Interventions for carers of people with dementia

Q9: For carers of people with dementia, do interventions (psychoeducational, cognitive-behavioural therapy counseling/case management, general support, training of caregivers, multi-component interventions and miscellaneous interventions) when compared to placebo/comparator, 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 that are different from usual treatment (information about resources and advice upon request, but they did not have formal counselling sessions for and their family members did not have contact with the counsellors). Although users report high levels of satisfaction with these services, narrative reviews on objective outcome measures, such as caregiver's burden and psychological health or institutionalization of people with dementia, have been inconclusive.

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

Population:	Carers of people with dementia
Interventions:	psychoeducational (total, active participation of caregivers, information provision only)
	cognitive-behavioural therapy
	counselling/case management
	general support
	training of caregivers

multi-component interventions

miscellaneous interventions (forms of interventions that were evaluated only in one or two studies were combined into this category because sub-analyses could not be computed)

Comparison: care as usual

Outcomes: caregiver burden

depressive symptoms

subjective well-being

ability/knowledge of caregivers

care receiver symptoms

institutionalization

List of the systematic reviews identified by the search process

INCLUDED IN GRADE TABLES OR FOOTNOTES

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.

EXCLUDED FROM GRADE TABLES AND FOOTNOTES

Brodaty H, Green A, Koschera A (2003). Meta-Analysis of Psychosocial Interventions for caregivers of people with dementia. *Journal of American Geriatric Society,* 51:657-64.

Thompson CA et al (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics,* 7:18.

Sorensen S, Pinquart M, Duberstein P (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 3:356-372.

Interventions for carers of people with dementia

All three meta-analysis above included less studies than the study chosen (see the PICO table).

PICO table

Serial no.	**Intervention/Comparison**	**Outcomes**	**Systematic reviews used for GRADE**	**Explanation**
1	Caregiver intervention vs. non-caregiver intervention	Caregiver burden Depressive symptoms SWB Ability/knowledge Caregivers outcome Institutionalization	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.	Most comprehensive systematic review

Narrative description of the studies that went into the analysis

The review carried out by Pinquart & Sorensen, 2006 included 127 intervention studies with dementia caregivers published or presented between 1982 and 2005. Ten studies were excluded because they provided insufficient information to calculate effect sizes and 41 because they did not include a no-treatment control group. Most studies were in English (119); six German studies, one Dutch and one Spanish study were included as well. The studies were coded by two PhD-level raters. Based on 20% of the studies, the average observed inter-rater agreement (Cohen's K) was 0.91. Twenty-nine studies focused on caregivers of patients with Alzheimer Disease, one study on caregivers for pre-senile dementia, and the remaining 97 on caregivers for dementia in general. With two exceptions, caregivers provided support at home for the patients with dementia. The number of intervention sessions ranged from one to 180 (median+9). Follow-ups were conducted in 32 interventions after an average of 11 months (S.D. =11.1). Group treatments and 11% combined group and individual treatments. The number of participants in the intervention condition ranged from four to 4151(median=23), and in the control group from four to 3944(median=22). Nonrandomised comparisons included in this review.

GRADE tables:

Table 1
Author(s): Castro-Costa E, Dua T, Huynh N
Date: 2009-08-14

Interventions for carers of people with dementia

Question: Should psychoeducation (active participation of caregivers) vs. no psychoeducation (active participation of caregivers) be used for caregivers of patients 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**	**psychoeducation(active participation of caregivers)**	**no psychoeducation(active participation of caregivers)**	**Relative (95% CI)**	**Absolute**		
Burden (Better indicated by lower values)												
28[1]	randomized trials[2]	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[2]	1102	0[6]	-	SMD 0.20 lower (0.32 to 0.07 lower)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
15[7]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[7]	585	0[6]	-	SMD 0.36 lower (0.58 to 0.15 lower)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
9[1,8]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[8]	322	0[6]	-	SMD 0.21 higher (0 to 0.43 higher)	VERY LOW	IMPORTANT
Ability, knowledge (Better indicated by lower values)												
18[1,9]	randomized trials	serious[3]	serious[4,10]	serious[5]	no serious imprecision	reporting bias[9]	757	0[6]	-	SMD 0.55 higher (0.26 to 0.085 higher)	VERY LOW	IMPORTANT
symptoms of caregivers (Better indicated by lower values)												

18[1,11]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[11]	690	0[6]	-	SMD 0.15 lower (0.31 to 0.01 lower)	VERY LOW	CRITICAL
Institutionalization												
2[1,12]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5,]	no serious imprecision	none	112/0 (0%)	0/0 (0%)[6]	OR 0.99 (0.5 to 1.99)	0 fewer per 1000 (from 0 fewer to 0 more)	LOW	IMPORTANT
								0%		0 fewer per 1000 (from 0 fewer to 0 more)		

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

[2] caregiver burden was measured using the Zarit Burden Interview and other scales.

[3] authors not mentioned clearly if all studies were RCT.

[4] I sq was not reported, but test for homogeneity of effect sizes indicates no heterogeneity.

[5] caregivers were from patients with AD (29 studies), for pre-senile dementia (1 study), and for dementia in general (97 studies). Not clear from the systematic review which are the study populations included for each of the outcomes.

[6] not reported.

[7] caregiver depression was measured by CES, BECK Depression Inventory and others measures.

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

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

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

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

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

Table 2

Author(s): Castro-Costa E, Dua T, Huynh N

Date: 2009-08-14

Question: Should psychoeducation (information provision only) vs. no psychoeducation (information provision only) be used for caregivers 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	

Interventions for carers of people with dementia

No of studies	Design	Limitations	Inconsistency	Indirectness	Imprecision	Other considerations	psychoeducation(information provision only)	no psychoeducation(information provision only)	Relative (95% CI)	Absolute		
Burden (Better indicated by lower values)												
12[1,2]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[2]	505	0[6]	-	SMD 0.03 lower (0.21 lower to 0.15 higher)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
12[1,7]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[7]	412	0[6]	-	SMD 0.10 lower (0.3 lower to 0.11 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
3[1,8]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[9]	reporting bias[8]	43	0[6]	-	SMD 0.31 higher (0.33 lower to 0.95 higher)	VERY LOW	IMPORTANT
Ability, Knowledge (Better indicated by lower values)												
15[1,10]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[10]	433	0[6]	-	SMD 0.28 higher (0.08 to 0.47 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
13[5,11]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5,11]	no serious imprecision	reporting bias[11]	396	0[6]	-	SMD 0.20 lower (0.41 lower to 0.01 higher)	VERY LOW	CRITICAL
Institutionalization												
2[1,12]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	none	242/0[6] (0%)	0/0 (0%)[6]	OR 1.28 (0.51 to 3.22)	0 more per 1000 (from 0 fewer to 0 more)	LOW	IMPORTANT
								0%		0 more per 1000		

										(from 0 fewer to 0 more)		

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

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

[3] authors not reported properly if all studies are RCT.

[4] I sq was not reported, but test of homogeneity indicates no heterogeneity.

[5] caregivers were for patients of AD, for pre-senile dementia and for dementia in general. Not clear from the systematic review which are the study populations included for each of the outcomes.

[6] not reported.

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

[8] SWB assessed with perceived quality of life scale, life satisfaction scale and other scales.

[9] Sample small (less than 100).

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

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

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

Table 3

Author(s): Castro-Costa E, Dua T, Huynh N
Date: 2009-08-14
Question: Should cognitive behavioural therapy vs. no cognitive behavioural therapy be used for caregivers of patients 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**	**cognitive behavioural therapy**	**No cognitive behavioural therapy**	**Relative (95% CI)**	**Absolute**		
Burden (Better indicated by lower values)												
9[1]	randomized trials	serious[2]	no serious inconsistency[3]	serious[1,4]	no serious imprecision	reporting bias[1]	144	0[5]	-	SMD 0.36 lower (0.73 to 0.01 lower)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
11[6,7]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[7]	230	0[5]	-	SMD 0.70 lower (1.1 to 0.3 lower)	VERY	CRITICAL

											LOW	
SWB(subjective well-being) (Better indicated by lower values)												
1[6,8]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	serious[9]	reporting bias[8]	19	0[5]	-	SMD 0.37 higher (0.27 lower to 1.13 higher)	VERY LOW	CRITICAL
Ability, knowledge (Better indicated by lower values)												
3[6,10]	randomized trials	serious[2]	serious[11]	serious[4]	serious[12]	reporting bias[8]	0	0[5]	-	MD 0 higher (0 to 0 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
10[6,13]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[13]	182	0[5]	-	SMD 0.29 lower (0.62 lower to 0.05 higher)	VERY LOW	CRITICAL
Institutionalization												
1[6,14]	randomized trials	serious[2]	no serious inconsistency	serious[4,14]	very serious[15]	none	19/0[5] (0%)	0/0 (0%)[5] 0%	OR 1.20 (0 to 0)[16]	0 more per 1000 (from 0 fewer to 0 fewer) 0 more per 1000 (from 0 fewer to 0 fewer)	VERY LOW	IMPORTANT

[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 not reported, test for homogeneity indicates no heterogeneity.

[4] caregiver were for patients with AD, for pre-senile dementia and for dementia in general. Not clear from the systematic review which are the study populations included for each of the outcomes.

[5] not reported.

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

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

[8] SWB assessed with perceived quality-of-life scales, life satisfaction scale and other drugs.

[9] small sample(less than 100 participants).

[10] ability/knowledge was assessed by questionnaires on coping abilities, caregiving-related elf-efficacy.

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

[12] small sample(less than 100).

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

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

[15] small sample (less than 50).

[16] confidence interval not reported.

Table 4

Author(s): Castro-Costa E,Dua T, Huynh N
Date: 2009-08-14
Question: Should counselling and case management vs. no-counselling and case management be used for caregivers of patients 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	counselling and case management	No counselling and case management	Relative (95% CI)	Absolute		
Burden (Better indicated by lower values)												
4[1,2]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[2]	137	0[6]	-	SMD 0.50 lower (0.86 to 0.14 lower)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
3[1,7]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[8]	reporting bias[7]	94	0[6]	-	SMD 0.20 lower (0.63 lower to 0.23 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
3[1,9]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[9]	104	0[6]	-	SMD 0.42 higher (0.01 lower to 0.85 higher)	VERY LOW	IMPORTANT
Ability, Knowledge (Better indicated by lower values)												

3[1,10]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[8]	reporting bias[10]	88	0[6]	-	SMD 0.43 higher (0.01 lower to 0.86 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
4[1,11]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[11]	137	0[6]	-	SMD 0.33 lower (0.69 lower to 0.02 higher)	VERY LOW	CRITICAL

[1] analysed from Pinquart & Sorensen (2006).
[2] caregiver burden was assessed using the Zarit Burden Interview and other scales.
[3] authors not reported properly if all studies were RCT.
[4] I sq was not reported, but test for homogeneity indicates no heterogeneity.
[5] caregivers were for patients with AD, for pre-senile dementia, and for dementia in general.
[6] not reported.
[7] caregivers depression was measured by CES-D, Beck Depression Inventory and other measures.
[8] small sample (less than 100 participants).
[9] SWB assessed with perceived quality-of-life, life satisfaction scale and other scales.
[10] was assessed by questions on coping abilities, caregiving-related self efficacy.
[11] caregivers outcomes were assessed by measures of behaviour problems, cognitive deficit, negative affect and deficit in functional abilities.

Table 5

Author(s): Castro-Costa E, Dua T, Huynh N
Date: 2009-08-14
Question: Should support vs. no-support be used for caregivers 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**	**Support**	**No support**	**Relative (95% CI)**	**Absolute**		
Burden (Better indicated by lower values)												
4[1,2]	randomized	serious[3]	no serious	serious[5]	no serious	reporting bias[2]	138	0[6]	-	SMD 0.01 higher (0.33 lower to 0.35	VERY	CRITICAL

	trials		inconsistency[4]		imprecision					higher)	LOW	
Depression (Better indicated by lower values)												
2	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[7]	reporting bias[8]	38	0[6]	-	SMD 0.05 higher (0.68 lower to 0.78 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
1[,9]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[7]	reporting bias[9]	26	0[6]	-	SMD 2.03 higher (1.36 to 2.7 higher)	VERY LOW	IMPORTANT
Ability, Knowledge (Better indicated by lower values)												
3[1,10]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[10]	332	0[6]	-	SMD 0.29 higher (0.03 lower to 0.61 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
2[1,11]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[7]	reporting bias[11]	65	0[6]	-	SMD 0.07 higher (0.44 lower to 0.58 higher)	VERY LOW	CRITICAL
Institutionalization												
3[1,12]	randomized trials	serious[3]	serious[13]	serious[5, 12]	no serious imprecision	none	101/0[6] (0%)	0/0 (0%)[6] 0%	OR 0.89 (0.15 to 5.5)	0 fewer per 1000 (from 0 fewer to 0 more) 0 fewer per 1000 (from 0 fewer to 0 more)	VERY LOW	IMPORTANT

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

[2] caregiver's burden was assessed using the Zarit Burden Interview and other scales.

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

[4] I sq was not reported, but test for homogeneity indicates no heterogeneity.

[5] caregivers were for patients with AD, for pre-senile dementia and for dementia in general. Not clear from the systematic review which are the study populations included for each of the outcomes.

[6] not reported.

[7] small sample (less than 100 participants).

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

[9] SWB assessed with perceived quality of life scale, life satisfaction scale and other scales.

[10] ability & Knowledge was assessed by questionnaires on coping abilities, caregiving-related self-efficacy.

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

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

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

Table 6

Author(s): Castro-Costa E, Du T, Hyunh N
Date: 2009-08-14
Question: Should training of caregivers vs. no training of caregivers be used for caregivers 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**	**training of caregivers**	**no training of caregivers**	**Relative (95% CI)**	**Absolute**		
Burden (Better indicated by lower values)												
6[1]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	serious[5]	reporting bias[1]	88	0[6]	-	SMD 0.17 lower (0.6 lower to 0.27 higher)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
4[7,8]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	serious[5]	reporting bias[8]	56	0[6]	-	SMD 0.01 higher (0.56 lower to 0.58 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
3[7,9]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	serious[5]	reporting bias[9]	41	0[6]	-	SMD 0.42 higher (0.18 lower to 1.01 higher)	VERY LOW	IMPORTANT

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Ability, Knowledge (Better indicated by lower values)												
2[7,10]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	serious[5]	reporting bias[10]	44	0[6]	-	SMD 0.12 lower (0.78 lower to 0.49 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
8[7,11]	randomized trials	serious[2]	no serious inconsistency[3]	serious[4]	no serious imprecision	reporting bias[11]	163	0[6]	-	SMD 0.35 lower (0.67 to 0.02 lower)	VERY LOW	CRITICAL

[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 not mentioned but test for homogeneity indicate no heterogeneity.

[4] caregivers were for patients with AD, for pre-senile dementia and for dementia in general. Not clear from the systematic review which are the study populations included for each of the outcomes.

[5] small sample (less than 100 participants).

[6] not reported.

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

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

[9] SWB assessed with perceived quality-of-life scale, life satisfaction scale and other scales.

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

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

Table 7

Author(s): Castro-Costa E, Dua T, Huynh N
Date: 2009-08-14
Question: Should multi-component interventions vs. no multi-component interventions be used for caregivers 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**	**multicomponent interventions**	**No multicomponent interventions**	**Relative (95% CI)**	**Absolute**		
Burden (Better indicated by lower values)												

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10[1,2]	randomized trials	serious[3]	no serious inconsistency	serious[4]	no serious imprecision	reporting bias[2]	2619	0[5]	-	SMD 0.03 lower (0.11 lower to 0.05 higher)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
8[1,6]	randomized trials	serious[3]	no serious inconsistency	serious[4]	no serious imprecision	reporting bias[6]	2841	0[5]	-	SMD 0.10 lower (0.26 lower to 0.06 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
2[1,7]	randomized trials	no serious limitations[3]	no serious inconsistency	serious[4]	serious[8]	reporting bias[7]	36	0[5]	-	SMD 0.13 lower (0.68 lower to 0.41 higher)	VERY LOW	IMPORTANT
Ability, Knowledge (Better indicated by lower values)												
2[1,9]	randomized trials	serious[3]	serious[10]	serious[4]	serious[8]	reporting bias[9]	36	0[5]	-	SMD 0.55 higher (0.55 lower to 1.55 higher)	VERY LOW	IMPORTANT
Symptoms of caregivers (Better indicated by lower values)												
9[1,11]	randomized trials	serious[3]	no serious inconsistency	serious[4]	no serious imprecision	reporting bias[11]	381	0[5]	-	SMD 0.11 lower (0.35 lower to 0.13 higher)	VERY LOW	CRITICAL
Institutionalization												
15[1,12]	randomized trials	serious[3]	serious[10]	serious[4,]	no serious imprecision	reporting bias[12]	5119/0[5] (0%)	0/0 (0%)[5] 0%	OR 0.65 (0.44 to 0.98)	0 fewer per 1000 (from 0 fewer to 0 fewer) 0 fewer per 1000 (from 0 fewer to 0 fewer)	VERY LOW	IMPORTANT

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

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

[3] authors nor reported properly if all studies were RCT.

[4] caregivers were for patients with AD, for pre-senile dementia, for dementia in general. Not clear from the systematic review which are the study populations included for each of the outcomes.

[5] not reported.

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

[7] SWB assessed with perceived quality-of-life scale, life satisfaction scale and other scales.
[8] small sample(less than 100 participants).
[9] was assessed by questionnaires on coping abilities, caregiving-related self-efficacy.
[10] test for homogeneity of effect sizes indicates heterogeneity.
[11] caregiver outcomes were assessed by measures of behaviour problems, cognitive deficit, negative affect and deficit in functional abilities.
[12] was measured by the percentage of members of the experimental group and control group who had been placed in a nursing home.

Table 8

Author(s): Castro-Costa E, Dua T, Huynh N
Date: 2009-08-14
Question: Should miscellaneous intervention vs. no intervention be used for caregivers 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	miscellaneous intervention	non-intervention	Relative (95% CI)	Absolute		
Burden (Better indicated by lower values)												
11[1,2]	randomized trials	serious[3]	no serious inconsistency[4]	serious[2,5]	no serious imprecision	reporting bias[2]	322	0[6]	-	SMD 0.20 lower (0.42 lower to 0.02 higher)	VERY LOW	CRITICAL
Depression (Better indicated by lower values)												
6[1,7]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[7]	229	0[6]	-	SMD 0.12 higher (0.15 lower to 0.38 higher)	VERY LOW	CRITICAL
SWB(subjective well-being) (Better indicated by lower values)												
1[5,8]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	serious[9]	reporting bias[8]	19	0[6]	-	SMD 0.37 higher (0.09 lower to 0.83 higher)	VERY LOW	IMPORTANT

Interventions for carers of people with dementia

Ability, Knowledge (Better indicated by lower values)											
1[1,10]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	Serious[9]	reporting bias[10]	20	0[6]	-	SMD 00.35 higher (0.48 lower to 0.06 higher)	VERY LOW	IMPORTANT
Symptoms of caregiver (Better indicated by lower values)											
8[1,12]	randomized trials	serious[3]	no serious inconsistency[4]	serious[5]	no serious imprecision	reporting bias[11]	0	0	-	MD 0 higher (0 to 0 higher)	VERY LOW	CRITICAL

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

[2] burden was assessed by the Zarit Burden Interview and other scales.

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

[4] I sq not reported, but test for homogeneity indicates not heterogeneity.

[5] caregivers were for people with AD, for pre-senile dementia, for general dementia. Not clear from the systematic review which are the study populations included for each of the outcomes.

[6] not reported.

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

[8] SWB assessed with perceived quality-of life scale, life satisfaction scale and other scales.

[9] sample small (less than 100 participants).

[10] was assessed by questionnaire on coping abilities, caregiving-related self-efficacy.

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

Additional information that was not GRADEd

In the study, both psychoeducation and multi-component interventions were stratified by active participation of caregivers/information provision only and structured approaches/unstructured approaches respectively. We decided to present psychoeducation separately, because results from two stratum are different, However, multi-component interventions results were displayed together because results of structured/unstructured approaches were consistent.

All of the carer intervention trials in this review were conducted in high income countries (HIC). Two LAMIC trials of a brief carer education and training intervention were published recently, one from India and one from Russia (see below). Although small in size, both indicated much larger treatment effects than are typically seen in trials of such interventions in HIC, on carer psychological morbidity and strain. Prevention or delay of institutionalization would confer a substantial societal benefit given the high cost in HICs.

Interventions for carers of people with dementia

Dias A et al (2008): *This was a randomized controlled trial in which the person with mild to moderate dementia-caregiver dyad was randomly allocated either to receive the intervention immediately or to a waiting list group which received the intervention after 6 months. Community based intervention provided by a team consisting of Home Care Advisors' who were supervised by a counsellor and a psychiatrist, focusing on supporting the caregiver through information on dementia, guidance on behaviour management, a single psychiatric assessment and psychotropic medication if needed. Caregiver mental health (General Health Questionnaire), caregiver burden (Zarit Burden Score), distress due to behavioural disturbances (NPI-D), behavioural problems in the subject (NPI-S) and activities of daily living in the elder with dementia (EASI) were measured. 81 families enrolled in the trial; 41 were randomly allocated to the intervention. 59 completed the trial and 18 died during the trial. The intervention led to a significant reduction of GHQ (-1.12, 95% CI -2.07 to -0.17) and NPI-D scores (-1.96, 95%CI -3.51 to -0.41) and non-significant reductions in the ZBS, EASI and NPI-S scores. A non-significant reduction in the total number of deaths in people with dementia in the intervention arm (OR 0.34, 95% CI 0.01 to 1.03) was also observed. The study concluded that home based support for caregivers of persons with dementia, which emphasizes the use of locally available, low-cost human resources, is feasible, acceptable and leads to significant improvements in caregiver mental health and burden of caring.*

Gavrilova SI et al (2008): *This study tests the effectiveness of the 10/66 caregiver intervention among people with dementia, and their carers in a single blind parallel group randomized controlled trial. Sixty family caregivers of people aged 65 and over with dementia were randomized to receive the intervention and medical care as usual (n = 30) or medical care as usual only (n = 30). Caregiver and person with dementia outcomes were assessed at baseline and after 6 months. The caregiver education and training intervention was delivered over five, weekly, half-hour sessions and was made up of three modules: (i) assessment (one session); (ii) basic education about dementia (two sessions); and (iii) training regarding specific problem behaviours (two sessions). Caregivers in the intervention group reported large and statistically significant net improvements at 6-month follow-up in burden compared to controls. No group differences were found on caregiver psychological distress and patient and caregiver quality of life. The low-level intervention seems to be as, if not more, effective than similar interventions applied in high income countries*

Reference List

Brodaty H, Green A, Koschera A (2003). Meta-Analysis of Psychosocial Interventions for caregivers of people with dementia. *Journal of American Geriatric Society,* 51:657-64.

Dias A et al (2008). The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomized controlled trial from GOA, India. *PLoS ONE,* 3:e2333.

Gavrilova SI et al (2008). Helping carers to care- The 10/66 dementia research group’s randomized control trial of a caregiver intervention in Russia. *International Journal of Geriatric Psychiatry,* 24:347-54.

Interventions 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.

Sorensen S, Pinquart M, Duberstein P (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 3:356-372.

Thompson CA et al (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics,* 7:18.

From evidence to recommendations

Factor	**Explanation**				
Narrative summary of the evidence base	**Outcome**	***Psychoeducation***	***Psychoeducation (active participation of caregivers)***	***Psychoeducation (information provision only)***	***Cognitive-behavioural therapy***
	Burden	**SMD -0.15(-0.2 to -0.04 favouring active treatment)**	**SMD -0.20(-0.32 to -0.07 favouring active treatment)**	SMD -0.03(-0.21 to 0.15, no difference)	**SMD -0.36(-0.73 to -0.01, favouring active treatment)**
	Depression	**SMD -0.27(-0.41 to -0.04 favouring active treatment)**	**SMD -0.36(-0.58 to -0.15 favouring active treatment)**	SMD -0.10(-0.30 to 0.11, no difference)	**SMD -0.70 (-1.10 to -0.30, favouring active treatment)**
	SWB (subjective well-being)	**SMD 0.24(0.04 to 0.44 favouring active treatment)**	**SMD 0.21(0.00 to 0.43 favouring active treatment)**	SMD 0.31(-0.33 to 0.95, no difference)	SMD 0.37(-0.27 to 1.01, no difference)
	Ability/ knowledge	**SMD 0.46(0.28 to 0.64 favouring active**	**SMD 0.55(0.26 to 0.85 favouring active**	**SMD 0.28(0.08 to 0.47, favouring active**	SMD 1.12(-0.23 to 1.62, no difference)

		treatment)	**treatment)**	**treatment)**	
	Symptoms of caregivers	**SMD -0.17(-0.29 to -0.04 favouring active treatment)**	**SMD -0.15(-0.31 to -0.00 favouring active treatment)**	SMD -0.20(-0.41 to 0.01, no difference)	SMD -0.29(-0.62 to 0.05, no difference)
	Institutionalization	SMD 1.09(-0.63 to 1.89 no difference)	SMD 0.99(-0.50 to 1.99 no difference)	SMD 1.28(-0.51 to 3.22, no difference)	SMD 1.20(there is no power enough to estimate 95%CI)
		Counselling/case management	***Support***	***Training of CR***	***Multi-component interventions***
	Burden	SMD -0.50(-0.86 to -0.14, favouring active treatment)	SMD 0.01(-0.33 to 0.35, no difference)	SMD -0.17(-0.60 to 0.27, no difference)	SMD -0.03(-0.11 to 0.05, no difference)
	Depression	SMD -0.20(-0.63 to 0.23, no difference)	SMD 0.05(-0.68 to 0.78, no difference)	SMD 0.01(-0.56 to 0.58, no difference)	SMD -0.10(-0.26 to 0.06, no difference)
	SWB (subjective well-being)	SMD 0.42(-0.01 to 0.85, no difference)	SMD 2.03(1.36 to 2.70, favouring active treatment)	SMD 0.42(-0.18 to 1.01, no difference)	SMD -0.13(-0.68 to 0.41, no difference)
	Ability/knowledge	SMD 0.43(-0.01 to 0.86, no difference)	SMD 0.29(-0.03 to 0.61, no difference)	SMD -0.12(-0.78 to 0.49, no difference)	SMD 0.55(-0.55 to 1.55, no difference)
	Symptoms of caregivers	SMD -0.33(-0.69 to 0.02, no difference)	SMD 0.07(-0.44 to 0.58, no difference)	SMD -0.35(-0.67 to -0.02, favouring active treatment)	SMD -0.11(-0.35 to 0.13, no difference)
	Institutionaliz	-	SMD 0.89(-0.15 to	-	**SMD 0.65(0.44 to 0.98, favouring active**

	ation		5.50, no difference)		**treatment)**
		Miscellaneous intervention			
	Burden	SMD -0.20(-0.42 to 0.02, no difference)			
	Depression	SMD 0.12(-0.15 to 0.38, no difference)			
	SWB (subjective well-being)	SMD 0.37(-0.09 to 0.83, no difference)			
	Ability/knowledge	SMD 0.35(-0.13 to 0.82, no difference)			
	Symptoms of caregivers	SMD -0.21(-0.48 to 0.06, no difference)			
	Institutionalization	-			
Summary of the quality of evidence	**Outcome**	***Psychoeducation***	***Psychoeducation (active participation of caregivers)***	***Psychoeducation (information provision only)***	***Cognitive-behavioural therapy***
	Burden	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Depression	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	SWB (subjective	VERY LOW	VERY LOW	VERY LOW	VERY LOW

	well-being)				
	Ability/knowledge	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Symptoms of caregivers	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Institutionalization	LOW	VERY LOW	VERY LOW	-
		Counselling/case management	***Support***	***Training of CR***	***Multi-component interventions***
	Burden	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Depression	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	SWB (subjective well-being)	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Ability/knowledge	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Symptoms of caregivers	VERY LOW	VERY LOW	VERY LOW	VERY LOW
	Institutionalization	-	VERY LOW	-	VERY LOW
		Miscellaneous intervention			

	Burden	VERY LOW			
	Depression	VERY LOW			
	SWB (subjective well-being)	VERY LOW			
	Ability/knowledge	VERY LOW			
	Symptoms of caregivers	VERY LOW			
	Institutionalization	-			
Balance of benefits versus harms	All the caregiver interventions have some benefits in some outcomes. Interventions had, on average, significant but small effects on burden, depression, subjective well-being, ability/knowledge and symptoms of care recipient. Only multi-component interventions reduced the risk for institutionalization. Psychoeducational interventions that require active participation of caregivers had the broadest effects. Effects of cognitive-behavioural therapy, support, counselling, day care, training of care recipient, and multi-component interventions were domain specific. Preliminary evidence from 2 RCTs (Dias et al from India and Gavrilova et al from Russia) from LAMIC indicated much larger treatment effects than are typically seen in trials of such interventions in HIC, on carer psychological morbidity and strain. More structured and more intensive interventions, especially ones that require active participation of the caregiver, are more effective than less structured interventions, one approach to improving interventions might be to promote more active participation of caregivers in applying theoretical knowledge. Also, clinicians should decide in advance whether specific or broad outcomes are desired because each goal may require different				

	intervention techniques. There is no evidence of harms associated with these interventions.
Values and preferences including any variability and human rights issues	Caregiving people with dementia impacts seriously in caregiver's health. Although, interventions with caregivers for patients with dementia have small meaningful effects on reducing their health problems. Those interventions should be continued applied and investigated to improve their quality of intervention
Costs and resource use and any other relevant feasibility issues	Training is required for delivery of psychological interventions. Number of sessions and time taken to administer (duration of intervention) for some of these interventions might be extra burden for the health care provider. Some of these interventions like CBT requires specialist training. Many of them require supervisory support. Psychoeducational/caregiver training/support interventions can be applied by non-specialist health care provide with minimal training and refresher courses. The time taken to administer is approximately 30-60 min and once every month.

Final recommendation

Psychoeducational interventions should be offered to family and other informal carers of people with dementia at the time when diagnosis is made.
Strength of recommendation: STRONG

Training of carers involving active carer participation (e.g. role playing of behavioural problem management) may be indicated later in the course of illness for carers who are coping with behavioural symptoms in people with dementia.
Strength of recommendation: STANDARD

Carer psychological strain should be addressed with support, counselling, and/or cognitive-behaviour interventions.
Strength of recommendation: STRONG

Depression in carers should be managed according to the recommendations for depression (see depression guidelines).
Strength of recommendation: STRONG

Interventions for carers of people with dementia

Limitations

Lack of head-to-head studies comparing different interventions does not allow to establish if some interventions are more effective than others.

Update of the literature search – June 2012

In June 2012 the literature search for this scoping question was updated. The following systematic reviews were found to be relevant without changing the recommendation:

Chan SW. Family Caregiving in Dementia: The Asian Perspective of a Global Problem. Dementia and Geriatric Cognitive Disorders 2010;30:469–478 , DOI: 10.1159/000322086

Chien LY, Chu H, Guo JL, Liao YM, chang LI, Chen CH, Chou KR. Caregiver support groups in patients with dementia: a meta-analysis. International Journal of Geriatric Psychiatry 2011; 26: 1089–1098.

Jones C, Edwards RT, Hounsome B. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. International Psychogeriatrics 2012, 24:1, 6–18, doi:10.1017/S1041610211001207