2.54*	1.19	*2.56*	1.16	2.47	1.19
Poverty	4.87	1.47	4.94	1.53	*5.37*	1.08	5.07	1.39
Social participation	2.81	2.14	*2.45*	2.58	*3.27*	2.40	2.85	2.42
Local concerns	1.52	0.33	*1.47*	0.30	*1.39*	0.31	1.45	0.32
Trust in local officials	0.74	0.47	0.83	0.40	*0.84*	0.46	0.80	0.47

Analysis of variance demonstrated significant differences between rural area type and health $F(2, 716) = 3.35$, $p \leq .05$; civic participation $F(2, 716) = 18.75$, $p \leq .001$; social resources $F(2, 716) = 4.85$, $p \leq .01$; material resources $F(2, 716) = 5.43$, $p \leq .05$; poverty $F(2, 716) = 9{,}65$, $p \leq .001$; social participation $F(2, 716) = 7.50$, $p \leq .001$; local concerns $F(2, 716) = 11.03$ $p \leq .001$; trust in local officials $F(2, 716) = 3.23$ $p \leq .05$. Post hoc group comparisons – Tukey B test: numbers that appear in italics (e.g. 4.81) constitute subsets with the highest values; numbers that appear underlined (e.g. 4.31) constitute subsets with the lowest values.

statistically significant predictors from which we draw important conclusion about how changes in the predictor values were associated with resources, representation and recognition.

Resources

Demographic variables and area type explained 18.4% of the variance in access to material resources $F(9, 709) = 19.00, p < .001$ (Table 20.2). Being younger, having better self-reported health, being never married compared to being married, being male, having a skilled occupation, and living in Area C compared to Area A predicted greater levels of material resources.

Demographic variables and area type explained a significant 11.3% of the variance in levels of poverty $F(9, 709) = 11.16, p < .001$ (Table 20.2). Better self-reported health, being married compared to being widowed or divorced, and living in Area C (affluent and accessible) compared to living in Area A or B (more remote and deprived), all predicted lower levels of poverty.

Recognition

Demographic variables and area type explained a significant 4.3% of the variance in social resources $F(9, 709) = 4.57, p < .001$ (Table 20.3). Never being married or being divorced compared to being married, and living in more remote and deprived areas (Areas A or B) compared to Area C was related to fewer social resources.

Demographic variables and Area type explained a significant 12.7% of the variance in social participation $F(9, 709) = 12.6, p < .001$ (Table 20.3). Individuals reporting better health, younger individuals, those who were married, and those living in Area C (least remote and deprived) compared to those living in Area A and B reported taking part in a greater number of activities with others.

Table 20.2 Hierarchical linear regression adjusted Beta values for individual economic resources: material resources and poverty

	Material resources	*Poverty*
	β	β
Age	−0.26***	0.01
Gender	0.17***	0.04
Never married	0.07*	0.02
Widowed	0.01	−0.12**
Divorced	−0.04	−0.15***
Socio-economic status	−0.16***	−0.01
Health	−0.17***	0.01***
Area A	−0.11**	−0.14***
Area B	−0.03	−0.14***
Adjusted R^2	*0.18*	*0.11*

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

Table 20.3 Hierarchical linear regression adjusted beta values for recognition: social participation and social resources

	Social participation	*Social resources*
	β	β
Age	−0.14***	−0.07
Gender	−0.06	−0.06
Never married	−0.10**	−0.15***
Widowed	−0.20***	−0.02
Divorced	−0.15***	−0.10**
Socio-economic status	−0.00	0.02
Health	−0.10**	−0.05
Area A	−0.09*	−0.12**
Area B	−0.17***	−0.11**
Adjusted R^2	*0.13*	*0.04*

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

Representation

Demographic variables, and area type explained a significant 3.3% of the variance in civic participation, $F(9, 709) = 3.72$, $p < .001$ (Table 20.4). Having a semi-skilled/unskilled occupation and living in Area A (remote and deprived) was related to lower levels of civic participation.

Demographic variables and area type explained a significant 7.8% of the variance in the average number of local concerns residents expressed $F(9, 709) = 7.74$, $p < .001$ (Table 20.4). Healthier and older individuals had on average fewer local concerns compared to less healthy and younger individuals. Those living in Area A and B had on average more local concerns compared to those living in Area C (affluent and accessible).

Demographic variables and area type explained significant 1.6% of the variance in the average amount of trust individuals had in local officials $F(9, 709) = 2.28$, $p < .05$ (Table 20.4). Healthier individuals and those living in Area C (affluent and accessible) had on average greater trust in local officials compared to less healthy individuals and those living in Area A (remote and deprived).

Discussion

This discussion focuses on intersectionality characterised as the cumulative effect of factors that contributed to inequalities for older people in rural areas (age, gender, marital status, health and socio-economic status) in relation to the distribution of resources, recognition and representation. The analysis did not find any evidence of amplification of inequalities by gender for different subgroups of older people in rural areas, that is, no interaction effects were observed.

Table 20.4 Hierarchical linear regression adjusted beta values for representation: civic participation, local concerns and trust in local officials

	Civic participation	*Local concerns*	*Trust in local officials*
	β	β	β
Age	−0.04	−0.23***	−0.07
Gender	−0.07	0.06	0.04
Never married	0.00	−0.00	0.01
Widowed	−0.08	0.04	0.02
Divorced	−0.07	0.02	−0.04
Socio-economic status	−0.08*	−0.07	−0.02
Health	−0.02	0.12**	−0.09*
Area A	−0.12**	0.16***	−0.10*
Area B	0.03	0.11**	−0.01
Adjusted R^2	*0.03*	*0.08*	*0.02*

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

Greater age negatively influenced resources (fewer material resources), recognition (lower social participation) and positively influenced representation (fewer local concerns). Elsewhere, we found that threats to the environment (reflected in the number of local concerns) mediated the relationship between the community type and aesthetic place attachment, whereby those that showed greater concern for the environment demonstrated higher levels of aesthetic attachment. Fewer local concerns at older ages may reflect a different type of attachment to the area. For example, at greater ages the socio-biographic connection to place may be more important than aesthetics, and issues such as new wind farms or other developments may be of less consequence than social relationships.

Compared to some of the other demographic factors, gender had a relatively narrow influence on inequalities effecting only resources but not recognition or representation: women had access to fewer resources (material resources) than men. On the other hand, marital status had a broader influence, effecting resources and recognition (but not representation).

Participants who had never married had greater levels of material resources than those that had married. This could reflect the greater likelihood of unbroken periods of employment and continued payment into occupational pensions or national insurance (for women) and fewer demands on lifetime earnings for men and women without family commitments. Participants that were divorced or widowed were more likely to experience poverty (but not fewer material resources) than those who were married. Thus, work and family histories intersect to impact on the risk of poverty in later life. Widows often 'inherit' pensions, and before April 2016, female divorcees could also claim a state pension using the National Insurance contribution that had been made by their husbands during the period that they were married. However, in both cases, widows and divorcees are more likely to live alone and housing

costs incurred by single person households are disproportionate. Consequently, while individual material resources may be similar, older divorcees and widows may experience poverty, unable to afford as many essential items as older people living as a couple.

In addition to the impact on resources, marital status also influenced recognition. Married participants had greater levels of social participation than participants with other types of marital status. Moreover, those that were never married or divorced had fewer social resources than those who were married. These results suggest that marrying entails gaining social resources, for example, combining the social support networks of both partners plus offspring. While these additional social resources are not accrued by those that never marry, or decline on divorce when amalgamated networks may be abrogated, they do not appear to be unduly influenced by widowhood. For widows, existing social relations with kin and non-kin endure beyond the death of a spouse. As new cohorts age other forms of long-term partnerships (e.g. civil partnerships or cohabiting couples) are likely to be more frequent and research will be required to explore the influence of these types of relationships on recognition in later life.

Socio-economic status (previous employment) influences resources and representation, but not recognition. While social participation and social resources do not differ by skilled/unskilled occupational status, the enduring nature of lower lifetime income from unskilled work results in fewer material resources in later life. Furthermore, participants in previous unskilled roles had lower levels of civic participation in later life. While an individual can 'choose' not to engage in civic activities, the interplay between choice and exclusion from representation is complex and requires more research to explore why people make such choices and what processes, structures or circumstances enable or prevent them participating.

In a qualitative study in rural areas of Wales older people said that low levels of civic participation were based on an active choice. In this case, the influence of socio-economic status on civic participation may have been a reflection of area-based disadvantage: some older people noted that they had chosen to withdraw from civic participation because of the increased workload and expectations being put upon volunteers in the face of austerity measures and local service cutbacks (Winter, 2017). In this instance exclusion from civic participation may jointly represent a failure in public services alongside a political failure to involve older people in the decision-making process (recognition) which assumes local voluntary resources will be made available to fill service gaps. Furthermore, where older people did participate in rural areas of Wales, civic action was focused on key issues, notably regeneration activities and environmental campaigns (Winter, 2017). Older people's involvement in such initiatives could be attributed to period and/or place effects and may be the product of agency to effect change in local communities (Walsh, O'Shea and Scharf, 2012). Consequently, the different forms and levels of older people's civic participation is likely to be variable across rural areas, and the influence of drivers,

such as socio-economic status, deserve further research investigation (Hennessy, Means and Burholt, 2014).

Arguably, one of the strongest influences on inequality in resources, recognition and representation is disability or health. Poor health (a result of functional or cognitive impairment) was associated with fewer material resources, lower social participation, more local concerns, and lower levels of trust in local officials. This is particularly pertinent as between one third and one-half of older adults experience some form of mobility impairment or limitation (Webber, Porter and Menec, 2010) with prevalence greater for women than men (Gale et al., 2017). Furthermore, cognitive impairment and the risk of dementia increase with age. The prevalence of dementia in the English population aged 65 years or more, is estimated to be around 6.5% (670,000 people) (Matthews et al., 2013). While the incidence rate of dementia is the same for women and men (Matthews et al., 2016), the greater life expectancy of older women brings about a greater number living with dementia at any one time. The age friendly movement has sought to make communities more physically accommodating in order to maintain 'spatial independence' (the freedom and choice to access public physical space). However, the lack of representation (greater local concerns, lower trust in local officials) may suggest that older people in poor health are marginalised in rural areas which, in turn, may have implications for access to services.

Access to services in rural areas has declined in recent years (Moles and Radcliffe, 2011). Although several epidemiological studies have found poorer health and a greater prevalence of disease in rural areas than in urban areas, the influence of environmental factors, such as access to health care (e.g. GPs, hospitals, preventative services and specialist services such as palliative care and memory clinics), social care (e.g. domiciliary services, respite care), retail (e.g. post offices), leisure and transport services on poor outcomes are often overlooked (Burholt and Dobbs, 2012).

The depletion of services due to shortages of staff and the closure of rural hospitals has led to a concentration of facilities in urban or rural-service centres. The lack of local care home provision in rural areas has meant that many older people have to leave familiar local communities to receive such services (Rural Development Sub-Committee, 2008). Many rural inhabitants have to travel to access remote services and driving is a 'key mobility practice for maintaining accessibility' (Parkhurst et al., 2014, 150). However, this can be problematic for those without the use of a private automobile or who have limited economic resources or mobility restrictions. Difficulties accessing distant health services, compounded by a lack of affordable and accessible transport in rural areas can deter health care utilisation and may result in delays in diagnosis and treatment (Wood, 2004). While older people living in countries with developed health and social care systems expect to be able to access the same quantity and quality of services regardless of the area in which they live, families or the voluntary sector often have to step in to provide support when services do not meet local needs in rural areas (Walsh et al., 2014).

Service design is frequently urban-centric, with policymakers often assuming that services are similarly appropriate in both rural and urban areas. However, there are substantial differences between geographic locations that influence service delivery. For example, the cost of delivery of care services in rural areas is often higher than in urban areas due to the greater distances that staff have to travel and increased overheads incurred in small rural service centres compared to those in urban areas. Often research in this field seeks to find ways in which the costs associated with delivery could be reduced (Burholt and Dobbs, 2012) and fewer studies focus on improving the quality of the experiences of older people. Without adequate rural representation of older people (especially those reliant on health and social care services), the voice of rural citizens continues to be constrained in relation to having a valid role in service design and choice (see also, Farmer et al., 2012).

Finally, the type of rural area also influences inequality across resources, recognition and representation. Overall, we observed that participants living in the most remote and deprived areas (Area A) had fewer material resources, greater levels of poverty, lower levels of social participation and resources, lower levels of civic participation, and trust in local official, but more local concerns than those in Area C (affluent and accessible). Participants living in Area B were more similar to those living in Area A than C experiencing greater levels of poverty, lower levels of social participation and resources and had greater level of local concerns than participants in Area C. What is particularly interesting about our results are that they do not support mythologising the rural idyll. Rural and remote areas (A & B) are less supportive and connected, and thus mis-recognised in popular, media and policy conceptions of the countryside.

The representation of the rural idyll – the pastoral myth of Western literature in which rural life is portrayed as bucolic and virtuous – has been reproduced in European literature and transported globally. Further to the media representations of rural living, policy discourse also reinforces the notion of rural supportiveness, suggesting that citizens within rural communities are resourceful, self-sufficient and interdependent (Woods and Goodwin, 2003). Thus, rural areas are encouraged to take responsibility for governance and tackling problems locally. However, this approach is in danger of glossing over issues of social justice in distribution of health and social care support, as some rural communities could be described as impoverished care environments and perhaps are least equipped, to meet a such agendas.

It is perhaps unsurprising that older people living in rural communities with varying abilities to live up to the 'self-help' stereotype portrayed and sanctioned in rural policy are under-represented in ways that afford them political authority (low civic participation, lower levels of trust and more local concerns). Unless the perspectives of rural older people are aligned with policy agendas, then it is likely that the future sustainability of health and social care policy in rural areas will be jeopardised. Policymaking needs to take a citizen-centred approach to give a voice to older people living in rural areas to shape recommendations for future health and social policy and services. As Fraser (2000) notes, institutionalised patterns of cultural value that simplify group identity,

deny recognition and constitute others as inferior or 'simply invisible' and as such the status of older people living in more remote and deprived rural areas of the countryside are subordinated.

Participants living in Area C are the most advantaged, in terms of resources, recognition and representation. Frost and Laing (2014) have argued that many well-connected small rural towns on the periphery of urban conurbations have been rebranded as 'villages'. While the rebranding may encourage employment and other economic benefits (such as leisure facilities, cafés and boutique accommodation), it also has social implications relating to rural identity, population displacement and authenticity of the rural experience. Average levels of 'affluence' may mask deprivation among non-migrant (indigenous) older people.

While the new rural 'village' may represent a refuge from modernity and appears to embody the 'good life' in terms of resources, representation and recognition, it is important to acknowledge that there are significant differences and inequalities between and within rural areas. While a new wave of British films are portraying social-realist dramas of bleak rural lives in the countryside, they are still rare. Similarly, there is little systematic academic evidence of how features of rural communities might structure rural life.

Our analyses have indicated that the normative expectations about rural living are, or are not achieved by subgroups with different modes of power relating to age, gender, marital status, health, class and in diverse rural settlement types. Unfortunately, the quantitative data do not permit exploration of intersectionality between sexual identity and/or ethnicity with resources, recognition and representation. Subsequently we need more research in rural areas that recognises diversity among older people, the intersectionality of the factors identified above and their relationship to resources/status/power in the countryside. The acronym PROGRESS has been used to highlight sampling of socially stratifying factors that drive variations in health outcomes that can similarly be applied to inequalities in resources, representation and recognition. PROGRESS refers to place of residence (e.g. types of rural area), race/ethnicity/culture/language, occupation, gender/sex, religion, education, socio-economic status and social capital (O'Neill et al., 2014). We would argue marital status should constitute a crucial element of social capital that should be explicitly studied in relation to social inequalities for older people in rural areas. Following Fraser's (2000) arguments, the redistribution of resources will only be achieved through a more nuanced portrayal and understanding of intersectionality in older people's lives in rural areas.

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21 Ageing in the workplace

Annette Cox[1, 2]

Introduction

Population ageing across many developed countries has major implications for the evolution of the supply side of labour markets and employment, as well as changes in the nature of demand for goods and services and how best to use limited public finances for the benefit of citizens (OECD, 2006). Some countries such as Japan have been grappling with this challenge for several decades (ibid.). Others, such as Germany, have more recently confronted skill shortage challenges as a result of an ageing workforce (European Commission, 2015), while in the US, vocal movements of older people have been prominent in shaping debates about rights and responsibilities of older citizens in work and in retirement. In the UK, the debate has been more muted but has gathered pace over the past ten years, driven by higher age requirements for state pension eligibility, introduction of anti-discrimination legislation on grounds of age and effects of recession and labour market restructuring (Finch and Rose, 2017).

Ageing within the population and workforce is being driven by increased life expectancy combined with lower fertility rates, illustrated in projected population shares of people aged over 60 rising from 9.7% in 2014 to 12% by 2039 (Government Office for Science, 2016). Older workers account for a growing number and share of workers. Evidence shows 9.4 million workers are aged over 50, making up around 30% of the workforce (CIPD/ILC-UK, 2015), a trend which has grown since the early 2000s. But labour market activity declines sharply by age between 55 and 69 although UK labour market participation is broadly comparable to the OECD average (Government Office for Science, 2016). This leads to a large pool of untapped potential human capital attracting state support instead, with over 2.9 million people out of work aged between 50 and the UK state pension age, on whom government spends around £7 billion per year on welfare benefits (ibid.). However, not all of this group are able to work, because they are affected by age-related health conditions or disabilities.

According to The Labour Force Survey (2011), of 7.2 million people aged 50 to 64 who are employed in the UK, 42% are living with a health condition or disability (Sinclair, Watson and Beach, 2013). These figures are likely to increase

because of the increased prevalence of health conditions such as diabetes and cardiovascular disease which are caused partly by 'lifestyle' factors (Heron, Bevan and Varney, 2016). At the same time as these developments in workforce ageing, future skills needs and projections raise questions about whether there will be a sufficient supply of alternative labour sources if any shortfall is not made up by older people (Cedefop, 2016; Brinkley and Crowley, 2017). This means the experience of older people in the workforce combined with policy drivers will be crucial in determining UK labour supply, and potentially individual organisational performance, national productivity and people's later life experience.

Like the other chapters in this collection, this review draws on the common framework of Fraser's typology of social justice as the analytic lens through which evidence is critically assessed (Fraser, 1998, 2005). The chapter explores her thesis that the oppositional dichotomy between resource allocation and recognition in understanding how (in)equality is fostered is unhelpful and illustrate the mutual enforcement mechanisms between these facets of social justice together with representation. The locus for the analysis is employing organisations. The centrality of employment in the lives of older people through offering access to resources, representation in economic life and positive recognition of their value to society is gaining prominence. This is driven by demographic changes and shifts in state pension provision noted earlier which mean that employment prospects in organisations exert a major influence on older people's experience of all three elements of social justice.

Resource distribution in this chapter's analysis encompasses tangible and intangible forms. Work is in itself a fundamental resource through which older people secure benefits such as income, social contact and purpose (Ipsos Mori/Centre for Ageing Better, 2015). Access to (suitable) work and workplace adjustments that make employment possible include flexibility in work schedules and location, adjustments to job content and mechanisms to enable these such as the support of occupational health services. Tangible financial resources cover pay and access to benefits such as pension provision and health insurance. Key intangible resources include access to career development, training and promotion opportunities.

Representation of older people in the workplace has two dimensions. First is the incidence of employment of older people, in part affected by their need for resources, and the quality and variety of job opportunities open to them. This in turn contributes to choices about labour market participation. Second is whether and to what extent older people's voices are expressed, heard and acted on to address workplace issues such as organisational strategy, job quality and application of management practices that will meet this group's needs.

*Recognitio*n covers two dimensions in the analysis. First, the chapter draws attention to the specific needs of older people. Paying attention to older workers as a group with common, distinctive needs in the workplace is supported by the UK Equality Act 2010, under which age is a protected characteristic. In practice, analysis and management of effective practice requires attention to the differing experience of subgroups and intersectionalities within those

groups, such as older women, older people from Black and minority ethnic groups, older people with higher or lower levels of skills and qualifications. Secondly, more positively, recognition covers specific contributions that older people can make in the workplace. Recognition within workplaces of older people's value, talents and achievements is a common theme which surfaces in accounts of older workers' desired experience of work and within human capital asset-based management debates. This also taps into the wider critical gerontology debates around the need to recognise social and economic value of older people through taking a more holistic perspective of societal contributions (Estes, 2001).

The evidence on which this chapter is based comes from a series of commissioned research projects conducted by staff at the Institute for Employment Studies since 2014, supplemented by wider literature. The first is a report for the CIPD (CIPD, 2016) based on 11 organisational case studies of effective practice in managing older workers aged over 50 in five countries – Germany, the Czech Republic, France, Denmark and the UK. The second is a large scale qualitative systematic review of factors which help or constrain organisations to support the health and well-being of older workers aged over 50 in the UK, New Zealand and Australia undertaken for the National Institute for Health and Care Excellence (NICE) (Cox et al., 2015). The third is a review of effective employment practice for older teachers aged over 50 in OECD countries undertaken for the Department for Education (Pollard et al., 2017). The fourth is a review of what fulfilling work looks like for older workers aged over 50 in OECD countries undertaken for the Centre for Ageing Better (Marvell and Cox, 2017). The evidence is applied and interpreted primarily for a UK context.

The chapter explores the empirical evidence on how each of the three types of social justice is played out in organisations and the relationships between them, specifically how the greater or lesser presence of each form affects the others. Lastly the chapter concludes with suggestions on how further research for the analysis of managing older workers could be advanced and recommendations for policy attention.

Resource distribution

Older people's choices about labour market participation are often dependent on level of access to resources which make work a necessity, feasible and/or desirable, such as personal finances, family structures, health and quality of work itself. This is reflected both in analysis of why older people drop out of work prematurely as well as why they choose to continue working even when they may be able to afford to retire, both before and after reaching state pensionable age. A systematic review found that income adequacy was a trigger for leaving work among older workers with early access to generous pensions and a reason to stay among lower paid people with inadequate retirement savings (Cox et al., 2015). Pressure to remain in work is likely to increase over

the medium-term as the age of eligibility for the state pension rises, combined with the decline of defined-benefit pensions (Silcock, Popat and Pike, 2016). But for those who have unconstrained choice, recognition and representation factors come into play because perceptions of quality of work then influence decisions about whether to work. This illustrates the interplay between the different dimensions of social justice and how they can operate in sequence in decision making about labour market exit. For example, research into teachers' decisions about retirement found that affordability of retirement was an initial consideration, after which teachers balanced the relative pull of spending time on hobbies and family against perceptions of resource-related factors such as workload and recognition factors, including relationships with colleagues and managers (Pollard et al., 2017).

Different forms of resources may be more important for some subgroups of older people than others. Qualitative research across four sectors in the UK shows that a higher share of women than men intended to continue working after the state pension age of 65 with the authors arguing that women's occupational pensions are often smaller than men's due to a combination of part-time working, lower wages and later enrolment into pension schemes (Vickerstaff, Shepherd and van der Horst, 2017). In addition, autonomy and flexibility and positive interpersonal relationships are associated with women's intentions to continue working. This may reflect the comparative greater likelihood of women seeking to combine work with care roles for older relatives or younger family such as grandchildren. In contrast, a more important factor for men is perceived centrality of work as a life activity and source of identity (Cox et al., 2015;Vlachantoni, Chapter 2).

A key trigger of labour market exit is (unanticipated) ill health, either of the individual or a family member. In this way, the personal resource of health or its deficits acts as an enabling or constraining factor which affects representation. Common conditions leading to early withdrawal from work are mental health conditions and musculoskeletal disorders (Hillage et al., 2008; Heron, Bevan and Varney, 2016). Substantial evidence shows that early intervention through multidisciplinary initiatives involving the workplace and clinicians can reduce absence and potentially future labour market withdrawal (Hillage et al., 2008). Research on the efficacy of using resources such as occupational health provision and interventions to prevent early exit due to mental ill health is scant, so the key question of whether investing greater resources will pay off in terms of reducing wasted human capital still requires investigation. The debate on supporting older workers has often focused on making adjustments which take account of cognitive or physical decline due to ageing, thus making work 'easier'. But work quality which includes an element of challenge can also help preserve mental capacity as a personal resource and is a fundamental element of designing work for older people (Sharit and Czaja, 2012; Marvell and Cox, 2017). Provision of complex, intellectually challenging work requiring ongoing learning is associated with delay in cognitive decline (Skirbekk, Loichinger and Barakat, 2012). This is dependent on active attention to job design and feeds

into a wider debate about how far it is possible to generate 'good jobs' or alleviate the problems associated with 'bad' jobs through offering modification and progression to healthier and more personally satisfying employment (Warhurst et al., 2017).

There is considerable qualitative evidence that access to (suitable) work and workplace adjustments which make employment feasible and fit round domestic commitments and preferences feature very highly in older workers' lists of desired attributes in a job (Marvell and Cox, 2017). As self-reported factors they are claimed to have deterred retirement among older people who undertake paid employment (Cox et al., 2015). The Department for Work and Pensions also notes a 'high level of unmet demand for flexible working and reduced hours amongst older people' (DWP, 2014, 24).

These adjustments cover both formal and informal practices (Atkinson and Sandiford, 2016). A number of studies have shown that offering flexible working, specifically part-time contracts and opportunities to work from home, to older employees is associated with positive attitudinal outcomes, and some managers believe that this can have a beneficial impact on staff retention (Cox et al., 2015). There is also evidence that older workers have reduced commuting patterns, although it is not clear whether this is determined solely by choice (ibid.). At the same time, applying line management discretion through informal adjustments to working-time such as access to convenient shifts and ability to leave the workplace at short notice can help older workers meet care needs of older relatives (CIPD, 2016; Wilson et al., 2018). This is important and again highlights the needs of specific subgroups of older workers who may be limited in their access to the full range of employment opportunities and thereby income derived from work because they act as an unpaid resource to look after family members in lieu of care provided by the state (ibid.).

Employers often find it more challenging to offer workplace adjustments to some roles, for example, workers in physically demanding occupations who can no longer perform their existing jobs for health reasons. It is dependent on managerial commitment to offering support such as retraining and availability of suitable alternative occupations in the same organisation. Workers in these kinds of roles are sometimes alleged to be reluctant to swap manual for sedentary jobs, and those with lower skill levels may find it more challenging to retrain (Cox et al., 2015). However, good practice has been identified in case studies where organisations have retained workers with physical age-related impairments through semi-automation or provision of manual handling equipment in industries as diverse as airports and ceramics manufacturing (CIPD, 2016). This depends on a managerial assessment of the return on investment of resources in specific groups of workers, their perceived labour market value as a human resource and management commitment to supporting the health and well-being of older staff. There is also a question here about the role of the state in supporting workers who need to transition between sectors which is picked up in the conclusions.

Access to intangible benefits such as training, development and promotion opportunities are common aspirations among older workers (Marvell and Cox, 2017). Older workers are much less likely to receive work-related training than young people (Canduela et al., 2012). In practice, access to opportunities on a similar basis as younger staff can be limited by management beliefs and sometimes stereotyping about older workers' motivations, interests and capabilities. This includes perceptions that older workers are less interested in training, less adaptable and more resistant to change, and that older people already possess the skills required when moving between jobs (Cox et al., 2015). In contrast, evidence from older workers suggests that they may lack self-confidence in seeking opportunities to learn, seek out opportunities in particular to develop IT skills and may prefer practical training that is tightly focused on job-related outcomes (ibid.). Critically, offering development opportunities is often highly valued by older workers (Marvell and Cox, 2017). This is partly because the investment of time and money acts as a signal of their value to their employer. In this way resource provision interacts with *recognition* of the (latent) talents and attributes that older workers offer. Where managers attach inferior status to older workers because of (biased) or inaccurate perceptions of weaker performance, this risks positioning older people as less valuable, endorsing segmentation in employment, less favourable work opportunities and confining less advantaged groups into 'precariat' status (Standing, 2011). In turn this can have wider implications about social status from which older people derive self-esteem (Honneth, 2007) and exacerbate inequitable outcomes. This points to the need to challenge stereotypes and engage in a wider understanding of the social construction of ageing (Phillipson, 1998).

Conversely, employers' resource limitations can also be key factors in determining access to employment for older people. First, some employers claim they prefer recruiting younger workers on the grounds that older workers are assumed to want full-time roles and will have expectations of higher pay levels (Cox et al., 2015), although this conflicts with evidence on preferences for part-time, flexible working among older people. Secondly, cost constraints can affect service sector employers, where salaries are the main source of expenditure. In the case of teachers, the requirement to pay more experienced (and therefore typically older) staff has commonly been cited as a deterrent to employing older staff (Pollard et al., 2017).

Representation

Older people's representation in the workplace has two dimensions. First is the incidence of employment among this group, in part affected by their need for resources, and the quality and variety of job opportunities open to them. This in turn contributes to their choices about labour market participation. Second is whether and to what extent older people's voices are expressed, heard and acted on to address workplace issues such as organisational strategy, job quality and application of management practices that will meet this group's needs.

There is increased incidence of older people working beyond the age of 50 and beyond state pension age evident in labour market trends. Overall, evidence suggests this is driven by structural labour market change related to population ageing combined with financial pressures to bridge any retirement savings gaps among older people. Evidence of active employer focus on recruiting and retaining older people is patchy.

Sectors facing imminent skill shortages due to an age profile skewed towards older workers are more likely to need to undertake initiatives to boost employment of older people. For example, in real estate, transport and storage and agriculture over 35% of workers are aged over 50 (CIPD, 2015). In contrast, fewer than 25% of workers are made up of those aged over 50 in finance/insurance and accommodation/catering (ibid.). There are patterns of mutually reinforcing trends where without sufficient representation and visibility of older workers in an organisation or industry, employers lack incentives and triggers to recognise their needs, contribution and value. In turn this limits and deters labour market participation from older people in those industries.

Issues of 'visibility' related to age also have broader dimensions relating to consumer marketing and public representation, based on presumptions about how society views the relative value of youthful versus mature attributes and personal aesthetic preferences for types of service labour (Nickson and Baum, 2017). High profile UK cases of unfair dismissal on grounds of age discrimination in broadcast media have surfaced (O'Reilly v BBC, 2011), along with those of people in customer-facing roles as in the recent case of a jewellery salesman (Dove v Brown and Newirth Ltd, 2015). This points to a need to shift not just employer perceptions, but also to activate pressure from wider public perceptions of the importance of fair treatment and representation on the grounds of age within a broader discourse of the value of social diversity (see Westwood, Chapter 2). UK citizens are the second most likely in Europe to regard age discrimination as a problem and over a third of people believe age discrimination towards people over 55 is commonplace (European Social Survey, 2010 cited in Government Office for Science, 2016). Within critical gerontology debates, this raises wider anxieties about the social position of older people (Estes, 2001). It suggests a need to re-energise forms of social solidarity in a way that articulates the needs and value of older people within economic production rather than solely outside it as welfare consumers within a new economic culture evolving in response to financial crisis (see Castells et al., 2013).

It is possible that the effects of population ageing and gradual growth in the numbers of workers who reach what would formerly have been considered 'normal' retirement age will prompt more organisations to accommodate older workers' needs (Lain and Loretto, 2016; Johnson, 2015). To date, both vicious and virtuous circles forming between recognition of older workers' needs and representation. This occurs virtuously where older worker representation builds to a critical mass and serves to stimulate managers to accommodate worker needs, thus attracting more older people into particular roles or sectors which become recognised for good age-related management practice. In contrast,

where managers offer limited or no accommodation of older workers' needs, disaffected workers are likely to quit jobs, reducing the share of older workers in specific roles or sectors. Providing an adequate alternative labour supply is available, this reduces levels of older people's representation and thereby management incentives to make age-related adjustments.

The research base shows why older workers choose to stay in employment and how premature labour market exit is linked to age. Studies examining why older people who can afford to retire stay in work have identified job enjoyment as a major explanatory factor (Cox et al., 2015). Conversely, there is a substantial amount of evidence indicating that older people who leave the labour market due to age-related treatable physical and mental health conditions perceive their exit as a forced choice because employers were unwilling or unable to accommodate their needs (Cox et al., 2015).

In the long-term, this has a series of adverse consequences for resource generation and allocation among the individuals affected, employers and the state. Evidence shows that those who perceive themselves to have retired involuntarily are more likely to report negative experiences of physical and mental ill health in retirement (ibid.). This brings with it additional health, welfare and social care costs usually met through the state and paid for by taxation. Outcomes are also differentiated by subgroups as those with higher incomes are more likely to be able to exert choice about timing of retirement while more support is needed to help people from ethnic minorities and those with disabilities plan optimally for retirement (ibid.).

Within organisations, individual and collective voice to articulate the needs and views of older workers can take many forms. They include opportunities to influence the wider organisation through seeking suggestions about change and taking older workers' opinions seriously, indicating respect for insights accumulated through working lives (Marvell and Cox, 2017). Many of the good practice examples available include principles of monitoring ergonomics, providing workers with health assessments and working collaboratively with worker representatives of all ages to define optimal working practices which give immediate benefits to older workers' health but also confer preventive ill health benefits across all staff (European Agency for Safety and Health at Work-OSHA, 2017). Yet there are risks here that not all voices are treated equally, reflecting the challenges of intersectionality and multiple disadvantage. Where low-paid workers are easily substitutable, work fewer than standard full-time hours, have lower levels of skills and education which can contribute to lack confidence in asserting their needs and rights, their views can be overlooked. Again, if older workers are not treated in ways they perceive as fair, this can have far-reaching links in later life. Systematic reviews of large scale cohort studies of the health of government employees in the UK have shown that in the long-term, cognitive abilities were significantly decreased among people who reported low levels of perceived organisational justice (Then et al., 2014).

Recognition – needs and contribution

The first dimension of recognition covers awareness and accommodation of individual needs related to ageing which may take the form of health issues, working time preferences, career ambitions and personal development requirements, underpinned by employment law which protects against age discrimination. Acting on some of these needs is dependent on recognising older workers as a distinct group in the labour market and the benefits, challenges and risks associated with dysfunctional labour turnover or under-employment of this group.

Recognition of the needs of older workers is often a key first step in attracting them into jobs and retaining them when employed. Employment law in the UK has recognised age as a protected characteristic within anti-discrimination legislation since 2006, while application of a default retirement age without a justifiable reason was abolished in 2011. As the evidence discussed in the introduction shows, the employment of older people in the UK has increased substantially over the past 20 years, particularly among those aged between 50 and the state pension age (DWP, 2014).

But research shows that, although employers have written age as a protected characteristic into their diversity and equality policies, not all organisations give the needs of older workers due attention in practice and positively recognising the value of attending to individual differences (Cox et al., 2015). Few employers are reported to monitor their workforce age profile, consider risks of bias in recruitment or express concern about workforce ageing or effective management of older workers (Adams et al., 2017). Rather than stimulating open discussion about older workers' ambitions and employment options, qualitative case study research in a mix of sectors shows that organisations have chosen to interpret abolition of the default retirement age to end discussion about older workers' intentions to retire or continue working (Lain et al., 2017). This is partly due to organisational concern about the legitimacy and legal consequences of initiating conversations about retirement in case employees interpret these adversely (Adams et al., 2017). It is also attributed to lack of confidence among line managers in raising age as a topic due to lack of training in discussing retirement planning with staff (Cox et al., 2015). This reflects broader negative associations for ageing (see Torres, Chapter 11). The UK has a stronger approach to enforcing the option of extending working life than some European countries such as France and Sweden where age-related default retirement has not been abolished. But in the UK, age-related discussions about performance and careers are not yet widespread in contrast to other countries. For example, in Denmark, senior conversations take place on an annual basis between older workers and their line managers covering training, career development, job content and working time preferences and where appropriate, retirement (CIPD, 2016).

There are three further reasons why employers may pay limited attention to recognising the needs of older workers and opportunities to extend working

lives. First, legal experts suggest that lacklustre employer efforts to mainstream age within diversity and equality policies occur partly because age is a universal and sometimes less noticeable characteristic of every worker. Age is measured on a continuum and is less visible than other protected characteristics such as pregnancy, sex or race (Eversheds, personal communication, 2015). Second, long-standing societal norms and state pension provision encode the practice and anticipation of retirement at set ages and shifting expectations through policy instruments such as raising the state pension entitlement age will take time. Third, where employers have access to sources of labour which they regard as less 'problematic' such as younger workers or immigrants because they will work for a lower wage or are more malleable in accepting poor working conditions (Cox et al., 2015), there may be less incentive to focus on employing older people. This illustrates how representation of older people within the workforce is influenced by employer interpretations of the value of different kinds of human resources. Reliance on sources of labour which are wholly adaptable to employer requirements is dependent on such workers being available, and future prospects and policy implications for this question are considered in the conclusions.

The second dimension of positive recognition involves effective management practice to acknowledge the contribution that older people bring to the workplace, which is dependent on attaching value to their characteristics through a resource-based view of HR management and strategy (Boxall, 1996). Evidence here is based more on characteristics that older people associate with fulfilling work (Marvell and Cox, 2017) and there is a lack of longitudinal research tracking older workers' choices about labour market participation linked specifically to management practices, the extent to which these desires are met and any impact on outcomes for older workers still in the workplace or organisations. Qualitative research, however, shows evidence of older workers dropping out of the labour market if they feel they are passed over for promotion, denied access to training or feel they are not treated with due respect (Marvell and Cox, 2017). Lack of recognition therefore results in denial of access to resources which make employment attractive to older workers, and through premature exit, denies employers access to a segment of the labour market. There are wider consequences for older people as well. Employment can function within critical gerontology debates as fostering social recognition, wider societal inclusion and bolstering individual self-esteem (Baars and Phillipson, 2014). The workplace as a normative source of influence on values attached to different groups of workers can shape collective perceptions and send wider signals about ageing and social value (Estes, 2001).

Ways of ensuring older colleagues feel valued include developing workplace cultures which are non-discriminatory and demonstrate positive value and respect for older workers from senior managers, line managers and colleagues (Paullin and Whetzel, 2012; Marvell and Cox, 2017). Practical ways of achieving this include providing frequent one-to-one meetings and regular performance appraisals, verbal praise from managers and public recognition of good work, skills and experience (Marvell and Cox, 2017). While these practices are

generally standard HR tools recommended for the whole workforce, there is an additional important set for older workers. The first focuses on acknowledging older workers' unique skills and capabilities by offering as much autonomy as possible to show respect for older workers' likely advanced skills in applying sound judgement and making decisions. The second focuses on harnessing the knowledge of older workers through offering roles as mentors or coaches to support younger staff and foster mutual learning.

All these practices are mutually beneficial in enhancing collective workforce capability, supporting inter-generational understanding and collaboration and offering personal satisfaction. They also ensure that valuable, often tacit, knowledge is transmitted across generations to protect organisational memory and understanding of business processes. In some cases there is reported evidence of benefits to organisational performance measures. For example, retailers and fast food outlets have compared performance between stores and found that mixed-age teams are positively associated with customer satisfaction (see, for example, Frith, 2016).

Conclusion

The starting point for this chapter was to apply Fraser's (1998, 2005) thesis that resource allocation and recognition are mutually interdependent rather than exclusive in the way they operate to produce more or less unequal outcomes in analysis of labour market participation for older people. To draw together the findings from the three parts of the analysis, Figure 21.1 shows relationships between each dimension of social justice in the workplace in diagrammatic form.

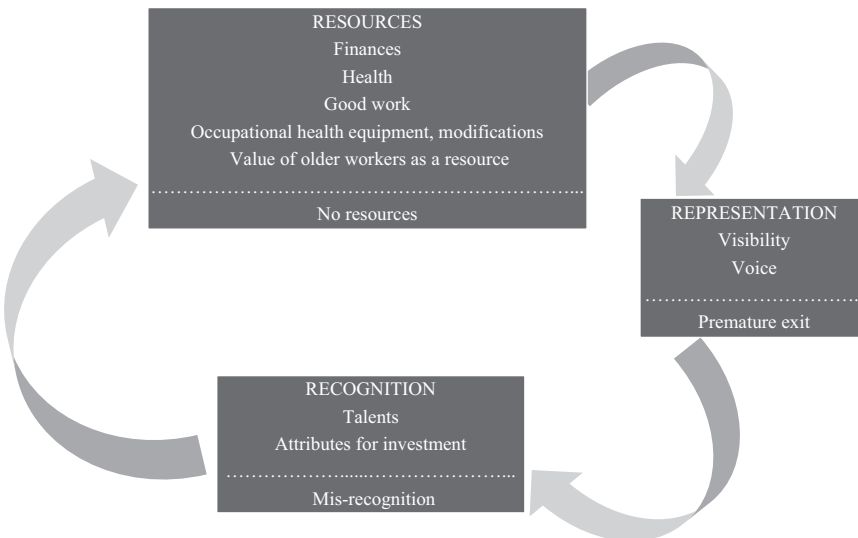

Figure 21.1 Links and reinforcement mechanisms between three dimensions of age-related workplace justice

Box 1 illustrates that individual personal financial and health resources either limit or open up choices made by older people about labour market participation. These then shape the level and type of labour market participation and reinforce intersectional inequalities between those with greater or lesser degrees of personal resources outlined in Box 2. Provision of resources by employers to accommodate the needs of older workers also enables or constrains labour market participation. For some employers, their own financial resources and willingness to invest in older people shapes provision of material support which influences labour market entry, retention and drop-out. In turn this leads to positive recognition or mis-recognition of older people's talents and value through Box 3. The employment outcomes arising can improve, reduce or reinforce initial resource levels of Box 1.

Representation of older workers both through visibility of older people across different strata and segments of the labour market and within organisations shapes employer awareness of the distinctive and varied needs of individuals within this group. Lower representation contributes to lower visibility of older people and less pressure on employers for effective HR practices and non-discrimination. The evidence shows a degree of employer passivity in taking action in this area, linked to lack of recognition of ageing as a factor which may demand customisation of HR practices and workplace adjustments to support older staff. Here demographic change is likely to shift employer awareness as organisations will have to confront an increasing number of older people in the workforce (Johnson, 2015), combined with the impact of legislative provision such as the abolition of the default retirement age and raising of the state pension age. Individual and collective voice within workplaces to raise the profile of older people's needs is dependent on older workers recognising and articulating a group identity. This is particularly acute in the context of labour market change, where reduced collective agency and heightened contractual precariousness among vulnerable groups may both provoke and limit older workers in exploring different forms of resistance and in enforcing employment rights and negotiating career trajectories (see Tams and Arthur, 2010).

Recognition of older workers' value and the potential benefits of investing in them is important to motivate employers to provide resources for training, development, promotion and to invest in resources to accommodate their needs. It is dependent on perceptions of the utility and value of older workers as a preferred resource segment among other competing groups in the labour market to shape investment choices. Where older people meet conditions that fulfil the criteria of a resource-based view of strategy in roles with skills that are rare, intangible, valuable and non-substitutable (Barney, 1991), employers are more likely to make adjustments that will foster positive choices about labour market participation. Conversely, in addition to a substantial minority in high skilled work, analysis points out that some older workers are concentrated in low-skilled jobs and find it difficult to access wider labour market opportunities (see Johnson, 2015). This highlights the risk of perpetuating potentially unfair treatment between different groups of older workers resulting in inequality of

access to decent work based on age (Standing, 2011). It points up the challenges of intersectionality based on skills, previous labour market experience, location, domestic situation and broad socio-economic status.

There are a number of implications from this analysis for employers, policymakers and individuals. For employers, developing awareness of older workers needs and impact of future demographic change will be critical for shaping improved HR practice. This will need careful consideration over the next few years together with wider workforce planning as the implications of the UK withdrawal from the European Union for access to alternative sources of labour such as migrant workers become clear. There is also an implementation gap to close in addressing line management behaviours. Some interventions show promise for overcoming employer stereotyping by confronting myths about older workers head on and challenging them with evidence (Gringart, Helmes and Craig Speelman, 2010) but have not yet been widely tested and exploited in a UK context.

For policymakers, promoting timely financial planning and retirement savings provision among the workforce is essential to support older people in building the resources they will need for later life. More widely, the state can help through providing careers, information, advice and guidance and retraining incentives for workers who will need to transition between sectors in the event of ill health as the UK experiment with 'mid life career reviews' has shown (Watts et al., 2015). Government engagement in this area through plans for a national retraining scheme and additional careers guidance support is an interesting avenue of development (HM Government, 2017). There is also a persistent gap in personal retirement savings, and while compulsory pension provision and auto-enrolment has started to tackle this, questions remain about whether the proportion of income committed will be sufficient to protect against poverty in old age.

Popular predictions of how working life may evolve suggest a series of evolutions and need for substantial investment in retraining due to increased life expectancy, rapid evolution in technology and labour markets causing job obsolescence and financial needs throughout the life course (Gratton and Scott, 2016). The thrust of that analysis is to focus on the responsibilities of individuals to navigate their way through an extended working life with careful attention to and investment in a longer career involving a greater number of job transitions and responsibility for personal financial planning. It is questionable however, whether all but the most financially secure will be able to make the investments of money and time that major career shifts demand given the attendant pressures of housing costs and family life, especially in mid-life. Policy safety nets to ensure smooth transitions for people needing to make such job changes via subsidies, loans or tax credits require exploration.

For future research priorities, there is remarkably little evidence which examines the comparative efficacy of different management practices to support the recruitment and retention of older workers and implications for effective retirement transitions. Longitudinal studies which track the experiences of

older people in work through to retirement outcomes are much needed along with robust evidence of the value of interventions to support them. Overall, while the direction of travel for managing older workers appears promising, the analysis reveals structural labour market inequalities between different subgroups and a slow pace of change. An evolutionary approach to managing older workers might allow emergence of improved practice over time, but a more activist approach would help advance current management approaches and bring about greater equality of outcomes for older people in employment.

Notes

1 This chapter was written while Annette Cox was Director, Employment Policy Research at the Institute for Employment Studies. The views expressed are the author's own and are not necessarily shared by either her current or previous employers.

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22 Ageing in prison

Helen Codd

Introduction

This chapter explores the nature, context and consequences of ageing in prison, focusing on the experiences and needs of older prisoners, and using the work of Nancy Fraser (2005, 2010) as an innovative and original framework for analysing and exploring ageing in prison as a social justice issue. In England and Wales, and many other countries, including Ireland, the US and Australia, older prisoners, including older women, make up a significant and growing minority within a penal estate populated primarily by young men (Davoren et al., 2015; Mann, 2012; Baidawi et al., 2011; Human Rights Watch, 2012; Stevens et al., 2018). Although older prisoner numbers are growing, older prisoners form a minority of prisoners, and older women form a minority within a minority, as around 95% of prisoners are male (Wahidin, 2011). Just as the number and proportion of older offenders is increasing, so is the published research, and there is a large and growing international literature which approaches issues related to older prisoners including perspectives from psychiatry, psychology, medicine, health and gerontology, sociology, social work, social and penal policy, criminology, corrections and prison management (Aday, 2003; Baidawi et al., 2011; Kim and Peterson, 2014; Fazel et al., 2001). This research literature has utilised a range of quantitative and qualitative methods to render older prisoners and their experiences and needs much more visible in criminological and penological contexts. This chapter uses the work of Nancy Fraser as a tool to develop an understanding of ageing in prison as an issue not only of criminal but also social justice.

Background and context

Whilst it is no longer appropriate to describe older prisoners as 'invisible' in penological research and policy development, due to the expansion of academic and practitioner interest in older offenders over the last two decades, a number of core questions still vex researchers. Although the UN has classified older prisoners as 'special needs prisoners' (United Nations, 2009) there is no agreement on national or international definitions of 'older prisoner' and the

threshold adopted by different researchers, agencies and policymakers ranges from 45 to over 70. The terms 'older' and 'elderly' tend to be used interchangeably (Kim and Peterson, 2014). International comparisons can thus be difficult as there is no shared common definition of an 'older' or 'elderly' prisoner, and this lack of consensus has been argued to impede the development of a sound evidence base (Baidawi et al., 2011). Setting the defining threshold at 45 or 50 may seem very low, but as Ginn (2012) pointed out, although a 50-year-old man living in the community would not usually be described as old, some commentators argue that typical prisoners are functionally older than their chronological age. It has been contended that some prisoners may experience 'accelerated ageing' as a result of previous lifestyle, lack of prior medical care, and the experience of incarceration, meaning that a person in their 50s in prison may have the physical appearance and health problems of someone at least 10 years older in the community (Turner and Peacock, 2016; Wahidin, 2011; Aday and Krabill, 2012). This point of view is controversial, however, and is not accepted universally (Spaulding et al., 2011), some commentators arguing that access to health care in the prison may mitigate the impact of accelerated ageing. It is important to recognise differences in ageing between individuals, as highlighted by Crawley in her evidence to the House of Commons Justice Committee (2013) in which she contended that 'people from all walks of life age differently' and that the current male retirement age when she was conducting her research, which was 65, was the point at which most people both within and outside prison begin to 'feel old' (cited at 9, para. 9).

It is interesting to note that the UK House of Commons Justice Committee (2013), when considering older offenders, stated that in their view it 'did not make sense to impose a rigid classification of age' in defining the older prisoner population, but went on to explain that in their view 'the duty to treat each prisoner as an individual should not inhibit the identification of common features among the older prisoner population that can inform policy' (15, para. 27). Thus, the precise point at which a prisoner can be defined as 'older' continues to vary widely.

Whatever definition is chosen, it is clear that in many jurisdictions the number of 'older' prisoners is increasing, for both men and women. For example, in England and Wales, the number of sentenced prisoners aged 60 and over rose by 164% between 2002 and 2015, and people aged 50 and over account for 14% of the prison population (Ministry of Justice, 2014). Older people may have been sentenced to imprisonment or remanded in custody later in life, or may have grown older in the prison while serving a long sentence. For some older offenders, their first experience of prison is in older age, whereas for others their lives have been lived within a pattern of regular short sentences. This expansion in numbers has been mirrored in many jurisdictions, and on a global scale, the number of older prisoners worldwide is projected to increase in the future. There are several reasons for this, although caution should be exercised in asserting that this is due to increased criminal behaviour by older people creating a so-called geriatric crime wave (Brogden and Nijhar, 2000). Instead, one

cause is pure demographics: in many countries advances in medicine and care have led to increased average life expectancy. Alongside this, where countries, including the UK, have abolished the death penalty, those offenders who at one time would have been executed for their crimes are now given long determinate, or indeterminate, sentences, including life imprisonment, some being handed a 'whole life tariff' or a sentence of 'life without parole' which specifies that they will never be released, thus creating a category of prisoners for whom ageing and dying in the prison is an expectation from the point of sentencing. There are also rising numbers of men being sentenced to prison for the first time when they are already in later life, especially for sexual offences, some of which are historic in nature (House of Commons Justice Committee, 2013). This reflects major shifts in understanding and attitudes towards sexual abuse and exploitation, especially of children and young people, and successful prosecutions being brought now for abuses committed many years ago. This shift in attitudes has been accompanied by advances in forensic science, including new techniques and approaches to evidence previously gathered in unsolved 'cold' cases, such as advances and improvements in the identification of DNA evidence, which has led to offenders being apprehended and convicted for previously unsolved crimes. Also, in some countries, changes in the political landscape and increased accountability for crimes of the powerful, including war crimes and human rights abuses, can mean offenders being sentenced to imprisonment for historical offences which were committed during former times of war and conflict.

The increase in academic interest in older offenders has been echoed in policy and practitioner concerns about appropriate policies and practices in relation to sentencing, prison environments, and specific aspects of inmate life such as accommodation, education, health care and release and resettlement planning and programmes. This has included a growing awareness of the changing role of prison staff working with older offenders, especially those who have extensive health care needs, including terminal illnesses, for whom end-of-life care has to be provided within the prison setting, thus requiring prisons to adjust to new roles as *de facto* care homes and hospices (Prison and Probation Ombudsmen, 2017; Maschi, Marmo and Han, 2014).

Nancy Fraser, social justice and ageing in prison

Nancy Fraser's work has been described as providing a 'highly sophisticated framework' for mapping problems of equality and social justice (Lynch, 2012, 49), identifying a three-dimensional theory of social justice based on principles of representation, recognition and resource distribution/access to resources (Fraser, 2005; Nash and Bell, 2007) building on her previous two-dimensional framework which neglected the role of political relations in generating injustice. Her work has been celebrated but is also controversial, prompting ongoing engagement with critics including Richard Rorty, Iris Marion Young and Judith Butler (Olsen, 2008). Alongside this, the institution of the prison has

long been linked to concepts not only of justice but also injustice, including debates around the justness or otherwise of offenders receiving prison sentences as a manifestation of the effects of other forms of inequality, such as crimes prompted by economic deprivation (Reiman and Leighton, 2012). The prison itself has been identified as a site for the reproduction of institutional inequalities and injustices (Scott and Codd, 2010). It is thus valuable to explore the relevance of Fraser's work to penology and sentencing, and, in this chapter, older prisoners.[1]

Representation

Fraser uses 'representation' in relation to political participation, and stresses that a key issue for promoting justice is that of participatory parity, i.e. that it permits all members of the global community to interact with one another as peers. As she writes (Fraser, 2010):

> The political constitution of society must be such as to accord roughly equal voice to all social actors. This condition rules out electoral decision rules and media structures that systematically deprive some people of the fair chance to influence decisions that affect them.
>
> (365)

Fraser (2009) elaborated on the principle of participative parity, and this further exposition of its normative meaning is of value in relation to older prisoners. In a published interview dialogue she explained her view that participative parity is 'an interpretive ideal of social justice, and, as such, does not exist' (Palacio Avendaño, 2009, 2); rather, it should be used as a critical ideal to reveal existing disparities in participation, identifying those obstacles to participation that are rooted in social relations:

> The question in this case would be, what are the structural conditions that prevent participative parity? This is how I understand this ideal, as a way of shining light on the obstacles to justice.
>
> (Palacio Avendaño, 2009)

The inclusion or exclusion of older prisoners in political participation is circumscribed by the legislative context of imprisonment in particular nation states. Opportunities for the democratic voices of older prisoners to be raised, and for those voices to be heard, are governed by controls on voting and limits on communication between prisoners and the 'outside world', including the media. The most obvious block on the participation and representation of older prisoners is a blanket ban on prisoner voting, such as that which continues to exist in the UK (Hodgson and Roach, 2017). Although it was announced in December 2017 that a very small number of prisoners will be permitted to register to vote, and to vote, these plans have not yet been implemented and,

in any event, are estimated to enfranchise only around 100 prisoners who are eligible for release on temporary licence (ROTL) (Bowcott, 2017). In jurisdictions where universal adult suffrage is the norm, it is not uncommon for prisoners to lose their right to vote, either during the period of their imprisonment (as in the UK) or for life (as in some US states). Indeed, in some US states felony disenfranchisement rules mean that the right to vote is lost for life upon conviction of any crime classed as a felony rather than a misdemeanour. That said, prisoner enfranchisement would need to be accompanied by provisions that would facilitate full and informed participation in the democratic process, including specific provision for disabled and ill prisoners.

Thus, older prisoners may be formally barred from participation in democratic decision making via the ballot box, not by reason of age but by reason of their status as prisoners. Although UK case law has made it clear that a prisoner retains all usual human rights except those expressly removed by the sentence of imprisonment (Scott, 2013), the removal of the right to vote reinforces antiquarian concepts of imprisonment as a form of 'civil death', with no political potential vote-winning benefit for policymakers in recognising and responding to the needs of prisoners, older or otherwise.

In the broader political public arena, the needs of older prisoners are becoming increasingly visible within research, publications and campaigns by activist groups and NGOs, leading to the publication of a number of reports which include rich qualitative accounts of older prisoners' own experiences and views (Joyce and Maschi, 2016). This is not, however, the same as participation in democratic political decision making, and the restrictive frameworks of the custodial setting make such participation in the public sphere almost impossible. Although there are strong principled voices advocating against this form of disenfranchisement, many politicians and mass media commentators continue to maintain that the loss of the right to vote is a justified consequence of criminal behaviour. This has been evident in the UK when, despite the insistence of the European Court of Human Rights that prisoner disenfranchisement contravenes the European Convention on Human Rights, the UK government has continued to refuse to implement any changes and has only recently conceded, as a consequence of pressure from other countries within the Council of Europe, that a tiny number of prisoners released on temporary licence (ROTL) would be eligible to register and to vote. The composition of the population of imprisoned older male offenders poses a particular challenge when arguing for representation and participation in decision making, as a substantial proportion of older male prisoners are serving sentences for sexual offences, and sex offenders are not only villified within the prison itself, occupying the lowest levels of the internal inmate hierarchy, but also experiencing social demonisation and stigmatisation (Rickard, 2016). Within Fraser's framework, therefore, not only is the political representation of older prisoners very limited, there is little political will to enable such participation and representation. This may not be simply a consequence of being older, but a consequence of social and political stigmatisation of sex offenders of all ages.

Recognition

Academic and practitioner interest in older prisoners has expanded over the last 25 years, with a corresponding expansion of published research findings and associated recommendations for policy and good practice in the design of penal settings, regimes and activities (Howse, 2003; Her Majesty's Inspectorate of Prisons, 2004; Her Majesty's Inspectorate of Prisons, 2008; Cooney and Braggins, 2010). That said, the scope of this recognition tends to focus on a narrow interpretation of ageing, focusing on medical and care needs. There is little recognition of the diversity of needs and experiences within the penal population of older prisoners and a tendency to assume homogeneity due to older age rather than diversity due to other elements of identity including ethnicity, religious faith, social class and sexual orientation.

The particular medical needs of some older prisoners are being recognised increasingly both as a challenge for prison management and health care, and also as a public health issue (Public Health England, 2017; Ginn, 2012). Older prisoners in the UK and elsewhere have a high incidence of multiple medical conditions and experience a heavy burden of disease (Fazel and Baillargeon, 2011). Chronic diseases are more prevalent in older people in prison than in both people of comparative age living in the community and with younger people in prison (Hayes, 2016). In one of the most influential studies, Fazel et al. (2001) found that 85% of male prisoners aged over 60 had at least one chronic illness recorded in their medical notes, and 83% reported at least one long-standing illness, most commonly including psychiatric, cardiovascular, musculoskeletal and respiratory disorders. More recently, Hayes et al. (2012) found that, globally, up to 90% of the older imprisoned population have at least one moderate or severe health condition, with more than 50% having three or more. Multiple medical conditions are common amongst older prisoners regardless of jurisdiction, with a high global incidence of non-communicable chronic diseases, including heart disease, COPD and arthritis. Social care needs often accompany medical needs, the typical older person in prison having six or more health or social care needs (Hayes et al., 2013). There are, however, significant differences in the needs of older prisoners, and whilst some older prisoners are still able to work, care for themselves and navigate the prison setting, others experience disability, mobility difficulties and cognitive impairment, and need high levels of assistance

Women's average life expectancy is longer than that of men, and so in theory there is a potential problem of women living in prisons until they are very aged indeed with multiple needs. In reality, however, women do not tend to be incarcerated for the types of crime which older men may be, such as historical sexual offences, and the nature of their offending may justify either a community penalty rather than custody, or a short prison sentence. That said, the specific health care and medical needs of older women in prison continue to be under-researched and under-recognised. Imprisoned older women facing a range of challenges including inconsistent access to breast and cervical

screening facilities and very mixed provision of preventive care, older women in prison tending to experience a greater level of functional decline than older male prisoners (Wahidin, 2011; Williams et al., 2006).

Prison establishments themselves have developed specific initiatives for older prisoners, the first special unit for older male offenders being opened at HMP Kingston in the early 1990s but later being closed after a highly critical inspection report. A number of other prisons have created designated wings for older prisoners, though not for women, or adapted cells to cater to the needs of older inmates. Similarly, some prisons have developed recreational, educational and social provision for older prisoners, for whom routine provision focusing on employability, skills development, sports and pre-release preparation may not be appropriate or suitable, but reflecting the fact that older prisoners remain engaged in such activities where they are suitable (Trotter and Baidawi, 2015; Joyce and Maschi, 2016). That is not to say that the development of designated separate provision for older prisoners is always desired by prisoners themselves: research has explored how many older offenders enjoy and benefit from interactions with younger prisoners, but also conversely may welcome the opportunity to have accommodation away from the noise and activities of younger inmates (Wangmo et al., 2017).

Older prisoners were the subject of a review by the House of Commons Justice Committee (2013), which considered oral and written evidential submission from a number of experts and organisations. There was, however, a tendency within this review process to take account of evidence provided by people speaking 'about' or 'for' older prisoners, with older prisoners themselves being far less visible. This reflects an approach to ageing in prison which responds to older prisoners as recipients and users of facilities and services, without necessarily recognising them being as having a role in the design and delivery of those services as informed service users and 'experts by experience'. In relation to older prisoners, there is some overlap between recognition, representation and resource allocation as sites of social injustice, and so to some extent these are interwoven so it is difficult to tease out each individual strand: taken together these three themes combine to highlight imprisonment as a site of social injustice for older people.

Resources

Access to resources, and related issues around just resource distribution, is one of Fraser's key elements of social justice. Issues around poverty, deprivation and disadvantage in relation to older prisoners are complex. For example, prisoners as a whole tend to come from backgrounds of socio-economic deprivation, but it cannot be said with any certainty that the same applies to older prisoners. In the context of sex offenders convicted and imprisoned in later life, they may have been in respected positions of power and trust, which to some extent facilitated their offending and in some cases led to accusations being disbelieved (Allnock and Miller, 2013). Indeed, as convictions of public figures have

demonstrated, 'fame and fortune' provided opportunities for them to meet and abuse young people. However, once the person is imprisoned the nature of the prison system means that although wealthy prisoners may not struggle with, for example, the cost of telephone calls, questions of relative wealth and disadvantage within the prison are less visible, simply because the nature of the regime means that all prisoners eat the same food and share the same accommodation.

Considering access to resources within prisons, it is important to appreciate the current funding context in England and Wales, in which prisons are experiencing ongoing funding restrictions which have had a direct and very negative impact on staff numbers, provision of activities and opportunities and, by extension, on safety for both staff and prisoners (Institute for Government. 2017). There is a core theoretical challenge in justifying allocation of resources to meet the specific needs of older prisoners, beyond the core legal obligations towards all prisoners in terms of food, accommodation and minimum exercise periods, as, with the exception of whole life tariff prisoners, most prison activities focus on addressing offending behaviour, ultimately with a view to release, resettlement and reintegration, the core aim being the reduction of risk and re-offending. Where older prisoners are concerned, there may be no prospect of release, and the traditional vocational focus of prison work and training may be largely irrelevant as the prisoner may be too old, or unable, to enter the labour market on release. That is not to say that training activities are irrelevant and unwelcome, as the research indicates that older prisoners may be keen to engage in educational and training activities (Joyce and Maschi, 2016). However, within a culture of results-based policy decision making, which utilises prevention of re-offending as a core criterion for funding of resources, older prisoners may find their needs being deprioritised in the face of the far larger numbers of younger prisoners incarcerated. This can lead to failings in the provision of suitable accommodation, for example, where the costs of adapting cells for prisoners with special needs may be prohibitive, or the age and design of the building itself makes structural modifications almost impossible. This has been highlighted at HMP Dartmoor, which was built in the early 1800s and is five storeys tall (Ginn, 2012). Prisoners have given accounts of being in their 70s, living with arthritis, but being allocated to a top bunk in a cell, or wheelchair-using prisoners being unable to fit their wheelchairs in through the doorway of their cells (Joyce and Maschi, 2016; House of Commons Justice Committee, 2013). Cells may be situated away from dining facilities and religious, educational and social areas, and in some cases older prisoners have found themselves eating alone in their cells because they cannot access the dining area due to mobility difficulties (Joyce and Maschi, 2016). Prisoners who need support in their daily living activities, such as help in dressing and washing, may not need full-time health care support such as to necessitate admission to the hospital/medical wing, but may also not have the care and support they need and instead rely informally on other prisoners' assistance (Ginn, 2012). This illustrates a contrast in some cases between the support that can be accessed by older people in the community, subject to resource limitations, and that available in prisons.

Access to appropriate health care in prisons has long been a focus of research on the needs and experiences of older prisoners. Concerns have been expressed around inadequate access to screening programmes, including breast cancer screening programmes for older women. Prison regulations, combined with mobility difficulties, may pose challenges to prisoners taking medication on time. In addition, the nature of the prison setting may mean prisoners whose conditions would benefit from gentle and regular exercise, such as walking, may not have that opportunity, and the same can be said of conditions where particular dietary changes are recommended. Facilities and access to resources such as mobility aids vary from prison to prison, and sometimes mobility aids such as walking sticks are deemed to pose a challenge to prison security and safety (Ginn, 2012; Aday and Krabill, 2012).

Resources can be more than simply economic and can include social capital, and resources of care, friendship and relationships. Access to resources of care, affinity and relationship are also significant and Lynch (2012) argues that affective inequality should be added to Fraser's tripartite framework as a fourth dimension of injustice. Older prisoners may experience loneliness and isolation in similar ways to some older people in the community, especially where, as they age, they have outlived friends and family or, pertinently, where either they have ceased contact with friends and family or, as is not infrequent, family and friends have ceased contact with them as a consequence of their offending and conviction (Mann, 2012). Within the prison, older prisoners may not develop their own contacts and friendships as easily as younger men, some of whom may have known fellow prisoners from time on the outside prior to imprisonment, or from previous sentences. That is not to say that older prisoners do not make friends or mix, however, but the dynamics of prison interactions cannot be assumed to be the same as for younger men. There are illuminating accounts in the published research literature of older prisoners being supported by other, often younger, prisoners, and also accounts of friendships between older prisoners themselves. That said, concerns have also been expressed about the possibility of bullying and coercion of older prisoners who need care and support (Stevens et al., 2018) and conversely, the exploitation of younger prisoners by older prisoners who are perceived as powerful within the prison, or whose reputation and outside contacts can be used to coerce younger and vulnerable fellow inmates (Joyce and Maschi, 2016).

Supportive family relationships have long been recognised as playing a significant role in promoting prisoner well-being during the prison sentence and also in preventing reoffending (Farmer, 2017). However, relatively little attention has been paid the experiences and needs of older prisoners and their families, either in terms of the family relationships of older prisoners or prisoners' partners and family members who are older themselves. Older people in the community may benefit from a variety of forms of unpaid caring by family and kin, and the nature of the prison means that the scope for older people to benefit from this kind of unpaid caring is highly limited. Family members can care for prisoners by paying for, and having sent in, books, magazines and hobby

materials, for example, but cannot assist in providing daily personal care, meals and social activities in the way that they might wish to.

Prison visiting rooms can be noisy, populated by young inmates with young partners and young children, and older prisoners may wish for a different kind of setting in which to spend time with their families. That is not to assume that all older prisoners want this, of course, but the focus on family relationships, and provision such as family days and so on, tend to focus on parents of young children, and there is less attention paid for to links, for example, between older prisoners and their grandchildren. In addition, the challenges of visiting prisons which are in rural areas, often without public transport links, have been well-documented, especially the challenges of travelling long distances to visit with young children: far less attention has been paid to the challenges of older people visiting older people. The research has explored the role of grandparent caregivers for prisoners' children, but far less attention has been paid to those older people who visit prisoners who are themselves older. Just as cells and the prison environment can pose problems of access, so can visiting rooms. Where prisoners are deemed low-risk, and approaching the end of their sentence (or serving their sentence in low-security open conditions) family and kin may be able to meet prisoners and spend time with them under the ROTL scheme, but this is far from universal and depends on the nature of the offence, the security categorisation of the establishment and the offender's risk (and indeed, the risk to their own safety in public). Research has explored grandparents caring for prisoners' children, but there is little awareness in the research literature of the role of prisoners as imprisoned grandparents, for example, nor discussion of how grandparenting is negotiated when one grandparent is in prison and the other is not. The sociology of grandparenthood has explored the role of grandparents within families and society but research with prisoners' families still tends to focus on the traditional 'nuclear' family unit centred on prisoners' partners and children, and the restrictions inherent in the prison setting limit imprisoned grandparents' access to family-based support.

The 'shadow' of the prison stretches beyond prison walls, and whilst offenders age in prison, so do their family members on the outside (Codd, 2008). Older prisoners may thus have limited social resources on which to draw outside the prison by reason not only of their age but also of their family, kin and friends. For example, the research demonstrates that prisoners' mothers often continue to visit prisoner long after marriages and romantic partnerships have ended, or after other family members have ceased contact (Codd, 2008). Simple issues of old age may mean that by the time older prisoners are in prison, their parents including their mothers may have died, or they experience the death and bereavement of older family members while in custody, which can be experienced as deeply distressing in the prison environment where the availability and adequacy of bereavement support varies from prison to prison (Masterton, 2014).

Older prisoners' experiences of release, resettlement and reintegration are under-researched and those of older women leaving prison are even less visible

(Crawley, 2004). When older prisoners are released, accessing resources can be challenging, especially if they have few friendship networks and no accommodation to which to return, or have special accommodation needs. Forsyth et al. (2015) found that older prisoners perceived release planning to be non-existent, discovering a reported lack of formal communication and continuity of care, causing high levels of anxiety. Older prisoners indicated high levels of anxiety about the prospect of living in probation-approved premises, but those who went on to live in such premises had their immediate health and social care needs better met than those who did not. Release planning for older prisoners is generally inadequate and there is currently a missed opportunity to address the needs of this vulnerable group. Voluntary organisations which focus on employing former offenders, may not be able to offer appropriate services for older ex-prisoners as they are not seeking a route into the labour market, so employment-focused release and resettlement schemes may not be relevant.

Conclusion

Fraser's concepts of representation, recognition and resource allocation offer a useful starting point for analysing ageing in prison, and for exploring the needs and experiences of older prisoners in terms of social justice. Fraser's concept of representation as political participation means that, by definition, prisoners cannot be said to have access to justice and imprisonment itself is thus socially unjust, echoing the arguments of penal abolitionists (Scott and Codd, 2010). The prison setting poses challenges to ideas of justice and equality, as the nature of imprisonment itself limits elements of freedom of choice, activity, participation and engagement which form the foundations of key human and civil rights and, by extension, a socially just society. In the context of custodial sentences in jurisdictions where prison voting is limited, and even if prisoners legally retain the right to vote ongoing restrictions on contact with the outside world and the media can limit prisoner engagement with political campaigning. Fraser's framework of analysis would support penal abolitionism on the grounds of social justice, not just for older prisoners but for all prisoners.

Within the limitations inherent in a prison sentence, however, there are questions around justice and equality *within* the prison and between older prisoners, staff and visitors which are themselves worthy of further discussion, analysis and exploration. Older prisoners are being recognised increasingly as an identifiable group, although responses to specific needs and age-aware provision of services and facilities caries widely between institutions, with the published research including both examples of well thought-out good practice but also institutional ageism. Older people in prison are a highly heterogeneous population (Mann, 2012) but the literature is still dominated by research with male prisoners, although limited issues of diversity in experience and needs have been explored, most notably in work with older women prisoners (Wahidin, 2011). That said, there are still many aspects of diversity in prison ageing which are under-researched and under-explored, and little attention has been

paid to the nuances of intersectional identities including the experiences of LGBTQ+ older prisoners, ethnicity, faith and class and gender. Further research is needed in order to develop intersectional perspectives which recognise the complexities of older prisoners' identities, some identities pre-dating the prison but becoming amended or augmented by the impact of the consequences of a criminal conviction and a prison sentence. To date, much of the published research has focused on documenting and exploring the needs and experiences of people ageing in prison, and on developing and implementing age-aware provision for older prisoners. By drawing on broader theoretical perspectives, such as those of Nancy Fraser, analyses of the needs and experiences of older prisoners can be developed which go beyond focusing on facilities, resources and programmes, and which situate issues relating to ageing in prison not just within concepts of criminal justice but as key aspects of social justice.

Note

1 For a discussion of the application of Fraser's approach to the criminal sentencing of indigenous offenders, as a form of affirmative social justice, see Anthony (2012).

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