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FORUM ARTICLE

New analytical tools and frameworks to understand dementia: what can a human rights lens offer?

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Abstract
The biomedical model has traditionally informed the dominant discourse on dementia and has significantly shaped practitioners', policy makers' and researchers' responses. This model contextualises dementia as a progressive neuro-degenerative cognitive disorder and focuses on deficits and underlying pathology, often overlooking the fact that the person can and should be an active partner in the treatment process. Beginning in the late 1990s, the exclusive reliance on the bio-medical model has come under increasing scrutiny with a growing awareness that by recasting dementia in broader social and more humanitarian terms, much can be done to promote the individual's quality of life. Different frameworks and analytical tools have been forwarded to help us better understand dementia. These include personhood, citizenship, public health, disability and human rights. This review examines the merits of framing dementia as a disability, a citizenship concern and a human rights issue. It highlights some of the potential gains that can arise for the individual in using a human rights model to enhance practice, inform policy and create a more balanced research agenda. The article concludes by arguing that the complexities and magnitude of dementia are such that it requires multiple responses and a broad range of interpretative frameworks.

Keywords: disability; human rights; practice; policy; research; citizenship

Introduction

Although most of us view dementia as a health condition, dementia is also a disability as defined in Article 1 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (UN, 2006) and as defined in many countries' Equality Acts and Disability legislation. Accordingly, while the diseases that contribute to dementia cause brain damage, they also result in the loss of abilities or impairments. These impairments interfere with peoples' abilities to: concentrate, problem-solve, remember, find precise words, recognise objects and people, plan future events, think rationally, and so on. In some instances, as for example with

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frontotemporal dementia, impairments can result in behavioural and personality changes (Jefferies and Agrawal, 2009). Of course, the disability of dementia can be aggravated or alleviated depending on how the physical (architectural and built) and psycho-social environment (attitudes) is manipulated. *Excess disability* can be created by the unintended and sometimes misguided actions of others (Sabat, 1994). Conversely, wellbeing, growth, confidence, participation, dignity, autonomy and independence can be promoted, if we adapt the built environment and eliminate prejudicial nihilistic attitudes.

As questioned by others (Shakespeare *et al.*, 2017), if dementia is a disability, is it not also a disability rights issue in a similar way to how cerebral palsy, motor neuron disease, stroke or indeed any physical impairment such as blindness is a disability rights issue? In the United Kingdom (UK), writers such as Ruth Bartlett, Carol Thomas, Christine Milligan and Jane Gilliard, amongst others, have highlighted the success disability activists have had over the years, exerting pressure on the government for appropriate services, demanding social inclusion and greater acceptance (Bartlett, 2000). But in the context of dementia, a comparable type of rights-based movement has been very slow to evolve (Mittler, 2016; Shakespeare *et al.*, 2017) and despite evidence of human rights breaches in dementia care (Swaffer, 2015), there have been no known cases where governments have been called to account by dementia activists. Dementia activism is only a recent and emerging phenomenon and, interestingly, when the powerful coalition of disabled peoples' organisations came together earlier this century to campaign for the UN Convention on the Rights of Persons with Disabilities (Sabatello and Schulze, 2014), the dementia community was not part of that movement. Since then, dementia advocates have been slow to forge alliances with disability activists, despite the fact that much can be gained by such a coalition (Cahill, 2018).

This absence of a coalition between the dementia community and disability activists has probably occurred for a number of reasons, not least the fact that the individual living with dementia may object to being labelled with another condition – a disability that may cause stigma (Mental Health Foundation, 2015). The disability labelling of dementia could also be perceived as distracting from or diminishing the global quest to find a cure for dementia.

The social model of disability was first developed to explain the experience of people with static physical impairments (Union of the Physically Impaired Against Segregation, 1976) or impairments of the body. One of its main proponents (Oliver, 1983) carefully differentiated between the term 'impairment' (biological deficit) and 'disability' (social construct). An example of an impairment forwarded by Oliver (1996) was lacking part of or all of a limb or having a defective limb. Disability occurred as a result of how the environment and society responded to the impairment (Degener, 2014). Historically, the disability model failed to contextualise impairments of the mind, or those arising due to degenerative illness such as dementia (Shakespeare *et al.*, 2017). As argued in this review, dementia is both an impairment as well as a disability, and the impact the impairment has on the individual may be profound. The social model is said to deny the impact of an impairment and how the latter can significantly affect a person's quality of life (Degener, 2014).

Deal (2003) claims that from the perspective of both disabled and non-disabled people, a hierarchy of impairments exists and the individual with dementia is

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located at the bottom end of this hierarchy. Goodley (2001) argues that in reducing impairments to biological deficits, people with a cognitive impairment experience discrimination. Others contend that there is an in-built bias in disability studies, reflecting ageism and that disability scholars and disability activists are clearly not that concerned about dementia as a disability (Gilliard *et al.*, 2005). In highlighting the limitations of the social model of disability, Shakespeare *et al.* (2017) argue for the utility of a relational model of disability for dementia. However, they acknowledge that it is unclear how such a model can be operationalised.

The citizienship model

An alternate approach for framing dementia and one gradually gaining momentum in recent years is the citizenship model (Bartlett and O'Connor, 2007, 2010; Kelly and Innes, 2012; Bartlett, 2014; Nedlund *et al.*, 2019; Seetharaman and Chaudhury, 2020). Defined as: a status bestowed on those who are full members of a community (Marshall, 1949: 18), the citizenship status confers rights and responsibilities on the individual (Kelly and Innes, 2012) and all those who have citizenship are considered equal and should be afforded the same opportunities. Bartlett and O'Connor (2010) note that the original idea of citizenship dates back to Aristotle and Roman Empire times when the concept first had a moral value. More contemporary views of citizenship, they claim, date back to the French Revolution when the concept was then linked to equality and rights (Bartlett and O'Connor, 2007). Although the meaning of the concept has changed over time, citizenship they contend is fundamentally concerned with the relationships people have with the State during the course of their lifetime and the rules, legislation and policies made by governments that influence peoples' lives (Bartlett and O'Connor, 2010).

The citizenship model is concerned with the use and misuse of power (Bartlett and O'Connor, 2007) and how in society power is afforded to some and not to others. Bartlett and O'Connor (2010: 37) have further expanded on this model by proposing a *social citizenship model* of *dementia*. Social citizenship they contend refers to the 'relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination and to have opportunities to grow and participate in life to the fullest extent possible'.

More recently, the citizenship model of dementia has expanded to incorporate the notion of *everyday citizenship* with recognition of *agency* or the ability a person has to influence their own personal circumstances (Nedlund *et al.*, 2019). Everyday citizenship has been used to shift the focus of the debate away from biomedical representations of dementia, such as diagnostic and post-diagnostic service supports, to seeing the person in their everyday habitual setting, undertaking activities of daily life.

Yet there are limits to the citizenship model when applied to contextualise dementia. First, the traditional view of citizenship assumes that every citizen is equal and has capacity to judge and make decisions to fulfil their obligations and exercise their rights. However, as noted by Bartlett and O'Connor (2007), the assertion of rights and responsibilities may no longer be that feasible for people whose dementia is more severe. Citizenship is generally actively practised, but people living with dementia are not always seen as active citizens because they cannot always

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meet their responsibilities independently. The citizenship model focuses on society and on its socio-political structures that serve to promote or deny an individual's rights as a citizen. In so doing, the model is unable to capture the essence of individuality or the complexities of human experience, especially the relationship between self and society (Bartlett and O'Connor, 2007).

Nor does the citizenship model consider theoretical understandings of embodiment that place the body and embodied practices at the centre of dementia representations (Kontos *et al*., 2017). The citizenship model of dementia also homes in predominantly on first-generational rights, or civil and political rights such as the right to be treated equally before the law and the right to participate fully in all aspects of everyday life. However, people with dementia also need their social, economic and cultural rights (second-generational rights) to be respected and upheld (Cahill, 2018).

The human rights model

Drawing on Degener's (2014) work, where she promotes a human rights model of disability; a model that focuses on the inherent dignity of the human being, similarily, I want to suggest the merit of using a human rights model of dementia to broaden our understanding. While, as stated here, the citizenship model of dementia homes in on civil and political rights, people with dementia also have social, economic and cultural rights that must be respected and upheld. The person needs shelter (accommodation), income (to eat, drink and survive) and stimulation (to promote well-being) through social engagement and cultural participation. The human rights model takes on board both of these sets of rights and in this way is more comprehensive than the social model. It expands on the social model by moving beyond promoting civil rights reform and anti-discriminatory policies to promoting economic policies and social policies. As an analytical tool, the human rights model remains under-developed and to date, it has not been used extensively to interrogate dementia policy, practice and research.

While the social model neglects the fact that people with a disability may experience pain associated with impairment (Degener, 2014), the human rights model acknowledges that impairments exist that can cause pain and distress and may ultimatly lead to an early death. For example, in the context of dementia, cognitive difficulties can impair how a person thinks, acts, behaves and experiences the world. The cognitive impairment can result in fear, embarrassment, frustration, stigma and so on, and can adversely affect that individual's quality of life. In contrast with the social model of disability that regards prevention policy to be problematic since the prevention of impairment and more particularly public messaging about prevention can be seen by some as discriminatory and at the extreme a 'policy of eliminating disabled persons' (Degener, 2014: 23), the human rights model, views prevention policy as critically important. Regarding dementia, primary prevention (the prevention of cognitive impairment), secondary prevention (the timely screening and detection of dementia) and tertiary prevention (risk reduction and delaying dementia through prudent lifestyle choices) (Wu *et al*., 2016) are important policy objectives in many countries' national dementia policy plans (Pot and Petrea, 2013; World Health Organization (WHO), 2017).

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Finally, the human rights model of dementia offers clear guidance for social and political change. It aims to empower the individual to know their rights and claim these rights on an equal basis with others. Specific tools for empowerment are located in a number of human rights instruments, including the UN Convention on the Rights of Persons with Disabilities (UN, 2006). The latter has challenged the long established stereotypical view that impairment causes disability and has drawn attention to the disabling barriers, society erects that make life a lot more difficult for a person with a disability. Each Article found in the UN Convention has direct relevance to the lives of people affected by dementia (Cahill, 2018). For example, Article 3 ensures respect for the inherent dignity of every individual, Article 12 offers legal protection, Article 19 ensures the right to live independently and remain in the community and Article 25 affords the right to health. Many of these Articles are cross-cutting and encompass civil and political rights along with cultural, social and economic rights.

So, if dementia-related practice, policy and research were to be underpinned by a human rights model, where might the emphasis lie?

Practice

First, it would mean that people worried about their memory and other cognitive, social, behavioural, psychological and physical symptoms would have a right to a timely diagnosis. This would mean the person obtaining a diagnosis at a time when the benefits of the diagnosis outweigh its risks (Brooker *et al*., 2014). It would also mean the timely disclosure of the diagnosis to the person and to their immediate family members. Disclosure would ideally be a therapeutic process, rather than a startling event (Prince, 2015), and at disclosure, the person would be told the truth about the dementia, its sub-type, their prognosis and the effectiveness of drug and non-drug treatments. It would mean that following diagnosis, the person would feel comfortable talking to others about their dementia, without fear of being ostracised, set apart and 'othered'.

Practice underpinned by a human rights model would mean that the person would have a right to post-diagnostic services that would be equitable, accessible, affordable, empowering, ethical and dignity enhancing. The person living with dementia would be assigned a designated key worker, link worker, co-ordinator or dementia advisor. Their role would be to advise, support and guide the individual and family members through the labyrinth of health and social care services not always otherwise accessible. Legal capacity would not be determined on the basis of mental capacity assessment but would be seen as decision-specific and the person would at all times be supported in their decision-making.

In compliance with Article 19 of the UN Convention (UN, 2006), it would mean that the person living with dementia would have access to a range of in-home community services, including the personal assistance required to support their living in the community. It would also mean that the person living in residential care would enjoy a good quality of life without being subjected to unfair treatments, including the inappropriate use of chemical and physical restraints. As a citizen and rights holder, the person in residential care could exercise choice and control over their daily life and would have access to a broad range of meaningful and culturally

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appropriate activities. In keeping with Article 9 of the UN Convention, the person living with dementia in residential care would be afforded regular opportunities to go outdoors and enjoy the fresh air (Argyle et al., 2016).

Policy

What format would public policy on dementia take if underpinned by a human rights model of dementia? It would mean that policy makers would at all times be required to understand human rights legislation and cross-check all new and pre-existing dementia policy plans against human rights standards and principles. For example, in the UK, economic, social and cultural rights are guaranteed in international human rights treaties to which the UK is legally bound. This includes rights to the workplace, social security, adequate housing, food, water, health care and education (Scottish Human Rights Commission (SHRC), 2010). In the UK, the Human Rights Act makes the main articles from the European Convention on Human Rights (ECHR) enforceable under British law (Kelly and Innes, 2012). Countries like the UK that sign up to the ECHR and that fail to respect the rights it espouses are breaking international law (British Institute of Human Rights, 2010; Kelly and Innes, 2012).

Accordingly, in formulating policy underpinned by a human rights model of dementia, policy makers would need to be familiar with all regional, national and international legislation on human rights to ensure that all policy plans are in compliance. In addition, and in keeping with the global action plan on dementia (WHO, 2017), policy makers would need to ensure that all government plans on dementia are consistent with 'the UN Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments' (WHO, 2017: 4).

WHO's (2017) global action plan is a useful example of a policy document heavily embedded in human rights principles. In fact, each of its seven cross-cutting principles either implicitly or explicitly relates to human rights. These principles are: (a) the human rights of people with dementia; (b) empowerment and engagement of people with dementia and their carers; (c) evidence-based practice for dementia risk reduction and care; (d) universal health and social care coverage for dementia; (e) equity; (f) multi-sectoral collaboration on the public health response to dementia; and (g) appropriate attention to dementia prevention, cure and care. The global action plan provides an authoritative template for governments committed to upholding and fulfilling the human rights of all those affected by dementia. Countries are expected to establish focal points within government ministries to ensure sustainable funding for dementia. Although the plan is not legally binding and WHO cannot force member states to commit, ministries in all member states must provide progress reports to WHO (three times over the seven years) (Rees, 2017). Civic society, including Alzheimer's Disease International and its members states, must also hold countries and members to account and take action when governments fail to perform (Marc Wortmann, personal communication, 2017).

Some useful examples of government policy firmly embedded in human rights principles can be seen in Scotland's three successive dementia strategies (Scottish

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Government, 2010, 2013, 2017). Noteworthy here is the original policy process that led to the development of the Scottish Charter of Human Rights for Persons with Dementia (Scottish Parliament's Cross-Party Group on Alzheimer's (SPCPGOA), 2009), a document that has informed and guided Scotland's dementia strategies. The development of the Charter was led by people who themselves were diagnosed with dementia. The Charter involved the establishment of the SPCPGOA, a group comprised of the Scottish Dementia Working Group (people living with dementia), members of the Scottish Parliament and civil society, including family members and representatives (SPCPGOA, 2009). The Charter drew on mental health legislation and human rights instruments to guide and inform Scotland's first dementia strategy and to improve outcomes for people living with dementia and their family members. Its aim was to empower the individual by guaranteeing that person and their carers the fullest possible realisation of their rights.

Today, Scotland's third national dementia strategy, 2017–2020 (Scottish Government, 2017), commits to delivering high-quality person-centred support to people with dementia and their family members (McKillop and Kelly, 2019). The Scottish government commits to providing one-year post-diagnostic supports to everyone newly diagnosed (Scottish Government, 2010). Scotland trail blazes in this area and the SHRC has a most useful website on human rights that includes access to training tools on rights (SHRC, 2010).

There are a number of other countries across the world that have developed dementia strategies or have updated their strategies to become more strongly rights-based. For example, rights-based approaches with an emphasis on autonomy, self-determination, independence, equality and choice have begun to penetrate Belgium and Luxembourg's national dementia plans, and the Norwegian, US and Australian more recently updated dementia plans are strongly rights-based (Cahill, 2018).

Research

Internationally there are gross inequalities in the allocation of research funding to different disease groups and dementia research is said to account for only 0.8 per cent of all public spending on research and development (Organisation for Economic Co-operation and Development, 2015). Compared with funding apportioned to cancer, stroke and coronary heart disease, Alzheimer's disease and the related dementias remain significantly under-funded (Luengo-Fernandez and Gray, 2010). UK-based research conducted some years back has demonstrated that relative to the economic impact of the disease, cancer receives 13.5 times more research funding support compared with dementia (Luengo-Fernadez *et al*., 2012). The inequitable allocation of research funding points to the need for further investment in policy analysis and for research that addresses the question of who are the decision-makers when it comes to resource allocation for medical research and why are decisions about research funding allocation often so discriminatory?

Even within dementia research, much competition exists regarding research prioritisation: the contest between the natural sciences and the social sciences and between research methodologies such as randomised controlled trials and

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observational/ethnographic studies continues to prevail. Likewise, competition for funding allocated to prevention, cause, cure and care also continues to prevail. This competition has probably heightened in recent years due to the changing diagnostic criteria for Alzheimer's disease (Alzheimer Europe, 2016), emergent theories on cognitive reserve (Solé-Padullés *et al*., 2009) and further evidence, highlighting the critical role modifiable risk factors play in the aetiology of many dementias (Kivipelto *et al*., 2013).

It has been noted that less than one-tenth of all population-based research into dementia is directed towards the two-thirds or more of cases living in developing parts of the world (Prince, 2015); numbers that are forecast to escalate over coming years. Research underpinned by a human rights model of dementia would mean that a more equitable focus would be placed on different population groups where significant inequalities currently exist cross-nationally. Likewise, a more equitable focus would be placed on studies investigating prevention, cause, cure and care.

Conclusion

Models are tools or aids that can be used to help us better understand complex and diverse phenomena. Although the disease model (biomedical) of dementia is the one with which most people are familiar, other theoretical models, including the social model (disability) and the citizenship model (including social citizenship and everyday citizenship) can also help to broaden the debate on dementia. Every model has its strengths and weaknesses, and none is without limitation. This review has highlighted some of the deficiencies of the biomedical model and some of the challenges encountered in applying the social model and citizenship model to expand thinking on dementia. Building on Degener's work, it suggests that a human rights model may provide new analytical tools that enable us to best capture the full spectrum of a person's overall situation when diagnosed with dementia. The intention here has been to show how the field of dementia studies can benefit drawing on constructs developed from a wide range of areas, including disability studies, human rights studies and citizenship studies. The magnitude and complexities of dementia are such that the condition requires multiple responses and a broad range of interpretative frameworks.

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