Reframing Dementia: How to promote rights and strengths-based care for people living with dementia and their carers

Georgia Hing

MSQW, University of Sydney

Abstract

By using a life course approach, this article seeks to discuss and analyse the impact on a carer when their older loved one experiences cognitive changes such as dementia, and the specific implications for people from culturally and linguistically diverse backgrounds. In Western contexts such as Australia, dementia is often understood through a biomedical lens and deficit-based frameworks. These dominant understandings can maintain ageist attitudes that construct older people and those with dementia as a social policy burden. This is further amplified for people from non-dominant cultures. This paper examines the marketisation of aged care in Australia and phenomena of ambiguous loss in identifying a range of issues for carers, including the specific experiences and challenges for culturally and linguistically diverse people. Finally, it discusses implications for critical social work practice and argues for radical change at structural and organisational levels. It proposes that a reframing of dementia as a shared social experience along with strengths-based and relational practice are key to creating more meaningful counter narratives that foster a sense of agency and empowerment for carers and people with dementia.

Key Words

Dementia, Life Course Perspective, Social Work, Ageism, CALD

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Introduction

Current dominant discourses and social policies in Australia can perpetuate ageist attitudes leading to the discrimination of people living with dementia. This paper will take a life course approach in exploring the experiences of this cohort and their carers within westernised models of care and the broader Australian society. It will first analyse the impacts dominant discourses surrounding ageing in Australia have on people with dementia and their carers, before examining common phenomena experienced such as ambiguous loss. A life course perspective (LCP) will also be used in identifying areas in which people with marginalised identities experience further disadvantage and oppression as they age, including how dementia specifically impacts culturally and linguistically diverse (CALD) people. Using the LCP also provides further insights into how social workers can better work alongside these populations to ensure care is not homogenous and remains culturally safe. Lastly, this paper puts forward a number of ways that social workers can apply critical perspectives to practice, enact strengths-based care, advocate for change and provide alternative knowledges.

Dementia in Australia

In Australia there are an estimated 487,500 people living with dementia and without a medical breakthrough that number is expected to rise to almost 1.1 million by 2058. It is also estimated that almost 1.6 million people in Australia are involved in the care of someone living with dementia (Dementia Australia, 2022). Dementia is not one specific disease, but an umbrella term used to describe a collection of symptoms caused by disorders affecting the brain. These can lead to the progressive decline in one's functioning which can include a loss of memory, rationality, perception, social skills, intellect and physical functioning.

At a macro level, it is evident that social policies and their underlying ideologies impact people in complex and diverse ways when it comes to navigating a life with dementia (Duffy, 2017; Macdonald & Mears, 2019; Phillips, 2018). Phillips (2018, p. 6) argues that entrenched and structural ageism in Australia is perpetuated by neoliberal agendas that favour individualism and free markets over "societal and human needs". The Royal Commission into Aged Care Quality and Safety's Interim Report stated that "Australia has drifted into an

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ageist mindset that undervalues older people and limits their possibilities" (Royal Commission into Aged Care Quality and Safety, 2019, p.1).

Ageism and Biomedical Understandings

Older people can be constructed as a burden or a social policy problem within health, economic and social services (Duffy, 2017). Power exercised through dominant discourses can enable ageism to be accepted as truth and internalised by all cohorts, including older people and their friends and family (Duffy, 2017, p. 2074). In terms of what it means to age, narratives in Australia are characterised by terms such as 'healthy', 'active', 'successful', and 'productive' which privilege mobility and movement, maintenance of a social life, financial independence and cognition (Duffy, 2017). A biomedical model lays the ground for deficit-based frameworks from which to understand the experience and pathologizes the physical ageing of the body and mind as a condition that should be diagnosed and treated (Macdonald & Mears, 2019). Thus, it is not always the most beneficial perspective when it comes to learning how to live a good life with dementia.

Macdonald & Mears (2019, p. 7) argue that dementia is not the tragedy, but rather the tragedy is that "modern western societies have come to conceptualise humanness as individualised substance" where people are assigned different values and statutes. In turn, this positions people living with dementia as a problem that needs to be dealt with. It presents dementia as a tragic illness that renders someone unproductive through a "slow and traumatising process of losing their personhood" (Macdonald & Mears, 2019, p. 4). Stigma can be further magnified by these ageist cultural attitudes that view the person as incapable (Macdonald & Mears, 2019). These attitudes can be harmful as people with dementia can be defined through a deficit-based lens, where the "starting point is negative"; the focus on illness rather than wellness (Macdonald & Mears, 2019, p. 8). It diminishes emotional, relational and sensual strengths by valuing a person's cognitive ability above all else (Macdonald & Mears, 2019, p.3). By not embracing a collective model or social understanding of cognitive change, dementia is viewed as a burden on society and continues to locate the problem within the individual.

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Marketisation of Aged Care

Neoliberal agendas of successive conservative governments have contributed to the marketisation of aged care with policy shifts towards consumer directed care (Henderson & Willis, 2020). The privatisation of aged care services in Australia can conflate human rights with consumer rights, i.e., it promotes the rhetoric that all older people have equal opportunity to choose they care they want (Henderson & Willis, 2020, p. 258). However, this fails to account for vulnerable populations and assumes that everyone has the capacity to choose between aged care services. People living with dementia must also compete alongside others to access to resources in a society based on self-interest (Macdonald & Mears, 2019, p. 23). Thus, their degree of disability can limit their capacity for consumer choice due to long wait lists for home care services or residential aged care facilities, further amplified by a scarcity of dementia specific services or facilities that can cater for diversity (Gilbert et al., 2022). The Royal Commission into Aged Care Quality and Safety's Interim Report described Australia's aged care system as "a shocking tale of neglect", that:

> Fails to meet the needs of our older, often very vulnerable, citizens. It does not deliver uniformly safe and quality care for older people. It is unkind and uncaring towards them. In too many instances, it simply neglects them. (2019, p. 1)

Ambiguous Loss

Ambiguous loss in the context of dementia can be used to describe the type of loss felt when a person with dementia is physically there but gradually losing their emotional and mental presence in their family members' lives as their cognition changes (Dupuis, 2002, p. 95). Viewing this from a life course perspective, we can see this as a gradual transition where family and carers lives are also affected by the change in trajectory given their relationship to one another (Hutchison, 2019). For example, a midlife adult's role may transform to a caregiving one as their parents age. According to Nathanson and Rogers (2021), the interaction of continuous loss and ambiguity "inherent in dementia yields worse mental health outcomes compared with other caregivers" (Nathanson & Rogers, 2021, p. 270). Compared with other chronic illness caregivers, dementia caregivers can experience an

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increased risk of anxiety, anger, guilt, depression, social isolation and low self-esteem. There are several reasons for this including reduced ability to communicate with their loved one in the final stages of illness, the culmination of ongoing losses as the dementia progresses, and the amount of time spend in the caregiving role (Arruda & Paun, 2017, p. 841). These losses are not always recognised or named, yet they can create disconnect and relational disruptions (Nathanson & Rogers, 2021, p. 268). Nathanson and Rogers (2021) use a dementia grief model to describe the sorts of loss carers can experience along the disease trajectory, including grieving the loss of the person they once knew, the loss of the relationship that once was, the transformation of one's role and changes to expected or planned futures. There's not always a sense of predictability nor closure in these relationships. Dupuis (2002, p. 100) also notes that ambiguous loss can be one of the greatest stressors in caring for a person with dementia, and that this loss can be felt even more deeply if that person has to move to a residential care facility. Carers can be caught in a "complex emotional conflict" throughout the illness journey, with feelings of confusion and emotional bereavement while also constantly adapting to changes and their own evolving caregiver role (Gillies, 2011, p. 672).

Spotlight on Culturally and Linguistically Diverse (CALD) Populations

As discussed earlier, the pervasive ageism that exists within western societies such as Australia directly impacts how older people and their families from non-dominant cultures understand and experience ageing and access to aged care services and facilities (Shanley et al., 2012). Dementia care can have its challenges for everyone in terms of structural burdens, including long wait lists and poor transparency around home care packages (Gilbert et al., 2022). However, these burdens can be amplified for older culturally and linguistically diverse (CALD) people and their carers, and manifest in different ways between different CALD groups (Royal Commission into Aged Care Quality and Safety, 2021). This paper acknowledges that the experiences of CALD communities is in no way homogenous, and no single model of care can meet the needs of the diversity of populations across Australia. However, a recognition of diversity in life course trajectories is helpful in identifying multiple facets of identities such as ethnicity, migration histories, socio-economic factors and differences in education and literacy (Gilbert et al., 2022, p. 7).

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Services: Accessing Services

A study by Gilbert et al. (2022, p. 1) found that family carers of CALD people living with dementia can experience "higher stress and unmet need than the general Australian population". They draw on the concept of structural burden to highlight how bureaucratic processes evident within Anglo-centric care systems play a significant role in contributing to this distress. They found that carers of CALD people with dementia are getting left behind by the current aged care system. This included difficulty navigating a fragmented and bureaucratic care and service systems and unfamiliarity with how the system worked. Managing language barriers created additional stress, particularly when many dementia support groups only had English-speaking staff. Further, consumer-directed care doesn't always consider how different vulnerabilities intersect, e.g., difficulty comprehending the home care package system intersecting with limited culturally appropriate care (Gilbert et al., 2022, p. 6).

Cultural Obligations

Tipping & Whiteside (2015), Boughtwood et al. (2011) and Shanley et al. (2012) note that many CALD families have greater filial obligations than families of Anglo-Celtic origins, particularly given the fact that many non-Western countries are considered collectivist cultures, rather than individualistic. Similarly, Caldwell et al. (2014) note that Chinese Australian caregivers prefer community-based services to aged care facilities and see these facilities as a last resort. Consequently, they prefer to or have cultural obligations to care for their family member with dementia at home and so value culturally specific community-based aged care agencies (Tipping & Whiteside, 2015, p. 185). However, these types of organisations are scarce and there have been appeals made for mainstream services to become more culturally sensitive to the unique experiences and needs of CALD families.

Social Work Implications

While numerous challenges exist for people living with dementia and their carers within Australia, there are a myriad of ways for social workers to exist in these spaces at macro, meso and micro levels. Critical and emancipatory social work practice can reframe dementia

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as a social experience in a way that enhances the quality of life for those living with dementia and to help them perceive it as a meaningful trajectory (Macdonald & Mears, 2019). That's not to say that living with dementia is something that people desire, nor is this paper trying to minimise its challenges, but rather, it asks the question of how can we better integrate this experience within society as one that has meaning? How can social workers counter stigma and misconceptions and use their skills to facilitate connection and purpose?

Emancipatory Practice through Reframing Dementia

Phillips (2018) argues that emancipatory practice can be fostered when we counter ideas about ageing as a burden and identify relationships as key tools of critical social work. Macdonald & Mears (2019) call for a reframing of dementia as a social experience to encourage approaches that enhance people's capacity to live with dementia. A social model unsettles the dominance of biomedical models by subverting ideas around fear and isolation. It provides a counter narrative and practices that go beyond deficit-based medical framing to revalue care and vulnerability as "intrinsic to all life" (Macdonald & Mears, 2019). It positions those who live with dementia and their carers as the real experts (Gillies, 2011). A critical social work approach counters power imbalances by identifying how marginalisation, social disadvantage and oppression exist within society (Duffy, 2017; Hutchison, 2019). Critical social work is informed by intersectionality; a theoretical perspective that identifies how "multiple systems of inequality work with and through one another, at multiple levels of society" (Bastos et al., 2018, p. 211). The intersection of different statuses and identities, such as gender, age, sexual orientation, cultural background, socioeconomic status, disability and religion, can combine or overlap to create different forms of discrimination and privilege, of experiences that are empowering or oppressing, contextualised within broader systems of power (Koehn et al., 2013, p. 446). Thus, by viewing discrimination through an intersectional lens, we can better understand how interlocking systems of power operate to oppress certain groups, specifically those most marginalised in society. This is particularly important in examining how CALD populations experience the compounding of ageism and racism.

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Armed with this knowledge, social workers can provide more holistic perspectives and interventions that ensure the experiences of those from CALD backgrounds for example are not homogenised or rendered invisible (Boughtwood et al., 2011).

Emancipatory Practice using a Life Course Perspective

A diagnosis of dementia can change the way people interact and engage with each other. Focusing on dementia as lived experience and as a transition in one's life course trajectory can be useful in understanding in how to find new meaning and take advantage of new opportunities that a diagnosis may bring. Carpentier et al. (2010) use the life course perspective as a lens through which to examine the care and disease trajectory of dementia. A LCP framework emphasises how family history, linked lives, human agency and organisational effects impact on a person living with their dementia and their carers. In terms of accessing services or transitions to aged care facilities, viewing dementia as a trajectory in one's life can alert social workers to specific elements that impact families and carers, such as previous interactions with health and care services, family dynamics, and the impacts of a diagnosis (Carpentier et al., 2010). Further, taking a LCP can be conducive to culturally safe practice that encourages cultural humility as it understands a person within their own context, including an awareness of their cultural background, the different life events they may have experienced compared to the wider population, as well understanding different reactions to certain transitions (Hutchison, 2019). We can then recognise key turning points in their journey and how potential disadvantages faced across their life course can impact them in later life and influence how they access help and support (Gillies, 2011; Hutchison, 2019). This holistic knowledge provides opportunities for social work to tailor interventions in specific ways with a trauma-informed lens.

Community Care

At a community level, there have been calls for more community-based aged care services given that the majority of families would prefer their family member at home rather than in an aged care facility, with this view even more evident within CALD communities (Tipping & Whiteside, 2015, p. 194; Royal Commission into Aged Care Quality and Safety, 2021).

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Community and local support can be better placed to promote human rights centred practice compared to institutions such as hospitals and residential aged care facilities. Research with carers of those with dementia have found that they are not opposed to external community services but rather have difficulty accessing and navigating supports. In the case of CALD communities, there are even fewer ethno-specific services which further limits their choice (Gilbert et al., 2022; Caldwell, 2014). Improving the quality, access to and navigation of aged care in Australia is high on the political agenda, including addressing gaps in the system that informal carers have been compensating for (Gilbert et al., 2022). Gilbert et al. (2022) suggest that in the context of CALD communities, the establishment and strengthening of community level support should be a key part of future reform for ethno-specific services. They also call for mainstream services to better respond to the needs of ageing CALD communities by utilising more translators and simplifying access to services and funding. Although the Aged Care Royal Commission placed significant importance on home care given older people's preference to remain at home, it remains to be seen whether the new Labor government and new social policies will meet the demand for home care services.

Strengths-Based Approaches – Relational Care

Using a LCP and Macdonald and Mears' (2019) framework of dementia as a social experience seeks to appreciate all humans as being fundamentally relational. When coupled with strengths-based social practice this mindset shifts problem-centred stories to empowering ones (Hutchison, 2019). We can view dementia as shared care that preserves personhood over the reactive management of behaviours, with a focus on what remains, rather than what has been lost (McGovern, 2015; Macdonald & Mears, 2019). Nathanson and Rogers (2021) propose that normalising ambiguous loss and its inevitability for carers of people with dementia is key in transforming the experience from one of hopelessness to one that's transformational and opportunistic. Further, an emphasis on human agency is consistent with approaches that focus on individual, family, community and organisational strengths (Hutchison, 2019). A strengths-focused approach can measure the quality of life in terms of relatedness, such as "shared moments rather than memories, feelings rather than thoughts" (McGovern, 2015, p. 409). Findings from McGovern's (2015) study found that 'we-ness' promotes a strengths perspective that can be sustained in the context of multiple

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losses. It encompasses family history through the emergence of a 'we' identity where family members use their family system and shared history to connect in the present. In addition, a strengths perspective can encourage families to share special times together rather than letting it be defined by capacity. For example, one participant in McGovern's study said, "I don't know what the movie is about…but in the moment, I have a perfect life" (McGovern, 2015, p. 413-414). A strengths approach can also allow for different areas of growth for carers including becoming more patient, building new skills, sharing new experiences like marking art, or finding a new sense of purpose. Macdonald and Mears (2019, p. 26) reiterate this idea; that caring for someone with dementia can be an opportunity to demonstrate loyalty and humanity, with an ability to promote their loved one's personhood and identity. These approaches are also useful in working with CALD families, to help them identify their range of strengths and resilience in the face of adversity. It's also particularly effective in its focus on family systems and relationships when working with people from collectivist cultures as it counters individualistic narratives, i.e., "living better with dementia requires joining with others in care partnerships" (McGovern, 2015, p. 417).

Education Provision

Greater knowledge of dementia as an illness has been shown to increase hope and decrease anxiety about it for carers which benefits the person with dementia (Dementia Australia, n.d.). Social workers can be well placed to assist with this education and provide clarification, particularly in hospital settings where an admission often precedes a move to residential care. Moving to aged care is a significant transition in the life of the person with dementia as well as their carers, family and partners (Fitzpatrick & Grace, 2019). While it can be incredibly difficult at times for hospital social workers to promote person and family centred care alongside pressure from the hospital to discharge and shorten lengths of stay, there remains opportunities for strengths-based practice. Transitions can be disempowering and incredibly stressful for carers yet social workers can emphasise the strengths of the person with dementia and their carers, normalise their experiences and validate their feelings (Macdonald and Mears, 2019). Research by Fitzpatrick and Grace (2019) also found that organising family meetings and spending time with the family to educate them on the illness were valuable for information sharing and collaboration. These small but powerful actions can

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foster positive interactions, give some control back to families and assist in lowering caregivers' fear or anxiety around dementia.

Conclusion

While there has been a significant shift in approaches to care for people living with dementia in the past twenty years, this paper argues that there needs to be more radical change at structural and organisational levels, so dementia is also viewed as a shared social experience (Macdonald and Mears, 2019). Living with dementia can be incredibly challenging but the impacts on carers can be further amplified when their experiences exist in an ageist society that values profit and individualism over care and vulnerability. While change needs to happen at a policy level to address the systemic inequalities and oppressions that exist in Australia's aged care system, social work also has a valuable place within this environment. Taking a life course perspective promotes strengths-based practice and values the importance of human relationships. Moving towards approaches such as these - that understand an individual within their own context and favour family and community care over individualistic objectives - can enhance the wellbeing of people with dementia and their carers. It also provides opportunities to create meaningful experiences and fosters a sense of agency and empowerment.

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