

Seeking respite: issues around the use of day respite care for the carers of people with dementia

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ABSTRACT

Ageing in Place policies have transferred responsibility for many frail elderly people and those living with dementia from residential to in-home care. Despite this placing a greater obligation on families, in Australia carers continue to under-use day respite services. This qualitative design study identified issues around the use of day respite care from the perspective of the family carer, focusing on barriers to attendance and strategies to facilitate attendance. Telephone interviews were held in 2007 with Tasmanian carers whose family member refused to attend day respite care (ten carers) and those whose family member attended (17). Carers considering day respite care were often overwhelmed by the quantity of information, confused about the process, and worried about the recipient's safety in an unfamiliar environment. They felt anxious about public acknowledgement of the condition leading to fear of embarrassment. Day respite care users appreciated the break it provided them and the opportunity for their family member to socialise. To facilitate a greater uptake of day respite care, reliable information sources and strategies to help carers deal with the emotions they face on a daily basis, together with a wider social acceptance of dementia, are important. Furthermore, carers need an opportunity to talk with others, enabling them to gain support from those who have successfully introduced a family member to day respite care.

KEY WORDS – carers, dementia, day respite, support, caregiving, Australia.

Introduction

Changing demographics in Australia, in line with global trends, have seen rapid growth in the proportion of older people in the population and an associated increase in the prevalence of dementia and chronic disease

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(Alzheimer's Disease International 2009; Australian Institute of Health and Welfare (AIHW) 2009*a*). This change places increasing demands on health-care services and is associated with a shift toward community-based care for many older people. Family carers of frail older people living in the community play a vital role in sustaining community-based care provision. Providing appropriate support for these carers has therefore become increasingly important, especially where they experience caregiving as a burden (AIHW 2007).

Respite care aims to alleviate carer burden, potentially increasing the length of time a person is able to live at home (Dröes *et al.* 2006; Treloar 2001). It can be provided for a duration varying from hours to months by services such as nursing homes, day centres, hospitals and in-home care providers (Neville and Byrne 2002). In Australia, in-home, residential, emergency, overnight and day care respite services can be accessed through a variety of government programmes such as the Home and Community Care Program (HACC), Residential Aged Care Program and National Respite for Carers Program (Bruen and Howe 2009). Access is based on eligibility, priority and need, with fees varying depending on type of service used (Department of Health and Ageing (DoHA) 2006). Commonwealth Respite and Carelink Centres located across Australia form part of the National Respite for Carers Program; these serve as sources of information for carers and can assist with organising respite care assistance packages (DoHA 2009). However, Australia lacks 'case management' (Robinson *et al.* 2010) and consumer-directed care approaches (Stockwell-Smith, Kellett and Moyle 2010) to the support of carers whereby carers may be supported to make a decision to access respite services, such as by initiating contact with these Centres and utilising the respite services that are offered. This is in contrast to some other countries such as England where programmes such as Caring with Confidence seek to empower and enable carers (Department of Health 2009).

Day respite care, the focus of this paper, involves the person accessing a day care centre which provides various social activities, with the associated stimulation and the company of like people (Al Mahdy 2004). Although not all research has found day respite care to be beneficial (*e.g.* Lee and Cameron 2004), many studies have reported benefits for both carers and recipients of day respite care (*e.g.* Mossello *et al.* 2008). Attendance at a day centre provides carers of frail older people with relief from caring duties; decreased worry, overload, anger and depression; freeing up of time to go to work or be with other family members; reduced time managing behaviour problems; improved sense of wellbeing; and improvements in ease of caring post-respite (Gaugler *et al.* 2003; Schacke and Zank 2006;

Zarit *et al.* 1998). Reported recipient benefits include decreased frequency of behavioural problems, decreased sleep-related problems, and a sense of feeling better (Femia *et al.* 2007; Gaugler *et al.* 2003; Mävall and Malmberg 2007; Mossello *et al.* 2008). Further, Madeo, Feld and Spencer (2008) report that carers' reasons for use of a day centre facility include some related specifically to the recipient, such as the recipient is safe, is engaged in useful or interesting activities, can socialise, is able to get out of the house, and that staff of the facility are caring.

Accepting respite is reported as being a 'gradual process resulting from the dynamic and complex interplay between recipient, caregiver and contextual factors' (Markle-Reid and Browne 2001: 282). Yet despite the benefits, respite care is under-utilised, even when readily accessible (AIHW 2007; Brodaty *et al.* 2005; Witt, Chenoweth and Jeon 2004), with carers often critical of the respite care provided (Ashworth and Baker 2000; Brody, Saperstein and Powell Lawton 1989). A key reason for lack of utilisation is an inability for the centre to meet the care recipient's needs with regard to level of disability (Brody, Saperstein and Powell Lawton 1989; Cohen-Mansfield *et al.* 1994). For example, people with dementia who also experience depression are likely to drop out of day care early, suggesting that their or their carers' needs are not being met (Mävall and Malmberg 2007). Other reasons include lack of awareness of available respite services, inconsistent client participation, cost, lack of transportation, shortage of respite places, geographical isolation, unwillingness on the part of the recipient to leave the home, lack of flexibility and time conflicts (Brody, Saperstein and Powell Lawton 1989; Cohen-Mansfield *et al.* 1994; Warren *et al.* 2003). Further, when preparing a relative for respite is a significant challenge for carers they are also less likely to use day care and gain the fewest benefits (Gaugler *et al.* 2003; Mävall and Thorslund 2007).

An important issue in the operation of day respite services relates to their ability to meet the needs of people with dementia. Although there are few data available on the characteristics of clients who attend day respite centres in Australia, statistics on residential respite clients suggest an elderly profile and a high prevalence of dementia among Australian day respite centre clients (AIHW 2003, 2009*b*). The majority (57%) of people with dementia in Australia are living in households rather than in cared accommodation (AIHW 2007), and therefore may need to access day respite. Moreover, in Australia care recipients with dementia are more likely to use respite services than those without (53% *versus* 37%) (AIHW 2004), while the existence of dementia-specific day respite centres and/or programmes highlights the importance of such services for carers (AIHW 2007). As such, day respite centres are an important component of the

management of an increasingly prevalent condition in a rapidly ageing population (AIHW 2003).

Stigma is a key issue which requires consideration in any exploration of the issues related to acceptance of day respite services for people with dementia (Burgener and Berger 2008; MacKenzie 2006; Werner and Heinik 2008). The operation of stigma has been found to delay the dementia diagnosis (Hansen *et al.* 2008; Vernooij-Dassen *et al.* 2005) and negatively impact on service use (Werner and Heinik 2008). Family carers are reported as perceiving there to be a stigma directed towards the person they care for, which in some cases leads to a desire to conceal both the diagnosis and the person with dementia in order to avoid rejection by others (MacKenzie 2006; Werner and Heinik 2008). Further, people with dementia themselves have been reported taking action, such as remaining indoors, to shield themselves from embarrassment and negative responses from others (Burgener and Berger 2008; Nomura *et al.* 2009). With regard specifically to day respite care, Ritchie (2003) reports that some 'private' families prefer to keep a family member at home rather than have them in day respite. Day care recipients (especially in early stage dementia) may be sensitive about their condition, seeing it or the associated behaviours as a source of embarrassment (Bacon and Lambkin 1997). This discomfort can manifest in reluctance to take part in particular activities, rigidity about routines within the care facility and even in refusal to attend (Bacon and Lambkin 1997; Ritchie 2003).

Regardless of the implications of the stigma associated with dementia, carers in any case describe the decision to accept respite as 'like passing a sentence' on their relative; a decision associated with significant carer guilt (de la Cuesta-Benjumea 2010; Hanson, Tetley and Clarke 1999: 1405). Carers may be ashamed that they cannot manage their situation without professional help (Cantegreil-Kallen *et al.* 2006), with the acceptance of respite accompanied by the realisation for the care recipient, their carer and the wider community that the family is unable to cope (Ashworth and Baker 2000; Nicoll *et al.*, 2002). In terms of addressing these issues, a number of authors argue that carers need to recognise the need for respite and to give themselves 'permission' to use it, while trusting that the family member is being provided with quality care (Brodaty *et al.* 2005; Cotrell 1996; Watts and Teitelman 2005). The latter point is important because new environments and routines present difficulties for both carers and recipients. Smyer and Chang (1999: 41–2) report that carers work 'long and hard to establish routines ... to give order to a chaotic existence', providing a controlling framework for the care-giving trajectory. However, when the care recipient attends respite and responsibility is handed over to a 'surrogate caregiver', carers worry that their 'hard work' will be 'undone'

(Smyer and Chang 1999: 42). Of note, maintenance of familiar patterns is associated with family carer confidence in respite care (Gilmour 2002).

So what prompts someone to seek day respite? Van Exel, de Graaf and Brouwer (2007) identified three groups of carers: those who need and ask for respite care, those who need but will not ask for respite care, and those that do not need respite care. It is the first two groups of carers that experience the greatest burden, would appreciate help with their task sometimes, and should be targeted by respite care programmes (van Exel, de Graaf and Brouwer 2007). Carer social and/or emotional needs and practical factors, such as poor carer health, are factors that prompt spouse carers to use respite services, while co-residing adult children carers identify employment and carer stress/exasperation as providing the primary impetus (Cotrell 1996). Braithwaite (1998) found that Australian carers were more likely to utilise respite if the demands of their role were high and if they were in a dysfunctional care-giving relationship with the recipient.

While these studies, together with those from Brodaty *et al.* (2005) and Witt, Chenoweth and Jeon (2004), shed some light on the Australian context, there is a lack of detailed information on the barriers and facilitators to the utilisation of day respite in Australia. More particularly, information is needed on what facilitates or frustrates family carers of people with dementia in accessing day respite care for a care recipient. Using data from telephone interviews, this paper examines these issues by telling the stories of two groups of carers of people with dementia in Tasmania, Australia: (1) those whose family member refuses to attend day respite care; and (2) those whose family member attends day respite care. The barriers to attending day respite care, how the carer deals with their family member's refusal to attend, how attendance at day respite care can be assisted, and the benefits of attendance are examined.

Methods

A qualitative approach, utilising telephone interviews, was adopted for this study which was conducted between August and December 2007 in Hobart, Tasmania, a city of around 150,000 people. In a literature review, Smith (2005) found that telephone interviewing is time effective compared with face-to-face interviewing, and may therefore be more acceptable to interviewees. Furthermore, participants can be easily contacted to clarify or to follow up information. However, telephone interviews with older adults present particular challenges; we therefore employed methods suggested by researchers such as Worth and Tierney (1993) and Berg

(2004) to enhance the effectiveness of the interviews. These included making contact with the participants to establish initial rapport and to reinforce the written information and consent mailed to participants prior to the interview, supporting comprehension by using clear, short, simple questions, and providing sufficient time for participants to respond. Using telephone interviews was a successful technique in this case, providing rich data. Participants were engaged with the topic and happy to share their – often lengthy – stories.

A semi-structured interview script was developed by the authors, drawing both upon the literature and their previous work. Table 1 lists the key questions, with additional questions asked as necessary to clarify issues and elicit greater detail.

The interviewer (third author), who had extensive experience in conducting telephone interviews, made notes during the interviews (as per Hemmings 1996). Where possible the participant's exact words and emphasis were noted – in some instances this was a phrase that could be quickly noted; at other times, if it seemed necessary to capture full sentences, the interviewer asked the participant to pause briefly while she made notes. This did not appear to disrupt the flow of the interview. Notes were typed up immediately following each interview and analysed for emergent themes using strategies drawn from grounded theory research (Speziale and Carpenter 2007). These early themes were revised and refined through the process of constant comparison of instances from the data and confirmed the direction of future interviews.

The soundness of this qualitative research was tested by Lincoln and Guba's (1985) criteria of credibility, dependability, confirmability and transferability. Credibility was established through the interviewer/researcher 'testing' the emerging themes with participants as the research progressed to ensure that they reflected his/her experiences. The purpose of this exercise is to validate the described experience with the reported findings, leading to dependability of the findings. Credibility was also enhanced by the interviewer/researcher discussing the data and emergent themes with a small team of skilled researchers with extensive qualitative research experience and clinical expertise in the care of people with dementia and their families. Confirmability requires the researcher to record accurately, and as clearly as possible, the evidence and thought processes which lead to the conclusions. Data were checked and rechecked and another author/researcher took a critical 'devil's advocate' role with respect to interpretation of findings. It is the responsibility of the user of the findings to make a judgement on the transferability – the probability that the findings have meaning to others in similar situations – of the results (Lincoln and Guba 1985).

TABLE I. *Telephone interview script listing the key questions asked of the carers of people with dementia*

Key interview questions

1. The decision to access day respite centre care:
 - (a) Why did you decide to try using a day respite centre?
 - (b) Was this an easy decision or a hard decision to make? Why was that?
 - (c) What could have made the decision easier for you to make? *OR* What could have helped you with making this decision?
 - (d) What things were important to you when you were deciding which day respite centre to access?
 - (e) How did (*name*) respond when you suggested that he/she attend a day respite centre?
2. The assessment and referral process:
 - (a) How did you find out about the day respite centre? How did the referral to the centre happen?
 - (b) What was your experience of the assessment and referral process for (*name*) to access the day respite centre? Was it an easy or difficult time? How long did the assessment and referral process take?
 - (c) How do you think the process of accessing a day respite centre could be improved or made easier?
3. Accessing the centre:
 - (a) Did (*name*) ever attend the day respite centre after he/she was referred to it?
 - (b) If yes continue below. If no, why not?
 - (c) Did you ever visit the centre?
 - (d) If yes continue below. If no, why not?
4. Day centre services, facilities and activities:
 - (a) What do you know about the programme of activities and services offered by (*name of day respite centre*)?
If the person referred to the centre attended the day centre or the carer visited the centre:
 - (b) What did you like about (*name of the day respite centre*)? What did you not like?
 - (c) What made a good or a bad impression for you?
 - (d) What did you notice about (*name*) after they attended the day respite centre?
5. Reason for discontinuing/non-attendance (if the centre was visited at least once):
 - (a) Why did (*name*) stop attending the day respite centre?
 - (b) Is there anything that could have been done to help you/encourage you to keep attending the day respite centre?
6. The needs of the carer and person referred to a day centre:
 - (a) Is there anything you would like the day respite centre to do or provide that is not already happening?
 - (b) Was there anything that (*name*) needs that was not provided by the day respite centre? If yes, was this one of the reasons why he/she stopped attending?
 - (c) Did you attempt to access other day respite centres? What happened?

Participants

All participants were carers of people with dementia who had been referred to one of ten day respite centres (existing solely as a respite service) via health services/professionals such as general practitioners (GPs) and HACC but who did not all accept the offer of this service. Twenty-seven

telephone interviews were conducted – ten with carers whose family member refused to attend day respite care (citations in the Results denoted by an ‘R’) and 17 with carers whose family member attended day respite care (denoted as ‘A’). By this point, data saturation was reached, with no new information being added to the themes that emerged. Average interview length was around 40 minutes. The majority of participants were female (78%). They ranged in age from early thirties to mid-nineties, with an average age of around 78 years. Most participants were caring for their spouse, while five were caring for another family member (parent or sibling). Some carers (ten) could identify the length of time they had assumed the role of carer (range: 1–12 years; mean: 5.7 years), with the remaining carers reporting that in general they gradually drifted into this role as care needs arose. During the interview, carers were asked to assess the stage of dementia for the person they were caring for. They were asked: ‘Could you tell me about your (*husband’s/wife’s etc.*) health?’ This was followed by probing to find out more about their level of dementia, guided by the knowledge that this was a sensitive topic for some participants. Some carers were able to give quite specific information (*e.g.* ‘mild to moderate dementia’) as the person they were caring for had been assessed by a geriatrician, while others were less certain (*e.g.* ‘bad memory loss’). No independent assessment was undertaken.

Recruitment

Recruitment was primarily third-party recruitment via service providers. This study was part of a larger project which examined the operation of ten day respite care facilities. Potential participants (*i.e.* carers of people who attended day respite care, or who had attended once or twice or not at all) were identified via the co-ordinators of the day respite centres. Telephone contact was made by the co-ordinator and if verbal consent was reached, the researchers posted out an information sheet and consent form to the carers. Response rates could not be calculated as the service providers did not systematically record how many carers they approached about the study. In three cases, recruitment was via a newspaper advertisement, placed to attract a larger group of carers whose family member refused to attend day respite care. These carers contacted the researchers directly and information forms and consent forms were then posted out to them.

Ethics

Ethics approval was received from the Tasmanian Social Sciences Ethics Committee No. H8665.

Results

The results were categorised into five key themes: (1) getting the right information about accessing day respite care (being confused, making sense of the maze of information); (2) feeling unsafe as a barrier to attending (leaving home comforts, potential for embarrassment); (3) reacting to refusal to attend (acceptance, frustration and despair); (4) helping to ease the transition to day respite care (promoting feelings of safety and security, not giving up); and (5) benefits of attending (for family member: being around others; for carer: having a break).

Getting the right information about accessing day respite care

Carers had differing responses to obtaining appropriate information about accessing day respite care. For some, the process was confusing, while for others the sheer volume of information proved overwhelming.

Most carers stated that their GP or geriatrician had played a key role in suggesting day respite care for their family member. However, they had difficulty recalling who they made contact with and how their family member was assessed. They spoke of ‘not being sure’ and ‘I can’t really remember’. One carer’s account of the process of accessing day respite care for her 88-year-old husband with moderate dementia 12 months previously typified the general response:

His geriatrician told us to find out about respite ... I think he gave us a number to ring. It’s all a bit vague, but I think a nice lady came around to the house. I’m not sure who it was, it could have been a nurse. I’ve forgotten who assessed him, but somehow we got the information about the centre and then he was accepted and that was that. (A₄)

Not surprisingly, carers were unsure of how they would go about accessing information relating to carer or family member support in the future. Most mentioned their GP as their first point of contact if they needed information. They appeared to be confused about the array of health professionals in the aged-care sector, and referred to them as ‘the nice lady who visited our home’ and ‘a welfare type of person’. As one carer in her eighties, whose husband was recently diagnosed, commented:

It’s all a bit hard when you are caring for someone who has dementia and you feel like you’re losing your marbles as well ... I’m getting just like him, all muddled. (R₄)

On the other hand, a few carers had a clear recollection of the difficult process they went through to access information and, in some cases, to successfully secure day respite care. Despite having a ‘drawer full of

brochures', 'lots of telephone numbers' and 'long lists of organisations' these carers spoke of their immense frustration when they tried to sort through the 'maze of information'. One woman in her forties who was caring for her older mother with moderate to severe dementia commented that carer respite 'saved her sanity'. She explained:

It's not that there is a lack of information ... there is a maze of information out there. I can use the internet and am confident and young. I can't imagine what it's like for older people looking after their husband or wife ... I couldn't make sense of all the brochures but there was this angel at carer respite who really helped. She said 'we're here to help you' and I just cried and cried. (A13)

This failure to make sense of the 'overwhelming amount of information' was also coupled with the carers' realisation of not knowing exactly what was needed for their family members. As one carer commented, 'the problem is that you don't really know what you need, so all the phone numbers and information are not really any help ... no one can give you the whole package'. Similarly, another carer spoke of coming home 'with all these brochures but still not knowing where to start'. The opportunity to build a relationship with a worker was important to these carers. As one carer, whose mother had moderate dementia, reported:

It's so important to get a person's name and to feel that they listened to what you said and that you don't have to repeat the story again. In the end I got a case worker and my whole life changed ... I wanted to fall down and kiss her feet! (A2)

Feeling unsafe as a barrier to attending

Carers perceived that their family member's feelings of being unsafe presented a barrier to them accepting day respite care. For some this proved an insurmountable barrier, while for others, it was a hurdle that could be overcome. Unsafe feelings were categorised as 'leaving home comforts' and 'potential for embarrassment'.

Most carers felt that a major barrier to their family member attending day respite care was their reluctance to leave the security, comfort and familiarity of home. They spoke of the everyday comforts of home such as 'family photos all round the room' and 'her special tea cup and comfy chair'. Many expressed the fear that their family member felt if they left the safety of their home, stating that 'it's a fear that he's got ... he has just got it into his head that the only safe place to be is at home where everything looks familiar'. This fear seemed to escalate with increasing age – 'the older she gets the more fearful she gets' – and in some instances, with advancing dementia. As one woman caring for her

86-year-old husband who had been diagnosed with ‘moderate’ Alzheimer’s disease reported:

At first he would go out to the park, sometimes even down to the shops. But now he won’t even go out to the post box ... I look at his face and all I can see is this fear ... he just wants to be around things that make him feel safe. There is no way I could get him on a bus to go to [day respite care]. (R2)

Carers also spoke of the safety that home provided for family members who feared possible embarrassment if they attended day respite care. These fears ranged from other clients at the centre ‘thinking he’s a dill’ or ‘noticing she is forgetful’ to being ‘worried that she might not look as good as the others’. In the context of a relatively small regional city, several carers referred to the ‘embarrassment’ that their family member would feel if clients at the centre included people that they had known through work or social activities (‘she would feel embarrassed if any of the ladies from her card club saw her there’). For some family members, their embarrassment was accentuated by an awareness of their deteriorating condition. For example, one carer stated how ‘he knows he’s getting odder so he likes to keep to himself’ and another that ‘it’s like looking into a mirror and that’s not very nice to see ... he can see what’s happened to him’.

Reacting to refusal to attend

Ten of the 27 carers interviewed were caring for family members who had either refused to attend day respite care, or who attended once or twice and then refused to attend again. Their reaction to this refusal ranged from acceptance to frustration and despair.

Despite carers recognising their own need for their family member to attend day respite care and for a break, they were generally accepting of their family member’s refusal to attend. They used phrases like ‘I wouldn’t want to force her to go’ and ‘I’ll just have to wait’. One man who cared for his wife explained that they had been married for over 50 years and that he felt he would be ‘betraying’ her if he kept ‘bringing up the subject of her going’. Another spoke of not being ready to ‘let go’ of his wife (recently reclassified from mild to moderate dementia) unless it was her decision:

I’m not ready to let go of her just yet ... it’s my decision but at this stage I can still cope and don’t want to push her into going somewhere she doesn’t feel comfortable. (R1)

For a few carers, their acceptance of the situation was not a gentle ‘giving in’ to their family member’s refusal, but rather a way of avoiding conflict over the issue. Some of them confided that ‘he gets nasty when I mention it, really nasty’ or ‘he feels like I’m trying to dump him off somewhere so I can’t even talk about it’.

Carers were adamant that the centres were not at fault for their family member's refusal to continue to attend after one or two visits. For example, carers commented that 'day respite was not at fault at all' and 'the people there are lovely'. Although a few carers said their family member had not liked aspects of the centre, such as 'everyone chattering', 'the whole day revolving around picking people up in the bus' or 'she didn't like the people', they believed that the reason behind their refusal was that 'they never really wanted to go in the first place'. As one carer explained, 'she just doesn't want to be there – it's as simple as that and I just have to accept it'. Generally carers believed that there was nothing the day respite centre could do to encourage their family member to attend, commenting that 'nothing would make it better for him at respite' and 'it's not the centre, there's nothing they could do'.

The fact that their family member could not be convinced to attend day respite care left some carers feeling frustrated. One full-time carer whose husband had refused to attend respite for over two years said, 'I have begged on my knees that he go to the day centre, but it makes no difference' and similarly another complained, 'I am so fed up with the whole situation. I don't know how to convince him that it would be a good thing. I don't think he will ever go'.

Despair often accompanied this frustration. Some spoke of the bleak future they faced, using phrases such as 'it's too hard to keep going' or 'I can't see any way out of it'. The absolute despair of one older carer who reported her husband to have 'bad memory loss' was evident in her repeated comment:

Things are only going to get worse ... life's a misery ... no one can truly help ... life's a misery. (R6)

Carers were also concerned about the welfare of their family member should they not be able to continue to care for them. These concerns weighed heavily on some carers' minds, who felt that attending day respite care could prepare their family member for an uncertain future. For example, one carer, whose husband had moderate dementia, said:

I'm always thinking into the future and what happens if I get sick? What will he do? He won't leave the house and won't socialise with anyone. Going to day care would help him get prepared for me not being around all the time ... I worry myself sick over it. (R9)

Helping to ease the transition to day respite care

When interviewing carers who had a family member attending day respite care, they were asked what they felt had contributed to their family

member's acceptance of going to the centre. Their responses were categorised as 'promoting feelings of safety and security' and 'not giving up'.

Carers spoke of the importance of ensuring that their family member felt as safe and secure as possible during the initial visits to day respite care. For some, this meant spending the first few hours, or days, at the centre 'helping him settle in', 'just holding her hand and making her feel less frightened' and 'being in the background so he knew I was there'. As one carer, whose husband had mild to moderate dementia, explained:

It was like taking a five-year-old to kinder for the first time. He didn't want me to leave him ... so I stayed for most of the first day. The staff were wonderful and they didn't make me feel awkward. The next time I had to stay again because he got very frightened, but the third time I just waved goodbye and off he went ... that was three years ago and he's never once not wanted to go ... it's all about them feeling safe about leaving you, just like we had to do for the kids on their first day at school. (A8)

Others spoke of different fears that had to be overcome before their family member felt comfortable about attending. For some, choosing the appropriate clothes caused difficulties. For example, one carer noted how 'he got all stressed about what clothes he would wear, so in the end I worked out a system of laying everything out the night before' while another reported how their family member 'likes to look nice and worries that she's let herself go, so our daughter comes and helps her choose her clothes for the day'. Fear about missing the bus was also raised as a common cause of anxiety, necessitating the carer and family member 'get[ting] up very early to make sure [the family member] is ready to go'. Another carer packed some 'special things' from home for his wife, who had mild dementia, on her first day at the centre:

She loves her special things and didn't want to leave them. So I just packed a few bits for her to take. She took a nice bag with a photo of our dog, some soap she likes to take out and smell, and her own mug ... she sat there all day holding them but at least she went, so it worked. (A1)

Most carers recalled that their family member was initially reluctant to attend day respite care, commenting that their family member 'hated it at first', 'told me he's not going back' and 'said they [others at the centre] were too old, even though she's 90'. Many carers recognised that the firm stand they took with their family member had resulted in their continued attendance. For example, one carer reported how she 'just put [her] foot down and said "I've had enough, you have to go" ... now he loves it of course'. Although they were aware of the fears their family member had about attending day respite care, carers spoke of the importance of 'not giving up' and to 'keep pushing and encouraging' for the 'sake of

everyone's sanity'. One carer, whose husband had had a stroke resulting in speech difficulty and some memory loss, suggested:

They need to go for at least a month and more than once a week to get the feel of it and get comfortable with the staff and the people there. I just had to push a bit in the beginning to get him there and then to get him to stay ... I think that people give up too easily and get a bit soft with them. But I needed it as much as him. (A5)

Similarly, another carer in her eighties who spoke about caring for her 'very demented husband' commented:

It's hard at first, but you have to do a bit of trial and error to work out what is going to suit ... maybe shorter days, maybe picking them up early ... all those things help but the most important thing is not to give up. I knew if I gave up that he wouldn't go back, but I needed it as much as him. That's my advice ... don't give up. (A6)

Benefits of attending

Without exception, carers who had family members attending day respite care agreed that it benefited both themselves and their family member. Family members benefited by the opportunity to be around others, while carers were provided with the opportunity to have a break.

The opportunity for family members to socialise with others was perceived by all carers as the greatest benefit of day respite care. For many family members this provided the only time to mix socially and gave them 'a reason to get up in the morning'. Many carers commented on the improvement they could see in the family member once they commenced day respite care, reporting that they 'have a smile on their face when they get home', 'seem less confused' and 'the social stimulation helps his mind'. The following response, from a carer whose husband had moderate dementia, was typical of those who had family members attend a day respite care centre:

He goes off with a big smile in the morning ... he's teamed up with a few other men there and they have great chats ... he helps out a bit and that makes him feel important ... when he comes home he's exhausted but happy. And on those days he doesn't seem as confused ... more like his old self again. (A2)

Carers also reported benefits for themselves from their family member attending day respite care. They recounted feeling a great sense of relief once day respite care became an established part of their family member's care. One spoke of 'quietly going around the bend' before respite and 'now feeling so free for those few hours a week'. Another commented, 'It's a welcome break because it's the only time in the week that I can do

exactly what I want'. The following extract powerfully demonstrates the importance of day respite care for one carer, both for her own wellbeing and to keep her elderly mother – with moderate dementia – at home for as long as possible:

Being a carer is rewarding but it's very draining as well. I feel as though we are the 'silent workers'. I am now my mother's parent and I feel as though I'm losing a little bit of her every day. At the end of the month you look back and realise how much she has deteriorated. People don't realise that we are so busy doing the things that have to be done for her like cooking and showering and keeping her safe. But I want to spend quality time with her as well. I want time to do her hair and her nails and have lovely quality time. I love her and know that she is going downhill very fast, but I'm not ready to let go of her just yet. That's why day respite is so important for me and for her. It keeps me from having carer melt-down and keeps her out of long-term care. (A16)

Discussion

This study provides insight into the experience of family carers who utilise the services of day respite centres to provide respite for caregiving activities, or who have been unable to avail themselves of this service. It captures the complexity and depth of human emotion involved with the placement (attempted or successful) of a loved one into day respite care in a way that previous studies have tended to miss. In particular, the descriptions carers give point to a need to increase the capability of carers to make the decision to use day respite services. The data show that a referral for day respite services is not adequate to ensure take-up; follow-up and support for the carer's decision to access respite is required. This finding has not been shown in the literature before.

The emphasis on depth of the data obtained meant that, for practical purposes, the sample size of the study needed to be small. This is common for qualitative studies. The restricted geographic area of study also limited generalisability. Future research could replicate this study in different geographical locales and expand upon it by incorporating the collection of quantitative data (*e.g.* survey based on the qualitative study findings) that would enable participation of a larger group of carers. A larger study would be particularly useful to delineate the differences between the cohorts of carers whose family member attended day respite care and those whose family member refused to attend. It would also be valuable to delve deeper into carers' belief systems and approaches to caring, as these may influence their acceptance and use of services (Manthorpe, Illiffe and Eden 2003; Twigg and Atkin 1994). In addition, it would be worthwhile to try to capture the feelings of people with dementia themselves about their

attendance or non-attendance at a day respite centre. This may raise a wider set of barriers to attendance.

A central and recurring theme identified in this study is the difficulty experienced by carers in accessing and making sense of the information they were provided with about services; a concern also acknowledged in the literature (Cheek *et al.* 2006). In the case of respite services, the literature acknowledges the problem with carers' lack of awareness of the existence of respite and lack of knowledge about how to obtain it (Hanson, Tetley and Clarke 1999; Ritchie 2003; Witt, Chenoweth and Jeon 2004). Many carers in the current study found the journey from the initial recommendation (or decision) that their family member attend day respite care to be fraught with anxiety and confusion. Their ability to seek and understand information was further impaired by the carers' own admission that they were elderly themselves and becoming easily confused. Even those carers who were resourceful and had well-developed skills in accessing information found the process to be overwhelming and disempowering. Most carers who were accessing respite remained unclear about the details of the services available and of how they were eventually able to access day respite care.

These findings parallel those from our earlier studies with carers of people with dementia who struggled to access information on available services and were often overwhelmed by the sheer quantity of information they had to deal with, experiencing 'emotional turmoil' and 'frustration and confusion' (*e.g.* Robinson *et al.* 2009). The current study extends this work by looking specifically at day respite services. Carers appeared to be confused about the array of health professionals they accessed to arrange respite. In most instances the GP was seen by the carers as the pivotal person to provide both the initial recommendation to access respite care and appropriate information. It was apparent, however, that other health professionals played an important role in the provision of information and assessment. Nevertheless, carers had little or no understanding of the role or scope of other health professionals working in the area: the wide range of health professionals and their varying roles and titles appeared to simply add to the complexity of the information. Again, this finding mirrors our more widely focused earlier work where carers were confused about the service providers who came into their homes (Robinson *et al.* 2009), which in many respects reflects the fragmentation of community service provision (Brodaty, Draper and Low 2003; Lemieux-Charles *et al.* 2005; Powell Davies *et al.* 2006).

Our findings of care recipients' reluctance to accept respite are similar to those reported in the literature (Brody, Saperstein and Powell Lawton 1989; Cohen-Mansfield *et al.* 1994). In particular, it is important not to

underestimate the significance of the problems associated with asking a frail care recipient to leave a familiar home environment. The findings highlight the fear of leaving home associated with a sense that the person's safety might be jeopardised. These findings suggest that if such fears cannot be overcome, alternative respite services such as in-home respite may be preferable to day respite care.

Related to this are concerns of a loss of dignity and feelings of embarrassment, also raised in the international literature (Bacon and Lambkin 1997; Brody, Saperstein and Powell Lawton 1989; Nomura *et al.* 2009; Richie 2003). In Nomura *et al.*'s (2009: 433) study of a small, rural Japanese community, some people with dementia felt 'compelled to stay indoors due to their disease'. Similarly, in the small regional city in which our study was conducted, where the chance of meeting up with familiar people is increased, such feelings appear to act as a strong disincentive to some people attending day respite. Here, Ritchie's (2003) concern with the stigma associated with attending a day centre is realised. From the accounts of the family carers it is apparent that care recipients' fear their attendance at a day respite centre will lead to embarrassment and that this will be associated with an experience of shame at what they have become. This is especially the case for people with dementia, who are high users of day respite services in the study context (Robinson *et al.* 2008).

Given the strength of the barriers to attending day respite care, it is understandable that some carers lacked the ability to manage family members who refused to attend day respite care. Despite recognising that there were benefits for both themselves and their family member, in agreement with the literature (Ashworth and Baker 2000; Brodaty *et al.* 2005; Brody, Saperstein and Powell Lawton 1989; Cotrell 1996; Smyer and Chang 1999), some also conceptualised this as a form of 'betrayal' which engendered a sense of guilt. Moreover, the findings also indicate instances where carers have little choice but to accept the situation given the strident opposition of the care recipient. It was clear that some carers experienced extreme levels of frustration and despair, evidence of this being a highly emotional time; this was likely to be compounded by high base levels of stress and strain, such as anxiety and mood disorders which have been found to be almost twice as high among Australian carers compared to their non-carer peers (Stirling *et al.* 2010). However, these carers did not have the strength/self-esteem or resources to manage the refusal and implement strategies that might assist the transition to day respite care. These carers did not feel that there was anyone with whom they could share their burden. This finding concurs with studies that have found higher levels of social isolation and loneliness among carers than among non-carers (Cooke *et al.* 2001; Stewart *et al.* 2006).

In contrast, those carers who did manage to facilitate the use of day respite care recognised that their family member was on the trajectory of decline, with the probable next phase being full-time care. Implicit in this process was easing the transition to using day respite services through a 'settling in' period, which sometimes involved the carer accompanying their family member to the centre and for others involved a ritual of preparation with an associated building of confidence. What is most apparent is the carer's determination to ensure their loved one did attend respite and their persistence in the face of what was often significant resistance. Interestingly, Toseland *et al.* (2002) note that people who reported encountering more barriers also used services more; they suggest this is because these carers were more persistent. It is also notable that unlike some of the literature (Brody, Saperstein and Powell Lawton 1989; Cohen-Mansfield *et al.* 1994; Cotrell 1996; Mävall and Thorslund 2007), all carers in this group reported positive experiences associated with day respite. It is possible that sampling a larger group of Tasmanian carers may find some disparate responses.

In conclusion, the findings of this study indicate that, crucially, being referred to day respite services does not necessarily ensure take-up by carers and hence, while carers recognise the importance of day respite care, there is a need to build their capability to make decisions about the care that is best for them and their family member. To facilitate this process they need information from one source only – not a myriad of brochures, names, professionals and phone numbers – and more active support from health professionals to make the decision. Although in Australia there exist Commonwealth Respite and Carelink Centres, with an accompanying national toll-free number, carers are not necessarily aware of these and need support to initiate contact with these Centres and to utilise any respite services offered. Carers need to be given strategies to help them deal with the guilt, anxiety, frustration and despair that they face on a daily basis in their role as carer. Further, they need to be given the opportunity to talk with others about their experiences, to debrief, and to learn strategies from other carers who have successfully introduced day respite care to their family member. Indeed, it appears that carers have low self-efficacy for managing life in such a demanding role. Ideally, future work needs to develop a profile of carers who, due to their circumstances, beliefs and attitudes, are more likely than other carers to struggle with their role and who may not accept the need for respite. These people need to be followed-up, such as with the use of decision aids to assist people to make health-care choices (O'Connor *et al.* 2009). To this end, we are involved with a programme of research on decision aids for carers of people with dementia. This type of more sophisticated approach to

working with carers is needed, as it respects the complex psychological needs that carers have.

It is imperative that the development of strategies to build the capability for self-efficacy of carers to facilitate the transition of a loved one into day respite when circumstances dictate are supported by policy changes. Changes are required with regard to service delivery to ensure services are both better integrated and more personalised (consumer-directed care), a need which has been expressed in Australia, as well as the United States of America and the United Kingdom (Access Economics 2010; HM Government 2008; Vickrey *et al.* 2006). For example, an integrated case management framework, whereby a case manager co-ordinates individual care (Robinson *et al.* 2010; Vickrey *et al.* 2006), could fulfil such a need. Case managers could employ the use of decision aids (O'Connor *et al.* 2009) and, together with programmes that build resilience among carers such as dementia cafés (Morrissey 2006), this would represent an important strategy to build carers' capability for self-efficacy to facilitate the transition of a loved one into day respite when circumstances dictate. The findings of this study indicate such attendance of the person they care for at a day respite centre will assist them to sustain their role as carers in the community. Furthermore, activities that empower people with dementia, such as the formation of dementia cafés and programmes to regain procedural skills and increase interaction with family members, other people with dementia and the community (Nomura *et al.* 2009), may assist with the acceptance of day respite care via destigmatisation of dementia.

Acknowledgements

We thank the Australian and Tasmanian Governments for funding the project through the Home and Community Care Program and Associate Professor Fran McInerney for reviewing drafts of the paper.

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Accepted 9 February 2011; first published online 14 March 2011

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