



Disability Human Rights and Reparations for People with Dementia in Long Term Care Institutions: An Empirical Study

COLLECTION:
DISABILITY HUMAN
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RESEARCH

LINDA STEELE 

KATE SWAFFER 

*Author affiliations can be found in the back matter of this article



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ABSTRACT

This article argues that reparations are a necessary response to human rights violations experienced by people living with dementia in long term care institutions (LTCI). In these settings, people living with dementia experience a range of human rights violations including institutionalisation, segregation, detention, violence, and neglect. As an important contribution to disability human rights scholarship, the article presents empirical findings from a research project which gathered perspectives on reparations from people living with dementia and their support networks. It reports on six key dynamics facing people living with dementia in LTCI which necessitate reparations: lack of human rights recognition, failure to recognise harm, invalidation of experiences of harm, denial of equal access to justice, absence of accountability, and lack of systemic change. The authors consider the implications of these empirical findings for disability human rights scholarship on access to justice and independent living.

CORRESPONDING AUTHOR:

Linda Steele

University of Technology
Sydney, Australia

linda.steele@uts.edu.au

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1. INTRODUCTION

People with dementia experience human rights violations in long term care institutions (LTCI). Violations include physical and sexual assault, neglect in medical and personal care, segregation from other residents and the wider community, restrictive practices, detention, and institutionalisation. Wide-ranging and ongoing impacts of these violations on people with dementia include physical and psychological injury, increased dependence and disablement (such as incontinence and physical immobility), exacerbation of existing impairments, loss of dignity, and death (Hardwick et al. 2022).

Governments have not systematically redressed these human rights violations. As a verb – how we use ‘redress’ in this article – ‘redress’ means to repair a wrong. Under domestic laws (laws made by a government), redressing institutional harm often involves monetary payments, provision of psychosocial support, future undertakings, or apologies; these are pursuable via civil litigation, complaint processes, and administrative schemes for victims of crime. However, governments have not ensured these pathways are accessible to people with dementia and their care partners and family members (Burns 2021; Harding 2017). Judicial remedies can be: (a) inaccessible due to cognitive, physical and financial barriers to legal information, lawyers and courts and lengthiness and complexity of proceedings, (b) ineffective due to limited capacity of judicial remedies to address systemic and structural conditions and ableism and ageism underpinning calculation of monetary remedies, (c) impossible if a person with dementia dies and families are too overcome by grief to pursue remedies, and (d) even inapplicable when harm is legally permitted (such as segregation, restrictive practices and detention) (Burns 2021; Steele & Swaffer 2022).¹ Complaint processes can also be inaccessible, punitive, and retraumatising (Wadiwel et al 2022). Another pathway sometimes available is a redress scheme designed specifically for harm experienced in a particular institutional setting (e.g., child welfare institutions) or policy context (e.g., removal of Indigenous children) (Gallen 2023). There have been no such redress schemes introduced for LTCI.

International human rights norms provide an alternative approach to redressing harm in LTCI: reparations. Reparations apply to ‘gross human rights violations’ (UNGA 2006) such as torture and systematic discrimination. Thus, in this article, ‘reparations’ refers to righting wrongs that constitute human rights violations. Reparations can involve multiple practices including compensation, restitution, rehabilitation, memorialisation, apologies, and law reform (Garcia-Godos 2020). Reparations take a ‘two-track approach’, addressing both impacts of past harm on individuals and systemic measures to prevent further perpetration of harm (Roach 2021: 88). UN Committee on the Rights of Persons with Disabilities’ Guidelines on Deinstitutionalization, Including in Emergencies (2022) (‘UN Deinstitutionalization Guidelines’) stipulate reparations are required for human rights violations associated with institutionalisation.

This article contributes empirical evidence to support reparations for people with dementia in LTCI. This evidence is drawn from qualitative research conducted in Australia with people with dementia, their care partners and family members, professional and volunteer advocates, and lawyers which identified a clear preference for a reparative approach to redressing human rights violations in LTCI (Steele, Swaffer et al. 2023). Based on these findings, we argue reparations are a necessary dimension of responding to harm in LTCI because they validate and ameliorate individual experiences of harm and provide foundation for recognition of human rights of people with dementia as a group.

We begin with a brief discussion of harm in LTCI as human rights violations and introduce reparations as an approach to responding to these violations, situating this discussion within disability human rights scholarship on access to justice and independent living and critical dementia studies and critical disability studies scholarship. Next, we introduce our research methods. We then discuss project findings by focusing on six dynamics which necessitate reparations for people with dementia in LTCI: lack of human rights recognition, failure to recognise harm, invalidation of experiences of harm, denial of equal access to justice, absence of accountability, and lack of systemic change. We then discuss implications for disability human rights scholars, beginning with three positive considerations (realising human rights,

¹ Judicial remedies may be less limited in jurisdictions with remedial provisions for human rights or Constitutional rights violations enshrined in domestic law (Roach 2021). But such options are not available in Australia, which is the jurisdiction of the empirical research discussed here.

transforming understandings of harm, and challenging economic dynamics of human rights violations); and two tensions requiring further exploration (inaccessible domestic justice systems and endurance of LTCI).

The article contributes to disability human rights scholarship in three key ways. First, it broadens understandings of disabled peoples' right to access justice beyond conventional domestic legal pathways. Second, it highlights reckoning with past injustices of institutions as central to realising a future of independent living. Third, it contributes to emerging scholarship on disability and reparations by providing empirical insights into how disabled people themselves understand what it means to redress human rights violations. Additionally, the article advances scholarship on human rights of older persons and those with dementia beyond establishing occurrence of violations to detailing reparations as one important response to such violations.

2. BACKGROUND: PEOPLE WITH DEMENTIA, HUMAN RIGHTS AND REPARATIONS

This section introduces harm in LTCI as human rights violations and reparations as a necessary response to these violations, situating this discussion within disability human rights scholarship on access to justice and independent living.

2.1. HUMAN RIGHTS VIOLATIONS IN LTCI

People with dementia have led advocacy efforts to have their rights as disabled people recognised, pursuant to UN Convention on the Rights of Persons with Disabilities (CRPD) (Batsch et al. 2017; Rochford-Brennan & Jenkins 2019; Swaffer 2018). These include rights within LTCI and rights within the community in a context of LTCI deinstitutionalisation (Dementia Alliance International 2022).

Existence of LTCI violates the right to independent living and community inclusion (CRPD: Art 19). Governments thus have an obligation to provide support and resources for individuals to live in the community and to 'adopt a strategy and a concrete plan of action for deinstitutionalization' (UN Committee on the Rights of Persons with Disabilities 2017: 11). People with dementia experience human rights violations within LTCI. Their rights to equality and non-discrimination, equality before the law, and liberty (CRPD: Arts 5, 12, 14) are violated through substitute decisions and use of force and restraint in their admission and detention in LTCI. Rights to equality and non-discrimination, freedom from violence, equality before the law, torture, liberty, physical and mental integrity, and health (CRPD: Arts 5, 12, 15, 16, 17, 25) are violated through their experiences of restrictive practices and unlawful physical and sexual violence. People with dementia segregated in 'secure dementia units' have reduced access to activities, healthcare, outside environments, and are excluded from the wider community, which violates rights to health, rehabilitation, and recreation (CRPD: Arts 25, 26, 30). Barriers to accessing justice for such harms violate rights to equality and non-discrimination, equal access to justice, and freedom from violence (CRPD: Arts 5, 13, 16).

Dementia human rights scholarship has focused on occurrence of human rights violations in LTCI. Some work explains why human rights apply in LTCI and how a wide range of violations occur (Cahill 2018; Green et al. 2022). Other contributions focus on specific violations, particularly related to substitute decision-making, restrictive practices, and detention (Grenfell 2019; Steele, Phillipson et al. 2023). Establishing relevance of human rights in LTCI unfortunately remains necessary because ableist and ageist logics continue to justify denying people with dementia are human rights subjects (Cahill 2018).

Disability human rights scholarship provides important insights supplementing dementia human rights literature. Work on the right to independent living focuses on legal and systems logistics of deinstitutionalisation, and on rights and access to housing, supports, and mainstream services within community settings (Brennan 2017; Palmisano 2017; Rimmerman 2017). Scholarship on the right to access justice highlights barriers to domestic justice systems for disabled people and importance of improving accessibility, staff knowledge and competency, and reasonable accommodations (Flynn 2017; Lawson 2016; Ruškus 2023). This work provides some strategies for addressing human rights violations in LTCI such as developing better community-based accommodation and support for people with dementia, enhancing access to domestic justice

2.2. CONTEXTUALISING DEMENTIA HUMAN RIGHTS VIOLATIONS

People with dementia are dehumanized through an ableist hierarchy of normalcy (Lewis 2022). They are positioned as falling short both of norms of younger, capable, productive citizens and norms of successful and healthy aging, and in turn are understood as dehumanised, burdensome and disposable (Chelberg 2023; Herron et al. 2021). This socio-cultural status of people with dementia enables and justifies a range of harms including coercive and violent interventions, neglect of personal and medical care, social isolation and segregation, and denial of voice and participation (Chelberg, 2023; Loughnan 2022; Spivakovsky & Steele 2022). Dehumanising people with dementia also provides opportunities for economic extraction such that their human rights violations are both a source of harm to them and a source of profit to others (Steele, Phillipson et al. 2023). In this context of dehumanisation, LTCI is viewed as necessary and non-violent and thus difficult to comprehend as a place of violence and extraction in need of political intervention or abolition (Herron et al. 2021). People with dementia are not a homogenous group, and their relative targeting for human rights violation is shaped by other dynamics of oppression including sexism, racism, and heterosexism (Sandberg & Ward 2023), as well as settler colonialism and globalisation (Fletcher 2024).

Some dementia human rights violations are associated with ableist relationships between law, capacity and violence. Guardianship, mental health and medical laws are grounded in medicalised understandings of mental capacity which enable third parties to decide on interventions in their bodies and lives – such as restraint, psychotropic medication, and detention in LTCI. These interventions are forms of ‘disability-specific lawful violence’ which, despite being without consent of persons with dementia, are viewed as benevolent, therapeutic, non-violent and just and render people with dementia illegible as victims (Chelberg 2023; Spivakovsky & Steele 2022).

Therefore, complex socio-cultural and legal dynamics of dementia human rights violations underscore the deeply entrenched structural and systemic nature of these violations and profound challenges to people with dementia being recognised as victims worthy of redress. This provides further impetus for exploring reparations.

2.3. REPARATIONS FOR HUMAN RIGHTS VIOLATIONS IN LTCI

Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law (also known as ‘van Boven Principles’), provide non-binding guidance to governments on reparations as one dimension of responding to ‘gross violations of human rights’ (UNGA 2006). ‘Gross human rights violations ... affect in qualitative and quantitative terms the core rights of human beings, notably the right to life and the right to physical and moral integrity of the human person’ (van Boven 2009). People with dementia experience gross human rights violations in LTCI because these violations are widespread, connected to legal and structural dimensions of LTCI, and grounded in structural discrimination including ableism and ageism (Steele & Swaffer 2022: 77). Pursuant to van Boven Principles, reparations can involve diverse practices including compensation, rehabilitation, public education, apologies, institutional and legal reform, and memorialisation (UNGA 2006: 7–9). An example of reparations for institutional violations is the reparations program for survivors of Chicago police torture and their families which includes monetary payments, counselling, and job training for survivors, free education for family members of survivors, and memorialisation and public education targeted at the broader community (Losier 2018).

Reparations have significant potential for redressing harm experienced by people with dementia in LTCI. Reparations are not dependent on contravention of domestic laws but rather on gross human rights violations (which are often legally or socially sanctioned). For example, restrictive practices violate multiple human rights but are legally regulated rather than prohibited by domestic law (Spivakovsky & Steele 2022). Moreover, reparations extend to transforming laws and systems, and thus can be a vehicle for necessary structural change such as deinstitutionalization and prohibition of restrictive practices.

Articles 13 and 19 of CRPD have each been interpreted to include reparations. International Principles and Guidelines on Access to Justice for Persons with Disabilities specifies states should ensure ‘effective remedies ... for human rights violations, including right to be free from disability-based discrimination and rights to restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition’ (Aguilar 2020: 24). These remedies should be ‘enforceable, individualized and tailored to meet the needs of claimants’, ensure ‘victims are protected from repeat violations of their human rights’, and ‘[a]ddress the systemic nature of human rights violations’ (Aguilar 2020: 24). UN Deinstitutionalization Guidelines also stipulate governments ‘should provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities who wish to seek redress, reparations and restorative justice, and other forms of accountability’ in relation to institutionalisation (UN Committee on the Rights of Persons with Disabilities 2022: 17). However, disability human rights scholarship on these Articles has not yet fully explored reparations either doctrinally, conceptually, or empirically.

Scholarship on disability and reparations focuses on mainstream reparations processes in post-conflict and postcolonial contexts (Clark 2023; Soldatic & Samararatne 2020) and international criminal law (Pons et al. 2022), with a focus on disability inclusion and accessibility. There is activism and emerging scholarship on reparations for people with disability including in contexts of forced psychiatric treatment (Katterl et al. 2023; Minkowitz 2021) and institutionalisation (Minkowitz 2023). Our research contributes to this body of work in-depth empirical analysis of experiences and perspectives of disabled people themselves regarding reparations in disability-specific contexts (Steele & Swaffer 2022; Steele, Swaffer et al. 2023).

3. METHODOLOGY

This project aimed to gather empirical insights on redressing harm experienced by people with dementia in LTCI. Its purpose was twofold: to initiate a scholarly field on dementia and redressing harm, and to inform advocacy and policymaking on redressing harm in LTCI. It coincided with a period of significant change in Australian LTCI, including relevant public inquiries and development of new LTCI legislation. Although a small-scale study, our methodology offers a guiding framework for larger studies on redressing human rights violations experienced by disabled people.

3.1. DISABILITY HUMAN RIGHTS METHODOLOGY

The project utilised a disability human rights methodology (see Arstein-Kerslake et al. 2020). This parallels inclusive and participatory research approaches advocated by other scholars across disability human rights, critical disability, and dementia human rights studies (e.g. Diaz-Gil et al. 2023; Fisher & Kayess 2019; Veitch and Rinaldi 2024). Such methodologies challenge ableism in empirical inquiry and knowledge production, resist paternalistic and discriminatory approaches, and actively involve disabled people in research impacting their lives: a principle and codified in CRPD. Our specific methodology was based on three key principles outlined by Arstein-Kerslake et al. (2020): prioritising disabled research leadership and participation, responding to specific rights concerns of the disability community, and developing and effectively communicating accessible and impactful outputs.

The project was initiated and led by people from the disability community, and people with dementia were involved throughout and in various capacities. One of the two project investigators (Swaffer) is a person with dementia and an international dementia rights activist. During project funding application development, people with dementia and Disabled People’s Organisations were consulted. The project was also supported throughout by People with Disability Australia and Dementia Alliance International and a paid advisory group comprising people with dementia, care partners and family members, disability and dementia rights advocates and lawyers, and social justice lawyers. People with dementia were also involved as focus group participants.

We responded to known human rights concerns amongst the disability and dementia community: access to justice and deinstitutionalisation of LTCI. Finally, the project was designed to develop a set of ‘Dementia Reparations Principles’ for practical use by policymakers, lawyers, and advocates. This ensured research informed action. These Principles and associated explanatory materials were shared with relevant public inquiries, and various government ministers and agencies. We also participated in consultations regarding new Australian LTCI legislation.

Beyond Australia, outputs were shared with relevant overseas inquiries, Disabled People’s Organisations, and key individuals in the UN human rights system. We also communicated findings in accessible ways to people with dementia (e.g., an Easy-Read summary of project findings and webinars involving paid speakers with dementia) so they could apply this knowledge to their personal lives or advocacy work. Our ongoing efforts to share project outputs reflects our commitment to community accountability and ‘sustainable and transformational change beyond the temporal parameters of research projects’ (Veitch & Rinaldi 2024).

3.2. QUALITATIVE METHOD

The project involved qualitative research utilising focus groups. Centering voices and perspectives of people with dementia through focus groups resists a paternalistic and passive approach to this group and recognises their agency and expertise. Focus groups provide individuals ‘[i]ncreased control over level of participation since there is less pressure to contribute than in individual interviews’ and can promote feeling ‘supported and empowered in a group with others who share similar experiences’ (Bamford & Bruce 2001: 141). Focus groups were also ideal because they enabled individuals to apply personal and professional experiences to discuss concepts and issues.

3.3. ETHICS

The project received approval from University of Technology Sydney Human Research Ethics Committee and was designed with particular attention to specific considerations relevant to research with people with cognitive impairment and experiences of harm. Easy-Read recruitment information was provided to people with dementia. Due to subject matter sensitivity and importance of maximising psychological safety, a trained counsellor supported focus groups in which people with dementia and care partners and family members participated. All participants were paid the rate for research participation recommended by People with Disabilities Australia.

3.4. RECRUITMENT

Four categories of participants were recruited (Table 1 below). One category was people with dementia, which included people who did not necessarily live in LTCI or have personal experience of harm but whose lived experience of dementia provided valuable perspectives on accessibility and inclusion. Three other participant categories were included due to their role witnessing or advocating against harm in LTCI and for human rights of people with dementia. These consisted of care partners and family members of people with dementia who have been harmed in LTCI, volunteer advocates (individuals working in an unpaid capacity to advocate for improved rights for people with dementia and who generally had experience as care partners or family members), and professional disability rights, older people’s rights and human rights advocates and lawyers. All participants were over 18 years of age.

Recruitment occurred through a project website, social media, and emails to relevant legal, advocacy, and support organisations. Participants in the first stage of focus groups were invited to participate at the second stage, but participation in both was not mandatory. Targeted recruitment of people with dementia was done through Dementia Alliance, People with Disability Australia, Dementia Australia, and StepUp for Dementia. Advisory group members were invited to participate in focus groups. There was separate recruitment material for each group and people with dementia were provided with Easy-Read information and consent forms, with consent sought for each focus group stage. Table 1 explains the final participant sample.

	FG1	FG2
People with dementia (PLWD)	6	9
Care partners and family members (CPFM)	13	11
Volunteer advocates (VA)	8	9
Professional advocates and lawyers (AL)	11	10
Total	38	39

Table 1 Research participation.

3.5. DATA COLLECTION AND ANALYSIS

Data collection and analysis occurred in Australia across two focus group stages. Focus group stage one (FG1) took place between November 2021 and February 2022. These focus groups first explored participants' understandings of what 'redress' means as a verb (i.e., what might be necessary to right wrongs in LTCI), and whether redressing harm experienced by people with dementia in LTCI was necessary. Because all participants supported redressing harm, discussion then explored ideas about precisely what should be involved in redressing harm for specific victims and for impacted care partners and family members, including if the victim is deceased. Participants were also asked about redressing harm at community and structural levels, including via the dementia and broader Australian communities, the LTCI sector, and legal and systems reform. Participants then discussed specific details around possible practices and processes of redressing harm. Each of the 11 FG1 sessions covered the same topics but were tailored to specific groups to enhance safety and inclusivity.

FG1 recordings were transcribed, deidentified, and data were thematically analysed using a coding schema to identify dimensions of 'who', 'what', 'why', and 'how' of redressing harm jointly developed by the authors. FG1 data were coded by author Steele. To ensure rigorous analysis, a research assistant who was not involved in FG1 coded all transcripts, and regular meetings between this assistant and author Steele discussed any variations and alterations to the coding schema. Analysis of FG1 data informed development of a set of draft principles, initially titled 'Dementia Redress Principles'. These were informed by analysis of international human rights norms on access to justice and reparations and analysis of design and lived experiences of other Australian redress schemes.

Second stage of focus groups (FG2) involved workshopping draft Dementia Redress Principles. Upon advice of the advisory group, participants could opt to participate in a session only with people from their participant group or with individuals from a mixture of participant groups. Eight FG2 were held during July and August 2022, each with the same structure and seeking participant feedback on draft Dementia Redress Principles. FG2 data were thematically analysed to inform changes to specific principles, and rigorous coding and cross-coding process utilised for FG1 was again employed. FG2 data were then used to revise draft principles as final 'Dementia Reparations Principles'. This new title reflected participants' preference for a human rights-based, reparative approach to redressing harm.

4. FINDINGS

This section reports on empirical findings on necessity for redressing harm experienced by people with dementia in LTCI. For data reporting, de-identified participants were allocated a code and a number reflecting the participant group to which they belonged (see [Table 1](#)) and order in which they registered to participate. For example, PLWD02 indicates 2nd person living with dementia to register.

All participants supported a reparative approach to redressing harm. Six dynamics emerged as reasons for redressing harm and reflect participants' interest in a balanced focus on past and future, individual and collective/structural dynamics; and impetus for harm prevention. The following section discusses six these dynamics in the current circumstances facing people with dementia in LTCI which necessitate reparations: lack of human rights recognition, failure to recognise harm, invalidation of experiences of harm, denial of equal access to justice, absence of accountability, and lack of systemic change.

4.1. LACK OF HUMAN RIGHTS RECOGNITION

Participants identified need to redress harm because of present lack of human rights recognition for people with dementia in LTCI. PLWD03 explained how people with dementia need to fight for rights recognition: 'Is it that we have to run behind the care providers and say, this is my right ...? No, it shouldn't be that way.' Participants also identified the widespread denial of human rights at the confluence of dementia and LTCI. VA03 explained: 'people just say, 'Oh, that person has dementia.' [...] it's as though all their rights have just gone out the window and it's just seen as a societal norm.' VA07 argued redressing harm was needed to recognise people with dementia's human rights to 'valu[e] the individual and the human rights, everyone [...] is deserving of human rights recognition.' Therefore, reparations are necessary for human rights recognition.

4.2. FAILURE TO RECOGNISE HARM

Participants identified need to redress harm because of failure to recognise harm in LTCI. They described diverse harms of varying scales, temporal duration, legality, and visibility. PLWD03 explained: 'It can be verbal. It can be physical. It can be sexual. It can be lots of things. Neglect our food, neglect of taking care of the person.' CPFM03 spoke of restraints used on his brother in LTCI including being parked at a dinner table and restrained so tightly around his wrists that a complete circumference bruise formed. Harm can be fleeting or apparently minor. PLWD01, who lived in a LTCI, told of a nurse ringing a bell near her: 'I have sensory problems and I went [...] "Please don't do that. [...] I've got sensory problems." So what did she do? She rang it again. And she said, "Do you mean like that?" [...] And I was beside myself and they said, "What are you making such a fuss for?"' CPFM08 described some harm as 'covert' and 'subtle' and difficult to identify. CPFM01 spoke of her parent becoming incontinent while in a LTCI because of a failure to provide support with toileting. CPFM13 spoke of no stimulation in her husband's dementia care unit ('no recreation, no music') and no access to outdoor areas ('built around busy roads, car parks, no gardens. And the elderly are sitting inside with no sun, no vitamin D, as prisoners').

Many participants spoke about normalisation of harm in LTCI. PLWD05, for example, stated 'what we are talking about as abuse, a lot of people would not see it as abuse. A lot of people say, well, that person's got dementia, they need to be locked up, they need to be restricted, they need to be limited in everything'. Some participants with dementia described harm as inherent to LTCI. PLWD12 observed the coercive context of LTCI, referring to conversations with residents at his wife's LTCI: 'When I ask most of the residents, none of them really want to be there. So [LTCI] in itself is a violation of a person's human rights.' PLWD06 and PLWD05 identified the segregation designed into LTCI as a form of abuse.

CPFM17 observed denial of individuality in LTCI: 'when people get old and go into a home their whole life ... is meaningless to the carer'. VA08 spoke of her friend's identity being effectively erased through her LTCI room which 'has no chair ... no bedside table ... no pictures on the wall. It has absolutely nothing. It looks like a completely empty room.' VA08 also spoke of a Lebanese friend in a LTCI being deprived of culturally appropriate food choices: 'we're talking about someone who's Muslim and you are offering them ham or cheese. But that's their idea of choice [...] they are all treated the same. Who they were collapses.' Thus, reparations are necessary to recognise diversity, complexity, breadth, and normalisation of harm.

4.3. INVALIDATION OF EXPERIENCES

Participants identified current invalidation of individuals' experiences of harm as a further reason why redressing harm is necessary. AL04 explained systematic disbelief towards people with dementia: '[they] aren't reliable witnesses. So it's only the bruises and things like that can be pointed to.' CPFM10 recounted police failure to respond to her mother-in-law being assaulted by staff because they assumed 'she would not be a good witness'. CPFM11 spoke of the LTCI provider denying a sexual assault against her mother by claiming 'she's just hallucinating. It's part of the disease. You're not accepting it.' Therefore, reparations are necessary to confirm and validate experiences of harm that are often trivialised or denied by LTCI and justice systems.

4.4. DENIAL OF ACCESS TO JUSTICE

Participants identified present denial of access to justice as necessitating redressing harm. VA02 noted how people with dementia do not receive equal legal protection from harm: 'police haven't gone and jumped in. Why? [...] It's saying that they're not full citizens'. VA01 similarly explained: 'if that happened to people who were not in LTCI, they would have civil [rights] [...] If somebody beats you up, for example, in the street, you can sue them. What's the difference [...] being in a [LTCI]?'

Participants identified complaint processes as unsafe, punitive, overly complex, and harmful. PLWD01 spoke of her experiences complaining at the LTCI where she lives: 'We have a residents meeting and these suggestions are brought up, but nothing happens. There's no follow through. [...] they don't listen to us.' She also mentioned fear of suffering retaliation when making a complaint: 'there's that fear of speaking up. Will you be heard? [...] I could be disadvantaged with my care because of that.' PLWD06 described complaint processes as 'too difficult to work out how to access'.

Turning to justice systems, AL06 described the ‘vacuum’ in the justice system for people with dementia: ‘they’re vulnerable people ... we know the violence and abuse does occur ... [but] there is a vacuum in the system for recognising their rights.’ AL07 referred to discriminatory limits of common law compensation and difficulties associated with securing criminal charges or disciplinary action. AL01 observed trauma arising from ‘a court system that’s completely broken when it comes to righting wrongs [...] everything’s so hard to prove’. Thus, reparations are necessary to facilitate access to justice.

4.5. ABSENCE OF ACCOUNTABILITY

Participants identified current absence of accountability in relation to harm as necessitating redress. Crucially, many connected lack of accountability to money-driven focus of LTCI. Referring to LTCI as a form of ‘commodification’, VA08 observed the profit model underpinning their operation, explaining how for-profit providers ‘are looking after shareholders, ... not looking after residents’ and ‘not-for-profits are building empires’. AL04 also suggested ‘harm, abuse and neglect, they are just externalities within that corporate model, that are embedded within it’. VA03 pointed out medical and legal professionals ‘also profit from harm’. Thus, accountability is vital because only through negative impacts – particularly financial – will LTCI be deterred from enabling ongoing harm.

4.6. LACK OF SYSTEMS CHANGE

Participants identified need to redress harm because of governments’ and LTCI providers’ failure to change systems to prevent further harm. PLWD05 – who was not living in a LTCI – shared ‘one of our greatest fears is that we’re going to end up in one of these places and it’s still going to be going on. [...] I just would like to see everybody recognising that this isn’t just a few cases here and there, that it’s fairly commonplace, [and] that it has been addressed.’ PLWD08 described need for ‘a paradigm shift’, ‘a cultural change’ in LTCI. PLWD09 identified importance of balancing power between people with dementia and LTCI providers: ‘no matter what way you look at it, we’re vulnerable. [...] how do you redress that imbalance? Not just for people who things have happened to, but we’re also redressing this imbalance for everyone.’ However, AL04 noted ongoing harm in and existence of LTCI may undermine capacity of redress to effect systemic change. Reparations are thus a necessary part of changing systems to prevent ongoing and future harm.

5. DISCUSSION

This section considers key implications for disability human rights scholars arising from our findings. Particularly for scholars specialising in rights to access to justice and independent living, empirical findings can provide basis for deeper exploration of the scope of these rights, strategies through which they may be realised, and intersections between them. The following discussion first covers three positive implications of reparations: realising human rights, transforming understandings of harm, and challenging economic dynamics of human rights. We then identify two tensions arising from the findings requiring exploration in future research: endurance of LTCI and inaccessible and harmful domestic justice systems.

5.1. REALISING HUMAN RIGHTS

Our empirical findings reflect importance of reparations for realising human rights for people with dementia, in numerous ways which align with scholars’ identification of importance of the right to access to justice for broader human rights recognition (Flynn 2017). First, noting the relationship between ableism, law and capacity, reparations provide a framework for redressing legal or socially sanctioned harms and where domestic justice systems are inaccessible. Second, in light of socio-cultural dynamics that normalise human rights violations, reparations can be a material and symbolic means of recognising citizenship, equality, and value of people with dementia. Reparations can provide a framework to humanise people with dementia by discursively framing them as human rights subjects who are victim-survivors of injustices entitled to equal recognition and redress of harm. Moreover, extending reparations to redress impacts on family members and care partners of harm to people with dementia humanises people with dementia through recognising them as relational beings with social value and grievable lives, thus resisting their positioning as burdensome and disposable. Third,

in validating people's experiences, reparations can give people voice and agency (Flynn 2017). However, given widespread exclusion of disabled people from mainstream transitional justice (Clark 2023; Pons et al. 2022) and from gaining justice through domestic systems (Flynn 2017; Lawson 2016; Ruškus 2023), the extent reparations achieves these three ideals will depend on whether design and administration of reparations resists ableism and ageism and is inclusive and accessible, and attentive to intersecting dynamics of oppression.

Participants' expressed desire for redressing harm to serve a preventive and transformative role in LTCI highlights need for independent living disability human rights research to recognise how past harms can inform strategies for breaking cycles of harm and creating new possibilities for future community living and participation. Emphasis on reparations' preventive and transformative potential also highlights access to justice disability human rights scholarship must not only address justice responses to individual experiences but have a focus on collective justice, social repair, and systems transformation.

With dementia human rights situated at intersections of disability and older persons' human rights, empirical findings also underscore importance of reparations being explicitly integrated into development of an Older Person's Human Rights Convention. Reparations could be considered in relation to rights to access to justice, autonomy, and independent living: all emerging foci of Open-Ended Working Group on Ageing and Independent Expert on the Enjoyment of all Human Rights by Older Persons (see e.g., Mahler 2022). Reparations in the context of the afore-mentioned institutional abuse example of Chicago police torture – many of whom are older people – also shows value of recognising and responding to human rights violations irrespective of survivors' age and of addressing intergenerational dimensions of harm and how it is redressed (all highly relevant to people with dementia who experience human rights violations often being older people or people who have since died).

5.2. TRANSFORMING UNDERSTANDINGS OF HARM

Participants identified redressing harm as critical to officially recognising diverse and normalised harm experienced by people with dementia. Reparations offer a way of redefining what might otherwise be seen as individual harms, as collective, community, and political injustice. This is because 'gross human rights violations' – the necessary basis for reparations – indicate mass, systemic dimensions (Steele & Swaffer 2022: 77). Because human rights violations include intangible harms such as violating dignity and individuality, reparations also provide a framework for naming and responding to harms that may not fit within typically narrow confines of domestic legal systems' codification of harm. Reparations might have capacity to disrupt socio-cultural and legal dynamics. Thus, reparations challenge domestic systems' monopoly on symbolic meaning and justiciability of harm.

5.3. CHALLENGING ECONOMIC DYNAMICS OF HUMAN RIGHTS VIOLATIONS

Participants identified redressing harm as critical to ensuring LTCI providers are held accountable both for direct harms and also for their associated financial gains. Empirical findings invite a nuanced and complex understanding of dementia human rights violations that recognises LTCI as extractive and engages with harm (detriment) *and* profit (gain) dimensions of violations, as identified in Section 2.2. This necessitates engaging in detailed analyses of the political economy of LTCI and specific ways economic gains occur and are normalised, for instance through warehousing, segregating, neglecting, and using restrictive practices against people with dementia. Disability human rights scholarship must interrogate the LTCI model itself, along with economic incentives to violate human rights arising from ineffective justice and regulatory systems. In turn, consideration of gains-based practices of reparations – such as restitution – must also be considered by disability human rights scholars.

5.4. DOMESTIC JUSTICE SYSTEMS

Participants identified failures of existing complaints and justice systems as a specific justification for redressing harm in LTCI. This indicates necessity of balancing disability human rights scholarship on reparations with further research and advocacy on access to and experiences of mainstream complaint and justice processes. Human right to equal access to justice means people with dementia should have equal access to courts, complaint systems,

and victim support schemes, and focusing on reparations must not risk further entrenching deficiencies in these mainstream processes (Wadiwel et al. 2022: 187–89).

5.5. ENDURING INSTITUTIONALISATION

Participants saw redress as critical to harm prevention in LTCI when it provides processes to validate and learn from individuals' past experiences and use these to inform behaviour change and systems transformation for collective future benefit. These findings support significance given by UN Deinstitutionalization Guidelines (2022) to reparations in design and operation of deinstitutionalization. In turn, findings underscore importance of disability human rights scholars of independent living engaging with reparations for past institutional harm as a strategy for future community living. However, as noted in Section 4.6., there is a tension in this approach in the context of LTCI. Reparations are often utilised in contexts of transition, where societies have committed to wholesale change and to transforming conditions enabling gross human rights violations (Garcia-Godos 2020). On the other hand, 'in many countries, [LTCI] is a well-established, state-sanctioned or -funded, and growing industry that many individuals and families depend on in the context of a vacuum of community-based options' (Steele & Swaffer 2022: 79), which could lead to ambivalence or limitations in engaging reparations in this context. Thus, disability human rights scholars must continue to challenge ableism and ageism framing LTCI as an exception beyond political intervention and abolition and ensure their work on reparations and deinstitutionalisation explicitly extends to LTCI (Herron et al. 2021).

6. CONCLUSION

This article has introduced to dementia and disability human rights scholarship empirical insights on reparations as an approach to redressing harm experienced by people with dementia in LTCI. Coinciding with growing interest in reparations in the context of disability institutions by reason of UN Deinstitutionalization Guidelines (UN Committee on the Rights of Persons with Disabilities 2022), this work provides a strong rationale for ensuring LTCI are included in research and action at the nexus of disability institutions and reparations; and complexities and nuances of this specific context are fully considered. Given people with dementia are impacted by both ableism and ageism, reparations in the context of international developments related to older people's human rights is vital. The project reported here demonstrates key aspects of good practice in disability human rights research through participation of people with dementia in multiple aspects and roles. For dementia and older persons' human rights scholars, we offer an invitation to shift from a focus on human rights violations to challenges of a reparative and transformative response to redressing violations. Our method of building a reparations framework drawing in part on people with dementia's lived experiences and perspectives also provides a model for further research and policymaking on redressing harm associated with institutionalisation, particularly noting the requirement of co-design of reparations (UN Committee on the Rights of Persons with Disabilities 2022: 18). Conceptually, the article illuminates how a reparative framework to CRPD opens new lines of inquiry in disability human rights scholarship around disability, justice and temporality, intersections of ageism and ableism, socio-cultural and legal dynamics of dementia human rights violations, and political economies of care (Herron et al. 2021).

DATA ACCESSIBILITY STATEMENT

Project received approval from University of Technology Sydney Human Research Ethics Committee (ETH21-6114). Public access to data is prohibited.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Both authors were involved in the study's conception, design, data collection, analysis and interpretation of results. Steele led draft manuscript preparation, with feedback on drafts from Swaffer. Both authors reviewed the draft manuscript, approved the final version of the manuscript, and agree to be accountable for all aspects of the Work.

AUTHOR AFFILIATIONS

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

University of Technology Sydney, Australia

Kate Swaffer  orcid.org/0000-0001-8963-2431

University of South Australia, Australia; University of Wollongong, Australia; University of East Anglia, UK

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