Table 3 - Carers

BPSD Review Project – In-Depth Systematic Review

Evidence Tables for Randomised Controlled Trials (RCT's) aimed at 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 qual 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 3. RCT's with interventions delivered to carers (n= 37 studies, 62 papers)- plus 3 qualitative studies (5 papers)

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, 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 (FU; 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								
Cognitive Behavioural Therapy (CBT)								
Glueckauf 2012 *Check 2013/14 paper for a full RCT and economic outcomes* (pilot study) Mixed methods – includes Qualitative data	To compare effects of telephone based CBT with face-to-face CBT TF: modified version of Pearlin's Stress Process Model	Carers who are African American And= 5, dementia with Lewy bodies n=2, vascular dementia n=2, dementia of unknown etiology n=2, ADL>1, IADL>2 Mean yrs education carer 13.8; pwd 11.8yrs; 11months care giving Mean age 58 91%F; 55% spouses of pwd **Setting:** Home/Commun	11 (IG 6, CG 5) PC not reported	IG: CBT – telephone based. Aims to change depressive affect and health status of carers, carer mood. Includes managing difficult behaviours Phase 1 = focus group about intervention experiences. Phase 2 = qualitative analysis of individual telephone interviews and quantitative findings from pilot + assess treatment fidelity. CG: face-to-face CBT **Duration & intensity** 12 weeks, 1 hour per week (7 group sessions, 5 individual sessions) **Providers:** counsellors	Carer outcomes: Primary: addressing difficult behaviours Depression (CES-D) Burden (subjective burden subscale of the carer appraisal inventory) Assistance support (assistance support subscale of the interpersonal support evaluation list) Health (physical symptoms subscale of the modified CG health and health behaviours inventory)	FU: 1 week post-intervention (3months): interviews and self-report d=1.05, MD= -4.33 (-9.64, 0.98), p=.03 not significant d=0.46, MD= 1.73 (-2.92, 6.38), p=.04 Not significant	Reduced carer depression and increased perceived support. No effect on burden or health. Preliminary support for both modalities, positive reductions in depression, burden and physical symptoms. Small sample size so undertook informal pattern analysis of differences in effect: moderate improvement in subjective burden and assistance appraisal for both methods; smaller treatment effect for face to face than telephone for depression; small effect for improvement in physical symptoms across both conditions. Overall results provide preliminary confirmation of effectiveness of CBT in reducing carer depression. ROB: 3/6 low Overall: unclear, small sample	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		ity **Country**: USA					size probably adequate for pilot	
Glueckauf 2012 QUALITATIVE DATA	As above appraisals of the intervention process and its impact on daily caregiving experiences,	FG (for phase one to ensure CBT is culturally appropriate), semi-structured interviews, analysis of CBT content and processes, perceived effectiveness of ACTs counselors, inferences of the proximal effects of intervention modalities (i.e. telephone v face to face)		Method Qualitative analysis of FG and semi structured interviews.	Analysis Method of analysis not specified	Main findings In discussing their counselling experiences, CGs highlighted the importance of the group interaction, goal setting, self-care, and assertiveness training. Particularly noteworthy was the importance CGs placed on peer exchange of information, tips, and support, particularly the reassurance they received from participants providing care for CRs in more advanced stages of dementia.	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings? Moderate **F4 -**usefulness of its findings for this review? Moderate	
Marriott 2000	To evaluate effectiveness of CBT intervention in reducing	Carers with psychological morbidity and pwd with AD, , who is mainly	42 (IG 14, CG1 14, CG2 14) 90% power	IG: CBT family intervention aims to relieve burden and distress in carers and improve symptoms in pwd. Consists of carer education,	Carer outcomes: care ratings, self-reports; non-cognitive symptoms, behaviour	FU: 3 months d=5.18, MD= -5.70, (-6.55, -4.85), p=.001	Reduced carer distress and depression, and improved ADL in pwd. No effect on pwd depression, psychiatric symptoms or behavioural disturbances.	1

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	burden of care TF: stress vulnerability family coping skills model	supported by carer and be living in the community with a carer who provided their main support; and the carer had to achieve psychiatric caseness with a score on the GHQ of 5 or above, indicating significant psychological morbidity Carer mean age IG 70, CG1 63, CG2 58. Pwd IG 77, CG1 76, CG2 78. ; Carer 69%F, pwd 71%F; 52% spouse of pwd, 40% adult child, 7% sibling **Setting:** Home/Community		stress management and coping skills training. 3 components: Carer education, stress management . Coping Skills, Four booklets at the start of the intervention. **Duration & intensity** Education: 14 sessions (hrs) with 2 week intervals; stress management (6sessions), coping skills (5 sessions) CG1: interview control. CFI audiotaped to derive ratings of expressed emotion. Interview covers areas of possible stress e.g. budgets, behaviour, and relationships. Takes approximately 90 minutes. Cathartic. CG2: no interview control. Usual care Providers: consultant clinical psychologist	Depression (BDI) General health (GHQ) Pwd outcomes: Depression ((Cornell Scale for Depression in Dementia) Psychiatric symptoms (MOUSEPAD psychiatric symptoms scale) Behavioural disturbances (MOUSEPAD psychiatric symptoms scale) ADL (CDR)	d=5.58, MD= -6.70, (-7.62, -5.78), p=.001 Not significant Not significant Not significant d=0.22, effect size 0.11, MD=-0.40, (-1.79, 0.99), p=.042	ROB: 4/6 low Overall: low/unclear AC	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Country: UK						
Marquez Gonzalez 2007	To evaluate CBT aiming to examine the role of modifying dysfunctional thoughts in reducing depressive symptoms. TF: cognitive model	Carers, >8 months caring Mean age IG 58, CG 55; education <10 yrs; carers >2years 80%F Majority were spouses of pwd. **Setting:** Home/Community **Country**: Spain	51 (IG 27, CG 24) PC not reported	CBT Modification of dysfunctional thoughts associated with caregiving (MDTC). Module 1 focussed on dysfunctional thoughts and most time spent on this module Module 2 focussed on behavioural skills – training in coping skills, eg help seeking, assertiveness, relaxation, strategies to increase pleasant activities. Homework given. **Duration & intensity** 8 weekly sessions, 2hrs each CG: Usual Care. Waiting List. **Providers:** trained psychologists	Carer outcomes: Addressing problem behaviours Depressive symptoms (CES-D) Pwd outcome - Frequency of problem behaviours (RMBPC) Appraisal of problem behaviours (MBPC) Dysfunctional thoughts about caregiving (DTCQ)	FU: post-intervention d=0.12, effect size 0.06, MD= -4.91, (-7.32, 4.32), p<.05 not significant d=0.33, effect size 0.16, MD= -0.69, (-1.45, 0.25), p<.05 d=0.28, effect size 0.14, MD= -5.21, (-9.70, 2.30), p<.05	Successful in reducing carers depressive symptoms and modifying their thoughts about caregiving. Also modified their appraisal of pwd's problem behaviours. Dysfunctional thoughts mediate the relationship between the intervention and levels of depressive symptoms. No effect on frequency of pwd behaviours. ROB: 4/6 low; Blinding and AC: high Overall: high	3
Wilz 2011 Schinkothe 2014	To evaluate the effectiveness of a CBT-based	Carers of people with dementia, burden?2, mean caregiving	IG: 126 CG1: 53 CG2: 50	IG: Goal attainment and treatment compliance First session conducted face to face in carers home and all following sessions	Carer Outcomes: Primary (No data to calculate effect sizes)	FU: 6 months 30.1% completed attainment 39.8% partial	Overall 72.3% of carers experienced positive change in terms of goal attainment. Two-thirds of the carers in both	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	telephone intervention TF: Beck's theory of dysfunctional thoughts, Ellis' model of rational-emotive therapy, Kanfer's system model of behaviour regulation, D'Zurilla's Problem-solving therapy & Model of Bereavement	5.7 yrs, GDS pwd mean 5.7 Carer Gender (IG + CG1) 85% female Relationship to PWD 52.4% spouse/partner 39.1% daughter/daughter-in-law 4.7% Son 3.8% Other Carers age IG: 61.58 CG1: 63.03 Duration of Caregiving IG: 5.05 CG1: 5.36 PWD Age IG: 78.4 CG1: 78.97 **Setting:** Community **Country:**		were via telephone. Therapists were free to differentially weight each of the 4 modules in order to adjust the treatment to the individual problems and needs of carers in each session. Content: utilisation of social & professional support, problem solving and coping with behaviour problems, modifying dysfunctional thoughts **Duration & intensity** 7 x 60 minute therapeutic sessions. The first 4 sessions took place on a weekly basis, sessions 5–6 on a fortnightly basis, and session 7 on a monthly basis, with a total intervention duration of 3 months. CG1: progressive muscle relaxation (PMR) from the stresses related to dementia caring was the	Goal Attainment (GAS) Evaluation of CBT Recommendation of intervention: Depression (CES-D) Burden from behaviour change (BIZA-D) Fatigue (GBB-24) Therapist Outcomes	attainment 24.1% no change 2.4% Exceeding 3.63% deterioration ($t_{(121)}$ = .97 p = .001) OR: -0.04, RR: 2.17 IG: 90.9% CG1: 74.3% Negatively correlated with GAS (-0.71, η^2=0.12, p<0.05) Not correlated Positively correlated with CES-D (0.04, η^2=0.11, p<0.05) And GAS (0.09, η^2=0.22, p<0.05) No correlation Negatively correlated	groups described the telephone setting as very good,. CBT was suitable, helpful, fulfilled expectations, showed a higher percentage of willingness to recommend the intervention and expressed a more intense desire to participate in such a trial again . ROB: 4/6 low Overall low/unclear AC	

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
		Germany, Berline/Brandenburg & Thuringia		focus of the intervention. CG2: Treatment as usual Administered by CBT trained clinical therapists x 6.	Therapists' Adherence Therapist competence (CTS) General Competence Session Structuring CBT Technique	with CES-D (-0.38, $\eta^2=0.16$, $p<0.05$) Positively correlated with BIZA-D (0.26, $\eta^2=0.14$, $p<0.05$) Negatively correlated with BIZA-D (-0.34, $\eta^2=0.13$, $p<0.05$) and Positively correlated with GAS (-0.34, $\eta^2=0.13$, $p<0.05$		
Life Enhancing Activities for Family Carers								
Dowling 2013 (pilot study)	To examine the effects of Life Enhancing activities for family carers (LEAF) on positive affect and psychological outcomes. TF: None Hypothesis: Under stressful conditions,	Family carers of pwd with Fronto-temporal Degeneration, perceived stress high in IG; CG distress NPI mean 18, burden, mean 45 Carer Age (mean): 59.5 Carer Gender 70.8% F	Total: 24 IG: 12 CG: 12 PC not reported but pilot study	Helping carers deal with BPSD IG: Focuses specifically on increasing positive affect. Teaches participants a series of behavioural and cognitive "skills" for increasing positive affect: Including, noticing and capitalizing on positive events, gratitude, mindfulness, positive reappraisal, focusing on personal strengths, attainable goals, and acts of kindness.	<u>Carer Outcomes:</u> Positive Affect (DES) Negative Affect (DES) Depressive Mood (CESDS)	FU: 10 weeks Effect Size: 0.323 F = 3.810, $p<0.05$ d= 0.38, MD= 1.77 (-1.99, 5.54), $p<0.05$ Effect Size: 0.378 F = 4.856, $p<0.05$ d= 1.10, MD= -3.22 (-5.58, -0.86), $p<0.05$ Not significant	The skill-building intervention promoted positive affect and improved psychological outcomes for family carers of people with dementia. Improvements in positive affect, perceived stress, burden, depression, and distress scores after the end of the intervention indicate beneficial effects and use of the skills learned. imrovements were even stronger 1 month after intervention. ROB: 2/6 low Overall: unclear	4

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	people may consciously seek out or create positive events that can increase their positive affect and as a result replenish their psychological resources and help to sustain their coping efforts.	90% White 10% Hispanic & African American Years caregiving (mean): 4.2 87.5% spousal carers **Setting**: Home / Community **Country:** 17 states USA		**Duration & intensity** One to one in person sessions with a facilitator. Between sessions, participants were asked to complete home exercises. CG: Engaged in 5 weekly one-on-one sessions with a facilitator. The sessions were comparable in length to the intervention sessions (approximately 1 h) but consisted of an interview and did not have any didactic portion or skills practice. Home practice for the control group consisted of the brief daily affect reports.	Perceived Stress (PSS) Carer Distress (NPI) Carer Burden (ZBI)	Effect Size: 0.49 F = 8.646, p <0.01 d= 1.20, MD=-6.33 (-10.58, -2.08), p <0.01 Not significant Effect Size: 0.289 F = 3.664, p <0.05 d= 0.0.4, MD=-0.51 (-10.01, 8.99), p <0.05		
Education & Training								
Psychoeducation								
Au 2010 Pilot study	To evaluate effects of intervention on carer distress, self-efficacy and coping. TF: none	Family carers of 6 months minimum of AD patients, 30 months of illness. Majority were daughters of pwd, (around 52%), or	27 (IG 13, CG 14) PC not reported	IG: Coping with Caregiving (CWC) – aimed to reduce distress through learning and practicing specific cognitive and behavioural skills. Teaching strategies to handle caregiving stress which includes how to manage bpsd- practical	Carer outcomes: includes self report Depression (CES-D) Self efficacy for obtaining respite (Revised scale for caregiving self	FU: 13 weeks Not significant Not significant	Increased self-efficacy for controlling upsetting thoughts and handling disruptive behaviours. Increased problem and emotion focused coping strategies. ROB:6/6 low Overall: low/unclear as ample	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		spouses (around 35%). Mean age IG 57, CG 51 100%F **Setting:** Home/community **Country:** Hong Kong		solutions. Chinese version of manual developed by Stanford (California) team. CG: wait list. Usual activities **Duration & intensity** Small groups, 5-8 carers, 2 hour workshop, 13 course culture weak. **Providers:** 2 trainee clinical psychologists	efficacy) Self efficacy in responding to disruptive patient behaviours (Revised scale for caregiving self efficacy) Self efficacy in controlling upsetting thoughts about caregiving (Revised scale for caregiving self efficacy) Coping- rational problem solving (CWOC) Coping – resigned distancing (CWOC) Coping seeking support and ventilation (CWOC) Coping – passive wishful thinking (CWOC)	d=0.59, MD=60.19, (-15.34, 135.72) p=.04 d=0.91, MD=96.95, (17.398, 176.502), p=.02 d=0.598, MD=1.03. (-0.32, 2.38) p=.005 d=0.59, MD= 1.48, (-0.43, 3.39), p=.03 Not significant Not significant	size is low but is a pilot	
Cristancho-Lacroix 2015	To evaluate the impact of the Diapason	Carers of pwd Care givers of	IG: 25 CG: 24	IG: The Diapason program was delivered in a free, password-protected, fully-	<u>Carer Outcomes:</u> <u>Primary:</u> Self Perceived Stress	FU: 6 months Not significant	No significant differences. ROB: 3/6 low	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
Lacroix 2013 protocol Mixed methods – includes QUALITATIVE DATA (Pilot)	program on carers' perceived stress. TP: cognitive approach, inspired by Lazarus and Folkman's stress and coping theory and Bandura's self-efficacy model,	AD, onset of symptoms 0.55-14.05, (mean) *4.62 years* Carer Age (mean) IG: 64.2 CG: 59.0; 65% F CG children of PWD IG: 64% CG; 54.2% CG High level of Education, 75% Living with PWD, 40-455 Visiting PWD Daily IG: 16% CG: 8.3% Visiting PWD weekly; 37 % CG with at least one other source of stress IG: 72% CG: 56%	80% power	automated website, to be used in an individual fashion, at home by the carers. IG targeted: a) carers' beliefs, about the illness and the caregiving role, b) carers' skills, to manage daily life difficulties, and c) carers' social support and help-seeking behaviour to obtain respite or financial support, and to meet and discuss with peers through a forum. Twelve thematic sessions were sequentially and weekly unblocked once the previous one was entirely visualized. Owing to the variability of 4 behavioural and psychological symptoms depending on the type of dementia, and the important impact of some of them on carers' stress (e.g. hallucinations, delusions), only Alzheimer's disease was targeted by this program.	<u>Secondary:</u> Self-efficacy (RSCS) Reaction to behavioural problems (RMBPC) Burden (ZBI) Depression (BDI) Self-perceived health (NHP) Dementia Knowledge (VAS) Coping (VAS) Stress (VAS) Quality of Relationship (VAS)	differences.	Overall: high (Outcome Blinding and AC)	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		CG with professional help (cleaner etc) IG: 72% CG: 75% Weekly hours of professional help IG: 26.7 CG: 8.2 PWD onset of symptoms (mean years) IG: 4.62 CG: 4.11 **Setting:** Community **Country:** France						
QUALTTAIVE DATA – LACROIX 2014	Perspective: Carers Aims as above TF: Not reported	25 carers Female: n=16 Mean age: 64 years		Method Semi structured	Analysis Thematic analysis	Main findings Carers found intervention useful, wished to receive personalized support, extensive information, specific assistance, and more	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings? Moderate **F4 -**usefulness of its findings for this review? Moderate	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
						communication with professionals and peers. Preferred topics offering strategies to maintain the pwd autonomy, teaching skills for coping with BPSD, less interested by the notion of self-care. Better perception of the disease or accepted diagnosis after the program .		
De Rotrou 2011	To test effects of intervention on carer's psychological condition and pwd's ADL TF: none	Carers and pwd with mild-moderate AD. Education, mean 11 years 54% spouses, 27% daughter of pwd. Pwd mean age 79, carer mean age 65. Pwd 56%F, carer 64%F **Setting:** Home/community	167 dyads (IG 79, CG 78) 80% power	IG: Psycho-educational programme (PEP) focused on education, problem-solving techniques and emotion-centred coping strategies, management of Patient's behaviour, communication skills, crisis management, resource information and practical advice. In each session, geriatrician, psychiatrist, social worker, speech therapist, OT gave carers detailed information on specific aspects of disease; coordinated by psychologist	Carer outcomes: Primary: Depressive symptoms (MADRS) Secondary: Burden (ZBI) Sense of competence (SCQ) Disease understanding (VAS) Ability of coping (VAS)	FU: 3 months and 6 months Not significant Not significant Not significant d=0.88, effect size 0.40, MD= 3.05, (1.77, 4.33), p<.001 d=0.43, effect size 0.21, MD=1.75, (0.25, 3.25), p=.02	Improved carers ability to cope, and disease understanding. No effects on pwd behaviour or functional status. ROB: 5/6 low Overall: low	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Country: France		CG: wait list **Duration & intensity** 12 sessions, 2 hrs per week for 12 weeks. **Providers**: various health professionals	Pwd outcomes: Primary: Functional status (DAD) Secondary: Behavioural disorders (NPI)	Not significant Not significant		
Gallagher Thompson 2008 Gallagher Thompson 2003	To evaluate effects of intervention on stress and depressive symptoms TF: none 2003 study compared efficacy of two different psycho educational (skill building) approaches for reducing carers psychological distress	Carers of pwd (MMSE< 24) unable to perform at least one ADL. Hispanic Latino (HL) 89, non-hispanic white (NHW) 95. Majority of HL were non spouses, majority of NHW were spouses. Mean age HL 51.4, NHW 63.4; 100%F; education; HL lower SES than NHW	184 (IG 97 45, CG 87 50) PC not reported	Based on REACH, an updated version of Coping with Caregiving (CWC) includes problem behaviours IG:techniques for managing CR’s problem behaviours (e.g., identify antecedents or ‘‘triggers’’ and plan how to change them), taking better care of the carer, including changing unhelpful thoughts, increasing assertive communication, and identifying everyday pleasant activities (both for self and shared with CR, planning for future needs of CR, how to obtain helpful community resources, each carer to develop her own ‘‘action plan’’ for how to apply helpful coping	Carer outcomes: Primary: Depressive symptoms (CES-D) Perceived psychological stress (PSS-10) distress related to BPSD (RMBPC) skill utilization (SUQ) Carer Outcomes: Depression (CES-D)	FU: 6 months; pre-post changes linear regression unstandardised beta = -2.135, p=.048 unstandardised beta = -1.530, p=.046 unstandardised beta = -.250, p=.007 unstandardised beta = 60.670, p=<.001 FU: 3 months data Not significant Treatment effect: d=0.35, p<.05	Improved depressive symptoms, life stress, and caregiving specific stress. Also increased use and perceived helpfulness of skills. Effective skill utilization may mediate the effect of treatment on outcome. Regardless of ethnicity, those in intervention group showed greater improvement from pre to post intervention than those in control on depressive symptoms, life stress, caregiving specific stress. Carers’ intervention group used skills more. Female carers benefit more from a skillbuilding approach to managing their distress than from support group membership alone. Ethnic groups are likely to benefit when services are provided to meet	3/4M

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Setting: Home/Community **Country:** USA		strategies to future (anticipated) stressful situations (e.g. grandchild's visit). **Duration & intensity** 2hrs per week for 13 weeks CG: Empathetic support for 15-20mins every 2 weeks – total of 7 calls over 4 months + educational materials mailed in English or Spanish from Alzheimer's Association and other downloadable internet sources. **Providers:** postdoctoral fellows or advanced psychology graduate students	Coping (RWCCL) Positive Scale Negative Scale Social Support (ISSP) Satisfaction Negative interaction Burden and Bother (RMBPC)	Not significant Not significant Treatment effect: d=0.19, p<.06 Not significant	their specific needs. ROB: 5/6 low Overall: low- unclear risk from small samples	
Gallagher Thompson 2010	To evaluate the effectiveness of a culturally tailored program TF: none	Carers from Chinese community for pwd; type and stage not reported; Majority were non spouse (68%), most low income, health rating for both	76 (IG 40, CG 36) PC not reported	IG: Skill training DVD (SKDVD) aims to increase skills to deal with carer stress. Illustrates preferred ways to handle difficult or disruptive behaviours of pwd and stressful family situations. **Duration & intensity**	<u>Carer outcomes:</u> self report forms returned by post Depression (CES-D) Positive affect (CES-D) Stress associated with	FU: 16 weeks Not significant d=0.52, MD=1.42, (0.12, 2.72), p=.010 d=0.60, MD= -0.31, (-0.57, -0.05), p=.012	Improved carer positive affect, and pwd behaviours were appraised by carers as less stressful and bothersome. No effect on carer depression or pwd behaviour problems. ROB: 5/6 low Overall: low- but small sample size, unclear risk	4

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		poor to fair Mean age IG 59.7, CG 57.8. 80%F **Setting:** Home/Community **Country**: USA		DVD is 2.5hrs long. CG: 2 DVDs with comprehensive information about dementia **Providers**: DVDs created by researchers	behaviour problems (RMBPC) Pwd outcomes: Number of behaviour problems (RMBPC) Process outcomes: Program evaluation (program evaluation questionnaire)	Not significant Satisfied with program, and believed they were able to care more effectively		
Garand 2002 Buckwalter 1999 (pilot studies)	To evaluate mood and immune outcomes of intervention for carers. TF: progressively lowered stress threshold (PLST) model	Carers of pwd with any type of dementia (65% AD, rest mixed); AD for 5 years Late stage of disease trajectory Spouses of pwd 73% Mean age 65 92% F 50% income $ 10-30K; 80% verbalised no financial burden; minimum 4	39 for 2002 study Around 50% power: Original study IG: 132 CG: 104 PC 72% High attrition, 30% in first 6 months	IG: The progressively lowered stress threshold (PLST) intervention aims to strengthen the psychological resources of carers by teaching methods of managing BPSD. CG: identical to IG with the exception for education based on PLST model. routine information, community based services, and case management/support group referral. **Duration & intensity**	Carer outcomes: Mood (POMS) Depression (GDRS) Depression (POMS) POMS depression (original study) GDS (original study) Effects by age Effects by education	FU: 6 months (2002) and 12 months (1999) Not significant GDRS effect size= -2.317, p=.025, POMS not significant $t_{(37)}$ = -2.09, [p = .044]). IG less depressed than control; Beta -3.061 P = .003 Increased in younger care givers by time Not significant	In the small 2002 study, carers reported an overall improvement in immune function, but not total mood, however the earlier larger study supports the effectiveness of intervention in decreasing depression among carers who received the experimental training. Additional analysis of factors associated with carer depression shows an increased trend for depression in younger people suggesting that younger carers perceive that they have more demands placed on them. The care-recipient stage of illness did not seem to have much impact on carer depression. "Long term" carers may have successfully	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		hours care/week; mean 13 years of education.		2 home visits, 3 hrs each. Telephone contact every other week for 6 months. **Providers**: psychiatric nurses	Effects by CR stage of illness (depression)	Not significant	adjusted to the rigors of caregiving, and had learned to cope with the demands of this task such that they were able to maintain a more positive mood over time.	
		38% used community-based services (e.g., home health or respite care) , 14 hours paid help per week; friends & family members assisted with caregiving average 2 hr/week; pwd repeatedly exhibited average 24 problematic behaviours over 2 weeks			carer relationship to care recipient	Spouses had higher levels of depression than other care givers	The pivotal role of psychiatric nurses in the assessment and treatment of depression among carers is important.	
					length of care recipient illness (median of 48 months since onset of memory problems).	Less time caring were more depressed than longer time caring		
					tension-anxiety (POMS)	Effect size= -4.05, p=.009	Subjective burden and relationship (spousal) to the care recipient were the best predictors of carer depression, accounting for 27% of the variance.	
					anger-hostility (POMS)	Effect size= -3.70, p=.016		
					fatigue-inertia (POMS)	Effect size= 3.07, p=.038	High attrition rates may reflect the late stage of the disease trajectory at which many care recipients were entered into the study.	
					confusion-bewilderment (POMS)	Effect size= -2.92, p=.009		
		Setting: Home/Community			vigor-activity (POMS)	not significant	ROB: 1/6 low Overall: unclear/high	
		Country: USA			mood (POMS total score)	not significant		

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
					Immune Response	improved		
Gerdner 2002	To evaluate the impact of the intervention on problem behaviours and carers response to problem behaviours, as well as on pwd's ability to perform ADL. TF: Progressively Lowered Stress Threshold (PLST) model	Carers of pwd with mild-severe dementia, 67% AD, rest mixed, GDS 57% moderate, 33% severe, 13% mild, GDS carers low at baseline Mean age 64.8 74%F, 44% 13-16 yrs, Cgs mean 52 months, 122 hours hands on caring/week 65% spouses of pwd **Setting:** Home/Community	237 (IG 132, CG 105) PC not reported	IG: Community-based psychoeducational nursing intervention grounded in Progressively Lowered Stress Threshold (PLST) model. Aims to teach carers to manage BPSD/problem beahviours. Care plan worked out between carer and research associate at first home visit, and reviewed at second home visit one week later. Also given written materials and referrals for case management and other support. **Duration & intensity** 4hrs of in-home intervention CG: general information about dementia and referral for community	<u>Carer outcomes:</u> Reaction to problem behaviours (RMBPC) Response to functional level of ADLs (RMBPC) <u>Pwd outcomes:</u> Problem behaviours (RMBPC) Functional status on ADLs (RMBPC)	FU: 3, 6, 9 and 12 months Not significant Not significant Not significant Not significant	No significant impact on the frequency of, or carer response to, problem behaviours or functional level of ADLs. Potential for adapting the educational content for cultural sensitivity and presenting it in a manner that is consistent with the learning style of that cultural or ethnic group ROB: 5/6 Overall low/unclear AC	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Country: USA		based services. Two 1hr visits, 2 weeks apart **Providers:** research associates				
Hebert 2003	To evaluate the efficacy of the intervention in reducing carers reactions to problem behaviours and thereby reducing burden, psychological distress and anxiety and improving perception of social support and well-being TF: transactional theory of stress and coping	Carers for pwd, mainly with AD (81%) displaying at least one behaviour problem per week. Mean age 59, 80%F, primary care CG for at least previous 6 months, moderate/severe burden, 60% spouse of pwd **Setting:** Home/community **Country:** Canada	118 (IG 60, CG 58) Reports sufficient power to detect a moderate effect	Psychoeducative Program aims to improve carers ability to cope with daily sources of stress Innovative, intensive program based on cognitive approach that focusses on managing troublesome behaviours and the stress they generate. Based on the transactional theory of stress and coping. 2 components: 1.Cognitive appraisal of the stressful situation and distinguishing changeable and unchangeable situations (4 meetings) 2. Coping strategies – choose the appropriate strategy (11 meetings**)** **Duration & intensity** Fifteen 2 hour weekly sessions plus home assignments	Carer outcomes: Primary: Reactions to depressive and memory problems (RMBPC) Reaction to disruptive behaviours (RMBPC) Secondary: Burden (ZBI) Psychological distress (14 item Ilfeld Psychiatric Symptoms Index) Affect (the Bradburn revised affect scale) Anxiety (Spielberger state-trait anxiety inventory) Perceived social	FU: 16 weeks d=0.41, MD= -0.30, (-0.57, -0.03), p=.04. d=0.42, MD= -0.27, (-0.69, -0.05), p<.01 Not significant Not significant Not significant Not significant Not significant	Decreased the frequency of behaviours for pwd and carer reactions to behaviours, particularly disruptive ones. No effect on carer burden, distress, affect, anxiety, social support, efficacy or desire to institutionalise. ROB: 6/6 low Overall: low	3

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
				CG: usual care **Providers**: health professional	support (The inventory of socially supportive behaviours) Personal efficacy Desire to institutionalise Pwd outcomes: Primary: Frequency of depressive and memory problems (RMBPC) Frequency of disruptive behaviours (RMBPC)	Not significant Increased in both groups but more in control group Not significant d=0.34, MD= -0.66, (-1.37, 0.05), p=.02 d=0.22, MD= -0.46, (-1.25, 0.33), p=.03		
Kwok 2013	To evaluate the effectiveness of a telephone-delivered psycho-educational intervention for family carers of PWD	Pwd with any stage of dementia Carer Age, most >40 years PWD IG: 66.7% F CG: 80% female	IG: 20 CG: 22	Helping carers deal with BPSD IG: Focuses on providing emotional support; directing carers to appropriate resources; encouraging them to attend to their own physical, emotional, and social needs; and educating them on strategies to cope	Carer Outcomes: Carer Burden (ZBI) Caregiving Self-efficacy (RSCSES); Controlling upsetting thoughts Obtaining respite	FU: 3 months d= 0.08, MD= -0.80 (-6.89, 5.29), p = 0.002 Not significant	Intervention protocol managed to significantly reduce the caregiving burden, as well as improve the carers' self-efficacy in obtaining respite. ROB: 4/6 low Overall low/unclear AC	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	in alleviating carer burden and enhancing caregiving self-efficacy. TF: Psychosocial transition and Stress Coping theory	Carers 71% F both groups Carer Education Most secondary/tertiary Carer Income IG, most<$20k Relationship:30/40 child Carer Marital Status; >50% married Daily time spent with PWD; two-thirds >4-6 hours **Setting:** Home / Community **Country:** Hong Kong		with ongoing problems. **Duration & intensity** 12 x 30 minute sessions. One session per week Delivered via telephone CG: Just the DVD at pretest **Facilitators**: Registered social workers	Responding to disturbing behaviours	d= 0.07, MD= -1.60 (-17.68, 14.48), p = 0.050 d= 0.17, MD= 3.70 (-10.06, 17.46), p = 0.075		
Martin Carrasco 2009	To evaluate the effectiveness of a psychoeducational	Carers of pwd with AD Mean age IG 55, CG 62, 69%F	115 (IG 55, CG 60) 75% power	IG: Psychoeducational Intervention Program (PIP) aims to help carer control their stress, teach them strategies for managing BPSD, and	Carer outcomes: Primary: Burden (Spanish validated version of the ZBI) Secondary:	FU: 4 and 10 months d=0.40, MD= -6.50, (-13.57, 0.57), p=0.0083	Improved burden, well-being and general health, and all other carer outcomes. Degree of effectiveness of the intervention on to carers of PWD of different dementia stages was	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	intervention in reducing carer burden TF: none	55% spouses of pwd, 38% child of pwd, 3% sibling, 3% other **Setting:** Home/Community **Country:** Spain		increase their satisfaction with life. **Duration & intensity** Eight, 90 min sessions, at 1-2 week intervals over 4 months CG: standard care **Providers**: PI and therapist	Quality of life – physical functioning (spanish validated version of carer quality of life (SF-36) Physical role (spanish validated version of carer quality of life (SF-36) Bodily pain (spanish validated version of carer quality of life (SF-36) General health (spanish validated version of carer quality of life (SF-36) Vitality (spanish validated version of carer quality of life (SF-36) Social functioning (spanish validated version of carer quality of life (SF-36) Emotional role (spanish validated	d=0.49, MD= 11.30, (1.12, 21.48), p=.0310 d=0.68, MD=27.90, (9.79, 46.01), p=.0074 d=0.54, MD= 12.30, (2.12, 22.48), p=.0157 d=0.78, MD= 13.30, (6.01, 20.60), p=.0011 d=0.88, MD= 14.90, (7.52, 22.28), p=.0002 d=0.48, MD= 12.10, (0.90, 23.30), p=.0488 d=0.59, MD= 26.10, (6.57, 45.64), p=.0160	not investigated, due to the relatively small sample size. It was believed that carers of pwd different dementia stages would have different needs, thus different coping strategies, as they would encounter different challenges. ROB: 6/6 low Overall: low	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
					version of carer quality of life (SF-36) Mental health. (spanish validated version of carer quality of life (SF-36) Perceived health (spanish validated version of GHQ-28 general health questionnaire)	Not significant d=0.94, MD= -5.60, (-8.29, -2.91), p=.0004		
Psychosocial								
Burgio 2003	To evaluate a skills training (REACH) intervention after 6 months and examine differential effect by race TF: Based on REACH	70 White, 48 African American dyads (20%) , AD with related dementia, MMSE <24 recruited carers only for intervention, mean age 63-65 yrs , 38-44% F,education mean 13 yrs, CR 12 yrs white, 9.7 yrs African CR age >75 yrs CG age in white (66yrs)	IG: 57 CG: 61 sample size varied across outcome measures according to the disposition status of the CG (i.e., active caregiving at home, long-term care placement,	IG: Manual guided intervention based on common needs and cultural preferences of White and African American family carers. Group workshops (3 hours) + 16 in home treatment sessions lasting one hour over 12 months. Workshops attended by 3 – 8 carers. 4 home visits in first month, 2 in second, and alternate phone calls and visits in months 3 -12. (8 therapeutic home visits and 2 phone calls in first 6 months). CG: Empathetic phone calls,	<u>PWD Outcomes:</u> Behaviour problems (RMBPC) <u>Carer Outcomes:</u> Behavioural Bother (RMBPC) Positive aspects of caregiving (PAC) Social Support	FU: 6 months d=0.33, md=1.31 (0.20, 2.42), p=.0002 Significant main effect of time, p=.01 Significant difference of race in MSC group, p<.05 Significant main effect for race, p=.02	Both interventions were well received by care givers.Both groups reported reduced problem behaviours and appraisals of behavioural bother, and increased satisfaction with leisure activities over time. White carers showed more improvement in the appraisal of distress related to problem behaviours in control group, African American CGs showed the greatest improvements in the skills training condition. Spouse and nonspouse carers also showed differential responses to intervention.	4

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		significantly greater than African (57 yrs) at least 4 hours supervision or direct care per day for last 6 months. pwd >=1 limitation in ADL, 3 problem behaviours identified by carer. **Setting:** community, referred from geriatric or memory clinics, home health care or other agencies **Country:** USA, Birmingham Alabama	or bereaved).	brief, 15 minutes, scripted prompts about physical health, active listening. Mailed generic written materials months 1 and 3, one page factsheets with suggestions about managing behaviour i.e. less prescriptive than for intervention group. If carer had specific problems, then materials related to problem sent additionally. Careful assessment of fidelity of intervention across 11 interventionists. Use of manuals, and contacts audiotaped and 20% checked.	Satisfaction with support (LSNI) Leisure time satisfaction Well-being (CES-D) Anxiety (STPI) Desire to Institutionalise	Significant main effect for race, p=.02 Significant change over time across both intervention groups =.02 No significant effects No significant effects Significant effects of Race: d= 2.01, md= -4.15 (-5.51, -3.51), P=.02	Brief manual-guided interventions can be effective with White and African American CGs, and greater attention should be paid to possible differential responses to interventions by race and relationship to care recipient. No costs, but authors 'believe this home based intervention can be administered with minimal modification through home health care agencies by either social workers of nurses'. ROB: 3/6 low Overall: unclear	
Czaja 2013	To evaluate the feasibility and efficacy of a technology based	Carers of PWD with AD and "other" IG Mean age: 57.47	Total: 110 IG: 38 CG: 36 PC not reported	Helping carers deal with BPSD- based on REACH IG: Designed to address five carer risk areas - Safety social support, problem	Carer Outcomes Depression (CESDS) Unconditional Bother (RMBOC)	FU: 5 months Not significant Statistically significant effect of time F=4.98,	Intervention participants experienced decreases in carer burden, increased positive aspects of caregiving and greater satisfaction with social support.	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	psychosocial educational and skills training intervention. A secondary aim was to examine difference in response to the intervention among black/African American and Hispanic American carers of patients with AD or dementia. TF: None Adapted from REACH II	CG: 61.46 >75% F IG Ethnicity; 53.3% Hispanic 46.7% African American CG: 50.8% Hispanic 49.2%. African American Mean Years Caring: 4-6 Relationship 30-35% Spouse 50% Child rest sibling, family and others PWD and CG education 60-63% >13 years **Setting**: Home/ community **Country:** USA		behaviours, depression and carer health. Problem solving strategies to deal with the pwd problem behaviours Support groups: Structured and up to 6 carers. They received topical information and shared experiences and concerns. **Duration & intensity** 6 x 1 hour monthly sessions. Two in home and 4 via videophone. CG: Mailed a packet of educational materials and received a brief telephone call at 3 months. **Providers:** Certified interventionists	Positive Aspects of caregiving Social Support; Satisfaction Negative interaction Recipient of Support	$p<0.001$ $X^2=5.93$, $p=<0.05$ No significant improvements Statistically significant effect of time $F=4.43$, $P=<0.04$ Significant improvement $X^2=10.27$, $p=<0.007$ IG: 46.2% CG: 16% No significant improvements No overall significant effect Statistically significant effect of time $F=8.89$, $p=<0.005$ Not significant Statistically significant effect of ethnicity $F = 22.83$, $p = 0.001$	ROB: 3/6 low Overall: unclear	
Farran 2004	To test the efficacy of a	Carers of pwd with AD or	295 (IG 141, CG 154)	IG: Carer skill building (CSB) intervention aims to	Carer outcomes: Primary:	FU: 18 months	Intervention was effective in reducing carer emotional distress	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
Farran 2007	carer skill building intervention compared with an information and support orientated protocol. TF: self efficacy theory	dementia with disruptive behaviours; mean MMSE 12 (mild/moderate) Mean age 64, 76%F 54% spouse of pwd, 48% non spouse Setting: Home/Community Country: USA	PC not reported	improve carer skills in dealing with behavioural symptoms of dementia. CG: generalised information and support which was not targeted to behavioural symptoms. **Duration & intensity** 12 weekly sessions consisting of 5 group sessions and 7 individualised telephone contact sessions. Further 2 group booster sessions and 'as needed' telephone contacts during the 12 month period. **Providers:** Trained professional nurses, social workers, met weekly with project director who supervised implementation.	Depressive symptoms (CES-D) Carer distress related to agitated behaviours (RMBPC) <u>Secondary:</u> Behaviour management skills (15 item BMS-R) <u>Pwd outcomes:</u> Behaviour symptoms (RMBPC) <u>Organisational outcomes:</u> Time to institutionalisation	Not significant Effect size= -.276, p=.01 Not significant Not significant Not significant	related to behaviours. Depression improved in both interventions. No difference in effect on behaviour symptoms or time to institutionalisation between groups. ROB: 6/6 low Overall: low	
QUALITATIVE DATA Farran 2003, Perraud 2004, Farran 2004b Related papers to	Perspective: carers To address the content and skills needed by carers for	N=177 of n=272 in study. Participants represented 48% of the cohorts in the study and all study regions		<u>No intervention</u> Analysis of group summaries following each session. Purposive sampling.	<u>Analysis</u> Analysis of group summaries. Summaries entered into the QSR NUD*IST-4 program	<u>Main findings</u> Major categories addressing pwd difficult behaviours and emotional responses. Responding to pwd	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings? Medium **F4 -**usefulness of its findings for this review? High	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
Farran 2004 (RCT aimed at addressing BPSD)	responding to pwd issues. Intervention: carer skill building for dealing with BPSD TF: Not reported	Recruited from Geriatric Assessment Clinics and Alzheimer's Disease Centers Demographics presented for main study only, not this sub-sample.			and analysed using content analysis.	PADL, IADL needs. Dealing with cognitive decline Narrative: confirmed that information and knowledge about CR care-related needs in at least three areas are essential: addressing difficult behaviours, responding to PADL/ IADL needs, and dealing with cognitive impairment.		
Gant 2007	To test effectiveness of a distance-based psychosocial intervention for male carers TF: none	Male carers of pwd with mainly AD (75%) and displaying behaviour problems. Carers with at least moderate levels of distress related to BPSD. Mean age 71.6, 100%M 88% spouse of	32 (IG 17, CG 15) PC not reported	IG: Distance based psychosocial intervention consisting of video/workbook/telephone coaching. Aims to improve carer mood, reduce frequency of problem behaviours and carer stress **Duration & intensity** 12 weekly phone calls, a 10 session video series and a workbook with information CG: 37 page booklet including information on dementia and suggestions	Carer outcomes: Upset with problem behaviours (RMBPC) Annoyance with problem behaviours (RMBPC) Positive affect (positive and negative affect scale) Negative affect (positive and negative affect scale)	FU: Not reported No significant effects.	No significant effects on any carer outcomes. No differences between groups but both improved significantly. *carers in sample reported low levels of distress related to bpsd at baseline, and also low levels of problems with ADL. Suggests intervention may not necessarily be appropriate for those with moderate or high levels of distress* ROB: 4/6 low-incomplete data and other Overall: low , small size, unclear	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		pwd, Education, mean 13 yrs **Setting:** Home/Community **Country**: USA		for dealing with variety of caregiving challenges. Approximately 7 bi-weekly phone calls by trained staff member using standard script. **Providers:** trained research staff	Self efficacy for obtaining respite (the revised scale for caregiving self-efficacy) Self efficacy for dealing with problem behaviours (the revised scale for caregiving self-efficacy) Self efficacy for controlling thoughts (the revised scale for caregiving self-efficacy) Upset with target behaviours (target complaints interview) Sadness with target behaviours (target complaints interview) Frustration with target behaviours (target complaints interview) Irritation with target		risk	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
					behaviours (target complaints interview)			
Moniz Cook 2008	To evaluate the effects of intervention training for community mental health nurses (CMHN) to enhance the skills of carers. TF: none	Carers and pwd. Carer mean age 63, pwd mean age 77. Mean duration of illness 34-39 months (range 5-135); onset of 32 months Carer 72%F, pwd 26%F 54% spouses of pwd **Setting:** Home/community **Country:** UK	113 dyads (IG 54, CG 59) PC not reported	IG: Psychosocial intervention, aims to reduce day to day problem behaviours and improve coping in carers. Family carers receive psychosocial support from trained CMHNs Psychosocial intervention based on problem solving, stress and coping, functional behaviour analysis **Duration & intensity** CMHN to attend in-service clinical supervision for the 18-month study duration, i.e. 2-h group supervision once a week for the first 6 months; once a fortnight for the next the 6 months; and individual sessions once a month for the last 5 months. CG: usual care	Carer outcomes: Primary: Difficulty coping with problem behaviours (the adapted-Gilleard Problem Checklist) Secondary: Depression (HADS) Anxiety (HADS) Global Deterioration Scale Pwd outcomes: Primary: Frequency of problem behaviours (the adapted-Gilleard Problem Checklist)	FU: 6, 12 and 18 months Effect size= -9.89, (-18.0, -1.77) p=.001 Effect size= -1.30, (-3.36, 0.76), p=.046 Effect size= -0.605, (-2.76, 1.55), p=.023 Effect size = -8.56, (-21.3, 4.18), p=.002	Improved coping with problem behaviours as well as the frequency of problem behaviours. Improved carer depression and anxiety. With regards to frequency of problem behaviours, there was a CMHN random effect, suggesting the effect of the intervention depended on the CMHN who delivered care. *suggests a long intervention of 12-18 months was needed to moderate carer mood.* ROB: 6/6low Overall: low	1

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
				Providers: CMHN				
Tremont 2008 **Tremont 2013** Tremont 2014	To examine the efficacy of a family intervention telephone tracking TF: Family Intervention: Telephone Tracking (FITT) theoretical model	Distressed carers of pwd with mild-moderate dementia Mean age IG 66, CG 61 Carer Gender 78% F 80% lived with pwd, 61% spouse of pwd, 39% adult child of pwd 77% diagnosed with AD 64% mild AD 31% moderate AD, CG age 63yrs, >75% F, Education, mean 15 yrs, caregiving mean 45 months (apprx 4 yrs); 50% spouse, 42% adult child	33 (IG 16, CG 17) PC not reported. Reports limited power. **Tremont 2013** FITT: 133 Telephone support: 117	Telephone delivered psychosocial intervention (Family Intervention: Telephone Tracking – Dementia (FITT-D)). Aims to enhance coping within the carer **Duration & intensity** 23 telephone calls over one year, consisting of weekly initial calls for 6 weeks (approx. 60 mins), 12 additional contacts (15-30 mins) every 2 weeks, and 4 monthly termination calls. Total contact between therapists and carers was approximately 12 hours. CG: standard care **Providers:** trained therapists. Tremont 2013- 6 months trial with adequate power: IG: Carers received 16	Carer outcomes: Primary: Burden (Zarit burden interview) Depression (GDS) (CES-D) Reaction to memory and behaviour problems (RMBPC) Secondary: AD knowledge (Alzheimer's Disease Knowledge Test) General health (SF 36 General Health) Self efficacy (Self Efficacy Scale) - Symptom Management - Support Services Perceived social support (Multidimensional Scale of Perceived Social	FU: 12 months- small sample 12m d=0.94, MD= -11.72, (-20.28, -3.16), p=.01 not significant d=1.11, MD= -11.56, (82.58, -18.57), p=.01 Not significant Not significant Not significant Not significant Not significant Not significant	Improved burden and less severe reactions to behaviour and memory problems. No effect on depression, AD knowledge, general health, self efficacy, social support, or family cohesiveness. These findings demonstrated clinical significance by showing that compared with TS, the FITT-C intervention resulted in a net improvement in depressive symptoms among 27% of carers, and in improved reactions to care-recipient overall memory and behaviour problems among 23% of carers. Findings provide preliminary evidence for the efficacy of FITT-D; a potentially highly accessible, low-cost intervention for dementia carers. Intervention developed because of concerns about cost and accessibility to dementia carers The current findings support the FITT-C as an evidencebased treatment for stressed family	3

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
		Pwd age 78yrs, 56%F, time since diagnosis, 30m, time since symptom onset 55m 96% Caucasian **Setting:** home **Country:** USA		telephone contacts distributed over 6 months that focused on providing dementia education, emotional support, directing carers to appropriate resources, encouraging carers to attend to their physical, emotional, and social needs, and teaching carers strategies to cope with ongoing problems CG: received nondirective support for carers through empathic and reflective listening and open-ended questioning.	Support) Family assessment (Family Assessment Device) Positive Aspects of Caregiving (PAC) QoL (Euro-QoL) CES –D NPI depression RMBPC Reactions to CR depressive behaviours-total score Carer burden (Zarit) NPI	Not significant P=0.041 Not significant 6 months – adequate sample size of RCT (NPI) diff 27% [95% CI 8%–47%]). (NPI diff 23% [95% CI 3%–42%]) due to large differences in depression-specific reaction scores (NPI diff 29%, [95% CI 12%–47%]). Net % improvement within IG larger (19%)	carers of individuals with dementia. ROB: 5/6 low Overall low An entirely telephone-based intervention improves carers' depressive symptoms and reactions to behaviour problems in the care recipient and is comparable with reported results of face-to-face interventions. Scores improved in both groups for family functioning, self-efficacy for support services, and health-related quality of life (EQ-5D). The only statistically significant finding was greater improvement for TS compared with FITT-C in positive aspects of caregiving (PAC, P 5.041). There were no significant interactions with treatment for carer relationship, carer race, carer gender, live-in status, or dementia type on any of the primary	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
						versus CG (9%),but no significant group differences	outcomes. A telephone intervention is more accessible and convenient for busy carers and has the potential for being less costly than in-office or home-based interventions due to fewer space needs and no travel costs.	
					RMBPC –depressive behaviour subscale			
					Expectations (Credibility/Expectation Questionnaire) More logical	% diff 10 (-10, 32)		
					Reduction in stress	IG perceived the intervention as significantly more logical (IG M 8.04, SD 5 1.46 vs.CG M 7.33, SD 1.87; P <.002 IG M 7.64,SD51.67 vs. CG 6.90, SD1.87; P<.002).		
					Treatment Satisfaction	Not significant		
Ulstein 2007	To evaluate whether a simple and cheap short term psychosocial intervention programme	Carers and pwd, mean duration 3-4 yrs, Carer mean age 65, pwd mean age 75, weekly face to face	171 (IG 87, CG 84) Reports PC	Psychosocial intervention aims to teach carers about symptoms, the normal course of dementia, and treatments. **Duration & intensity** 3hr educational	<u>Carer outcomes:</u> <u>Primary:</u> Burden (RSS) <u>Pwd outcomes:</u> <u>Primary:</u> BPSD (NPI)	FU: 12 months No significant differences	No effect on carer burden, or BPSD or ADL for pwd. No effect on primary outcomes although more carers in control group converted from low stress to medium or high than in intervention group.	2

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	could be effective with pwd and carers. TF: none	with pwd 62% F 70% spouses of pwd, 30% adult children. **Setting:** Memory Clinic **Country:** Norway		programme. 6 group meetings of 2hrs. lasted for 4.5 months. CG: usual care **Providers:** physicians (geriatricians and psychiatrists, nurses)	Secondary: ADL (DAD) Cognitive Functioning (MMSE)		Both MMSE and DAD scores fell in both groups but no significant difference. More control participants admitted to nursing home but not significantly different from intervention group. Gender important influence on NPI score – significant effect of intervention for female patients. Predominantly negative results emphasise need for individually tailored intervention for carers. ROB: 3/6 low Overall: unclear/high	
Training and education- SKILLS TRAINING								
Bourgeois 2002 Feasibility study	To evaluate the relative efficacy of two skills training approaches with equivalent training and follow-up on	Primary and secondary carers of pwd with probable AD, mean MMSE 7-10, CG 28-29, Dementia severity approx. 2, problem	Patient-change Group (PC):22 Self-Change Group (SC): 21 CG: 20 PC: n= 17	12 weeks intervention During week 1 staff scheduled two 1-hr home visits with each carer. During the first visit, carers were administered the baseline assessment battery. During the second visit, carers were instructed	PWD and carer outcomes: Problem behaviour frequency Problem Behaviours (Behave-AD) total	Follow-up: post-test, 3, 6 months FU: 6months: PC: d= 0.84, MD= -2.1 (-4.15, -0.05), p<0.01, SC: Not significant Not significant	Both treatment groups learned skills that helped reduce or improve targeted behaviours (patient problem behaviours and carer mood, respectively) and had some effect on related outcomes (temporary effects on depression and perceived stress and delayed effects on perceived strain).	2/3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	patient change (PC) and carer self change (SC) TF not reported	behaviours, 16-19; Primary carer Age mean 70-73 yrs Gender, 50-57% F; Race: mostly white; 100% spouses Secondary carer Age 45-51yrs, Gender: PC: 59% F, SC: 37% F,CG: 65% F, Race mostly white relationship approx. 70% adult child, rest neighbour, other PWD Age 72-76 yrs PWD Gender, 50-57% F, race mostly white **Setting:** Home	severe 2-3 scores 5 moderate 1-1.5 SC: n=16, severe, 5=moderate CG: severe 16, moderate=4	in procedures for recording the frequency of patient problem behaviours including identifying the 3 most stressful problem behaviours then generating operational definitions of the behaviours and finally practicing through role play. IG: Patient Change: Focused on dementia symptoms IG: Self-Change: Focused on problem solving PC Group: Staff helped carers identify the most frequent and stressful problem behaviour based on their observational data and discussed potential management plans for changing antecedents or consequences related to that behaviour problem, followed by staff and carer weekly. Individualised the skills training to carers' needs. SC Group: Reviewed carers' Problem Behaviour	Aggressive activity	PC: d= 0.86, MD= -2.8 (-4.94, -0.66), p<0.05 SC: d= 1.03, MD=-3.2 (-5.27, -1.13), p<0.01.	Established feasibility of teaching behavioural skills to care givers Behavioural interventions aimed at teaching carers to change their own behaviour in response to caregiving challenges is effective; specific behavioural skills enabled them to cope with specific caregiving challenges. Effects of the interventions were most evident for the outcomes that directly reflected the skills targeted by the training (i.e., teaching behaviour management skills reduced problem behaviour; teaching mood elevating procedures improved mood ratings) and less so for those outcomes that were hypothesized to be related to the skills, but not directly trained (i.e., anger, perceived health, etc.). Future interventions should assess the individual carer's specific training needs and tailor intervention to address directly those issues to maximize the desired outcomes. Future interventions could be	
					Behave-AD Psychosis	Not significant		
					<u>Carer Outcomes:</u>			
					Carer strain (CSS)	PC: Not significant SC: d= 0.75, MD= -14.8 (-28.37, -1.23), p<0.01.		
					Negative Affect (SAES)	Not significant		
					Self-Efficacy (CSEA)	PC: d= 0.73, MD=2.0 (0.05, 3.95), p<0.05, SC: Not significant		
					Patient Management			
					Self-Management	Not significant		
					Mood	PC: d= 0.28, MD=0.4 (-0.63, 1.43), p<0.01. SC: d=1.09, MD=1.8 (0.66, 2.94), p<0.01,		
					Perceived Stress (PSS)	Not significant		
					Depression (CES-D)	Not significant		
					Perceived Physical	Not significant		

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Country USA		Tracking forms and asked about medication changes prior to the skills training portion of the visit. Each of the three self-change strategies (Increasing Pleasant Events, Problem Solving, and Relaxation Techniques) were reviewed in separate visits over the **Duration & intensity** During Week 2, each carer participated in one 3-hr workshop at the university PC: Weeks 3 – 12 Visited each carer for 1 hr in their home. . SC: 10-week in-home training period. The number of visits per topic varied as a function of carer interest in the strategy; minimally each strategy was reviewed during three separate visits. CG: Typical support group meetings and discussions during home meetings.	and Emotional health (CHI) Satisfaction	47% very helpful 34% somewhat helpful 5% Not at all helpful 11% did not receive 3% no response	designed to offer a menu of behaviour change strategies with therapist guidance in the selection process based on carer needs assessment ROB: 3/6 low Overall: low/unclear AC	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
				Providers: therapists				
Gavrilova 2009 Guerra 2011 QUALITATIVE Shaji 2003	To investigate the effects of 10/66 care giver intervention on carer and pwd outcomes TF: none	carers and pwd, with mean 4.5 yrs of dementia DSM 4 criteria Carer mean age 60, pwd mean age 79 Carer IG 68%F, CG 78%F, pwd IG 70%F, CG 77%F. **Setting:** Home/Community **Country**: Russia, & multisite	60 (IG 30, CG 30) 80% power.	IG: The 10/66 carer intervention aims to provide basic education about dementia and specific training on managing BPSD. Targets main carer plus members of immediate and extended family, family counselling skills to maximise cohesiveness and support 10/66 originally developed in India, with input from the wider 10/66 group including experts from more developed countries. It was specifically designed for diverse low and middle income country settings characterized by limited health and social care resources The intervention needed to be capable of being delivered in the home setting using existing resources. The content and level of the intervention was tailored to this, as well	Carer outcomes: Burden (ZBI) Distress related to BPSD (NPI) Mental health (the Self Reporting Questionnaire) QOL – physical health (17 item WHOQOL-BREF) QOL – psychological (17 item WHOQOL-BREF) QOL – social relationships (17 item WHOQOL-BREF) QOL – environment	FU: 6 months, interviews Crude MD = 0.75 (0.18, 1.31), adjusted MD = 0.64 (0.05, 1.23). crude effect size= 0.75, adjusted effect size= 0.64. p=0.03 Not significant Not significant Not significant Not significant Not significant	Improved carer burden. No other significant effects for carers. No effect on BPSD or QOL for pwd. After extensive piloting, the intervention is now supported for those delivering it, by a structured, manualized 2-day training program comprising vignettes, role, play and live interviews. Challenge is recruiting primary health care works , important if rolling out to health care system The Peru setting (Guerra 2011) showed similar results, ROB: 4/6 low Overall: unclear	2/3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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 to cultural contexts. The 10/66 intervention is centred around the concept of the Multi-Purpose Health Worker (MPHW).(outreach) The training aims to provide: generic counselling skills; assessment skills to identify the problems experienced by the patient's family and the available resources for care; sufficient knowledge to educate the family about dementia and general caregiving strategies; and family counselling skills to maximize cohesiveness and support. **Duration & intensity** Three manualised modules for main carers and extended families delivered 5 weekly half hour sessions. CG: usual medical care **Providers:** newly qualified	(17 item WHOQOL-BREF) Pwd outcomes: BPSD (NPI) QOL (DEMQOL)	Not significant Not significant Not significant		

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
				trained doctors as outreach workers/primary health care workers not possible				
QUALITATIVE Shaji 2003 (related paper to Gavrilova 2009)	Perspective: Carers To explore care arrangements for people with dementia and the strain experienced by their family carers in India TF: not reported	N=17 carers of pwd with AD 88%F 65% daughter – in-law of pwd Country: India TF: Not reproted		Methods: Unstructured interviews Informant based strategy	Analysis: Manually recorded. Constant comparison technique Content coding included ordering the data in relation to the objectives of the study; categorizing answers that had similar characteristics; and examining the data for possible associations.	Qualitative data comes from the implementation of an intervention developed by experts internationally, including Europe , but examined in India. The principal sources of carer strain were and incontinence. Strain was exacerbated by the lack of supportive response by local health services, and by lack of support and, sometimes, criticism and family conflict. The majority of carers experienced significant deterioration in their mental health.	Helpful components of the intervention were educational support providing better understanding of dementia and related symptoms, improve coping skills, learning coping strategies and managing carers' emotional problems. Reliability & usefulness; Medium	
Hepburn 2001	to determine whether	Carers and pwd with behaviour	117 (IG 72, CG 45)	IG: Minnesota family workshop (MFW). Aimed at	Carer outcomes:	FU: 5 months	Improvement in carer beliefs, response to behaviour,	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
Ostwald 1999	family carers would benefit from a program designed to provide them with the knowledge, skills and caregiving outlook TF: stress and coping theory	problems as perceived by the carer, included at least one other family member. Severity not progressed beyond the functional assessment staging (FAST) stage Carer mean age 65, pwd mean age 77 Carers 70%F, pwd 44.4%F 65% spouses of pwd, 28.3% adult children Mean income $20-40K' , some schooling after high school **Setting:** Home/Commun	PC not reported	providing a training program built around the notion of caring as a role or desirable job. Focused on reducing adverse stress outcomes by developing or strengthening the knowledge, skills, and beliefs family members needed to perform well in their role Training provided similar to what would be provided to a clinician : 5 components: **Duration & intensity** Group settings in weekly 2 hour sessions over the course of 7 weeks. CG: wait list **Providers**: multidisciplinary team (nurse, educator, family therapist, occupational therapist)	Reaction to behaviours (RMBPC) Depression (20 item CES-D) Burden (22 item revised Zarit burden scale) Belief about caregiving (BACS) Pwd outcomes: Behaviours (RMBPC)	d=0.32, MD= -1.37, (-3.00, 0.25), p=.019 d=0.50, MD= -4.09, (-7.29, -0.89), p=.040 d=0.54, MD= -5.57, (-8.87, -2.28), p=.05 d=0.35, MD= 2.39, (-0.07, 4.85), p=.025 for nurturing beliefs Not significant	depression and burden. Related papers supports that it reduced carer's negative reactions to disruptive behaviours and burden. No effect on pwd behaviours. Regression analyses seek to link beliefs to outcomes ROB: 2/6 low Overall: high	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		ity **Country:** USA						
Huang 2003 (pilot study)	To investigate the effectiveness of a home-based carer training program TF: Progressively Lowered Stress Threshold Model	Carers and pwd with mild-severe dementia and behavioural problems, Pwd scored 50 or above on the Cohen mansfield Agitation inventory. All carers reported being bothered by the behavioural problems of pwd Carer age range 28-80, pwd age range 65-88 Duration of time caring: 0 – 72 months (average 26.8). Daily amount of	48 families (IG 24, CG 24) PC not reported	IG: Carer training programme aims to provide carers with skills and strategies to lower environmental stresses for pwd, and give training in managing difficult pwd behaviours. **Duration & intensity** two sessions in-home training program, separated by one week. 2-3 hr sessions. Follow up calls once a week for 2 weeks. CG: general information about dementia and social contact follow up calls once a week for 2 weeks. **Providers:** Gerontological nurse	Carer outcomes: Self efficacy for managing behaviour problems (Agitation Management Self-efficacy scale) Self efficacy for managing physically non aggressive behaviours (Agitation Management Self-efficacy scale) Self efficacy for managing physically aggressive behaviours (Agitation Management Self-efficacy scale) Self efficacy for managing verbally non aggressive behaviours (Agitation Management Self-efficacy scale) Self efficacy for	FU: 3 months d=2.03, MD=29.25, (21.10, 37.40), p<.001 d=0.18, MD= -1.71, (-7.11, 3.69), p=.001 d=0.25, MD=0.67, (-0.88, 2.22), p=.045 d=0.02, MD= -0.13, (-5.16, 4.90), p=.010 d=0.62, MD= -2.75,	Carer self efficacy for all behaviours increased. All pwd behaviours improved at follow up except physically aggressive behaviours. ROB: 2/6 low Overall: high	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		time: 3 – 20 hours (average 10.9). Carer 73%F, pwd 63%F Spouse of pwd 35%, daughter in law 31%, daughter 21%, son 13% **Setting:** Home/Community, **Country:** Taiwan			managing verbally aggressive behaviours (Agitation Management Self-efficacy scale)	(-5.27, -0.23), p=.010		
					<u>Pwd outcomes:</u>			
					Behavioural problems (Chinese version of CMAI)	d=0.21, MD= -6.12, (-22.79, 10.55), p<.001		
					Physically non aggressive behaviours (Chinese version of CMAI)	d=0.18, MD= -1.71, (-7.11, 3.69), p=.001		
					Physically aggressive behaviours (Chinese version of CMAI)	not significant		
					Verbally non aggressive behaviours (Chinese version of CMAI)	d=0.02, MD= -0.13, (-5.16, 4.90), p=.010		
					Verbally aggressive behaviours (Chinese version of CMAI)	d=0.62, MD= -2.75, (-5.27, -0.23), p=.010		
Teri 2005b Check Logsdon 2005b	To investigate whether community consultants could be trained to	Carers and pwd with moderate AD for mean 5 yrs, and agitated or depressed	95 dyads IG: 47, CG: 48 PC not reported	STAR-Carers aims to teach problem solving approach to behaviour change, develop behaviour management plans, improve communication,	<u>Carer outcomes:</u>	FU: 6 months (post test, 2 m)	Improved carer depression, burden, sleep quality, and reactivity to behaviour problems. Reduced frequency and severity of pwd behaviours and improved pwd QoL	3
					Depression (CES-D,	d=0.36, MD= -3.30, (-7.73, 1.13), p=.023,		

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
	teach family carers a systematic behavioural approach for reducing mood and behaviour problems. TF: gerontological and social learning theories	behaviour problems; MMSE 14 (7.0)=moderate Carer age range 22-91, (mean 65) pwd mean 78-81yrs, most white pwd: post high school 47-56% carer: 70-72% Carer 69%F, , pwd 66%F 55% spouses of pwd . **Setting:** Home/Community, assisted living **Country:** USA, Seattle		pwd mood, and carer strategies for enhancing support **Duration & intensity** Consultant training = 2 hour orientation then second training with a supervisor, and a pilot case. Consultants met with carers for 8 weekly sessions followed by 4 monthly phone calls CG: routine medical care **Providers:** trained consultants, master's level health care professionals who were currently practicing in community settings serving older adults.	Depression (Hamilton depression scale) Burden (SCB) Reaction to problem behaviours (RMBPC) Sleep quality (carer sleep questionnaire) Pwd outcomes: Behaviour (RMBPC) QOL (QOL-AD)	d=0.37, MD= -1.80, (-4.15, 0.55), p=.041 d=0.34, effect size 0.17, MD= -4.40, (-10.72, 1.92), p=.029 d=0.10, effect size 0.05, MD= -1.50, (-8.78, 5.78), p=.037 d=0.02, effect size 0.01, MD=0.10,(-2.27, 2.47), p=.033 p<.0001 d=0.04, effect size 0.02, MD= 0.20, (-2.23, 2.63), p=.031	ROB: 5/6 low (last domain) Overall: low.	
Wright 2001	To evaluate a nurse education and counselling program	Primary carers of pwd with AD Pwd dementia rating severity	IG: 68 CG: 25 PC not calculated	IG: 1) carers identified the most troublesome behaviours in the pwd. Strategies for handling such behaviours as hiding and	PWD Outcomes: Cognitive and functional impairment (BDRS)	Follow-up: 12 months Not significant	No significant treatment effects for care recipient agitation, carer stress, depression, and physical health, and no significant differences between	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		higher in control group, (2-15) vs (3.5-15); agitation IG (30–133) CG: (44–116) Carer age 57-60 yrs Carer Education (years): 12, 4yrs postgraduate Relationship IG: 50% spouse, 35% daughters, 15% other relatives CG: 44% daughters, 32% spouses, 24% other relative Carer Gender 76% F Carer ethnicity 54% White PWD Age 76-78 yrs PWD No. of		hoarding of objects, repetitive questions, or restlessness were discussed, and a plan to implement a new approach was developed. In addition, pwd medications were monitored. 2) the carers' emotional and physical health was addressed with supportive counselling. Carers were encouraged to openly express their anger, frustrations, and sadness. Strategies for getting help were discussed. Referrals to home health agencies, support groups, and other AD programs were made. Also, referrals to psychotherapy for carer if necessary **Duration & intensity** 5x discussions/meetings Time 1: 1-2 weeks after discharge. Home Visit Time 2: 5-6 weeks. Home visit Time 3: 12 weeks. Home visit	Agitation (CMAI) No. of days before institutionalisation Institutionalised Days prior to death <u>Carer Outcomes:</u> Stress (CHS) Depression (CES-D) Physical Health (MAI) Deceased At home/community No of days at home before institutionalisation	Not significant Not significant Not significant Not significant Not significant Not significant Not significant Not significant IG:61%, CG 56% (report chi sq p<0.05) RR 1.07(0.71, 1.6) not significant Not significant	groups in rates of institutionalization Longitudinal data, however, revealed several important trends. Pwd rose steadily for CG, Times 3 through 5 but declined for IG. Carer depression increased for CG Time 5, but declined for IG. Carer physical health declined for CG Times 4 and 5 but was maintained for IG. A higher number of pwd were still at home among IGs at the end of the one year study (number s are different in randomised groups). ROB: 0/6 low Overall: unclear	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		coexisting medical conditions 4 **Setting**: home **Country** USA		Time 4: 6 months. Phone call Time 5: 12 months. Phone call. **Providers:** A gerontological or mental health clinical nurse specialist provided the interventions				
Environment								
Home environmental								
Gitlin 2001 Gitlin 2003, 2005	Aimed to determine whether the intervention would affect behavioural difficulties and functional dependency of pwd as well as carer's self efficacy in these areas. TF: none	Carers of pwd with behavioural problems (e.g wandering, agitation), and difficulties with ADL or IADL. Excludes severe stage of dementia, carers confronted with difficulties in managing problem behaviours Mean age 60, 41-49 months caregiving,	202 (IG 100, CG 102) PC not reported	Home environmental intervention. Targeted programme. Aimed to help carers develop a supportive environment which reduces disruptive behaviours and decline in ADL and IADL **Duration & intensity** Five 90 min sessions approx. every other week over 3 months. CG: Usual care Providers: Delivered by 10 licensed OTs after 20 hours of training for the study.	<u>Carer outcomes:</u> Self efficacy for managing behaviours (likert scale) Self efficacy for managing ADL (likert scale) Self efficacy for managing IADL (likert scale) Upset in managing BPSD (likert scale) Upset in managing ADL dependence (likert scale)	FU: 3 months Not significant Not significant Not significant Not significant Not significant	Reduced decline in IADL for pwd. No effect on behaviour problems or decline in ADLs. No effect on carer self efficacy or upset. Intervention group compared to control at 3 months post-test. • Fewer declines in patients' instrumental ADL. • Less decline in self-care. • Fewer behaviour problems. Spousal carers less upset than non-spousal. Women reported enhanced self-efficacy in managing behaviours, and women and minorities reported enhanced self-efficacy in managing functional dependency.	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		income $3-4K per months			Upset in managing IADL dependence (likert scale)	Not significant	ROB: 6/6 low Overall:low	
		62%F, mostly white, education mean 14 yrs, income $10-50K			Pwd outcomes:			
		63% non spouse, 37% spouse			Frequency of behaviour problems (MBPC)	Not significant		
		Setting: Home/Community			Level of dependency in ADLs (modification of the Functional Independence Measure)	Not significant		
		Country: USA, Philadelphia			Level of dependency in IADLs (modification of the Functional Independence Measure)	d=0.42, adjusted MD= -.13 (-.24, -.01), p=.030.		
					Process outcomes:			
					Participation (number of visits)	Participated in an average of 80% of visits		
					Adherence (researcher developed measure)	An average of 11 strategies were acceptable to carers		

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
Gitlin 2003b	To examine the 6 month effects from the Environment Skills Building Program on carer wellbeing and care recipient functioning and whether effects vary by carer gender, race (white or not) or relationship to care recipient (spouse or not)	C-resident carers, >=4 hours caring pending. Recruited from local Aging agency and media advertisements.	IG: 89 CG: 101 (at 6 months)	IG: More intense than previous 3 month intervention, i.e. more OT time in home and implementation of special equipment and other low cost environmental strategies as not actually provided in previous study. Environmental modification to help manage daily problems with dementia care included education about dementia, instruction in problem seeing, implementing environmental strategies. **Duration & intensity** Five 90 minute home visits and 30min telephone contact by OT based on assessing problems and setting goals and providing education. Interventionists had 25 hours of training.	<u>PWD Outcomes:</u>	FU: 6 months	The Environmental Skill Building Program reduces burden and enhances carer wellbeing in selected domains and has additional benefits for women and spouses.	
					Occurrence of behavioural problems (RMBPC)	No sig. differences		
					ADL (FIM)	No sig. differences		
					IADL (FIM-modified)	No sig. differences		
					<u>Carer Outcomes:</u>			
					Objective Burden			
					Hours doing	No sig. differences		
					Hours helping	No sig. differences		
					Total days	95% CI 0.66, 0.97, p=0.026		
					Subjective burden			
					Memory-related	d=0.16, md=0.13 (-0.36, 0.10), P=.027		
					Disruptive behaviours	No sig. differences		
					IADL assistance	No sig. differences		
					ADL assistance	No sig. differences		
					Mastery (MI)	No sig. differences		
					Skill enhancement (TMSI)	No sig. differences		
					Well-being (PCI)	No sig. differences		
Multicomponent								
REACH								

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
Mahoney 2003[1] Mahoney 2001[3] Eisdorfer 2003[1] Burgio 2003[4] McGinnis 2006[3] (overview) Elliott 2010[4] Burns 2003[2]- Dyads Belle 2006[4]- DYADS- *related to Nichols 2011/2005* Martin dale-Adams –*related to Nichols 2005/2011 see telephone Support* Gallagher Thompson 2003[5] Gitlin 2003b[6] Gitlin 2005[7] *See Psychoeducation section, environment above*	To test the effectiveness and efficacy of various interventions in helping carers to manage disruptive behaviours. TF: Pearlin's model of AD carer's stress	Carers and pwd **Setting:** Home/Community **Country:** USA	various	All interventions to assist carers managing pwd with disruptive behaviours REACH TLC Technology (interactive voice response) **Memphis REACH** Behaviour management compared to behaviour management plus carer stress-coping management **Miami REACH** Structural ecosystems therapy, compared to structural ecosystems therapy plus computer telephone integrated system. Family based therapy delivered by one therapist that identifies specific problems that carers experience and range of community and family support that is available. 12 month intervention; weekly for first 4 months; biweekly months 5,6; monthly months 7-12. Sessions 60 – 90 minutes. Average	Carer outcomes: Bother related to BPSD anxiety depression Burden Pwd outcomes: Behaviours (RMBPC)	FU: 18 months[1]; 24m[2]; 12m[3]; 6m[4]; 3m[5]; 6, 12 & 18m[6]; 6 & 12m[7]; Not significant for REACH TLC,.Memphis. Philadelphia, REACH VA. significant for Palo Alto (p=.03), Alabama (p=.01) Not significant not significant for REACH TLC, Memphis and REACH. Significant improvement in depression in Miami (approaching 5 point reduction). Significant in Philadelphia (p=.001). significant in Palo Alto (p<.0001), REACH VA (p=.009) significant for REACH VA (p=.001) Significant for Alabama (p=.0002),	Interventions have differential impacts according to ethnic group and the carer-pwd relationship. Interventions should be tailored to match the users' characteristics and preferences. Focusing only on pwd behaviour does not reduce carer distress. Depression in carers is related to chronic stress of caring. Problem behaviours contribute to depression Careful assessment of fidelity of intervention across 11 interventionists. Use of manuals, and contacts audiotaped and 20% checked. No costs, but authors 'believe this home based intervention can be administered with minimal modification through home health care agencies by either social workers of nurses' The Environmental Skill Building Program reduces burden and enhances carer wellbeing in selected domains and has additional benefits for women	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
These are findings for all REACH papers – these are discussed separately according to target group.				contact time per carer: 14 hours (range 34 minutes – 34 hours). Average of 13 sessions per carer CG 1: Computer telephone integrated system. Links between carer and other family members. CG2: Biweekly calls for 6 months. **Alabama REACH** Skills training. CG: Brief 15 mins empathetic phone calls. Mailed generic written materials at 1 and 3 months. Palo Alto REACH CWC Psychoeducational compared to enhanced support group **Philadelphia REACH** Home environmental skill building. Environmental modification to help manage daily problems with dementia care included education about		REACH VA (p=.04)	and spouses. Mahoney & related papers: ROB: 5/6 low Overall: low/unclear AC	

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
				dementia, instruction in problem seeing, implementing environmental strategies. Five 90 minute home visits and 30min telephone contact by OT based on assessing problems and setting goals and providing education. Interventionists had 25 hours of training. **REACH VA** Education, support and skills training. REACH Psychosocial CG: Given reference book with module 1 of IVR intervention on strategies to manage disruptive behaviours.				
RELATED REACH PAPERS – KEY DATA								
Eisdorfer 2003- related to Mahoney 2003	To examine the efficacy of a family therapy and technology-based	Two culturally different groups of carers: Cuban Americans and White (non-Hispanic)	IG1: 77 IG2: 75 CG: 73	IG1: Family based therapy delivered by one therapist that identifies specific problems that carers experience and range of community and family	<u>Carer Outcomes:</u> <u>Secondary:</u> Depression (CES-D)	Follow up: 18 months No significant differences.	Overall, subjects in the SET+CTIS group had reduced depression relative to the other interventions at 6m and 18m. Efficacy varied with ethnicity and type of carer	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
	intervention in reducing depressive symptoms amongst family carers of Alzheimer's patients	Americans who were co-resident with a person with Alzheimer's disease, giving >=4 hours care per day and where there was one other family member that supported the carer		support that is available. 12 month intervention; weekly for first 4 months; biweekly months 5,6; monthly months 7-12. Sessions 60 – 90 minutes. Average contact time per carer: 14 hours (range 34 minutes – 34 hours). Average of 13 sessions per carer IG2: CTIS facilitates links between carer and other family members and local resources outside the home, and enhanced therapist access. Monthly allowance for long distance calls to family. Custom built Philips screen phones allow text and voice to be sent during interactive session in user's homes, comprising handset, base unit, display. 3 therapist visits for set up and training. CTIS sessions took place in the last 6 months. Average contacts using CTIS system = 56; average time CTIS used = 19 hours per carer.			Conclusion states that CTIS technology is extremely cost – effective as remains in the home; family therapy is extremely expensive. There is a need to evaluate CTIS without family therapy Depression in carers is related to chronic stress of caring. Problem behaviours contribute to depression.	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
				CG: Minimal support control. By telephone, to prevent differential drop out; Biweekly calls for 6 months, monthly calls months 7 – 12. Calls last 5 – 15 minutes and consist of empathetic listening and comments, when appropriate, - no information, recommendations or education given. Generic educational information given on AD and local contact numbers at outset				
Elliott 2010- related to Mahoney 2003	To enhance the relationships between changes from baseline to pose REACH intervention in carer self-reported health, burden and bother		IG: 238 CG: 257	IG: 9 in home and 3 telephone sessions over 6 months CG: 2 check in telephone calls.	Carer Outcomes: Self-rated health (primary) Carer Sleep Mood improvement Physical improvement	FU: 6 months. Treatment effects d=0.30, md=-0.26 (-0.41, -0.11), P<.01 No sig. differences d=0.35, md=0.17 (0.08, 0.26), P<.05 d=0.25, md=0.11 (0.03, 0.19), P<.05	After the intervention carers reported better health, sleep quality, emotional health, less burden and bother. Changes in depression seemed to mediate the changes. Some ethnic and racial group differences	
McGinnis 2006- Overview				Analysis of 694 carers who received face to face	Carer Outcomes:	FU: 12 months	Racial or ethnic concordance between carer and	

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
				interventions from 36 interventionists at 5 sites.	Depressive symptoms (CES-D) Burden (RMBPC)	No sig, differences No sig. differences	interventionist didn't affect loss to follow up or changes in depression or burden. African American carers with interventionist of same race or ethnicity had larger decreases in depression but result has to be treated with caution as only 2 African American interventionists.	
Cheng 2014 (Pilot Study)	To examine whether the intervention reduced burden and depression in a small randomized trial. To describe the intervention and implementation issues, TF: Cognitive Behavioural approach	Family carers of pwd with mild-moderate dementia Carer Mean Age 54 yrs, 75-85%F, 70-75% married Education IG <Primary: 31% Secondary: 69% CG: <Primary: 17% Secondary: 50% Tertiary: 33% Relationship IG; Spouse: 23% Child: 69% Other 8%	IG: 14 CG: 12 Power: 0.80	Helping carers to deal with BPSD IG: The benefit-finding intervention combines standard psycho-education (information and problem solving) with positive reappraisal coping that is intended to help carers construe the demands of caregiving in more positive ways. CG: Just psycho-educational **Duration & intensity** Group sessions Weekly for 2 hours. **Facilitators:** psychology	<u>Carer Outcomes:</u> Carer Burden (ZBI) Burden (RO) Depression (HDRS)	FU: 8 weeks Not significant Not significant Effect Size: 0.14, F = 3.56, p = 0.073 d= 0.66, MD= -2.54 (-5.74, 0.66), p = 0.073	Controlling for pre-test, the benefit-finding group had lower depression than the psycho-education group at post-test, despite the fact that some carers found benefit-finding challenging. The two groups did not differ on overload and burden. However, within-group analysis suggested that both groups showed significant reductions in overload from pre-test to post-test. ROB: 4/6 low Overall: unclear	

First Author, year And related papers	**Research question/aim and theoretical framework (TF) used**	**Study population, 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 (FU; 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
		CG; Spouse: 8% Child: 64% other: 17% Co-habiting with PWD IG: 69% CG: 50% IG; Mild AD: 23% Moderate: 77% CG Mild AD: 25% Moderate: 75% **Setting:** Home / community **Country** USA		graduates who had experience working with dementia carers and were trained and supervised by the first author who is a clinical geropsychologist.				
Organisational								
Translation of Dementia Care Giver Support program in health care system REACH VA Nichols 2011 *This study is included here, but relates to REACH*		REACH for VA Stressed care givers of pwd carers who fit the REACH criteria: (see Belle 2006 DYADS)	Clinical translation REACH RCT; N=127 care givers at 24 facilities (22.8%) did not provide 6-month follow-up	IG: Like REACH II, the 6-month REACH VA intervention, structured through a protocol and individualized through a risk assessment, targeted education, support, and skills training to address caregiving	At enrollment, the carer outomes: overwhelmed (86%), feeling like crying (80%), being frustrated as a result of caregiving (89%), feeling cut off from family/friends (56%),	FU: 6 months (one group) Estimated improvement (Mean, sd), 95% CI,	Authors conclude that this clinical translation achieved outcomes similar to the REACH II randomized controlled trial, providing clinically significant benefits for carers of a veteran with a progressive dementing disease. This model of carer support can inform public	2/3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
interventions Belle 2006, Martin Dale 2013 – specifically on translation into health care system for carer		coresident family , >=4 hrs care per day for at least 6 months, and endorsing at least 2 caregiving stress behaviors from a list (overwhelmed, often needing to cry, angry/frustrated, cut off from family/friends, moderate/high levels of stress, and declining health). Pwd: Alzheimer disease or related dementia, at >=1 ADL, >=2 IADL. **Setting:** Home based Primary care VA medical centres	data no significant baseline differences between follow up . Effect sizes were estimated as mean change relative to estimated population standard deviation	risk areas of safety, social support, problem behaviours, depression, and health HBPC is patient focused **Duration & intensity** 12 individual inhome and telephone sessions and 5 telephone support group sessions. Like REACH II, the 6-month REACH VA intervention included nine 1-hour individual home sessions, three 0.5-hour individual telephone sessions, and five 1-hour monthly telephone support group sessions. **Providers:** Trained HBPC clinical staff , Memphis	being lonely (53%), and having worse health than last year (39%). **60% of carers rated stress at 6 or higher.**		policy in providing assistance to carers. Carers showed significant improvements in burden, depression, impact of depression on daily lives, and caregiving frustrations (screaming or yelling, feeling like hitting or slapping). The difference of almost 2 hours in the amount of time per day spent on duty trended toward significance. At enrolment, carers reported that, in the past month, the veteran exhibited memory problems (87%) and behaviour problems such as arguing or waking the family up at night (61%). Most (78%) reported having to help with daily activities such as bathing. From baseline to program end, carers reported 1 fewer troubling behaviour exhibited by the veteran, which was a significant decrease These behaviours included difficulties with activities of daily living such as	
					Burden	2.88 (0.86), 95%CI 1.17 to 4.59 p<.001 ES: .33		
					Depression	1.49 (0.55) 95% 0.39 to 2.59 p<.009 .ES26		
					Depression impact on daily life	0.29 (0.11) 95% CI 0.07 to 0.51, p< .01 ES.26		
					Caregiving frustrations	0.26 (0.09) 95% CI 0.09 to 0.44 p<.003 ES.30		
					Time on duty,	h 1.75 (0.92) −0.09 to 3.58 P<.06 .ES 19		
					Time providing care,	NS		
					Bother with	NS		

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Country: USA; 15 states			behaviours General health Health behaviours Safety Social support Pwd: Behaviours	NS NS NS NS NS Ns 1.02 (0.49) 95% CI 0.04 to 2.00 p<.04 ES .20	bathing and dementia related behaviours such as repeated questions. ROB: Overall unclear (as Belle 2006 DYADS)	
Support								
Support groups								
Chu 2011	To investigate the effects of a support group on depression levels and burden TF: none	Carers of pwd with AD or VD (diagnosed SDAT), caring for minimum 4 hrs/day, care giver role for minimum 6 months 57%F, 62% university education 64% adult children of pwd, 32% spouses **Setting:** Home/Community	60 (IG 30, CG 30) PC not reported	IG: Structured support group aims to reduce carer depression and burden. Some sessions were focused around problem behaviours of pwd and the pwd's reactions Discussed carers' emotions and feelings about caregiving, care receivers' reactions and common behaviour problems of dementia patients, carers' need to take care of themselves and to do positive things with the dementia patient; availability of Taiwanese community resources, how in-home	Carer outcomes: Primary: Depression (BDI-II) Burden (CBI)	Fu: 1 month Decreases of 3.63, p=.01 Not significant	Decreased carer depression, but no significant effect on burden. ROB: 2/6 low Overall: unclear	3

First Author, year And related papers	Research question/aim and theoretical framework (TF) used	Study population, 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 (FU; 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
		Country: Taiwan		services could help them and meet the patient's medical needs; communication problems between carer and care receiver and other family members, group progress was reviewed and carers were assisted to develop future plans for care. **Duration & intensity** 12 sessions over 12 weeks CG: usual care **Providers:** masters level mental health nursing students				

Support groups & Counselling								
Livingston 2013 Knapp 2013 (not relevant for economics check with HG)	To assess whether a manual based coping strategy compared with treatment as usual reduces depression and anxiety symptoms in carers of family members with dementia. To assess whether the START (STrAtegies for RelatTives) intervention added to treatment as usual is cost effective compared with usual treatment alone. TF: None	Carers and pwd with AD Carer age IG: 62 CG: 56.1 most F PWD Mean Age, 79 yrs, 57-59%F Carer Ethnicity White UK: 76% Black/Minority: 18-20% PWD Ethnicity White UK: 73% Black/Minority: 19% Carer Marital Status Married/Co-habiting: 65-71% PWD Marital Status Married/Co-habiting: 47% Carer Education Further: 41-45% PWD Education IG Further – 30-38%	IG: 173 dyads CG: 87 dyads PC: 80%	Helping carers deal with BPSD Manual based coping intervention comprising eight sessions and delivered by supervised psychology graduates to carers of family members with dementia. The programme consisted of psycho-education about dementia, carers stress, and where to get emotional support; understanding behaviours of the family member being cared for, and behavioural management techniques; changing unhelpful thoughts; promoting acceptance; assertive communication; relaxation; planning for the future; increasing pleasant activities; and maintaining skills learnt. Carers practised these techniques at home, using the manual and relaxation CDs. CG: treatment as usual **Providers**: Supervised psychology graduates	PWD Outcomes: Behaviours (NPI-proxy) Impairment (CDR-proxy) QOL (QOL-AD-proxy) Carer Outcomes: Primary: Mood (HADS) Total Depression Secondary: Depression Cases Anxiety Anxiety Cases Abusive Behaviour (CTS) QOL (HSQ) mental health subscale Coping Strategies (COPE-brief) Economic Outcomes: Service Use (CSRI)	FU: 8 months Not reported Not reported Not significant Mean Diff: -1.80 (95% CI; -3.29, -0.31), p = 0.02 -0.88 (95% CI; -1.68, -0.09) ES: 0.11 OR 0.25 (0.08, 0.81) -0.62 (95% CI; -1.43, 0.19), ES: 0.14 OR: 0.35 (0.11, 1.18) OR: 0.48, (0.18, 1.27) mean difference 4.09, 95% confidence interval 0.34 to 7.83 Not significant Outpatient hospital and general practice services were used by high proportions of	Mean total scores on the hospital anxiety and depression scale were lower in the IG over the eight month evaluation period: Carers in the IG were less likely to have case level depression and there was a non-significant trend towards reduced case level anxiety. Carers' QoL was higher in the IG but not for the recipient of care. Carers in the IG reported less abusive behaviour towards the recipient of care compared with those in the treatment as usual group, although this was not significant. Costs were no different between the intervention and usual treatment groups (£252 (−28 to 565) higher for START group). The cost effectiveness calculations suggested that START had a greater than 99% chance of being cost effective compared with usual treatment alone at a willingness to pay threshold of £30 000 per QALY gained, and a high probability of cost effectiveness on the HADS-T measure. Adjusting for centre and baseline score and for factors related to outcome (carers' age and sex, neuropsychiatric inventory score, and Zarit burden interview	

		Carer Employment Retired: IG 46% CG: Retired: 26% PWD Living with Carer IG: 65% CG: 57% Relationship IG Spouse/Partner: 36-45% Child: 41-48% Other: 15% **Setting:** Community / Outpatient **Country:** UK			Admittance to Care home Cost:	participants. 4% of CG 6% IG No statistically significant difference £14 (95% CI; -239, 211) No significant difference	score). ROB: 5/6 low Overall: low	
Mittelman 2006 Mittelman 1993 Mittelman 1995 Mittelman 1996 Mittelman 2004 Mittelman 2004b Mittelman 2007 Qualitative Venooji Dassen 2010	To examine the effectiveness of the intervention on pwd institutionalization, and examine the role of other characteristics TF: none	Carers of pwd with AD (32% moderate, 41% moderately severe, 29% severe) 59%F 47% spouses of pwd **Setting**: Home/Community Country: USA	203 (IG 103, CG 103) PC not reported	The NYU-ADRC carer intervention. Individual and family counselling and support group, with access to help and advice as needed. Designed to maximise the support provided to carers. Counselling - 2 sessions with the carer alone, and 4 sessions with carer and family within 4 months of intake. Additional session with carer at follow up. 4 months after intake, carers joined a support group – unlimited sessions. Ad hoc	Carer predictors of nursing home placement: Mental health Burden (Zarit burden interview) Reaction to behaviours (RMBPC) Carer outcomes: Self-rated health (adapted from OARS)	FU: 3 y (2007); 4 12 & 18m (1995; 2006); 12, 24, 36, 48m (2004); 12, 24, 36, 48, 60m (2004b); Not significant Not significant Not significant Not significant	IG had less than half as many nursing home placements at follow up. Nursing home placement was also affected by pwd's need for assistance with ADL. Intervention improved carer self-rated health. Qualitative data: see below ROB: 6/6 low Overall: low	3

				counselling available. Providers: counsellor	Pwd predictors of nursing home placement:			
					ADL (structured researcher questions)	OR 1.04, 80% CI (1.02, 1.06) p<.01		
					Frequency of behaviours (RMBPC)	Not significant		
					Process outcomes:			
					Intervention evaluations			
RELATED MITTLEMAN STUDIES								
Mittelman 2004- related to above			IG: 203 CG: 203		PWD Outcomes:	FU: 4 years	Carers in the active treatment condition reported lower reaction scors on average than usual carers across all assessments after baseline. This difference became significantly stronger across increasingly longer follow-up intervals.	
					Freq. of problem behaviours (MBPC)	No sig, differences		
					Carer Outcomes:			
					Appraisal of bother associated with problem behaviours	Treatment Effect: P=.0226 Time Effect: p=.0368		
Mittelman 2004b	Examine the long term effect of counselling and support on symptoms of depression in spouse carers of	Spouse of patient with clinical diagnosis of AD, recruited in 2 phases Setting: Community	IG: 203 CG: 203	IG: Enhanced counselling and support. **Duration & intensity** First: 6 sessions, 2 individual and 4 family counselling. Then joined support group	Carer Outcomes:	FU: 5 years	Counselling and support lead to sustained benefits in reducing depressive symptoms in spouse-carers of Alzheimer's disease patients; authors suggest should be widely available to provide effective, evidence-based intervention for family carers.	
					Depression (GDS)	Year 1: d=0.15, md=0.80 (-0.28, 1.88), p=.02		
					Proportion of subjects above the threshold for clinically	Remained higher in control group Year 1: RR= 1.47		

	patients with Alzheimer's Disease. Covers first 5 years after enrolment. Carers followed until 2 years after death.	Country: New York USA		(4m after enrolment) and met weekly. Thirdly: Received ad hoc ongoing counselling to help deal with crises. Delivered by counsellors with advanced degrees in social work and allied professionals. Each participant assigned to a counsellor for continuity. CG: Usual care (also available to intervention group) Was information about resources and advice on request? No contact counsellors but were free to join support groups accessed by intervention group - so was more than the usual "usual care".	significant depression	(0.78, 2.75) Year 3: RR=1.23 (0.61, 2.49) Year 5: RR=1.15 (0.56, 2.36		
Mittelman 2006	To determine the effectiveness of a counselling and support intervention for spouse carers in delaying the time to nursing home placement, and identify the	Carers of patients with Alzheimer's Disease recruited through hospital clinic. Setting: Community Country: New York USA	IG: 203 CG: 203	IG: Enhanced counselling and support for carers: **Duration & intensity** 6 sessions of individual and family (4) counselling, support group participation and continuous availability of ad hoc telephone counselling. Carers assigned a family counsellor & counselling sessions in first 4 months & tailored to needs. After that,	PWD Outcomes: Nursing home placement Physical health Freq. of memory and behaviour problems Carer Outcomes: Physical health	FU: Time of nursing home placement 95% CI 0.54, 0.94, p=.015 95% CI 1.04m 1.45, P=.014 95% CI 1.03, 1.05, P<.0001 95% CI 1.06, 1.57, P=.011	Carers in the intervention group were able to keep their spouses at home longer than carers in the usual care control group	

	mechanisms through which the intervention achieved this.			encouraged to join support group. CG: Routine services. Generally no contact with counsellors.	Average satisfaction with support network	95% CI 0.76, 0.91, P<.0001		
					Reaction to memory and behaviour problems	95% CI 1.03, 1.04, P<.0001		
					Depressive symptoms	95% CI 1.03, 1.07, P<.0001		
					Burden	95% CI 1.03, 1.05, P<.0001		
Mittelman 2007	All details as Mittelman papers To determine the effects of counselling and support on the physical health of carers of spouses of people with AD		IG: 203 CG: 203	As described in Mittelman papers	<u>PWD Outcomes:</u> Nursing home placement <u>Carer Outcomes:</u> Physical health Average satisfaction with support network Depressive symptoms	FU: 3 yrs 2 years: p=.05 3 years: Not significant	Counselling and support preserved self-rated health in vulnerable carers. Enhancing carers social support, fostering more benign appraisals of stressors and reducing depressive symptoms may yield indirect health benefits. Psychosocial intervention studies with biological measures of physical health outcomes are warranted Authors suggest that in order to be maximally effective, these interventions should include a structured component and be provided over a long period of time.	
QUALITATIVE Venooij dassen 2010* Related to Mittelman papers	Perspective: Counsellors (service providers of intervention developed and provided	N=3 Recruited from counsellors who delivered the intervention.		<u>Method</u> Group interviews Purposive sampling	<u>Analysis</u> Interviews transcribed. Grounded theory	<u>Main findings</u> 6 themes were identified: family problems, ways to deal with these family problems, barriers	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings? High **F4 -**usefulness of its findings for this review? High	

(RCT)	to carers) To gain insight into the provision of the effective NYUCI carer intervention in order to enhance its implementation Intervention: NYU carer intervention (family focused psychosocial intervention for carers TF: Grounded theory	Age range 65-95 100%F				encountered by counsellors, ways to deal with these barriers, facilitators or rewards of being a counsellor, perceived effectiveness. The problem categories were conflicts with families, past experiences and personality, and daily living with dementia. ways of helping carers included problem clarification, barrier was reluctance to be helped. Dealt with by acknowledging carers' need for control over situations. participation reduced anger and awareness of more and new options for dealing with dementia		
Pillemer 2002 Mixed methods – Qualitative data	To test the specific benefits of peer support, in the absence of other program components. TF: empirical work in sociology and	Carers of pwd with AD Age range 35-87, mean 58 71%F 60% adult child of pwd, 40% spouse **Setting:**	115 (IG 61, CG 54) PC not reported	Peer support aims to improve psychological well being and buffer effects of stressful caregiving situations. PSP did not involve professional intervention. Instead, it emphasized "indigenous social support," that is, support that persons in the same life	<u>Carer outcomes:</u> Depression (CES-D) Self esteem (Rosenberg Self-Esteem Scale) Stress related to disruptive behaviours (shortened version of George's Index of Disruptive	FU: Approx. 6 months Not significant Not significant Not significant	No significant differences, suggests social support alone is not a sufficient intervention for carers. Most carers described the most positive aspect of the intervention as the contact with someone with similar experience. More than 95% of visits were characterised as positive and enjoyable. ROB: 2/6 low Overall: unclear	2

	social psychology related to the importance of similar associates as supporters to persons undergoing stressful life-course transitions	Home/Community **Country:** USA		situation can provide to one another without professional intervention **Duration & intensity** 8 weekly session of approx. 2 hours each. Dyadic rather than group CG: waiting list **Providers:** Trained community volunteers who had themselves been carers to a relative with AD. Volunteers were recruited to the program by the Alzheimer's Association of Central New York	Behaviours) Process outcomes: Satisfaction with intervention (2 global satisfaction items & open ended questions)			
Pillemer 2002 QUALITATIVE DATA	Perspective: Carer Aims as above	unclear		Method: interviews	Analysis Provision of participants quotations given in the interviews without giving specific analysis methods.	Main findings confirmed prediction that carers would highlight similarity with the volunteer as a key componet of their experience. When asked to describe the most positive features of the project, most carers expressly mentioned experiential similarity. A parallel analysis of the experience of the volunteers echoes this finding. the	**Reliability and usefulness:** **F3 -** reliability/trustworthiness of its findings? Unclear **F4 -**usefulness of its findings for this review? Unclear	

						volunteers reported that they considered sharing similar experiences to be the most successful feature of the project. volunteers reported on each individual visit and more than 95% of the visits were characterised as positive and enjoyable.		
Martindale-Martindale-Adams 2013- related to belle-reach II See translational data from Nichols 2011 (protocol) (Related to Nichols 2005)	To determine if telephone support groups for dementia carers have an effect on bother with patient behaviours, burden, depression and general well-being. Hypothesised that carers in a telephone support grou, compared to those in a control condition who received a packer of printed information	Carers of pwds, troubling behavioural problems, pwd mean MMSE 15(7.2),mean ADl 3 (0-6), IADL 7.5 (0-8) 24 carers of veterans Carer age (mean) 64yrs >80% F Carer Ethnicity IG White: 78.7% Black 27.3% Carer employment 22-27% Carer Married 83-88% Carer education	IG: 75 CG: 77	IG: Based on the 6-month REACH II intervention of 12 individual in home and telephone sessions and five telephone support group sessions. CONNECT treatment arm comprised of 15 support groups, each with 5-6 carers and a trained group leader. Targeted caregiving risks-associated with emotional physical well-being safety, burden, social support and pat behaviour management **Duration & intensity** Met biweekly for 2 months and monthly thereafter for 1 year for a total of 14 hour long sessions. Met 14 times over one year	Carer Outcomes: Health (SF-36) Self-care (REACH II) Preventative health measures (REACH II) Burden (ZBI) Depression (CES-D Well-being (GWBS) Bother of dementia behaviours (RMBPC) Nichols 2011 – translational data	FU: 12 months No significant group or time interactions in carer outcomes Translational data Supports REACH VA findings of significantly reduced burden, depression, impact of depression on daily life, caregiving frustrations, and number of troubling dementia-related behaviors. A 2-hour decrease in hours per day on duty	No significant differences; authors conclude that telephone support groups are an efficient way to interact with carers. Different models of care that target needs or occur frequently may provide better support for carers of people with a worsening condition of dementia ROB: 2/6 low Overall: unclear Clinical translation achieved outcomes similar to the REACH II randomized controlled trial, providing clinically significant benefits for carers of a veteran with a progressive dementing disease. Authors suggest this model of carer support can inform public policy in providing assistance to carers.	

	would show improved bother with patient behaviours burden depression and general well being TF: based on REACH	(years) 12.8 Carer household income ($) 35k Relationship to pwd Spouse 72.7% Child 23.4% Length of time carers 49m Caregiving hours of duty IG: 16.4 CG: 16.5 PWD Age (mean) 77yrs PWD Gender 12% F PWD Education (years) 11.2 yrs IG: 11.2 CG: 11.2 **Setting:** community **Country,** USA, MemphiS, Tennessee		CG: Master's prepared group leaders		approached significance. Carers (96%) believed that the program should be provided by the VA to carers.		
Technology								
Night monitoring system								
Rowe 2009 Rowe 2010	to develop a system specifically	Carers and pwd with moderate dementia (81%	43 dyads (IG 26, CG 27)	IG: Night monitoring system aims to provide information to the carer	<u>Pwd outcomes:</u> Nightime injuries and	FU: 12 months RR= 0.24 (0.02, 0.82),	Reduced injuries/exits. Participants were satisfied with the system.	1

	designed to alert carers when care recipients left their beds and then track them as the recipients moved about the house. TF: none	AD) and night-time behavioural disturbances Carer mean age 62 yrs, Pwd mean age 79yrs Carer IG 73%F, CG 85%F. pwd IG 42%F, CG 52%F; 86% college education Carer Race IG 70% white. CG: 85% white Relationship with PWD IG 61% spouse 35% child CG 43% spouse 57% child Carer 30-35% employed **Setting:** Home/Community **Country:** USA	PC not reported	regarding the whereabouts of the pwd during night time to reduce injuries etc. Text, voice and alarm sound when PwD leaves bed and location announcements made as PwD moves through home. Emergency alarm if outside door opened. Announcement made if PwD returns to bed. CG: usual care. Paid $15 each time data collected and some education material and assist with registration to Safe Return Program (administered by Alzheimer's Association to assist in recovering individuals who become lost in the community). **Provider:**	unattended exits from home (number of events) Subjective Sleep (time spent sleeping and sleep quality) Objective Sleep (wrist activity) <u>Carer Outcomes:</u> Distress (new measurement) <u>Process outcomes:</u> System reliability Satisfaction with intervention	p=.03 No significant effect No significant effect No significant effect No evidence of false negatives Participants satisfied with system	NMS represents a technology that can significantly improve the ability of informal carers to provide a safe environment throughout the night in homes of pwds The nms has the potential to ameliorate the devastating triad of consequences that results from night time activity and possibly delay nursing home placement. ROB: 2/6 low Overall: unclear	

***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