

# Stigma and style of care may explain underuse of respite

Research into the effectiveness of dementia-based respite care in delaying entry into residential aged care is lacking, and these services remain largely underused. **Andrew Hanna, James Donnelly** and **Christina Aggar** summarise some of the key reasons for this and propose methods to improve the quality and uptake of these services

Cited as one of the most frequently expressed needs of caregivers (Carers Australia 2017), respite care is thought to offer several benefits for people with dementia and their informal caregivers. Likewise, carers who choose to use these services report high levels of satisfaction with the support received and have identified respite as being critical to their caring efforts (Madeo *et al* 2008; O'Connell *et al* 2012).

However, despite high anecdotal support from carers, statistics indicate that 87% of dementia carers in Australia have never used a respite service (Johnson 2006). While several explanations are considered, this finding suggests that the forms of respite care currently available in Australia do not meet the needs of the people who require them (Brandão *et al* 2016; Phillipson *et al* 2019). There is also limited empirical support for the potential benefits of respite care (Lee & Cameron 2004; Maayan *et al* 2014), as well as recognised methodological and practical challenges to designing quality outcome studies in this area (Zarit *et al* 2017).

This article summarises some of the critical issues related to the underuse of dementia based-respite services, with an emphasis on Australian research. It begins with a discussion of the known benefits and risks of engaging respite for people with dementia and their informal carers. Explanations for the underuse of these programs are then reviewed in the context of caregiver perceptions and complaints about service quality.

Additionally, the social consequences of framing dementia within a biomedical model are considered, with a focus on the implications for improving respite services and facilitating a much-needed culture change within the Australian aged care sector.



Carers have consistently expressed a preference for services that provide age-appropriate social and recreational activities. Photo: Freepik.com

## Benefits and risks

O'Connell *et al* (2012), explored the experiences of Australian caregivers of people with dementia who attended private or public respite programs. The authors identified three primary reasons for carers using these services, including assistance with managing care, taking a short break, and so they could attend to their own health needs (O'Connell *et al* 2012). Close to 80% of the carers surveyed also believed that accessing respite care was beneficial to the person for whom they cared (O'Connell *et al* 2012).

Similarly, in another study involving 100 Australian dementia caregivers, more than half reported physical and emotional rest, and relaxation as the primary reasons for using respite (Neville & Byrne 2008). Other carers have stated that these services helped them to gain confidence and information about the caring role, reduce feelings of isolation, and validate their experiences (Hancock *et al* 2007). Use of day-respite services has also been associated with reduced biomarkers of stress among caregivers (Liu *et al* 2017), as well as

improvements in sleep quality (Lee *et al* 2007) and general health (Liu *et al* 2015).

Investigations of the influence of respite care on levels of caregiver burden have, however, revealed mixed results and the efficacy of respite in this regard remains unclear (Gresham *et al* 2018; Lee & Cameron 2004; Vandepitte *et al* 2016). For instance, there is evidence to suggest that respite use is associated with an increased risk of institutionalisation (Vandepitte *et al* 2016). However, it is hypothesised that this is primarily due to caregivers accessing services late in the progression of dementia, or that respite services present a transitional stage from home to residential care (Shaw *et al* 2009; Tang *et al* 2011).

There is also the possibility that respite is, at times, used to trial residential services and that carers may change previously held negative views about institutional care, especially when their experiences with respite are positive (AIHW 2012; Shaw *et al* 2009).

Other factors which negate the benefits of respite care include having difficulties adjusting to the service and the limited effect of respite to reduce the frequency of psychological and behavioural symptoms (Witt *et al* 2004). In fact, some carers have described a worsening of the intensity of responsive behaviours in their family members following periods of respite (Phillipson *et al* 2014).

Additionally, brief stays in residential respite have been shown to negatively affect client quality of sleep, although these effects seem to be limited to the time spent in care (Lee *et al* 2007). Other authors have drawn attention to the risk of respite disrupting client routines and emphasised that several inconsistencies in the research remain in determining the actual risks and benefits of respite (Tang *et al* 2011; Willoughby *et al* 2018).

### Underuse of services

Considering the expressed demand for respite, the low uptake of these services among dementia caregivers is unexpected (Neville *et al* 2015; AIHW 2017; Phillipson *et al* 2014). This finding is likely the result of several complex, interacting factors and various explanations have been proposed.

Some authors point to the challenges associated with the accessibility of respite services, and the need for better communication and prompt referral from healthcare providers (Brodaty *et al* 2005; Shaw *et al* 2009).

The underuse of respite may also be the result of misconceptions of poor-quality service, high costs, or a lack of flexibility in service arrangements

(Carers NSW 2016; Phillipson *et al* 2014; Phillipson *et al* 2013).

Other studies have indicated that there may be negative connotations with respite use, for instance, that the person with dementia is a burden, that the carer is not able to cope, or that using respite will result in deleterious outcomes (Madeo *et al* 2008; Neville *et al* 2015; Phillipson *et al* 2013; Robinson *et al* 2012).

There is an apparent need to destigmatise dementia, but destigmatising respite care itself may also be required. For example, considering the harmful effects of the language used to describe services, which can be perceived as pejorative or infantilising, may be part of the solution. Accordingly, the adoption of more socially acceptable and inclusive terms have been proposed, such as 'restorative care' and 'adult or visitor programs', as opposed to 'respite' or 'adult day-care' (O'Shea *et al* 2017b). There is, of course, a proportion of carers who do not see a need to use these services, or who see caring as a personal or cultural responsibility (Brandão *et al* 2016; Brodaty *et al* 2005).

### Improving respite use

Research suggests that the characteristics of the respite service itself, and not those of the caregiver or person with dementia, are most influential in predicting satisfaction with respite (O'Shea *et al* 2017a; Phillipson & Jones 2011). Accordingly, tailoring the style of available programs to better suit the preferences and needs of carers and clients will likely improve the rate of use.

It is well documented that carers require services that are accessible, affordable, and adaptable to their changing circumstances, especially for those with degenerative conditions (Neville *et al* 2015; O'Connell *et al* 2012). Ensuring that information about available services is appropriately disseminated to potential consumers will also increase uptake and use of respite (Carers Australia 2017).

Carers have consistently expressed a preference for services that provide age-appropriate social and recreational activities, while also promoting personal growth and opportunities for learning and support (Madeo *et al* 2008; Phillipson *et al* 2013).

Nevertheless, in order to better engage carers and clients, and improve prevailing beliefs about respite care, these programs must also address the legitimate concerns about service quality (Carers NSW 2016; Phillipson *et al* 2019). Qualitative studies investigating carer

experiences have revealed common complaints about inadequate staff-to-client ratios, repetitive or inappropriate client activities, and an inability to deliver personalised care (Neville *et al* 2015; Witt *et al* 2004).

Other carers have expressed their frustration with the limited dementia-specific expertise of staff, who appear ill-equipped to manage responsive behaviours (Johnson 2006). These staff actually complain to the client's family, often resulting in the carers and clients disengaging from the service (Carers Australia 2017).

Following a review of predominantly Australian research, Tang *et al* (2011) concluded that in order to adequately meet the needs of people with dementia and their families, respite services should progress from traditional, custodial models of care to evidence-based psychological approaches. This could be achieved by strengthening referral pathways and associations with local allied health services, in addition to placing a greater emphasis on professional development programs for respite care staff (Tang *et al* 2011).

There are, however, several barriers to improving the quality of dementia-based respite services in Australia, not the least of which refers to unhelpful perceptions of dementia held by many, including those in the caregiving workforce.

### Beyond the biomedical

To fully appreciate the significance of this problem, it is worth reflecting on the historical context in which these issues have arisen. Until recently, the predominance of international research has framed dementia within a biomedical model of disease (Davis 2004). Although a necessary stage in progressing our understanding of cognitive decline, the medicalisation of dementia is inherently deficit-focused and as such, has had a negative impact on the social construction of dementia and its care. Essentially, considering cognitive changes in this way seems to perpetuate harmful stigma, a focus on loss rather than empowerment, and the neglect of the personal experiences of individuals with dementia (O'Sullivan *et al* 2013).

These issues have, in turn, contributed to other concerns such as the overuse of antipsychotic medication (Ervin *et al* 2019) and caretaker models of respite services which aim to pacify clients or position them as recipients of care, instead of active participants (Burton *et al* 2008; Kirkley *et al* 2011).

In a review of the biomedical

approach, O'Sullivan *et al* (2013) went so far as to argue that the medical construction of dementia is "the basis of excess disability and unequal relations that have marginalised people with dementia" (p483). While some may believe this critique to be overly harsh, there is little doubt that these traditional paradigms should give way to a renewed focus on enablement, acceptance of cognitive change, and the preserved capacity for meaningful life experiences and personal growth (Buron 2008).

## Conclusion

In this spirit, person-centred approaches, such as those advocated in Montessori-based methods, may provide a useful framework for dementia-based respite services moving forward. At their core, the Montessori philosophy and methods aim to foster greater independence and encourage the client, and all involved, to work together to maintain or establish

meaningful roles (Camp *et al* 2017; Hanna *et al* 2018). These authors suggest that we help develop innovative behavioural 'ramps' that enable clients to overcome sensory, cognitive or motor barriers to continuing what they enjoy.

Client-focused models such as this may also serve to challenge the status quo by promoting a culture of older adult care with collaboration, inclusivity, and dignity as the priorities.

However, if these imperatives are to be adopted by the formal caregiving workforce, this process must begin with addressing outdated, unconstructive perceptions of dementia and aging, and ultimately, reframing the idea of 'respite care'. ■

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■ From left: Andrew Hanna is a registered psychologist and is a doctoral researcher at Southern Cross University, Coffs Harbour, NSW, investigating a Montessori approach to dementia-based respite care; Dr James Donnelly is a registered psychologist, lecturer and PhD supervisor in the School of Health and Human Sciences, Southern Cross University, Coffs Harbour, NSW; Dr Christina Aggar is Associate Professor in the School of Health and Human Sciences, Southern Cross University, Billings, QLD. To follow up on this article, contact Andrew at [a.hanna.23@student.scu.edu.au](mailto:a.hanna.23@student.scu.edu.au)

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## Health service use by people with dementia

The Australian Institute of Health and Welfare (AIHW) has released what it says is one of the first studies of its kind in Australia, on the use of health services by people with dementia in their last year of life.

The study examined health service use in NSW and Victoria (including public hospital admissions, GP and specialist visits, emergency department care, and dispensing of prescription medications) by more than 70,000 people in the 12 months prior to their death in 2013, of whom 19,222 (or 27%) were identified as having dementia and 50,928 (73%) had no record of dementia.

The report found that:

- People with dementia who died aged 65 and over used health services less than people without dementia in their last year of life, with the exception of GP services (people with dementia used an average of 21 GP services in their last year of life, compared with 18 for those without dementia).
- 66% of people with dementia who died aged 65 or over had a hospital admission in their last year of life.
- 68% of people with dementia who died aged 65 or over presented to the emergency department in their last year of life.
- People with younger onset dementia used health services more than older people with dementia.

"By bringing together different sources of data to tell a more complete story, the study demonstrates the potential for integrated health data to address gaps in our current understanding of a range of health issues, in this case dementia," said AIHW spokesperson Dr Fleur de Crespigny.

The AIHW says its report did not look closely at the interrelationship between health care service use in the last year of life and use of aged care services, nor in depth at the role of palliative care, but these issues will be explored future using more comprehensive linked data assets.

*Patterns of Health Service Use By People With Dementia In Their Last Year Of Life* is available on the AIHW website at <https://bit.ly/2XnJleN>.

## Does telehealth work?

Australian researchers have conducted a non-inferiority randomised controlled trial into the use of telehealth to support people with dementia and informal care partners, and concluded that it is feasible to offer dyadic interventions via telehealth, that it reduces travel time and importantly that it results in similar benefits for families.

A non-inferiority trial attempts to establish whether or not a new treatment is no worse than an established treatment for which efficacy has been determined in placebo-controlled trials.

The study involved randomising 63 dyads (a person with dementia and a care partner) to receive either telehealth or home visit delivery of the same intervention program (an adapted version of the occupational therapy COPE program, Care Of Persons with Dementia in their Environment, developed by Gitlin *et al*).

Associate Professor Kate Laver from Flinders University was the lead researcher for the study which was published in March 2020 in the *American Journal of Geriatric Psychiatry*.