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Ending confinement and segregation: barriers to realising human rights in the everyday lives of people living with dementia in residential aged care

Linda Steele[a], Kate Swaffer[b], Ray Carr[a], Lyn Phillipson[c] and Richard Fleming[d]

[a]Faculty of Law, University of Technology Sydney, Sydney, Australia; [b]School of Psychology, Social Work and Social Policy, University of South Australia, Adelaide, Australia; [c]School of Health and Society, University of Wollongong, Wollongong, Australia; [d]Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, Australia

ABSTRACT
Human rights are increasingly being considered in Australian law reform and policy discussions on how to improve the circumstances of people living with dementia in care homes. This article enriches understanding of the views on human rights held by people living with dementia and those who support, advocate and care for them, in order to ensure that law and policy reforms that promote human rights can be meaningfully enjoyed in practice. Drawing on data from focus groups and interviews with people living with dementia, care partners, aged care workers, and lawyers and advocates, this article argues that there is general support among stakeholders for human rights. However, this support was qualified by their acknowledgement of entrenched economic, cultural and sociolegal barriers to the recognition of human rights in the everyday lives of people living with dementia. The article concludes that urgent action is required to transform the cultural, economic and social drivers of ambivalence and resistance to dementia and human rights within aged care and the broader community.

KEYWORDS
aged care; confinement; dementia; human rights; stigma; United Nations Convention on the Rights of Persons with Disabilities

Introduction

Internationally, there is increasing pressure to recognise the human and legal rights of people living with dementia, in part due to the advocacy of people living with dementia and their representative organisations and allies (Dementia Alliance International 2016; Swaffer 2018; see also Swaffer 2014a). Recently, attention has been paid to the rights of people living with dementia in the context of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Devandas-Aguilar 2019). In Australia, the human rights of people living with dementia are beginning to be considered, with a particular focus on improving their circumstances in residential aged care facilities (care homes) (Grenfell 2019; Maker and McSherry 2019; Steele et al. 2019). In Australia, the focus has largely been on reforming legal and regulatory frameworks, notably those pertaining to accreditation of care homes and use of restrictive practices within care homes.

CONTACT Linda Steele linda.steele@uts.edu.au

Complementing this policy level work, this article enriches understanding of the numerous practical barriers to the recognition of human rights in the everyday lives of people living with dementia, in order to ensure that human rights can be meaningfully enjoyed in practice. It does so by exploring the views on human rights held by people living with dementia and those who care, support and advocate for them. Drawing on empirical data, the article explores human rights as they pertain to confinement and segregation of people living with dementia in care homes. While the data confirms general support among stakeholders for human rights, it also illuminates three sets of barriers to realising the human rights of people living with dementia in practice. These are: (i) economic (marketisation of aged care); (ii) cultural (lack of cohesive and supportive communities; stigmatising people living with dementia; invisibility and dehumanisation); and (iii) sociolegal (conflict with risk and safety; incapacity and epistemic negation). In this article we argue that urgent action is needed to address the cultural, economic and social drivers of ambivalence and resistance to dementia and human rights within aged care and the broader community. We posit that central to these actions must be an explicit adoption of the CRPD framework with two goals: in the short term, to improve circumstances within aged care; and, in the long term, to facilitate deinstitutionalisation, in order to transform support and housing for people living with dementia.

The article begins by mapping the human rights of people living with dementia in Australian aged care, focusing on confinement and segregation. It then outlines the methods for the interviews and focus groups and presents key findings on barriers to human rights. In the penultimate section, we situate the findings in social science and humanities scholarship on the social status and experiences of people living with dementia. The article concludes with the implications of the findings for Australian human rights scholars and practitioners.

Human rights of people living with dementia in residential aged care

Historically, people living with dementia have not been seen as bearers of rights (Cahill 2018). Instead, they have been positioned as incapable of exercising autonomy, and third parties have been legally empowered to make decisions in their best interests. However, the past decade has seen increased human rights recognition by reason of the coming into force of the CRPD. As Cahill (2018, 66) notes, the CRPD 'allows for a new and exciting dialogue to emerge, where the framing of dementia is no longer characterized by stigma, fear and exclusion, but rather, where the individual with dementia is viewed as a legitimate part of mainstream society' (see also Harding 2017, 122–24). The shift towards human rights brought about by the CRPD is supported by various UN bodies. For example, in 2015, Rosa Kornfield-Matte, UN Independent Expert on the Enjoyment of All Human Rights by Older Persons, called on 'all States and other stakeholders to adopt a rights-based approach when addressing dementia', stating that '[p]ersons with dementia should be able to enjoy their rights and fundamental freedoms in any circumstances' and that '[t]heir dignity, beliefs, needs and privacy must be respected at all stages of the disease' (Cahill 2018, 3). In 2019, the Special Rapporteur on the Rights of Persons with Disabilities called on States to 'implement a number of measures to improve the rights of older persons with disabilities' (Devandas-Aguilar 2019, 16). She identified a range of human rights issues for people living with dementia, including 'stigma and stereotypes', being ‘assumed to possess weak or even no agency’, and being at greater risk than other older people of ‘violence, abuse and neglect’ (Devandas-Aguilar 2019, 12).

Law, policy discussions, and reforms in Australia are also reflecting this emerging recognition for people living with dementia. For example, the preamble to the Royal Commission into Aged Care Quality and Safety’s (Aged Care Royal Commission) Terms of Reference recognises that ‘some people residing in aged care facilities … have disabilities and Australia has undertaken relevant international obligations, including to take all appropriate legislative, administrative and other measures for the implementation of the rights of people with disabilities’ (Royal Commission into Aged Care Quality and Safety 2018, 1–2). The Terms of Reference also direct the Commissioners to have regard to ‘dignity’ and ‘choice and control’ (3). Earlier inquiries have also mentioned human rights in relation to people living with dementia in care homes (Australian Law Reform Commission 2014, 2017; Australian Senate Community Affairs References Committee 2016). Australia has recently ratified the Optional Protocol to the Convention Against Torture (OPCAT), and civil society and legal scholars are advocating for care homes to be considered ‘primary places of detention’ for the purposes of OPCAT monitoring (see, e.g., Australian OPCAT Network 2020; Grenfell 2019).

Human rights are also becoming increasingly evident in the regulation of service delivery in Australian care homes. The new Aged Care Quality Standards that came into effect on July 1, 2019 have a greater orientation towards human rights than the previous standards, which had been in effect for 21 years. The new standards support the existing Aged Care Charter of Rights, which includes rights to dignity, respect, freedom from abuse, choice, and independence (https://agedcare.health.gov.au/quality/single-charter-of-aged-care-rights; Field 2016, 53–54). Although, it should be noted that the Aged Care Charter of Rights is a soft rights document, in the sense that it is not enforceable.

In this context, the issues of confinement and segregation of people living with dementia in care homes are emerging as particularly significant (Australian OPCAT Network 2020). Confinement and segregation can occur through a variety of means, including restrictive practices (such as chemical, physical and mechanical restraint). They are also evident in the physical congregation of people living with dementia in separate dementia care units (DCUs), which are typically locked or physically isolated from other sections of the care home. On a day-to-day basis, transport and staffing are frequently inadequate to facilitate resident access to medical, social, cultural and recreational opportunities in the community. Similarly, the exclusion of people living with dementia from the full range of recreational and social group activities on offer in care homes and the removal of means of maintaining physical mobility are also commonplace (Steele et al., forthcoming).

The extent of confinement and segregation in Australian care homes and the harms and injustices that they cause have been recently recognised through both the Oakden Older Persons Mental Health Service scandal (Grenfell 2019) and a Human Rights Watch report on chemical restraint (Brown 2019). In its interim report, the Aged Care Royal Commission also identified widespread use of restrictive practices (Royal Commission into Aged Care Quality and Safety 2019b, 193–216; see also 2019a). Confinement and segregation give rise to breaches of various human rights found in the CRPD, including rights to equality, liberty, personal integrity, freedom from torture, freedom from violence, legal capacity, accessibility, independent living and community inclusion, and recreational and social participation (see, e.g., Steele et al. 2019). Indeed, the CRPD presents a bold challenge to confinement and segregation by reason of Article 19, which provides that people with disabilities should have the right to live in the community and have the associated support to choose where they live. At a structural level, this requires deinstitutionalisation and thus the complete transformation of the aged care system (Steele et al. 2019). This is a significant challenge to the current aged care system, which is fundamentally premised on large-scale institutional settings, particularly for people living with dementia.

Recent human rights developments in Australia are promising an alternative to the limitations of domestic law in challenging confinement and segregation. In some instances, confinement might technically amount to unlawful detention (*Public Advocate v C, B* [2019] SASCFC 58) and give rise to breaches of various legal rights that are enforceable in Australian law (Lewis 2019). While these legal rights have the potential to trigger structural change that could prevent the repetition of these harms for people living with dementia, there are profound barriers to this occurring in practice. These barriers are practical (e.g. isolation from legal and advocacy support due to institutional setting), procedural (e.g. legal incapacity preventing standing in court), and economic (e.g. the cost of proceedings) (Australian House of Representatives Standing Committee on Legal and Constitutional Affairs 2007; Ellison et al. 2004; Gray, Forell, and Clarke 2009). Moreover, many of the harmful circumstances arising from confinement and segregation in care homes are beyond legal remedy because they are legally permitted. For example, substituted decision making laws and the doctrine of necessity render confinement and segregation of particular individuals lawful in certain circumstances (Steele 2015, 2017; Australian Senate Community Affairs References Committee 2015). Additionally, confinement and segregation might not be reducible to isolated acts against specific individuals but, rather, might be part of the macro-ordering of services (e.g. the existence and government funding of large-scale institutional care and DCUs) and embedded in the physical design of care homes (DCUs; locked doors and gates) (Steele et al. 2019). In this light, while domestic law is useful to provide opportunities for specific individuals to access remedies for their confinement and segregation, human rights provide an ethical framework to guide the transformation of systems and society, including the structural legal conditions and cultural attitudes that cause confinement and segregation to be deemed acceptable for people living with dementia as a population. The extent to which human rights can be successful in this respect depends not only on the willingness of politicians and policymakers to change legal and regulatory frameworks but also on the engagement of civil society with human rights. This engagement can be gauged, in part, by the attitudes and enthusiasm of community members, people living with dementia, and those who provide advocacy and support.

To better understand the readiness of the Australian cultural and legal context for such transformation, we now turn the discussion to our empirical research, which explores the perspectives of key stakeholders on human rights as they relate to the confinement and segregation of people with dementia in care homes.

Methods

This article reports on the findings of an Australian project involving interviews and focus groups with people living with dementia, care partners, care home workers, and lawyers and advocates. Aged care regulatory officials were contacted but did not respond to our invitation to participate. The interviews and focus groups explored views on human rights related to confinement and segregation in care homes. The project researchers constitute an interdisciplinary team traversing law, public health, dementia design, psychology, and science and technology studies, and include a leading international advocate on rights of persons living with dementia who herself has younger onset dementia (Author 2). The project was guided by an advisory group that included people living with dementia, care partners, care home professionals, and lawyers and advocates for people living with dementia. Ethics approval was granted for the interviews and focus groups by the University Human Ethics Committee.[1]

Recruitment

We recruited a convenience sample of participants by promoting the research via organisations membership or staff in the relevant groups, e.g. aged care organisations, lawyer professional organisations, and dementia advocacy groups. Promotion occurred via email, websites, Facebook, and Twitter and across Australian states and territories.

Establishing free and informed consent

All those who responded to initial promotions were provided with the participant information statement (PIS) and were required to provide written consent to participate. Capacity to consent is recognised as having four key elements: understanding; appreciation; reasoning; and expression of choice (Appelbaum and Grisso 2001). To support free and informed consent for participants with cognitive impairment, a more supported and structured approach was utilised. This included all participants with dementia reviewing the PIS and consent form with the support of a researcher face to face or via the phone. The researcher offered support to talk through each section of the PIS. Capacity to consent was assessed using the principles from the Older Adults' Capacity to Consent to Research (Lee 2010). Where capacity was not evident, the protocol specified the need for proxy consent of a guardian or family carer. All members of the research team were also familiar with the principles of monitoring and establishing consent, assent and dissent when conducting research with people with dementia (Dewing 2002). As such, consent was seen as something that required re-establishment during the research contact. To ensure this, the team reminded participants at the start and regularly during the data collection of their freedom and right to consent, participate or withdraw from the focus group or interview. Participants were also given opportunities to ask for support or to take a break during the data collection process.

It was particularly important to include in the research the views of people living with dementia, by reason of their historical exclusion from contributing to research and knowledge production (Bindels et al. 2014; Brooks, Savitch and Gridley 2017; Ries and Thomson 2019; Schicktanz 2014; see also Dementia Alliance International 2014a, 2014b). In relation to the participant category of lawyers and advocates, 'lawyers' refers to Australian legal practitioners providing legal services to individual clients, and 'advocates'

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[1] This study was approved by the University of Technology Sydney Human Research Ethics Committee: "Safe and Just Futures for People Living with Dementia in Residential Aged Care", UTS HREC REF NO. ETH18-2508.

refers to individuals working in community legal centres and organisations for people living with dementia who are involved in individual citizen advocacy or systemic advocacy.

Our targets for recruitment were as follows in Table 1.

Data collection

We gave respondents the choice of participation in an individual interview (via Zoom or phone) or a focus group (face to face) depending on their preference. This was to maximise participation and to support access issues, which varied for the different populations. Participants were asked questions about their current awareness and experiences of community access and freedom of movement, as well as questions about their views on human rights (the former is reported in a separate article: Steele et al., forthcoming). Our exploration with participants of their views on human rights focused on specific rights contained in particular Articles of the CPRD: accessibility of public spaces and services (Art 9), equal liberty and non-arbitrary detention (Art 14), and independent living and community inclusion (Art 19). Questions included:

- Are we currently meeting human rights in relation to community access? If yes, on what basis? If no, why not?
- What are the barriers and challenges to meeting these rights in relation to community access?
- What changes are needed to meet these human rights in relation to community access?

Interviews ran for approximately 40–60 minutes, and focus groups ran for 1.5–2 hours. To maximise participant contributions, comfort and freedom, the two focus groups, with a mixture of participant groups, were conducted in two stages. The first, on current practice, involved separating participants with dementia and care partners from care home professionals. At the second stage, all participants came together to discuss human rights.

Analysis

The researchers thematically analysed the qualitative data, combining inductive and deductive approaches. Initial coding was undertaken manually by Authors 1, 3 and 4. Each engaged in iterative coding of a small sample of transcripts, identifying themes that emerged. Following discussion of these themes, a coding schema was applied to identify

Table 1. Recruitment targets

Participant group	Target sample size	Actual sample size
People living with dementia	15	5
Care partners	10	19
Care home professionals	15	12
Lawyers and advocates	10	9
Total	50	45

Table 2. Coding schema

Primary node	Code	Examples	Themes
Human rights general agreement			
Human rights, but …	Affordability, funding and resources	Funding and support Not enough service providers or infrastructure	Lack of cohesive and supportive communities
	Capacity or medical condition	Medicalisation	Marketisation of aged care
	Choice and communication	Advocacy Choice to take risks or be in community Communication or advocacy	Perceived conflicts with safety and duty of care
	Community attitudes and knowledge		Stigmatisation of people living with dementia
	Community environment		
	Education of aged care staff about dementia or disability		Incapacity and epistemic negation
	Enforceability		
	Epistemic negation		Invisibility and dehumanisation
	Exceptionality or othering	Ageism Personhood	
	Facility design		
	Intersectionality	Care leavers	
	Lack of understanding or knowledge of rights among care workers, community, or people with dementia		
	Model or systems limitations	Regulatory restrictions	
	Political traction		
	Profit imperative		
	Safety or duty of care		
	Status quo, normalising, or invisibility		
	Technology		
	Valuing disability or age		

whether there was support for a human rights approach to community access and freedom of movement of people living with dementia. Transcripts were uploaded into NVivo 12 to support systematic coding by Author 2. Author 1 then identified themes for discussion in this paper, choosing those themes that were particularly relevant to enhancing human rights scholars' and practitioners' engagement with confinement in care homes. This process is illustrated in Table 2.

Findings

Following extensive recruitment efforts, our final sample of participants consisted of n=5 people living with dementia, n=19 care partners of people living with dementia, n=12 care home professionals, and n=9 lawyers and advocates. Overall, this was consistent with our targets as detailed in Table 1, with the exception of the low number of people with dementia who took part (ten fewer than the target number). Four of the participants living with dementia lived in the community, and one lived in a care home (but not in a locked DCU). All five participants were actively involved with advocacy and community organisations and expressed familiarity with research consent and interview/focus group processes. While level or stage of dementia was not formally established, all participants were assessed as capable of providing written informed consent with none requiring proxy consent. Two of the five participants living with dementia participated in focus groups. The other three participated in interviews—two by themselves, and one with her husband/care partner. All were able to participate with minimal support.

Overall, we found that, across all participant groups, there was support at a general level for human rights for people living with dementia. Lawyer and advocate participants were drawing on formal international legal approaches to human rights, whereas other participants approached human rights in a more general sense of morality, in terms of the treatment of people living with dementia. For example, reflecting the latter approach to human rights, one care partner stated:

> [T]hey should still be allowed to do what every other person has the right to do. So, it's a right that if you live in a supposed free democracy then you have the right to do a lot of things within the law that are not criminal.
>
> You have the freedom of the ability to do that. If they restrict people from doing it then they're taking away something that's a natural right to other people, and they're taking it away simply because they've been labelled with somebody having dementia. (IV 9, care partner)

Despite the general support for human rights among stakeholders, the overwhelming majority of participants across all groups identified barriers on a *practical* level to realising human rights related to confinement and segregation. These barriers can be situated in three categories: economic, cultural, and sociolegal.

Economic barriers

We found economic barriers to the everyday realisation of the human rights of people living with dementia, notably the marketisation of aged care. This was evident in the attribution of clinical, social and human rights failures to the current profit-driven model of service delivery:

> I think the way we've got residential care organised in this country, it's run on a business model, not on a quality of care model. And as long as it's run on a business model and there for profit, one way or another, it's never going to prioritise having the sort of resources that are needed to provide the quality of support and care that people with dementia need. (IV 6, care partner)

The marketisation of aged care arguably suggests the objectification and dehumanisation of people living with dementia because they become a source for extraction of profit. These concerns were voiced by an advocate and a lawyer:

> The places that are running these [specific care homes], they're private businesses. So, they're making money out of that model. Obviously, it's a business model. I don't think the government are looking at other options simply because of the economic factor. (IV 12, advocate)

> [I]t's a business and you've got to make a profit, and locking people up in a ward is a lot cheaper than getting a lot of people to support them and entertain them and do this and do that. It is cheaper. (IV 14, lawyer)

The marketisation of aged care also shows clear economic incentives to continue with human rights abuses—not only by providing poor quality of care but also by sustaining the institutional model at a structural level.

Cultural barriers

A second set of barriers to everyday support for human rights concerns the cultural dynamics of dementia in the broader community.

Lack of cohesive and supportive communities

Participants noted that realising human rights of people living with dementia in care homes was challenging because contemporary Australian communities lack cohesion, with people not being able to seek support from neighbours or family members. A person living with dementia who still lives in the community stated:

> People have become entitled and insular, and they've just forgotten that they've got parents, they've got aunties or uncles, whatever, they've got that old neighbour … My family tell me, 'We're just too busy to pick up the phone, we're just too busy, we've got really busy lives, of course we love you'. (IV 5, person with dementia)

Another person living with dementia who lives in the community and a care partner also expressed these concerns:

> [If] you live alone and you don't have a carer, you're stuffed. … I mean, I live in a retirement village. I chose to do that because I thought it was the first step in eventually having a closer community and, luckily, I've got lots of nosey neighbours who will notice when I'm out at odd times and say, 'Oh, you're leaving very early in the morning every day. Are you intending to do that?' (FG 1, person with dementia)

> And I think that's what it comes down to because I'm a sole carer, right? There's no family on her side or my side that's available to support us, and there are no immediate people in the neighbourhood that are prepared to regularly support us either. Or local friends. (FG 1, care partner)

An advocate stated that, as a society, we need to:

> … get back and embrace a culture where people were prepared to look after their families. Where people weren't mobile, they weren't living on the other side of the world or the other side of the country. People were much more in their local community, and it became a community responsibility to look after the older people, the people with dementia. But I think that kind of congregate care is here to stay for the foreseeable future, for a number of reasons. (IV 11, advocate)

The lack of cohesion and support observed in communities suggests that barriers to realising human rights not only arise in care homes but also in the broader community. This was suggested by a participant living with dementia:

> I often refer to the pub test: what does the ordinary ocker bloke think is okay and not okay, at the pub, at the bar? And my way of educating would be— is to say, 'How would you like to be treated when you're in aged care?
>
> Would you like to still be able to go out and have a beer with your mates? Would you still like to be able to, if you can't do proper big bowls, to do lawn bowls? Would you like to be able to listen to your favourite music, than have something forced on you?
>
> And they're all saying, 'Yes, yes, yes'; well I'm thinking, 'Well this is already not happening'.
>
> I do think there needs to be some public awareness around it, but I'm not sure that the role is just up to the providers of the care facilities. But I think it's all levels of government, community awareness campaigns around what is dementia.
>
> Like, for example, there would be a public outcry if people with diabetes weren't allowed to access the community. So, the difference is perhaps people's— it's the same with mental illness. People's behaviours is often the symptoms of their illness, which scares the community. (IV 5, person with dementia)

The views around lack of cohesive and supportive communities suggest the enormity of the challenge of realising the rights of people living with dementia.

Stigmatising people living with dementia

Participants noted that a further cultural barrier to human rights is that people with dementia are stigmatised. This was evident in the view that the community at large either had an interest in keeping them locked up and out of sight or were simply not aware or did not care about their circumstances, making human rights related to liberty and community inclusion difficult to achieve. One care partner participant put this simply:

> People without dementia don't want the people with dementia coming out. (FG 1, care partner)

Another care partner participant explained this stigma as being associated with fear of dementia:

> [M]any people with dementia can experience the stigma of having a condition that causes behaviours to be different to what people are accustomed to or what people expect. And they become, understandably, fearful of what they don't understand. …
>
> And my heart used to go out to my husband who was such a lovely, affable man and, you know, just didn't have an enemy in the world. And he was a lovely warm, outgoing soul, and to see people regarding him as a potential threat because he was saying hello to a child or talking too long to the dog or whatever, and behaving in a way that people are not expecting or accustomed to, is just very sad when you see that happening. And we can understand how it all happens, but it's the thing about understanding and acceptance of differences and a better educated community … (IV 6, care partner)

This was also corroborated by a care home professional participant:

> And it's also the stigma within the communities. Because a lot of people won't even tell their next-door neighbours that their husband or their wife has dementia. There is still a huge stigma. (IV 18, care home professional)

A lawyer participant noted that this stigma gives rise to exclusion and maintaining a distance from people living with dementia:

> [T]here's these subtle cues that people with dementia aren't welcome into this world. People are trying to exclude it as a way of keeping it away from themselves. (IV 4, lawyer)

This participant also suggested advocacy directed towards rights of older people is situated within a 'healthy ageing' paradigm, which results in exclusion of dementia even within the context of human rights for older people:

> And a lot of older persons' networks want to portray [an image], which is not frailty of ageing. There's all these fine and subtle exclusions and discriminations. … There's so much stigma attached to dementia or mental health or acquired brain injury, but that's sort of part of it, yes, that hiddenness. (IV 4, lawyer)

The pervasive nature of stigma illustrates the significance of cultural views about dementia (which are grounded in complex intersections of disability and age) to the practical realisation of human rights of people living with dementia.

Invisibility and dehumanisation

The invisibility of people living with dementia, and ultimately the common denial of their personhood, was also raised by a number of participants as a barrier to realising their human rights. One advocate participant (IV 12) stated that 'a lot of people don't even think about people with dementia living in aged care facilities'; a lawyer (IV 17) referred to 'some people think[ing], oh well, they've got dementia, and therefore they're sort of written off'; and another lawyer referred to the issues facing people living with dementia as 'hidden', observing that the mention of dementia 'is the end of the whole conversation' because that fact 'they've got dementia [is assumed to be] the full explanation for everything' (IV 4, lawyer).

A care partner participant observed that people living with dementia can be viewed as a burden and a waste:

> But then there's this one size fits all. This idea of the elder person who is no longer productive, therefore a waste and a burden on society. And lives at home for a certain while, but to prevent that person being a burden on the rest of the busy family, well, they're into care and hopefully it'll work out. But it's nothing to do with the human rights of that person and how that person wants to live their last years of life. (FG 1, care partner)

These kinds of ideas illuminate the profound dehumanisation of people living with dementia.

Some participants noted that human rights need to be recognised in ways that acknowledge the diversity of the identities of people living with dementia—e.g. Indigeneity, gender, sexuality, ethnicity, and histories of trauma, poverty, and government control and surveillance. For example, a care home staff participant (IV 15) noted that human rights for those previously in the child welfare system (referred to as 'care leavers' or 'Forgotten Australians') require recognition of the impacts of their childhoods on how they perceive and experience aged care. These impacts include their feelings of fear, trauma and mistrust pertaining to institutional practices common to both child welfare and aged care systems, such as medical intervention, medicalisation, and restraint.

Sociolegal barriers

A third set of barriers relates to the intersection of lay understandings of legal norms and everyday social practices and attitudes about people living with dementia.

Rights in conflict with risk and safety

Another obstacle to realising human rights is that recognition of human rights (notably to liberty and autonomy) would conflict with the need to address safety concerns. One advocate participant stated:

> Well, I certainly think that everyone should have the same right as other people, but again, we have people without disability that are risky and dangerous and perhaps shouldn't have the same rights to freedom if they're going to create an accident or injury or death to themselves or others.
>
> But I think it would need to be assessed on an individual basis, not just a blanket statement to say all people with this stage of dementia can't access these spaces. (IV 12, advocate)

Another advocate recognised that an individual's circumstances vary over time and so safety must continually be considered (i.e. the practical realisation of rights will vary over time):

> So, it would be an ongoing continuum of balancing that decision-making and risk, versus the person's safety. (IV 11, advocate)

This highlights the largely unquestioned nature of safety and risk as bases on which to deny human rights through the continual confinement of all people living with dementia.

One lawyer participant was of the view that practical realisation of human rights might conflict with legal obligations in terms of duty of care:

> Yes, look, I mean I can understand the theories behind it, but I guess that has to be weighed against the safety of the patients, and, at some times, the locking of doors or having secure units is for their own health, because it's very common for the dementia patients to escape.
>
> I think there's a real conflict between their human rights, which I wholeheartedly agree that they have them, but that needs to be balanced against the facility's duty to also keep them safe. (IV 17, lawyer)

In contrast, another lawyer participant, in describing isolation through confinement and segregation in care homes, agreed with the interviewer's characterisation (based on CRPD commentary) of disability-specific detention in DCUs as torture. In the course of doing so, this participant expressed the view that duty of care is interpreted too narrowly so as not to extend to prevention of this treatment:

> Interviewer: Would you go so far to label that torture in the aged care context?
>
> Lawyer: Yes. Yes. If any human being is too socially isolated, then that can be a form of torture. And did you know that, in this country—and you can look up the stat in the newspaper

> reports—more people, in general, die in old age of social isolation, like being too isolated, compared to obesity. It's a real issue.
>
> . . .
>
> Interviewer: [W]hy don't aged care providers see their duty of care extending to preventing torture? Why is it that they see their duty of care to prevent someone being hit by a car or being injured . . . ?
>
> Lawyer: They don't see it that way. … It's because they're running a business. … [I]t's a business and you've got to make a profit, and locking people up in a ward is a lot cheaper than getting a lot of people to support them and entertain them and do this and do that. It is cheaper. (IV 14, lawyer)

This exchange highlights the narrow focus on physical safety, as well as the economic/profit incentives that potentially underpin this narrow interpretation of 'duty of care'.

Some care home professionals noted that regulatory and legislative frameworks are premised on physical risk and thus contribute to organisational-level preferences for confinement and segregation, despite these being barriers to enjoying human rights to liberty and autonomy.

The positioning of duty of care as a barrier to recognising human rights highlights the cultural view of dementia as inherently risky. It also highlights current conceptions of safety as narrow and dehumanising, because they fail to consider as harm the negative impacts of confinement on the physical, mental and personal state of people with dementia. Indeed, this barrier clearly intersects with the cultural barriers discussed earlier, highlighting that perceptions of legal norms, as well as stigma and cultural ideas about dementia, inform the daily dehumanising practices of staff, including the way that they conduct interactions with people living with dementia.

Incapacity and epistemic negation

Both care home and lawyer/advocate participants noted that mental capacity could be a barrier to practical realisation of human rights:

> Interviewer: [Y]ou talked about human rights being about that choice and control. Does that inability to make those choices mean that other rights go or that everything gets forfeited?
>
> Care home professional: Well, it depends … [B]eing a clinician, I think I go back to the seriousness of the affliction of dementia. So, depending on— if you're end-stage dementia, you can't decide for yourself anymore. You can't even know where the toilet is. You won't know where the toilet— you wouldn't even know how to pull your pants down or eat, so who's going to decide for you? That's where my question is. (FG 1, care home professional)

An advocate expressed the difficulty she had grappling with the dominance of the 'capacity' justification in being able to engage with and advocate for people living with dementia:

> [F]rom a legal perspective, the capacity is really a bit of a sticky point in terms of— so, for example, our community legal centre will work with people who have cognitive capacity, or their power of attorney, or their guardian. If it's deemed that they don't have capacity. But as we know capacity is a— yes, a concept, and somebody might— the people I talk to, they do have some capacity. . . .

> [F]or me, I think we need to see the person, and I feel sometimes frustrated that the services is like, 'Well no, I'll need to speak to the power of attorney or the guardian', from a legal perspective. I think the advocates have more scope in terms of working with the person themselves, and I certainly have the scope to work with the person themselves around just listening and what is it that's going on for you. (IV 13, advocate)

She also explained how the inability to see them as people meant their needs were not being recognised and addressed:

> [T]o just be a person. To be a person first. … [B]eing a person, a human, on the planet. And yes, the right to have their say about what they want, and their rights. …
>
> But I genuinely feel that they are so at risk because there is that sense that people don't see them as people. They see them as the diagnosis. And often they talk about their challenging behaviours or their management of their condition or their— without seeing that person. (IV 13, advocate)

These observations demonstrate the tension caused by the way in which medicalised characteristics associated with dementia become a basis on which to deny people living with dementia the ability and opportunity to articulate their own needs. There is a profound tension between in principle support for human rights while seeing incapacity (which is a medicalised characteristic almost inevitably associated with dementia) as a barrier to the realisation of human rights or, indeed, even to the recognition of people living with dementia as humans per se.

To conclude our discussion of the findings, the identified barriers to human rights highlight significant social, cultural and economic dynamics that cast people living with dementia as incapable, dangerous, and burdensome, and ultimately as less than full humans.

Discussion

There is a growing interest in social science and humanities scholarship and advocacy to address the inadequate social status and aged care experiences of people living with dementia, in recognition of their human rights. Findings from this empirical study add to this scholarship and calls for action, by underscoring the importance of addressing broader social and cultural dynamics in which potential human-rights-informed law reforms will be situated.

Firstly, the findings indicate that pathologisation of people living with dementia is a key cultural dynamic that can impede practical realisation of human rights. By 'pathologisation', we mean that changes in memory, cognition, personality and behaviour are viewed dominantly through a medical lens as clinical problems to be managed (see, e.g., Dupuis, Wiersma, and Loiselle 2012), ignoring psycho-social and environmental determinants. Associated with pathologisation, dementia becomes perceived as risky to the self and others (Dreyfus, Phillipson, and Fleming 2018, 108), leading to 'securitised' and hierarchical forms of relating, at the borders of the residential care unit (Graham 2019, 4). As Harbison (2016, 6) notes in the context of elder abuse, 'frequently in the context of addressing mistreatment named as an issue of risk, solutions to abusive treatment exact an unacceptable price from older people with regard to their individual rights and equal social membership' and fail to address, and thus perpetuate, 'ageist societies'.

Pathologisation of dementia also extends to expressions of distress and resistance towards one's circumstances (Boyle 2008, 761)—this being particularly perverse and pernicious in a human rights context, where behaviour that *should* be valued as an expression of one's will and choice is instead persistently seen as a symptom of a medical condition justifying denial of will and choice. Swaffer referred to these expressions of will and choice as 'normal human responses' as part of a campaign she instigated during World Alzheimer's Month in September 2018 to ban the use of the term 'BPSD', an acronym widely used in clinical and aged care settings to refer to 'behavioural and psychological symptoms of dementia' (Swaffer 2019).

Building on this scholarship, our findings also highlight the role of the lack of cohesive and supportive communities in contemporary Australia, the marketisation of aged care, and the stigmatisation of people with dementia in providing a context in which pathologisation can flourish in practice, even while being challenged by academics and advocates through human rights frameworks.

People living with dementia are stigmatised, resulting in 'social exclusion and inequality by depriving persons living with dementia of their human rights, and threatening health, well-being, and quality of life' (P. Kontos et al. 2018, 1). People living with dementia are profoundly dehumanised. They are positioned outside of full personhood by reason of social norms associated with continuity over the life-course of memory, cognition and personality. Given that dementia is associated with old age, social norms of youthfulness compound with norms of cognitive ability. When people living with dementia are perceived as failing to meet these norms, they are dehumanised in a very particular way: by being associated with waste and death. The association between dementia and death is evident in representations of people living with dementia as 'effectively dead' (Argyle, Dening and Bartlett 2017, 1005) or 'zombies'—inhabitants of a liminal zone between life and death (Aubrecht and Boafo 2020; Matthews 2016, 1082; see also discussion of necropolitics and dementia in Robertson and Travalgia 2019). Media and popular culture contribute to degrading and dehumanising understandings of people living with dementia (Cahill 2018, 42–43; Swaffer 2014b) through references to dementia crises and financial burdens of care (Aubrecht and Keefe 2016) or 'apocalyptic demographic discourse' (Petonito and Muschert 2018, 137), which can be exacerbated by neoliberal efficiency and profit-driven approaches to dementia care (Grigorovich, P. Kontos, and A.P. Kontos 2019). Dehumanisation can be exacerbated when people living with dementia additionally experience discrimination by reason of other dynamics of oppression, such as racism, heterosexism, and sexism, or because of the compounding factors of past experiences of institutionalisation, abuse and intergenerational trauma. Dehumanisation effectively negates the valued existence and personhood of people living with dementia and supports their exclusion not merely from public space but from personhood and humanity (Mittler 2016, 3–4; Cahill 2018, 42–43). Our findings highlight the contradiction of participants seeing stigmatisation, dehumanisation and neoliberal marketisation as reasons why human rights might not be enjoyed in practice, even though human rights arguably should elevate individuals living with dementia to a position of equal humanity and personhood.

Epistemic invalidation was evident in the responses of our participants, who illustrated how people living with dementia are denied the status of 'legitimate knowers' who can give meaning to themselves and their experiences (Liegghio 2013, 123; in the specific context of dementia, see Matthews 2016; Young et al. 2019). This epistemic invalidation (Wendell 1996) or epistemic injustice (Fricker 2007) (or, as some argue, 'epistemic violence' (Roper 2018, 2019; Roper and Gooding 2018) or 'symbolic violence' (Beaupert 2018a, 2018b)) in turn authorises others to make decisions on what happens to their bodies and lives and negates the status of these individuals as political actors, capable of exercising resistance to legal and medical authority (Beaupert 2018a, 2018b; Joseph 2014). As Aubrecht and Keefe (2016) also point out, a person with dementia is only taken as credible if they make a safe and 'responsible' decision, according to socially constructed norms of risk and responsibility. Cultural dynamics of pathologisation and epistemic invalidation are evident in participants' concerns about cognitive incapacity as a factor necessarily limiting enjoyment of human rights and individuals' dementia-related behaviour giving rise to concerns about risk and safety that require protection rather than empowerment.

Human rights are often associated with bringing about positive shifts in the political status and cultural understanding of marginalised groups, dislodging negative views and stereotypes. However, our findings suggest that negative views, and associated stereotypes and stigma, surrounding dementia are so deeply engrained in our communities that these views might not be easily dislodged. Such views will inform the interpretations those on the ground (such as aged care workers, dementia lawyers and advocates, and carers) give to human rights and people living with dementia as bearers of human rights.

Implications for Australian human rights scholars and practitioners

Recent international and domestic legal and political developments related to aged care and disability rights have the potential to challenge harmful and unjust circumstances experienced by people living with dementia arising from their confinement and segregation. It is promising that people living with dementia and those who support and advocate for them are, in principle, in favour of human rights, and this should be harnessed. However, discussion of our findings has highlighted the need to address the barriers to the practical realisation of human rights. We now turn to identify six implications of our findings for Australian human rights scholars and practitioners, particularly in light of the opportunities presented by the CRPD and by current political and regulatory developments, notably those pertaining to the Aged Care Royal Commission, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), and the new Aged Care Standards.

The first implication is the need to ensure that engagement with the current Royal Commissions utilises the framework of the CRPD and begins from the premise that people living with dementia are full humans, equal to everyone else. Such an approach should also be taken in any dementia and human rights education directed towards care home professionals, lawyers, and care partners. We must not assume that recognition in the CRPD of human rights specifically for people with disability will shift the social status of people living with dementia. Rather, our findings have highlighted that views about the inequality and discrimination of people living with dementia endure irrespective of human rights, even ten years after the entry into force of the CRPD. Indeed, they underscore the ambivalence and sometimes even resistance to the everyday realisation of human rights by those who support or advocate for people living with dementia. Thus, it is necessary to emphasise equality. Such an emphasis can help prevent logics and ideas about dementia (which might be buried in seemingly apolitical and medical ideas about dementia) being transplanted into the way human rights (notably those articulated in the CRPD) are interpreted and applied in the everyday lives of people living with dementia.

On a related note, it is vital to emphasise the indivisibility of human rights. One may not choose to recognise only those rights that are consistent with or minimally disruptive of the status quo (such as the rights to privacy and recreation); one must also recognise the others (such as the right to liberty, even though it could manifest in the form of freedom to leave the care home or live in the community, potentially leading to abolition of the home care system). (For a discussion of this problem in the context of government inquiries on disability sterilisation, see Steele 2016). To this end, recognition of the right to equality and non-discrimination is essential—there cannot be different thresholds of rights on the basis of dementia, disability or cognitive incapacity.

The second (related) implication is that human rights scholars and practitioners should consider how they can more meaningfully place the voices of people living with dementia and their representative organisations at the centre of their work. This is particularly urgent given that the Aged Care Royal Commission did not include any Commissioners living with dementia and did not foreground their perspectives and expertise in its consultation process. In part, this might involve challenging assumptions about mental incapacity, and safety and duty of care. The absence of involvement of people living with dementia is also evident in the Disability Royal Commission, which suggests that ageism and stigma associated with dementia extend through all strata.

A third implication is that human rights scholars and practitioners should think creatively about how to engage care home professionals and care partners on the CRPD and human rights more broadly. This could be done by reference to the new Aged Care Quality Standards, which could provide incentives (including governance and economic incentives) for care homes to consider human rights in their service delivery.

Fourth, human rights scholars and practitioners should consider how they can improve community views about dementia and support the development of communities that are inclusive and supportive of people living with dementia. In saying this, there is a need to be mindful of the risk of nostalgically romanticising how safe and inclusive the community used to be (noting the historical injustices related to various marginalised populations that are continuing to come to light). In thinking about how to transform communities to create a stronger culture of mutual obligation, human rights scholars and practitioners need to take a cautious approach to existing dementia-focused initiatives. The worldwide Dementia Friendly Communities and Dementia Friends initiatives have not been shown to do more than raise awareness of dementia and so should not be seen as the solution to public education. Indeed, the UN Special Rapporteur on the Rights of Persons with Disabilities recently noted: ‘Of particular concern is the emergence of dementia villages in developed countries, which represent a systemic form of disability-based segregation and isolation’ (Devandas-Aguilar 2019). It is also important to consider intersectionality, in order to build communities that are not only free from discrimination based on disability or age but also address interlocking systems and histories of oppression, including through building more political alliances across different anti-oppression groups working towards more socially just societies (Steele et al. 2019, 19).

Fifth, human rights scholars and practitioners must engage with the political economy of the aged care system and challenge the ways in which regulatory frameworks, funding, and contractual arrangements prevent the realisation of human rights.

Last, while recognition of human rights within care homes is a fundamental goal in the short term, it is vital for human rights scholars and practitioners to advocate for the transformation of the aged care system, away from a model focused on large-scale institutional care. Article 19 of the CRPD is unequivocal in its demand for deinstitutionalisation, such that people with disability can meaningfully choose where in the community they live, receive support to make that choice, and receive appropriate support to enable them to live where they have chosen (see Steele et al. 2019). It is concerning that the Aged Care Royal Commission's interim report, while recognising the need to strengthen and expand community living and support options, does not explore (let alone recommend) deinstitutionalisation. People living with dementia continue to be institutionalised en masse, notwithstanding that this institutional model is a major structural barrier to the full realisation of their human rights.

ORCID

Linda Steele http://orcid.org/0000-0001-6944-7888

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