Respite care for carers of people with dementia

Q10: For carers of people with dementia, does respite care when compared to care as usual, produce benefits/harm in the specified outcomes?

Background

Worldwide, there are estimated to be 25 million people with dementia, Alzheimer's disease accounts for 60% whereas vascular dementia accounts for approximately 30% of the prevalence in low and middle income countries (LAMIC). It is a devastating illness that results in a progressive decline in cognitive ability and functional capacity, causes distress to patients, their carers, and families, and has a large societal impact. Providing care for a patient with dementia is stressful, and informal caregivers of people with dementia show higher levels of psychological distress than carers of physically frail elderly people and non-caregivers. Several forms of interventions for dementia caregivers have been suggested, such as practical assistance (e.g. respite), education, emotional support provision, and multi-component interventions. Although users report high levels of satisfaction with these services, narrative reviews on objective outcome measures, such as caregiver's burden or psychological health have been inconclusive.

Respite care is the temporary provision of care for a person with dementia at home or in an institution by people other than the primary caregiver. This is to give the primary caregiver respite from their caregiving responsibilities and hopefully ameliorate, to some degree, the stresses associated with being a caregiver. The provision of respite care is based on the assumption that the reduction in stress to the caregiver produced by a temporary relief from caregiving will allow the person with dementia to remain in the community for longer, to have a better relationship with his or her caregiver, and to receive better care while in the community. Respite care is a blanket term used to describe a very diverse set of services which vary over a number of dimensions. The first of these dimensions is place; respite care can take place in the home of the person with dementia, a daycare centre or a residential setting. Respite care may also vary in terms of who provides care; this may be done by trained and untrained staff or volunteers. The care provided may also differ in duration, ranging from a couple of hours to a number of weeks. Respite care may be planned or unplanned and may involve overnight care or daytime-only care. The different types of respite care are so diverse that they are likely to differ in the extent to which they are useful to what is an equally diverse set of users. In many circumstances, caregivers may be using informal types of respite care such as help from family and friends.

Population/Intervention(s)/Comparison/Outcome(s) (PICO)

Population:	caregivers/carers of people with dementia
Interventions:	respite care

Respite care for carers of people with dementia

Comparison:	no respite care
Outcomes:	caregiver strain/Burden
	caregiver psychological distress and health
	caregiver quality of life
	caregiver social support
	caregiver physical health

List of the systematic reviews identified by the search process

Lee H, Cameron MH (2004). Respite care for people with dementia and their carers (Review). *Cochrane Database Systematic Reviews,* 1:CD004396, updated May 2008.

Pinquart M, Sorensen S (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics,* 18:577-95.

PICO table

Serial no.	Intervention/Comparis**on**	**Outcomes**	**Systematic reviews used for GRADE**	**Explanation**
1	respite care vs. no respite care	Caregiver burden Hamilton Depression Hamilton Anxiety Brief Symptom Inventory Affective Support Confident Support	Lee H,Cameron MH (2004). Respite care for people with dementia and their carers (Review). Cochrane Database Systematic Reviews, 1:CD004396, updated May 2008.	This review included only one study but it is a RCT; more recent than Pinquart M & Sorensen S; information provided more complete

Respite care for carers of people with dementia

2	respite care vs. no respite care		Pinquart M, Sorensen S (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? International Psychogeriatrics, 18:577-95.	This review included 44 studies, however authors did not specify reported the proportions of RCT and no RCT trials;

* both systematic reviews have been GRADEd, However the review by Lee and Cameron is the primary review being considered and additional evidence as provided by Pinquart M & Sorensen S to draft the recommendation.

GRADE tables

Table 1

Author(s): Castro-Costa E, Dua T, Hyinh N.
Date: 2009-08-17
Question: Should respite care vs. non-respite care be used for caregiver burden?
Settings:
Bibliography: Lee H, Cameron MH (2004). Respite care for people with dementia and their carers (Review). *Cochrane Database Systematic Reviews,* 1:CD004396, updated May 2008.

Quality assessment							**Summary of findings**					**Importance**
							No of patients		**Effect**		**Quality**	
No of studies	**Design**	**Limitations**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**respite care**	**non-respite care**	**Relative (95% CI)**	**Absolute**		
Caregiver Burden (Better indicated by lower values)												
1[1]	randomized trials	no serious limitations[2]	no serious inconsistency[5]	serious[3]	Very serious[4]	none	11	10	-	SMD 5.51 lower (12.38 lower to 1.36 higher)	VERY LOW	CRITICAL
Hamilton-Depression (Better indicated by lower values)												

1[1]	randomized trials	no serious limitations[2]	no serious inconsistency[5]	serious[3]	Very serious[4]	none	32	23	-	SMD 0.18 lower (3.82 lower to 3.46 higher)	VERY LOW	CRITICAL
Hamilton_Anxiety (Better indicated by lower values)												
1[1]	randomized trials	no serious limitations[2]	no serious inconsistency[5]	serious[3]	Very serious[4]	none	32	23	-	SMD 0.05 higher (3.76 lower to 3.86 higher)	VERY LOW	CRITICAL
Brief symptom Inventory (Better indicated by lower values)												
1[1]	randomized trials	no serious limitations[2]	no serious inconsistency[5]	serious[3]	Very serious[4]	none	32	23	-	MD 0.04 higher (0.29 lower to 0.37 higher)	VERY LOW	CRITICAL
Affective Support (Better indicated by lower values)												
1[1]	randomized trials	no serious limitations[2]	no serious inconsistency[5]	serious[3]	very serious[4]	none	9	10	-	SMD 0.44 lower (2.85 lower to 1.97 higher)	VERY LOW	CRITICAL
Confidant Support (Better indicated by lower values)												
1[1]	randomized trials	no serious limitations[2]	no serious inconsistency[5]	serious[3]	very serious[4]	none	9	10	-	MD 1.30 higher (1.04 lower to 3.64 higher)	VERY LOW	CRITICAL

[1] Analysed from Lee & Cameron (2004).

[2] RCT study, dropouts not reported.

[3] information from only one study.

[4] less than 100 participants.

[5] not applicable.

Table 2

Author(s): Castro-Costa E, Dua T, Huynh N
Date: 2009-08-14
Question: Should respite intervention vs. non-respite intervention be used for caregivers of people with dementia?

Respite care for carers of people with dementia

Settings:
Bibliography: Pinquart M, Sorensen S (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics,* 18:577-95.

Quality assessment							Summary of findings					Importance
							No of patients		Effect		Quality	
No of studies	Design	Limitations	Inconsistency	Indirectness	Imprecision	Other considerations	respite intervention	non-respite intervention	Relative (95% CI)	Absolute		
Burden (Better indicated by lower values)												
12[1]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[1]	781	0[5]	-	SMD 0.26 lower (0.39 to 0.12 lower)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
10[6,7]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[7]	577	0[5]	-	SMD 0.12 lower (0.24 lower to 0 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
5[6,8]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[8]	251	0[5]	-	SMD 0.27 higher (0.03 to 0.51 higher)	VERY LOW	IMPORTANT
Ability, knowledge (Better indicated by lower values)												
2[6,9]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[9]	213	0[5]	-	SMD 0.06 lower (0.58 lower to 0.46 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
5[6,10]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[10]	218	0[5]	-	SMD 0.08 lower (0.34 lower to 0.18 higher)	VERY LOW	CRITICAL

Respite care for carers of people with dementia

Institutionalization												
10[6,11]	randomized trials	serious[2]	serious[12]	serious[11]	no serious imprecision	none	786/0 (0%)	1/0 (0%)[5]	OR 0.76 (0.44 to 1.32)	0 fewer per 1000 (from 0 fewer to 0 more)	VERY LOW	IMPORTANT
								0%		0 fewer per 1000 (from 0 fewer to 0 more)		

[1] caregiver burden was assessed using the Zarit Burden Interview and other scales.

[2] authors not reported properly if all studies were RCT.

[3] I sq was nor reported, but test for homogeneity indicates no heterogeneity.

[4] caregivers were for patients with AD, for patients with presenile dementia and for patients with dementia in general.

[5] not reported.

[6] analysed from Pinquart & Sorensen (2006).

[7] caregiver depression was measured by CES-D, Beck Depression Inventory and other measures.

[8] Subjective well-being (SWB) assessed with perceived quality of life, life satisfaction scale and other scales.

[9] ability and knowledge was assessed by questionnaires on coping abilities, caregiving-related self-efficacy.

[10] caregivers outcomes were assessed by measures of behaviour problems, cognitive deficit, negative affect and deficit in functional abilities.

[11] was measured by the percentage of members of the experimental group and control group who had been placed in a nursing home.

[12] test for homogeneity of effect sizes indicates heterogeneity.

Narrative description of the studies that went into the analysis

The review carried out by Lee & Cameron, 2004 (updated 2008) included three randomized studies. These studies all compared outcomes for a group provided with an intervention aimed to provide rest or respite for the primary caregiver with a control group. There were few other similarities between the studies and this will have consequences for the extent to which the studies are able to be compared. The reviewers requested additional study data from the authors of all included trials. In one study, the participants were 55 people with probable Alzheimer's disease and their spousal caregivers. Diagnosis of Alzheimer's disease was established through neurological and neuropsychological test or form an existing diagnosis made by a physician. In other two studies, participants were 632 people with dementia and their caregivers and 24 people with dementia living in the community and their caregivers. Regarding diagnosis criteria, they were that the caregiver took primary responsibility for the care of the patient who was diagnosed with Alzheimer's Disease or related disorder by a physician or an existing diagnosis made by a physician respectively.

Reference List

Lee H, Cameron MH (2004). Respite care for people with dementia and their carers (Review). *Cochrane Database Systematic Reviews,* 1:CD004396, updated May 2008.

Respite care for carers of people with dementia

Pinquart M, Sorensen S (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics,* 18:577-95.

From evidence to recommendations

Factor	Explanation	
Narrative summary of the evidence base	**Outcome**	**Respite care**
	Caregiver burden	1 study, SMD -5.51(-12.38 to 1.36) no difference
	Hamilton Depression	1 study, SMD -0.18(-3.82 to 3.46) no difference
	Hamilton Anxiety	1 study SMD 0.05(-3.76 to 3.86) no difference
	Brief Symptom Inventory	1 study SMD 0.04(-0.29 to 0.37) no difference
	Affective Support	1 study SMD -0.44(-2.85 to 1.97) no difference
	Confident Support	1 study SMD 1.30(-1.04 to 3.64) no difference
Summary of the quality of evidence	**Outcome**	**RESPITE CARE**
	Caregiver burden	VERY LOW
	Hamilton Depression	LOW
	Hamilton Anxiety	LOW
	Brief Symptom Inventory	LOW

Respite care for carers of people with dementia

	Affective Support	VERY LOW
	Confident Support	VERY LOW
Balance of benefits versus harms	Insufficient evidence regarding the beneficial effect of respite care for caregivers; no evidence available on harm.	
Values and preferences including any variability and human rights issues	Some surveys of caregivers report increased availability and flexibility of respite care as a very common request, thus caregivers value respite services. There are also studies which report that when offered respite care, only “slightly over half of caregivers” avail themselves of this service. Some of the reasons for limited use of respite care could be that many caregivers may be using informal types of respite care such as help from family and friends. Alternatively, caregivers may think that respite care provides benefits of self-care and relief to themselves at the cost of the safety and comfort of their family members during respite care episodes; they feel torn between the necessity to have a break and their anxiety about the impact of institutional respite care on the person with dementia. Other perceived reasons are the feelings of guilt, despondency, being ’let-down’ or emotional devastation some caregivers experience when a respite care period ends. A further possibility is that the type of respite care preferred by the caregiver is not available in their area of residence, implying that it is not respite care in general, but the mode of service delivery, which needs to be considered. Careful attention thus should be given to local preferences, which may be culturally determined regarding the appropriateness for respite care. The issues to be considered are provision of respite care outside of the home vs. in home and to be provided by professionals vs. extended family members.	
Costs and resource use and any other relevant feasibility issues	In many settings, respite care through admission to residential care homes or day care centres may not be an option owing to absence of these facilities. Also even if paid home carers may be available these are unlikely to be trained professionals. Consideration to be given to encouraging the members of extended family to relieve the burden temporally to caregiver.	
Final recommendation (with strength) Where feasible, home based respite care may be encouraged for carers of people with dementia.		

Respite care for carers of people with dementia

Strength of recommendation: STANDARD
Any additional remarks Better research to evaluate respite care intervention in caregivers of people with dementia

Update of the literature search – June 2012

In June 2012 the literature search for this scoping question was updated. No new systematic reviews were found to be relevant.