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Hidden in plain sight: Women and gendered dementia dynamics in the Australian Aged Care Royal Commission

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ABSTRACT

Dementia is known to unequally affect women, whether as women living with dementia, or women who provide unwaged or paid care, yet dementia and long-term care ('LTC') research and policy often ignore gender. Using Australia as a case study and building on critical dementia, critical disability, and feminist scholarship, this discourse analysis study explored representations in the Australian Royal Commission into Aged Care Quality and Safety ('ACRC') Final Report of experiences of women with dementia, and women care partners of people with dementia, using long-term care. This paper argues gender remained an overlooked topic in relation to dementia in the ACRC Final Report. This paper found women and dementia were co-constructed according to normative gendered scripts of passive femininity. In particular, harms experienced by women with dementia in long-term care were overlooked, while the feminised labour of women care partners was taken for granted. In failing to address normative gendered patterns, the ACRC Final Report entrenches rather than unseats marginalisation of women in dementia research and policy and is a missed opportunity to address gendered labour, discrimination and harms in long-term care. Ultimately, the paper highlights the need to recognise long-term care as a key site for critical dementia and feminist scholarly and activist interventions and intersectional approaches in reforms.

Introduction

Gender is a central, yet overlooked, dynamic in dementia and long-term care ('LTC') services.[1] Dementia, as a health and social issue, has a two-fold influence on the lives of women globally. The majority of people living with dementia ('people with dementia') are women, and the majority of people providing paid or unwaged care to people with dementia are also women (Erol, Brooker, & Peel, 2015; Lotherington, 2023). Adopting Australia as a case study that reflects global patterns, this paper surfaces normative gendered structures of long-term care and how these shape both women's experiences – as people with dementia and care partners of people with dementia – and failure of political processes and subsequent law and policy reform to recognise and respond to these experiences. In doing so, it contributes to emerging critical dementia studies scholarship on intersectional and feminist approaches to dementia (Lotherington, 2023; Sandberg, 2018, 2023).

In Australia, dementia disproportionately affects women. Nearly two-thirds of Australians with dementia are women and dementia is the leading cause of 'burden' of disease and death for women (AIHW, 2023d). Further, most people using long-term care services are older women (AIHW, 2023e) and most women in residential facilities hold a diagnosis of dementia (AIHW, 2023c). Most people who provide care for people with dementia are women, whether unwaged care partners or paid long-term care workers (AIHW, 2023; Department of Health, 2021).[2]

Women with dementia in residential long-term care exercise

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[1] In this paper, the term LTC is used to refer to aged care services provided by paid workers to older people, primarily within a facility (also known in Australia as residential aged care or nursing homes) but also in at-home services.

[2] Compared to experiences of women with dementia, the feminised nature of the LTC workforce is relatively well studied, see for example (Baines, Dulhunty, & Charlesworth, 2022). Women are 87 % of LTC workers (Department of Health, 2021; The Senate, 2023) and care providers operate on "gendered expectations of unending emotional labour expected of all women, regardless of wages, working conditions or other responsibilities" (Baines et al., 2022, p. 141).

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resistance against institutionalisation, discrimination and marginalisation (Koncul, Kelly, Aubrecht, & Bartlett, 2023). Women with dementia voice their lived experiences and perspectives on dementia and long-term care, including in research projects, advocacy campaigns, and social media (Rochford-Brennan & Jenkins, 2018; Savitch, Abbott, & Parker, 2015) and are active in advocating for human rights of people with dementia, and transformation of long-term care beyond its current institutional, segregated and coercive character (Broders & Wiersma, 2022; Swaffer, 2018).

Yet, despite both the gendered environment of, and gendered public discourse relating to, long-term care, gendered dynamics and normative gender roles shaping experiences of women in long-term care are underexamined in global dementia research and policy (Bartlett, Gjernes, Lotherington, & Obstefelder, 2018; Sandberg, 2018). A recent gender-based analysis of the Canadian government's dementia strategy found the policy "only scratch[es] at the surface of women's gendered and intersectional lived experiences of dementia" (Wyndham-West, 2021, p. 1682). Gendered dementia dynamics are thus 'hidden in plain sight'. Savitch et al. (2015) explain this contradiction:

> Women are disproportionately affected by dementia, whether they are living with dementia, or caring or working for people with dementia. But the voices of women are missing (Title page).

The recent Royal Commission into Aged Care Quality and Safety ('ACRC') – the largest and highest-level public inquiry into long-term care in Australia's history – provides an opportunity to explore gender, women and dementia in the Australian system.[3] The ACRC was given wide-ranging scope to inquire into and make recommendations about long-term care, and in doing so, examined the current system and made recommendations for a new system. Relevant to this study, under its Terms of Reference, the ACRC was explicitly required to inquire into dementia and dementia care, in addition to the extent of substandard long-term care including mistreatment, abuse and systemic failures and "any actions that should be taken in response" (ACRC, 2018, p. 2 (a), (b) (ii)). While the ACRC identified itself as a "policy advisory inquiry" ((ACRC, Pagone and Briggs, 2021g), p. 30), tasked with developing policy recommendations, its Terms of Reference did not limit its powers of inquiry nor prohibit it making referrals for wrongdoing (ALRC, 2010; Tjandra, 2022).

In light of its wide scope and focus on dementia, there is opportunity to question whether the ACRC Final Report ('Final Report') identified and critically engaged with gendered aspects of dementia and potential implications of these for long-term care policy reform. Contributing to increasing gender awareness in dementia research and emerging intersectional literature about gender, women, dementia and long-term care, our study aimed to understand the particular way the ACRC recognised, engaged with, and represented experiences of women with dementia using long-term care services and as care partners of people with dementia as *gendered* experiences.

The paper achieves this aim through analysing case studies and evidence in the Final Report to identify intertwined representations of women and dementia. The paper finds that the Final Report continues, rather than challenges, marginalisation of women in long-term care, and this occurs in particular and different ways depending on whether women have dementia or are care partners.

These findings are timely now for several reasons. First, there is emerging discussion at an international level of human rights violations experienced by women with dementia and older women who are care partners (Devandas-Aguilar, 2019; Mahler, 2021). Second, the ACRC remains influential, with Australian long-term care currently undergoing significant structural and legislative reform informed by the Final Report (Australian Government Department of Health and Aged Care, 2023; Department of Health and Aged Care, 2023a). The paper makes an important contribution to recognising and understanding limits and silences of the Final Report, so these are not implanted into any long-term care reforms, and provides a cautionary tale to other jurisdictions currently undertaking or looking to undertake major reviews and overhauls of long-term care. Third, there is increased awareness of centring and listening to women's perspectives of sexual violence and other harm in policy and law reform (Ailwood, Loney-Howes, Seuffert, & Sharp, 2022). Discussion in this paper of marginalisation, pathologisation and erasure of women's voices and experiences contributes to developing a strong evidence base for the urgency of better practices in policy reform and feminist activism that centre women with dementia. This is particularly so given high rates of gender-based violence and assault in long-term care (Fileborn, 2017; Smith, Bugeja, Cunningham, & Ibrahim, 2018; Smith, Wright, & Ibrahim, 2022). Fourth, financial and political recognition of women's care labour continues to be a significant policy issue, with a recent Australian government inquiry into work and care recognising the majority of care partners are women and women are more disadvantaged in economic and social outcomes as a result (The Senate, 2023). For other jurisdictions grappling with this issue, this paper provides insights into ways official processes rationalise, compartmentalise and legitimise gendered inequalities in care and thus demonstrates how possibility for transformative change is undermined even where the issue is recognised.

Background

Despite their physical presence in long-term care, there has been little attention in dementia research to women's experiences of dementia (Sandberg, 2021; Savitch et al., 2015; Tolhurst, Weicht, & Runacres, 2023) and feminist perspectives on dementia (Lotherington, 2023; Sandberg, 2018). Dementia research focusing on women tends to be on female care partners, rather than female citizens with dementia (Bartlett et al., 2018; Erol et al., 2015). Limited literature that does exist on women with dementia has explored aspects such as: use of belongings in memory support (Buse & Twigg, 2014), identity sustaining behaviours (Scott, 2022), relational subjectivity (Tolhurst et al., 2023), and intertwined identities of gender and dementia (Wiersma, Harvey, & Caffery, 2023). However, this literature has not been situated within broader policy and reform of long-term care.

In contrast, gender is an emerging focus of critical dementia studies, drawing attention to complex gendered interrelationships between cultural norms of gender, aging and disability, subjective and embodied experiences of dementia, and enacted dimensions of care relationships (Fletcher & Capstick, 2023; Ward & Sandberg, 2023). Critical dementia studies scholars argue the absence of intersectional approaches homogenises the "elliptical category of 'people with dementia,'" and minimises the importance of gender, sexuality, race, age, social location, and life experience (Sandberg & Ward, 2023, p. 4; Boyle, 2017; Hulko, 2009; Savitch et al., 2015; Wiersma et al., 2023). People with dementia are constructed as 'abject' and dehumanised based on loss of cognitive function, loss of self-control, and dependence on others. Sandberg links this abjection with loss of bodily control and rationality, and disruption of gender intelligibility and performativity (2021). This experience is gendered because it is "linked to both a de-gendering of dementia and a particular kind of unwanted femininity and masculinity that threatens the heterosexual matrix" (Sandberg, 2018, p. 26).

Where abjection of people with dementia is associated with being "beyond recognisability" (Sandberg, 2021, p. 2), abjection of women with dementia is specifically associated with "loss of respectable femininity" (Sandberg, 2018, p. 26). Abjection results in dehumanisation and disposability that enables violence through neglect and coercive interventions of individuals with dementia (Chelberg, 2023; Loughnan,

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[3] A Royal Commission is an independent public inquiry in the Westminster tradition that investigates matters of significant public importance, with broad powers to hold public hearings, call witnesses under oath and compel evidence in order to make recommendations to government about what should change, as well as referrals for wrongdoing.

2022; Spivakovsky & Steele, 2022; Steele, Phillipson, Swaffer, & Fleming, 2023) who are ultimately ungrievable in their suffering and death (Butler, 2004; Dehm, Loughnan, & Steele, 2021). Loughnan points out this violence against people with dementia is harder to see when it is the outcome of neglect – what she terms '*un*treatment' – that often fails to lead to accountability of individuals or organisations, rendering long-term care as "zones of neglect" (2022, p. 1).

Critical dementia studies research suggests although "men's identities are more readily maintained than women's in dementia", reinforcing normative gendered biographies and embodiments may "overlook gendered power asymmetries" (Sandberg, 2018, pp. 30, 29). Indeed, lives of people with dementia are often narrated in ways that reinforce rather than resist "traditional sex roles, such as women as carers and men as professionals, [and] other narratives of self may be lost" (Sandberg, 2018, p. 29). Likewise, heteronormative long-term care practices that "treat everyone the same" risk erasing core identities for LGBTQ+ people (Clayton, 2023, p. 18). Scholars have observed "subjectivity in dementia has predominantly been defined in terms of loss or unbecoming" (Sandberg, 2023, p. 206). Women with dementia experience epistemic injustice – being denied recognition as legitimate knowers (Fricker, 2007) – through being deprived of authority to know and voice their experiences of dementia (Matthews, 2016). Drawing on feminist tools, Sandberg highlights the importance of "rethinking knowledge production, including the ways we may understand dementia as an Othered position and people with dementia as a marginalised or oppressed group" (2023, p. 202), thus pointing to the importance of discourse and representation in political status and material conditions of women with dementia. Considering "who are understood as legitimate subjects of knowledge" is necessary where "people with dementia, in particular women and others on the margins living with dementia, are in society dominated by cognitive ableism still not understood as legitimate producers of knowledge" (Sandberg, 2023, p. 209).

Foregrounding gender in dementia studies reveals unmistakeable patterns of women caring for people with dementia – where the majority of people with dementia are women – positioning dementia as both a "feminised field" (Lotherington, 2023, p. 84) and feminist issue (Harding, 2017). In Australia, most people with dementia live in the community (AIHW, 2023b), while three out of four care partners of people with dementia are women, often wives and daughters, who provide many hours of unpaid care each week (Australian Institute of Health & Welfare 'AIHW', 2023). Unwaged, familial care labour is likewise strongly gendered: "women are often constituted as the most ideal carers, by practitioners, policymakers and sometimes their own family members" (Funk & Hounslow, 2021, p. 456). Women care partners balance care responsibilities with competing personal and career commitments and are often meeting generational familial obligations (Erol et al., 2015).

Feminist scholarship argues caring by women represents social reproductive labour that not only sustains individual families but is central to nation-building and national and global economies (Goldblatt & Rai, 2020). In a neoliberal context, women's unwaged caring labour is vital to minimising costs associated with people who themselves are not considered 'productive' (such as children, people with disability, and older people) and privatised as an individual responsibility of families and women family members, rather than a state obligation (Maker, 2022). Dominant constructions of women's care labour repeat the "stereotype of the self-sacrificing (female) carer" (Lai, 2020, p. 600). Care is "framed as a medical, rather than socio-political issue" and naturalised as an inherent aspect of female gender roles that reproduces gender hierarchies (Klostermann et al., 2022, p. 7).

However, women's care labour is not limited to personal and domestic tasks. Care partners perform a substantial range and amount of "system navigation" to assist older people negotiate a complicated and fragmented long-term care system (Funk, Dansereau, & Novek, 2019). System navigation work includes "search[ing] for information about available services, the effort needed to access them, and the ongoing monitoring and advocacy required to ensure health and social needs are met" (Funk, 2019, p. 1). System navigation demands significant social, emotional, and economic labour. Care partners must be "resourceful, literate and persistent" (Funk, 2019, p. 5), yet balance "assertiveness with being 'nice' and even 'charming'" to avoid being framed as difficult (Funk et al., 2019, p. 432). While women (usually daughters) often act consistently with gendered norms of familial care, including navigation work, they are reluctant to describe care of a parent as a burden, make complaint or appear uncaring or selfish (Funk & Hounslow, 2021). Care partners describe attempts to resolve disputes as futile despite "battles and long delays" (Harding, 2017, pp. 136, 167). Indeed, care partners say they are "routinely let down" by service providers (Harding, 2017, p. 167), report anger and frustration (Funk et al., 2019), exhaustion and failure (Funk, 2019), and adopt a 'battle', 'fight' and 'struggle' discourse in relation to long-term care systems (Peel & Harding, 2014), sometimes even for years after the person has died (Steele et al., 2023).

System navigation labour is arguably embedded into long-term care structures – a form of invisible and unrecognised feminised labour – that 'downloads' onus onto individuals in a "private struggle" rather than "public responsibility" (Funk, 2019, p. 1). Yet the normative role of gendered care remains largely overlooked and unaddressed in long-term care systems. Women themselves may not recognise gendered patterns in familial care responsibilities nor interpret family care as a feminist issue (Funk & Hounslow, 2021).

While women, either as women with dementia or care partners, experience discrimination and marginalisation, the interests and rights of these two groups can be in tension (Lai, 2020; Maker, 2022). In particular, sometimes claims for recognition and rights for care partners' can contribute to understandings of those they care for as passive objects and dependent burdens (Lai, 2020; Maker, 2022).

Ultimately, statistical and scholarly contexts of women, dementia and long-term care indicate the need for specific and nuanced attention in the Final Report to the presence, absence, silence and representation of women, and understanding gendered socio-cultural dynamics that contribute to this.

Methods

This discourse analysis studied representations of gender and dementia in the Final Report, with a particular focus on women. The study concentrated on the eight-volume Final Report because public inquiry reports are rhetorical, archival texts providing opportunity to investigate public, stakeholder and official discourse associated with social questions and problems (Ashforth, 1990). While the scope of the ACRC addressed long-term care broadly, the Final Report contained substantial and specific evidence about dementia and long-term care from clinicians, academics, government and regulators, providers, and other stakeholders (ACRC et al., 2021d, p. Chapter 3). It also included accounts and experiences of a small number of people with dementia (although only two reported witnesses were identified in the Final Report as having dementia (Chelberg & Swaffer, 2023)), as well as many family members and care partners of persons with dementia, of which many are women. This evidence was presented in the Final Report through various case studies, as well as quotes from oral evidence given at public hearings and written submissions.

Coding and analysis involved a three-stage process. The first stage was a preliminary scoping coding of the Final Report searching for 'gender OR sex OR women OR men' (including synonyms and inflections) to identify explicit reference to gender by the ACRC, from which extraneous results were removed ($n = 84$). A separate search for 'trans OR transgender OR intersex OR non-binary' identified ACRC references to gender diversity ($n = 16$). This was followed by a second closer coding of Final Report extracts related to gendered long-term care topics particularly relevant to women, such as workforce, unwaged care, identity, socio-economic factors, diversity, and sexual assault, as well as detailed analysis of all dementia case studies on women with dementia or that refer to women care partners ($n = 281$). In the third and final stage, the total sample ($n = 381$) was thematically coded and organised by themes informed by the literature (described in Background above) relating to intersecting discourses about gender, women, care and dementia. These stages were iterative. The following is a worked example of a coded extract:

> Ms. Danijela Hlis also told us how she was pushed to the brink by being an informal carer for her parents before her mother moved into residential care [*Female, daughter*] (ACRC et al., 2021e, p. 341).
>
> (Coded: female sacrifice; female experience of caring; relational nature of care; negative toll; promise keeping.)

The authors acknowledge several limitations of this study. First, on the basis there are few reported voices of people with dementia in the Final Report, case studies provide limited evidence about gendered experiences of dementia articulated by people with dementia *themselves*, including women with dementia. Second, while the authors acknowledge experiences of substandard care and harms are not limited to people with dementia, this study aims to address knowledge gaps in gendered patterns in long-term care for people with dementia. Therefore, where possible, extracts were selected that explicitly relate to dementia, although at times the Final Report did not state whether an individual had dementia. However, because dementia prevalence in long-term care is estimated at 70 % (ACRC et al., 2021d, p. 67), identified themes are arguably indicative of the Australian system as it applies to people with dementia. Third, it was beyond the study's scope to explore experiences of people of other genders, although they will have particular experiences of dementia and long-term care. This study focused on women due to their high physical presence yet discursive absence in dementia research and policy. Finally, shaped by the ACRC's focus of inquiry and reporting, the study was not able to explore diverse experiences (including other intersectional identities such as disability, race and social-location) of gender and dementia, whether as people with dementia or as care partners of people with dementia. The ACRC's failure to deeply consider diversity results in discursive presences and absences in the Final Report — it is precisely these gendered dimensions this study aims to foreground.

Findings: everywhere and nowhere

This part reports key findings about women's gendered dementia discourses in the Australian long-term care system, based on analysis of the Final Report. Several related emergent themes about gender, women and dementia have been organised as either relating to women with dementia or women care partners of people with dementia. While the study was hoping to explore women's experiences of dementia in long-term care, their voices were not well represented in the data. Instead, representations of gendered and normalised patterns of paid and unwaged feminised care labour in the Final Report emerged as self-evident, while stories of women with dementia in long-term care were either lacking or reinforced gendered asymmetries. Drawing these findings together, gender is exposed in the Final Report as a central, yet overlooked, issue in public examination of dementia and long-term care practices, where representations of women are either taken for granted (as care partners) or not there at all (as women with dementia).

Findings begin with the Final Report's representations of women with dementia, followed by those of women as care partners. Extracts are used to illustrate these representations as it is not possible to reproduce entire case studies in this paper. However, we have avoided 'dissecting' case studies in ways that might undermine or minimise the power of these narratives to honour the lives, agency and experiences of these women. The findings also observe noticeable gendered silences and absences in the Final Report, as compared to the clear presence of women in the Australian long-term care system.

1. *Women with dementia*

This section discusses four key themes in relation to discursive absence of women with dementia in the Final Report. In particular, this section illustrates an absence contributing specifically to lack of inclusion in the Final Report of direct experiences of long-term care by women with dementia, with their presence being determined and constructed by others. When women with dementia are present, their representation is (re)produced along normative gendered scripts of passive femininity, while dimensions of harm particular to women are overlooked.

As a preliminary note, we generally compare discussion and representation of women with dementia to men with dementia, but where possible, have also included examples of representations of people with dementia of other genders.

1A. *Lack of life story*

Women with dementia are primarily represented in the Final Report in relation to their dementia and their family. This theme emerged from gender-based distinctions in 'life stories' of ACRC case study subjects, which detail the individual's background and situate their experience of long-term care within their life course. The Final Report does not contain any direct evidence from women with dementia living in long-term care themselves, and information reported about these women by the ACRC was drawn from evidence (transcripts and statements) by their family members. While it was beyond the scope of this study to compare the information provided *to*, and reported *by*, the ACRC, this highlights the absence of voice for women with dementia in the Final Report's official discourse, with the women's representation storied by others.

In case studies of individuals with dementia there is a gendered dissimilarity where pre-dementia family, work and hobbies of men were emphasised, while pre-dementia focus for women was *only* on their family:

> The late Mr. Clarence Hausler was born in 1926. He grew up on a family farm in Morgan, South Australia. He married Betty in 1954 and they had five children, one of whom is Ms. Noleen Hausler. Mr. Hausler worked for much of his life as an orchardist on the same farm on which he grew up. He loved his community and was the Chairman of the Morgan Lions Club. Mr. Hausler enjoyed restoring paddleboats on the Murray River and was a keen fisherman. In about 1991, Mr. Hausler developed dementia (ACRC et al., 2021d, p. 193).
>
> Mr. Reeves was born in 1946. On 18 October 1974, Mr. Reeves married his wife, Lillian. Together they have three children, Michelle McCulla, Natalie Smith and Ian Reeves. Mr. Reeves worked for 40 years as a technician with Telstra. He took a redundancy to "start a simpler life" and joined Mrs. Reeves working at Kings Safety Wear. In October 2009, they both retired. They had a dream to travel Australia. In 2010, Mr. Reeves was diagnosed with Alzheimer's disease (ACRC et al., 2021d, p. 79).

In these extracts, pre-dementia identities of men with dementia as active masculine subjects are (re)produced through attention to career, achievements, community reputation and hobbies, in addition to family. In comparison, pre-dementia identities of women centre only on family and relationships, erasing career, interests or life story. Framing of women with dementia as primarily relational can be seen in the following examples:

> Mrs. CA was born on 5 June 1936. She was 82 years old at the time of the Sydney Hearing. Mrs. CA is married with five daughters and two sons. Mrs. CA was diagnosed with Alzheimer's disease in or around 2010. She lived at home with her husband until May 2018 (ACRC et al., 2021d, p. 122).

> Mrs. CO was born in England in 1934. She and her husband travelled to Australia in December 1959 and had four children. In December 2010 Mrs. CO was diagnosed with dementia (ACRC et al., 2021d, p. 109).

There is scant background information in case studies about women with dementia, who are generally described by date of birth, husband and number of children, without details of work or hobbies.[4] In stark contrast to men in the earlier extracts, pre-dementia identity for women is relationally located in family, rather than activities or ambitions, producing women as passive feminine subjects. That these representations of women with dementia reflect their social experience of marginalisation is illustrated by a male care partner's account of difficulty finding dementia programs for his wife, "which target typically male interests, like a Men's Shed" (ACRC et al., 2021d, p. 16).

In addition to *lack* of life story for women with dementia, the Final Report includes an example of *re-storied* life story of a transwoman in long-term care:

> [An] example of lack of cultural safety and discrimination [occurred] towards a transgender woman when she was receiving home care: A lot of the staff that would come and care for her would say, "But you're a male, you're not a female" and that was quite disturbing to her. A lot of her paperwork used to come in her former male name even though she had changed her name quite a few years ago; there was no recognition of that (ACRC et al., 2021a, p. 138).

While it is not stated whether this woman has dementia, the example is included here to show cis-women with dementia are not the only gender category in the Final Report to have their identity and experiences erased or re-storied by others at the cost of enforcing normative gender, albeit this happens in diverse ways depending on each category's proximity to normative and abnormal gender. This example indicates a potential area for further exploration of nuances of gender and dementia in relation to people with dementia who are trans or non-binary.

1B. (Un)intelligible gendered scripts

People with dementia are abjectly 'de-gendered' due to dementia's disruption of normative gender expressions and performances. In the Final Report, abject representations of individuals with dementia as 'beyond' recognition are intertwined with discursive scripts related to (un)intelligible gendered behaviours and 're-gendering' practices that seek to restore normative gender intelligibility. While these re-gendering practices were observed in particular and different ways for men and women with dementia in long-term care, the focus in this paper is the Final Report's representation of gendered scripts for women with dementia.

Representations of women with dementia in the Final Report were in constant discursive (re)production into intelligible gendered subjects in several important ways. This emerged in extracts where older women resisted constructions of being *always already* frail and forgetful based on gender and aged-based assumptions of cognitive decline:

> Ms. UX told us that staff members assumed that her mother had dementia because she was frail and in her 80s.
>
> Ms. Daryl Melchhart said: "Living in an aged care facility, I have a never ending battle to be seen as a fully competent adult. My thoughts and wishes are mostly disregarded by some of the staff and I am treated by some of the staff as if I am a child or have dementia."
>
> Ms. Beryl Hawkins, who receives home care, said: "In my experience, people talk around me or to my carers as though I can't understand them. It makes me feel alone".
>
> Ms. Beverley Johnson, a woman living in residential aged care, said: "Frequently, new staff do not introduce themselves and when asked their name, their reply can be, 'You won't remember it, dear'" (ACRC et al., 2021a, p. 219).

These extracts reflect familiar gendered representations of older women as helpless whose expressed preferences are dismissed by those who 'know better'. In other extracts, 'novel' behaviour by older women disrupted dominant scripts of passive femininity in long-term care:

> It was demonstrated that it is possible to allow for dignity of risk in a balanced way. Mr. Mamarelis told us if a 95-year-old woman wanted to ride a Harley Davidson, they would make that happen. Mr. Lipmann spoke of a woman in her eighties who wanted to get a tattoo. Not all steps to balance dignity of risk and safety need to be as novel as these examples (ACRC et al., 2021d, p. 188).

In particular, women who did not behave like 'sweet old ladies' were seen as in tension with cultural norms of respectable femininity. Gendered scripts in representations of women with dementia were present in the Final Report case studies in two key forms: (1) emphasis on intelligible feminine behaviours, and (2) discursive 're-gendering' into recognisable female subjects. Both forms of gendered scripts are visible in the case of Mrs. CO's (discussed in Finding 1A), who entered long-term care in 2013. Mrs. CO's case study records issues between her family and the long-term care provider related to her dental, physiotherapy and podiatry care. Following an incident in mid-2018 when she was missing for several hours, Mrs. CO was administered psychotropic medication in response to agitation, anxiety and 'wandering' associated with dementia. The first script is evident in description of Mrs. CO's behaviours in terms consistent with intelligible norms of passive and emotional femininity:

> Mrs. CO was distressed and crying over the loss of her baby son years before.
>
> Dr. Ginger saw Mrs. CO and concluded that she was agitated, distressed and was showing "signs of being depressed". Dr. Ginger prescribed 45 mg of the anti-depressant mirtazapine to be taken at night. […] Dr. Ginger was aware that Mrs. CO had a history of wandering, had anxiety and cried quite a lot. At that point in time, Mrs. CO had not been diagnosed with depression but had only showed signs of suffering from it. […] According to Ms. DL, Ms. Tinley said that Mrs. CO was often found crying and distressed. Ms. Tinley suggested that if Mrs. CO continued that way she would probably have to go into the secure facility inside Brian King Gardens, known as Everglade (ACRC et al., 2021d, p. 114).

In this extract, Mrs. CO's crying, distress and depression is not interpreted by medical professionals or staff as a legitimate response to the death of her child. Rather, her 'emotional' feminine behaviours were medicalised as excessive and disruptive to long-term care – sufficient to justify psychotropic medication and secure isolation – conforming with familiar constructions of 'hysterical' femininity. While the ACRC does express concern about use of psychotropic medication in these circumstances, its focus was largely on the issue of absence of consent rather than the pathologising of grief and sadness. Indeed, apart from the concerns about Mrs. CO getting lost, the case study does not identify what was 'wrong' with Mrs. CO's crying and distress. The second script is seen in efforts to sustain Mrs. CO's pre-dementia gendered biography, (re)constructing her coherent identity as a mother through feminised activities:

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[4] The authors wish to acknowledge attention to marriage and children for women with dementia in this demographic may be consistent with social norms of that era, and indeed, many of these women might choose to be relationally 'storied' in this way. The authors thank the anonymous reviewer for making this distinction. What is significant however, are the *discursive* gendered patterns of reporting between men and women with dementia in ACRC official discourse.

> Ms. Tinley gave evidence that at this time Mrs. CO's grief was really distressing […] These interventions included spending one-on-one time with Mrs. CO, outside walks, doll therapy, and music and group activities (ACRC et al., 2021d, p. 115).

The Final Report observes Ms. Tinley's failure to consider more intensive 'dementia behaviour management' interventions. Thus, the ACRC's interpretation further entrenches rather than disrupts the gendered pathologisation of Mrs. CO's behaviour.

In contrast, behaviours of men with dementia are represented as rational, powerful and contiguous with their pre-dementia identity, which is consistent with literature that men's identities are more easily maintained than women's. The following illustrates this sustaining and re-gendering of intelligible active masculinity:

> [W]e had a 74-year-old gentleman who […] was throwing furniture, he was scaling fences. […] when he moved in we identified that this was a tradesperson and he was used to waking up very early in the morning and doing physical activities. […] he was sitting idle and playing bingo, and so he was becoming more aggressive. And so the environment and activities were, essentially, triggering him. […].
>
> And so we brought him a small bucket of paint and a small paint brush and we asked him to paint the fence of the home, in consultation, obviously, with the family and them agreeing. And he ended up doing physical work. Every day he would wake up really early in the morning, he would do the fence, he would do—we have a pool in that house, and so he would tend to the pool, do gardening (ACRC et al., 2021a, p. 102).

As a further comparison, the following example is of a transgender woman who chose not disclose her gender to the long-term care provider:

> [T]his woman feels she will not 'come out', revealing her gender, "because the environment isn't safe". […] That person is not feeling safe, is not feeling included, is listening to transphobic slurs that are happening across the organisation and, you know, so they're just sort of hiding themselves and just going along and pulling the line and pretending that everything is fine (ACRC et al., 2021e, p. 475).

As for the example in 1 A above, although it is not stated this transwoman has dementia, this extract suggests the woman has acted to (self)construct recognisable and 'safe' gender within long-term care. This is consistent with submissions to the ACRC that restraint may be associated with older LGBTI people being seen as "disruptive or troublesome" for behaviour 'outside' heteronormative stereotypes (LGBTIQ+ Health Australia, 2020, p. 9).

These Final Report examples juxtapose normative representations of 'masculine' behaviours of men with dementia against 'feminine' behaviours of women with dementia. This finding has revealed discursive processes of de-gendering and re-gendering of people with dementia, and the particular yet different ways abject representations of behaviours of women and men with dementia are constructed and 'corrected' in heteronormative care practices to produce intelligible gendered identities within long-term care.

1C. Overlooking gendered harms

In a context where widespread harms experienced in long-term care was a central issue driving the ACRC, we generally found the Final Report discussion of harms experienced by people with dementia was similar across genders. In particular, the Final Report included evidence about both men and women with dementia being subjected to restraint (physical, chemical and confinement to 'secure' dementia units), overuse or misuse of medication, and neglect. However, two areas of distinction were observed of harms particular to women: (1) sexual assault, and (2) type of restraint.

In the first area, the ACRC condemned significant levels of sexual assault in long-term care, and shared personal experiences of assault and abuse told on behalf of individuals or their family members (ACRC et al., 2021a, pp. 159–160; 96–97). However, the Final Report made minimal engagement with gendered aspects of sexual assault against women that connects with broader gendered dynamics of sexual violence, including predominance of male perpetrators, staff pathologising and disbelieving physical and mental signs of women's sexual assault, and failure of justice systems to respond to gender-based violence in long-term care. Moreover, the Final Report did not engage in detailed exploration of barriers to accessing justice and support for victims of sexual assault nor abuse, nor make any recommendations for reforming justice systems or introducing redress schemes to hold wrongdoers to account.[5]

The second area relates to disparity in ACRC reporting related to use of restraints[6] in long-term care between men and women with dementia. Reflecting our findings in 1B about intelligible gendered scripts, we observed these scripts were repeated and reinforced in discussion of restraints in long-term care. This emerged both in relation to justification of restraint use, as well as types of restraint applied, to 'manage' behaviours of people with dementia. There was little evidence in the Final Report on the prevalence and circumstances of restraint use in long-term care, and available data was not gender disaggregated (Office of the Royal Commission into Aged Care Quality and Safety, 2019, pp. 11–13). However, our findings suggest for women with dementia, 'emotional' representations of feminine behaviour such as crying and distress were associated with administration of psychotropic medication that was not reported as chemical restraint. This is evident in Mrs. CO's case study (discussed in 1B above), who was administered an excessive dose of anti-depressant medication for agitation, crying and distress:

> [W]e note that [DM, her daughter] visited her mother that morning with two of Mrs. CO's grandchildren to celebrate her birthday because that was the time when her mother was "usually pretty sprightly".
>
> Ms. DM said that her mother was fast asleep, fully dressed on her bed and that they could not wake her. She was told by a nurse that her mother was very sleepy and as a result went to the café to allow her to finish what they thought was a "nanna nap". When they came back 45 min later, she was still "out to it" (ACRC et al., 2021d, p. 117).

While the ACRC found the LTC provider inappropriately administered psychotropic medication without consent, Mrs. CO's case study is not reported as an instance of chemical restraint. This might in part be due to technical definitional issues surrounding restrictive practices excluding interventions for medical treatment rather than behavioural management reasons (although reference is also made in the case study to the failure to consult dementia behaviour management advice, suggesting it was viewed as a behavioural rather than medical issue). It also raises the question 'what is the *risk* or danger in *crying*?' Yet, medicalisation of women's grieving behaviour as 'hysterical' makes it easier to frame medication interventions as 'treatment' rather than naming them a restraint practice.

In comparison, restraint for men with dementia in the Final Report was typically associated with 'aggressive' and 'threatening' representations of behaviour, which is framed as a safety risk that required an immediate management response from LTC providers. For example, Mr. Terance Reeves' case study, where physical restraints were applied to manage "excessive wandering, agitation, and intrusion", explicitly examined physical and chemical restraint of an individual with dementia (ACRC et al., 2021d).

Despite women's high physical presence and high rates of physical restraint in long-term care (ACRC et al., 2021a,), the Final Report did not

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[5] This is in contrast to the move in Australia and many other jurisdictions to make such reforms in response to institutional sexual abuse in child welfare institutions.

[6] Known in Australia as 'restrictive practices'.

include a case study about application of physical restraint to a woman. Indeed, the term ‘restraint’ tended not to be used in relation to women with dementia, discursively excluding women from the ACRC’s inquiry to “reduce or eliminate the use of restrictive practices” (ACRC, 2018, p. (i), (viii)). In this sense then, while the ACRC enquired into use and regulation of restraints in long-term care, it did not engage with gendered dimensions of the type and manner of restraint used on women and men with dementia. This silence in the Final Report reflects the limits of the ACRC’s engagement with, and listening to, experiences of women with dementia in long-term care. Where legislative reforms post-ACRC now require express consent for use of restraints, emergent findings in this study suggest disparity in long-term care restraint practices to ‘manage’ dementia behaviours between men (physical) and women (chemical, with accompanying ambivalence of whether this is restraint or medication) may leave women outside regulatory reform of restraints. The ACRC failed to explore these gendered nuances of restraint use, extending the potential for disproportionate application of restraint reforms. This points to an important area of future research into gendered characterisations and ethics of dementia restraint practices.

1D. Disposability and death

While many people with dementia die in long-term care, including because of violence and neglect, within neoliberal long-term care structures the abjected lives (and deaths) of women with dementia in the Final Report are represented as unremarkable, undervalued and overlooked. Disposability and ungrievable death as the culmination of constructions of women with dementia in long-term care – lack of story, intelligible gendered scripts and gendered harms – are graphically represented in Mrs. Santoro’s case study (ACRC et al., 2021d, pp. 286–314). Mrs. Santoro moved into long-term care in “reasonable health for her age” at 93 years, although she had several medical conditions including diabetes, chronic pain, and was later diagnosed with dementia. Mrs. Santoro’s case study opens with limited engagement with her pre-dementia life:

> Mrs. Santoro was born in Italy in 1924 and grew up there before migrating to Australia in 1956. After settling in Australia, Mrs. Santoro married her husband when she was 40 years old. Together they raised a family, including their daughter, Ms. Ng. […].
>
> To help her mother adjust to life at Assisi Centre, Ms. Ng made a “social story” for Mrs. Santoro in March 2018. It was in the form of a photograph album and was designed to help Mrs. Santoro understand who she was and who the people around her were. Ms. Ng found that going through the album helped to settle her mother.
>
> Ms. Ng gave evidence that, although she encouraged staff to look at the album with her mother, particularly when her mother was upset, she never once saw them do so. She said that she often found the album packed away in her mother’s drawers when she visited her (ACRC et al., 2021d, pp. 287–288).

Subsequently, Mrs. Santoro had several hospital admissions related to diabetes, pneumonia, fractures from several falls, and an untreated urinary tract infection. Mrs. Santoro’s experience was characterised by substandard care, record keeping and communication about her medical condition by her doctor and LTC provider, as reflected in her weight loss:

> On 12 May 2018, Mrs. Santoro was weighed by Assisi staff and found to have lost around $5^1/_2$ kg since her weight had last been recorded at Assisi on 12 March 2018. Her weight loss over that time, from 54.5 kg to 48.9 kg, represented about 10 % of her total body weight. Although Mrs. Santoro was then given dietary supplements by Assisi staff, her weight was not subsequently monitored on a regular basis (ACRC et al., 2021d, pp. 293–294).

Following surgery, Mrs. Santoro was discharged with a surgical wound on her hip and a pressure injury on her right heel, both of which became infected and required specialist wound care and pain management:

> Dr. Tay also accepted that pressure injuries, such as the one on Mrs. Santoro’s heel, could be very painful. He acknowledged that, given Mrs. Santoro’s chronic pain syndrome, pain management for her heel wound was absolutely vital. That was particularly so, he agreed, because Mrs. Santoro’s dementia meant that behaviour such as agitation might result from an inability to communicate about her pain. […].
>
> Ms. Ng only received a full description of the [anti-psychotic] medications taken by her mother and their doses in an email from one of Dr. Tay’s colleagues on 20 September 2018. By that time, she had become concerned about the possible side effects of medications on her mother and, in particular, her mother’s drowsiness (ACRC et al., 2021d, pp. 299, 301).

The case study reports Mrs. Santoro showed “behaviour such as agitation” for which psychotropic medication was administered without consent. Critically however, the Final Report provides scant detail of the nature or extent of Mrs. Santoro’s ‘behaviours’, nor discussion of whether medication was properly characterised as treatment or restraint. Mrs. Santoro’s agitation was read as coherent with intelligible feminine scripts, rather than a justified pain response, and corrected with psychotropic medication that was not identified as restraint.

Over the course of Mrs. Santoro’s time in long-term care, she experienced slow, violent multi-faceted neglect, including inappropriate medication, significant unaddressed weight loss, irreversible wound and bone infection (including maggots), inadequate pain management and deficient palliative care. These circumstances culminated in her death:

> Not long after being told on 11 October 2018 about the extreme seriousness of their mother’s heel wound, Ms. Ng and her brothers were forced to think about palliative care for their mother. Around 15 October 2018, a doctor from Austin Outreach told Ms. Ng that, unless she was prepared for Mrs. Santoro to have her foot amputated, palliative care was the only realistic option for her mother. Mrs. Santoro was then moved to Assisi’s makeshift palliative care room on 17 October 2018. The room was noisy and unfit for that purpose. People entered the room to use a sink in the room until a sign was placed on the door. By this time, Ms. Ng and her brothers had arranged for one of them to be with their mother around the clock ‘to make sure her pain was managed’. […].
>
> On 25 October 2018, only two weeks after Ms. Ng had been belatedly told about the seriousness of her mother’s heel wound, Mrs. Santoro died (ACRC et al., 2021d, pp. 309–310).

Circumstances leading to Mrs. Santoro’s death reveal the natural endpoint of long-term care practices of mistreatment and ‘*un*treatment’, with death itself being the result of cumulative neglect. While the ACRC found “systemic deficiencies” by doctors and staff were “significant and compromised the quality and safety of care delivered to Mrs. Santoro” (ACRC et al., 2021d, p. 314), no referrals for investigation or prosecution of wrongdoing were made. Mrs. Santoro’s case study is representative of disposability of women with dementia in long-term care systems. While documenting the lives and untimely deaths of Mrs. Santoro and others, the ACRC did not make any recommendations for public recognition and memorialisation of these lives lost through institutional- and state-sanctioned harms.

Yet, we also observe in this case study assertions by family members for recognition of Mrs. Santoro’s individuality, humanity and dignity, and persistent interventions and resistance to the *un*treatment of Mrs. Santoro. This also signals the role of care partners in advocating for better circumstances and treatment, and their truth-telling role in extreme but frequent cases where women with dementia experience fatal harm in long-term care. On this note, we now turn to explore representation of women care partners in the Final Report.

2. Women as care partners

This section discusses two key themes in relation to the taken for granted status of women as care partners: feminised labour of complaints and expectation of self-sacrifice. Both identified themes are consistent with representations of women that accord with gendered expectations of passive femininity.

2A. Carer advocate/navigators: feminised labour of complaints

There was a compelling presence of an entrenched feminised labour of complaints in long-term care systems. This was identified based on predominance of female care partners – mostly daughters, sometimes wives – speaking about navigating, advocating or complaining as part of their experiences of providing care for people with dementia. This labour by 'carer advocates/navigators' took the form of negotiating 'broken' long-term care systems:

> Ms. DI explained that she and her sister: spent a lot of time […] sharing that information and making sure we felt 1000 per cent comfortable that they fully understood what Mum needed in the absence of us being able to provide that care for her at home *[Female, daughter]* (ACRC et al., 2021d, p. 139).
>
> Dad entered what was to be the first of three residential facilities and it quickly became apparent that we were negotiating a system that was "broken". I kept moving him, hoping in vain to find the best possible care *[Female, daughter]* (ACRC et al., 2021f, p. 72).

System advocacy and navigation requires essential and significant labour by care partners dealing with clinical care, government, legal and financial services, as well as home and residential long-term care providers. Moreover, many women in the Final Report undertook activities beyond advocating and navigating to complaining: from *following up* promised information and services, *checking* instructions are being adhered to; *pushing* service providers to meet contractual obligations; *objecting* to poor service; *reporting* grievances to management; to formal processes of *complaint*. These carer advocate/navigators carried the responsibility of their parent's care:

> It felt like the staff at the facility weren't taking Dad's needs seriously and I was convinced they were not following the hospital's directions. I did not have any confidence in that facility's ability to get Dad's care right […] We put him in the aged care facility because he needed complex care and we thought that he would get it there, but it appears that is they just – really just house you and feed you, and any type of care that you need is the family's responsibility [*Female, daughter*] (ACRC et al., 2021e, pp. 682–683).

As discussed in Mrs. Santoro's case study in 1D, this labour may continue until the untimely and unjust death of an individual with dementia, death brought about by the very circumstances the care partner has persistently called out and tried to change.

Necessity for care partners to take up advocacy and navigation activities reflects the system's reliance on feminised complaint labour. Critically, this labour is normatively 'built-in' to long-term care systems, forming a routine and expected part of the care partner's role in order for individuals to receive basic levels of care. Despite their "best efforts" to advocate or complain on behalf of their parent, women described LTC systems failed to deliver on care promises:

> Ms. DM outlined how disappointed the family was with the care provided to Mrs. CO and asked what action would be taken to rectify the problem. [*Female, daughter*] (ACRC et al., 2021d, p. 112).
>
> Ms. DI and Ms. DJ were dissatisfied with the level of information they were receiving from Bupa Willoughby […] We felt very confused and out of the loop [*Females, daughters*] (ACRC et al., 2021d, p. 160).
>
> I received notification about six months after his death last year that a [home care] package was available. How does that happen in a system which has sifted through everything about us? I felt guilt, frustration and sadness as he diminished despite our best efforts *[Female, wife]* (ACRC et al., 2021f, p. 64).

Women reported this labour extracted an emotional cost. Advocate/navigator carers described "battling and fighting for everything", feeling ignored, and frustrated, guilty, and "being given the run around when they tried to get a satisfactory response to their concerns" (ACRC et al., 2021c, p. 507).

Some women's caring labour extended to making complaints. Formal complaint processes lacked accountability and transparency, leaving women care partners feeling "disappointed", "not empowered" and that it was "useless to complain" (ACRC et al., 2021e, pp. 363–364). Daughters experienced intimidation, exclusion, exhaustion, grief, and felt they were failing their parent:

> I felt like I was failing her [mother]. It felt like no matter what I tried, I wasn't able to access the right kind of care for her. Bupa sent people to try and smooth over my complaints, but nothing changed [*Female, daughter*] (ACRC et al., 2021e, p. 639).
>
> Ms. Ruddock explained that she felt she had to advocate for her father's care because it was not being provided by Alkira Gardens. Due to this, Ms. Ruddock was not able to enjoy time with her father in his final months and weeks because she was preoccupied with ensuring her father received appropriate and humane care. […S]he felt like she had been "in a battle" […] and just wanted to […] focus on caring for her father [*Female, daughter*] (ACRC et al., 2021d, p. 216).

At the same time, complaining itself was problematic, and daughters risked being framed as 'angry and difficult', which might in turn compromise care of their parent. When daughters persisted with complaints, they were treated as troublesome:

> A record of the meeting notes that staff at Japara referred to Ms. Hausler as "the smiling assassin" […she] was called names by carers and […] "vexatious" [*Female, daughter*] (ACRC et al., 2021d, pp. 204, 206).
>
> The speaker said she felt the facility treated her like a troublemaker when she raised care issues: I was bullied and intimidated by management […] before my mother passed away I was told that she was taking up too much of the staff's time [*Female, daughter*] (ACRC et al., 2021f, p. 54).

The Final Report extracts show navigating, advocating and complaining as a normalised duty of women care partners and implicit work of female caring. Further, although feminised labour of complaints is known to cause harm, women were praised in the Final Report for "ongoing and tireless advocacy" (ACRC et al., 2021c, p. 549) and resilience:

> These were stories of hardship and fortitude. Many of the witnesses conveyed the sense that they had struggled alone, advocating for the person they cared for, without adequate support from government services (ACRC et al., 2021e, p. 341).

2B. Female relational identity: expectation of self-sacrifice

The Final Report revealed a second key theme relating to normalised and harmful gendered familial care patterns. This was identified in repeated accounts of women care partners honouring relational promises to individuals with dementia:

> Ms. Cameron simply took her husband home and did her best to care for him as his disease progressed [*Female, wife*] (ACRC et al., 2021b, p. 204).

> Mrs. Reeves had not had a break during the many years she had been caring for Mr. Reeves at home [*Female, wife*] (ACRC et al., 2021d, p. 80).

Women care partners describe doing their “best to care” without a “break” within relational care partnerships. Women may be motivated to care as a risk prevention approach to avoid or minimise harms, and thus similar to our observation on complaints in 2A, their expected ‘sacrifice’ might ultimately accommodate ‘broken’ long-term care systems. When no longer possible to support an individual to live at home, care partners described despair and guilt, evident in the following examples:

> Mrs. Kay Gray told of how, in 2018, she organised two weeks of respite care at a residential aged care facility for her husband, Mr. Clive Gray. […] The poor care and rapid decline in her husband’s health led to her decision to withdraw him from respite early […] This experience was very difficult for Mrs. Gray: I felt really bad about it, and I kept saying – I thought it was my fault, but the family kept saying to me, “No, Mum, it wasn’t your fault.” But it made me feel that no way would I ever, you know, put him in another facility *[Female, wife]* (ACRC et al., 2021e, p. 350).
>
> Ms. DI said that her mother was “adamant she did not want to enter respite or aged care”, so she and her sister arranged in-home support for their mother [*Female, daughter*] (ACRC et al., 2021d, p. 138).

Expectations to honour familial responsibilities were associated with harms for women care partners who deprioritised their own health, social and economic needs:

> Dad did not want to put Mum in care, but we saw this as a good opportunity to take the first step towards permanent care. With Dad having had surgery, we were able to get her into respite care. By that stage my sister [DG] had quit her job and was getting called out to their house every second day to help with things [*Female, daughter*] (ACRC et al., 2021d, p. 123).
>
> Ms. Dunn described her priorities in this way: “I didn’t consider my own life choices. So it meant that if my social life was to be impacted, so be it. If work was impacted, so be it. Even if my own health was impacted, so be it.” [*Female, granddaughter*] (ACRC et al., 2021b, p. 204).

Harms associated with familial care were experienced by women care partners, such as emotional and material losses, including reduced employment hours, isolation, lack of support, feelings of guilt, grief, anger, frustration and failure (ACRC et al., 2021e, p. 348).

> “It wasn’t a good experience when I was still working. It was just too hard”. As her grandmother’s health deteriorated, she reduced her hours of employment to meet the demands of her caring role: I guess there came a point where I knew something was going to give [*Female, granddaughter*] (ACRC et al., 2021e, pp. 348, 349).
>
> Mrs. Cameron shared her struggle with exhaustion and despair: “I just learnt that I was on my own, you know, and I couldn’t rely on anyone else to get me through that”. Ms. Cameron described how she felt when her husband was refused care after just a few days into a respite stay: “I cried silently all of the way home. That was the closest I have ever felt to ending it all for both of us. I was exhausted and didn’t know how much longer I could stay on my feet to look after Don, and I couldn’t trust anyone else to care for him and not mistreat him.” [*Female, wife*] (ACRC et al., 2021e, p. 348).

These extracts are consistent with knowledge long-term care systems operate on gendered structures of unwaged care resulting in unrecognised disproportionate disadvantage for women and an absence of recognition of structural drivers of this harm. Yet, as these examples demonstrate, these structures persist in normalised and harmful embedded practices of feminised emotional and economic labour positioning care as a private problem, rather than a public obligation:

> One speaker described her struggle to obtain community services to help her keep her father, who had dementia and feared residential care, at home. She was unable to access residential respite for a break. “As carers, we carry the burden of the system and funding failures [...] in the absence of system reform, these failures will continue” [*Female, daughter*] (ACRC et al., 2021f, p. 53).
>
> There must be a recognition that the services provided by carers such as myself, are saving the country a fortune, but often at great personal cost. [*not stated*] (ACRC et al., 2021f, p. 57).
>
> [I]nformal carers often step in to provide care because of the long wait times for a Home Care Package. This may mean that the carer is required to give up their own job. This may affect the carer’s ability to obtain re-employment as carers are often in their 50s or 60s (ACRC et al., 2021d, p. 14).
>
> [The] evidence illustrated that informal carers do vital work. They may do so for many years, in increasingly difficult circumstances as they and their loved ones get older. In many cases, they do so with inadequate support and little respite. The carer’s role can be socially isolating and potentially harmful to their own health and wellbeing, not to mention their working life and finances (ACRC et al., 2021e, p. 339).

Finally, there was limited engagement by the ACRC on how transwomen or lesbian women negotiate unwaged long-term care structures and practices, both as people with dementia and as care partners. Relational factors may be complicated for these women based on reduced access to familial care, support networks not being recognised, or increased expectations to care based on perceptions of being “unencumbered with their own family life” (LGBTIQ+ Health Australia, 2020, p. 7). One Final Report extract demonstrates this is a key area for further research:

> I believe that a service that is meant to support you and help keep your loved one home for longer failed Edie and I miserably. I am still angry and sickened about that. I had to place Edie in residential care earlier than I wanted as I was completely worn out, defeated and demoralized [*Female, wife*] (ACRC et al., 2021e, p. 488).

Discussion

Against the known background of dementia prevalence and mortality for women and women’s central role in paid and unwaged dementia care, coupled with resistance and advocacy by women with dementia, this study sought to understand how the ACRC Final Report represented women’s experiences in relation to dementia in the Australian long-term care system. Seeking deeper understanding of intersecting gender, care and dementia discourses, our analysis has confirmed existing research speaking to lack of attention to gender, and in particular, women, in long-term care policy and research. Our analysis confirms an absence of direct accounts of women with dementia in long-term care themselves; rather their stories are told by others (Savitch et al., 2015). In contrast, while women’s experiences and injustices of unwaged care labour were present and praised, there was little critical reflection on these or recognition of need for transformative structural change to improve the situation for women care partners. Overall, there was lack of meaningful engagement by the ACRC with gender as a central dynamic to understanding dementia and long-term care. Ultimately, women are hidden in plain sight in the Final Report because recognition of the role of gender in dementia care is either taken for granted (in the case of care partners) or not there at all (in the case of women with dementia). Indeed, turning from the rich detail of the Final Report volumes to the 148 final recommendations, only one recommendation identifies gender equality and this relates to wage equity in long-term care systems.

Post-ACRC this pattern continues, as evidenced by two recent examples. First, while acknowledging high dementia prevalence and mortality for women, the Australian Government's proposed National Dementia Action Plan does not recognise gender itself, nor gender inequality and sexism in its proposed objectives. This lack of recognition is even apparent in Objective 1 on "Tackling stigma and discrimination" (Department of Health and Aged Care, 2023b). Second, the Government's consultation papers on new long-term care legislation do not mention women or gender, even in the entire section devoted to accountability and complaints handling (an area of feminised care labour) (Department of Health and Aged Care, 2023a, pp. 54–63).

In focusing on gendered dynamics of women and dementia, we are aware interrelations between multiple identity factors shape individual experiences of dementia (Hulko, 2009), as well as the ways dementia may destabilise or emancipate gendered identities (Sandberg, 2018; Ward & Price, 2016). Future research is needed to more fully explore complexities of this topic, particularly in two respects. First, future research might explore intersectional dynamics such as experiences and representations of First Nations women, LGBTIQ+ women, and women from culturally and linguistic diverse backgrounds. While the Final Report did not provide this depth of data, submissions to the ACRC have drawn attention to particular experiences of trans women and lesbian women (LGBTIQ+ Health Australia, 2020) and ACRC media coverage points to particular experiences of other marginalised groups of women such as First Nations women (Martin, 2019). Second, on the basis gender is not synonymous with 'women' nor a binary concept, further research is needed on gendered experiences of dementia and long-term care of people of other genders, including experiences of men (including trans men) and non-binary people because Australian research indicates their experiences are also shaped by gendered dynamics and normative gender identities (Ansara, 2015).

We now turn to identify three areas of recommendation to foreground gender in long-term care policy and future research to support and further deepen critical scholarship on women, dementia, and care generally.

Listening and epistemic justice

Our analysis highlights that, additional to women's *hidden physical presenc*e, their *voices are silenced* in long-term care and the Final Report. Silencing occurs in multiple ways within long-term care, including pathologising and medicating women with dementia who express distress, ignoring or dismissing women with dementia when they speak, interpreting women's communication and behaviour through gendered stereotypes of normative femininity, and problematising or marginalising women care partners who call out harm and injustice. The Final Report did not include any direct perspectives and experiences of women with dementia living in long-term care and, while including voices of many women care partners, did not demonstrate meaningful engagement with and recognition of women care partners' experiences in its outcomes. Indeed, consistent with findings in other jurisdictions, "women's subjugated and situated knowledges [were] not folded into" the ACRC findings and recommendations (Wyndham-West, 2021, p. 1682). These gendered silences are repeated in the Final Report in at least three particular ways: (1) limited representation of non-normative gender expressions and experiences of women and people of other genders; (2) lack of specific recommendations to address acknowledged disproportionate impacts on women in long-term care; and (3) failure to refer any person or organisation for investigation of harms described by women with dementia and women care partners.

Ultimately, these representations contribute to women being subjected to profound epistemic injustice in long-term care and reform processes, and serve to further entrench ableist, ageist and sexist assumptions about disabled and older women and women care partners as not being legitimate knowers of their experiences. It is also indicative of a failure to "listen" (Ailwood et al., 2022), in the sense women *are* expressing themselves (as demonstrated by resistance and activism by women with dementia mentioned in the Introduction) but their stories and perspectives are not meaningfully 'heard' and acted upon either within the long-term care system nor the ACRC. Consistent with critical dementia studies and feminist literature summarised in the Background above, this failure to listen is also reflected in recent research on complaints and justice pathways in long-term care (Steele & Swaffer, 2023; Wadiwel et al., 2022).

Despite their marginalisation, the Final Report indicates women want to and do articulate their experiences, exercise resistance to their circumstances, and demand recognition and justice for themselves and those close to them. There is emerging activism in Australia to centre voices of women with dementia who experience sexual assault/abuse in long-term care, such as through the "#SheToo Campaign" (OPAL Institute, 2016) and "#ReadytoListen project" (OPAN, 2021).

Thus, further research could turn to scholarship in feminist (Fricker, 2007; Matthews, 2016) and sociolegal scholarship (Ailwood et al., 2022) on 'listening' to explore what a politics and practice of listening might look like in relation to women with dementia and women care partners. For example, drawing on similar approaches in queer, crip and mad theory and activism, Sandberg proposes exploration of a "demented standpoint" as a:

> way to recast dementia from a medical category to a political one, and to prioritise the perspectives of people with dementia before those of professionals, the health sciences and medicine in ways which have hitherto been regarded as unthinkable […] people with dementia, in particular women […] are in society dominated by cognitive ableism [and] still not understood as legitimate producers of knowledge (Sandberg, 2023, p. 209).

Likewise, Lotherington calls for critical feminist dementia research to "produce new liberating knowledge" recognising people with dementia as "human knowers and doers" (2023, p. 88). However, in recognising women with dementia as women, it is important not to re-gender individuals in ways that reinforce normative gender roles and asymmetrical power relations (Sandberg, 2018) nor focus solely on gender categories (Lotherington, 2023). Specific exploration of ways to achieve listening (Hulko, 2009) and epistemic justice (Steele, Swaffer, et al., 2023) for diverse experiences of people with dementia is vital. In this respect, this paper expands sociolegal literature critiquing legal and political processes, including Royal Commissions, for failing to bear witness to people's harm and injustice (Loughnan, 2022; Spivakovsky, 2018) and for lacking intersectional approaches that ultimately silence female voices (Marchetti, 2008).

Valuing women

Consistent with scholarship on marginalisation of people who are female, disabled, older and unwaged/non-professional and undervaluing of reproductive and caring labour, our findings establish women are devalued in long-term care and the ACRC.

Women with dementia are socially undervalued. Where dementia challenges cultural expectations of masculinity, the male pre-dementia identity "lost" to dementia is (re)constructed and emphasised as rational, active and agential in strategies to "fight back" to preserve identities for men with dementia (Tolhurst & Weicht, 2017), and evident in re-gendering practices that sustain recognisable masculinity (Sandberg, 2018). While we contest representations of dementia as "loss and unbecoming", gendered differences in valuing women and men's lives indicate men are assigned what Butler refers to as "grievable", and women as "ungrievable" (Butler, 2004). This finding nuances scholarship on dementia and grievability (Dehm et al., 2021; Steele & Swaffer, 2023; Steele, Swaffer, et al., 2023).

This paper evidences social devaluing of women with dementia reflected in absence of direct experiences, erasure of pre-dementia lives, and overlooking of gendered harms. Emerging research suggests women with dementia perceive *themselves* as having gendered experiences of dementia connected with cultural constructions of women. Wiersma et al. found women with dementia were aware of being treated differently to men – including misdiagnosis of symptoms as depression, being dismissed and not taken seriously – but were unsure if these differences were due to gender or dementia (2023, p. 12). This connects to lack of accountability within long-term care for neglectful *un*treatment of women's bodies (Loughnan, 2022) as well as medicalisation of women's behaviour making it easier to frame interventions as 'treatment' not restraint. Consequently, women are excluded them from regulatory frameworks and political and activist discussion on reducing and eliminating these practices (Spivakovsky, Steele, & Wadiwel, 2023).

Our findings provide further evidence base for the need to ensure review and development of long-term care policy does not explicitly or implicitly rest on devaluing people with dementia, particularly women with dementia. This requires deliberate and reflexive processes of recognising, reckoning with and dismantling sexism, ageism, ableism and their intersections in long-term care policy and practice. Moreover, valuing women with dementia might require more far-reaching measures beyond the scope of this article to explore. One of these is surfacing the productive tension between devaluing of women with dementia and enriching of others. Consideration is needed of forms of value, including financial, others gain through long-term care and the potential for even higher gains through devaluing – e.g., through institutionalisation, restraint and neglect – of women. The other is to explore the gendered nature of institutionalisation itself, and how valuing women with dementia hinges on abolition of institutional models of care (Herron, Kelly, & Aubrecht, 2021; Steele, Swaffer, et al., 2023).

Women care partners are economically undervalued. The ACRC acknowledged, but did not significantly engage with, economic undervaluing of unwaged care as 'natural', unskilled labour all women are capable of and expected to perform in extensions of pre-existing relationships. Further, despite recognising women's navigation, advocacy and complaint labour, the absence of commentary on structural change to financially and socially support care partners, suggests the ACRC's valorisation of women's 'fortitude' anticipates their unwaged labour will continue to benefit 'broken' long-term care systems. Indeed, while the ACRC accepted the need for improved wage conditions for the workforce, in the Final Report the economic cost of unwaged care was kept separate to discussions of financing, normalising women's care labour as essential to financial sustainability of long-term care systems. Failure of the ACRC to substantially engage with gendered structures profiting long-term care systems disregards emotional and material harm implicated in familial dementia care (Funk et al., 2019) and is consistent with normative cultural care ideologies (Klostermann et al., 2022) that responsibilise care as a private, rather than public, concern (Funk, 2019) to the "gendered next of kin" (Lotherington, Obstfelder, & Ursin, 2018, p. 130).

Harm was a key thread running through the ACRC, and many words are given in the Final Report to women describing experiences of harm in long-term care in relation to people with dementia or as their care partners. Despite this, these words did not translate into ACRC outcomes (recommendations and referrals), indicating these ungrievable experiences failed to activate long-term care reform. Ultimately, this confirms intersections of sexism, ableism and ageism shaping women's status in long-term care systems. This suggests need for exploration of how economic and social value is understood and assigned in relation to marginalised groups and political processes of long-term care reform. Exploration might also extend to alternative approaches to disability and care rejecting neoliberal understandings of labour and humanness.

Greater accountability and rejecting the label of 'difficult woman'

Our findings highlight women in long-term care are not only devalued – they are also represented as tiresome and troublesome, whether due to complaining or dementia-related behaviour, and thus undeserving of justice. The Final Report extracts disclose narratives about advocating and complaining labour by women care partners on behalf of people with dementia in long-term care consistent with literature on women acting as system navigators (Funk et al., 2019) and carer advocates (Funk & Hounslow, 2021). In addition to experiencing frustration, guilt and grief on behalf of the individual in long-term care, some women acting as carer advocate/navigators were subject to ridicule or labelled as a 'difficult woman' when they complained about treatment (including *un*treatment). That this complaint labour was exerted in the context of deficient complaint management processes in respect of provider facilities (ACRC et al., 2021a, p. 206) and the regulatory body (ACRC et al., 2021c, p. 507) simultaneously undermines *and* outsources supply of feminised labour in neoliberal long-term care systems.

These findings confirm recent feminist scholarship on complaint (Ahmed, 2021), adding to literature on problematisation of complaining in the disability support (Wadiwel et al., 2022) and long-term care contexts (Funk et al., 2019). Ahmed argues being labelled a complainer is a form of dismissal because "to be heard as complaining is not to be heard" and the individual who is labelled becomes infantilised into the permanent status of "problem child" (Ahmed, 2021, p. 1). Further, complaint labour is never resolved: "it often requires you do more and more work. It is exhausting, especially given that what you complain about is already exhausting" (Ahmed, 2021, p. 5).

Women with dementia who exercise resistance or express anger and distress were likewise problematised in the Final Report as difficult and disruptive to long-term care structures. These findings add to existing literature calling for "older women's anger and discontent" be recognised as loud defiance to injustices (De Vuyst & De Graeve, 2023) or, at least, a reasonable response to harmful long-term care systems (Spivakovsky et al., 2023).

Ultimately, women as carers or with dementia are both interpreted as behaving in ways contradicting feminine normative gender roles, thus positioning them (rather than the harmful long-term care practices) as the problem and as undeserving of justice. Further exploration is required of how long-term care systems operate in mundane and routine ways to generate harmful conditions that, by design, necessarily require complaint, resistance, anger and distress. Also, consideration of how women's resistance – as care partners or women with dementia – can be recognised and engaged with to produce important insights into broken and harmful long-term care systems and ultimately transformational change. Consideration is also required of how these gendered scripts have impacts into justice systems, informing the views and conduct of lawyers, police and judges responding to harms in long-term care. Ultimately, disrupting these gendered scripts, and exploring intersections of sexism, ageism and ableism, might be central to addressing impunity and supporting demands for accountability and reparations for systemic and structural harm in long-term care (Steele, Swaffer, et al., 2023).

Conclusion

Adding to calls to "put gender on the dementia studies agenda" (Sandberg, 2018, p 30), this paper provides a basis to put gender on the dementia policy agenda. This remains a pressing issue in Australia, despite (and indeed in part because of) the ACRC Final Report, which has further entrenched the marginalised position of women in long-term care. Using discourse analysis of the Final Report, this paper examined representations of gender and dementia in long-term care, in particular women with dementia and women care partners of individuals with dementia, and found gender remained unseen. While these findings reflect both the gendered environments of long-term care, as well as the gendered lens of the Final Report, this paper's focus was to foreground the latter. Women in long-term care, whether as women with dementia or care partners, were discursively represented as primarily relational and in constant (re)production to conform with respectable, intelligible femininity. Considering new ways to understand and respond to experiences of women in long-term care is a global challenge. By paying particular attention to representation, marginalisation and erasure of women in official legal and political processes that serve as precursor to long-term care reform, we can develop an evidence base to call out exclusion at intersections of ageism, sexism and ableism, and make claims for more equitable, just and transformative dementia policy centring women and people of other non-binary genders.

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CRediT authorship contribution statement

Kristina Chelberg: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Linda Steele:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization.

Data availability

The data used in this study is publicly available in the Royal Commission into Aged Care Quality and Safety Final Report at https://www.royalcommission.gov.au/aged-care.

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