



Perspectives of Australian family carers of people with dementia on the 'cottage' model of respite: Compared to traditional models of residential respite provided in aged care facilities

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Abstract

The majority of people living with dementia reside in the community and are often reliant on the support of informal carers to do so. Family carers face many challenges in supporting the person with dementia to remain at home, and short-term respite care is a valued service that offers a temporary break from the role. Respite cottages provide short-term care in a residential home-like setting with a limited number of clients and is a more flexible approach to accessing the service. Disproportionate use of cottage respite in Australia suggests this model is preferred over traditional respite within residential aged care facility (RACF) settings, yet limited research exists to compare these models. This study sought to understand the perceptions of carers who had used cottage respite in comparison to other models, and explore the contribution of cottage respite for supporting carers to continue in their role and maintain their care recipient (CR) living at home. Semi-structured interviews were conducted with 126 family carers who had used one of two New South Wales-based respite cottages within a 2-year period; 67 of whom had also used RACF respite. Thematic analysis revealed four main themes around the benefits of cottage respite: (a) an effective essential service, (b) flexibility, (c) familiarity and (d) appropriateness, especially for early stage or younger onset dementia. Carers indicated that the more homely, familiar and intimate cottage model of respite care was preferential to that of the larger, institutional-style RACF respite setting. Carers credited the cottage model of respite service with delaying their need for permanent residential placement by over 12 months. The cottage respite model provides an important avenue to supporting the individual needs of dementia dyads, with potential to delay permanent placement, and should be offered more broadly to provide people with more choice about their care.

KEYWORDS

cottage respite, dementia, family carer, long-term care, respite

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1 | INTRODUCTION

An estimated 376,000 Australians have dementia; projections suggest this may increase to 550,000 by 2030 (Australian Institute of Health and Welfare (AIHW), 2018). Most people (70%) living with dementia reside in the community, and recent estimates suggest that over 1.2 million Australians provide informal care to someone living with dementia (Alzheimer's Australia, 2014). The importance of informal care in helping people with chronic conditions to remain living in the community has long been recognised (Golodetz, Evans, Heinritz, & Gibson Jr, 1969; Shanas, 1979). Research suggests that both carers and care recipients (CRs), for the most part, wish to remain living in the community for as long as possible (Alzheimer's Australia, 2014; Brodaty & Cumming, 2010).

Carers often derive considerable satisfaction from providing care to a loved one, and the role can positively affect health and well-being (Brown et al., 2009; Poulin et al., 2010). However, caring for a community-dwelling person with dementia is not without challenges. Many aspects of carers' lives can be adversely impacted by the role. This can include their employment, financial security, social life, family relationships and mental and physical health (Pinquart & Sörensen, 2007; Poulos, Beattie, Gresham, & Harkin, 2016; Roepke et al., 2011; Rubin & White-Means, 2009; Schulz & Sherwood, 2008; Sörensen & Conwell, 2011; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004;; Wang, Shyu, Chen, & Yang, 2011). These impacts are often chronic because the caring role can be prolonged (Rait et al., 2010; Wolfson et al., 2001; Xie, Brayne, & Matthews, 2008).

While disease-modifying treatments for dementia remain elusive (Baskys & Hou, 2007; Winblad et al., 2016), the interim focus must be on maintaining the health and well-being of both members of the dyad living in the community (Rausch, Caljouw, & van der Ploeg, 2017). Policy makers must therefore enact appropriate supports that maximise potential for CRs to remain at home while also reducing the negative impacts on carers (Brodaty & Cumming, 2010). Short-term respite care is one support service that carers can utilise to help maintain their own health and well-being. Respite serves three main purposes for carers: (1) temporary rest and relief from the role; (2) opportunity to participate in other aspects of life beyond the role and (3) mitigation of the emotional and physical health issues that are sometimes associated with the caring role (Gusi, Prieto, Madruga, Garcia, & Gonzalez-Guerrero, 2009; Leggett, Zarit, Taylor, & Galvin, 2011; Neville, Beattie, Fielding, & MacAndrew, 2015).

In Australia, daytime respite is offered in-home and at day centres; overnight respite is available in residential aged care facilities (RACFs) and small cottages located within community settings (Brodaty & Cumming, 2010; O'Connell, Hawkins, Ostaszkiwicz, & Millar, 2012). In contrast to RACFs, cottage respite is delivered in small home-like facilities that accommodate a limited number of clients at a time (Department of Health (DOH), 2018). Cottage respite can be more expensive to operate than RACF models because they cannot achieve the same economies of scale, with a limited number of clients (Svensson, Edebalk, & Persson, 1996). Given that traditional residential respite models have shown adverse effects for both carers and CRs

What is known about this topic

- The majority of people with dementia reside in the community, and prefer to continue doing so
- Family carers play a vital role in supporting their loved one to remain at home
- Short-term respite offers an important temporary break from the caring role

What this paper adds

- Family carers and people with dementia largely prefer the cottage respite model when compared to the residential aged care facility setting
- Carers perceive cottage respite as offering respite that is a more homely, intimate, flexible, familiar service than many residential aged care facilities
- Carers overwhelmingly indicated that cottage respite played an important role in delaying permanent placement into residential aged care for their care recipient with dementia

(Vandepitte et al., 2016), evaluation of alternatives, such as the cottage model, is paramount. There is limited research on how cottage respite compares to other models, most probably because in-home and RACF respite are the most commonly used options (Hancock & Jarvis, 2005; O'Connell et al., 2012). There are 2,460 RACF respite services Australia wide (AIHW, 2017), compared to approximately 55 'cottage-respite' facilities; only 24 cottages operate 7 days a week in stand-alone community settings (AIHW, 2019); the remainder operate over variable periods, are attached to other facilities or both. Respite cottages represent just 2.0% of out-of-home overnight respite services yet provided over 6.0% ($n = 3,559$) of all Government-funded overnight respite in 2016–2017 (ACFA, 2018; AIHW, 2017).

This disproportionate use suggests a preference for the cottage model of care, yet little is known about outcomes such as the carer experience and perspectives about whether it contributes to delaying placement into permanent care.

The aim of this study was to explore carers' perceptions of cottage respite. In particular, we sought to understand how cottage-style respite compared to other forms of respite, and what impact cottage respite had on helping carers maintain their CRs at home.

2 | MATERIALS AND METHODS

2.1 | Study design and setting

This study builds upon previous work, *Beyond Respite*, which explored the lived experiences of carers and included participants who had also used cottage respite (Poulos et al., 2016). Interview data

from four *Beyond Respite* study participants who had used the same two respite cottages were included in this study. This study was designed to build on this preliminary data by conducting semi-structured interviews with carers to determine their experiences with using cottage respite. The respite cottages described in this study (herein referred to as Cottage 1 and Cottage 2) have been in operation for over 10 years and are run by the same not-for-profit service provider; services are accessed through a government subsidised aged-care program (DOH, 2018). The cottages offer short-term residential respite (i.e. 1–10 consecutive nights per admission), and unlike many RACFs, have no mandatory minimum periods of stay (Carers Australia, 2017). They are typical suburban homes that have been repurposed for overnight respite, yet retain domestic aspects that could be recognised as familiar and homely. A comprehensive history informed by family at intake supports each CR's personhood through the provision of individualised care. Both Cottages can accommodate five CRs concurrently, with an option for carers to stay to ease transition. Cottage 1 includes one high-dependency bed with lifting equipment for people with more complex health needs. Two staff are on duty round-the-clock, and a manager is on-site during weekdays.

2.2 | Participants

Following approval from the University of New South Wales Human Research Ethics Committee, cottage management provided a list from service records identifying carers who had used either Cottage 1 or Cottage 2 on two or more occasions, with at least one visit falling within the study period (between 1st October 2012 and 30th September 2014). These carers were sent a letter describing the study, and advising that they would be contacted by telephone in subsequent weeks to ascertain their interest in taking part in a short telephone interview about their experiences and reflections on their use of the cottages and any other respite services they may have used.

2.3 | Data collection

The semi-structured telephone interview (Table 1) was developed by the last author (CP) to explore carers' experiences of respite. Questions covered the dyadic relationship, experiences with respite services and whether carers thought cottage respite made any contribution towards maintaining the CR at home or delaying their placement into permanent care.

Once participants completed the 30-min semi-structured telephone interview, all were offered an opportunity to participate in a longer in-depth telephone interview that was intended to explore the initial findings in greater detail. Interviews were conducted between June and October 2015 by MRB. Once interviews were conducted and transcribed, data from the *Beyond Respite* study (collected by DH; Poulos et al., 2016) were included for qualitative analysis. Both researchers were independent of either cottage.

TABLE 1 Overview of semi-structured interview questions

Status of dyadic relationship
<ul style="list-style-type: none"> • Are you still caring for [CR]? <ul style="list-style-type: none"> ◦ Has [CR] gone into permanent care/passed away? • What is/was your relationship with [CR]? • How long have you been/were you the primary carer for [CR]?
Exploratory topics: respite experience
<ul style="list-style-type: none"> • Cottages • Other forms of respite • RACFs
Role of cottage respite in delaying permanent care placement (if CR was placed in permanent care)
<ul style="list-style-type: none"> • What role did respite for [CR] in [COTTAGE NAME] have in delaying the need for permanent nursing home care? <ul style="list-style-type: none"> ◦ Likert scale of 1 to 10, with "1" being "Didn't have any role in delaying the need for permanent care", and "10" being "Had a very definite role in delaying the need for permanent care" ◦ If you feel that access to respite in [COTTAGE NAME] was <i>helpful in delaying the need</i> for [CR] to be placed in permanent nursing home care, for what extra time do you think you were able to provide care for [CR] at home because of [COTTAGE NAME]?
Role of cottage respite in preventing permanent care placement (if CR not placed in permanent care)
<ul style="list-style-type: none"> • If you feel that access to respite in [COTTAGE NAME] <i>has been helpful in preventing the need</i> for [CR] to be placed in permanent nursing home care? <ul style="list-style-type: none"> ◦ For what extra time do you think you have been able to care for [CR] at home because of the availability [COTTAGE NAME]?
Reflections on cottage respite
<ul style="list-style-type: none"> • Is there anything else you would like to tell us about respite in [COTTAGE NAME]?

Abbreviations: CR, care recipient; RACF, residential aged care facility.

2.4 | Analysis

Surveys and interviews were audio-recorded and independently transcribed. Transcripts were read and re-read. They were analysed inductively, thematically coded, reviewed, re-coded and categorised using NVIVO 11 (NVivo qualitative data analysis software, 2010). Analyses were conducted separately by the first and third authors, DH and MRB, and reviewed in discussion to resolve interpretations and confirm analysis (Braun & Clarke, 2006). Themes were supported with direct quotations, coded according to participant number (e.g. P1), gender (male, M; female, F) and data origin (*Beyond Respite*, BR; Cottage study, CS).

3 | RESULTS

Of the 361 potential participants who were sent a letter about the study, 81 could not be subsequently contacted by telephone (and were lost to follow-up). A further 118 were excluded for not meeting inclusion criteria. Of the 162 carers who met the

criteria, 36 declined to participate and 126 completed the telephone survey, representing 77.8% response rate of those invited to participate (73.4% for Cottage 1; 84% for Cottage 2). In-depth interviews were ceased after the first five generated no new information beyond that already collected in the 30-min interviews.

Participant demographic details are in Table 2. The majority of CRs, but not all, had a primary diagnosis of dementia (77%). The remaining 23% had an alternative diagnosis (e.g. Parkinson's disease, cerebrovascular accident or frailty), with no further data available on the CR's cognitive status. Almost half (44.4%; $n = 56$) of the CRs were still being cared for at home; just over a third (35%; $n = 44$) had moved to permanent care; the remaining 20.6% ($n = 26$) had died (of these, 84.6% ($n = 22$) had died while in permanent care). Over half (59.5%) of dyads used cottage respite five times or more and 21.4% had used it on 11 or more occasions. Dyads had used a range of respite services to complement the use of cottage respite. Sixty-seven carers had experienced both cottage and RACF respite; of these, 83.6% preferred the cottage model.

3.1 | Cottage respite to delay permanent placement

The overwhelming majority (93.6%, $n = 118$) of carers indicated that cottage respite was helpful in maintaining the CR at home. Sixty-six CRs had been placed in permanent care. Half of their carers (50%, $n = 33$) reported that cottage respite had definitely contributed to delaying placement.

For placement delay data, see Table 3. Thirty-four carers offered a specific timeframe for the estimated delay in placement, ranging from 6 months to 6 years, with an average delay of 15.6 months.

The other 32 carers did not offer a timeframe for delay. Offering instead, various reasons why cottage was "not helpful" or the determinant factor in delaying placement. Their reasons illustrate not only the complexity of dyadic life, but highlight how challenging circumstances, often health-related, can overtake the lives of dyads, often leaving placement as the only option.

3.2 | Features of cottage care

Carer-identified 'good features of care' in cottage respite were categorised into nine themes (Table 4). Five themes accounted for nearly 80% of responses; these included: 'personalised care and attention' including "excellent" care from staff with a "can-do" approach that contributed to their CR's physical and mental health not being adversely affected by cottage respite; 'general positive comments' about the cottage experience; specific 'cottage attributes' including their smaller size and setting; 'good staff and management' and a 'homely atmosphere'. Unlike RACF respite, carers reported that their CRs were not "coming home deteriorated" from cottage respite (P5-F-CS). The home-like nature of the cottages also made transitioning

TABLE 2 Demographic characteristics of participants at the time of interview

	Cottage 1 ($n = 68$)	Cottage 2 ($n = 58$)	Combined ($n = 126$)
Care recipient			
Male (%)	46.3% (32)	62.1% (36)	53.5% (68)
Age (mean, years)	82.8	80.3	81.6
Primary diagnosis of dementia	73.5% (50)	81% (47)	77% (97)
Carer			
Female (%)	77.9% (53)	81.0% (47)	79.4% (100)
Time in role (mean, years)	7.5	6.4	7.0
Caring status at survey (%)			
Still caring at home	39.7% (27)	50.0% (29)	44.4% (56)
Entered RACF	32.3% (22)	37.9% (22)	35.0% (44)
CR Deceased (RACF)	22.1% (15)	12.1% (7)	20.6% (22)
CR Deceased home/hospital/respite	5.9% (4)	0% (0)	4% (4)
No. cottage Admissions (% carers)	(2–45 visits)	(2–82 visits)	($n = 126$)
2–3	33.8% (23)	25.9% (15)	30.1% (38)
4–6	30.9% (21)	31.0% (18)	31.0% (39)
7–10	16.2% (11)	19.0% (11)	17.5% (22)
≥11	19.1% (13)	24.1% (14)	21.4% (27)
Use of respite services			
Day centre	54.4% (37)	81.0% (47)	66.6% (84)
In-home (day)	75.0% (51)	60.3% (35)	68.3% (86)
In-home (overnight)	13.2% (9)	13.8% (8)	13.5% (17)
Exclusively cottage	4.4% (3)	1.7% (1)	3.2% (4)
RACF	57.4% (39)	48.3% (28)	53.2% (67)
Respite Preference (% carers who had used both cottage and RACF respite)	($n = 39$)	($n = 28$)	($n = 67$)
Cottage	92.3% (36)	71.4% (20)	83.6% (56)
RACF	2.6% (1)	3.6% (1)	2.9% (2)
No preference	0.0% (0)	10.7% (3)	4.5% (3)
Don't know	5.1% (2)	3.6% (1)	4.5% (3)
Declined to answer	0.0% (0)	10.7% (3)	4.5% (3)

Abbreviations: CR, care recipient; RACF, residential aged care facility. Refer to Table 1 for associated survey questions.

between home and respite less disruptive and distressing. Cottage respite, as one carer said: "feels like a home not a facility. She slips back into her normal routine at home very easily" (P6-F-CS). A large proportion of carers reported that "nothing could be improved" about cottage respite. However, some carers suggested improvements such as

	Cottage 1 (n = 68)	Cottage 2 (n = 58)	Combined (n = 126)
Role of cottage respite in helping to continue caring at home (% carers) ^a	(n = 68)	(n = 58)	(n = 126)
Not helpful			
1-3	1.5% (1)	0.0% (0)	0.8% (1)
4-6	5.9% (4)	3.5% (2)	4.8% (6)
Helpful			
7-10	92.6% (63)	96.5% (55)	93.6% (118)
Did not answer question	0.0% (0)	1.7% (1)	0.8% (1)
Role of cottage respite in delaying placement for the CRs moved into permanent care ^a	(n = 37)	(n = 29)	(n = 66)
Limited role			
1-3	35.1% (13)	24.1% (7)	30.3% (20)
4-6	0.0% (0)	10.3% (3)	4.5% (3)
Definite role			
7-10	43.2% (16)	58.6% (17)	50% (33)
Did not answer question	21.6% (8)	6.9% (2)	15.1% (10)
Carers' estimate of placement delay attributable to cottage respite	(n = 19) ^b	(n = 15) ^c	(n = 34)
Months, mean (range)	15.3 (6-60)	16.0 (6-72)	15.6
Carers who provided no estimate of delay but gave other reasons for doing so	(n = 18)	(n = 14)	(n = 32)
Helpful in delay, but no time given	22.2% (4)	28.6% (4)	25% (8)
Carer health issue	11.1% (2)	7.1% (1)	9.4% (3)
CR health issue	27.8% (5)	14.3% (2)	21.9% (7)
CR and carer health issues	5.5% (1)	21.4% (3)	12.5% (4)
Early stage dementia	0.0% (0)	14.3% (2)	6.25% (2)
Used cottage late in progression	5.5% (1)	0.0% (0)	3.1% (1)
RACF place became available	11.1% (2)	0.0% (0)	6.25% (2)
HP urged placement	11.1% (2)	7.1% (1)	9.4% (3)
Ambiguous response	5.5% (1)	7.1% (1)	6.25% (2)

Abbreviations: CR, care recipient; HP, health professional; RACF, residential aged care facility. Refer to Table 1 for associated survey questions.

^aLikert scale responses.

^bA total of 37 eligible to answer: 19 time-based answers provided, 18 did not specify.

^cA total of 29 eligible to answer: 15 time-based answers provided, 14 did not specify.

facilitating longer respite stays (like those available at RACFs), more beds available at short notice (emergency beds), more physical activities and outings for CRs, ensuring CRs with comparable levels of dementia visited at the same time and providing staff with additional training.

3.3 | Benefits of cottage respite

Thematic analysis of participant survey, in-depth interviews and *Beyond Respite* data using NVIVO software for data management generated four main themes around the benefits of cottage respite: *an effective service, flexibility, familiarity and appropriateness.*

TABLE 3 Role of respite cottages in supporting dyads

3.3.1 | Theme 1: Cottage respite, an effective service

The first theme was the extent to which carers viewed respite as an *effective*, valued and much needed service. It was, for many, an essential pillar of support. Once accessed, respite not only provided welcome necessary relief from the carer role but also contributed greatly to carers' quality of life, and ability to continue in the role. One carer who accessed cottage regularly said her husband:

goes to respite for 4 nights a month up at [cottage], so I get that break..., I think I'd go nuts without it.

(P1-F-BR)

TABLE 4 Thematic representations of carer-identified 'good features' of cottage respite

Carer identified good features—Themes	Responses (n = 122) Frequency (%)
Personalised care and attention	102 (20.7)
General positive comment	85 (17.2)
Cottage attributes (small size, high staff ratio)	83 (16.8)
Good staff and management	66 (13.4)
Homely atmosphere	57 (11.6)
Outings, in-house activities, socialisation	46 (9.3)
Care recipient liked it	24 (4.9)
Carer able to relax	17 (3.4)
Other (close to home, clean and tidy)	13 (2.6)
Total	493 (100)

Another said:

Using [cottage] helped in the early stage of the dementia journey and I became comfortable with the fact I could leave him overnight. The first time I left him at [cottage] I cried but I desperately needed the respite even if it was only to sleep.

(P7-F-CS)

Carers deemed respite vitally important because many had found the caring role life altering and at times, overwhelming. One carer recounted how he had sacrificed his career, social life and even his fiancée to care for his mother. Despite having a close, loving relationship with her, he admitted that the role could be stressful and demanding. His mother's behaviour on occasion, "got a bit much", and he would have to "go outside in the backyard and scream for a while" (P2-M-BR).

Similarly, the financial stress another carer experienced after stopping work to care for her husband was now being compounded by social isolation:

Not that many people call anymore, because once they realise that he couldn't really hold a proper conversation people stopped coming. So you're sort of left in this... world, basically on your own

(P3-F-BR)

This carer said she had experienced a psychological "breakdown" because of the role. Another carer who was "struggling" in the role acknowledged the difference respite made to his life:

I think, the greatest thing for me, was that, that respite care for my wife

(P4-M-BR)

Carers highlighted that overnight respite not only enhanced well-being, but helped maintain the CR at home. There were not many support services, one said, that actively help with this.

Respite is a necessity for people who care. They do need the break. Even though you love someone and love to look after them, towards the end it really was difficult. Respite prolongs your sanity and wellbeing. It is really important to have respite.

(P8-F-CS)

I couldn't have managed without the overnight respite. There are really very few services to help people to stay at home longer.

(P9-F-CS)

3.3.2 | Theme 2: Flexibility of service

Carers reported that the cottages were more flexible and responsive to their and their CR's needs than other respite services. Cottages facilitated the gradual introduction of CRs to respite in contrast with the mandatory minimum period common in RACF respite. As one carer noted:

If I've got to tell my mother that she is going to go into respite for two weeks, she is going to figure that I have abandoned her.

(P2-M-BR)

Carers appreciated that they could also stay overnight with their CRs to ease their adjustment to cottage respite. Carers were able to extend respite visits as CRs became more comfortable with the cottages. Recounting his mother's initial visits to the cottage, one carer said his mother had:

liked it, she went to it twice, she liked it, so I am hoping that she will go the third time and like it... And eventually I can wean her into the idea of respite care, for... for 2 or 3 weeks at a time

(P2-M-BR)

3.3.3 | Theme 3: Familiarity

This theme encompassed a range of aspects that articulated why cottage respite resonated so strongly with both carers and CRs. Carers who had experienced both cottage and RACF respite said they valued the cottages because they were not "institutions". One carer, contrasting the different respite experiences, said that the RACF her mother went to for respite was:

a big institutional nursing home, [whereas the cottage was like] a home away from home

(P10-F-CS)

going there. He loved the people. When asked by the staff if he would come back, his response was "I know when I'm on a good thing".

(P15-F-CS)

This point of distinction was reiterated frequently:

[cottage] was like a home—It was a lovely place to stay. [cottage] was a lovely experience.

(P11-F-CS)

Another carer said his wife "liked it. I'd get a smile on her face when we pulled up outside".

(P16-M-CS)

Just like a home away from home.

(P12-F-CS)

Carers indicated that the smaller scale of the cottages meant staff were readily accessible. These factors, carers said, were central to their CRs' cottage respite experience. Carers said cottage staff provided care that felt inherently personal. Cottage was:

Small, like a home. Caring, well-chosen [staff]. One-to-one care. [they] took him for walks to see the ducks up the road

(P13-F-CS)

less institutionalised, far more individual, holistic. [CR] is involved in choices

(P17-F-CS)

Further analysis of carers' observations on the home-like nature of the cottages indicated that the carers were not only referring to the architectural, spatial order and layout of the cottages, but their comments were also a reflection of other, more ill-defined, characteristics. This was evidenced by comments from numerous carers. One carer explained why the 'homely' aspect resonates so strongly with people of his CR's generation. Once an older person goes:

into an institution, once you go into that regimentation, the, the army barracks syndrome, it loses all the things that the elderlys (sic) have done, is created a home. And what they have spent coming through the depression or war, and they have a family, they create a home, all of a sudden they are in to the army barracks of old age?

(P2-M-BR)

3.3.4 | Theme 4: Appropriateness

The fourth theme related to the *appropriateness* of cottage respite for the CRs. Some carers felt the RACF respite environment was not appropriate for their CRs:

I don't think he is suitable. He has younger onset dementia (diagnosed before age 60 years) and his level of dementia is mild to moderate. He is not suitable for residential nursing home respite because of his age; he's too young.

(P18-M-CS)

My father was unhappy in nursing home environment. He felt he was too young to be there.

(P19-F-CS)

Similarly, another said:

I think old people are more comfortable in that [cottage] environment, similar to the environment they remember growing up.

(P14-F-CS)

Others said their CRs found RACF respite confronting and distressing, especially if they were placed with people whose dementia condition was more advanced than their own:

[RACF] was not really suitable for my mother—she was not physically incapacitated. The circumstances of other residents really distressed my mother—other residents were more severe, screaming and calling out all the time.

(P20-F-CS)

In addition, carers said cottage staff encouraged their CRs to engage and participate in 'familiar' activities like "peeling the potatoes" (P2-M-BR).

Some carers indicated that the familiar, homely environment and actively engaging staff contributed to their CRs developing close connections with the cottages and their staff. This was reflected not only in the frequency of return visits but also in comments CRs made to their carers about their cottage experiences. One carer's husband "loved":

At the nursing homes [CR] was placed in with very severe dementia patients when he was cognitively competent. It was very confronting for him to see what his future was.

(P21-F-CS)

When you go into respite in an institution [RACF] you are staring at your future.

(P26-F-CS)

Carers appreciated that cottage management were mindful of CR distress, which they attempted to mitigate by coordinating cottage stays with CRs with similar and compatible impairments. This also fostered better social interaction between CRs during their stays and ensured everyone had the same capacity for engaging and participating in shared activities, such as meal preparation, if they wished to do so.

Guests got involved in everyday things, like wiping up, like at home. There was lots of chit chatting to her [by the staff].

(P23-M-CS)

[Managers made] the best fit with my father's abilities and the other people who stayed there at the same time

(P24-F-CS)

Carers recognised that a point would inevitably come when they would no longer be able to care for their CR at home. One carer hoped that:

as this thing moves on further and further and further, [...] hopefully, that I can find respite and [...], permanent care in something like [cottage], with that same philosophy. I don't know if I am going to find it.

(P2-M-BR)

CRs were also cognisant of the difference between cottage and other forms of respite:

Mum liked it [cottage] and she wasn't willing to go anywhere else.

(P25-F-CS)

4 | DISCUSSION

This study reports findings from interviews with family carers of people with dementia who have used overnight cottage respite. This is, to the best of our knowledge, the first evaluation of cottage respite use in Australia. Findings suggest that, with respect to the two cottages included in this study, cottage respite is preferred over traditional RACF models.

While there have been longstanding calls for improvement in the quality and evaluation of interventions targeting dementia dyads (Pinquart & Sörensen, 2006; Van't Leven et al., 2013; Zarit, Bangerter, Liu, & Rovine, 2017), recent review studies offer different conclusions on the effectiveness of respite (Maayan,

Soares-Weiser, & Lee, 2014; Parker, Mills, & Abbey, 2008; Steering Committee for the Review of Government Service Provision, 2018). Some authors maintain that the approaches of previous reviews assessing respite are methodologically inappropriate and more dyadic-centric approaches must be undertaken (Van't Leven et al., 2013; Zarit et al., 2017). However, our carers consistently said that cottage respite was an effective support for them and, importantly, that it contributed to delaying placement of the CR into permanent care.

There remains relatively little research on carers' perceptions around respite care (Phillipson, Jones, & Magee, 2014). This study goes some way towards addressing that deficit. Our carers, like others, do not wish to supplant formal care in place of their own efforts but wish to use temporary respite as one of the supports that enable them to continue in the role for as long as the situation permits (Gitlin & Schulz, 2012).

Carers report that the cottage model offers a more effective, personalised approach to care, the importance of which cannot be underestimated in the progressively changing landscape of dementia support. Following studies suggesting that larger institutions are not always the best places for meeting the needs of people with dementia (Brody, Lawton, & Liebowitz, 1984; Rule, Milke, & Dobbs, 1992), there has been a global move towards providing care for people with dementia in smaller facilities (Annerstedt, 1994; Verbeek, Van Rossum, Zwakhalen, Kempen, & Hamers, 2009; Wimo & Morthenson Ekelöf, 2004). These smaller, more personal environments can foster positive effects for the person living with dementia, such as: meaningful relationships between staff and CRs (de Rooij et al., 2012), reducing prominence of symptoms of dementia, delayed functional decline and enhanced quality of life on measures such as privacy, dignity, meaningful activity, autonomy, emotional well-being and better social engagement (Annerstedt, 1994; te Boekhorst, Depla, de Lange, Pot, & Eefsting, 2009; Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Given these findings, it fits that the dyads in this study overwhelmingly viewed cottage respite positively. Carers reported that the 'home-like' setting of the cottages was pivotal in facilitating these positive experiences. The call for the provision of respite care in home-like environments is not new (Perks et al., 2001; Shanley, 2006), and scholars increasingly recognise the contribution that 'home-like' environments make to the quality of life and wellness of older people (Gillsjö, Schwartz-Barcott, & von Post, 2011; Molony, 2010). Therefore, it is perhaps unsurprising that dyads in our study preferred accessing respite in a 'home-like' setting.

The respective distribution of respite cottages and RACFs nationwide may be a reflection of the higher costs associated with smaller-scale operations (Svensson et al., 1996). However, given the positive outcomes and experiences reported here, and the belief that cottage respite delayed placement, it is possible that cottage respite may be associated with cost savings.

People living with dementia and their family carers want to remain at home for as long as possible (Alzheimer's Australia, 2014; Brodaty & Cumming, 2010). In a time when dyads are increasingly

being afforded more control over their funding and the caring process, it is incumbent upon policy makers to support respite choices that reflect these preferences and needs.

In this study, carers identified the “homely atmosphere” as a positive feature of cottage respite. Further positives were that the cottages were not ‘institutions’, they conferred a sense of ‘familiarity’, intimacy and even agency by engaging CRs in daily activities. The latter is important because it recognises the importance of the autonomy and personhood of the person with dementia (Kaufmann & Engel, 2016; O’Shea, O’Shea, Timmons, & Irving, 2019). Within the cottages, CRs could choose to engage in social or functional activities with others (such as helping with meal preparation), enjoy spending time in the garden or simply relax in their rooms. This aligns with previous studies highlighting the benefits of smaller settings to promote CR engagement and foster activity (Gnanamanickam et al., 2018; Kuhn, Fulton, & Edelman, 2004; Smit, de Lange, Willemse, & Pot, 2012). The cottages were renovated homes located in the types of neighbourhoods that would have been very familiar to many of the dyads (Poulos et al., 2016). Indeed, it has long been recognised that the home is more than a structure within which one resides. The literature describes how “home” can represent multiple meaning in the human psyche. It can variously represent a social unit, individuality, self-expression, belonging and a reflection of ‘self’ (Appleyard, 1979; Sixsmith, 1986; Young & Wilmott, 2013). The family home provides the symbolic, emotional and physical link to ‘home’, family, friends, social support, neighbourhood and community (Means & Evans, 2012; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Home also embodies an individual’s ties to the society within which they live (Sixsmith, 1986). In contrast, accessing respite in more institutional settings, where many CRs will inevitably move into permanent care, can cause distress because it can illustrate their care trajectory. This was supported in comments by carers in this study that an important feature of cottage respite is that it is familiar “like a home”, and it is easier for CRs to transition in and out.

In addition to “familiarity”, carers also emphasised that cottage management’s flexible approach to respite visits helped to allay one of the main concerns that some of our carers had with putting their loved ones into respite; namely, the distress CRs sometimes experience in unfamiliar environments. Feeling distressed by unfamiliar environments, carers felt, would only be compounded by accessing respite in settings with mandatory minimum respite periods, as is common in RACF respite (Carers Australia, 2017). Another concern carers raised was the appropriateness of the CR’s respite environment. Not just in facility size, but that people with similar levels of dementia should be grouped together to enhance their opportunity for social engagement and reduce the possibility of observing confronting symptoms in people with more advanced disease.

Despite citing many positive aspects of cottage respite, most carers also utilised other forms of respite. This could be a reflection not only on the variable availability of the limited cottage respite places

but also that carers require multiple supports to continue caring. This also supports the notion that once engaged, carers are willing to make use of varied support services but are limited by knowledge and availability of appropriate services (Brodaty, Thomson, Thompson, & Fine, 2005; Phillipson et al., 2014). The paucity of cottages nationwide leaves dyads with few opportunities to exercise choice (AIHW, 2019).

This study has a number of limitations that must be considered. Participants were taken from respite services in two specific areas of greater Sydney, which limits the generalisability of results. However, this limitation also reflects the reality that there are very few respite cottages available in a geographical area serving a population of c.5m. This study did not capture the views of people who do not use respite, or have only used other models of respite. However, as Zarit et al. (2017) maintain, recruiting participants who actively access respite makes assessing the effectiveness of respite more rigorous. In addition, other studies suggest that respite is often under-utilised because carers are not ready to avail themselves of services or are unaware of their existence (Brodaty et al., 2005; Phillipson et al., 2014). Indeed, some long-term carers in the earlier *Beyond Respite* study (Poulos et al., 2016) did not know that the cottages existed. The two facilities in this study were classed as predominantly ‘low-care’. Staffing levels did not permit the level of supervision required to provide respite to many CRs with higher needs (e.g. more advanced dementia), therefore the sample mostly included people with mild-moderate dementia. Appropriate funding with additional supports and services would allow cottage respite to cater to people with higher needs, which would provide a more representative sample in future studies. Nonetheless, a marked strength of the study is the large number of participants, which adds weight to the findings.

Overall, carers saw the cottages as a more appropriate respite model because they perceived cottages’ focus was on providing personalised optimal care and, most importantly, effective respite for dyads, rather than efficiencies for service providers (Vandepitte et al., 2016). Overnight respite that is intimate, personal, homely and familiar does seem to breed contentment.

5 | CONCLUSION

Family carers are a crucial support that enables people with dementia to continue residing in the community. This study contributes additional insights into the respite experiences of dementia dyads. Carers viewed cottage respite not only as an effective support service for their health and well-being but also credited it with delaying permanent placement of their CRs. As dementia progresses, the needs of dyads will undoubtedly change; policy makers should focus on providing support services that reflect the aims of policy, which prioritise choice and helping people remain at home for as long as possible (DOH, 2015; New South Wales Health, 2014). Despite carers in our study reporting a preference for cottage respite over

the RACF model, respite cottages are not broadly available across Australia. Future work should further evaluate the benefits of cottage respite with the ultimate aim of facilitating more personal choice around care.

CONFLICT OF INTEREST

The authors have no conflicts.

AUTHOR CONTRIBUTIONS

CJP conceived of the study. M-RB managed data collection. DJH and M-RB conducted qualitative analyses. DH and CO drafted the manuscript. All authors reviewed, edited and approved the final manuscript.

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