

Review

Literature review: use of respite by carers of people with dementia

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Accepted for publication 1 November 2013

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What is known about this topic

- Caring for a person with dementia at home is preferred by families, but is associated with significant psychological, physical, financial and social consequences, and necessary support such as respite care is required.
- Respite is not fully utilised, indicating that the outcomes of respite care are questionable.

What this paper adds

- The usefulness and impact of respite care is examined carefully so that it may be continued as an effective adjunct to the home management of people with dementia.
- The respite services that currently exist may not be achieving the right balance to meet the needs of carers, people with dementia and the staff working in the respite services.

Abstract

Respite care is a cornerstone service for the home management of people with dementia. It is used by carers to mitigate the stress related to the demands of caring by allowing time for them to rest and do things for themselves, thus maintaining the caring relationship at home and perhaps forestalling long-term placement in a residential aged care facility. Despite numerous anecdotal reports in support of respite care, its uptake by carers of people with dementia remains relatively low. The aim of this paper was to examine the factors that constitute the use of respite by carers of people with dementia by reviewing quantitative and qualitative research predominantly from the years 1990 to 2012. Seventy-six international studies of different types of respite care were included for this review and their methods were critically appraised. The key topics identified were in relation to information access, the barriers to carers realising need for and seeking respite, satisfaction with respite services including the outcomes for carers and people with dementia, the characteristics of an effective respite service and the role of health workers in providing appropriate respite care. Finally, limitations with considering the literature as a whole were highlighted and recommendations made for future research.

Keywords: adult day care, carer burden, dementia, older people, respite

Introduction

Alzheimer's Disease International has estimated that there were 36 million people with dementia in the world in 2010. This figure is predicted to increase to 66 million by 2030 and 115 million by 2050. The global cost of dementia in 2010 was set at \$604 billion. This is 1% of the global GDP and these costs will rise as the proportion of people with dementia increases (Alzheimer's Disease International 2012). The majority of people with dementia live at home in the care of family; for example, in Australia, the percentage of people with dementia living in the community is 70% (Australian Institute of Health and Welfare 2012). Although these unpaid carers can save governments a lot of money, the burden and stress experienced by family carers place them at greater risk of physical and psychological health problems (Wright 1999, Shanks-McElroy & Strobino 2001, Musil *et al.* 2003). Respite is intended to mitigate this risk of physical and psychological health problems so that carers can continue in their role.

Conceptually, respite can be defined as:

A pause, a temporary cessation, or an interval of rest. (Chappell *et al.* 2001, p. 202)

However, debate by key researchers in this area has determined that respite has a dual conceptualisation. Respite can be seen as an 'outcome' or as a 'service' (Noyes 1996, Chappell *et al.* 2001). In their work, which considered respite as an outcome, Chappell *et al.* (2001) sought the experience and meaning of respite from family carers, which included carers of people with dementia. They found that more than half of their sample (61.3%) viewed it as an internal experience where caregivers described it as taking a break without removing themselves from the care-giving situation. Simple, routine activities were seen as a 'stolen moment' such as the time taken for their own personal care or watching television and times when the care receiver was happy, comfortable and angst-free. Additionally, there were some carers who did not see taking a break from their care-giving role as important or necessary to them. The other 38.6% of the sample described respite as an external experience where there was a separation in some way from their care-giving situation. This type of respite was referred to as time taken without the care receiver, for a complete break, to get mental and physical relief, to engage in mental and physical activities and to be socially involved with other people. Engagement in such activities as vacations, sport, hobbies and going out to work was considered important. However, to achieve this external experience, carers may have to use some form of a respite service to replace them in their care-giving role.

Respite services may be delivered informally by family and friends or it may entail the use of a formal service. Formal respite services encompass different types of services, which range from in-home, adult day care (ADC) centres, residential aged care facilities (RACFs) to hospitals. The type is determined by the needs of the carer and the person with dementia and the availability of services in the locality. These needs also determine the length of time required for respite, which can vary from several hours to several weeks and the different reasons it is required for, such as, emergency, regular or intermittent. The type of respite, the length of time for respite and the reason it is being sought can have varying implications on the experience of respite for the carer and the person with dementia. For example, if it is a regular weekly break for a pleasurable activity (going to the movies with friends) and a well-known, competent respite worker attends in-home, the experience may be positive. However, if it is for an unforeseen emergency

and the person with dementia has to go into residential respite care in an unfamiliar facility, it could be a stressful and worrying experience for all concerned. Respite has the potential to be delivered in flexible and positive ways to meet the needs of carers and people with dementia.

For a considerable period of time, respite has been one of the most frequently expressed needs of carers themselves (Leong *et al.* 2001, Alzheimer's Australia's 2009). Therefore, it is somewhat surprising that the actual usage of formal respite services by carers of persons with dementia has been repeatedly shown to be relatively low (Larkin *et al.* 1988, Montgomery 1988, Cox 1997, Braithwaite 1998, Choi & Liu 1998, Zarit *et al.* 1999, Robinson *et al.* 2005, Brodaty *et al.* 2005, Donath *et al.* 2009, Australian Institute of Health and Welfare 2011, Tang *et al.* 2011). Possible conclusions here are that if respite services are under-utilised, then they may not be satisfying carer needs as identified above or there are negative connotations associated with its use (Nolan & Grant 1992, Hanson *et al.* 1999). Negative connotations that the person with dementia is a burden, that the carer is not able to cope and respite is primarily for the carer's benefit can be pervasive, lead to the need to use alternative more socially acceptable terms instead of 'respite', for example, 'short-term care', 'adult day care', 'adult day service', 'adult day centre', 'adult day programme' and 'visitor's programme' (Beisecker *et al.* 1996, Hanson *et al.* 1999, Wishart *et al.* 2000, Leitsch *et al.* 2001, Madeo *et al.* 2008, Lebel *et al.* 2009). Despite the varying connotations that may occur and terms that may be used, researchers have consistently found that carers who choose to use respite have high levels of satisfaction with the services received (Adler 1992, Larkin & Hopcroft 1993, Theis *et al.* 1994, Beisecker *et al.* 1996, Mason *et al.* 2007, Madeo *et al.* 2008) while keeping in mind that there will always be carers who will choose not to use respite services (Cox 1997, Chappell *et al.* 2001, Kosloski *et al.* 2001).

Literature review method

Given the contrast between reported respite needs, satisfaction and use, the aim of doing this review was to summarise recent research findings on the use of respite by carers of people with dementia living in the community. Previous literature reviews in the area have been either (i) limited to intervention studies (e.g. systematic reviews or meta-analyses) or (ii) limited in scope, e.g. to a particular country or a particular type of respite care. Because of the nature of the dementia syndrome and the consequences of

withholding respite for research purposes, this is a difficult area in which to conduct fully or even quasi-experimental designs. In addition, carers may use multiple types of respite care, even simultaneously. Therefore, this review looks at all of the recently available evidence on the topic and makes no restrictions on level of evidence or geographical or respite type.

Using EBSCOhost via CINAHL, MEDLINE and PsycINFO databases, search terms included Alzheimer's disease, dementia, respite, adult day care, carer* and caregiv*. Further studies were found via related articles and article reference lists. The main time period covered was 1990–2012, but a few highly relevant earlier articles were also reviewed. English language articles were included in the review if they focused primarily on carers of people with dementia and people with dementia and their use (or non-use) of respite services. Studies that did not include carers of people with dementia were excluded. The search yielded 76 articles (Table 1), which were analysed and graded according to the following system to give clarity to the evidence presented throughout the review.

- Level A = Evidence from meta-analyses or systematic reviews
- Level B = Evidence from randomised controlled trials (RCTs)
- Level C = Evidence from quasi-experimental studies
- Level D = Evidence from observational studies or quantitative surveys
- Level E = Expert opinion, case reports, focus groups or qualitative studies.

The specific studies are shown by their level of evidence and country of origin in Table 2.

Literature review

The review is narrative in structure, summarising the literature in a topical manner rather than organising it according to the levels of evidence identified above. The topics to be explored include in order: (i) accessing information about respite services; (ii) barriers to carers realising need for and seeking respite; (iii) satisfaction and positive as well as negative outcomes of

using respite for both the carer and persons with dementia; (iv) the characteristics of respite related to respite effectiveness; and (v) the role of health workers in providing respite that meets the needs of carers and people with dementia. Finally, problems with considering the literature as a whole will be examined and recommendations made for future research.

Accessing information

Quasi-experimental and survey-based studies have demonstrated that lack of knowledge by carers of the availability and offerings of respite services are significant contributors to its poor usage (Beisecker *et al.* 1996, Raivo *et al.* 2007). A qualitative study observed that the lack of adequate medical practitioner diagnosis and referrals to support services impeded utilisation of respite services (Connell *et al.* 1996). On the other hand, in another qualitative study, carers reported an excess of information as being overwhelming (Robinson *et al.* 2009).

Barriers to seeking respite

Misinformation cannot be the only impediment to poor respite utilisation. A mixture of experimental, survey and qualitative studies found usage to be low even when carers were informed of and provided with various respite services, often at subsidised or no financial cost (Adler 1992, Cox 1997, Larkin *et al.* 1988, Montgomery 1988, Australian Institute of Health and Welfare 2011). Strang and Haughey (1998) proposed that accepting and obtaining respite services involved three steps for the carer:

- 1 recognising the need to get out of the carer world
- 2 giving themselves permission to leave it temporarily
- 3 having the availability of social support resources to facilitate 'getting out'.

Recognising respite need

One literature review of non-use of government services in general noted that carers often assert that help is not needed (Brodaty *et al.* 2005). Some interview-based studies found carers who reported coping

Table 1 Summary of evidence: country of origin, number of studies and evidence levels

Country	Level A	Level B	Level C	Level D	Level E	Total
Australasia	3	–	1	6	6	16
United States and Canada	3	6	10	23	7	49
United Kingdom	1	–	–	1	1	3
Europe	–	–	2	5	1	8
Total	7	6	13	35	15	76

Table 2 Summary of studies included by level of evidence and country of origin

Evidence level	References				Total (N = 76)
	Australasia	United States/Canada	United Kingdom	Europe	
Level A – Evidence from meta-analyses or systematic reviews	Brody and Gresham (1992), Neville and Byrne (2007), Tang <i>et al.</i> (2011)	Acton and Kang (2001), Flint (1995), Lee and Cameron (2004)	Mason <i>et al.</i> (2007)		7
Level B – Evidence from randomised controlled trials		Burdz <i>et al.</i> (1988), Conlin <i>et al.</i> (1992), Grant <i>et al.</i> (2003), Montgomery (1988), Rothman <i>et al.</i> (1993), Wishart <i>et al.</i> (2000)			6
Level C – Evidence from quasi-experimental studies	Kane <i>et al.</i> (2010)	Beisecker <i>et al.</i> (1996), Berry <i>et al.</i> (1991), Cho <i>et al.</i> (2009), Kosloski and Montgomery (1993a,b), Kosloski <i>et al.</i> (2001), Leitsch <i>et al.</i> (2001), McCann <i>et al.</i> (2005), Robinson <i>et al.</i> (2005), Tompkins and Bell (2009), Zarit <i>et al.</i> (1998)		Mossello <i>et al.</i> (2008), Schacke and Zank (2006)	13
Level D – Evidence from observational studies or quantitative surveys	Arai <i>et al.</i> (2004), Braithwaite (1998), Brodaty <i>et al.</i> (2005), Choi and Liu (1998), Clark <i>et al.</i> (1995), Jeon <i>et al.</i> (2007)	Adler (1992), Adler <i>et al.</i> (1995, 1993), Campell and Travis (1999), Cox (1997), Gaugler <i>et al.</i> (2005), Henry and Capitman (1995), Hirsch <i>et al.</i> (1993), Jarrott <i>et al.</i> (2005), Jelinski and Fettig (1993), Kosloski and Montgomery (1995), Larkin and Hopcroft (1993), Larkin <i>et al.</i> (1988), Lebel <i>et al.</i> (2009), Lund <i>et al.</i> (2009), Madeo <i>et al.</i> (2008), Malone Beach <i>et al.</i> (1992), Musil <i>et al.</i> (2003), Shanks-McElroy & Strobino (2001), Sussman and Regehr (2009), Theis <i>et al.</i> (1994), Wright (1999), Zarit <i>et al.</i> (1999)	Lee <i>et al.</i> (2007)	Donath <i>et al.</i> (2009), Evert and Kukulka (1996), Mavall and Malmberg (2007), Raivo <i>et al.</i> (2007), Van Exel <i>et al.</i> (2008)	35
Level E – Expert opinion, case reports, focus groups or qualitative	Gilmour (2002), Perry and Bontinen (2001), Phillipson and Jones (2011a,b, 2012), Robinson <i>et al.</i> (2009)	Connell <i>et al.</i> (1996), Gendron and Adam (2005), Hasselkus and Labelle (1998), O'Connor (2007), Richey and Hodges (1992), Strang and Haughey (1998), Watts and Teitelman (2005)	Parahoo <i>et al.</i> (2002)	Albinsson and Strang (2003)	15

currently, yet were putting off respite for the future when circumstances changed and their need was greater (Cox 1997, Braithwaite 1998). Cox (1997) proposed that the knowledge that respite is available when needed may contribute to carers' feelings that they can cope. On the other hand, one qualitative study concluded that some carers may not realise the extent to which caring will become a burden as the dementia progresses and may need respite long before they ask for it (Parahoo *et al.* 2002).

In other studies, carers reported that having other available informal carers, such as family or friends, to share the caring load, and being satisfied with that, decreases the need for service use (Cox 1997, Kosloski *et al.* 2001). Those whose needs are already being satisfied by another form of service, e.g. regular health

worker visits, may also not seek respite (Cox 1997). Several quasi-experimental or survey-based studies have explored the recognised needs behind why carers seek respite. Kane *et al.* (2010) identified differences in needs associated with the type of dementia; for example, the exaggerated behaviours of fronto-temporal lobe dementia increased carer burden and this needed to be considered when planning delivery of respite. Other needs have been identified as physical rest, alleviation of emotional stress, time for recreational activities and household duties (Adler 1992, Larkin & Hopcroft 1993, Adler *et al.* 1995). Several studies confirmed that those who seek and use respite tend to care for persons with greater activities of daily living needs or who have more difficulty managing these needs (Braithwaite 1998, Kosloski

et al. 2001, Robinson *et al.* 2005). Supporting this, carers who stated they needed respite reported lower levels of life satisfaction and higher burden, overload, or resentment than those who do not recognise a need for respite (Kosloski *et al.* 2001, Brodaty *et al.* 2005). However, in a quasi-experimental study of carers, Robinson *et al.* (2005) found perceived burden to be unrelated to use of services. This disparity again highlights the critical distinction between feeling the need for respite and actually seeking it.

Giving permission for respite

Strang and Haughey's (1998) interpretation of the above disparity is that self-permission to utilise respite can be a significant barrier. In a number of interview studies, both quantitative and qualitative, carers appeared conflicted about giving themselves permission to initially use respite services (Larkin & Hopcroft 1993, Robinson *et al.* 2009). Guilt from perceptions of abandoning the person with dementia, failure in the fulfilment of their marital or familial duty, severance of social bonds and apprehension in case the person with dementia becomes angry, resentful or distressed from respite are common themes identified (Larkin & Hopcroft 1993, Evert & Kukulka 1996, Cox 1997, Kosloski *et al.* 2001, Robinson *et al.* 2009, Phillipson & Jones 2011a). Quasi-experimental, survey and qualitative studies have all found that spouses may feel a greater sense of duty or bond to the person with dementia than carers in other types of relationships, and thus tend to be reluctant to use respite services (Henry & Capitman 1995, Zarit *et al.* 1999, McCann *et al.* 2005, Robinson *et al.* 2005, Phillipson & Jones 2011a). For some carers, it may be recognising the needs of the person with dementia rather than themselves that will lead to respite use (Beisecker *et al.* 1996, Madeo *et al.* 2008, Phillipson & Jones 2011a). Two high-quality studies demonstrated that if carers see respite as only benefitting themselves and not the person with dementia, they were less likely to accept and use the service (Malone Beach *et al.* 1992, Beisecker *et al.* 1996).

Availability of social support resources

Strang and Haughey's (1998) third step refers to whether appropriate social support resources are available to facilitate 'getting out'. Barriers to 'getting out' can occur at three levels: individual, societal and institutional (Robinson *et al.* 2005). As discussed, perceived need and permission could be considered as individual barriers that originate from within the carer themselves. Societal barriers would include resistance to respite from the person with dementia (Clark *et al.* 1995, Zarit *et al.* 1999, Parahoo *et al.* 2002,

Brodaty *et al.* 2005), from other family with views against respite use (Van Exel *et al.* 2008) or from society at large where social stigma associated with dementia or with 'hand-outs' or 'welfare' plays a part (Connell *et al.* 1996, Jeon *et al.* 2007). Institutional barriers are described as factors related to accessibility to suitable or dementia-specific resources, long waiting lists or lack of flexibility in offerings (Beisecker *et al.* 1996, Alzheimer's Australia's 2009, Phillipson & Jones 2011a, Tang *et al.* 2011).

A number of quasi-experimental and quantitative studies, as well as a few qualitative studies, discovered that respite use was influenced by carer concerns about the quality of care. For example, factors such as inadequate staff in terms of knowledge, compassion and numbers, not person-centred, limited dementia-specific programmes, poor nutrition, dirty facilities, limited resources or general atmosphere limited carer uptake of respite (Kosloski & Montgomery 1993a, Clark *et al.* 1995, Beisecker *et al.* 1996, Evert & Kukulka 1996, Tompkins & Bell 2009, Phillipson & Jones 2011a,b). Available respite programmes may also be unsuitable for younger persons with dementia and those from culturally and linguistically diverse backgrounds (Alzheimer's Australia's 2009). Cost and lack of health insurance cover can be another significant barrier to usage (Henry & Capitman 1995, Beisecker *et al.* 1996, Connell *et al.* 1996, Cox 1997).

Satisfaction with respite

Studies at all levels of evidence have demonstrated high levels of satisfaction with respite use among carers of people with dementia and the factors underlying this satisfaction (Adler 1992, Larkin & Hopcroft 1993, Theis *et al.* 1994, Beisecker *et al.* 1996, Mason *et al.* 2007, Madeo *et al.* 2008). It is important to note that these studies only considered the views of those who did use external respite services. As demonstrated by Chappell *et al.* (2001), there are many carers who chose not to use external respite services; therefore, high levels of satisfaction may not relate to all carers. One qualitative study (Perry & Bontinen 2001) identified three major categories of carer's experiences of respite:

- 1 self-care
- 2 relief from the caring role
- 3 comfort and safety of the person with dementia.

Self-care

Within self-care, the following themes were upheld by multiple studies from levels C to E: maintaining family and social relationships, catching up on sleep and rest and maintaining own health (Richey &

Hodges 1992, Larkin & Hopcroft 1993, Strang & Haughey 1998, Perry & Bontinen 2001, Parahoo *et al.* 2002, Gendron & Adam 2005, Lee *et al.* 2007, Sussman & Regehr 2009, Tompkins & Bell 2009). Although Theis *et al.* (1994) also found improvements in physical and emotional health following extended use of respite services, there was no improvement in general quality of life. Additionally, in literature reviews, Flint (1995) and Mason *et al.* (2007) found a lack of strong evidence that respite had significant effects on carer physical or mental health. Given that persons with dementia have declining health status over time, respite may still be moderating the negative effects of the caring role.

Relief from the caring role

As the name suggests, 'respite' services intend to offer relief and decrease the burden of carers; however, research in this area has been conflicting. In qualitative interviews, carers reported that respite provides them with relief from stress and worry (Perry & Bontinen 2001). Quantitative studies (two at the RCT level) have shown ADC-like respite to be significantly associated with decreased levels of carer burden (Wishart *et al.* 2000, Arai *et al.* 2004, Mossello *et al.* 2008) and, after 3 months or more of regular use, decreases in levels of stress (Conlin *et al.* 1992, Zarit *et al.* 1998). Two quantitative studies (one at the RCT level), however, found no decrease in burden with ADC (Rothman *et al.* 1993, Theis *et al.* 1994). Finally, other quantitative studies (one an RCT) have suggested that ADC only has an effect upon certain measures of carer burden and stress (Kosloski & Montgomery 1993b, Grant *et al.* 2003, Schacke & Zank 2006).

In cases of longer periods of respite, such as residential respite, where burden or stress of carers has been observed to reduce, it has been transient, only to return to baseline levels within 2 weeks of return to the caring role (Adler 1992, Larkin & Hopcroft 1993, Neville & Byrne 2008). One RCT found burden to be unrelated to respite use (Burdz *et al.* 1988), whereas a quasi-experiment found that perceived burden is not related to use of services in general (Robinson *et al.* 2005). Similar to stress, while some level C and level D studies reported an association between respite use and decreased anger and depression (Leitsch *et al.* 2001, Jarrott *et al.* 2005), others found no effect (Zarit *et al.* 1998, Mossello *et al.* 2008).

The consensus of systematic literature reviews is that the evidence does not support the hypothesis that any form of respite is able to assist carer outcomes (Flint 1995, Acton & Kang 2001, Lee & Cameron 2004, Mason *et al.* 2007). However, it is stated that

these findings may be due to the lack of high-quality research currently in the area (Lee & Cameron 2004) or that burden may be too global a factor to accurately assess in the context of respite (Acton & Kang 2001). Another possible explanation is the carers who use respite services are those suffering the greatest degree of burden and therefore the room for explaining variation is reduced (Adler *et al.* 1995).

Although respite has, on occasion, been found to have no negative effect for many carers (Adler 1992), it is not always an entirely positive experience. While being separated from the person with dementia, carers may experience worry and guilt, miss the person with dementia and, upon reuniting, have difficulties in readjustment to the caring role (Adler 1992). In more in-depth interviews with carers, Watts and Teitelman (2005) related that negative outcomes may result from carers attempting to complete as much as possible and thereby not achieving a mental break. Additional carer burden can also be attributed to the greater amount of work generated from preparing the person with dementia for respite (Lebel *et al.* 2009), the disruption to routine caused by respite usage (Sussman & Regehr 2009) and difficulties of the person with dementia adjusting to respite care (Berry *et al.* 1991, Beisecker *et al.* 1996, Connell *et al.* 1996, Perry & Bontinen 2001). In responding to closed-ended questioning, lack of adequate respite time was a common reason given by carers for ending use (Mavall & Malmberg 2007) with Cho *et al.* (2009) finding that respite utilisation is greater in the services offering a full-day attendance as opposed to half day sessions.

Comfort and safety of the person with dementia

In an early quantitative study, respite users could not identify any benefits for the person with dementia, while half could identify negatives (Adler 1992). The negatives identified in level D studies included the person with dementia feeling abandoned or depressed, physical and mental deterioration, increased disorientation, exhaustion, disruption of home patterns and routine, difficulty readjusting upon discharge to home and disruption to sleep patterns (Adler 1992, Jelinski & Fettig 1993, Lee *et al.* 2007). However, half of the carers in Theis *et al.*'s (1994) study reported improvement in the person with dementia and the majority of carers in two other quantitative studies reported benefits (Adler 1992, Beisecker *et al.* 1996). Positive aspects reported for the person with dementia included health assessments received during respite, activities encouraging stimulation, socialisation and keeping active, improvement in self-esteem, physical health,

cognition and conversation, enjoyment of respite, the provision of a safe environment and the chance to have time out of the house and away from family care (Adler 1992, Beisecker *et al.* 1996, Wishart *et al.* 2000, Perry & Bontinen 2001, Madeo *et al.* 2008).

In terms of behavioural symptoms, reports have differed across studies from levels B to D from improved (Burdz *et al.* 1988, Cox 1997, Mossello *et al.* 2008) to unchanged (Adler *et al.* 1993) to temporarily worsened behaviour (Hirsch *et al.* 1993). Reviewing six high-quality studies examining behaviour symptoms following residential respite, Neville and Byrne (2007) found a similar variety of results and concluded that overall research did not suggest residential respite permanently altered behavioural symptoms. Yet, the ability of respite to moderate behaviour is important, as greater behavioural symptoms are associated with a greater propensity to leave ADC service within 12 months (Mavall & Malmberg 2007).

The stigma associated with respite care for some, and therefore preventing its use, may be the feeling that it is a precursor to full-time RACF placement of the person with dementia (Parahoo *et al.* 2002, Tang *et al.* 2011). Like much respite-related research, however, the findings relating to respite use and its association with RACF placement are conflicting. Three level C or D studies had contradictory results, with the probability of RACF placement being negatively associated with respite use (Kosloski & Montgomery 1995), negatively or not associated with RACF placement depending on the type of respite used (Gaugler *et al.* 2005) and positively associated with chance of RACF placement (McCann *et al.* 2005). One explanation is that when respite increased institutionalisation rates, carers may have accessed services late in the severity of cognitive decline where permanent placement would be shortly required (Zarit *et al.* 1999). Indeed, it has been shown that utilising respite earlier delays institutionalisation, possibly due to greater opportunity to receive support and acclimatise to the caring role (Gaugler *et al.* 2005). In a quasi-experimental study, the severity of behavioural symptoms exhibited was the factor associated with shorter trajectories to RACF placement (Cho *et al.* 2009).

Current literature reviews have not found that respite delays RACF placement, or indeed that respite has any demonstrable benefits or adverse effects in terms of cognition, function or physical health for person with dementia (Flint 1995, Lee & Cameron 2004, Mason *et al.* 2007). When responses to respite have been sought from the person with dementia themselves, they are reported to range from happy to

angry (Gendron & Adam 2005). In the end, therefore, it may be that many of the outcomes can be attributed to individual differences and reactions to respite exposure.

Respite programme characteristics

In their study of ADC, Henry and Capitman (1995) found that features of the carer and person with dementia were not useful in predicting satisfaction with respite, and suggested that characteristics of the respite service itself may be more influential. Researchers have included questions about preferences for different types of respite in both quantitative and qualitative studies. For instance, carers have been shown to have a preference for in-home care rather than care outside the home (Malone Beach *et al.* 1992, O'Connor 2007). Stated reasons included maintaining quality of life, preserving the cohesion and integrity of the household, ease of use, lack of transportation, inconvenient external service locations and, in some cases, assistance with household tasks (Montgomery 1988, Kosloski & Montgomery 1993b, Parahoo *et al.* 2002). The discomfort of having strangers in the home, however, can be a deterrent to in-home respite for some carers, who may instead turn to external respite (Cox 1997).

When using institutional respite (whether for the day or for an extended period), carers have shown a preference for respite that has social or recreational activities enjoyed by the person with dementia and that are age-appropriate (Malone Beach *et al.* 1992, Parahoo *et al.* 2002, Madeo *et al.* 2008, Phillipson & Jones 2011a, 2012). Activities that promote personal growth, lifelong learning and ongoing support and interaction with the carer appear to encourage more use of respite than programmes using other activities (Henry & Capitman 1995). A social model was viewed as more home-like by carers, whereas the medical model was thought to be of greater use for the person with dementia with ongoing health problems (Leitsch *et al.* 2001). Making a choice with regard to which of the great variety of different respite service types is most suitable for carers will ultimately depend on whether the service offered meets their individual situation and needs (Kosloski & Montgomery 1993b).

When considering respite care generally, a common theme is that carers want more control over the care provided (Raivo *et al.* 2007, Madeo *et al.* 2008, Tompkins & Bell 2009). One quasi-experimental and two quantitative surveys documented that carers wanted more communication with staff about the respite experience. Carers have also expressed the

wish to be able to specify which staff provide care during respite (Malone Beach *et al.* 1992). Maintaining the stability of the same respite care staff was seen as important for building rapport, and in the case of in-home care, not disrupting the household and personal routines (Parahoo *et al.* 2002).

Another frequent concern and added subjective burden for carers noted in interview (qualitative and quantitative) studies were the lack of convenient and reliable respite. This included personal carers not arriving on schedule or not at all, not being able to schedule assistance at convenient times, bureaucratic inefficiency (Malone Beach *et al.* 1992, Phillipson & Jones 2011a), having too many forms to complete (Cox 1997) and long waiting lists (Connell *et al.* 1996, Arai *et al.* 2004). The approach to how respite services are offered and funded may also influence outcomes for carers. For example, in a quasi-experimental study, Tompkins and Bell (2009) found that two more flexible types of respite services (Savvy caregiver Programme and a voucher system) had a positive effect on carer depression.

Although carers have been reported to express a desire for greater amounts of available respite time, two quantitative studies (Kosloski & Montgomery 1993b, Madeo *et al.* 2008) found that it was not the amount of respite used that was associated with positive carer outcomes, but rather whether or not respite was used at all. Two other surveys (one quantitative study and one qualitative study) concluded that there may be an optimal amount of respite needed for the carer and that greater hours of use may not necessarily result in more effective respite (Campbell & Travis 1999, Gendron & Adam 2005). When Lund *et al.* (2009) found that only 46% of carers were only somewhat satisfied or not very satisfied with how they spent their time, they determined that the amount of time provided by respite may not be as important as what the carer did with their respite time and the satisfaction these activities brought them. It was therefore recommended that facilitators should be employed to work individually with carers to identify activities and goals for respite time that are most likely to improve their well-being (Lund *et al.* 2009).

The role of health workers

Staff are a key feature of respite success. Attributes that tend to be well regarded by carers included showing respect, providing emotional support, being willing to listen and talk to the carer, relieving the family's feelings of guilt and providing education and information (Albinsson & Strang 2003, Raivo *et al.* 2007, Madeo *et al.* 2008). Gilmour (2002) con-

cluded that staff were a critical part in the facilitation of carers' ability to hand over care and that they should place themselves in a secondary and supporting role to the carer.

Problems can be encountered, however, by placing staff in this role secondary to the carer. Part of the information reported to be desired by carers is what the person with dementia did during the day. Madeo *et al.* (2008) found that this presented staff with both practical and ethical issues. Practically, if written reports were required, these are time consuming and communicating with the carers could be difficult if the carer did not transport the person with dementia to and from respite. Ethically, there were concerns about the amount of information that could be given while respecting the right to autonomy and privacy of the person with dementia.

Other issues for staff often concern the limits of care. Services may have insufficient resources to manage the behavioural and psychological symptoms of dementia (Zarit *et al.* 1999). Decisions may then have to be made as to whether respite has to be terminated, especially when there is a need for one-on-one care (Hasselkus & Labelle 1998) or aggressive behaviour putting the staff or other respite clients at risk (Gendron & Adam 2005). Feelings of attachment by all stakeholders make such decisions difficult to accept (Hasselkus & Labelle 1998).

Conclusion

Based on the current literature, it is challenging to predict which carers will benefit from respite and reasons why this may be so (Mavall & Malmberg 2007). The challenge derives from the enormous diversity of all of the following: the people involved, the nature of the services delivered and the types of research carried out to date. Characteristics of the carers and people with dementia vary in terms of their relationships, living arrangements, socioeconomic status, age, education, sources of support, role expectations, impairment severities, types of behavioural and psychological symptoms of dementia, physical health and reasons for seeking respite (Brodaty & Gresham 1992, Strang & Haughey 1998, Lee & Cameron 2004, Mavall & Malmberg 2007). Respite services differ in terms of availability, programmes, hours of operation, convenience, staff numbers, staff training and provision of transport. Different governments (countries and even states or provinces) differ in their levels and models of funding for respite services for carers. The research itself varies in outcomes measured, sample sizes, methodology, time length and even definitions of respite. As noted in some of the previous

research, it may also be that the outcomes measures of interest, such as burden, are too complex, or influenced by too many factors, to be accurately assessed by current means (Theis *et al.* 1994, Perry & Bontinen 2001, Mavall & Malmberg 2007).

The result of the many confounding factors mentioned, as well as the sometimes conflicting results reported, is that definite conclusions about the use of respite care by carers are difficult. Only a small number of experimental studies (RCTs) have been carried out in the area, leaving previous systematic literature reviews with a limited scope (Flint 1995, Acton & Kang 2001, Lee & Cameron 2004, Mason *et al.* 2007, Neville & Byrne 2007). Other reviews were topically or geographically limited (Tang *et al.* 2011). As a result, a lot of valuable, significant and relevant research was not covered in previous literature reviews.

A major strength of the current review is the inclusion of worldwide literature of all levels of evidence; synthesising this led to an overall picture of the state of the science on the topic of respite use by carers of people with dementia. In dividing the literature by level of evidence, this review illustrates which questions have been confirmed by rigorous research techniques (e.g. that RCTs and quasi-experimental studies have shown that adult day centres lead to decreases in carer stress and burden) and others that have yet to be confirmed (e.g. no systematic review has yet found any positive benefits of respite to the person with dementia). About two-thirds of the articles included in this review were at level D or E (survey or qualitative), and this research provided valuable evidence beyond that available from level A to C on, for instance, the barriers that impede carers from accessing respite care. As with every review, choices must be made about scope. Therefore, this review may have suffered by not including (more) articles whose focus was on respite use among carers of frail older people, rather than specifically on those with dementia. However, two of the systematic reviews discussed (Mason *et al.* 2007, Neville & Byrne 2007) did have a wider focus on frail older people. A further potential limitation of the review methodology employed here was the use of the word 'respite' itself – although the word is commonly used in the literature for the topic of interest, some relevant articles could have been missed.

The concept of respite used for this study was that presented by Chappell *et al.* (2001) who defined it as 'a pause, a temporary cessation, or an interval of rest' viewed as an 'outcome' rather than a 'service' (p. 202). The outcome can be respite perceived as an 'internal' experience where caregivers take a

break without removing themselves from the caregiving situation or do not perceive the need to do so. Respite as an 'external' experience occurs when there was a separation in some way from the caregiving situation. When we examined the strength and weaknesses of this concept in relation to the review findings, we have determined that although current research is predominantly about the delivery of respite services, a lot of the outcome measurement has been in relation to carers and people with dementia as opposed to the services themselves, i.e. type and frequency of services used. We found evidence to support the concept of respite and that internal and external respite processes can benefit each other for better health outcomes for carers and people with dementia.

Inadequate access to information or too much information and limited referrals by medical practitioners were some reasons identified for the poor utilisation of respite services. Better utilisation of respite may come about by enhancing the experience of people to use internal respite through access to counselors or support groups to help identify and implement strategies that make the most of stolen moments, by minimising the importance of caregiving and enjoying periods of angst-free care. For those who need to seek external respite options, a thorough assessment of their actual needs and the provision of need-specific respite services (informal or formal) may be required. The provision of information along these lines would streamline the experience for carers and health workers alike to boost their confidence in being more proactive in the reception and provision of respite.

The notion of internal respite is certainly supported through outcomes identified in the research literature. Brodaty *et al.* (2005), Cox (1997), Braithwaite (1998) and Kosloski *et al.* (2001) found that carers often asserted that respite was not needed or they had arrangements in place with family and friends. Despite this, health workers need to be aware of the stoicism often displayed by carers or their being unaware of the insidious effects of physical and emotional exhaustion and the possibility of carers only seeking respite when it is long overdue (Adler 1992, Larkin & Hopcroft 1993, Adler *et al.* 1995, Kosloski *et al.* 2001, Brodaty *et al.* 2005). One aspect identified in the literature not readily addressed from Chappell *et al.*'s (2001) concept of respite is how to deal with the negative connotations associated with respite. The degenerative nature of dementia and the fact that many carers, especially spouses, are elderly mean that respite services are required. To overcome carers' feelings of guilt and failure and negative societal

views, it may be that the benefits of respite for the carer and also the person with dementia need to be recognised (Adler 1992, Malone Beach *et al.* 1992, Beisecker *et al.* 1996). Respite, whether it is to be an internal or external experience, needs to be a positive experience for both the carer and the person with dementia. For example, it can be designed to be person-centred, dementia-specific, culturally specific and/or age-appropriate (Malone Beach *et al.* 1992, Parahoo *et al.* 2002, Madeo *et al.* 2008, Phillipson & Jones 2011a, 2012).

Respite can work in a cyclic fashion with internal respite benefiting from external respite and vice versa. The review identified that the use of external respite services does allow carers time for self-care; it gives them relief from the caring role and respite services can be proactive to ensure comfort and safety of the person with dementia so that the carer has no concerns (Adler 1992, Beisecker *et al.* 1996, Wishart *et al.* 2000, Perry & Bontinen 2001, Madeo *et al.* 2008, Stockwell-Smith *et al.* 2010). This relief may strengthen coping mechanisms for internal respite and consequently reduce the need for external respite. However, the potential of respite can only be realised if it is conceptualised from what carers consider to be effective respite for them and the person for whom they care (Chappell *et al.* 2001).

From a future research perspective, this review has demonstrated that by looking more broadly, a fuller picture of the current evidence on the topic is possible. For example, a much greater understanding of the role of respite in carer's lives can be gained by interviewing carers (whether in a structured or more in-depth way), rather than by doing strictly controlled interventions. If specific interventions were to be tested, those studies might benefit from looking for innovative ways to control for confounding variables, such as by employing cluster randomised trials (e.g. at the level of a community or specific service). Other methodological factors to consider (as recommended by previous reviews) include sample size (Neville & Byrne 2007), lack of explicit definitions of respite and respite type studied and unspecified participant inclusion/exclusion criteria (Flint 1995, Lee & Cameron 2004). While some authors preferred to address different types of respite separately (Lee & Cameron 2004, Phillipson & Jones 2011a,b, 2012), others argued convincingly that a wider approach would serve better for understanding how respite services can meet individual carers' needs (Flint 1995).

A potentially useful study would be one with a sufficiently large and diverse sample size to explore the influence of background characteristics on how

and why carers of people with dementia use (or do not use) the different available types of respite, their satisfaction or dissatisfaction with the services and their opinions about its impact on themselves and the person they care for. Another topic, as yet mostly unexplored, is that of understanding the provision of respite from the perspective of service providers and the staff who provide the daily care. Also of vital importance is to recognise the implications of research results for policy decisions regarding the funding models and availability of respite services.

Acknowledgements

The authors were very grateful for the funding from the Trust Company. Thank you to David Ross for contribution to the literature review.

Conflict of interest

There is no conflict of interest.

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