

Human Rights Issues in Later Life

“We should not lavish too much on the old.” (Beveridge 1942)

Main points

- There is no Golden Age of Old Age. Old age has always occupied an ambiguous status throughout history
- Old age is socially constructed: The ‘problem’ of old age has dominated public discourses since the middle of the 19th Century
- Responses to this problem have tended to deny older people dignity and personhood
- The emergence of the Third Age has pushed Human Rights issues to the Fourth Age and the end of life
- Ageism and Human Rights abuses in the care of older people continue to be a significant problem
- They deny older people selfhood and citizenship
- Ultimately most of us will experience old age, through our parents and of course our own.

Introduction

Thinking about old age in Human Rights terms is a fairly recent phenomenon, although one that has gained in legitimacy in health

and social care (Kelly and Innes 2013). This is to be welcomed as, all being well we will all live a long healthy and interesting life into old age and any of us could experience a breach of our Human Rights. Since the middle of the 19th Century, Western industrialised countries have experienced what is known as population ageing. This demographic trend however is not often framed in positive terms. In fact it tends to be viewed in alarmist ways. This matters a great deal. Indeed what Katz (2003) called alarmist demography plays a significant role in how older people are viewed and 'treated' in everyday life. Negative stereotypes of old age and old people abound. Yet it would be easy to think that they are now being replaced by more positive images of old age. There continue to be circumstances in which old people are victims of neglect and violence. These may seem like exceptional, headline grabbing, cases. But there are also less visible examples of exclusion and discrimination – ageism – which arguably deny people citizenship, humanity and selfhood. Framing ageism as a Human Rights issue, enshrined in legislation, means that we recognise the risks, ambiguities and complexities of old age (Minois 1989) without denying older people their basic rights. This also means that everyone is concerned: governments, policy-makers, practitioners and professionals who monitor quality.

The Problem of Old Age

Consider the headlines in the following documents:

<http://forumblog.org/2012/04/the-grey-tsunami-how-to-reap-a-healthy-longevity-dividend/>

<http://www.whichstairliftsuk.com/news/news-items/items/the-financial-burden-of-old-age.html>

<http://www.economist.com/node/13933716>

<http://dl.nfsa.gov.au/module/39/>

Whether or not they seek to change attitudes about old age and its consequences, these documents all adopt the same language. Old age is, variously, a burden for the economy, the viability of welfare systems, or even the ability of emergent economies to cope with demographic changes, or it may be a burden for individuals. These claims are part of the same *discourse*: that old age and burden belong in the same space. Trying to put a positive spin on old age, by defining it as a time of opportunity or a triumph of modern living, does not eliminate the definition of old age as a problem. It simply shifts it. The solutions to this putative problem tend to remain pretty similar: cost containment and shifting the responsibility for its achievement onto individuals.

Population Ageing

It is undoubtedly true that British society has witnessed a great increase in the number of people aged 65+, from 700,000 in 1841 (4% of the population) to 10.3m (17% of the population) in 2012! The projections put the figure for this age group at 16.9m in 2035. Of

course population projections should be viewed with some caution because of cyclical variations in birth rates, but the direction of travel is pretty clear. Being old in Britain is no longer a minority experience and being very old is becoming more widespread too. Indeed what the above figures are masking is the increase in the numbers and proportions of what we might call the very old, ie those aged 85+. Today, 1.4m people have lived at least 85 years, of whom 12,500 are centenarians.

There are several reasons why these changes have taken place (Victor 2005): 1. A fall in the birth rate (until the 1940s), 2. A decline in mortality for all, especially at and around birth. This means we all have a chance to make it into middle and later life. 3. Improvements in sanitation and nutrition, life circumstances and a reduction in industrial accidents and diseases, and 4. Improvements in medical care which can now help prolong lives in middle and late life. The latter, though important, are less significant than general improvements in life circumstances. They are however good at addressing the diseases of long lives. 5. The ageing of babyboomers is contributing to current demographic patterns.

To understand why these demographic shifts should concern us we can turn to Sociology and, in particular, the idea that old age is socially constructed.

Sociological Insights

What does it mean that later life is 'socially constructed'? It refers to the historical and cultural variability of how later life is interpreted, represented, managed and experienced. In short, what it is to be old depends on where and in which historical period you happen to live. We all age (it is not just the experience of the old), right from the moment we are born (Bond et al 2007). This inescapable process means we undergo all sorts of changes, some visible (such as gaining height), some felt (such as experiencing growing pains), some less visible (such as developing heart disease over a period of years). Some of these changes are not life-threatening but they may threaten our cultural position. These changes are not meaningful in themselves; the point is that what happens to our bodies is given *meaning* only in *social* and *cultural* contexts.

However we do give primacy to these biological processes to define and universalise ageing and old age. The reason for this has its roots in the *medicalization* of old age. The emergence of modern social constructions of later life begins in the Modern period, from around the end of the 18th Century and the start of the 19th Century. One of the principal elements of the social construction of older age is the advent of modern medicine, or biomedicine. So old age became medicalised, that is, it became the focus of attention of doctors who became authorities on the ageing process. Such expertise was earned by dissecting bodies and by comparing the bodies of the old with those of the young. The findings from these dissections were published in volumes such as *Clinical Lectures on the Diseases of*

Old Age (Charcot, 2009 [1881]), which promoted a distinct biology of ageing and made old age an object of scientific inquiry. These developments in medicine entailed a number of consequences for our perceptions of old age.

- Old age became perceived as a *biological process* first and foremost, to the exclusion of other indicators, and as a biologically distinctive part of life of the biological organism, open to observation and description. The clinical signs of old age could be shown and described
- Ageing and old age were constructed as *deviation* from the norm, the norm being found in the functioning of young adults' cells, tissues, organs and systems.
- Old age was confirmed as the *precursor* to death (as opposed to death being part of life itself).
- Ageing was understood as inevitable decline towards malfunction, corruption and eventually death, and biological decline was used to explain psychological, social and intellectual decline.

Biological ageing can be used to explain the costs associated with increasing numbers of old people as residing primarily in universal and irreversible biological processes, as residing in the *bodies* of people as they age.

Bodies – as organisms - come to occupy a central role, at the expense of other dimensions of ageing, including identity. The issue of social and cultural inclusion/exclusion can therefore be signposted

here. As I showed earlier, the growth in the proportions and numbers of people aged 65+ and the association of old age with decline combine into the dominant discourse of ageing and old age, from which flow fairly naturally any legitimacy for talking about old age as a problem.

Body and Culture: the Third and Fourth Age

It is now well understood that we live in Consumer Society in which appearance is key to our sense of self and well-being. Ageing increases the risk of disease and death, but it also affects our physical appearance. Looking old(er) is problematic as it sends all sorts of signals to other people – none of which particularly positive. We can certainly postpone or mask the appearance of age, using clothing, cosmetics and surgery. But there will come a point when this will not be possible. However, in the 1990s, Peter Laslett (1996) argued that the experience of being old had been transformed, with the advent of what he termed the Third Age. He presented the Third Age as a time of leisure, independent and fulfilment through consumption following retirement. Retirement was therefore no longer the antechamber of death. We could continue deriving considerable life satisfaction well into our 70s, cushioned by the financial security given to us by generous pensions. There is no doubt that the above model of *active citizenship* struck a chord with many maturing people. Here was a chance to escape negative stereotypes of old age - old age as a time of decline, ill-health, helplessness and rolelessness – whilst having fun and maintaining identity.

Laslett's theory of the Third Age, whilst indeed acknowledging a changing cultural context in which we might envisage our old age, and eliminate the stigma of age, received some criticism. Jones et al (2008), in a review of the Third Age model of ageing, conclude that being in the Third Age is the result of favourable cultural and structural conditions that enabled the emergence of new aspirations and new identities, based on consumption. There are therefore dangers about reconstructing the later years as a time of affluence and new possibilities for all as not everyone can be included in the new Third Age vision of old age. Poorer older people or people with intellectual impairments are excluded. There are two other significant obstacles: the Mask of Ageing and the Fourth Age.

Featherstone and Hepworth (1995) have shown that most older people experience ageing as the imposition of a mask behind which their self, which they experience as ageless, is no longer visible. Onlookers cannot get past people's aged appearance and attribute to older persons characteristics which they experience as demeaning and dehumanising. In other words onlookers see 'the older person', as an objective 'social' category, informed by medicalisation, rather than the individual with his or her own personality traits, life experiences and and sense of identity. This process of depersonalisation is exacerbated as physical and cognitive abilities decrease to any significant extent. Indeed, the Third Age does not last forever. What Laslett did not fully consider in the brave new world of the Third Age is the next stage: the Fourth Age. The Fourth Age is the age of frailty, dementia and proximity to death. According

to Gilheard and Higgs (2000) it is a time of social and cultural death, upon which wider anxieties about decline and oblivion are increasingly affixed. There are penalties for being a frail old person: complete social and cultural marginalisation, spatial exclusion, dependency on others, the loss of control over one's actions, and the loss of self. In fact using Goffman (1968) we could say that the Fourth Age leads to spoiled identity.

Welfare and Later Life

We have already seen that old age is socially constructed and that the emergence of modern or biomedicine contributed in large part to the formation of a new discourse of old age characterised by decline. We have also alighted on the risks that this new discourse posed for older persons: stigma, de-personalisation and objectification. Whilst consumption provides some measure of protection against this discourse, this has serious limitations. I propose we now turn briefly to Welfare, because this is where much of the response to the problem of old age has been articulated.

The creation of 'the elderly'

Until the creation of the Welfare State in 1948, from the middle of the 19th Century, older people were constructed by society as being either helpless, poor but thrifty, and deserving, or, as irresponsible, amoral, lacking virtue and undeserving. Throughout the early years of the 20th Century, however, debates about pensions and retirement took place in reaction to older, punitive forms of welfare such as the

Poor Law. The idea that retirement was a time of hard earned rest, should be available to all and that people should receive some financial support, emerged in this period. In many respects the enactment of the Welfare State was a great advance for older people, affirming their citizenship and making them visible under the official category of 'the elderly', and to them, but it was not without its drawbacks. Beveridge (1942) stated in his welfare report that not too much should be lavished on the old, as children and workers should take precedence. Narratives of the dependent, non-productive older person who is a burden on society were never far from policy decisions and affected debate about the level at which the State Pension should be set (Tulle and Lynch 2010). To this day, there has developed deep anxiety among policy-makers about the proportion and associated costs of older people relative to the rest of the population: the problem of old age!

Another key issue to note here is that services to dependent older people were poorly developed. Despite the abolition of the Poor Law in 1948, old workhouses continued to be used to house residential care homes in particular. Until the 1990s, social work with older people was most often performed by untrained social workers as part of a mixed caseload (Fuller and Tulle-Winton 1996). Intervention was underpinned largely by negative stereotypes of older people and issues of identity maintenance were not given primacy in negotiations and care decisions. Nor were people or their carers involved to any significant extent in decision-making about their future (until the Community Care Act 1995 and the introduction of provisions for

Carers). In fact working with older people was perceived by health and social care practitioners as an unattractive option, too steeped in unpleasant and hands-on bodily care (Twigg 2000), and therefore has often been left to low status workers. It was also under-resourced and pretty unimaginatively organised. But more importantly, cases of neglect and violence drew attention to the particular vulnerabilities engendered by poorly thought out and under-resourced services, insufficiently trained practitioners and the inability of public services to protect the interests of older adults and their relatives. This situation prompted formulations of the problem as manifestations of ageism, in a nod to Butler's (1969) definition, ie discrimination based on age.

ageUK definition of ageism: "Ageism is discrimination or unfair treatment based on a person's age. It can impact on someone's confidence, job prospects, financial situation and quality of life. It can also include the way that older people are represented in the media, which can have a wider impact on the public's attitudes. "<http://www.ageuk.org.uk/work-and-learning/discrimination-and-rights/what-is-ageism/>

The identification of discrimination as a real, well-documented risk paved the way for a transformation in the language of old age and the promotion of anti-discriminatory practice (Dalrymple and Burke 2006).

The subjection of welfare to market principles was also held up as a way of solving the issue of discrimination by giving 'service users' (ie older people and their significant others) greater choice and power. It

was argued that the market would lead to the natural elimination of under-performing providers because nobody would want to buy their product. In fact, the problem has not been eliminated and we can now turn to the consideration of specific Human Rights issues.

Human Rights Issues

I have already alluded to the issue of physical appearance and the reduction of individual older people to categories. More generally naturalising old age by reducing it to its biological manifestations enhances the risk of discrimination because it denies people individuality and turns them into the social category of 'patient' with spoiled identity. More to the point, what I have done thus far is set out the context in which the Human Rights of older people, in particular people entering the Fourth Age, might be at risk. Indeed there are particular moments in old age when this might be the case:

- at the end of life
- if we experience dementia

Brogden (2001) in his book *Geronticide: Killing the Elderly* (there is no equivocation in the title of this book as to its purpose) goes even further. He argues that there is substantial evidence to show that older people have been at particular risk of ill-treatment and death-hastening practices in various cultures and at various historical points, from direct killing to attrition of their physical and mental resources leading to death, either at home, in residential institutions or in hospitals. Citing Do-Not-Resuscitate instructions, Physician

Assisted Suicide in the Netherlands and the infamous murders of Harold Shipman, Brogden puts forward the thesis that in modern industrial societies, it is the routinisation of death and the regulation of older people (for instance in care homes) which facilitates the potential for abuse.

He goes on to show that in the Netherlands, where physician-assisted suicide (PAS) is both tolerated and strictly regulated, abuses nevertheless occur. Surveys of people with terminal and painful illnesses reveal that they would not opt for PAS if they were offered a range of alternative options, including adequate pain management and a strong support framework, including help for informal carers. Patients would prefer to retain their dignity by exercising control over their circumstances. Although some older people do choose PAS, the decision is mostly steered by the physician, which means that the decision-making process is underpinned by uneven power relationships. In cases where patients are unable to make decisions (because they are too ill or they have left no living will), physicians will tend to opt for PAS on behalf of the patient, invoking the patient's condition rather than his or her wishes or that of their immediate relatives. Therefore PAS becomes involuntary euthanasia. In his argument Brogden does not give the other side of the coin sufficient attention: the right of people to refuse life-prolonging treatment, a right which was provided for in the 1948 Universal Declaration of Human Rights.

<http://www.who.int/genomics/public/patientrights/en/>

Kelly (2010) and Kelly and Innes (2013) have documented breaches of Human Rights in the care of people with dementia. Dementia impairs cognitive capabilities and there is substantial literature documenting interpretations of cognitive impairments as loss of selfhood and identity. In other words, people with dementia are often argued to have lost their self, having become empty shells, from which all traces of their past have been erased. Carers of relatives with dementia will often comment that their significant other is no longer the person they used to know. This is of course very confusing and very upsetting. What this draws attention to however, is the very specific risks at which people with dementia are of depersonalisation and abuse. Kontos (2004), in an analysis of a painter's (Willem de Kooning) output after his diagnosis of Alzheimer's, argued that in fact selfhood and intention were still present. They are not necessarily manifested in the type of sentient volition that we normally associate with unimpaired decision-making. Instead they are embedded in our bodies and continue to define us. Another option, which is one adopted by Kelly (2010: 106), inspired by the work of Sabat (2001), is to restore selfhood by adopting a more complex, flexible, contingent and ultimately sensitive and empowering definition of selfhood:

"Self 1 is that which expresses first-person pronouns or identifiers 'I', 'me', 'myself', 'mine' or 'ours'. [...]"

Self 2 comprises one's physical, mental or emotional characteristics and attributes, and also one's beliefs and desires about them. [...]"

Self 3 is the publicly presented aspect of ourselves; the roles we take on and the ways in which we behave in social situations. We have many Selves 3, which we express in different social circumstances; as

parent, friend, professional, carer or cared-for person. [...]"

Using specific articles from the European Convention on Human Rights (1950, extended 2003), Kelly and Innes (2013) have shown how abusive treatment emerges from and contributes to the denial of selfhood, ultimately compromising citizenship. They also propose that an approach to selfhood should enable significant others and professionals to look out for the selfs of loved ones and patients and nurture them, thus achieving a person-centred approach to care (Kitwood 1997) which is really meaningful because it protects the self.

What this work does highlight is the issue of power inequalities (Vincent 1999) that come with being older, frail and therefore vulnerable to abuse. It also highlights the empathy we all need to develop to work effectively and sensitively with people in the Fourth Age and of course to face up to our own old age.

To finish, and to bring all the issues presented above together, please watch this Panorama programme, broadcast in 2012, which documents abuse in a residential care home. Note that you will have to confirm that you are aged 16 and over before you can watch this programme because of the level of violence portrayed therein. I advise you to download the programme onto your desktop rather than watch it whilst streaming.

http://www.bbc.co.uk/iplayer/episode/b01gybn7/Panorama_Undercover_Elderly_Care/

You will need to set aside 30 minutes to watch this.

When you are watching the film, consider the following ECHR articles (Kelly and Innis 2013: 63):

- the right to life (Article 2)
- the right not to be ill-treated or subjected to treatment or punishment which is inhuman or degrading (Article 3)
- the right to liberty and security (Article 5)
- the right to respect for private and family life (Article 8)
- freedom of expression (Article 10)
- prohibition of discrimination (Article 14)

and the following questions:

- what techniques are used to bring Jane's mother's self to life before she was diagnosed with dementia?
- what agency did Jane rely on to choose the home in which she eventually put her mother?
- What historical, cultural, and interpersonal factors would you identify as contributing to the events taking place in this film?

References

Beveridge, W. (1942) *Social Insurance and Allied Services*. London: HMSO.

Bond, J., Peace, S., Dittmann-Kohli, F. and Westerhof, G. (Eds.), (2007), *Ageing in Society* (3rd. Ed.), Sage Publications.

Brogden, M. (2001) *Geronticide: Killing the Elderly*. London: Jessica Langley.

Butler, R. N. (1969). 'Age-ism: Another form of bigotry', *The Gerontologist*, 9: 243-246.

Charcot, J.M. (2009 [1881]) *Clinical Lectures on the Diseases of Old Age*. Cornell: Cornell University Library.

Dalrymple, J. and Burke, B. (2006) *Anti-Discriminatory Practice* (2nd. Ed.), Buckingham: Open University Press.

Featherstone, M. & Hepworth, M. (1995) 'The Mask of Ageing and the Postmodern Lifecourse' in M. Featherstone, M. Hepworth & B.S. Turner (eds.) *The Body: Social Process and Cultural Theory*, London: Sage.

Fuller, R. and Tulle-Winton, E. (1996) 'Specialism, genericism and others: does it make a difference? A study of social services to elderly people.' *British Journal of Social Work*, 26: 679-698.

Goffman, E. (1968) *Stigma: notes on the management of spoiled identity*. London: Penguin.

Jones, I.R., Hyde, M., Victor, C.R., Wiggins, R.D., Gilleard, C. and Higgs, P. (2008) *Ageing in a Consumer Society: From Passive to Active Consumption in Britain*. Bristol: The Policy Press.

Kelly, F. (2010) 'Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care ',

Ageing & Society 30(1): 103-124.

Kelly, F. & Innes, A. (2013) 'Human rights, citizenship and dementia care nursing', *International Journal of Older People Nursing* 8(1): 61-70.

Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

Laslett, P. (1996) *A Fresh Map of Life: Emergence of the Third Age*. London: Palgrave Macmillan.

Minois, G. (1989) *History of Old Age: From Antiquity to the Renaissance*, trans. Sarah Hanbury-Tenison, Oxford: Oxford University Press.

Sabat, S. (2001) *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Oxford: Blackwell.

Tulle, E. and Lynch, R. (2010) Sociological Perspectives on Later Life, Pp 116-137 in Yuill, C. and Gibson, A. (eds) *Sociology for Social Work: An Introduction*, London: Sage.

Twigg, J. (2000) *Bathing: The Body and Community Care*, London: Routledge.

Victor, C., (2005), *The Social Context of Ageing: A Textbook of Gerontology*, London: Routledge.

Vincent, John A., (1999), *Politics, Power and Old Age*, Buckingham:
Open University Press.