Table 2 - Dyads

BPSD Review Project – In-Depth Systematic Review

Evidence Tables for Randomised Controlled Trials (RCTs) aimed at addressing BPSD and/or how carers deal with BPSD.

Total included: 68 studies…(115 papers) plus 4 Qualitative studies (7 papers related to 4 RCTS)

- **People with dementia (pwd);** (n=7 studies, 9papers)
- **Dyads (People with dementia and carers)** (n=24 studies, 44 papers)- plus 1 qualitative study
- **Carers;** (n= 37 studies, 62 papers)- plus 4 qual study (6 papers)

Abbreviation	Full description	Abbreviation	Full description	Abbreviation	Full description
RCT	Randomised controlled trial	IG	Intervention group	MCI	Mild cognitive impairment
Pwd	People with dementia	CG	Control group	FU	Follow-up
QOL	Quality of life	RR	Risk ratio		
BPSD	Behavioural and psychological symptoms of dementia	OR	Odds ratio	ns	Not significant
AD	Alzheimer's disease	d	Cohen's d		
VD	Vascular dementia	MD	Mean difference		
F	Female	TF	Theoretical framework		
M	Male	ANCOVA	Analysis of variance, F test		
PC	Power calculation				

Table 2 – studies evaluating an intervention that includes BPSD symptoms as a component of the overall intervention delivered to people with dementia (pwd) and carers (DYADS);

Primary and secondary outcomes are indicated if reported and classified by the paper.

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, setting and country of study	Sample size Include PC if available	Description of intervention	Outcome variable(s) (measures shown in brackets)	Main results at follow up (reported as IG vs CG unless otherwise specified) (95% confidence intervals shown in brackets)	Evidence summary Quality (ROB=risk of bias No of domains 'low risk' out of 6; overall risk)	*Applicability to the UK populations and settings Score 1-4
Behavioural								
Behaviour management therapy								
Burns 2003	To test two 24 month primary care interventions to alleviate psychological distress of carers of people with Alzheimer's disease	167 dyads, Person with Ad and related dementia, < 24 MMSE, care (CR) recipients severely demented, limitations in >=1 ADL. Recruited through primary provider Mean age CareG 64.2 yrs;>80% F; >40% black' mean 13 yrs education, IG higher income; >4 yrs caring Pwd: Mean age 80 yrs, 50% F, 10-11	IG: 85 CG: 82 76 completed without placement or bereavement.	REACH IG: Patient behaviour management. CG: Patient behaviour management plus caregiver stress and coping management **Duration & intensity** 25 targeted education materials on behaviours (4 p.a.) Planned 30 minutes per office visit. an average of 3 hours intervention received over 24 m. Not clear if this includes telephone calls,	<u>Carer Outcomes:</u> (pwd had behavioural problems) Well-being (M-GWBS) Depression (CES-D) Caregiver Affect (RMBPC)	FU: every 6m for 24m No significant group differences. However, there were significant time effects (as follows): d=0.68, md=9.00 (2.84, 15.16), p=.004 d=0.41, md=-4.50 (-9.48, 0.48), p=.007 d=0.48, md=-5.6 (-10.83, -0.37), p=.010	General Wellbeing and depression improved for enhanced group Bother from problem behaviours –improved for both groups Brief primary care interventions may be effective in reducing caregiver distress and burden in the long-term management of the dementia patient. Interventions that focus only on care recipient behaviour, without addressing caregiving issues, may not be as	3

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		yrs education, **Setting:** Primary care (for home/community)-Memphis site **Country:** USA TF: Lazarus and Launier's action-oriented, individual-environment model of stress and coping		which the method implies were given to both groups Method states 10 minute phone calls – 2 per month in the first six months and 1 per month thereafter and this seems to apply to both groups, but ambiguous. Enhanced group received 4 hr face to face contact/telephone (20 mins) **Provider:** master's-prepared health educator–interventionist			adequate for reducing caregiver distress. ROB: 2/6 low; high attrition Overall: unclear	
Teri 2000 Weiner 2002	To determine which treatments are most effective in reducing agitation in pwd TF: none	Carers and pwd with AD and agitated behaviours; approx. 5 years diagnosed with probable AD Pwd mean age 75 Carers IG 68%F, DC1 59%F, DC2 89%F, Placebo 56%F. pwd IG 54%F, DC1 59%F, DC2 41%F, placebo	148 (IG 41, drug comparison (DC) 1= 34, DC 2=37, placebo = 36) 80% power	Behavioural management therapy aims to treat agitation. **Duration & intensity** IG: Eight weekly and 3 bi-weekly structured sessions, and structured assignments in and out of sessions. CGs: 11 clinical visits over 16 weeks. 2 drug comparison groups and 1 placebo.	<u>Primary:</u> Alzheimer's Disease Cooperative Study Clinical Global Impression of Change <u>Secondary:</u> <u>Pwd outcomes:</u> Agitation and behaviours (BRSD) Agitation and	FU: 16 weeks; 12 months (76/148) Not significant-clinically meaningful improvement in patient's condition Not significant Not significant	Symptoms did not respond differentially to the different treatments. No effect on carer outcomes. 34% of subjects improved relative to baseline in both groups. Fewer adverse effects in behavioural management group. ROB: 6/6 low Overall: low	2

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		67%F Around 70% spouses of pwd. **Setting:** Home/Community **Country**: USA		DC 1: Mean dose = 1.8mg/day DC 2: Mean dose = 200mg/day **Providers**: Conducted by the therapists with Master's degrees and at least 1 year clinical experience.	behaviours (RMBPC) Agitation and behaviours (CMAI) Agitation and behaviours (ABID) Coognitive Functioning <u>Carer outcomes:</u> Burden (SCB) Distress related to BPSD (RMBPC)	Not significant Not significant (FU: 12 months only in Weiner 2002). ns Not significant Not significant		
Cognitive Behavioural Therapy								
Spector 2014 (in press) Spector 2012 (protocol)	This study aims to develop a CBT for anxiety in dementia manual and to determine its feasibility in a pilot RCT.	PWD with mild-moderate dementia and carers (16-25 MMSE); people with severe agitation unable to engage were excluded PWD Age (mean): IG: 78 CG: 79	50 dyads IG: 25 CG: 25 80% power	CBT plus treatment as usual 1) Assessment and formulation. Key aims are to build a collaborative relationship, socialisation to the CBT model, identifying goals and establishing the involvement of the carer. The carer's role is to support the PWD	<u>PWD Outcomes:</u> <u>Primary</u>: Anxiety (RAID) <u>Secondary:</u> Mood (HADS) QOL (QOL-AD) Cognitive Function (MMSE)	FU: 15 weeks, 6 months -4.59 (95% CI -9.34, 0.15) Not significant Not significant Not significant Lower in CBT+ group	CBT can improve anxiety at 15 weeks and 6 months and is cost neutral. CBT was feasible (in terms of recruitment, acceptability and attrition) and effective. A fully powered RCT is required. Willingness to participate, low level of withdrawal, feasible for those with mild	2

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	TF: CBT	IG: > 60%f CG: F 60% Carer Age (mean): IG: 69 CG: 66 IG: F 56% CG: F 74% PWD Education (years) IG: 9 CG: 10 Carer relationship to PWD IG 72% spouse 28% child CG 44% spouse 36% child 20% other Time spent carer (months) (median) IG: 24 CG: 24 Hours/week caring (median) IG: 61		2) Application of change processes, which the therapist will adapt according to the needs and strengths of the individual. 3) Ending the therapy and developing a blueprint for the future. Telephone contact offered between sessions. Facilitators: clinical or counselling psychologists, with experience of working with PWD CG: Treatment as usual **Duration & intensity** 10 weekly sessions, each lasting 1 h hour.	Depression (CSDD) Quality of relationship (QCPR) <u>Carer Outcomes:</u> Mood (HADS) Quality of relationship (QCPR) <u>Economic Outcomes:</u> Cost (CSRI)	(-5.08, 95% CI; -9.25, -0.92) Not significant Not significant Not significant At baseline: mean difference of £834.27 (95% CI; -£285.77, £3069.38)- although not statistically significant 15 weeks: mean difference of £321.97 (95% CI; £345.94, £946.85) - although not statistically significant 6 months: £1085.02, (95% CI; -£354.81, £4078.64) – Although not statistically significant	to moderate dementia. increased emphasis on behavioural rather than cognitive techniques, greater involvement from family carers in the more moderate stages of dementia. Participants with dementia who were able to identify (a) unhelpful persistent negative automatic thoughts, conditional beliefs ('rules for living') or self-defeating cognitive (b) more helpful alternative approaches, were also able to retain information and demonstrate the ability to 'Stop, think and do differently' without necessarily needing prompts from family carers. In cases where the person was unable to engage in such processes, family carers who had engaged with the CBT rationale were able to support the person to apply coping statements and techniques such as distraction and relaxation.	

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		CG: 15 Use of Anxiolytic medication IG: 8% CG: 24% Antidepressants IG: 48% CG: 36% Antipsychotic Medication IG: 0% CG: 8% **Setting:** Community **Country:** UK					ROB: 5/6 low Overall: low	
Paukert 2010 (related to Stanley 2013) pilot study)	To describe the intervention results of an open trial evaluating the feasibility and utility of the intervention and assessment procedures	Veterans with dementia (AD, vascular & not otherwise specified) and their carers (family or friend) Mean PWD Age 77 PWD Gender 5 male 3 female	8 dyads	Provided over 6 months. First 3 months, up to 12 weekly in person sessions, lasting 30-60 minutes in the participants' home. Each session was followed by a brief telephone call. Next 3 months of treatment, telephone booster sessions weekly for 4 weeks and biweekly for 8 more weeks for a total of 12 weeks.	<u>PWD Outcomes:</u> <u>Primary:</u> Anxiety (NPI-A) (RAID) <u>Secondary</u> (PSWQ-A) (GAI) Depression (GDS) Memory, Behaviour and mood (RMBPC)	Follow-up: 6 months 66% improved 57% improved 43% improved 43% improved 57% improved 14% improved	open trial suggests potential benefits of Peaceful Mind, CBT for anxiety. High completion rate indicates that intervention is feasible. The average number of sessions completed (9.5) is notable,and the average length of each session indicated that participants were able to maintain attention and involvement in the treatment. Overall,	

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	TF: Cognitive Behavioural	Pwd Ethnicity 6 Caucasian 1 Hispanic 1 African-American 5 AD 2 Vascular Dementia 1 Not specified 7 taking a combination of Psychiatric medications Relationship with carer 3 Wife 1 husband 3 Son 1 Daughter Setting: Community		Included modules teaching self-awareness, breathing, calming statements, increasing activity, and sleep skills. Clinicians could decide which skills best fit the symptoms and abilities. Advanced clinical psychology doctoral graduate students.	Satisfaction (CSQ) <u>Carer Outcomes:</u> Distress over anxiety (NPI-A distress) Distress over memory, behaviour & mood Satisfaction (CSQ)	28.8 (average) 50% improved 57% improved 29.7 average	participants and carers reported that they were satisfied with and benefited from the treatment in terms of anxiety, depression, and carer distress, which indicates that the intervention has potential utility.	
Stanley 2013 (Pilot Study) Paukert 2010	To assess feasibility and to conduct a preliminary evaluation of outcomes following Peaceful Mind, a	PWD with mild and moderate dementia receiving care through outpatient clinics at VA medical centres. IG 56.3% AD 6.3% Lewy Body 12.5% Vascular	IG: 16 CG: 16	IG: Skills were presented and practiced during the weekly sessions; and telephone booster appointments allowed skills review, reinforcement of skills practice, questions and answers, and problem-solving to integrate skills into daily life.	<u>PWD Outcomes:</u> <u>Primary:</u> Anxiety (NPI-A) (RAID) (GAI) <u>Secondary:</u> Worry (PSWQ-A) Depression (GDS)	Follow-up: 6 months Not significant Not significant Not significant Not significant Not significant	Overall, carers were very satisfied with the service they received; all reported that the program helped them know how to respond to their loved one's anxiety, and all but one noted positive effects on communication. No consistent negative impacts	

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	CBT-based intervention for anxiety in dementia, relative to usual care (UC). TF: Cognitive behavioural	25% Not specified CG 68.8% AD 6.3% Vascular 25% Not specified PWD Age (mean) IG: 77.6 CG: 79.6 PWD Gender IG: 62.5% F CG: 56.3% F PWD Education (mean years) IG: 37.5% <High School 62.5% College CG 56.3% <High School 43.8% College PWD Ethnicity IG 75% White 6.3% Black 18.8% Other CG 56.3% White 37.5% Black 6.3% Multiracial **Setting;** Home/Community		Carers were involved in weekly skill learning and served as a coach for the patients' practice between sessions. The carer's role as a coach was determined jointly by the patient, carer, and clinician, based on the patient's and carer's level of understanding, patient preferences, and carer availability. CG: Enhanced Usual Care **Duration & intensity** Over 6 months and included up to 12 weekly in-home sessions over the initial 3 months and up to 8 brief telephone booster appointments during months 3 to 6.	QOL (QOL-AD) <u>Carer Outcomes:</u> Distress (NPI-A) Depression (PHQ-9) Satisfaction (CSQ) Ten (90.9%) carers from the 11 dyads completing Peaceful Mind rated the quality of the program	Not significant Not significant Not significant Carers thought the service quality was excellent (M = 3.9, SD = .32), and Peaceful Mind helped them a great deal to manage their problems more effectively (M = 3.7, SD = .48).	were noted. Fifty percent of carers had no suggestions for changing the program, two recommended longer treatment, two had suggestions for altering materials for patients, and one mentioned a need to adapt the program further, as many patients cannot retain information. ROB: 4/6 low Overall: low/unclear AC; sample size small	

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		Country, USA, Texas, Houston						
Education and training								
Psychosocial skills and education								
Belle 2006	To test the effects of structured multi component intervention on quality of life and rates of institutional placement of care recipients in 3 diverse racial or ethnic groups. TF: As REACH	Care recipients (CR)with AD, mean ADL ~3, IADL 7, and carers, with > 15 years of caring Hispanic or Latino; MMSE 11-15 across groups; behaviour frequency score 20-25 Carers:mean age from 57-64 years across 3 groups; Income of ethnic groups low compared with white or Caucasian, 30-505 <$20, 000; <30% employed fulltime, 24-40% spouse, 35-43% child CR: mean age across 3 groups 77.5-80.8 yrs; 40-	IG: 323 CG: 319 PC given based on previous effect sizes from REACH, 80% power	REACH II systematically targets several problem areas, tailored to individual needs in ethnically diverse population, engaging carer in intervention process. Active techniques, such as role playing and interactive practice, problem solving, skills training for managing problem behaviours IG: 12 in home and telephone sessions over 6 months. 0.5-1.5 hours, plus 5 structured telephone support 6 month intervention. CG: 2 brief check in calls, invited Carers to workshop Providers: certified interventionists	<u>QoL indicators: 5 primary domains closely linked to components of intervention</u> <u>PWD Outcomes:</u> <u>Primary:</u> *Problem Behaviours (RMBPC)* <u>Secondary:</u> Institutionalisation <u>Carer Outcomes:</u> <u>Primary:</u> *Depression (CES-D)* *Burden (ZCBI)* *Self-care* *Social Support* *Received* *Satisfaction* *Negative interactions*	FU: 6 months Net improvement across all 5 domains: IG: 45.1% CG: 6.9% Diff 38.2% (11.2, 64.4) Hispanic /Latino Net improvement 36.3% (13.2-56.7) P<0.001, Not significant d=1.53, md=-28 (-30.99, -25.01), P=.001	Hispanic or Latino and white or Caucasian, improved QoL significantly but not Black or African population. However black or African American Spouses in IG showed significantly more improvement than spouses in CG A multicomponent structured intervention adapted to individual risk profiles can increase the QoL of ethnically diverse dementia carers. No significant differences in institutionalisation at 6 months. ROB: 3/6 low Overall: unclear	4

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		60% <high school (ethnic groups, 25 % white/Caucasian **Setting;** five sites recruited dyads- Alabama, Memphis, Miami, California and Philadelphia **Country:** USA			Clinical depression (CES-D) Secondary: Prevalence of CG clinical depression	 IG;12.6 % vs CG: 22.7%, p<0.001		
Gitlin 2010a	To test a Non-pharmacologic, bio-behavioural approach to support physical function and quality of life for patients with dementia and the well-being of their carers. TF: none	Carers and pwd needing help with ADL or with behavioural symptoms Pwd mean age 82, carer mean age 62 Carer 89%F, pwd 68%F 38% spouse **Setting:** Home/Community **Country:** USA	209 dyads (IG 102, CG 107) 90% power	IG: COPE (care of persons with dementia in their environments). Aims to support pwd capabilities by reducing environmental stressors and enhancing carer skills. Biobehavioural home based training in safety, stress reduction, simplifying tasks **Duration & intensity** Up to 10 sessions over 4 months with occupational therapist, 1 face to face and 1 telephone session with an advance practice nurse. CG: up to three 20 min telephone calls from trained research staff	<u>Pwd outcomes:</u> Functional dependence (15 item measure modelled after the Functional Independence Measure) QOL (Quality of Life - AD scale) Frequency of agitated behaviours (Agitated Behaviour in Dementia Scale) Engagement (activity engagement scale) <u>Carer outcomes:</u>	FU: 4 and 9 months Adjusted MD= 0.24, (0.03,0.44), d=0.21, p=.02) Not significant Not significant Adjusted MD= 0.12 (0.07,0.22), d=.26, p=.03	Improved pwd engagement and functional dependence. Improved carer well-being and confidence using activities. IG carers reported greater benefits. No effect on pwd QOL or frequency of behaviours. Significant effects are at 4 months. No significant effects at 9 months ROB: 6/6 low Overall: low	4

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				Providers: occupational therapist, advance practice nurse, trained research staff	Confidence using activities (investigator developed items) Perceived benefits for carers (11 item survey) Well-being (13 item Perceived Change Index)	 Adjusted MD= 0.81 (0.30,1.32), d=.54, p=.002 p<.001 Adjusted MD=0.22, (0.08, 0.36), d=.30, p=.002		
Gitlin 2010b Gitlin 2007	To evaluate intervention effects on target behaviours carer identifies as distressing TF: stress health process model	Carers and pwd who live together and are managing problem behaviours MMSE mean 12 Problem behaviours, no. 10, frequency mean 13.5 Carer mean age 66, pwd mean age 82 Carer 82%F, pwd 53%F Carer and pwd 70%	272 dyads (IG 137, CG 135) 80% power	IG: Advancing caregiver training (ACT) to target problem behaviours identified by carers as most troublesome and provide strategies to manage them. Problem solving potential triggers **Duration & intensity** 16 week active phase of up to 9 occupational therapy (OT) sessions and 2 nursing sessions and a maintenance phase (16-24 weeks) of 3	<u>Pwd outcomes:</u> <u>Primary:</u> Frequency of target behaviour (carer report) <u>Carer outcomes:</u> <u>Primary:</u> Upset (10 point scale) Confidence in managing target behaviour (4 point scale)	 RR 1.47, (1.47, 1.85), p=.002 (FU: 16 weeks) Adjusted MD= -0.93 (-1.76, 0.10), d=.30, p=.03) (FU: 16 weeks) Adjusted MD= .33, (0.08,0.58), d=.30, p=.01 (FU: 16 weeks)	Improved target problem behaviour, reduced carer upset with, and enhanced confidence managing, the behaviour. Carers reported less upset with all problem behaviours, less burden and better well-being. ROB: 6/6 low Overall: low	3

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		white **Setting:** Home/Community **Country**: USA		brief OT telephone contacts. **Providers:** occupational therapists and nurses. Health professionals identify potential triggers of patient behaviours, including communication, environmental factors; trained carers in strategies to modify triggers and reduce their upset. Action plan with treatment goals provided. Carers instructed in stress reduction and self-care skills. Low cost assistive devices. Advanced practice nurse provided education on common medical problems that could exacerbate problem behaviours e.g. pain, dehydration, reviewed medications. CG: no contact	Burden (Zarit burden scale) Upset with problem behaviours overall <u>Secondary:</u> Perceived change in well-being (perceived change index) Depression (CES-D) Skill enhancement (task management strategy index) Perceived study benefits (11 item measure)	Adjusted MD= -1.61, d=.67, p=.04 (FU: 24 weeks) Adjusted MD= -0.82, d=.33, p=.002 (FU: 24 weeks) Adjusted MD= 0.29, d=.43, p=.001 (FU: 24 weeks) Not significant (FU: 24 weeks) Adjusted MD= 0.14, d=.24, p=.005 (FU: 24 weeks) IG reported greater improvements. (FU: 24 weeks)		
Judge 2012 Judge 2010 QUALITATIVE DATA- INCLUDED	To examine the impact of the dyadic intervention for carers	Carers and pwd AD 50%, dementia any type 25%, mixed dementia 0.8%, mild cog impairment 5.9%,	128 dyads (IG 68, CG 60) PC not reported	IG: Acquiring new skills while enhancing remaining strengths (ANSWERS). Aims to train both carers and pwd on a core set of skills for managing and coping	<u>Carer outcomes:</u> <u>Primary:</u> Mastery (caregiver appraisal measure)	FU: Approx. 15 weeks post-baseline d=0.22, MD= 0.37, (-0.23, 0.97) Unstandardized beta=	Decreased emotional health strain, depression and anxiety for carers. Also decreased dyadic relationship strain, role captivity and improved	2

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	and pwd on psychosocial outcomes. TF: Stress Process Model	VD 5.1%, other memory diagnosis 13.6%; MMSE mean 22, problem behaviours, mean 7.5-8.5 (mild to moderate) Carer mean age 65, pwd mean age 77 Carer 74%F, pwd 56%F 60% spouses of pwd; 50% retired **Setting:** Home/Community **Country:** USA		with the symptoms of dementia. **Duration & intensity** six, 90 minute sessions CG: standardised educational resource packet of information **Providers**: 4 masters level intervention specialist	Emotional health strain (Bass, Noelker & Rechlin, 1996) Physical health strain (Bass, Noelker & Rechlin, 1996) Self efficacy (Pearlin, Mullan, Semple, & Skaff, 1990) Role captivity (Pearlin, Mullan, Semple, & Skaff, 1990) Dyadic relationship strain (Bass, Tausig & Noelker, 1989) Depression (short form CES-D) Anxiety (Zung, 1980)	.81, p=.01 d=0.40, 0.20, MD=-1.11, (-2.12, -0.10) Unstandardized beta= -1.68, p=.01 Not significant Not significant d=0.51,MD= -0.94, (-1.61, -0.27) Unstandardized beta= -.86, p=.01 d=0.43, MD= -1.32, (-2.44, -0.20), Unstandardized beta= -1.47, p=.01 d=0.28, MD= -0.89, (-2.02, 0.24) Unstandardized beta= -1.10, p=.04 d=0.33, 0.16, MD= -1.66, (-3.46, 0.14), Unstandardized beta=	caregiving mastery. No effect on carer physical health strain, self efficacy, QOL or self-esteem. ROB: 4/6 low Overall unclear randomisation/AC	

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						-2.69, p=.01		
					QOL (Logsdon, Gibbons, McCurry & Teri, 1999)	Not significant		
					Self-esteem (Rosenberg SES)	Not significant		
Judge 2010 QUALITATIVE DATA- mixed data	Perspective: carer, pwd Aims: report results of acceptability and feasibility of intervention protocols	As above		open ended questions	Answers given from some participants without providing specific analysis methods	No themes identified, quotations:: Carer: clear and helpful, identify actual symptoms and explain them The training helped for improving skills on a day to day basis in everyday life Pwd: Very helpful programme. It gave ideas to help patients to express their thoughts clearly and to discuss what the patient wants or needs.	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings - Low **F4 -**usefulness of its findings for this review-Low	
Systematic Care Program for Dementia								
Spijker 2013 Spijker 2011	To evaluate the effectivenes	Carers and pwd; 48% mild (IG) IG: 48% mild, CG	IG: 155 CG: 140	BPSD for pwd and helping carers deal with BPSD	<u>PWD Outcomes:</u> <u>Primary:</u> Institutionalisation	FU: 12 months Not significant	No significant differences SCPD might prevent a	

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Spijker 2009 (protocol)	s of training healthcare professionals in the SCPD and its subsequent use by CMHSs in institutionalization in comparison to usual care. The second objective was to examine the strongest predictors of patient institutionalization.	40% Moderate: IG 60% CG:38% NPI>10 Care NPI-Q >10 Caregiver Mean Age IG: 58.4 73.5% F CG: 59.2 75% F PWD Mean Age IG: 80.1 69.7% F CG: 80.1 64.3% F Caregiver & pwd ethnicity IG Dutch: 98.7% CG Dutch: 97.9% Caregiver Education IG Low: 31% Intermediate: 45.2% Higher: 21.3% Other: 2.2% CG: similar PWD Education	Power: 80%	3 sessions of 2 hours each. The SCPD consists of training professionals in the systematic assessment and interpretation of the caregiver's sense of competence and depressive symptoms, as well as strategies about how to deal with deficiencies. The assessment covers a wide range of individual caregiver problems and triggers the awareness of professionals in connecting proactive interventions to those problems. This is one of the tasks of the CMHS.	(RUD) Severity of Behavioural Problems (NPI-Q) related to carer used as covariate <u>Caregiver Outcomes:</u> Used as co-variates Competence (SCQ) Depressive Symptoms (CES-D) Distress (NPI-Q)	Not significant Not significant Not significant Not significant	deterioration of the sense of competence in the intervention group. The intensity of a program is crucial and should be prescribed on the basis of evidence rather than left to the discretion of health professionals. Future controlled trials in daily clinical practice should use a process analysis to control for compliance ROB: 4/6 Overall low (AC unclear)	

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		IG Low: 64.5% Inter: 19.4% Higher: 7.7% Other: 7.1% CG; similar Low: 60.7% Inter: 23.6% Higher: 10% Other: 5.7% Relationship Partner: 49.4% Child: 47.8% Other: 70.9% Shared Living Arrangement IG 32.3% **Country:** Holland						
Multicomponent								
Baglio 2014 Related papers Farina 2006a, 2006b; Farina 2002	To improve PWD condition in different disease domains: cognition, behaviour, and motor functioning.	Pwd with probably AD – Mild to moderate stages NPI>14 PWD Age: IG: 75.61 CG: 76.50 Gender ratio (m:f)	IG: 28 CG: 24 70% power adequate for the trial	PWD with BPSD IG: 3 levels of treatment; (1) Focused on PWD. This involved Reality Orientation activities and cognitive exercises, physical activity, occupational activities and recreational activities.	<u>PWD Outcomes:</u> <u>Primary:</u> Neuropsychiatry (NPI) Distress subscale (NPI) Secondary:	FU: 32 weeks d= 3.46, MD= -4.30, (-5.0, -3.60), p = 0.019 Not significant	Results supported the initial hypothesis that MST has an impact on at least 2 AD domains: behaviour-reduction of BPSD and improvement in some cognitive abilities. ROB: 5/6 low Overall: low	2/3

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	Hypothesis: Multistimulation Group Therapy has an impact on at least 2 AD domains: behaviour-reduction of BPSD and improvement in some cognitive abilities TF: None	IG: 13:15 CG: 10:14 Education: IG: 8.61 CG: 9.43 **Setting**: Home / Community **Country**: Italy		**Duration & intensity** 1. MST 30 rehabilitation sessions (2.5 hours a day, 3 days a week). (2) Involved the caregiver. Standardized short group educational program with a rehabilitation therapist. (3) Included the dyad PWA–caregiver. **Facilitators:** psychologist and a rehabilitation therapist CG: Treatment as usual	AD (ADA); Overall Global Word recall Naming Memory Spoken Language Functional Skills (FLSAS) QOL – Mental (SF-36) QOL – Physical (SF-36) Brain Activation (VFT & fMRI)	Not significant Mean Difference: -0.25,p = 0.045 d= 4.1, MD= -0.41,p = 0.004 Not significant d= 2.82, MD= -0.38. p = 0.010 Not significant Not significant Not significant Significant intervention related increase in activation of the bilateral superior temporal area p<0.05		

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Integrated rehabilitation programme								
Onor 2007	To evaluate the effects of intervention for carers and pwd. TF: none	Carers and pwd with mild-moderate AD Pwd mean age IG 68, CG 72 Pwd 44%F Setting: Home/Community Country: Italy	16 (IG 8, CG 8) PC not reported	Integrated Rehabilitation Programme consisting of Reality orientation , reminiscence therapy (RT) and occupational therapy (OT) for pwd and psychoeducation for carers. Aims to target cognitive function, behavioural aspects and functional skills for pwd. Aims to reduce stress, anxiety and depression for carers. Pwd: Three 60 min sessions per week in 2 phases. Phase 1: 24 sessions of formal OT over 8 weeks. Phase 2: 12 sessions of activities through OT and RT Carers: 16 sessions, sixty min weekly sessions over 4 months. CG: no intervention Providers: psychologist	<u>Pwd outcomes:</u> ADL (activities of daily living) IADL (instrumental activities of daily living) Depression (GDS) <u>Carer outcomes:</u> Burden (CBI) Anxiety (brief symptom inventory) Depression (brief symptom inventory)	FU: 2 and 4 months Not significant Not significant d=1.65, MD= -8.37, (-13.36, -3.38), p=.005 d=0.70, effect size 0.33, MD= -9.00, (-21.65, 3.65), p=.011 d=0.00, effect size 0.00, MD=0.00, (-3.51, 3.51), p=.014 d=0.62, effect size 0.30, MD= -2.37, (-6.13, 1.39), p=.035	Improved pwd depression, and also reduced carer burden, depression, and anxiety. No effect on pwd ADL or IADL. Alzheimer's patients had more stable cognitive status and improved mood. Carers improved anxiety and depression. Also coping skills increased and preserved and valued support. ROB:1/6 low Overall: unclear	3

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Reducing disability in Alzheimer Disease program								
Teri 2003	To evaluate effectiveness of intervention in reducing functional dependence and delaying institutionalisation for pwd. TF: none	Carers and pwd with moderate-severe AD (4-5 years) Carer age range 24-91, pwd age range 55-93 Carer 70%F, pwd 41%F 60% spouses of pwd **Setting:** Home/Community **Country:** USA	153 dyads (IG 76, CG 77) 80% power	IG: The reducing disability in Alzheimer Disease program (RDAD). Aims to improve pwd-carer interactions, physical health, affect and behavioural distress. Consists of exercise and behavioural management CG: Routine medical care **Duration & intensity** 12 sessions x 1 hour (6 sessions in first 3 weeks, then weekly for 4 weeks, then bi-weekly for 4 weeks). Then 3 follow up sessions in next 3 months to consolidate. **Providers**: home health professionals experienced in dementia care	<u>Pwd outcomes:</u> <u>Primary:</u> Physical health (short form Health Survey SF-36) Depression (CSDD)(affective status) <u>Secondary:</u> Problem behaviours (RMBPC) <u>Carer outcomes</u>: Distress related to behaviours (RMBPC) <u>Economic:</u> None reported, other than trend for less institutionalisations at 2 years in RDAD group.	FU: 3 and 24 months d=0.06, MD= 10.89 (3.62,18.16), p=.003 d=0.27, MD= -1.03, (-0.17, 1.19), p=.02 Not significant Not significant	Improved pwd depression. At follow up, IG showed a trend for less institutionalisation due to behavioural disturbances. No effect on pwd problem behaviours or on carer distress related to behaviours. At 3 months, RDAD exercised more, fewer days of restricted activity, improved depression. At 2 years, RDAD better physical role functioning and trend for less institutionalisations. Group with worse depression at baseline improved more in RDAD group at 3 months and 2 years. ROB: 6/6 low Overall: low	3

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Danish Alzheimer Intervention								
Waldorff 2012 Vogel 2010 Waldorff 2010 Jensen-Dahm 2012 Phung 2013 Waldemar 2011 QUALITATIVE Sorensen 2008	To investigate the efficacy of the DAISY intervention TF: based on constructivist principles	Carers and PWD with AD, mixed AD with vascular component or Lewy body dementia; mild dementia; 60%>1 co-morbidity PWD mean Age IG: 76.5 CG: 75.9 Carer mean Age IG: 65.5 CG: 66.5 Carer 67%F, pwd 54%F 65% spouses of pwd or co-habiting **Setting**: Community primary care and memory clinics **Country:** Denmark	330 dyads (IG 163, CG 167) PC conducted but not reported	IG: Danish Alzheimer intervention (DAISY). Multifaceted, semi-tailored psychosocial counselling and support programme. Consists of information and support to pwd and carers during initial months after diagnosis. Aims to prevent depressive symptoms and further impairment to QOL, loss of social network, for pwd and carers. **Duration & intensity** Counselling: up to 7 sessions. Information/support courses: 5 sessions for pwd, 5 sessions for carer. Each lasting 2 hrs. telephone contact 5-8 times during study period at 3-4 week intervals. Delivered over 8-12 months. CG: Same as IG without additional DAISY component	<u>Pwd outcomes:</u> <u>Primary:</u> Global Cognitive Functioning (MMSE) Depression (CSDD) QOL (EQ-VAS, QOL-AD patient and proxy rated) Behaviours (NPI) ADL (ADSC-ADL) <u>Carer outcomes:</u> Depression (GDS) QOL (EQ-VAS)	FU: 12 months and 36 months Not significant MD −0.81 (−1.46 to −0.16), p = 0.0146 (12m) Not significant Not significant Not significant Not significant Change Not significant Change	No significant effects on pwd or carer outcomes at 12months. Small difference observed in depression in favour of intervention group patients. No long-term effect of an intensive psychosocial intervention (DAISY) on patients and carers beyond the effect of structured follow-up support. ROB: 5/6 low Overall: low	2/3

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				Providers: nurse with specialist training, counsellor, teacher, local study coordinator				
Sorensen 2008 – Qualitative related paper to Waldorff 2012	Perspective: Pwd and carer To identify and analyse the participants' experienced outcome of the intervention. Intervention psychosocial with tailored counselling, education and support groups. TF: Not reported	N=11 dyads out of n=165 dyads who received intervention. Carers married or cohabiting with pwd with mild AD. Carer age range 65-85, pwd age range 65-81 Carer 50%F, pwd 50%F Country: Denmark		<u>Method</u> Semi-structured interviews maximal variation sampling strategy	<u>Analysis</u> Interviews transcribed. Coded by in-vitro codes. The analytic/ interpretive process consisted of iterative cycles between organising, connecting and corroborating codes, and collecting them into increasingly abstract concepts A template organizing style of interpretation was used.	<u>Main findings</u> patients and carers found the intervention stimulating and rewarding. All participants became more aware of the disease and the consequences for everyday life and social relations. Subsequently, they sought suitable support groups they could join as a permanent activity and carers also sought permanent counselling. There were no apparent negative outcomes of the intervention. Patients found support groups particularly	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings? LOW **F4 -**usefulness of its findings for this review? MEDIUM	

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						Relevant, stimulating to be with peers, supported their self-esteem, in finding new ways of managing everyday life and social relations. Carers considered all parts of the intervention relevant. During and after the intervention, they were better able to cope with the challenges their partner's disease involved, and they were able to face everyday life and social relations with more serenity and competence		
Organisational interventions								
Preserving Identity and Planning for Advance Care								
Hilgeman 2014	To advance intervention	Family carers and PWD with early or	IG: 9 dyads	BPSD for PWD	* Proxy and Self-report	FU: 1 week post intervention	At post-treatment assessment, intervention	

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Pilot	research focused on identity in PWDs. To examine the impact of the PIPAC intervention on coping strategies in the early stages of dementia. TF: None	mild stage dementia <u>PWD</u> Age; IG: 80.80 CG: 84.25 ADL>1, IADL>5, most taking meds for mood/memory IG: 70% F CG: 75% F IG: 10% African American CG: 0% Education IG: 13.9 years CG: 16.75 years <u>Carer</u> Age; IG: 66.20 CG: 68.57 IG: 60% F CG: 71.4% F IG: 10% African American CG: 14.3% African	CG: 8 dyads PC not calculated	IG: Preserving Identity and Planning for Advance Care (PIPAC) Family contacts are invited but not required to attend. Intervention utilizes a strength-based approach of documenting what it has meant for the individuals to 'live well' in the past and what it means for them to 'live well' in the future. Combines one self-adjusting, future planning component and one self-maintaining, reminiscence-based component to maximize coping. **Duration & intensity** 4 sessions over 4 – 6 weeks. CG Comparison: A minimal support-based intervention focused on empathic listening and supportive reflection was administered via telephone.	<u>PWD Outcomes Primary: Emotional and health related</u> Depression (CSDD)* Anxiety (CSDD)* QoL (QOL-AD)* & (BASQID) Meaning of Life (MLS) Social Engagement (MDS 2.0)* Emotional Support and Connectedness (ES & ASS) Health Related QoL (EQ-5D)* Mobility	Effect Size: 0.27 F = 5.50 p = 0.03 d= 0.38, MD= -1.33, , p = 0.03 Not significant Proxy QOL-AD Effect size = 0.28, F = 5.41, p = 0.04 d= 0.63, MD= 2.57, p = 0.04 not significant Not significant Not significant Not significant Not significant	PWDs reported significantly lower depressive symptomatology than controls. Corroborated by proxy-reported observations of medium-sized effects of the intervention on depressive symptoms post-intervention on the CSDD and the more global estimate of anxiety and depression on the EQ-5D. Differences by group were not reported on a measure of social engagement or items assessing anxiety Full scale RCT required ROB:4/6 low Overall: unclear, small size, AC unclear	

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		American Education IG: 15.8 years CG: 16.29 years **Setting**: Home / Community **Country**: USA		2 calls a week for 4 weeks. Each call was between 10 – 30 minutes Facilitator: Interventionist	Self-Care Usual Activities Pain/Discomfort Anxiety/Depression Subjective Health Perceptions of Uncertainty (DSS) <u>Secondary:</u> Coping Strategies (IMMEL)	Not significant Not significant Not significant Not significant Effect Size: 0.21 F = 3.74, p = 0.07 Effect Size: 0.17 F = 3.35, p = 0.09		
Collaborative care								
Callahan 2006	To test the effectiveness of a collaborative care model to improve the quality of care for pwd with AD. TF: collaborative care model	Carers and pwd with moderate AD Pwd mean age IG 77, CG 78. Carer mean age IG 60, CG 62. Pwd 43%F, carer 89%F 49% of pwd black **Setting:** Home/Community **Country:** USA	153 dyads (IG 84, CG 69) PC reported. 80% power on NPI, but limited power to detect smaller differences in ADL	IG: Collaborative care model aims to identify, monitor and treat BPSD. Consisted of behavioural interventions, education on communication skills, coping skills, pwd exercise guidelines, legal and financial advice <u>Minimum intervention</u> for all was: Cholinesterase inhibitor, and Education, from GNP, on communication skills, legal and financial advice, patient exercise guidelines, caregiver guide.	<u>Pwd outcomes:</u> <u>Primary;</u> BPSD (NPI) <u>Secondary:</u> Depression (CSDD) ADL (activities of daily living scale) Cognitive Status (MMSE) <u>Carer outcomes:</u> Depression (PHQ-9)	FU: 6, 12 and 18 months d=0.53,MD -2.8, (-8.3, 2.6), p=.01 not significant Not significant Not significant d=0.43, MD -1.6 (-3.0, -0.2), p=.02	Reduced behavioural symptoms, and improvements continued at 18 months. Also reduced depression in carers. Carers had improved stress related to BPSD at 12 months but not at 18 months No effect on pwd depression or ADL. ROB: 6/6 low Overall: low	4

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				At each meeting caregiver completed Memory and Behaviour Problems Checklist to ascertain current symptoms and stressors, from which individualised recommendations made. Specific items checked activated specific behavioural intervention protocols (- non pharmacological, 8 in all, - personal care, repetitive behaviour, mobility, sleep, depression, agitation/aggression, delusions /hallucinations, caregiver physical health) Voluntary group sessions: patients got exercise led by health psychologist and care manager; carers got social psychologist on stress **Duration & intensity** Maximum 12 months. Bimonthly, then monthly visits CG: Augmented usual care	Stress related to BPSD (NPI) Organisational outcomes: Resource use (physician and nurse visits, hospitalisation rates, hospitalisation days, nursing home placement) Process of care (frequency of initiation of behavioural protocols) No formal cost calculation. Intervention resources: Mean (SD) contacts with care manager: 14.4 (8.9), median 13, range 0-51; face-to-face 7.7 (5.8), 7, 0-28;	Significant at 12 months but not 18 months. MD −2.2 (−4.2 to −0.2), P=.03 CG had fewer physician or nurse visits over 12 months of intervention and at 18 months. Was effective with a mean of 4 per participant from a possible 8. Estimated per patient annual costs of CCM $1000, based on case manager case load of 75 patients pa, + establishing the computer- based tracking system + access to expert consultants + group sessions + CCM group had more physician and nurse visits, more cholinesterase		

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				Providers: primary care physician, geriatric nurse practitioner (care manager)	telephone 6.7 (5.8), 5, 0-35; 89% of contacts triggered >=1 protocol, mean 4/8 per patients; 56% attended >=1 voluntary sessions	inhibitors (@$1200 pa), more anti-depressants (no difference in psychotics and sedatives).		
Care consultation								
Clark 2004	To evaluate the effects of care consultation delivered within a partnership between a managed health care system and Alzheimer's Association chapter TF: empowerment conceptual framework	Carers and pwd with dementia or memory loss. **Setting:** Home/Community **Country**: USA	89 dyads PC not reported	IG: Care consultation – multicomponent telephone intervention aims to identify strengths and resources within the family and community, and to develop strategies to improve psychosocial outcomes. Creates an individualised care plan. Intervention has structured protocol - structured initial assessment to identify problems and challenges and develop coping strategies. Flexible approach with individualised care plans. **Duration & intensity** Follow up initially bi-weekly	<u>Pwd outcomes:</u> Depression (CES-D) <u>Organisational outcomes:</u> Health care utilisation Service use variables from medical records: hospital admission in 12 month periods Y/N; ED admission in 12 month period Y/N; number of physician visits in 12 month period.	FU: 12 months Unstandardized beta= 0.33, p=.07 IG had fewer physician visits, less likely to have hospital visit or admission, and more satisfied with managed care services	Decreased depression for pwd. Intervention patients with more severe impairment have fewer physician visits and less likely to have emergency department visits or hospital admissions. Also more satisfied with managed care services and have lower depression and stress. ROB: 1/6 low Overall: unclear	4

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				decreasing to one month and three month intervals (more frequently if needed - up to daily in difficult periods). When no unaddressed problem, trained volunteers make follow up contacts. On average 10 direct communications per year by care consultants with patients/carers but large variation in extent to which participants engage with programme. CG: usual care, includes consulting Alzheimer's Association and use resources, but not proactively encouraged. **Providers**: Alzheimer's Association staff, master's level				
Home Care								
Dias 2008	To evaluate a flexible stepped care model delivered by home care	Carers and pwd wild mild-moderate dementia (DSM IV, CDR) Mean age pwd IG	80 (IG 40, CG 40) PC not reported, but	IG: Home care program aims to reduce carer burden and pwd behavioural problems, and improve carer mental health. Consists of	<u>Pwd outcomes:</u> <u>Secondary:</u> Severity of behavioural problems (NPI (translated into Knonkani))	FU: 3 and 6 months Not significant	Improvement in carer mental health and distress related to BPSD. No effect on carer burden. No effect on pwd behaviours, functional ability or	4

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	advisors TF: none	79, CG 77, carer IG 53, CG 54 Carer 75%F, pwd 34%F 34% spouses of pwd **Setting:** Home/Community **Country:** India	suggests low power	education, support, information and advice. involves MDT intervention Team of 2 full time Home Care Advisors in each taluka (district), trained intensively for one week, and supervised by part time counsellor and part time psychiatrist. HCAs supported carer with information on dementia, guidance on behaviour management. Stepped care model, flexible. Single psychiatrist assessment for patient and psychotropic medications if necessary. Each HCA met psychiatrist and counsellor once a fortnight to review patients. **Duration & intensity** Minimum once per fortnight for 6 months. But more frequently if HCA thought necessary. CG: wait list. Given intervention after 6 months	Functional ability (Everyday Abilities Scale for India (EASI) (translated into Knonkani)) Mortality (death records) <u>Carer outcomes:</u> <u>Primary:</u> Mental health (GHQ (translated into Knonkani)) <u>Secondary:</u> Burden (Zarit Burden scale (ZBS) (translated into Knonkani)) Distress related to BPSD (NPI (translated into Knonkani))	Not significant Not significant. OR=0.34 (0.01, 1.03) Effect size= -1.12, (-2.07, -0.17)- significant effect of time not significant effect size= -1.96, (-3.51, -0.41) significant effect of time	mortality. ROB: 5/6 low Overall low; AC not possible, unclear	

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				and given information on dementia during the wait. **Providers:** community team (home carer advisors, psychiatrist, lay counsellor)				
Case management								
Lam 2010a	To evaluate a case management (CM) model for people with mild dementia, whereby resources within the family and in the community were mobilized and optimally used TF: none	Carers and pwd with mild dementia; NPI 14-17 Pwd mean age 78.5 Carers 74%F, pwd 58%F 29% spouses of pwd **Setting:** Home/Community **Country:** Hong Kong	102 dyads (IG 59, CG 43) 80% power	IG: Case management – advised carers on coping strategies, skills training and behavioural management. Encouraged use of local services. Monitored family by phone and home visits and offered phone hot line. **Duration & intensity** Regular home visits for 4 months; Median no. of home visits 3; phone calls 8; Outpatient clinic 2. CG: no access to case management **Providers:** trained occupational therapist (case manager)	<u>Pwd outcomes:</u> <u>Secondary:</u> Neuropsychiatric symptoms (NPI, Chinese version) Depression (Cornell scale for depression in dementia) QOL (PWI-ID) <u>Carer outcomes:</u> <u>Primary:</u> Burden (ZBS) QOL Psychological distress <u>Secondary:</u> <u>Organisational outcomes:</u>	FU: 12 months Not significant Improved difference at 4 and 12 months but not significant 4m: IG: _1.0 [_4.8, 1.0]; CG: _0.5 [_3.0, 2.0] Not significant, 12m Not significant Not significant Not significant IG: 1.0 [_2.0, 5.5](sig) CG: 0.0 [_2.0, 3.0] Z=-2.2, p=0.03	Reduced pwd depression at 4 months but not at 12 month follow up. Significant reduction in NPI scores for pwd in both groups (p<.01). Improved carer psychological distress. No effect on carer burden or QOL. Use of domestic helpers and day care increased significantly in case management group Case management for Chinese persons with mild dementia outpatients did not show significant effects in reducing carer burden, but encouraged family carers to seek external support. ROB: 4/6 low	4

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					Use of care services: use of paid helpers Use of day care Use of home help Use of respite care	 RR 2.21 (1.04, 4.67), p<.05 RR 1.95, (1.23, 3.07)m p<.05 Not significant Not significant	Overall low/unclear AC	
Physical and structured								
Occupational therapy								
Gitlin 2008	To test effects of the intervention on neuropsychiatric behaviours, engagement and carer well-being. TF: environmental vulnerability or reduced stress-	Carers and pwd with moderate dementia. Carer mean age 65, pwd mean age 79 Carers 88%F, pwd 43%F 62% spouses of pwd. 100% living with pwd. **Setting:** Home/Community **Country:** USA	60 dyads (IG 30, CG 30) PC not reported	Tailored activity program (TAP). Aims to reduce behavioural disturbances by identifying preserved capabilities, previous roles and interest, and devising activities that build on them. Developed 8 activities per patient, written plans & goals. Carers instructed in stress reduction activities **Duration & intensity** TAP involved 6x90 home visits + 2x15 minute telephone contacts by OT over 4 months..	<u>Pwd outcomes:</u> <u>Primary:</u> Behaviours (16 items from agitated behaviours in dementia scale, 2 from the RMBPC, 4 from previous research and 2 others) <u>Secondary:</u> Depression (CSDD) Activity engagement (activity engagement index)	FU: 4 months d= 0.72, (-0.55,-0.09) p=.009 Not significant d=0.61, (0.02,0.41), p=.029	Improved behaviours overall, and particularly shadowing, repetitive questioning, and agitation. Also improved engagement. Reduced carer objective burden and improved their skills. No effect on pwd depression or QOL. No effect on carer subjective burden or depression. ROB: 5/6 low Overall: low	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, setting and country of study	Sample size Include PC if available	Description of intervention	Outcome variable(s) (measures shown in brackets)	Main results at follow up (reported as IG vs CG unless otherwise specified) (95% confidence intervals shown in brackets)	Evidence summary Quality (ROB=risk of bias No of domains 'low risk' out of 6; overall risk)	*Applicability to the UK populations and settings Score 1-4
	threshold model			CG: wait list; Received treatment after 4 months **Providers:** occupational therapists	QOL (QOL-AD) <u>Carer outcomes:</u> Subjective burden (ZBI) Objective burden (hours caring for pwd) Objective burden (hours feel on duty) Depression (CES-D) Mastery (task management strategy index) Confidence using activities (researcher developed items) Task simplification use (task management strategy index) Acceptability	Not significant Not significant d=1.14, (0.36, -0.07) p=.005 d=1.01, (-0.37, -0.12), p=.001 not significant d=0.55, (0.08,0.60), p=.013 d=0.74, (0.41, 2.94), p=.011 d=0.71, (0.04, 0.46), p=.023 Dyads: approx 70% engaged very well, showing much pleasure 85% carer reported it		

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, setting and country of study	Sample size Include PC if available	Description of intervention	Outcome variable(s) (measures shown in brackets)	Main results at follow up (reported as IG vs CG unless otherwise specified) (95% confidence intervals shown in brackets)	Evidence summary Quality (ROB=risk of bias No of domains 'low risk' out of 6; overall risk)	*Applicability to the UK populations and settings Score 1-4
						as very useful 89% indicated had a positive effect 100% carers demonstrated good understanding ofstrategies		
Exercise								
Lowery 2013 Cerga-Pashoja 2010	To evaluate the effectiveness of a dyadic exercise regimen for BPSD TF: none	Carers and pwd with BPSD. Dementia and Suspected Dementia. >65% AD; ~60% < 2 yrs diagnosis Carer mean age IG 65, CG 61, pwd mean age IG 79, CG 78 Carer IG 75%F, CG 61%F, pwd IG 52%F, CG 61%F Carer distress NPI, mean 11.9 (8.1), CG similar Setting: Community Country: UK	131 dyads 90% power	EVIDEM-E Dyadic exercise regimen (individually tailored walking program) Designed to become progressively intensive and last between 20-30 mins, at least 5 times per week. Supported by 3 hours therapist input. CG: treatment as usual Providers: registered exercise professional Intensity: prescribed 12-14 rating of perceived exertion, which participants exerted; frequency walks 5x a week	<u>Pwd outcomes:</u> <u>Primary</u> BPSD (NPI) <u>Secondary:</u> QOL (DEMQOL – proxy) <u>Carer outcomes:</u> Burden (ZBI) Mental health (GHQ) Distress related to BPSD (NPI)	FU: 6 & 12 weeks Not significant Not significant OR= 0.18 (0.05,0.69) p=.01 Not significant Not significant	No evidence that exercise is effective e intervention for BPSD. Intervention did improve carer burden. No effect on pwd QOL, carer mental health or distress related to BPSD. Prescribed frequency of walks achieved by 30.8% of IG, prescribed intensity in 53.2% of walks ROB: 6/6 low Overall: low	1
Sleep therapy								

McCurry 2005 McCurry 2003 McCurry 2011	To evaluate effectiveness of a comprehensive sleep education program TF: none	Carers and pwd with AD and sleep problems, >4 (freq of behavioural, sleep problems) (BPSD) with depression, 39% Carer mean age IG 63, CG 64, pwd mean age IG 78, CG 78, 31% depressed Carers 72%F 58% were spouses and 100% lived with pwd. **Setting:** Community **Country:** USA	36 dyads (IG 17, CG 19) PC not reported	IG: NITE-AD - sleep education program aims to improve sleep in pwd. Provides a sleep hygiene program and training in behaviour management skills. Also instructed to walk daily and increase daytime light exposure with use of a light box. CG: general dementia education and carer support.	<u>Pwd: primary outcomes:behavioural</u> Night wake time (actigraphy) Number of night awakenings (actigraphy) Percentage of time asleep (actigraphy) Wake index (actigraphy) Duration of night awakenings (actigraphy) Time in bed (actigraphy) Days per week exercise (carer report) Depression (CSDD) depression (RMBPC)-carer reports <u>Carers:</u>	FU: 6 months d=0.42, MD= -0.60, (-1.51, 0.31), p=.03 d=0.42, MD= -4.00, (-10.10, 2.10), p=.01 not significant d=0.32, MD= -0.40, (-1.24, 0.44), p=.03 d=0.17, MD= -0.30, (-1.51, 0.91), p=.04 not significant d=0.00, MD= 0.00 (-1.58, 1.58), p=.01 not significant d=0.07, MD= 0.06, (-0.51, 0.63), p=.007 not significant Change at post-test 2m CG: 0.74 +/- 0.67 IG 0.79 +/- 0.62; 6m: CG 0.85+/- 0.94 IG: 0.91 +/-0.71 P<0.007 NITE-AD carers Benefited substantially from	Pwd with AD experiencing sleep problems can benefit from behavioural techniques. Reduced nighttime awakenings, total time awake at night and pwd depression. Carers benefitted with significant improvements in percentage of sleep time, Walking, light exposure, and their combination are potentially effective treatments for improving sleep, but consistent adherence to treatment recommendations is required. Carers in active treatment were more successful in setting goals related to sleep scheduling and increasing daytime activity than controls. Clinicians need to be aware that many carers need active assistance setting up and implementing a sleep hygiene program. Simply providing carers with education is often insufficient. ROB: 5/6 low Overall: low	3

					Adherence	treatment (50% NITE-AD vs 41% CONT), they better understood the nature of sleep problems in AD (58% vs 47%), and they felt more confident managing their relatives' sleep disturbances (42% vs 35%). Consistency of Bedtimes: IG 83%; CG 38% , p<0.002 Rising time consistency IG: 96%, CG: 59%, P<0.009 IG Carerswho wanted to reduce patient napping 70% success IG: 28% p<.005. IG patients walked 86% of the days, CG walked 7% of the days (p=0.001).		
Structured intervention								
Nobili 2004	To assess the effectiveness of a structured intervention on carer stress and pwd	Carer and pwd with behavioural problems; CG 23% >3 ADL, IG 37% >3 ADL; 50% 1-3 behavioural problems Carer mean age IG 53, CG 59, pwd	69 (IG 35, CG 34) PC not reported	IG: Structured intervention to provide information and support to families to help them deal with behavioural disorders. Consists of visits by psychologist and an occupational therapist. Assessment and advice on:	<u>Pwd outcomes:</u> Frequency of problem behaviours (SBI-C) Mortality	FU: 6 and 12 months d=0.74, MD= -2.70, (-5.09, -0.31), p<.03 (small numbers did not allow statistical comparison)	Improved frequency of problem behaviours. Level of carer stress was the main determinant of institutionalisation. No effect on level of carer stress. ROB: 3/6 low; 3/6 high	2

	institutional isation rate. TF: none	mean age IG 74, CG 75 Carers IG 89%F, CG 74%F, pwd IG 60%F, CG 59%F **Setting:** Home/Community **Country:** Italy		• Relationships in the family • Care burden of carer and psychological consequences • Changes on communication • Verbal and non-verbal communication • How problems dealt with by carer and family • Psychological support and training **Duration & intensity** Psychologist visit averaged 60 mins, occupational therapist visit averaged 90 mins to advice on: Strategies to control reactive behaviour and maintain / improve functional abilities Modifications to home, adapt environment to meet patient needs CG: free help line, and practical information Providers: psychologist and occupational therapist	institutionalisation Functioning (ADL) <u>Carer outcomes:</u> Stress caused by caring for pwd (RSS)	(small numbers did not allow statistical comparison) No differences Not significant	Overall: high	
Support								
Counselling								
Burns 2005 Mixed methods-includes Qualitative data	To assess whether a psychothera peutic	Carers and pwd with mild to moderate AD Mean age IG 74, CG 78; 48%F	40 (IG 20,CG 20) Reports adequate	Psychodynamic interpersonal therapy focusing on interpersonal conflicts and difficulties. Joint sessions focused on	<u>Pwd outcomes:</u> Global measure of change symptoms (Clinician's Interview-	FU: 6 weeks and 3 months Not significant	No improvement on outcome measures, although suggests that therapy improved carer reactions to some	2

	approach directed towards pwd could benefit cognitive function, affective symptoms and global well-being. TF: none	75% spouse of pwd **Setting**: Home/Community **Country:** UK	power	symptoms considered to be important and distressing. Sessions occurred in own home. **Duration & intensity** 6 sessions lasting 50 mins each CG: standard care. General advice and outpatient review. **Providers:** psychotherapist	Based Global Impression of Change) ADL(Bristol activities of daily living scale) Depression (Cornell scale for depression in dementia) Cognitive function (MMSE) <u>Carer outcomes:</u> Coping (ways of coping checklist) Reactions to behavioural problems (RMBPC) Ways of coping checklist in intervention Carer benefit	Not significant Not significant Not significant Not significant 3month: IG: 7.2 (range0-42) CG: 5.1 (range 0-12) Significant MD -2.7 (-3.2,-2.15), d=3.22 carer's interaction with other people as an aid to coping Carer of pwd with less cognitive impairment (>24) benfited more from intervention- they blamed themselves less for the problems IG: 0.14; CG: 0.35, p<0.031	symptoms. Brief psychotherapeutic approaches for those with AD was acceptable and helpful individually (especially where there was less cognitive impairment) ROB: 3/6 low Overall: unclear	

					Psychological distress (GHQ) Depression (BDI)	Not significant Not significant		
QUALITATIVE DATA FROM BURNS 2005	Perspective: Pwd and carer As above Intervention : "the identification of interpersonal conflicts or difficulties, which are causing or helping to maintain emotional distress. TF: Not Reported	N=20 recruited from referrals to the memory clinic in South Manchester, UK. Mean age 74 Country: UK 50% F		<u>Method</u> Semi structured open ended interviews Joint sessions with participants and carers hleped the therapist to focus on those symptoms that were considered important and distressing. "	<u>Analysis</u> The 20 participants who received ther-apy were visited between 6 and 12 months after recruitment. A semi-structured open-ended interview was carried out. No further information given re analysis	<u>Main findings</u> Reports: recollection of the sessions, found intervention helpful. No themes identified, but examples of positive comments: able to confide, new knowledge, beneficial. Carers reported opportunity to discuss problems, less guilty about making time for myself and the home	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings . MODERATE **F4 -**usefulness of its findings for this review? MODERATE	
Mittelman 2008	To assess effectiveness of the intervention combined with an available drug treatment for AD. TF: stress	Carers and pwd with mild-moderately severe AD Majority were in age range 70-79. IG 58%F, CG 54%F 100% spouses of pwd.	158 dyads (IG 79, CG 79) 80% power	IG: NYU-ADRC caregiver intervention combined with drug treatment for pwd. Focus of intervention was the importance of emotional support and assistance for carer. Consist of individual and family counselling sessions tailored to individual. **Duration & intensity**	<u>Pwd outcomes: Secondary: aberrant behaviours</u> ADL (AD Cooperative Study - Activities of Daily Living Inventory) Frequency of problem behaviours (RMBPC) <u>Carer outcomes:</u>	FU: 24 months Not significant Not significant Unstandardized beta= -0.38, p=.031	Decreased carer depression and distress related to BPSD. Improved carer emotional support. Benefit increased over 2 years, even though the counselling sessions occurred in the first 3 months. No effect on pwd problem behaviours or ADL	1

	process model	**Setting:** Home/Community **Country**: UK, USA and Australia		5 sessions of individual and family counselling within 3 months of enrolment and continuous available ad hoc telephone counselling on demand. Donepezil for patients. 2 individual sessions and three that included family members; content customised to carer need but focussed on importance of emotional support for carer. 5 counselling sessions (2 individual, 3 family) CG: resource information, help in an emergency, routine care **Providers:** counsellors	<u>Primary:</u> Depression (BDI) Social support (the stokes social network list) Reactions to problem behaviours (RMBPC) No cost reported , authors refer to intervention as 'modest'	Emotional support: unstandardized beta= 1.413, p=.035. Unstandardized beta= 0.227, p<.001	depression scores improved in IG but deteriorated in control group. Benefit significant after adjusting for variables. Effective counselling and support interventions can reduce symptoms of depression in carers when patients are taking Donepezil. Note: cholinesterase inhibitors temporarily improve or slow rated progression. ROB: 6/6 low Overall: low	

***Applicability score:**

1 = Applicable across a broad range of populations and settings

2 = Applicable across a broad range of populations and settings assuming appropriately adapted

3 = Applicable only to populations or settings included in the studies, and broader applicability is uncertain

4 = Applicable only to settings or populations included in the studies