National Institute for Health and Care Excellence

Final

Supporting Adult Carers

RQG - Evidence reviews for providing psychological and emotional support to adult carers

NICE guideline NG150

Evidence reviews

January 2020

Final

These evidence reviews were developed by the National Guideline Alliance part of the Royal College of Obstetricians and Gynaecologists

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ISBN: 978-1-4731-3654-0

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Providing Psychological and Emotional Support to Adult Carers

Review question

What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Introduction

Evidence from Carers UK's 2018 State of Caring, the NHS England Commitment to Carers programme and other organisations supporting carers clearly indicate the emotional and psychological impact of caring. Caring may be long-term. It can affect a whole family and the psychological and emotional consequences of early retirement from employment; isolation and loneliness because of lack of cover for external activities and concerns for the person needing support can be considerable. There is consensus that psychosocial support for carers should be personalised according to individual circumstances and preferences, but an ongoing debate about options. It could include good quality information about the condition of the person they care for, should encourage and support the development of personalised strategies and building carer skills and confidence and, importantly, provide advice on how the carer might look after their own physical and mental health and emotional and spiritual well-being. Peer support may be particularly important for many carers, Carers UK's State of Care survey finding that 70% of carers responding reported isolation and related emotional and mental health issues. The development of digital resources (through Carers UK in particular) have offer safe places to share anxieties; feel more confident and benefit from other carers' solutions to emotional stress and practical challenges.

However, caring is seldom static; it may involve multiple services and sources of support and carers may face special challenges at times of transition, for example between home and residential unit or when the condition of the person cared for has deteriorated or changed. There may be particular challenges when young people transition from childrens to adult services, with significant impact on young adult carers who might wish to move moved on to education or employment. There is general agreement that psychological and emotional support should be integrated with information, advice and practical support. However, there is currently a lack of information and evidence about the range of relevant services (such as psychological therapies, cognitive behavioural therapy, group-based options etc) which might support carers and the relative acceptability of different approaches.

Summary of protocol

Please see Table 1 for a summary of the Population, Intervention, Comparison and Outcome (PICO) characteristics of this review.

Table 1: Summary of the protocol (PICO table)

Population	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • Relevant social-/health-care and other practitioners involved in providing care.
Intervention	Any psychological or emotional support intervention whose primary aim is to provide support to adult carers, including:

	• psycho-educational interventions (for example skills building, self-help, self-management/coping skills/peer support) • psychotherapy/counselling (for example cognitive behavioural therapy or similar, relationship counselling) • cognitive-/emotion-oriented/activity-based interventions • low-level/informal and other support interventions (for example helpline or relatively unstructured support; befriending/buddy programs) • interventions to maintain or create new relationships or support networks (for example family interventions) • multicomponent (for example case/care management) interventions (that is those that address more than one carer domain such as maintenance of relationships, disease education, safety, carer health and well-being) • interventions to support carer in caring for person at end of life (for example grief or bereavement counselling) and/or after the person receiving care dies, including anticipatory grief (see RQH).
Comparison	• no intervention • other interventions within the same category.
Outcome	Quantitative outcomes: • Critical impact of caring on carer caring-related morbidity • Important ○ Social capital ○ Carer quality of life ○ Carer choice/control/efficacy Qualitative outcomes: • satisfaction with the intervention • perceived appropriateness of the intervention • perceived acceptability of the intervention • barriers and facilitators.

For full details see the review protocol in appendix A

Evidence

Included studies

This is a mixed-methods review so qualitative and quantitative studies were eligible for inclusion. The objective of this review was to establish whether there are any types of practical support interventions for adult carers that are effective, cost-effective, and acceptable to them.

For the quantitative part of the review, we looked for systematic reviews and randomised control trials (RCTs). For the qualitative part of the review, we looked for studies that collected and analysed data using qualitative methods (including focus groups, interviews, thematic analysis, framework analysis and content analysis). Surveys restricted to reporting descriptive data that were analysed quantitatively were excluded.

Evidence is summarised in a GRADE table for the quantitative studies and GRADE-CERQual tables for qualitative studies. These are provided in appendix F.

Quantitative component of the review

20 RCTs were included (Aboulafia 2014, Blom 2015, Chambers 2014, Charlesworth 2016, Creemers 2014, Cristancho 2015, Hirano 2016, Hubbard 2016, Jones 2016, Leach 2015, Liljeroos 2016, Livingston 2014, Losada 2015, Martin-Carrasco 2014, Martin-Carrasco 2016, Núñez-Naveira 2016, Prick 2015, Vazquez 2016, Wilz 2017, and Woods 2016). 1 further paper was used only for data collection (Cooper 2016), as it included the same study's population as reported in Livingston, 2014. An overview of the 20 included RCTs is provided in Table 2.

Most of the studies including carers from Spain (Losada 2015, Martin-Carrasco 2014, Martin-Carrasco 2016, and Vazquez 2016), 4 studies were from the UK (Charlesworth 2016, Livingston 2014, Jones 2016, and Woods 2016), Australia (Chambers 2014, Hubbard 2016, and Leach 2015) and the Netherlands (Blom 2015, Creemers 2014, and Prick 2015), one was a multi-country study (Núñez-Naveira 2016: Denmark, Poland, and Spain), with ten trials coming from a range of other countries – that is: France, Germany, Japan, Sweden (see Table 2). They were published between 2014 (Aboulafia 2014, Chambers 2014, Creemers 2014, Livingston 2014 and Martin-Carrasco 2014) and 2017 (n=1: Wilz 2017).

Most of the studies included in the review were two-arm RCTs, with the exception of a three-arm RCT (Losada 2015), and a four-arm RCT (Charlesworth 2016).

Overall the included RCTs provided data on 3114 adult carers of people living with A mixture of conditions, ranging from a minimum sample size of 17 (Leach 2015) to a maximum of 462 carers of people living with dementia (Woods 2016). The included RCTs focused on carers of people with the following conditions:

- Alzheimer disease and other dementias (n=13 studies –Table 2, for a total of 2074 carers)
- cancer (Chambers 2014, for a total of 336 carers)
- schizophrenia (Martin-Carrasco 2016, for a total of 223 carers)
- heart failure (Liljeroos 2016, for a total of 155 carers)
- amyotrophic lateral sclerosis (ALS) (Creemers 2014, for a total of 223 carers)
- bipolar disorder (Hubbard 2016, for a total of 32 carers)
- and psychosis (Jones 2016; for a total of 28 carers)

One RCT (Vazquez 2016, for a total of 170 carers), evaluating the efficacy of a cognitive-behavioral intervention, included carers with elevated depressive symptoms (including carers of people living with dementia and other conditions).

The 20 included RCTs form 4 clusters of psychological or emotional support interventions for adult carers:

- Psychosocial and psycho-educational interventions (n=9 studies –Table 2, for a total of 1560 carers) including manual-based psycho-educational programmes (Livingston 2014), web-based psycho-educational interventions (Blom 2015, Cristancho 2015, Núñez-Naveira 2016), group-based psycho-educational interventions (Hubbard 2016, Martin-Carrasco 2014, Martin-Carrasco 2016), educational and psychosocial interventions (Liljeroos 2016), and peer support (Charlesworth 2016).
- Cognitive behavioural therapy (CBT) (n=5 studies –Table 2, for a total of 680 carers), including individualised CBT (Chambers 2014, Wilz 2017, Losada 2015), and group-based CBT (Aboulafia 2014, Vazquez 2016).
- Cognitive-/emotion- /activity-based interventions –including:
    - emotion-oriented interventions (n=3 studies –Table 2, for a total of 643 carers), including acceptance and commitment therapy (Losada 2015), reminiscence therapy (Charlesworth 2016, Woods 2016), and transcendental meditation (Leach 2015)

  - activity-based interventions (for a total of 42 carers), including a leisure activity program (Hirano 2016)
  - written emotional disclosure (for a total of 28 carers) (Jones 2016).
- Multi-component interventions (n=3 studies –Table 2, for a total of 191 carers), including case management (Creemers 2014), psycho-education plus disease education combined with an activity-based intervention (Prick 2015), and peer support plus reminiscence therapy (Charlesworth 2016).

2 studies were also included in another evidence review of this guideline (that is RQE: Training for carers to provide practical support), as these trials compared two interventions relevant for both topic areas of the guideline (Livingston 2014; and Núñez-Naveira 2016). Data relevant to review question F are reported in this evidence report.

Qualitative component of the review

17 qualitative studies were included (Camic 2013, Elvish 2014, Greenwood 2017, Hamill 2012, Hopkinson 2013, Jones 2016, Linacre 2016, Melunsky 2015, Milne 2014, Osman 2016, Roberts 2011, Robinson 2005, Smallwood 2017, Sommerlad 2014, Unadkat-Shreena 2017, Whitney 2012, and Williams 2014). 1 further paper was used only for data collection (Akhtar 2017) as it included the same study's population as reported in Greenwood, 2017.

Table 3 provides a summary of the 17 included qualitative studies. They were published between 2005 (Robinson 2005) and 2017 (Greenwood 2017, Smallwood 2017, and Unadkat-Shreena 2017). They focused on carers of people with the following conditions (Table 3):

- dementia: (n=9 studies –Table 3, for a total of 162 carers)
- psychosis: (Jones 2016, and Smallwood 2017, for a total of 47 carers)
- acquired brain injury: (Williams 2014, for a total of 5 carers)
- advanced cancer: (Hopkinson 2013, for a total of 26 carers)
- eating disorders: (Whitney 2012, and Linacre 2016, for a total of 33 carers)
- mental health problems: (Roberts 2011, for a total of 8 carers)
- and stroke: (Robinson 2005, for a total of 14 carers)

The majority of included studies collected data via semi-structured or unstructured interviews, with 5 studies which used questionnaires (Milne 2014, Jones 2016, Camic 2013, Linacre 2016, and Sommerlad 2014). Data analysis methods included content analysis and thematic analysis, with the latter being the most common method across included studies. According to the study design, ten analyses were 'pure qualitative' studies (Elvish 2014, Greenwood 2017, Linacre 2016, Melunsky 2015, Osman 2016, Roberts 2011, Robinson 2005, Smallwood 2017, Unadkat-Shreena 2017, and Williams 2014), whilst 7 studies were mixed-methods researches (that is using quantitative and qualitative methods in the same study). 3 studies integrated qualitative with quantitative observational evaluations (Camic 2013, Hamill 2012, and Milne 2014), while four were 'mixed-methods RCTs' (Hopkinson 2013, Jones 2016, Sommerlad 2014, and Whitney 2012).

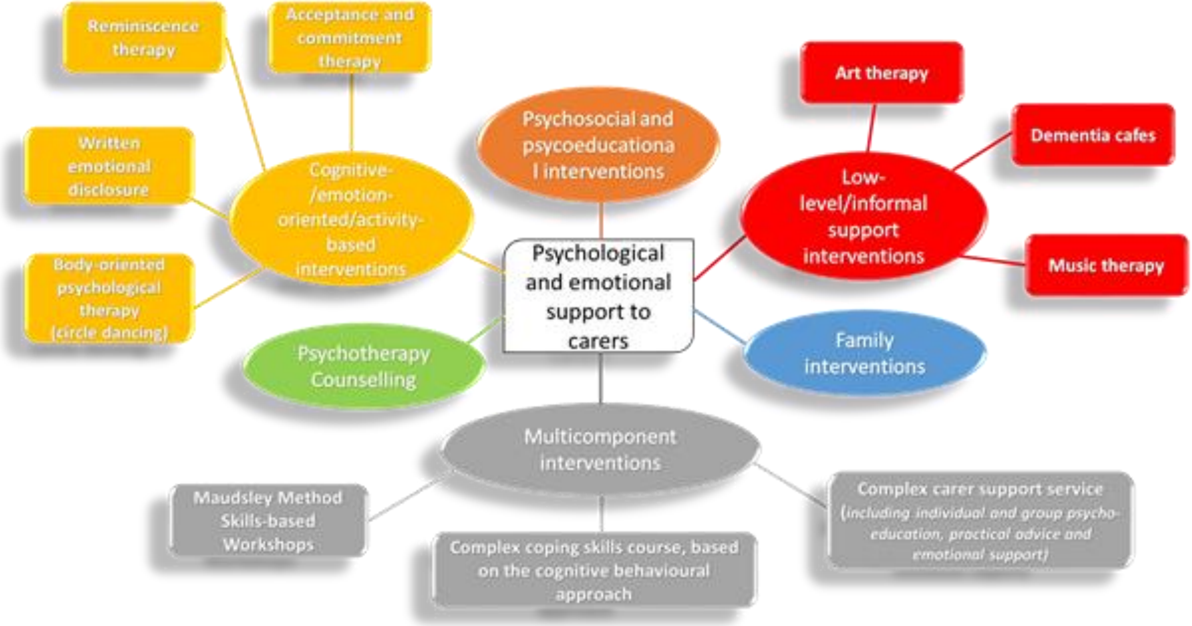
All studies were conducted in the UK. Except for 1 study, which recruited carers across England and Wales (Unadkat-Shreena 2017), all included studies took place in England, with the majority conducted in London (Greenwood 2017, Hamill 2012, Melunsky 2015, Smallwood 2017, and Whitney 2012). All studies focused on adult carers (n=285), ranging from a sample size of 5 (Williams 2014) to 75 carers (Sommerlad 2014). Most of the qualitative studies focused on the overall experience of carers using the following interventions:

- low-level/informal support interventions –including art therapy, music therapy, and 'Dementia cafés' (Camic 2013; Greenwood 2017; Osman 2016; Roberts 2011; and Unadkat-Shreena 2017)

- cognitive-/emotion- /activity-based interventions –including acceptance and commitment therapy, body-oriented psychological therapy, reminiscence therapy, written emotional disclosure (Hamill 2012; Jones 2016; Melunsky 2015; and Williams 2014)
- psychosocial and psychoeducational interventions (Hopkinson 2013; Sommerlad 2014; and Milne 2014)
- multicomponent psychological interventions (Linacre 2016; Robinson 2005; and Smallwood 2017)
- psychotherapy/counselling (Elvish 2014)
- family interventions –including 'individual family work' and 'multi-family workshops' (Whitney 2012)

As shown in the theme map (Figure 1), these concepts have been explored in a number of central themes and subthemes.

Figure 1: Theme map



Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of studies included in the evidence review

A summary of the studies that were included in this review are presented in Table 2 and Table 3.

Quantitative component of the review

A summary of the quantitative studies that were included in this review are presented in Table 2.

Table 2: Summary of included quantitative studies

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
Aboulafia 2014	**Setting** • Switzerland **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a cognitive-behavioural group therapy and a psycho-education group programme, on cortisol secretion in carer of people with moderate Alzheimer's disease **Study dates** • N/R **Follow-up** • 6 months	N = 35 **Carer characteristics** • Age Mean (SD): ○ I = 59.42 (6.67) ○ C = 55.07 (10.68) • Gender (M/F - N): ○ I = 0/12 ○ C = 5/10 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = Cognitive–behavioural group therapy • C = Psycho-education group programme	• Cognitive behavioural therapy
Blom 2015	**Setting** • The Netherlands **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, an internet psycho-education course "Mastery over Dementia" and usual care only (e-bulletins), to provide adult carer of people living with dementia with psychological and emotional support **Study dates** • 2010 -2012 **Follow-up** • 6 months from intervention completion	N = 251 **Carer characteristics** • Age - Mean (SD): ○ I = 61.54 (11.93) ○ C = 60.77 (13.07) • Gender (M/F - N): ○ I = 45/104 ○ C = 30/66 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = Internet course Mastery over Dementia • C = E-bulletins	• Psychosocial and psycho-educational interventions
Chambers 2014	**Setting** • Australia **Study type**	N = 336 **Carer characteristics**	• I = Psychologist-Delivered Five-Session Cognitive	• Cognitive behavioural therapy

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	- Multicentre 2 groups RCT **Aim of the study** - This RCT was aimed to compare the effectiveness of two interventions, a single session of nurse-led self-management intervention and a five-session psychologist cognitive behavioural intervention delivered by telephone, to provide adult carer of people with cancer with psychological and emotional support **Study dates** - 2009 – 2010 **Follow-up** - 3, 6, and 12 months from intervention completion	- Age - Mean (SD): 52.52 (12.71) - Gender (M/F - N): 295/41 **Carer recipient (condition)** - Cancer	Behavioural Intervention - C = Nurse Single-Session Self-Management	

Charlesworth 2016	**Setting**
	- UK
	Study type
	- Factorial pragmatic 4 groups RCT
	Aim of the study
	- This RCT was aimed to evaluate the effectiveness of two interventions - separately or together, an one-to-one peer support and reminiscence therapy - alone or combined (in comparison with usual care), to provide adult carer of people living with dementia with psychological and emotional support
	Study dates
	- 2010 – 2012
		N = 291
		Carer characteristics
		- Age - Mean (SD):
		  ○ I 1= 69.0 (10.5)
		  ○ I 2= 66.3 (11.8)
		  ○ I 3= 65.8 (12.4)
		  ○ C = 66.8 (14.7)
		- Gender (M/F - N):
		  ○ I 1 = 19/29
		  ○ I 2 = 27/72
		  ○ I 3 = 31/66
		  ○ C = 17/30
		Carer recipient (condition)
		- Dementias and Alzheimer's disease
			- I = One-to-one peer support to family carer from experienced carer (carer Supporter Programme; CSP); group reminiscence therapy (Remembering Yesterday, Caring Today; RYCT)
			- C = TAU (N/R)
				- Psychosocial and psycho-educational interventions
				- Cognitive-/emotion-/activity-based interventions
				- Multi-component interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	Follow-up • 12 months from baseline			
Creemers 2014	**Setting** • The Netherlands **Study type** • Multicentre cluster 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a case management plus usual care and usual care only, to provide adult carer of people living with Amyotrophic lateral sclerosis (ALS) with psychological and emotional support **Study dates** • 2009 - 2011 **Follow-up** • 4, 8, and 12 months from baseline	N = 126 **Carer characteristics** • Age - Mean (SD): ○ I = 63 (11) ○ C = 62 (11) • Gender (M/F - N): ○ I = 40/31 ○ C = 39/25 **Carer recipient (condition)** • ALS	• I = Case management + TAU • C = TAU (neuropalliative care by multidisciplinary - secondary care teams)	• Multi-component interventions
Cristancho 2015	**Setting** • France **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a web-based fully automated psycho-education al program (called Diapason) plus usual care and usual care only, to provide adult carer of people living with Alzheimer's disease with psychological and emotional support **Study dates** • 2011 – 2013 **Follow-up**	N = 49 **Carer characteristics** • Age - Mean (SD): ○ I = 64.2 (10.3) ○ C = 59.0 (12.4) • Gender (M/F - N): ○ I = 9/16 ○ C = 9/16 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = Web-Based Psychoeducational Program • C = TAU (information only)	• Psychosocial and psycho-educational interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	- 3, and 6 months from baseline			

Hirano 2016	**Setting**
	- Japan
	Study type
	- 2 groups RCT
	Aim of the study
	- This mixed-methods research was aimed to compare the effectiveness and the acceptability of two interventions, a periodic leisure activity program (30 min/3 times/week for 24 weeks) and usual care, to provide adult carer of people living with dementia with psychological and emotional support
	Study dates
	- N/R
	Follow-up
	- post-intervention
		N = 42
		Carer characteristics
		- Age - Mean (SD):
		  ○ I = 73.9 (4.5)
		  ○ C = 76.2 (4.7)
		- Gender (M/F - N):
		  ○ I = 10/11
		  ○ C = 7/14
		Carer recipient (condition)
		- Dementias and Alzheimer's disease
			- I = leisure activity program (30 min/3 times/week for 24 weeks)
			- C = TAU (N/R: "normal care activities")
				- Cognitive-/emotion-/activity-based interventions

Hubbard 2016	**Setting**
	- Australia
	Study type
	- 2 groups RCT
	Aim of the study
	- This RCT was aimed to compare the effectiveness of two interventions, a brief group psycho-education and wait-list control, to provide adult carer of people with bipolar disorders with psychological and emotional support
	Study dates
	- N/R
	Follow-up
	- 1 month from intervention completion
		N = 32
		Carer characteristics
		- Age - Mean (SD):
		  ○ I = 50.50(11.63)
		  ○ C = 45.07(18.87)
		- Gender (M/F - N):
		  ○ I = 6/8
		  ○ C = 7/11
		Carer recipient (condition)
		- Bipolar disorder
			- I = Brief group psycho-education
			- C = Waitlist group
				- Psychosocial and psycho-educational interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
Jones 2016	**Setting** • UK **Study type** • 2 groups (Mixed-methods) RCT. This was a feasibility mixed-methods trial **Aim of the study** • The aims of this mixed-methods RCT were to explore the feasibility and acceptability of written emotional disclosure and a control writing task in a feasibility trial of caregivers of people with psychosis. **Study dates** • N/R **Follow-up** • 1 month from intervention completion	N = 28 **Carer characteristics** • Age - Mean (SD): ○ I = 59.7 (9.51) ○ C = 59.3 (6.77) • Gender (M/F - N): ○ I = 1/13 ○ C = 0/14 **Carer recipient (condition)** • Psychosis	• I = Written emotional disclosure • C = 'controlled writing task'	• Cognitive-/emotion-/activity-based interventions
Leach 2015	**Setting** • Australia **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a 12-week (14-hour) transcendental meditation training program plus 12-week follow-up and 24-week wait-list control, to provide adult carer of people living with dementia with psychological and emotional support **Study dates** • 2013 – 2014 **Follow-up** • 24 months from baseline	N = 17 **Carer characteristics** • Age - Mean (SD): ○ I = 69.4 (7.3) ○ C = 63.2 (8.8) • Gender (M/F - N): ○ I = 1/7 ○ C = 1/8 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = 12-week (14-hour) Transcendental Meditation training program plus 12-week follow-up • C = 24-week wait-list control	• Cognitive-/emotion-/activity-based interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
Liljeroos 2016	**Setting** • Sweden **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a dyadic educational and psychosocial intervention plus usual care and usual care only, to provide adult carer of people with heart failure with psychological and emotional support **Study dates** • N/R **Follow-up** • 24 months from baseline	N = 155 **Carer characteristics** • Age - Mean (SD): ○ I = 69 (13) ○ C = 73 (10) • Gender (M/F - N): ○ I = 49/22 ○ C = 68/16 **Carer recipient (condition)** • Heart failure	• I = Dyadic educational and psychosocial intervention plus TAU • C = TAU (no intervention: focus only on care recipients)	• Psychosocial and psycho-educational interventions
Livingston 2014	**Setting** • UK **Study type** • Multicentre 2 groups RCT **Aim of the study** • To evaluate effectiveness and cost-effectiveness of manual-based coping skills training for dementia carers in short- and long-term **Study dates** • 2009 to 2013 **Follow-up** • 8, 12, 24 months	N=260 carers **Carer characteristics** • Age - Mean (SD): ○ I = 62.0 (14.6) ○ C = 56.1 (12.3) • Gender (M/F - N): ○ I = 57/116 ○ C = 25/62 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = Manual-based coping strategy programme • C = TAU	• Psychosocial and psycho-educational interventions
Losada 2015	**Setting** • Spain **Study type** • 3 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of three interventions, a cognitive–behavioural therapy,	N = 135 **Carer characteristics** • Age - Mean (SD): ○ I 1 = 61.48 (12.40) ○ I 2 = 61.69 (15.31) ○ C = 62.28 (12.92) • Gender (M/F - N): ○ I 1 = 4/38 ○ I 2 = 8/37 ○ C = 10/38	• I = Cognitive–behavioural therapy; Acceptance and Commitment Therapy • C = Minimal support control group (2-hr workshop, including psycho-education on dementia)	• Cognitive behavioural therapy • Cognitive-/emotion-/activity-based interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	Acceptance and Commitment Therapy and minimal support (2-hr workshop, including psycho-education on dementia), to provide adult carerwith significant depressive symptom of people living with dementia with psychological and emotional support **Study dates** - N/R **Follow-up** - 6 months from intervention completion	**Carer recipient (condition)** - Dementias and Alzheimer's disease		

Martin-Carrasco 2014	**Setting**
	- Spain
	Study type
	- 2 groups RCT
	Aim of the study
	- This RCT was aimed to compare the effectiveness of two interventions, a psycho-education al Intervention Group Programme plus usual care and usual care only, to provide adult carer of people living with dementia with psychological and emotional support
	Study dates
	- 2009 - 2010
	Follow-up
	- 4 months from intervention completion
		N = 238
		Carer characteristics
		- Age - Mean (SD):
		  ○ I = 61.0 (13.6)
		  ○ C = 63.2 (14.1)
		- Gender (M/F - N):
		  ○ I = 26/89
		  ○ C = 28/95
		Carer recipient (condition)
		- Dementias and Alzheimer's disease
			- I = Psycho-educational Intervention Group Programme + TAU
			- C = TAU (standard support delivered to carer from the day centre or memory clinic where the people living with dementia were treated)
				- Psychosocial and psycho-educational interventions

Martin-Carrasco 2016	**Setting**
	- Spain
	Study type
	- Multicentre 2 groups RCT
	Aim of the study
		N = 223
		Carer characteristics
		- Age - Mean (SD):
		  ○ I = 59.2 (11.4)
		  ○ C = 61.1 (11.6)
		- Gender (M/F - N):
			- I = Psycho-educational Intervention Group Programme + TAU
			- C = TAU (standard support delivered to carer from the
				- Psychosocial and psycho-educational interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	• This RCT was aimed to compare the effectiveness of two interventions, a psycho-education al intervention group programme plus usual care and usual care only, to provide adult carer of people with schizophrenia with psychological and emotional support **Study dates** • March to May 2012 **Follow-up** • 4, and 8 months from baseline	○ I = 22/87 ○ C = 31/83 **Carer recipient (condition)** • Schizophrenia	outpatient psychiatric service where the people with schizophrenia were treated)	
Núñez-Naveira 2016	**Setting** • Denmark, Poland, and Spain **Study type** • Multicentre 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a internet psyco-educational course over dementia (The UnderstAID Application) and usual care, to provide adult carer of people living with dementia with psychological and emotional support **Study dates** • N/R **Follow-up** • 3 months from baseline (that is intervention completion)	N = 61 **Carer characteristics** • Age - Mean (SD): ○ I = N/R ○ C = N/R • Gender (M/F - N): ○ I = 9/21 ○ C = 13/18 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = The UnderstAID Application: Internet course over Dementia [5 modules with information about 15 different topics: Module 1, Cognitive Declines Module 2, Daily Tasks; Module 3, Behavioural Changes; Module 4, Social Activities; and Module 5, You as a Caregiver] • C = not usage of the application and maintained their usual lifestyle	• Psychosocial and psycho-educational interventions
Prick 2015	**Setting** • The Netherlands **Study type** • 2 groups RCT **Aim of the study**	N = 111 **Carer characteristics** • Age - Mean (SD): ○ I = 73 (9.91) ○ C = 71 (10.31)	• I = Physical exercise + support (Education about dementia and its impact, its impact on patient behavior	• Multi-component interventions

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	• This RCT was aimed to compare the effectiveness of two interventions, a physical exercise plus psychological support and information only, to provide adult carer of people living with dementia with psychological and emotional support **Study dates** • 2008-2012 **Follow-up** • 3, and 6 months from baseline	• Gender (M/F - N): ○ I = 19/38 ○ C =12/42 **Carer recipient (condition)** • Dementias and Alzheimer's disease	and function and how to modulate their own responses to problems • C = TAU (information only)	
Vazquez 2016	**Setting** • Spain **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a group problem-solving programme and usual care, to provide adult carers with elevated depressive symptoms with psychological and emotional support **Study dates** • N/R **Follow-up** • 3, 6, and 12 months from baseline	N = 170 **Carer characteristics** • Age - Mean (SD): ○ I = 55.7 (9.7) ○ C = 54.5 (8.2) • Gender (M/F - N): ○ I = 26/62 ○ C =19/63 **Carer recipient (condition)** • Carers with elevated depressive symptoms (including carers of people living with dementia –n=84, and other conditions – n=86)	• I = Group intervention, based on the depression problem-solving (carried out in 5 sessions) • C = TAU (unrestricted access to standard social and health care services for treatment of depression symptoms)	• Cognitive behavioural therapy
Wilz 2017	**Setting** • Germany **Study type** • 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness of two interventions, a telephone-based cognitive behavioural	N = 105 **Carer characteristics** • Age - Mean (SD): ○ I = 61.44 (9.74) ○ C = 61.30 (8.56) • Gender (M/F - N): ○ I = 11/67 ○ C = 7/20 **Carer recipient (condition)**	• I = Telephone-based cognitive behavioural intervention (multi-component CBT intervention focused on managing behaviour problems and personality changes of the care recipient, caregivers'self-care, reduction of social	• Cognitive behavioural therapy

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	programme and written educational material only, to provide adult carer of people living with dementia with psychological and emotional support **Study dates** • NR **Follow-up** • 24 months from baseline	• Dementias and Alzheimer's disease	isolation, utilization of professional and informal support, stress reduction, regulation of emotions, reinforcement of positive activities, and acceptance of role change and loss) + TAU • C = TAU (written educational material)	
Woods 2016	**Setting** • UK **Study type** • Multicentre 2 groups RCT **Aim of the study** • This RCT was aimed to compare the effectiveness and the cost-effectiveness of two interventions, a group reminiscence therapy and usual care, to provide adult carer of people living with dementia with psychological and emotional support **Study dates** • 2008-2010 **Follow-up** • 3, and 10 months from baseline	N = 487 **Carer characteristics** • Age - Mean (SD): ○ I = 69.6 (11.6) ○ C = 69.7 (11.6) • Gender (M/F - N): ○ I = 126/142 ○ C = 101/138 **Carer recipient (condition)** • Dementias and Alzheimer's disease	• I = Group reminiscence therapy (Remembering Yesterday, Caring Today; RYCT) • C =TAU (unrestricted access to standard social and health care services, except for the reminiscence groups)	• Cognitive-/emotion-/activity-based interventions

C: Control group; CBT: Cognitive behavioural therapy; F: Female; I: intervention group; M: Male; N: Number; N/R: not reported; SD: Standard deviation; TAU: Treatment as usual; RCT: Randomised controlled trial

Qualitative component of the review

A summary of the qualitative studies that were included in this review are presented in Table 3.

Table 3: Summary of included qualitative studies

Study and aim of the study	Participants	Methods	Themes
Camic 2013 **Aim of the study**	N=10 adult carers **Carer** • Age = N/R	• **Recruitment period:** N/R	• **Low-level/informal and other support**

Study and aim of the study	Participants	Methods	Themes
• The aims of this mixed-methods study were to evaluate if participation in a community singing group had a positive impact on both people living with A dementia and their carers by increasing well-being, improving day-to-day functioning and reducing social exclusion.	• Gender (M/F - N) = N/R **Care recipient** • Condition = Dementia	• **Data collection & analysis methods:** o Data were collected through semi-structured interviews (lasting 30 minutes) and through standardised questionnaires. o Interview data were analysed using thematic analysis.	**interventions - Music therapy** o Perceived benefits: social support o Perceived benefits: emotional support
Elvish 2014 **Aim of the study** • The aims of this qualitative study were to explore the meaning of counselling/psychotherapy from the perspective of carers of people living with dementia and to explore the processes of change within therapy.	N=6 adult carers **Carer** • Age = Range, years: 55 to 80 • Gender (M/F - N) = 1/5 **Care recipient** • Condition = Dementia	• **Recruitment period:** N/R • **Data collection & analysis methods:** o Data were collected through semi-structured interview. o Data were analysed using a specific form of narrative analysis: 'holistic-content' analysis.	• **Psychotherapy/counselling** o Enabling factors: professionals delivering psychotherapy o Enabling factors: information sharing o Perceived benefits: self-confidence
Greenwood 2017 **Aim of the study** • The aims of this qualitative study were to explore the views of 11 carers from five dementia cafés in and around London.	N=11 adult carers **Carer** • Age = Range, years: 41 to 80 • Gender (M/F - N) = 3/8 **Care recipient** • Condition = Dementia	• **Recruitment period:** N/R • **Data collection & analysis methods:** o Data were collected through face-to-face semi-structured interviews guided by a topic guide. o Thematic analysis was used to analyse data.	• **Low-level/informal and other support interventions - Dementia cafés** o Enabling factors: dementia café co-ordinators o Perceived benefits: emotional support o Perceived benefits: social support
Hamill 2012 **Aim of the study** • The aims of this mixed-methods study were to evaluate the effects of a circle dance group therapy on people living with dementia, and their carers.	N=7 adult carers **Carer** • Age = Range, years: 61 to 91 • Gender (M/F - N) = 3/4 **Care recipient** • Condition = Dementia	• **D Recruitment period:** N/R • **Data collection & analysis methods:** o No details are reported.	• **Cognitive-/emotion-oriented/activity-based interventions - Body-oriented psychological therapy** o Perceived benefits: personal awareness and peer support

Study and aim of the study	Participants	Methods	Themes
Hopkinson 2013 **Aim of the study** • The aims of this mixed-methods study were to evaluate a the potential for a psychosocial intervention, the Macmillan Approach to Weight and Eating, to mitigate weight- and eating-related distress in carers of people with advanced cancer.	N=26 adult carers **Carer** • Age = Mean (range, years): 66 (33 to 84) • Gender (M/F - N) = 2/24 **Care recipient** • Condition = Advanced cancer	• **Recruitment period:** 2006/2007 • **Data collection & analysis methods:** o Data were collected through semi-structured interviews the end of the quantitative analysis. o Interview data were analysed using content and thematic analysis.	• **Psychosocial interventions - the Macmillan Approach to Weight and Eating (MAWE)** o Perceived benefits: acceptance o Perceived benefits: self-management, understanding, and reassurance
Jones 2016 **Aim of the study** • The aims of this mixed-methods qualitative study were to explore the acceptability of written emotional disclosure and a control writing task in a feasibility trial of caregivers of people with psychosis. This quantitative component of this study has been included in the quantitative component of the review.	N=21 adult carers **Carer** • Age = Mean (SD): 59.5 (8.10) • Gender (M/F - N) = 1/27 **Care recipient** • Condition = Psychosis	• **Recruitment period:** N/R • **Data collection & analysis methods:** o Data were collected through a questionnaire. o Thematic analysis was used to analyse data.	• **Cognitive-/emotion-oriented/activity-based interventions - Written emotional disclosure** o Enabling factors: lack of time o Perceived benefits of 'WED - written emotional disclosure': stress relieving
Linacre 2016 **Aim of the study** • The aims of this qualitative study were to explore the views of carers of people with eating disorders on how the skill-based workshops were received	N=10 adult carers **Carer** • Age = Range, years: 31 to 60 • Gender (M/F - N) = xx **Care recipient** • Condition = Eating disorders	• **Recruitment period:** 2014 • **Data collection & analysis methods:** o Data were collected through a questionnaire, including both the quantitative and qualitative data collection. o Thematic analysis was used to analyse data.	• **Multicomponent interventions - Maudsley Method Skills Workshops** o Enabling factors: structure of the Workshops o Perceived benefits: personal awareness and social support
Melunsky 2015 **Aim of the study**	N=10 adult carers **Carer**	• **Recruitment period:** 2012	• **Cognitive-/emotion-oriented/activity-based interventions -**

Study and aim of the study	**Participants**	**Methods**	**Themes**

• The aims of this qualitative study were to explore the views of 18 family carers of people living with dementia attending 'Remembering Yesterday Caring Today' groups (reminiscence therapy).	• Age = Range, years: 41 to 85
	• Gender (M/F - N) = 6/12
	Care recipient
	• Condition = Dementia
		• **Data collection & analysis methods:**
		  ○ Data were collected through semi-structured interview.
		  ○ An inductive thematic analysis was used to analyse data.
			Reminiscence therapy
			  ○ Predisposing factor: expectations with reminiscence therapy
			  ○ Perceived benefits: peer support
			  ○ Perceived benefits: interpersonal relationship with the cared for
			  ○ Perceived benefits of reminiscence therapy: reassurance

Milne 2014
 	
Aim of the study
• The aims of this mixed-methods study were to evaluate a multi-component psychoeducational intervention for relatives of people living with A recent diagnosis of mild to moderate dementia.
	N=73 adult carers
	
	Carer
	• Age = Mean (years): 64
	• Gender (M/F - N) = N/R
	Care recipient
	• Condition = Dementia
		• **Recruitment period:** 2008/2009
		• **Data collection & analysis methods:**
		  ○ Data were collected through a questionnaire, including both the quantitative and qualitative data collection.
		  ○ Thematic analysis was used to analyse data.
			• **Psychosocial interventions - Medway 'Carers Course'**
			  ○ Enabling factor: style, timing and content of the course
			  ○ Enabling factors: unhelpful aspects of the programme
			  ○ Perceived benefits: social support and reassurance
			  ○ Perceived benefits: Understanding, stress management, coping, and knowledge about support available.

Osman 2016
 	
Aim of the study
• The aims of this qualitative study were to explore the views of carers of people living with dementia about the impact of Singing for the BrainTM, an intervention based on group singing activities developed by The Alzheimer's Society.
	N=18 adult carers
	
	Carer
	• Age = N/R
	• Gender (M/F - N) = N/R
	Care recipient
	• Condition = Dementia
		• **Recruitment period:** N/R
		• **Data collection & analysis methods:**
		  ○ Data were collected through semi-structured interviews.
		  ○ Interview data were analysed using thematic analysis.
			• **Low-level/informal and other support interventions - Music therapy**
			  ○ Perceived benefits: emotional support
			  ○ Perceived benefits: social support

Roberts 2011 **Aim of the study**	N=8 adult carers **Carer**	• **Recruitment period:** N/R • **Data collection & analysis methods:**	• **Low-level/informal and other support interventions - Art therapy**

Study and aim of the study	**Participants**	**Methods**	**Themes**
- The aims of this qualitative study were to understand the psychological and social aspects of how art-viewing, in a public art gallery, could be used as an activity to support family carers of people with mental health problems.	- Age = Range, years: 30 to 60 - Gender (M/F - N) = 1/7 **Professionals** - N=2 (facilitators) **Care recipient** - Condition = Mental health problems	○ Data were collected through semi-structured interviews after intervention was completed. ○ Analysis was a "constant comparative analysis".	○ Perceived benefits: personal awareness ○ Perceived benefits: social and emotional support
Robinson 2005 **Aim of the study** - The aims of this qualitative study were to develop and evaluate a new service for carers of people with stroke which would (1) enable carers to effectively manage the stress and problems associated with their role; (2) maintain or improve their well-being; and (3) improve their knowledge about stroke, available services and financial support.	N=14 adult carers **Carer** - Age = Range, years: 38 to 74 - Gender (M/F - N) = N/R **Care recipient** - Condition = Stroke	- **Recruitment period:** N/R - **Data collection & analysis methods:** ○ Data were collected through semi-structured interviews. ○ Data collection and analysis were guided by grounded theory methodology. Sampling ended when data saturation was achieved (that is, no new themes emerged).	- **Multicomponent interventions - Coping skills course** ○ Perceived benefits: understanding, coping, stress management, and knowledge about support available.
Sommerland 2014 **Aim of the study** - The aims of this qualitative research were to explore the experiences of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), demonstrated in a randomised-controlled trial to reduce affective symptoms.	N=75 adult carers **Carer** - Age = mean age - range (years): 59,3 | 18-65 - Gender(M/F - N)= 26/49 **Care recipient** - Condition = Dementia	- **Recruitment period:** 2009/2013 - **Data collection & analysis methods:** ○ Data were collected using self-completed questionnaires. ○ Data were analysed by two researchers using thematic analysis.	- **Psychosocial interventions - manual-based coping strategy programme (STrAtegies for RelaTives, START)** ○ Enabling factors: timing to taking part in the intervention ○ Enabling factors: unhelpful aspects of the programme ○ Perceived benefits: disease understanding, coping, emotional and stress management, and knowledge about support available. ○ Perceived benefits: social support

Study and aim of the study	Participants	Methods	Themes
Smallwood 2017 **Aim of the study** • The aims of this qualitative study were to explore the views of carers of people with psychosis about a newly-developed support service, offering individual and group psychoeducational, practical advice and emotional support, working alongside usual community mental health provision for people with established psychosis.	N=26 adult carers **Carer** • Age = N/R • Gender (M/F - N) = N/R **Care recipient** • Condition = Psychosis	• **Recruitment period:** 2013/2014 • **Data collection & analysis methods:** ○ Unclear methods of data collection. ○ Data were analysed by using thematic analysis.	• **Multicomponent interventions - Carer support service** ○ Perceived benefits: personal awareness ○ Perceived benefits: psychological and emotional
Unadkat-Shreena 2017 **Aim of the study** • The aims of this qualitative study were to evaluate how group singing benefits people living with dementia and their partners.	N=10 adult carers **Carer** • Age = Mean (range, years): 70 (61 to 89) • Gender (M/F - N) = 5/12 **Care recipient** • Condition = Dementia	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through open interviews guided from a topic guide. ○ Interview data were analysed using thematic analysis: Concurrent data collection and analysis was carried out in order to allow for the initial codes to direct sampling. Sufficient data were achieved.	• **Low-level/informal and other support interventions - Music therapy** ○ Enabling factors: group facilitators ○ Perceived benefits: emotional support ○ Perceived benefits: social support
Whitney 2012 **Aim of the study** • The aims of this mixed-methods study were to evaluate treatment efficacy, carer satisfaction and the process of change associated with two family interventions provided as a supplement to inpatient care for	N=23 adult carers **Carer** • Age = Mean (range, years): 47 (21 to 62) • Gender (M/F - N) = 10/13 **Care recipient** • Condition = Eating disorders (Anorexia nervosa)	• **Recruitment period:** 2011 • **Data collection & analysis methods:** ○ Data were collected through semi-structured interviews. ○ The interviews were analysed using Interpretive Phenomenological Analysis.	• **Family interventions - Individual family work and multi-family workshops** ○ Enabling factor: professionals delivering family interventions ○ Enabling factors: structure of family interventions ○ Enabling factors: components of family interventi

Study and aim of the study	Participants	Methods	Themes
anorexia nervosa—individual family work and family day workshops.			○ Perceived acceptability of family interventions: when and how ○ Perceived acceptability: where ○ Perceived benefits of family interventions: disease understanding, emotional and social support.
Williams 2014 **Aim of the study** • The aims of this qualitative study were to explore the views of acquired brain injury carers who attended an acceptance based group intervention.	N=5 adult carers **Carer** • Age = Range, years: 55 to 64 • Gender (M/F - N) = 1/4 **Care recipient** • Condition = Acquired brain injury	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through semi-structured interviews ○ Interview data were analysed using inductive thematic analysis.	• **Cognitive-/emotion-oriented/activity-based interventions - Acceptance and commitment therapy** ○ Perceived benefits: personal awareness ○ Perceived benefits self-acceptance ○ Perceived benefits: reinforcing existing perspectives on coping ○ Perceived benefits: peer support

F: Female; M: Male; N: Number; N/R: not reported

See the full evidence tables in appendix D.

Quality assessment of outcomes included in the evidence review

See the evidence profiles in appendix F.

Economic evidence

Included studies

5 studies were identified with respect to the cost-effectiveness of psychological and emotional support interventions to adult carers for maintaining and/or improving their health and well-being (Livingston 2014; Allen 2016; Chatterton 2016; Vroomen 2016; Woods 2016). Table 4 provides a brief summary of the included studies.

See also the economic evidence study selection chart in appendix G.

Table 4: Summary of included studies (economic evidence)

Study	Population	Intervention/Comparison	Perspective and cost year	Comments
Livingston 2014 Cost-utility analysis conducted alongside an RCT UK	Family carers of people living with dementia	START (STrAtegies for RelaTives) – 8 session, manual-based coping intervention delivered by supervised psychology graduates Treatment as usual	Health and social care 2009-10 prices	Sensitivity analysis addressed baseline characteristics and predictors of missing values
Allen 2016 Cost analysis As part of before-and-after study UK	Carers of people living with dementia	CBT for Carers groups (after) No CBT for Carers groups (before)	Health and social care 2014 prices	The reporting of costs is limited
Chatterton 2016 Cost-utility analysis conducted alongside an RCT Australia	Adults caring for people with cancer who called cancer helplines	5 sessions of an individualised cognitive behavioural intervention with a tele-based psychologist Minimal telephone support and education with a nurse counsellor with self management materials	Australian health sector 2011-12 prices	Parameter uncertainty was evaluated by varying unit costs by 20% in one-way sensitivity analyses
Vroomen 2016 Cost-utility analysis alongside a prospective controlled cohort study Netherlands	Informal caregivers and people living in the community with dementia	Intensive Care Management Model (ICMM) Linkage Model (LM) No access to case manager	Societal 2010 prices	Propensity scores were used to address baseline differences and possible selection bias arising from the non-randomised study design
Woods 2016 Cost-effectiveness	People with mild/moderate dementia living	Reminiscence groups using the “Remembering	Public sector perspective including the	No sensitivity analysis undertaken but

Study	Population	Intervention/Comparison	Perspective and cost year	Comments
and cost utility analysis alongside an RCT UK	in the community and their carers	Yesterday, Caring Today.” (RYCT) manual Treatment as usual	NHS and local government 2010 prices	confidence intervals reported for ICERs

CBT: Cognitive behavioural therapy; ICER: Incremental cost-effectiveness ratio; RCT: Randomised controlled trial.

Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of studies included in the economic evidence review

A UK study (Livingston 2014) reported on an economic evaluation undertaken alongside a RCT. The participants in the trial were family carers of people living with dementia not living in 24 hour care. The study compared a psycho-educational intervention (START) with treatment as usual. START comprised of 8 sessions delivered by trained and supervised psychology graduates. Treatment as usual was based on NICE guidelines and comprised “assessment, diagnosis and information, drug treatment, congnitive stimulation therapy, practical support, treatment of neuropsychiatric and cognitive symptoms and carer support”. Costing was undertaken using a health and social care perspective with costs presented in UK pounds sterling at 2009-10 prices. Costs and QALYs were discounted at 3.5% in line with the NICE reference case. At 8-months follow-up carers who received START had higher health and social care costs although the difference was mot statistically significant at the 95% level (£252; 95% CI -£28 to £565). The incremental cost-effectiveness ratio (ICER) was £6,000 per QALY and a probabilistic sensitivity analysis (PSA) suggested that there was a >99% probability of START being cost-effective when using a cost-effectiveness threshold of £30,000 per QALY. For the longer term analysis at 24-months the intervention group had higher costs but again the difference was not statistically significant (£336; 95% CI -£223 to £895). The ICER was £11,200 per QALY with PSA indicating a 75% chance that START was cost-effective at a cost-effectiveness threshold of £30,000 per QALY. Sensitivity analysis which adjusted for baseline difference on demographic and clincical predictors of missing values and disparity in baseline characteristics produced similar ICERs to the base case result.

A cost analysis (Allen 2016) of CBT for Carers of people living with dementia was carried out in the UK as part of a before-and-after study. The CBT for Carers group intervention comprised of the following content:

- information giving
- understanding the feelings of those with dementia
- managing stress
- coping with difficult behaviours and feelings

The study compared contacts with Accident and Emergency departments, inpatients, outpatients and mental health pre- and post intervention. The authors reported that before the intervention there were 245 contacts with Accident and Emergency, inpatient and outpatient departments compared with 36 contacts after, for a saving of £11,855 across the 22 study participants. They also reported a reduction in mental health contacts from 119 before CBT for Carer groups to 18 contacts after, with an estimated saving of £35,451. They noted that community contacts increased from 6 to 7 after the intervention for an estimated increase in cost of £351. Total savings were reported at £47,000 for a project cost of £15,000.

An Australian cost utility analysis (Chatterton 2016) compared an intervention of individualised cognitive behavioural intervention led by a psychologist with nurse-led self-management for carers of people with cancer with low and high distress at baseline. The analysis was undertaken from the perspective of the Australian health sector. Costs, reported in 2011-12 prices, included the costs of the interventions and the health-care resources of cancer patients and their carers. As costs and outcomes were only collected at 1-year no discounting was applied. The assesment of quality of life – 8 dimensions (AQOL-8D) was used to derive the utility values used to estimate QALYs. The psychologist led intervention was more costly in both the high distress and low distress groups but the differences in total costs were not statistically significant at the 5% level. Nor were there significant differences in the QALYs for carers across high and low distress groups, although the point estimates were higher for the psychologist led intervention. The incremental net monetary benefit (iNMB) of the psychologist led intervention for carers with high distress was 3,047 AUD (95% CI: -2,526 AUD to 8,620 AUD) and -1,669 AUD (95% CI: -4,316 to 978 AUD) for carers with low distress. PSA using bootstrapping suggested that there was a 21% and 89% chance of the psychologist led intervention being cost-effectiive for carers with low distress and high distress respectively at a cost-effectiiveness threshold of 50,000 AUD per QALY. Sensitivity analysis addressing assumptions for missing data and unit costs did not affect study conclusions. The authors noted that the 12 month time horizon was an important limitation as any longer term potential cost impact was unclear. Another limitation was that no comparison was made with treatment as usual although the authors argue that the identification and treatment of depressed people with cancer has been shown to be likely to be cost-effectiive by other researchers. The authors conclude that the psychologist led intervention is likely to be cost-effectiive for high distress carers but that for low distress carers the nurse led intervention is more likely to be cost-effectiive.

A cost utility analysis in a Netherlands setting (Vroomen 2016) compared 2 forms of case management with no case management for informal caregivers and people living in the community with dementia. Case management has been defined as a “collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote quality and costeffective outcomes.” (Case Management Society of America, 2015). Case management with ICMM involved the appointment of case managers in a single organisation specialised in dementia care. These case managers provide guidance and support for a long period of time and use their own organisation to provide medical and psychosocial services. There is a collaborative arrangement between the case manager, the organisation multidisciplinary team and the informal care giver. Case management according to LM involves the collaboration of multiple providers of care. Following diagnosis, the case manager provides disease related advice in addition to educational, emotional and practical support. The case manager also gives recommendations on the availability of supportive health and social services. QALYs were based on EuroQol (EQ-5D-3L) reported by the carer, both for themselves and also on behalf of the person they care for with dementia. QALYs were summed for the dyad of carer and the person with dementia. The analysis was undertaken from a societal perspective with costs based on a 2010 price year and reported in Euros. In order to address baseline differences and possible selection bias arising from the non-randomised study design, propensity scores were calculated and used as sampling weights.The study found that ICMMM had the lowest total mean costs but that the differences were not statistically significant at the 5% level. Probabilistic sensitivity analysis suggested that there was a high probability that ICCM was the most cost-effectiive intervention.

A UK economic evaluation (Woods 2016) compared the cost-effectiveness and, as a secondary analysis, the cost utility of reminiscence therapy compared with treatment as usual for people living with mild/moderate dementia in the community and their carers. The intervention was based on the “Remembering Yesterday, Caring Today.” (RYCT) manual and comprised weekly group sessions for 12 weeks followed by 7 maintenance sessions at monthly intervals for the patient/carer dyad. Costing was based on a public sector perspective using a 2010 price year. The primary outcome measure was quality of life for the person with dementia (measured using the Quality of Life in Alzheimer’s Disease scale; QoL-AD) and carer’s mental health (assessed using the General Health Questionnaire). The general quality of life of carer and the person with demential was assessed using EQ-5D-3L as a secondary outcome measure. The study found no statistically significant differences between the intervention and control in the primary outcome measures. The mean cost of the intervention was £9,433 which worked out at £964 per dyad. The ICER was £2,586 per one point change on the QoL-AD scale. A cost per QALY was not calculated as there was a negligible difference in QALYs between the intervention and the control and markedly higher costs for RYCT and the authors reasoned an ICER was not required to demonstrate that the intervention was not cost-effectiive. The authors noted as potential limitations that only 57% of participants attended the group sessions in the intervention arm and that the study withdrawal rate was higher in the treatment as usual control.

Economic model

No economic modelling was undertaken for this review because, although this was identified as a high priority, there were a number of included economic studies for this review. Additionally, because the quantitative evidence was conflicting and condition specific, the committee did not make recommendations that needed modelling to demonstrate evidence of cost-effectiveness.

Evidence statements

Each evidence statement has an identifying code to ensure ease of reference to the data during presentation and committee discussions. The code is derived from the title of the review and in this case is ‘PES’ and then a number. PES stands for (providing) psychological and emotional support to adult carers

Quantitative and qualitative components of the review.

Evidence statements from the included studies are organised by intervention category and then by outcome within each category, starting with quantitative data and then relevant themes from the qualitative studies.

Psychosocial and psycho-educational interventions

Impact of caring on carer

- **PES1** Very low to low quality evidence from 2 RCTs, one from France and one from Denmark, Poland, and Spain, could not differentiate levels of perceived burden on adult carers receiving web-based psycho-educational interventions versus a control condition. Very low quality evidence from 1 RCT, including adult carers of people living with dementias and Alzheimer's disease, could not differentiate levels of burden (Zarit Burden Interview: ZBI) or levels of bother or upset reactions following behaviour problems of care recipients (Revised Memory And Behaviour Checklist: RMBPC) between carers receiving the intervention (that is a web-based psychoeducational program) versus usual care (that is information only) at 6 months follow - up. Low quality from 1 RCT, including adult carers of people living with dementias and Alzheimer's disease, could not differentiate levels of subjective burden (Revised Caregiving Satisfaction Scale: RCCS) in carers receiving the intervention (The UnderstAID Application: Internet course over Dementia) versus usual care (not usage of the application and maintenance of the usual lifestyle) at 3 months follow – up.

- **PES2** Moderate quality evidence from 1 RCT from Australia, including adult carers of people with bipolar disorder, found improved levels of burden (Burden Assessment Scale: BAS) in carers receiving a group-based psycho-educational intervention (that is immediate brief group psycho-education) versus waitlist control condition at 1 month follow - up from intervention completion.
- **PES3** Low quality evidence from 2 RCTs from Spain showed that there was conflicting evidence about the effectiveness of group-based psycho-educational interventions on perceived levels of burden in adult carers of people living with dementia and people with schizophrenia. Low quality evidence from the meta-analysis of these RCTs, including carers of people living with dementia and schizophrenia, could not differentiate levels of burden (Zarit Burden Interview: ZBI) between carers receiving the group-based psycho-educational intervention plus usual care versus usual care only (that is standard support delivered to carers from the day centres or memory clinics where the people living with dementia were treated) at 4 months follow – up. However, low quality evidence from one RCT, including carers of people with schizophrenia, found improved levels of burden (Zarit Burden Interview: ZBI) in carers receiving the same group-based psycho-educational intervention if compared to carers receiving usual care at 8 months follow – up.
- **PES4** Low quality evidence from 1 RCT from Sweden, including carers of people with heart failure, could not differentiate levels of burden –including the sub-dimensions of general strain, disappointment, emotional, and environment (Caregiver Burden Scale: CBS) in carers receiving a dyadic psycho-educational intervention versus usual care (that is focus only on carers' recipients, no intervention for carers) at 24 months follow – up.
- **PES5** Low quality evidence from 1 UK RCT, including carers of people living with dementia, could not differentiate levels of emotional distress (Caregiver Distress Scale of the Neuropsychiatric Inventory: NPI-D), positive aspects of caring (Carers of Older People in Europe Index: COPE index), or subjective burden (Positive scale from the Positive and Negative Affect Schedule: PANAS; Personal Growth Index: PGI; and Quality of Caregiver–Patient Relationship: QCPR) between carers receiving the intervention (that is one-to-one peer support) versus usual care (not described) at 12 months follow – up.

Caring-related morbidity

- **PES6** Moderate quality evidence from 1 RCT from the Netherlands, including adult carers of people living with dementias and Alzheimer's disease, found improved levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) and anxiety (Hospital Anxiety and Depression Scale: HADS-A) in carers receiving a web-based psycho-educational intervention (Internet-based course: Mastery over Dementia - MoD) versus control (that is a minimal intervention consisting of e-bulletins) at 6 months follow - up (from intervention competition).
- **PES7** Very low to low quality evidence from 2 RCTs, one from France and one from Denmark, Poland, and Spain, could not differentiate levels of caring-related morbidity on adult carers receiving web-based psycho-educational interventions versus a control condition. Very low quality from 1 RCT, including adult carers of people living with dementias and Alzheimer's disease, could not differentiate levels of perceived stress (Perceived Stress Scale: PSS), depressive symptoms (Beck Depression Inventory: BDI) or levels of perceived health status (Nottingham Health Profile: NHP) between carers receiving the intervention (a web-based psychoeducational program) versus usual care (information only) at 6 months follow - up. Low quality evidence from 1 RCT, including adult carers of people living with dementias and Alzheimer's disease, could not differentiate levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) in carers receiving the intervention (that is The UnderstAID Application:

Internet course over Dementia) versus usual care (that isnot usage of the application and maintenance of the usual lifestyle) at 3 months follow – up.

- **PES8** Moderate to low quality evidence from 1 UK RCT, including adult carers of people living with dementia, showed that there was conflicting evidence about the impact of specific carer training programmes on caring-related morbidity. This RCT found improved levels of anxiety and depression (HADS-Total score) at 24 months follow-up, anxiety (HADS-anxiety subscale) at 12 and 24 months follow-up, depression (HADS-depression subscale) at 8, 12 and 24 months follow-up, health-related quality of life (QoL-AD) at 24 months follow-up, and mental health (Health Status Questionnaire) at 24 months follow-up in carers receiving a manual-based coping strategy programme (that is START, STrAtegies for RelaTives) versus usual care. However, this RCT could not differentiate levels of reduced carer abusive behaviours with care recipients (Modified Conflict Tactics Scale) 8, 12 and 24 months follow-up, anxiety and depression (HADS-Total score), and mental health status in the short term period follow-up. This professional led training intervention focused on coping skills and was delivered to carers face-to-face and was tailored to carer needs (in relation to the condition of the person being supported).
- **PES9** Moderate quality evidence from a meta-analysis of 2 RCTs, both from Spain and including carers of people living with dementia and schizophrenia, found improved levels of perceived mental health status (General Health Questionnaire: GHQ) in carers receiving a group-based psycho-educational intervention plus usual care versus usual care only (that is standard support delivered to carers from the day centres or memory clinics where the people living with dementia were treated) at 4 months follow – up.
- **PES10** Very low to low quality evidence from 2 RCTs from Australia and Spain, could not differentiate levels of caring-related morbidity on adult carers receiving group-based psycho-educational interventions versus a control condition. Very low quality evidence from one RCT, including carers of people with schizophrenia could not differentiate levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) and perceived mental health status (General Health Questionnaire: GHQ) between carers receiving a group-based psycho-educational intervention plus usual care versus usual care only (that is standard support delivered to carers from the day centres or memory clinics where the people living with dementia were treated) at 4 or 8 months follow – up. Additionally, low quality evidence from a RCT, including adult carers of people with bipolar disorder, could not differentiate levels of depressive symptoms and anxiety (Depression Anxiety and Stress Scale: DASS) between carers receiving a group-based psycho-educational intervention (that is immediate brief group psycho-education) versus a waitlist control condition at 1 month follow - up from intervention completion.
- **PES11** Low quality evidence from 1 RCT from UK, including carers of people living with dementia, could not differentiate levels of depressive symptoms (Hospital Anxiety and Depression Scale – Depression: HADS-D) or anxiety (HADS-A) between carers receiving the intervention (that is one-to-one peer support) versus usual care (not described) at 12 months follow – up.

Social capital

- **PES12** No data reporting on this outcome.

Carer quality of life

- **PES13** Low quality evidence from 1 RCT from UK, including adult carers of people living with dementia, could not differentiate levels of HR-QoL (Quality of Life-Alzheimer's disease - QoL-AD) carers receiving a manual based coping training programme (that is START, STrAtegies for RelaTives) versus usual care at 8, 12 and 24 months follow – up.
- **PES14** Moderate to low quality evidence from 1 RCT from Spain, including carers of people living with dementia, showed that there was conflicting evidence about the impact of a group-based psycho-educational intervention on perceived carer quality of life (Short-

Form Health Survey 12: SF-12). This RCT could not differentiate levels of perceived HR-QoL (in terms of physical function, role physical, bodily pain, vitality, social functioning, role emotional, mental health dimensions) at 4 months follow-up in carers receiving a the psycho-educational intervention versus usual care. However, this RCT found improved levels in the HR-QoL dimension "General health" in carers receiving the psycho-educational intervention versus usual care only (that is standard support delivered to carers from the day centres or memory clinics where the people living with dementia were treated) at 4 months follow – up.

- **PES15** Low quality evidence from 1 UK RCT, including carers of people living with dementia, showed that there was conflicting evidence about the impact of one-to-one peer support on perceived HR-QoL (UK Short Form Health Survey: UK SF-12; and EQ-5D VAS, Visual analogue scale) between carers receiving the intervention (that is one-to-one peer support) versus usual care (not described) at 12 months follow – up.

Carer choice/control/efficacy

- **PES16** Very low to low quality evidence from 2 RCTs, one from France and one from Denmark, Poland, and Spain, could not differentiate levels of carer self-efficacy on adult carers receiving web-based psycho-educational interventions versus a control condition. Very low quality from 1 RCT, including adult carers of people living with dementias and Alzheimer's disease, could not differentiate levels of perceived self-efficacy in obtaining respite, in responding to carers' recipient behaviours, or in controlling upsetting behaviours (Revised Scale for Caregiving Self-Efficacy: RSCS) between carers receiving the intervention (a web-based psychoeducational program) versus usual care (information only) at 6 months follow - up. Low quality evidence from 1 RCT, including adult carers of people living with dementias and Alzheimer's disease could not differentiate levels of perceived competence (Caregiver Competence Scale: CCS) in carers receiving the intervention (The UnderstAID Application: Internet course over Dementia) versus usual care (not usage of the application and maintenance of the usual lifestyle) at 3 months follow – up.
- **PES17** Moderate quality evidence from 1 Australian RCT, including adult carers of people with bipolar disorder, found improved levels of knowledge (Knowledge of Bipolar Disorder Scale) and perceived self-efficacy (Bipolar Self-efficacy Scale) in carers receiving a group-based psycho-educational intervention (that is immediate brief group psycho-education) versus a waitlist control condition at 1 month follow - up from intervention completion.

Qualitative themes

- **PES18 Factors enabling carers to take part in a psychosocial intervention.** There is low quality evidence from 2 UK studies that many adult carers of people living with dementia found the timing of invitations to be critical in enabling them to take part in complex psychological interventions. Many carers attending the START (STrAtegies for RelaTives) programme felt that the time at which they received interventions was central to their experiences. Some of the carers reported that earlier engagement with the coping skills programme would have helped them improve their communication and be better carers. It would also have given them essential information about dementia to help them make major decisions regarding social care. In contrast, other carers who wanted to be engaged with START later felt it would have helped them cope with their relative's later deterioration.
- **PES19 Unhelpful aspects of psychosocial interventions.** There is low quality evidence from 2 UK studies that many adult carers of people living with dementia described time constraints, the impersonal nature of the interventions and the lack of discussion of some topics (for example 'managing aggression'), as the main unhelpful aspects of psychoeducational programs. For example, carers who received a complex psycho-educational programme for relatives of people living witha recent dementia diagnosis (that is Medway 'Carers Course) suggested that 'managing aggression', 'how to manage guilt',

and ‘being tired … on duty 24/7’ were the principal elements missing from the Course, as these topics were not addressed. Other carers of people living with dementia who received a coping skills programme (that is START) felt that their caring and employment responsibilities were major obstacles to put the coping strategies into practice once the protected programme time had finished.

- **PES20 Perceived benefits of psychosocial interventions: acceptance.** There is low quality evidence from 1 UK study that many adult carers of people with advanced cancer reported feelings of reduced distress (weight-related and eating-related) when receiving a psychosocial intervention (including advice on eating well, information provision, reassurance, and support for self-management). In particular they felt the intervention improved their acceptance of the involuntary weight loss and/or eating difficulties experienced by the person they supported.
- **PES21 Perceived benefits of psychosocial interventions: social support, disease understanding, coping, emotional and stress management, and knowledge about support available.** There is moderate quality evidence from 3 UK studies that many adult carers of people with advanced cancer or dementia reported feelings of improved emotional support, disease understanding, coping and stress management, and knowledge about support available, after receiving support from complex psycosocial interventions.

Psychotherapy/counselling (including cognitive behavioural therapy)

Impact of caring on carer

- **PES22** Very low quality evidence from 1 RCT from Switzerland, including carers of people living with dementia, could not differentiate levels of burden (Zarit Burden Interview: ZBI) between carers receiving the intervention (that is cognitive–behavioural group therapy) versus the control condition (that is psycho-education group programme: EDUC) at 2 months follow – up.
- **PES23** Moderate quality evidence from 1 RCT from Spain, including carers with elevated depressive symptoms (including carers of people living with dementia and other conditions), found improved levels of burden (Zarit Burden Interview: ZBI) in carers receiving the intervention (that is cognitive-behavioural programme in a group format) versus the control condition (that is unrestricted access to standard social and health care services for treatment of depression symptoms) at 3, 6 and 9 months follow – up.
- **PES24** Moderate to low quality evidence from 2 RCTs could not differentiate levels of subjective burden between carers receiving the intervention (that is telephone-based cognitive–behavioural therapy) with those receiving the control condition. Moderate quality evidence from 1 RCT from Australia, including carers of people with cancer, could not differentiate levels of perceived positive impact of caring (Post-traumatic Growth Inventory: PTGI) between carers receiving the intervention (that is psychologist-led five-session cognitive behavioural intervention) versus the control treatment (that is nurse-led single-session self-management) at 6 and 12 months follow – up (from intervention completion). Further, low quality evidence from 1 RCT from Spain, including carers of people living with dementia, could not differentiate levels of perceived burden, in terms of ‘dysfunctional thoughts’ (Dysfunctional Thoughts About Caregiving Questionnaire), ‘caregiving experiential avoidance’ (Experiential Avoidance in Caregiving Questionnaire), or (Leisure Time Satisfaction Scale) between carers receiving the intervention (that is individualised cognitive–behavioural therapy) with those receiving the control condition (that is Minimal support: 2-hr workshop, including psycho-education on dementia) at 6 months follow – up (that is from intervention completion).

Caring-related morbidity

- **PES24** Moderate quality evidence from 1 RCT from Spain, including carers with elevated depressive symptoms (including carers of people living with dementia and other conditions), found improved levels of perceived emotional distress (General Health Questionnaire: GHQ) in carers receiving the intervention (that is cognitive-behavioural programme in a group format) versus the control condition (that is unrestricted access to standard social and health care services for treatment of depression symptoms) at 3, 6 and 9 months follow – up.

- **PES25** Low to very low quality evidence from 1 RCT from Switzerland, including carers of people living with dementia, showed that there was conflicting evidence about the effectiveness of group-based cognitive-behavioural therapy interventions on caring-related morbidity for supporting adult carers. Low quality evidence from this RCT found improved levels of anxiety traits (State–Trait Anxiety Inventory, Trait: STAI-T), in carers receiving the control condition (that is psycho-education group programme: EDUC) versus those carers receiving the intervention (that is cognitive–behavioural group therapy) at 2 months follow – up. However, very low quality evidence from the same RCT could not differentiate levels of depressive symptoms (Beck Depression Inventory: BDI), anxiety state (State–Trait Anxiety Inventory, State: STAI-S), or perceived stress (Perceived Stress Scale: PSS) between carers receiving the intervention versus the control condition at 2 months follow – up.
- **PES26** Moderate quality evidence from 1 RCT from Australia, including carers of people with cancer, could not differentiate levels of perceived cancer-specific distress (Impact of Events Scale: IES) or psychological distress (Brief Symptom Inventory: BSI) between carers receiving the intervention (that is psychologist-led five-session cognitive behavioural intervention) versus the control treatment (that is nurse-led single-session self-management) at 6 and 12 months follow – up (from intervention completion).
- **PES27** Moderate to low quality evidence from 1 RCT from Spain, including carers of people living with dementia, showed that there was conflicting evidence about the effectiveness of individualised cognitive-behavioural therapy interventions on caring-related morbidity. Moderate quality evidence from this RCT indicates improved levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) in carers receiving the intervention (that is individualised cognitive–behavioural therapy) with those receiving the control condition (that is Minimal support: 2-hr workshop, including psycho-education on dementia) at 6 months follow – up (from intervention completion). However, the same RCT could not differentiate levels of anxiety (Tension-Anxiety subscale from the Profile of Mood States: POMS) between intervention groups at 6 months follow – up (from intervention completion).
- **PES28** Very low quality evidence from 1 RCT from Germany, including carers of people living with dementia, could not differentiate levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) or perceived health status (Visual Analogue Scale: VAS) between carers receiving the intervention (that is telephone-based cognitive–behavioural therapy) with those receiving the control condition (that is written educational material) at 24 months follow – up.

Social capital

- **PES29** No data reporting on this outcome.

Carer quality of life

- **PES30** Very low quality evidence from 1 RCT from Germany, including carers of people living with dementia, could not differentiate levels of depressive symptoms (World Health Organization quality of life, BREF: WHOQoL-BREF) between carers receiving the intervention (that is telephone-based cognitive–behavioural therapy) versus the control condition (that is written educational material) at 24 months follow – up.

Carer choice/control/efficacy

- **PES31** No data reporting on this outcome.

Qualitative themes

- **PES32 Factors enabling carers to take part in psychotherapy/counselling: information sharing**. There is low quality evidence from 1 UK study that many adult carers of people living with dementia receiving counselling/psychotherapy perceived it as helpful to talk to someone [the therapist] who was not personally involved and felt they got a 'better response'. For example, many carers reported a lack of support from other family members, and the counselling relationship offered a forum to divulge information.
- **PES33 Factors enabling carers to take part in psychotherapy/counselling: professionals.** There is low quality evidence from 1 UK study that many adult carers of people living with dementia felt that the age of the therapist was a factor enabling them to receive counselling/psychotherapy, as they tended to associte age with life experience; whilst they felt that the therapist's counselling/psychotherapy qualifications were not the most important attribute. Carers reported they needed to feel 'comfortable' in the presence of the therapist, and they listed various attributes that they believed were essential to underpin the therapeutic relationship. These included the therapist being open, understanding, friendly, easy to talk to, and 'non- judgemental'.
- **PES34 Perceived benefits of psychotherapy/counselling: self-confidence**. There is low quality evidence from 1 UK study that many adult carers of people living with dementia reported feelings of improved self-trust and self-confidence as a consequence of receiving counselling/psychotherapy. Partly, they felt that the therapeutic relationship provided a 'bridging' relationship following changes in the intimate relationship with the person they support. They also felt more self-confident as a result of the intervention, enabling them to take on new caring roles and manage challenging situations.

Cognitive-/emotion- /activity-based interventions

Impact of caring on carer

- **PES35** Moderate to low quality evidence from 1 RCT from Spain, including carers of people living with dementia, showed that there was conflicting evidence about the effectiveness of acceptance and commitment therapy on carers' subjective burden. Moderate quality evidence from this RCT indicates improved levels of subjective burden, in terms of 'caregiving experiential avoidance' (Experiential Avoidance in Caregiving Questionnaire) in carers receiving the intervention (that is acceptance and commitment therapy) versus the control condition (that is Minimal support: 2-hr workshop, including psycho-education on dementia) at 6 months follow – up (from intervention completion). However, the same RCT could not differentiate levels of subjective burden in terms of 'dysfunctional thoughts' (Dysfunctional Thoughts about Caregiving Questionnaire), or 'leisure' (Leisure Time Satisfaction Scale) between intervention groups at 6 months follow – up (from intervention completion).
- **PES36** Low quality evidence from 2 UK RCTs could not differentiate levels of subjective burden between carers receiving the intervention (that is reminiscence therapy) with those receiving the control condition. Low quality evidence from 1 RCT, including carers of people living with dementia, could not differentiate levels of emotional distress (Caregiver Distress Scale of the Neuropsychiatric Inventory: NPI-D), positive aspects of caring (Carers of Older People in Europe Index: COPE index), or subjective burden (Positive scale from the Positive and Negative Affect Schedule: PANAS; Personal Growth Index: PGI; and Quality of Caregiver–Patient Relationship: QCPR) between carers receiving the intervention (that is reminiscence therapy) versus usual care (not described) at 12 months follow – up. In addition, low quality evidence from the other UK RCT, including 487 carers of people living with dementia, could not differentiate levels of subjective burden (QCPR) between intervention groups (that is reminiscence therapy and usual care) at 3 and 10 months follow – up.

- **PES37** Low quality evidence from 1 RCT from Japan, including carers of people living with dementia, found improved levels of burden (Zarit Burden Interview: ZBI) in carers receiving the intervention (that is leisure activity program: 30 minutes x 3 times/week for 24 weeks) versus the usual care (not clear: "normal care activities") at post-intervention follow – up.

Caring-related morbidity

- **PES38** Low quality evidence from 1 RCT from Spain, including carers of people living with dementia could not differentiate levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) and anxiety (Tension-Anxiety subscale from the Profile of Mood States: POMS) between carers receiving the intervention (that is acceptance and commitment therapy) versus the control condition (that is Minimal support: 2-hr workshop, including psycho-education on dementia) at 6 months follow – up (from intervention completion).
- **PES39** Low quality evidence from 2 UK RCTs could not differentiate levels of caring-related morbidity between carers receiving the intervention (that is reminiscence therapy) with those receiving the control condition. Low quality evidence from 1 RCT, including carers of people living with dementia, could not differentiate levels of depressive symptoms (Hospital Anxiety and Depression Scale – Depression: HADS-D) or anxiety (HADS-A) between carers receiving the intervention (that is reminiscence therapy) versus usual care (not described) at 12 months follow – up. In addition, low quality evidence from the other UK RCT including 487 carers of people living with dementia, could not differentiate levels of depressive symptoms (Hospital Anxiety and Depression Scale – Depression: HADS-D), anxiety (HADS-A), perceived mental health status (General Health Questionnaire: GHQ), or perceived distress (Relatives Stress Scale: RSS) between intervention groups (that is reminiscence therapy and usual care) at 3 and 10 months follow – up.
- **PES40** Low quality evidence from 1 UK RCT from UK, including carers of people with psychosis, showed that there was conflicting evidence about the effectiveness of written emotional disclosure on carers’ caring-related morbidity. Low quality evidence from this feasibility mixed-methods RCT indicates improved levels of perceived physical health (RAND 36-item Health Survey) in carers receiving the intervention versus the control condition (that is ‘neutral writing task’) at 3 months follow – up (from baseline). However, the same RCT could not differentiate levels of subjective carers’ caring-related morbidity in terms of psychological well-being (Patient Health Questionnaire, PHQ-9), Physical and psychological well-being (Caregiver Wellbeing Support Scale), depression andanxiety (Hospital Anxiety and Depression Scale), or perceived mental health (RAND 36-item Health Survey) between intervention groups at 3 months follow – up (from baseline).

Social capital

- **PES41** No data reporting on this outcome.

Carer quality of life

- **PES42** Low quality evidence from 2 UK RCTs could not differentiate levels of HR-QoL between carers receiving the intervention (that is reminiscence therapy) with those receiving the control condition. Low quality evidence from 1 RCT, including carers of people living with dementia, could not differentiate levels of perceived HR-QoL (UK Short Form-12 Health Survey: UK SF-12; and EQ-5D VAS, Visual analogue scale) between carers receiving the intervention (that is one-to-one peer support) versus usual care (not described) at 12 months follow – up. In addition, low quality evidence from the other UK RCT, including carers of people living with dementia, could not differentiate levels of carers’ HR-QoL (EQ-5D VAS) between intervention groups (that is reminiscence therapy and usual care) at 3 and 10 months follow – up.

- **PES43** Low quality evidence from 1 Australian RCT, including carers of people living with dementia, could not differentiate levels of perceived HR-QoL (Assessment of Quality of Life 8-dimension: AQoL-8D) between carers receiving the intervention (that is 12-week transcendental meditation training program plus 12-week follow-up: TRANSCENDENT) versus the control group (that is 24-week wait-list control) at 12 weeks follow – up.

Carer choice/control/efficacy

- **PES44** No data reporting on this outcome.

Qualitative themes

- **PES45 Perceived benefits of acceptance and commitment therapy (ACT): reinforcing existing perspectives on coping, acceptance, personal awareness, and peer support.** There is low quality evidence from 1 UK study that many adult carers of people with acquired brain injury attending ACT reported beneficial aspects of mutual social support, self-acceptance, personal awareness and coping. Following the ACT programme, many carers reported feelings of improved personal awareness regarding their emotional experiences as carers (that is of the physical and mental symptoms of stress and the interplay between these two). Some of these carers felt that the self-awareness achieved in the programme had been difficult and painful at times. This appeared to represent a process of uncovering difficult feelings that perhaps some participants had been making efforts to suppress. Other carers attending ACT described how different metaphors had helped them to engender greater self-acceptance. For example, one carer discussed acceptance of thoughts as they occur, and appeared to be describing a skills development process regarding mindful awareness. In contrast, other carers discussed their own strategies, which, for them focused on attempts to avoid difficult thoughts and feelings; these carers did this by keeping busy, and by trying to think about unrelated matters. Some carers viewed the course as reinforcing existing perspectives on coping; in contrast, other carers reported difficulty deciding whether to implement some of the principles outlined in the programme.
- **PES46 Perceived benefits of reminiscence therapy: interpersonal relationship with the cared for, peer support, and reassurance.** There is low quality evidence from 1 UK study that many adult carers reported that by gaining practical coping strategies this increased their confidence in dealing with similar situations in the future. Learning and comparing coping strategies with each other, enabled carers attending ‘remembering yesterday caring today’ (RYCT) to perceive many beneficial effects. They reported positive feelings regarding receiving and experiencing supportive relationships with other carers. This was considered especially important for carers who reported feelings of isolation, identifying that meeting other carers reduced feelings of loneliness. Other carers reported that being with carers who had similar experiences provided a space where such behaviours were considered ‘normal’ and did not draw unwanted attention and allowed them to relax. Finally, most carers attending RYCT reported feelings of improved shared experience which carers could use to create ‘fresh’ discussions with their relative. Through reminiscing, some carers learnt new information about their relatives’ lives; this also promoted new areas of conversation. The time spent with the person they support was described as ‘quality time’, in contrast to time outside the sessions which is focussed on practical day-to-day tasks.
- **PES47 Perceived benefits of body-oriented psychological therapy (circle dancing): personal awareness and peer support.** There is very low quality evidence from 1 UK study that many adult carers of people living with dementia attending circle dancing (as body-oriented psychological therapy) felt the group helped them to acknowledge the reality of the dementia diagnosis and process their feelings about the person they support (for example grief, and loss). These carers reported that before the circle dancing group the burden of care often meant that they focused predominantly on the problems but that participation in the group helped them to re-connect with the person they support.

- **PES48 Factors enabling carers to receive written emotional disclosure (WED): lack of time.** There is low quality evidence from 1 UK study that many adult carers of people with psychosis felt that the writing stimulated negative emotions. They reported that lack of time featured as a reason not to attend the writing interventions. Other carers commented on the concentration required to write recommending that it should be done at the start of the day when it is easier to concentrate.
- **PES49 Perceived benefits of WED: stress relieving.** There is low quality evidence from 1 UK study that many adult carers of people with psychosis reported feelings of reduced stress as a consequence of writing (either therapeutic or non-therapeutic). For these carers, writing created an opportunity to escape routine responsibilities, with 'time for myself', relaxation and enjoyment.

Low-level/informal and other support interventions

Impact of caring on carer

- **PES50** No data reporting on this outcome.

Caring-related morbidity

- **PES51** No data reporting on this outcome.

Social capital

- **PES52** No data reporting on this outcome.

Carer quality of life

- **PES53** No data reporting on this outcome.

Carer choice/control/efficacy

- **PES1** No data reporting on this outcome.

Qualitative themes

- **PES54 Perceived benefits of art therapy: personal awareness, social and emotional support.** There is low quality evidence from 1 UK study that many adult carers of people with mental health issues who used art therapy (that is art viewing, art-making, and audio recording) felt valued as a carer by being helped to decrease the sense of stigma and social isolation. Other carers who used art therapy felt the intervention helpful to externalise their problems as individuals or families. Most of these carers felt that looking at art in a group elicited strong emotions connected with their individual identities as carers, improving their personal awareness.
- **PES55 Factors enabling carers to attend 'dementia cafés': dementia café co-ordinators.** There is 1 quality evidence from one UK study that many adult carers of people living with dementia attending 'dementia cafes' felt that café co-ordinators made an important contribution to their experiences and they valued particular personal attributes (being emotionally intelligent, approachable, and open).
- **PES56 Perceived benefits of 'dementia cafés': social and emotional support.** There is low quality evidence from 1 UK study that many adult carers of people living with dementia attending 'dementia cafes' felt a very helpful aspect of attending cafés was being able to compare themselves with other carers. In particular, these carers felt that cafes were places where they could hear how other carers coped in similar situations and they could ask each other for adviceSome carers felt that attending cafés helped to reduce social isolation, and they reported that going to a café and being with other people helped them to feel connected with others. Other carers reported feelings of enjoyment and relaxation. Some of them found that in the cafes it was normal and acceptable to be a carer. They enjoyed participating in activities at the cafes which were unrelated to dementia (for example, chatting and singing)

- **PES57 Factors enabling carers to attend music therapy: professional facilitators.** There is low quality evidence from 1 UK study that many adult carers of people living with dementia receiving support from music therapy ('group singing model in dementia for couple dyads') felt that being an active part of the singing group was very helpful. They found that effective group facilitators were key to this and without them further benefits of group singing were not experienced. They described ‘encouraging participation’, ‘person-centeredness’, and ‘equality’ as part of the role of an effective group facilitator.
- **PES58 Perceived benefits of music therapy: emotional support.** There is low quality evidence from 3 UK studies that many adult carers of people living with dementia experienced enjoyment, stimulation and emotional support from music therapy programmes. For example, carers attending 'group singing model in dementia for couple dyads' felt positive about the pleasure and enjoyment derived from singing, even in cases where the overall group singing experience was not enjoyed. Carers attending SftB ('Singing for the Brain') program also felt that the programme had a positive impact on their mood and well-being, by stimulating and regulating emotions, providing enjoyment and relieving stress. Finally, carers of people living with dementia attending a 'Singing Together Group' felt the experience of singing in a group was very important, reporting enjoyment and stress relief.
- **PES59 Perceived benefits of music therapy: social support.** There is low quality evidence from 3 UK studies that many adult carers of people living with dementia experienced improved social support and reduced social isolation throughmusic therapy programmes. For example, carers attending a 'group singing model in dementia for couple dyads' reported feelings of increased belonging to a social group, shared experience, and developing a group identity. Carers of people living with dementia using the SftB programme also reported feelings of improved social support and inclusion. Other carers attending a 'Singing Together Group' reported enjoying the atmosphere of the group, the venue, the music facilitator and other carers, indicating a sense of security and belonging. In particular, many cares reported feelings of improved social inclusion, being able to meet other carers in the same situation, going through the same life experiences and having the opportunity to focus on something other than illness, doctor visits and diagnosis.

Family interventions

Impact of caring on carer

- **PES60** No data reporting on this outcome.

Caring-related morbidity

- **PES61** No data reporting on this outcome.

Social capital

- **PES62** No data reporting on this outcome.

Health-Related Quality of Life

- **PES63** No data reporting on this outcome.

Carer choice/control/efficacy

- **PES64** No data reporting on this outcome.

Qualitative themes

- **PES65 Factors enabling carers to attend family interventions: professionals**. There is low quality evidence from 1 UK study that many adult carers of people with eating disorders who received family interventions (either individual family work [IFW] or family day workshops [FDW]) reported conflicting views on their relationships with the professionals facilitating the interventions. Some carers felt that their relationship with professionals was extremely valuable. Other carers reported feeling judged or blamed by the professionals facilitating the sessions, expressing dissatisfaction and questioning their qualifications.

- **PES66 Factors enabling carers to attend family interventions: structure and components of family interventions**. There is low quality evidence from 1 UK study that many adult carers of people with eating disorders who received family interventions reported several factors that would enable them to access these interventions. Most of them, for example, found that the main barrier to attending the sessions was their duration - –they felt shorter sessions would have been more manageable. Other carers reported mixed feeling about the components of family work (either IFW or FDW) for example family sculpture, the therapeutic writing task, family meal and psycho-education/skills training. While for some carers, the act of writing and sharing the letter was perceived as painful but was also an emotional release (specially to hear different family members' perspectives); other carers found it intrusive and embarrassing to hear the personal accounts of the other family members. Finally, some carers felt the family meal provided a sense of normality around the preparation and sharing of meals; and other carers found the experience tense, anxiety-provoking 'false' and only feasible in a hospital setting.
- **PES67 Perceived acceptability of family interventions: when, how, and where**. There is low quality evidence from 1 UK that many adult carers of people with eating disorders who received family interventions (either IFW or FDW) reported mixed views on when and how the intervention should be presented to them. Some carers responded negatively to the manner in which family work was introduced and were very defensive from the outset – they were reluctant to take time off work and did not want to burden other family members. Many of these carers reported mixed views on where the intervention should be held. Some carers felt the setting (a room on the inpatient unit) was a 'safe and controlled' environment in which to explore difficult and sensitive family issues. Other carers perceived the setting as too contrived and artificial.
- **PES68 Perceived benefits of family interventions: disease understanding, emotional and social support**. There is low quality evidence from 1 UK study that many adult carers of people with eating disorders who received family interventions reported feelings of improved communication, disease knowledge, social support, and empowerment. Many carers felt that following the intervention they communicated more effectively and were able to address difficult issues and emotions which they would have otherwise avoided. Other carers improved their knowledge of the disease of their relative, making them more optimistic.

Multi-component interventions

Impact of caring on carer

- **PES69** Moderate quality evidence from 1 RCT from the Netherlands, including carers of people living with amyotrophic lateral sclerosis, could not differentiate levels of perceived strain (Caregiver Strain Index: CSI) between carers receiving the intervention (that is case management at the individual participant level, based on a patient advocacy case management model) versus usual care (that is neuropalliative care by multidisciplinary, secondary care teams, plus community and social services –including general practitioners, district nurses, home care services, paramedics, social workers, and voluntary workers) at 4, 8, and 12 months follow – up.
- **PES70** Very low to low quality evidence from 1 RCT from the Netherlands, including carers of people living with dementia, showed that there was conflicting evidence about the effectiveness of a multi-component dyadic intervention (including 8 home visits with coach, physical exercise, and psycho-education and communication skills training) on carers' burden. Low quality evidence from this RCT indicates improved levels of bother or upset reactions following behaviour problems of care recipients (Revised Memory and

Behaviour Checklist: RMBPC) in carers receiving the multi-component intervention versus the usual care (that is information only) at 6 months follow – up. However, very low quality evidence from the same RCT could not differentiate levels of bother or upset reactions following behaviour problems of care recipients (RMBPC) between intervention groups at 3 months follow – up, or subjective burden (Self-Perceived Pressure from informal Care: SPICC) at 3 and 6 months follow – up. Furthermore, very low quality evidence from this RCT could not differentiate levels of subjective burden (Self-perceived Pressure from Informal Care: SPICC) at 3 and 6 months follow – up between intervention groups.

- **PES71** Low quality evidence from 1 RCT, including carers of people living with dementia, could not differentiate levels of subjective burden (Quality of Caregiver–Patient Relationship: QCPR) between carers receiving the intervention (that is reminiscence therapy combined with one-to one peer support) versus usual care (not described) at 12 months follow – up.

Caring-related morbidity

- **PES72** Very low quality evidence from 1 RCT from the Netherlands, including carers of people living with dementia, could not differentiate levels of depressive symptoms (Center for Epidemiologic Studies Depression Scale: CES-D) between carers receiving the intervention (that is multi-component dyadic intervention: including 8 home visits with coach, physical exercise, and psycho-education and communication skills training) versus the usual care (that is information only) at 3 and 6 months follow – up.

Social capital

- **PES73** No data reporting on this outcome.

Health-Related Quality of Life

- **PES74** No data reporting on this outcome.

Carer choice/control/efficacy

- **PES75** No data reporting on this outcome.

Qualitative themes

- **PES76 Factors predisposing carers to seek support from Maudsley Method Skills-based Workshops: structure of the Workshops**. There is very low quality evidence from 1 UK study that many adult carers of people with eating disorders who attended Maudsley Method Skills-based Workshops (including cognitive remediation therapy, mindfulness, and acceptance and commitment therapy) reported negative feelings with the use of role play and the use of too “detailed slides”.
- **PES77 Perceived benefits of Maudsley Method Skills-based Workshops: personal awareness and social support**. There is very low quality evidence from 1 UK study that many adult carers of people with eating disorders who attended Maudsley Method Skills-based Workshops (including cognitive remediation therapy, mindfulness, and acceptance and commitment therapy) reported feelings of improved social support, skills and self-awareness.
- **PES78 Perceived benefits of a complex coping skills course (based on the cognitive behavioural approach): understanding, coping, stress management, and knowledge about support available.** There is low quality evidence from 1 UK study that many adult carers of people with stroke who followed a coping skills course (based on the cognitive behavioural approach - including information, emotional adjustment, stress management, and enhancing self-efficacy and self-worth) reported feeling more optimistic and empowered as a result. They found that the course was beneficial in terms of information about stroke and available services, problem solving, meeting other carers, giving and receiving support, relaxation skills, and knowledge about financial support available.

- **PES79 Perceived benefits of a complex carer support service (including individual and group psycho-education, practical advice and emotional support): personal awareness, psychological and emotional support.** There is very low quality evidence from 1 UK study that many adult carers of people with psychosis who useda multicomponent carer support service (including individual and group psychoeducational, practical advice and emotional support) reported many psychological benefits at the end of the course (for example, self-awareness, reduced distress, social support, emotional coping, and peer support).

Economic component of the review

- **PES80** One partially applicable cost-utility analysis from the UK found that START (STrAtegies for RelaTives), a psychosocial intervention, was cost-effective for carers of people living with dementia. With an incremental cost-effectiveness ratio of £11,200 per QALY. This analysis is characterised by minor limitaions.
- **PES81** One partially applicable cost analysis reported net savings from CBT for carers groups. This analysis is characterised by very serious limitations.
- **PES82** One partially applicable cost-utility analysis from Australia found that a cognitive behavioural intervention of telephone counselling led by a psychologist was cost-effective for high distress carers of people with cancer but not for carers with low distress. This analysis is characterised by potentially serious limitations.
- **PES83** One partially applicable cost-utility analysis found that the Intensive Case Management Model was cost-effective for carers of people living with dementia, dominating the Linkage model of case management and no case management. This analysis is characterised by minor limitations.
- **PES84** One partially applicable found that reminiscence groups based on the “Remembering Yesterday Caring Today” manual was not cost-effective for carers of people living with dementia being dominated by treatment as usual. This analysis is characterised by minor limitations.

The committee’s discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This evidence review includes both qualitative and quantitative outcomes. Evidence on most of the outcomes considered during protocol development was identified.

The impact of caring on carers (including resilience, distress, and burden) and caring-related morbidity (including physical and mental health) were considered to be of critical interest for drafting recommendations. Carer choice/control/efficacy, carer quality of life and social capital (that is the range of social contact that provides access to social/emotional/practical support) were considered to be the important outcomes. Quantitative evidence was identified in relation to both critical outcomes, except in relation to the following two clusters of interventions: low-level/informal support interventions (for example helpline or relatively unstructured support, such as art or music therapy); and interventions to maintain or create new relationships or support networks (for example family interventions). Furthermore, no study reported social support.

The committee focussed their discussion mainly on 6 qualitative outcomes (or themes), including the predisposing, enabling, and impeding factors for carers to receive psychological and emotional support for the six clusters of interventions considered for the quantitative evidence: theme 1) psychosocial or psychoeducational support (including factors enabling carers to take part in a psychosocial interventions, unhelpful aspects of psychosocial interventions, and perceived benefits of psychosocial interventions); theme 2) psychotheraputic and counselling interventions (including factors enabling carers to take part in psychotherapy/counselling, and perceived benefits of psychotherapy/counselling); theme 3) cognitive/emotion/activity-based interventions (including perceived benefits of reminiscence therapy, perceived benefits of body-oriented psychological therapy [circle dancing], factors enabling carers to receive written emotional disclosure [WED], and perceived benefits of WED); theme 4) low-level/informal support interventions (including perceived benefits of art therapy, factors enabling carers to attend ‘dementia cafés’, perceived benefits of ‘dementia cafés’, factors enabling carers to attend music therapy, and perceived benefits of music therapy); theme 5) family interventions (including factors enabling carers to attend family interventions, perceived acceptability of family interventions, and perceived benefits of family interventions); and theme 6) multicomponent interventions (including factors predisposing carers to seek support from Maudsley Method Skills-based Workshops, perceived benefits of Maudsley Method Skills-based Workshops, perceived benefits of a complex coping skills course based on the cognitive behavioural approach, and perceived benefits of a complex carer support service).

The quality of the evidence

In terms of quantitative evidence, 20 RCTs were included in the review. The quality of the quantitative evidence was assessed using the GRADE methodology. The quality of evidence from these twenty studies ranged from very low to moderate, and covered most areas considered during protocol development (including psychosocial or psychoeducational support, cognitive behavioural therapy, cognitive/emotion/activity-based interventions [that is WED], and multicomponent interventions [that is case management]). The quality of the evidence across all outcomes was commonly downgraded because of design limitations (risk of bias) of the included RCTs and high to very high rates of imprecision in the effect estimates, due to the small number of events/participants. Most often, design limitations in the studies were due to the unclear risk of selection bias regarding either random sequence generation or the allocation concealment, unclear to serious risk of performance or detection bias (with many RCTs not blinding the treatment allocation of included carers and / or outcome assessors); and potential selective reporting of findings (with many RCTs not reporting their research protocol and using customised outcome measures, making it difficult to assess whether outcome reporting was sufficiently complete and transparent to protect against bias). Also, the small sample size and its convenience nature in most included studies, along with the lack of the discussion in relation to the statistical power, were considered to be major methodological issues.

Seventeen studies were included in the qualitative component of the review. The quality of evidence for the various themes identified in the qualitative review ranged from very low or moderate, according to GRADE-CERQual. The committee agreed that the data from the included studies were applicable across the UK population of adult carers. It was also noted by the committee that the populations of carers in the studies were mixed (in terms of age, gender, and conditions of people being supported), and the data were highly adequate (in terms of richness and quantity). The quality of the included qualitative evidence was mostly downgraded due to design limitations in the studies (for example recruitment, data collection and analysis methods, and lack of disclosure of the relationship between researcher and participants).

Synthesis of quantitative and qualitative data

During their discussion of the evidence, the committee synthesised the quantitative and qualitative data, making judgements about the extent to which the combined findings could be used as a basis for recommendations.

For psychosocial or psychoeducational support interventions, both quantitative and qualitative data were located. Whilst there was some quantitative data to support the use of psychosocial or psychoeduational interventions, including evidence used to support recommendations in other NICE guidance, the overall evidence was not conclusive. Whilst based on their knowledge and experience the committee considered that such interventions were likely to be of benefit, they accepted that the quantitative evidence was mixed and not sufficiently clear to warrant a strong recommendation. Therefore, they used the data and their knowledge and experience to inform a recommendation that psychosocial or psychoeducational support be considered for carers. They used the qualitative data in order to specify the important elements of that support. Also on the basis of qualitative data, they specified that this support should be available in a group format and that the timing of support should be tailored to the carers' needs and circumstances.

In relation to psychotherapy/ counselling, quantitative evidence in relation to carers of people living with dementia was conflicting and qualitative evidence was low quality. With these combined findings in mind, and based on their knowledge and experience, the committee therefore agreed not to recommend the intervention for carers in general but instead, when a mental health problem has been identified, which is in line with existing NICE guidance.

The quantitative evidence in relation to cognitive or emotion oriented or activity based interventions as well as multi-component interventions was also conflicting. Although related qualitative data suggested beneficial aspects, the low quality of the evidence led the committee to disregard these synthesised data.

Although there was no quantitative data about the effectiveness of low level support and family interventions, the qualitative data suggested a range of benefits experienced by carers. However, with concerns about the confidence in the qualitative review findings, combined with the lack of effectiveness data, the committee did not draft recommendations in these areas.

Benefits and harms

The committee did not recommend further research in the areas not covered by the evidence (for example about the lack of quantitative data on low-level/informal support interventions, family interventions or the paucity of quantitative data on the outcome 'social support'), because they were not considered as priorities compared with other gaps identified during development.

Psychosocial or psychoeducational support

There were both quantitative and qualitative data about psychosocial or psychoeducational support interventions for carers, covering carers with a range of caring needs or circumstances.

Based on quantitative evidence, the committee discussed that psychosocial or psychoeducational support was important to carers and helped improve levels of anxiety, depression and health related quality of life. The committee noted that qualitative evidence (which was of moderate quality and about carers with different needs and circumstances) supported these findings. According to the qualitative evidence many carers reported feelings of improved emotional support, disease understanding, coping and stress management, and knowledge about available support, after receiving psychosocial or psychoeducational support. These findings were also in accordance with the committee's experience. Based on the combined quantitative and qualitative evidence and strengthened by the committee's expertise the committee considered that carers' psychosocial or psychoeducational support should include a variety of elements to improve psychological and emotional wellbeing: such as developing personalised strategies, building carer skills, advice on how to look after their own physical and mental health and their emotional and spiritual well-being, and information about emotional support services and psychological therapies for carers and how to access them.

Other factors were also considered relevant to and important for psychosocial and psychoeducational support such as education about the condition, training to help them provide care, and advice on planning for the future. However these were viewed as better suited for merging with recommendations based on the findings in Evidence Report E (Training for carers).

The quantitative evidence led the committee to discuss the importance of ensuring group-based opportunities in delivering psychosocial or psychoeducational support for carers. A large body of relatively good quality evidence , from diverse settings and including various carers' circumstances, indicated that carers receiving group-based psychosocial or psychoeducational support improved levels of impact of caring, morbidity, and levels of choice/control/efficacy. The evidence chimed with the committees' experience and they also noted that the qualitative findings about the carers' perceived benefits of psychosocial interventions supported the quantitative findings. In addition, based on the qualitative evidence, they noted that carers perceived improved social support, reduced social isolation, and improved emotional awareness, when psychological interventions were delivered in a group. Therefore, based on the strength of both quantitative and qualitative evidence, the committee recommended that the range of psychosocial or psychoeducational support offered to carers should include group-based options, to ensure that carers could improve their self-esteem, understanding and expectations of the caring role, besides improving their caring-related morbidity and self-efficacy.

In addition, some qualitative evidence showed that many carers found the timing of interventions to be critical in enabling them to take part in psychological interventions. In particular, many carers attending the START (STrAtegies for RelaTives) programme felt that the time at which they received interventions was central to their experiences; with some of them reporting that earlier engagement with the psychological programme would have helped them improve their communication skills and be better carers, and others who wanted to be engaged with START later on felt it would have helped them cope with the deterioration of their relative's condition or abilities. The committee agreed with these findings, and in order to improve carers' acceptability and uptake of psychosocial or psychoeducational support they recommended that the timing of the support should be tailored and customised to suit carers' circumstances, taking into account other commitments such as work and other caring responsibilities. Also, based on their knowledge, the committee agreed that the timing of support should fit with the carers' changing needs during different stages of the caring experience. An emphasis was placed upon regularly asking carers whether they feel they would benefit from psychological and psychoeducational support.

Based on their knowledge and experience, the committee noted that professionals involved in offering psychosocial or emotional support to carers should take account of a variety of elements to ensure the suitability of the support to the carer's circumstances (including for example the carer's preferred location, family responsibilities, whether they need support to attend, physical accessibility, the carer's preferred format, the cultural appropriateness of the intervention and the follow-up that may be needed).

Psychotheraputic and counselling interventions (including cognitive behavioural therapy)

All the reviewed evidence on the effectiveness of psychotherapy/counselling to improve carers' outcomes was focussed on cognitive behavioural therapy for carers of people living with dementias or Alzheimer's disease. Also, the committee noted that for this topic there was conflicting evidence about the effectiveness of cognitive-behavioural therapy interventions on all outcomes, either critical or important. Additionally, the committee did express concern that the qualitative findings from this area of the review were low quality, and only covered some specific carers' circumstances (that is carers of people living with dementias or Alzheimer's disease). Hence, based on the limited body and strength of the evidence, the committee agreed not to draft any recommendations on psychotherapy/counselling (including cognitive behavioural therapy). However, they agreed it was important to support carers of people with identified mental health problems, by providing them with effective and tailored emotional support. Based on their knowledge and experience, the committee agreed to recommend interventions in line with existing NICE guidelines, to provide psychotherapy and counselling to carers with mental health problems. In particular they discussed two relevant NICE guidelines; Depression in adults (CG90) and Post-traumatic stress disorder (NG116)

Cognitive-/emotion-oriented/activity-based interventions

The quantitative evidence showed that there were conflicting findings about the effectiveness of cognitive/emotion-oriented/activity-based interventions (including acceptance and commitment therapy, reminiscence therapy, leisure activity therapy, and a transcendental meditation training programme) on carers' burden, carers' caring-related morbidity, and on carers' quality of life. However, qualitative evidence on this area of the review showed that many carers attending such interventions reported beneficial aspects of mutual social support, self-acceptance, personal awareness and coping. The committee did express concern that the quality of this evidence ranged from very low to low quality, which made it difficult to draft recommendations. The committee therefore did not draft any recommendations relating to this area of the evidence review.

Low-level/informal and other support interventions

No evidence was identified about the effectiveness of low-level/informal support interventions to improve carers' outcomes. However, qualitative evidence showed that many carers felt there were very helpful aspects of attending low-level/informal support interventions (including art therapy, music therapy, or 'dementia cafés') including being able to compare themselves with other carers, being helped to decrease the sense of stigma and social isolation, improved social support and reduced social isolation. The committee did express concern that this evidence only referred to very specific carers' circumstances (for example carers of people living with dementia) and it was low quality. The committee therefore did not draft any recommendations on this area of the evidence review.

Family interventions

No evidence was identified about the effectiveness of family interventions to improve carers' outcomes. However, qualitative evidence showed that many carers reported very helpful aspects of family interventions (including individual or family day workshops) such as improved communication, disease knowledge, social support, and empowerment. The committee did express concern that this evidence only referred to very specific carers' circumstances (for example carers of people with eating disorders) and that it was low quality. The committee therefore did not draft any recommendations on this area of the evidence review.

Multicomponent interventions

The quantitative evidence showed conflicting findings about the effectiveness of multicomponent interventions (including either case management at the individual carer level, or home visits with coach combined with physical exercise, plus psycho-education and communication skills training) on carers' burden, carers' caring-related morbidity, and on carers' quality of life. However, qualitative evidence showed that many carers attending such interventions reported beneficial aspects of mutual social support, self-acceptance, and personal awareness. The committee nevertheless expressed concern that the quality of this evidence ranged from very low to low quality, which made it difficult to make recommendations. The committee therefore did not draft any recommendations on this area of the evidence review.

Cost effectiveness and resource use

The committee noted that there was included economic evidence on psychosocial or psychological intervention, psychotherapy/counselling (including cognitive behavioural therapy), cognitive/emotion based interventions and multicomponent interventions.

The committee noted that the START intervention provided evidence for the cost effectiveness of psychosocial or psychological interventions to support adult carers. However, they also noted that this intervention was targeted specifically at those caring for people with dementia and was therefore too condition specific to be recommended within this guideline. The committee were aware that the NICE Dementia guideline (NG97) had also chosen not to recommend START as a specific intervention, but rather as a basis for the type of topics that should be covered by this type of intervention. Therefore the committee made the decision that it would be cost-effective to adapt the recommendation in NG97 so they would be applicable to all adult carers. The committee noted that there is considerable regional variation in the psychosocial and psychoeducational support available for carers, and agreed that these recommendations could lead to an increase in take-up and demand. However, the committee believed that such programmes would help reduce future mental health problems in the carer with important benefits for the well-being of both the carer and the person being cared for, as well as on demand for expensive mental health services.

The committee considered the 2 included economic studies on psychotherapy/counselling interventions (including CBT). Whilst 1 study suggested that substantial net cost savings were possible, this was a poor quality economic analysis underpinned by a non-randomised study design with a high risk of bias and focusing on carers with dementia. Whilst the other included study was of higher quality it did not include usual treatment as a comparator and was concerned only with carers of high distress care recipients with cancer.Therefore the committee did not think the reviewed economic evidence would support cost-effective recommendations for this area of the guideline. More generally the committee noted that the quantitative evidence on psychotherapy interventions related to carers of people with dementias or Alzheimer’s disease and that there was conflicting evidence on effectiveness. However, they were aware of existing NICE guidelines (CG90 and NG116) which recommended providing emotional support to carers with mental health problems and therefore they made a similar recommendation for adult carers indentified with mental health problems.

The one included economic study on a cognitive/emotion based intervention reported that it was not cost-effective. The committee noted that the population was adult carers for people with dementia and was not therefore necessarily generalisable to all adult carers. However, other quantitative evidence reviewed gave conflicting evidence with respect to the effectiveness of cognitive/emotion based interventions and therefore the committee was of the view that there was not cost-effectiveness evidence which would support recommendations in this area of the guideline and no recommendations were drafted.

Whilst the committee noted that there was a study that suggested a multicomponent intervention was cost-effective they took into account that the intervention was targeted at people with dementia and their carers. Futhermore, the committee considered that the interventions reflected a Netherlands setting and were not easily generalisable to an English setting. As the broader quantitative review undertaken for this guideline indicated conflicting evidence with regard to the effectiveness of multicomponent interventions, the committee did not think there was sufficiently robust cost effectiveness evidence to make recommendations.

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Unadkat S, Camic PM, Vella-Burrows T. Understanding the Experience of Group Singing for Couples Where One Partner Has a Diagnosis of Dementia. Gerontologist 2017;57(3):469-478.

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Appendices

Appendix A – Review protocols

Review protocol for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Table 5: Review protocol

Field (based on PRISMA-P)	**Content**
Review question	What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?
Type of review question	Systematic mixed studies review
Objective of the review	The objective of this review is to establish whether there are any types of psychological or emotional support interventions for adult carers that are effective, cost-effective, and acceptable to them.
Eligibility criteria – population/disease/condition/issue/domain	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • Relevant social-/health- care and other practitioners involved in providing care.
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Any psychological or emotional support intervention whose primary aim is to provide support to adult carers, including: • Psychosocial interventions (for example skills building, self-help, self-management/coping skills/peer support) • Psychotherapy/counselling (for example cognitive behavioural therapy or similar, relationship counselling) • Cognitive-/emotion-oriented/activity-based interventions • Low-level/informal and other support interventions (for example helpline or relatively unstructured support; befriending/buddy programs) • Interventions to maintain or create new relationships or support networks (for example family interventions)

Field (based on PRISMA-P)	**Content**
	• Multicomponent (for example case/care management) interventions (that is those that address more than one carer domain such as maintenance of relationships, disease education, safety, carer health and wellbeing) • Interventions to support carer in caring for person at end of life (for example grief or bereavement counselling) and/or after the person receiving care dies, including anticipatory grief Themes from the qualitative evidence regarding views and experiences of adult carers, and related professionals, may include: • Satisfaction with the intervention • Perceived appropriateness of the intervention • Perceived acceptability of the intervention • Barriers and facilitators
Eligibility criteria – comparator(s)/control or reference (gold) standard	• No intervention • Other active interventions (see above)
Outcomes and prioritisation	CRITICAL OUTCOMES • Impact of caring on carer (for example resilience, distress, burden; ability to work/study or remain a carer) (minimally important difference [MID]: statistical significance) • Caring-related morbidity (including physical and mental health [anxiety, depression, stress/emotional wellbeing only]) (MID: statistical significance) IMPORTANT OUTCOMES • Social capital (that is range of social contact that provides access to social/emotional/practical support: Measures include Social Support Index and Social Support Survey Instrument) (MID: statistical significance) • Carer quality of life (MID: statistical significance) • Carer choice/control/efficacy (Note that quality of life measures, such as Adult Carer Quality of Life Questionnaire [AC-QoL], personal Wellbeing Index-Adult [PWI-A] Warwick-Edinburgh Mental Well-being Scale [WEMWBS] includes questions about this) (MID: statistical significance) *For the relevant outcomes above, only validated scales will be included.* Results of the qualitative evidence synthesis will be determined by thematic analysis and the use, if appropriate, of thematic maps.

Field (based on PRISMA-P)	**Content**
	The final results of the review will be determined by the mixed studies qualitative synthesis of all studies.
Eligibility criteria – study design	No restrictions on study designs will be made. That is, quantitative, qualitative, and mixed methods studies will all be considered. Studies will be categorised according to their relevance to answer a specific aspect of the question - for example RCTs or observational studies to assess the effectiveness of the intervention; qualitative research for assessing the acceptability of an intervention – in line with the typology of evidence for social interventions developed by Muir Gray (1996) and in consultation with the GC. References • Muir Gray, JM. (1996). Evidence-based healthcare. London, UK: Churchill Livingstone.
Other inclusion exclusion criteria	*Additional inclusion criteria* • Setting of intervention can be people's own homes and any other health and social care setting (including neighbourhood and community) in which adult carers provide care and support • Only studies from the following geographical areas/countries will be included: UK, Australia, Canada, Europe, Japan, New Zealand, South Africa, and USA. Studies from other countries will not be included due to substantial differences in their carer populations and/or social-/health-care systems. • Full-text English-language articles published in or after 2003 • Full-text reports of complex/multi-component interventions will be assessed for relevance to this review question *Exclusion criteria* • Conference abstracts will be excluded as they typically do not provide sufficient information to evaluate risk of bias/quality of study. • Non-English language articles A step-wise approach to the included evidence will be used if required: although only studies published in or after 2003 will be initially included, subsequent modifications to the inclusion criteria may be warranted, subject to ratification by the GC, if the volume of studies to examine is very high. For example, studies may be restricted to those conducted in the UK or a more recent date of publication may be used. If changes to the initial inclusion criteria are deemed necessary, reasons for these will be explicitly noted in the methods section of the guideline.
Proposed sensitivity/sub-group analysis, or meta-regression	Stratified/subgroup analysis • Category of intervention • Adult carers providing support or who have provided support for people at the end of life (presented as part of review question 8)

Field (based on PRISMA-P)	**Content**
	- Changes to the caring role, defined as: (i) changes to the setting in which caring is performed, (ii) transition of the person receiving care to adulthood, (iii) change of carer status or circumstances (presented as part of review question 9) Further stratification/subgroup analysis (for example socioeconomic factors), if needed, will be directed by the GC and be contingent on the themes or patterns that are revealed by the initial synthesis of the quantitative and qualitative evidence
Selection process – duplicate screening/selection/analysis	Duplicate screening will be performed using STAR - minimum sample size is 10% of the total for <1000 titles and abstracts, and 5% of the total for ≥1000 titles and abstracts. All discrepancies are discussed and resolved between 2 reviewers. Any disputes will be resolved in discussion with the Senior Systematic Reviewer. Data extraction will be supervised by a senior reviewer. Draft excluded studies and evidence tables will be discussed with the Topic Advisor, prior to circulation to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair.
Data management (software)	Pairwise meta-analyses, if appropriate, will be conducted using the Cochrane Review Manager (RevMan5). GRADEpro will be used to record (and assess) the quality of quantitative evidence for outcomes relevant to establishing the effectiveness of interventions. NGA STAR software will be used for generating bibliographies and citations, study sifting, data extraction and recording quality assessment of studies. A GRADE-CERQual Microsoft Excel template will be used to record the overall quality of findings from the qualitative evidence; a Microsoft Excel template will also be used to record the findings of questionnaire surveys.
Information sources – databases and dates	Sources to be searched: • ASSIA, CDSR, DARE, Embase, IBSS, Medline, Medline In-Process, PsycINFO, Sociological Abstracts, Social Services Abstracts, Social Policy and Practice Filters: • Systematic review • RCT • Qualitative study • NICE UK geographic • Standard animal/non-English language exclusion Limits: • Date from 2003

Field (based on PRISMA-P)	Content
Identify if an update	This review question is not an update
Author contacts	Developer: The National Guideline Alliance
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual
Search strategy – for one database	For details please see appendix F of the guideline
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix G (evidence tables) or H (economic evidence tables) of the guideline.
Data items – define all variables to be collected	For details please see evidence tables in appendix G (evidence tables) or H (economic evidence tables) of the guideline.
Methods for assessing bias at outcome/study level	The following checklists will be used to assess risk of bias/quality of individual studies: • ROBIS for systematic reviews/meta-analyses of interventions studies • Cochrane RoB tool v2 for (individual or cluster) RCTs; • Cochrane ROBINS-I for non-randomised (clinical) controlled trials, cohort studies, and historical controlled studies • CASP Case Control Checklist for case control studies • The appropriate EPOC RoB Tool will be used for (i) complex interventions involving randomised and/or non-randomised interventions, (ii) controlled before-after studies, (iii) interrupted time series studies, and • JBI Checklist for cross-sectional studies • IHE Checklist for case series (that is non-controlled longitudinal studies) • Boynton & Greenhalgh checklist for cross-sectional surveys and survey questionnaire studies • Newcastle-Ottawa Scale for studies examining associations between variables (this does not include variables relevant to clinical diagnosis and prognosis). • CASP Qualitative Checklist for individual qualitative studies
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual

Field (based on PRISMA-P)	**Content**
Methods for analysis – combining studies and exploring (in)consistency	Synthesis of quantitative and qualitative data will be done separately: • Mean differences (MDs) or standard mean differences (SMDs) for continuous outcomes, risk ratios (RRs) for dichotomous outcomes, and hazard ratios (HRs) for time to event outcomes, will be used for outcomes relevant to establishing the effectiveness of interventions. Heterogeneity will be assessed using the i^2 statistic. GRADE will be used to assess the quality of these outcomes. • Meta synthesis will be used to elucidate any themes or patterns revealed across the included qualitative or mixed methods studies relevant to establishing the acceptability of an intervention. GRADE-CERQual will be used to assess the quality of evidence for a theme across studies. The integration of quantitative and qualitative data will be conducted by the committee.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. If sufficient relevant RCT evidence is available, publication bias will be explored using RevMan5 software to examine funnel plots.
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual. For assessing confidence in the qualitative evidence prior to the mixed methods qualitative synthesis of evidence, GRADE-CERQual will be used. A mixed methods qualitative synthesis will be used to summarise and interpret the evidence.
Rationale/context – Current management	For details please see the introduction to the evidence review in the guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by the National Guideline Alliance and chaired by Mr. Phil Taverner in line with section 3 of Developing NICE guidelines: the manual. Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
Roles of sponsor	NICE funds the National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England

Field (based on PRISMA-P)	**Content**
PROSPERO registration number	Not registered in PROSPERO

AMSTAR: Assessing the Methodological Quality of Systematic Reviews; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; MID: minimal important difference; NICE: National Institute for Health and Care Excellence; RCT: Randomised Controlled Trial; RoB: Risk of Bias; SD: Standard Deviation.

Appendix B – Literature search strategies

Literature search strategies for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

The search for this topic was last run on 7th November 2017.

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	Searches
1	caregiver/ use emez or caregivers/ use mesz, prem or caregivers/ use psyh or caregiver burden/ use psyh
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	exp *cognitive therapy/ or (counseling.hw. and exp *counseling/) or *friend/ or *friendship/ or *group dynamics/ or *group process/ or *group therapy/ or *hotline/ or *mindfulness/ or *peer group/ or *problem solving/ or *psychotherapy/ or *reality therapy/ or *relaxation training/ or *self-help/ or *social adaption/ or *social network/ or *social support/ or exp *support group/
5	*advance care planning/ or *bereavement/ or *case management/ or *crisis intervention/ or *friends/ or *group process/ or *group therapy/ or *human relation/ or exp *peer group/ or *social network/ or *support group/ or *terminal care/
6	4 or 5
7	6 use emez
8	exp counseling/ or cognitive behavioral therapy/ or mindfulness/ or patient centered care/ or problem solving/ or psychotherapy*.sh. or exp psychotherapy, group/ or reality therapy/ or relaxation therapy/ or social support/
9	bereavement/ or case management/ or crisis intervention/ or education, nonprofessional/ or friends/ or group processes/ or hotlines/ or interpersonal relations/ or palliative care/ or exp peer group/ or professional family relations/ or exp psychotherapy, group/ or self-help groups/ or exp social networking/ or terminal care/
10	8 or 9
11	10 use mesz, prem
12	case management/ or client centered therapy/ or exp cognitive behavior therapy/ or exp counselling/ or exp group psychotherapy/ or mindfulness/ or exp problem solving/ or psychotherapy/ or reality therapy/ or exp relaxation therapy/ or social support/
13	advocacy/ or bereavement/ or crisis intervention services/ or crisis intervention/ or “death and dying”/ or friendship/ or group dynamics/ or group counseling/ or hot line services/ or interpersonal relationships/ or outreach programs/ or palliative care/ or peer counseling/ or peer evaluation/ or peer relations/ or peers/ or exp peer relations/ or exp social networks/ or self help techniques/ or social networks/ or social group work/ or support groups/ or terminally ill patients/
14	12 or 13
15	14 use psyh
16	*internet/ or *computer/ or *computer network/ or *internet/ or *online system/ or exp *computer assisted therapy/ or *social media/ or *social network/ or exp *telecommunication/
17	16 use emez

#	Searches
18	computers/ or computer assisted instruction/ or computer communication networks/ or exp internet/ or online systems/ or o social media/ or exp social networking/ or therapy, computer assisted/ or telecommunications/ or telemedicine/
19	18 use mesz, prem
20	computer assisted instruction/ or computer assisted therapy/ or computers/ or exp computer mediated communication/ or exp online therapy/ or exp internet/ or exp social media/ or exp social networks/ or telecommunications media/ or telemedicine/
21	20 use psyh
22	or/17,19,21
23	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
24	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
25	counsel*.ti,ab.
26	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
27	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
28	((communit* or social) adj2 support*).ti,ab.
29	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
30	or/7,11,15,22-29
31	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
32	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
33	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
34	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab.
35	((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab. or (peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
36	((bereav* or death or dying or end of life or grief* or ((palliative or terminal) adj care)) adj3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or anticipatory grief).ti,ab.
37	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
38	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
39	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
40	(psychoeducat* or psycho educat*).ti,ab.

#	Searches
41	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
42	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
43	((emotion* or one to one or transition*) adj support*).ti,ab.
44	(lay adj (led or run)).ti,ab.
45	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
46	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
47	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
48	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
49	(carer* network* or support group*).ti,ab.
50	or/31-49
51	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
52	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
53	(information adj (needs or provision or support)).ti,ab.
54	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
55	or/51-54
56	*education/ or *health education/ or *education program/ or *first aid/
57	56 use emez
58	caregiver/ed or education/ or first aid/ or exp health education/
59	58 use mesz, prem
60	client education/ or education/ or educational programs/ or health education/
61	60 use psyh
62	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
63	(psychoeducat* or psycho educat*).ti,ab,hw.
64	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
65	or/57,59,61-64
66	exercise*.hw. or exp *physical activity/ or *"physical education"/ or exp *sports/
67	66 use emez
68	exp exercise/ or physical exertion/ or exp "physical education and training"/ or exp sports/
69	68 use mesz, prem
70	exercise/ or exp physical activity/ or "physical education"/ or exp sports/

#	Searches
71	70 use psyh
72	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
73	or/67,69,71-72
74	exp *employment/ or exp *return to work/ or *supported employment/ or *vocational education/ or *vocational rehabilitation/ or *work/ or *work resumption/ or (employment and rehabilitation).hw.
75	74 use emez
76	employment/ or employment, supported/ or rehabilitation, vocational/ or return to work/ or unemployment/ or vocational education/ or work/ or workplace/ or (employment/ and rh.fs.)
77	76 use mesz, prem
78	employment status/ or exp vocational rehabilitation/ or reemployment/ or (employment and rehabilitation).hw. or vocational education/ or work adjustment training/
79	78 use psyh
80	*child welfare/ or *financial management/ or *social care/ or *social security/ or *social welfare/ or “social work/
81	80 use emez
82	“aid to families with dependent children”/ or child welfare/ or financing, government/ or government programs/ or public assistance/ or social security/ or social welfare/ or social work/
83	82 use mesz
84	government programs/ or social security/ or child welfare/ or "welfare services (government)/ or community welfare services/ or exp social case services/ or social services/ or social security/
85	84 use psyh
86	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
87	((individual placement adj2 support) or ips model).ti,ab.
88	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
89	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
90	rehabilitation counsel*.ti,ab.
91	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
92	(volunteering or (work adj2 placement*)).ti,ab.
93	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
94	(return adj to* adj (education or study or training or work*)).ti,ab.
95	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support

#	Searches
	fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
96	(signpost* or sign post*).ti,ab.
97	or/75,77,79,81,83,85-96
98	*day care/ or *respite care/
99	98 use emez
100	day care, medical/ or respite care/
101	100 use mesz, prem
102	adult day care/ use psyh or day care centers/ use psyh or respite care/ use psyh
103	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
104	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
105	or/99,101-104
106	*assistive technology/ or *occupational therapy/ or *telehealth/ or *telemedicine/ or *telemetry/ or *telemonitoring/
107	106 use emez
108	assistive technology/ or occupational therapy/ or self-help devices/ or telemedicine/ or telemetry/ or telemonitoring/
109	108 use mesz, prem
110	assistive technology/ or occupational therapy/ or telemedicine/ or telemetry/
111	110 use psyh
112	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
113	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
114	(gps track* or location technology).ti,ab.
115	occupational therap*.ti,ab.
116	or/107,109,111-115
117	exp acupuncture/ use emez or exp alternative medicine/ use emez or biofeedback/ or massage/ use emez or meditation/ use emez or acupressure/ use mesz, prem or massage/ use mesz, prem or acupuncture/ use mesz, prem or exp complementary therapies/ use mesz, prem or exp mind body therapies/ use mesz, prem or exp alternative medicine/ use psyh or biofeedback/ use psyh or massage/ use psyh or mind body therapy/ use psyh
118	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
119	meditation.sh. or meditat*.ti,ab.
120	(acceptance adj2 commitment therap*).ti,ab.
121	dyadic intervention*.ti,ab.
122	(reminiscence adj (group* or therap*)).ti,ab.
123	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
124	art/ or art therapy/ or music/ or music therapy/ or singing/ or painting/ use emez or singing/ use emez, mesz, prem or paintings/ use mesz, prem
125	124 use emez,mesz
126	art/ or art education/ or art therapy/ or "painting (art)/ or music/ or music education/ or music therapy/ or singing/

#	Searches
127	126 use psyh
128	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
129	or/117-123,125,127-128
130	30,50,55,65,73,97,105,116,129
131	3 and 130
132	interviews as topic/ or qualitative research/
133	132 use emez
134	interviews as topic/ or anthropology, cultural/ or focus groups/ or exp tape recording/ or personal narrative/ or narration/ or nursing methodology research/ or observation/ or qualitative research/ or sampling studies/ or cluster analysis/ or videodisc recording/
135	134 use mesz, prem
136	cluster analysis/ or "culture (anthropological) or interviews/ or narratives/ or observation methods/ or qualitative research/ or tape recorders/
137	136 use psyh
138	(interview* or action research or audiorecord* or ((audio or tape or video*) adj5 record*) or colaizzi* or (constant adj (comparative or comparison)) or content analy* or critical social* or (data adj1 saturat*) or discourse analys?s or emic or ethical enquiry or ethno* or etic or experiences or fieldnote* or (field adj (note* or record* or stud* or research)) or (focus adj4 (group* or sampl*)) or giorgi* or glaser or (grounded adj (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or human science or husserl* or ((life or lived) adj experience*) or maximum variation or merleau or narrat* or ((participant* or nonparticipant*) adj3 observ*) or ((philosophical or social) adj research*) or (pilot testing and survey) or purpos* sampl* or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or tape record* or taperecord* or testimon* or (thematic* adj3 analys*) or themes or theoretical sampl* or unstructured categor* or van kaam* or van manen or videorecord* or video record* or videotap* or video tap*).ti,ab.
139	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)).ti,ab,hw,pt.
140	or/133,135,137-139
141	"*attitude to health"/ or *consumer/ or *consumer attitude/ or *health care quality/ or *patient attitude/ or *patient compliance/ or *patient preference/ or *patient satisfaction/
142	141 use emez
143	*attitude to health/ or comprehensive health care/ or exp consumer participation/ or exp consumer satisfaction/ or "patient acceptance of health care"/ or patient care management/ or patient centered care/ or exp patient compliance/ or patient satisfaction/ or "quality of health care"/
144	143 use mesz, prem
145	exp client attitudes/ or client satisfaction/ or consumer attitudes/ or exp health attitudes/ or exp consumer attitudes/ or patient satisfaction/ or treatment compliance/
146	145 use psyh
147	((carer* or caregiv* or care giv* or famil* or friend* or mother* or father* or son or daughter*) adj3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or buy in* or choice* or co?operat* or co operat* or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or

#	Searches
	perceive* or (perception* not speech perception) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry)).ti,ab.
148	((consumer or patient) adj2 (focus* or centered or centred)).ti,ab.
149	or/142,144,146-148
150	or/140,149
151	clinical trials as topic.sh. or (controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or (placebo or randomi#ed or randomly).ab. or trial.ti.
152	151 use mesz, prem
153	(controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or drug therapy.fs. or (groups or placebo or randomi#ed or randomly or trial).ab.
154	153 use mesz, prem
155	crossover procedure/ or double blind procedure/ or randomized controlled trial/ or single blind procedure/ or (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab.
156	155 use emez
157	(assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab. use psyh
158	or/152,154,156-157
159	meta-analysis/
160	meta-analysis as topic/ or systematic reviews as topic/
161	“systematic review”/
162	meta-analysis/
163	(meta analy* or metanaly* or metaanaly*).ti,ab.
164	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
165	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
166	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
167	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
168	(search* adj4 literature).ab.
169	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
170	cochrane.jw.
171	((pool* or combined) adj2 (data or trials or studies or results)).ab.
172	or/159-160,163,165-171 use mesz, prem
173	(or/161-164,166-171) use emez
174	meta analysis/ use psyh or or/163-171 use psyh
175	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review* or qualitativ*)).ti,ab,hw,pt.
176	or/172-175
177	or/158,176
178	exp case control study/ or cohort analysis/ or cross-sectional study/ or follow up/ or longitudinal study/ or observational study/ or prospective study/ or retrospective study/
179	178 use emez

#	Searches
180	exp case control studies/ or exp cohort studies/ or cross-sectional studies/ or epidemiologic studies/
181	180 use mesz, prem
182	(cohort analysis or followup studies or longitudinal studies or prospective studies or retrospective studies).sh,id. or (followup study or longitudinal study or prospective study or retrospective study).md.
183	182 use psyh
184	((epidemiologic* or observational) adj (study or studies)).ti,ab.
185	(cohort*1 or cross section* or crosssection* or followup* or follow up* or followed or longitudinal* or prospective* or retrospective*).ti,ab.
186	(case adj2 (control or series or stud*)).ti,ab.
187	(nonequivalent control group or posttesting or pretesting or pretest posttest design or pretest posttest control group design or quasi experimental methods or quasi experimental study or time series or time series analysis).sh.
188	(((nonequivalent or non equivalent) adj3 control*) or posttest* or post test* or pre test* or pretest* or quasi experiment* or quasiexperiment* or timeseries or time series).tw.
189	or/179,181,183-188
190	177 or 189
191	190
192	united kingdom/
193	(national health service* or nhs*).ti,ab,in,ad.
194	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
195	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in,ad.
196	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
197	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.

#	Searches
198	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
199	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
200	or/192-199 use emez
201	exp united kingdom/
202	(national health service* or nhs*).ti,ab,in.
203	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
204	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
205	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
206	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
207	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
208	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
209	or/201-208
210	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
211	209 not 210
212	211 use mesz, prem
213	(national health service* or nhs*).ti,ab,in,cq.
214	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.

#	Searches
215	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.
216	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq.
217	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq.
218	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq.
219	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq.
220	or/213-219 use psyh
221	or/200,212,220
222	150 and 221
223	131 and or/177,222

Database: Social Policy and Practice, Health Management Information Consortium - OVID

#	Searches
1	(carer* or caregiv* or care giv*).ti,ab.
2	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
3	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
4	counsel*.ti,ab.

#	Searches
5	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
6	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
7	((communit* or social) adj2 support*).ti,ab.
8	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
9	or/2-8
10	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
11	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
12	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
13	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab. or ((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab.
14	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief").ti,ab.
15	(peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
16	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
17	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
18	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
19	(psychoeducat* or psycho educat*).ti,ab.
20	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
21	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
22	((emotion* or one to one or transition*) adj support*).ti,ab.
23	(lay adj (led or run)).ti,ab.
24	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
25	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
26	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
27	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
28	(carer* network* or support group*).ti,ab.
29	or/10-28

#	Searches
30	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
31	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
32	(information adj (needs or provision or support)).ti,ab.
33	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
34	or/30-33
35	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
36	(psychoeducat* or psycho educat*).ti,ab,hw.
37	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
38	or/35-37
39	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
40	39
41	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
42	((individual placement adj2 support) or ips model).ti,ab.
43	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
44	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
45	rehabilitation counsel*.ti,ab.
46	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
47	(volunteering or (work adj2 placement*)).ti,ab.
48	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
49	(return adj to* adj (education or study or training or work*)).ti,ab.
50	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
51	(signpost* or sign post*).ti,ab.
52	or/41-51

#	Searches
53	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
54	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
55	or/53-54
56	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
57	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
58	(gps track* or location technology).ti,ab.
59	occupational therap*.ti,ab.
60	or/56-59
61	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
62	meditation.sh. or meditat*.ti,ab.
63	(acceptance adj2 commitment therap*).ti,ab.
64	dyadic intervention*.ti,ab.
65	(reminiscence adj (group* or therap*)).ti,ab.
66	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
67	or/61-66
68	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
69	68
70	or/9, 29, 34, 38, 40, 52, 55, 60, 67, 69
71	1 and 70

Database: Social Services Abstracts, Sociological Abstracts, International Bibliography for Social Sciences (IBSS), Applied Social Sciences Index and Abstracts (ASSIA) - Proquest

#	Searches
S1	noft (carer* or caregiv* or “care giv*”)
S2	noft (psychotherap*)
S3	noft (((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
S4	noft (((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
S5	noft (“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*)))
S6	noft (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
S7	noft ((“person centred” or replacement) near/1 (care or therap*))

#	Searches
S8	noft ((communit* or social) near/2 support*)
S9	noft ((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*))
S10	S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9
S11	noft (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*)))
S12	noft ((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
S13	noft ((peer* or support* or voluntary or volunteer*) near/2 group*)
S14	noft ((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*))
S15	noft (((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
S16	noft ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
S17	noft (((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
S18	noft (((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”)
S19	noft (((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*)))
S20	noft (psychoeducat* or “psycho educat*”)
S21	noft ((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*)))
S22	noft ((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*))
S23	noft ((emotion* or “one to one” or transition*) near/1 support*)
S24	noft (lay near/1 (led or run))
S25	noft ((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
S26	noft ((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
S27	noft (advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system))))
S28	noft ((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*))
S29	noft (carer* network* or “support group*”)
S30	S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29
S31	noft (helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*)))
S32	noft (helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
S33	noft (information near/1 (needs or provision or support))

#	Searches
S34	noft (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
S35	S31 or S32 or S33 or S34
S36	noft (((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train)))
S37	noft (psychoeducat* or “psycho educat*”) ti,ab,hw.
S38	noft (((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement)))
S39	S36 or S37 or S38
S40	noft (“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”)
S41	S40
S42	noft (((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*))
S43	noft ((“individual placement” near/2 support) or “ips model”)
S44	noft ((permitted or voluntary or rehab*) near/3 work*)
S45	noft ((psychosocial or “psycho social” or social) near/2 rehab*)
S46	noft (“rehabilitation counsel*”)
S47	noft ((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
S48	noft (volunteering or (work near/2 placement*))
S49	noft (((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
S50	noft (return near/1 to* near/1 (education or study or training or work*))
S51	noft (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
S52	noft (signpost* or “sign post*”)
S53	S42 or S43 or S44 or S45 or S46 or S47 or S48 or S49 or S50 or S51 or S52
S54	noft (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*))
S55	noft (((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*)
S56	S54 or S55

#	Searches
S57	noft ((assistive near/2 (platform* or technolog*)) or “interactive health communication”)
S58	noft (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
S59	noft (“gps track*” or “location technology”)
S60	noft “occupational therap*”
S61	S57 or S58 or S59 or S60
S62	noft ((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
S63	noft (meditat*)
S64	noft (acceptance near/2 “commitment therap*”)
S65	noft (“dyadic intervention*”)
S66	noft (reminiscence near/1 (group* or therap*))
S67	noft ((emotional or self) near/1 disclosure)
S68	S62 or S63 or S64 or S65 or S66 or S67
S69	noft (art or cafe or cafes or gallery or music or sing or singing)
S70	S69
S71	s10 or s30 or s35 or s39 or s41 or s53 or s56 or s61 or s68 or s70
S72	S1 and S71
S73	noft (interview* or “action research” or audiorecord* or ((audio or tape or video*) near/5 record*) or colaizzi* or (constant near/1 (comparative or comparison)) or content analy* or “critical social*” or (data near/1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field near/1 (note* or record* or stud* or research)) or (focus near/4 (group* or sampl*)) or giorgi* or glaser or (grounded near/1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) near/1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) near/3 observ*) or ((philosophical or social) near/1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or “structured categor*” or “tape record*” or taperecord* or testimon* or (thematic* near/3 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)
S74	noft (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) near/1 synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or “meta anal*” or synthes* or “systematic review*”))
S75	noft ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) near/3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
S76	noft ((consumer or patient) near/2 (focus* or centered or centred))
S77	S73 or S74 or S75 or S76
S78	noft (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) near/1 blind*) or factorial* or placebo* or random* or volunteer*)

#	Searches
S79	S78
S80	noft (“meta analy*” or metanaly* or metaanaly*)
S81	noft ((systematic or evidence) near/2 (review* or overview*))
S82	noft (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) near/1 synthes*) or metasynthes*)
S83	S80 or S81 or S82
S84	noft ((epidemiologic* or observational) near/1 (study or studies))
S85	noft (cohort* or “cross section*” or crosssection* or followup* or “follow up*” or followed or longitudinal* or prospective* or retrospective*)
S86	noft (case near/2 (control or series or stud*))
S87	noft (((nonequivalent or non equivalent) near/3 control*) or posttest* or “post test*” or “pre test*” or pretest* or “quasi experiment*” or quasiexperiment* or timeseries or “time series”)
S88	S84 or S85 or S86 or S87
S89	S77 or s79 or S83
S90	S72 and S89

Database: CINAHL – EBSCO

1	(mh "caregivers")
2	tx (carer* or caregiv* or “care giv*”)
3	#1 or #2
4	(mh "counseling+")
5	(mh "psychotherapy, group+")
6	(mh "cognitive therapy+")
7	(mh "mindfulness")
8	(mh "patient centered care")
9	(mh "problem solving")
10	(mh "reality therapy")
11	(mh "simple relaxation therapy (iowa nic))
12	(mh "social support (iowa noc)) or (mh "support, psychosocial")
13	tx (psychotherap*)
14	(mh "case management")
15	(mh "crisis intervention")
16	(mh "crisis intervention (iowa nic))
17	(mh "education, nonprofessional")
18	(mh "social networks")
19	(mh "group processes")
20	(mh "interpersonal relations")
21	(mh "professional-family relations")
22	(mh "support groups")
23	(mh "peer group")
24	(mh "psychotherapy, group")
25	(mh "social networking+")
26	(mh "computers and computerization")
27	(mh "computer assisted instruction")
28	(mh "computer communication networks")

29 (mh "online systems")
30 (mh "social media+")
31 (mh "therapy, computer assisted")
32 (mh "telecommunications")
33 (mh "telemedicine")
34 (mh "internet+")
35 (mh "social networking+")
36 tx (((psychological* or psychosocial or psychotherapeutic) n2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
37 tx (((behaviour* or behavior*) n2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) n3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
38 tx (“case manag*” or counsel* or ((“person centred” or replacement) n1 (care or therap*)))
39 (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) n1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
40 tx ((“person centred” or replacement) n1 (care or therap*))
41 tx ((communit* or social) n2 support*)
42 tx ((intervention* or therap* or program* or workshop*) n7 (caregiver* or “care giver*” or carer*) n7 (burden or distress* or stress*))
43 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
44 tx (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) n1 (person or worker*)))
45 tx ((peer* or voluntary or volunteer*) n3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
46 tx ((peer* or support* or voluntary or volunteer*) n2 group*)
47 tx ((peer* or support* or voluntary or volunteer*) n3 (intervention* or program* or rehab* or therap* or service* or skill*))
48 tx (((peer* n3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* n3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
49 tx ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) n1 care))
near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
50 tx (((communit* or family or social) n1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
51 tx (((carer* or caregiv* or “care giv*”) n2 (mentor* or support*)) or (unpaid n3 support*) or “mentoring scheme*”)
52 tx (((carer* or caregiv* or “care giv*”) n3 (communication or integrat* or relations or relationship*) n3 (practitioner* or professional* or worker*)) or (famil* n3(intervention* or program*)))
53 tx (psychoeducat* or “psycho educat*”)
54 tx ((emotion* n1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) n1 (adapt* or reintegrat* or support*)))
55 tx ((dyadic or loneliness or psychosocial* or “psycho social*”) n2 (assist* or intervention* or program* or support* or therap* or treat*))
56 tx ((emotion* or “one to one” or transition*) n1 support*)
57 tx (lay n1 (led or run))

58 tx ((crisis or crises or emergenc*) n3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
59 tx ((coping or resilien* or “well being” or wellbeing) n2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
60 tx (advocate or advocacy or ((support* n3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* n1 (service* or system))))
61 tx ((network* or peer*) n2 (discuss* or exchang* or interact* or meeting*))
62 tx (carer* network* or “support group*”)
63 #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64 tx (helpline or “help line” or ((phone* or telephone*) n3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) n2 (assist* or based or driven or led or mediat*)))
65 tx (helpseek* or ((search* or seek*) n3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
66 tx (information n1 (needs or provision or support))
67 tx (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
68 #64 or #65 or #66 or #67
69 (mh "education")
70 (mh "health education")
71 (mh "first aid") or (mh "first aid (iowa nic))
72 tx (((carer* or caregiv* or “care giv*”) n5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) n3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) n3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) n1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* n2 (build* or coach* or educat* or learn* or train)))
73 tx (psychoeducat* or “psycho educat*”) ti,ab,hw.
74 tx (((medication or pain) n2 manag*) or “pain control program*” or ((educat* or train*) n5 (handling or movement)))
75 #69 or #70 or #71 or #72 or #73 or #74
76 (mh "exertion")
77 (mh "exercise+")
78 (mh "physical education and training+")
79 (mh "sports+")
80 tx (“aerobic train*” or exercis* or gym* or jog* or (physical n1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure n2 (activit* or intervention* or program* or therap*)) or “leisure based”)
81 #76 or #77 or #78 or #79 or #80
82 (mh "employment")
83 (mh "employment, supported")
84 (mh "rehabilitation, vocational")
85 (mh "job re-entry")
86 (mh "unemployment")
87 (mh "vocational education")
88 (mh "work")
89 (mh "work environment")
90 (MH "Dependent Families")
91 (mh "child welfare")
92 (mh "financing, government")
93 (mh "government programs")
94 (mh "public assistance")

95 (mh "social welfare")
96 (MH "Economic and Social Security")
97 (mh "social work")
98 tx (((employ* or job* or reemploy* or vocation* or work*) n3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* n2 employ*) or (work n2 coach*))
99 tx ((“individual placement” n2 support) or “ips model”)
100 tx ((permitted or voluntary or rehab*) n3 work*)
101 tx ((psychosocial or “psycho social” or social) n2 rehab*)
102 tx “rehabilitation counsel*”
103 tx ((prevocat* or vocat*) n3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
104 tx (volunteering or (work n2 placement*))
105 tx (((carer* or “care giv*” or caregiv*) n3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
106 tx (return n1 to* n1 (education or study or training or work*))
107 tx (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) n3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) n7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) n7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
108 tx (signpost* or “sign post*”)
109 #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110 (mh "day care")
111 (mh "respite care") or (mh "respite care (iowa nic))
112 tx (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) n3 support*))
113 tx (((crisis or volunteer) n1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) n2 break*) or signpost*)
114 #110 or #111 or #112 or #113
115 (mh "assistive technology")
116 (mh "occupational therapy")
117 (mh "assistive technology devices+")
118 (mh "telemedicine")
119 (mh "telemetry")
120 (mh "telenursing")
121 tx ((assistive n2 (platform* or technolog*)) or “interactive health communication”)
122 tx (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
123 tx (“gps track*” or “location technology”)
124 tx “occupational therap*”
125 #115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126 (mh "acupressure")
127 (mh "massage")
128 (mh "acupuncture")
129 (mh "alternative therapies+")

130 (mh "mind body techniques+")
131 (mh "medicine, chinese traditional")
132 (mh "moxibustion")
133 tx ((alternative or complementary) n2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching n2 lo) or cizhen or dianzhen or electroacupunctur* or (jing n2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
134 (mh "meditation") or (mh "meditation (iowa nic)) or tx (meditate*)
135 tx (acceptance n2 “commitment therap*”)
136 tx “dyadic intervention*”
137 tx (reminiscence n1 (group* or therap*))
138 tx ((emotional or self) n1 disclosure)
139 (mh "self disclosure")
140 (mh "art")
141 (mh "music")
142 (mh "singing")
143 (mh "paint")
144 (mh "art therapy")
145 (mh "singing")
146 tx (art or cafe or cafes or gallery or music or sing or singing)
147 #126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148 #3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)
149 (mh "cluster analysis") or (mh "qualitative studies") or (mh "observational methods") or (mh "narratives") or (mh "audiorecording") or (mh "videorecording") or (mh "focus groups") or (mh "anthropology, cultural") or (mh "structured interview") or (mh "unstructured interview") or (mh "semi-structured interview")
150 tx (interview* or “action research” or audiorecord* or ((audio or tape or video*) n5 record*) or colaizzi* or (constant n1 (comparative or comparison)) or “content analy*” or “critical social*” or (data n1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field n1 (note* or record* or stud* or research)) or (focus n4 (group* or sampl*)) or giorgi* or glaser or (grounded n1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) n1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) n1 observ*) or ((philosophical or social) n1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or ”tape record*” or taperecord* or testimon* or (thematic* n1 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)
151 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))
152 (mh "attitude to health") or (mh "consumer participation") or (mh "consumer satisfaction+") or (mh "patient centered care") or (mh "patient compliance") or (mh "quality o health care")
153 tx ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) n3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not “speech perception”) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))

154 tx ((consumer or patient) n2 (focus* or centered or centred))
155 #149 or #150 or #151 or #152 or #153 or #154
156 (mh "clinical trials") or (mh "randomized controlled trials") or ab (placebo or randomised or randomized or randomly) or ti (trial)
157 (mh "meta analysis")
158 (mh "systematic review")
159 tx (“meta analy*” or metanaly* or metaanaly*)
160 tx ((systematic* or evidence*) n2 (review* or overview*))
161 tx (“reference list*” or bibliograph* or “hand search*” or “manual search*” or “relevant journals”)
162 tx (“search strategy” or “search criteria” or “systematic search” or “study selection” or “data extraction”)
163 (search* n4 literature)
164 tx (medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit)
165 so cochrane
166 tx ((pool* or combined) n2 (data or trials or studies or results))
167 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))
168 #157 or #158 or #159 or #160 or #161 or #162 or #163 or #164 or #165 or #166 or #167
169 #155 or #156 or #168
170 #148 and #169

Database: Cochrane Library - Wiley

#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2
4	mesh descriptor: [counseling] explode all trees
5	mesh descriptor: [psychotherapy, group] explode all trees
6	mesh descriptor: [cognitive behavioral therapy] this term only
7	mesh descriptor: [mindfulness] this term only
8	mesh descriptor: [patient centered care] this term only
9	mesh descriptor: [problem solving] this term only
10	mesh descriptor: [reality therapy] this term only
11	mesh descriptor: [relaxation therapy] this term only
12	mesh descriptor: [social support] this term only
13	(psychotherap*):ti,ab,kw
14	(mesh descriptor: [case management] this term only
15	mesh descriptor: [crisis intervention] this term only
16	mesh descriptor: [education, nonprofessional] this term only
17	mesh descriptor: [friends] this term only
18	mesh descriptor: [group processes] this term only
19	mesh descriptor: [hotlines] this term only
20	mesh descriptor: [interpersonal relations] this term only
21	mesh descriptor: [professional family relations] this term only
22	mesh descriptor: [self-help groups] this term only
23	mesh descriptor: [peer group] explode all trees
24	mesh descriptor: [psychotherapy, group] explode all trees
25	mesh descriptor: [social networking] explode all trees
26	mesh descriptor: [computers] this term only
27	mesh descriptor: [computer assisted instruction] this term only
28	mesh descriptor: [computer communication networks] this term only
29	mesh descriptor: [online systems] this term only
30	mesh descriptor: [social media] this term only
31	mesh descriptor: [therapy, computer assisted] this term only
32	mesh descriptor: [telecommunications] this term only
33	mesh descriptor: [telemedicine] this term only
34	mesh descriptor: [internet] explode all trees
35	mesh descriptor: [social networking] explode all trees
36	(((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*):ti,ab,kw
37	(((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”):ti,ab,kw
38	(“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*))):ti,ab,kw

39	(((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”):ti,ab,kw
40	((“person centred” or replacement) near/1 (care or therap*)):ti,ab,kw
41	((communit* or social) near/2 support*):ti,ab,kw
42	((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*)):ti,ab,kw
43	#4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
44	(befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*))):ti,ab,kw
45	((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)):ti,ab,kw
46	((peer* or support* or voluntary or volunteer*) near/2 group*):ti,ab,kw
47	((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*)):ti,ab,kw
48	(((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*))):ti,ab,kw
49	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief"):ti,ab,kw
50	(((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”):ti,ab,kw
51	(((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”):ti,ab,kw
52	(((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*))):ti,ab,kw
53	(psychoeducat* or “psycho educat*”):ti,ab,kw
54	((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*))):ti,ab,kw
55	((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*)) :ti,ab,kw
56	((emotion* or “one to one” or transition*) near/1 support*):ti,ab,kw
57	(lay near/1 (led or run)):ti,ab,kw
58	((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)):ti,ab,kw
59	((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*)):ti,ab,kw
60	(advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system)))):ti,ab,kw

61	((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*)):ti,ab,kw
62	(carer* network* or “support group*”):ti,ab,kw
63	#44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64	(helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*))):ti,ab,kw
65	(helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))):ti,ab,kw
66	(information near/1 (needs or provision or support)):ti,ab,kw
67	(selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport) :ti,ab,kw
68	#64 or #65 or #66 or #67
69	mesh descriptor: [education] this term only
70	mesh descriptor: [health education] explode all trees
71	mesh descriptor: [first aid] this term only
72	(((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train))):ti,ab,kw
73	(psychoeducat* or “psycho educat*”) ti,ab,hw.
74	(((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement))):ti,ab,kw
75	#69 or #70 or #71 or #72 or #73 or #74
76	mesh descriptor: [physical exertion] this term only
77	mesh descriptor: [exercise] explode all trees
78	mesh descriptor: [physical education and training] explode all trees
79	mesh descriptor: [sports] explode all trees
80	(“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”):ti,ab,kw
81	#76 or #77 or #78 or #79 or #80
82	mesh descriptor: [employment] this term only
83	mesh descriptor: [employment, supported] this term only
84	mesh descriptor: [rehabilitation, vocational] this term only
85	mesh descriptor: [return to work] this term only
86	mesh descriptor: [unemployment] this term only
87	mesh descriptor: [vocational education] this term only
88	mesh descriptor: [work] this term only
89	mesh descriptor: [workplace] this term only
90	mesh descriptor: [aid to families with dependent children] this term only
91	mesh descriptor: [child welfare] this term only
92	mesh descriptor: [financing, government] this term only
93	mesh descriptor: [government programs] this term only
94	mesh descriptor: [public assistance] this term only

95	mesh descriptor: [social security] this term only
96	mesh descriptor: [social welfare] this term only
97	mesh descriptor: [social work] this term only
98	(((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*)):ti,ab,kw
99	((“individual placement” near/2 support) or “ips model”) :ti,ab,kw
100	((permitted or voluntary or rehab*) near/3 work*):ti,ab,kw
101	((psychosocial or “psycho social” or social) near/2 rehab*):ti,ab,kw
102	“rehabilitation counsel*”:ti,ab,kw
103	((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)):ti,ab,kw
104	(volunteering or (work near/2 placement*)):ti,ab,kw
105	(((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”) :ti,ab,kw
106	(return near/1 to* near/1 (education or study or training or work*)):ti,ab,kw
107	(“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))):ti,ab,kw
108	(signpost* or “sign post*”):ti,ab,kw
109	#82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110	mesh descriptor: [day care, medical] this term only
111	mesh descriptor: [respite care] this term only
112	(“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*)):ti,ab,kw
113	(((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*):ti,ab,kw
114	#110 or #111 or #112 or #113
115	mesh descriptor: [assistive technology] this term only
116	mesh descriptor: [occupational therapy] this term only
117	mesh descriptor: [self-help devices] this term only
118	mesh descriptor: [telemedicine] this term only
119	mesh descriptor: [telemetry] this term only
120	mesh descriptor: [telemonitoring] this term only
121	((assistive near/2 (platform* or technolog*)) or “interactive health communication”):ti,ab,kw
122	(“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*):ti,ab,kw

123	(“gps track*” or “location technology”):ti,ab,kw
124	“occupational therap*”:ti,ab,kw
125	#115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126	mesh descriptor: [acupressure] this term only
127	mesh descriptor: [massage] this term only
128	mesh descriptor: [acupuncture] this term only
129	mesh descriptor: [complementary therapies] explode all trees
130	mesh descriptor: [mind body therapies] explode all trees
131	mesh descriptor: [medicine, chinese traditional] this term only
132	mesh descriptor: [moxibustion] this term only
133	((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci) :ti,ab,kw
134	meditation.sh. or meditat*:ti,ab,kw
135	(acceptance near/2 “commitment therap*”):ti,ab,kw
136	“dyadic intervention*”:ti,ab,kw
137	(reminiscence near/1 (group* or therap*)):ti,ab,kw
138	((emotional or self) near/1 disclosure):ti,ab,kw
139	mesh descriptor: [self disclosure] this term only
140	mesh descriptor: [art] this term only
141	mesh descriptor: [music] this term only
142	mesh descriptor: [singing] this term only
143	mesh descriptor: [painting] this term only
144	mesh descriptor: [art therapy] this term only
145	mesh descriptor: [singing therapy] this term only
146	(art or cafe or cafes or gallery or music or sing or singing):ti,ab,kw
147	#126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148	#3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)

Non-database searches

In addition to the above databases, searches were undertaken in a range of websites and other relevant sources:

1. Agency for Healthcare Research and Quality
2. Care Quality Commission
3. Carer Research and Knowledge Exchange Network
4. Carers Trust
5. Carers UK
6. Centre for Mental Health
7. Centre for International Research on Care, Labour and Equalities
8. Department of Health
9. Department for Work and Pensions
10. Directors of Adult Social Services
11. Equality and Human Rights Commission
12. Eurocarers

13. Google UK
14. Health and Social Care Information Centre
15. Health in Wales
16. Healthcare Improvement Scotland
17. Healthcare Quality Improvement Partnership
18. Institute for Public Policy Research
19. Joseph Rowntree Foundation
20. Kings Fund
21. National Audit Office
22. New Policy Institute
23. NHS England
24. NHS Improving Quality
25. Office for National Statistics
26. Research in Practice
27. Royal College of General Practitioners
28. Royal College of Nursing
29. Royal College of Physicians
30. Royal College of Psychiatrists
31. SIGN
32. Turning Point
33. Welsh Government

Economics

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	**Searches**
1	caregiver/ use emez or caregivers/ use mesz, prem
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	budget/ or exp economic evaluation/ or exp fee/ or funding/ or health economics/ or exp health care cost/
5	4 use emez
6	exp budgets/ or exp "costs and cost analysis"/ or economics, nursing/ or economics, pharmaceutical/ or economics/ or exp economics, hospital/ or exp economics, medical/ or exp "fees and charges"/ or value of life/
7	6 use mesz
8	budget*.ti,ab.
9	cost*.ti.
10	(economic* or pharmaco?economic*).ti.
11	(price* or pricing*).ti,ab.
12	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
13	(financ* or fee or fees).ti,ab.
14	(value adj2 (money or monetary)).ti,ab.
15	or/5,7-14
16	3 and 15

Database: Cochrane Library – Wiley

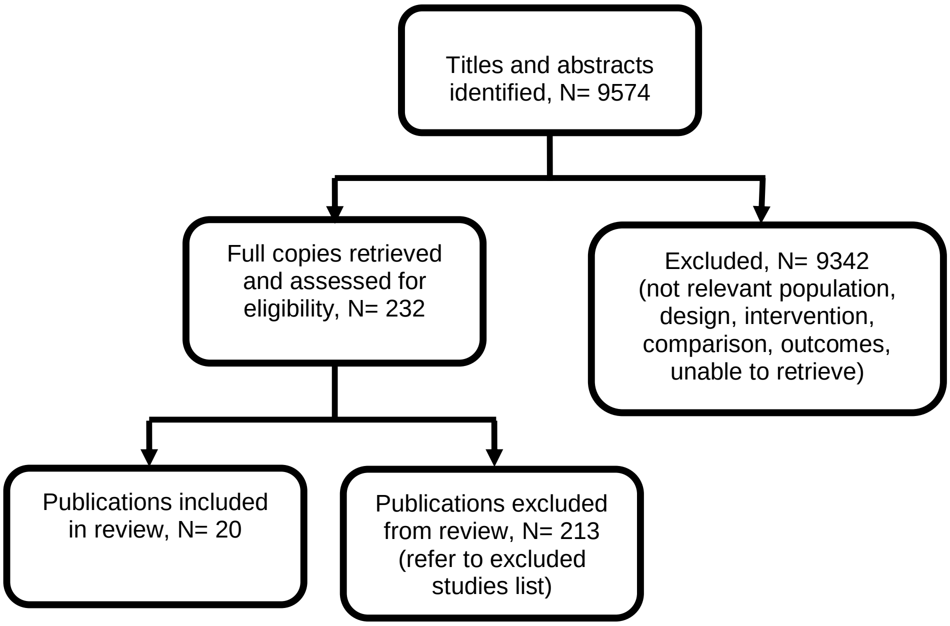
#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Study selection for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

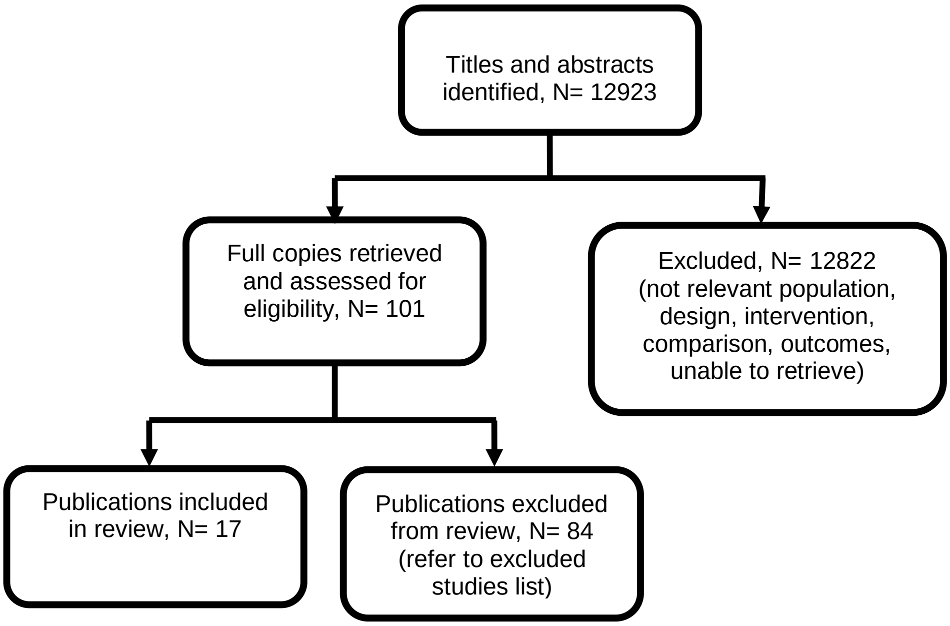
Quantitative component of the review

Figure 2: Flow diagram of quantitative article selection for providing emotional and psychological support for adult carers review



Qualitative component of the review

Figure 3: Flow diagram of qualitative article selection for providing emotional and psychological support for adult carers review



<Start typing text here>

Appendix D – Evidence tables

Evidence tables for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Quantitative component of the review

Table 6: Evidence tables for the quantitative studies

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>**Full citation**
Aboulafia-Brakha, T., Suchecki, D., Gouveia-Paulino, F., Nitrini, R., Ptak, R., Cognitive-behavioural group therapy improves a psychophysiological marker of stress in caregivers of patients with Alzheimer's disease, Aging & mental health, 18, 801-808, 2014

Ref Id
519237

Country/ies where the study was carried out
Switzerland

Study type
2 groups RCT

Aim of the study</td>
<td>**Sample size**
N = 35
- Intervention (n): 17
- Control (N): 18

Characteristics Carer
- Age Mean (SD): Intervention= 59.42 (6.67); control= 55.07 (10.68)
- Gender intervention (N): 0/12; control (N): 5/10
- Relationship to care recipient</td>
<td>**Interventions**
- Intervention (according to the protocol) - CBT
- Name of Intervention (as named in the paper) - cognitive –behavioural group therapy
- Control (according to the protocol) - Psycho-educational intervention
- Name of control (as named in the paper) - psychoeducation group programme (EDUC)
Mode of delivery
- Face-to-face</td>
<td>**Details**
- Randomization methods - The assignment to each intervention group was done during the first contact by phone, in alternating order. No details about the allocation concealment
- Blinding methods - No details
- Follow-up outcome measurement - Follow-up time not described in sufficient detail</td>
<td>**Results***
<table>
<tr><td colspan="7">*follow-up not reported*</td></tr>
<tr><td>**Measure**</td><td colspan="3">**INTERVENTION - CBT**</td><td colspan="3">Control</td></tr>
<tr><td></td><td>**MEAN**</td><td>**SD**</td><td>**N**</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Burden, ZBI (Zarit Burden Interview), Portuguese version</td><td>9.4</td><td>5.7</td><td>12</td><td>7.9</td><td>4.8</td><td>15</td></tr>
<tr><td>Caring-related morbidity: Stress, PSS (Perceived Stress Scale)</td><td>19.5</td><td>5.3</td><td>12</td><td>16.8</td><td>7.1</td><td>15</td></tr>
</table>
</td>
<td>**Methodological quality assessed using Cochrane risk of bias tool v2. Limitations**
- Random sequence generation - high risk: Selection bias (biased allocation to interventions) due to inadequate generation of a randomized sequence
- Allocation concealment - unclear risk: Not described</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>This RCT was aimed to compare the effectiveness of two interventions, a cognitive-behavioural group therapy and a psychoeducation group programme, on cortisol secretion in carers of patients with moderate Alzheimer's disease

Study dates
• Publication date: 2014
• Data collection: N/R

Source of funding
The project was funded by the Associa¸c~ao Fundo de Incentivo a Pesquisa (AFIP) for cortisol determinations. T. Aboulafia-Brakha is currently supported by the SNSF [grant number PMCDP1_151305].</td>
<td>parents (N): 3; spouses (N): 21; other/undisclosed (N): 3
• Living with care recipient (yes/not -n) 25/10
Carer recipient (condition)
• Dementias and Alzheimer's disease</td>
<td>• Group</td>
<td>• Sample size statistical power: Achieved</td>
<td><table>
<tr><td>Caring-related morbidity: Depression, BDI (Beck Depression Inventory)</td><td>9.4</td><td>5.7</td><td>12</td><td>7.9</td><td>4.8</td><td>15</td></tr>
<tr><td>Caring-related morbidity: Anxiety, State–Trait Anxiety Inventory (STAI-S), Portuguese version</td><td>45</td><td>8.6</td><td>12</td><td>39</td><td>9.5</td><td>15</td></tr>
<tr><td>Caring-related morbidity: Anxiety, State–Trait Anxiety Inventory (STAI-T), Portuguese version</td><td>47.4</td><td>10.9</td><td>12</td><td>39.6</td><td>8.6</td><td>15</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td>
<td>in sufficient detail
• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - unclear risk: Not described in sufficient detail
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - unclear risk: Insufficient information to permit judgment
• Other risk of bias - low risk</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>Overall RoB - very serious</td></tr>
<tr>
<td>Full citation
Blom, M. M., Zarit, S. H., Groot Zwaaftink, R. B., Cuijpers, P., Pot, A. M., Effectiveness of an Internet intervention for family caregivers of people with dementia: results of a randomized controlled trial, PLoS ONE [Electronic Resource], 10, e0116622, 2015

Ref Id
710241

Country/ies where the study was carried out
The Netherlands

Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, an internet psycho-education course "Mastery over Dementia" and usal care only (e-bulletins), to provide adult</td>
<td>Sample size
N = 251
Intervention (N): 149; Control (N): 96

Characteristics Carer
Age - Mean (SD): Intervention= 61.54 (11.93); control= 60.77 (13.07)
Gender - intervetion (N): 45/104; control (N): 30/66
Relationship to care recipient - spouses (N): 143; other/undisclosed (N): 108
Living with care</td>
<td>Interventions
Intervention (according to the protocol) - Psycho-educational intervention
Name of Intervention (as named in the paper) - Internet course Mastery over Dementia (MoD)
Control (according to the protocol) - TAU
Name of control (as named in the paper) - e-bulletins
Mode of delivery
Online materials + video
Individual
Post-intervention reinforcement</td>
<td>Details
Randomization methods - The assignment to each intervention group was done by a researcher not connected to the study using a computerised random-number generator for block randomization with variable sizes
Blinding methods - Participants did not know whether the intervention they received was the experimental or the comparison intervention. The data were all collected via the Internet with</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 6 months follow - up from intervention competition</i></td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION - MoD</th><th colspan="3">Control</th></tr>
<tr><th>MEAN CHANGE</th><th>SD</th><th>N</th><th>Mean change</th><th>SD</th><th>N</th></tr>
<tr><td>Caring-related morbidity: Depression (Center for Epidemiologic Studies Depression Scale, CES-D)</td><td>2.35</td><td>8.21</td><td>149</td><td>-0.34</td><td>7.51</td><td>96</td></tr>
<tr><td>Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale, HADS-A)</td><td>1.69</td><td>3.26</td><td>149</td><td>0.47</td><td>3.41</td><td>96</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
Random sequence generation - low risk
Allocation concealment low risk
Blinding of participants and personnel - low risk
Blinding of outcome assessment - low risk
Incomplete outcome data - Unclear risk: Attrition bias due to amount of incomplete outcome data in both</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
carers of people with dementia with psychological and emotional support **Study dates** - Publication date: 2015 - Data collection: 2010 - 2012 **Source of funding** The project was funded by Alzheimer Nederland (Dutch Alzheimer's Society), Geriant and the VU University. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.	recipient (yes/not - n) - 148/103 **Carer recipient (condition)** - Dementias and Alzheimer's disease		no intermediary interviewer. - Follow-up outcome measurement - 6 months follow - up from intervention completion - Sample size statistical power: achieved/no achieved - Insufficient information to permit judgment	*** Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used**	intervention groups (Much higher dropout rate in the intervention). For intention-to-treat analysis, missing data due to dropout after baseline were imputed by using demographics, the scores on primary and secondary outcome measures, and additional measures as predictors - Selective reporting - low risk - Other risk of bias - unclear risk: Insufficient information to permit judgment on sample size statistical power

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>Overall RoB - no serious</td></tr>
<tr>
<td>Full citation
Chambers, Sk, Girgis, A, Occhipinti, S, Hutchison, S, Turner, J, McDowell, M, Mihalopoulos, C, Carter, R, Dunn, Jc, A randomized trial comparing two low-intensity psychological interventions for distressed patients with cancer and their caregivers, Oncology nursing forum, 41, E256-66, 2014
Ref Id
710320
Country/ies where the study was carried out
Australia
Study type
Multicentre 2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a single session of nurse-led self-management intervention and a five-session psychologist cognitive behavioral intervention delivered by telephone, to provide adult carers of</td>
<td>Sample size
N = 336
• Intervention (N): 167
• Control (N): 199

Characteristics Carer
• Age - Mean (SD): 52.52 (12.71)
• Gender - 295/41
• Relationship to care recipient - N/R
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)
• Cancer</td>
<td>Interventions
• Intervention (according to the protocol) - CBT
• Control (according to the protocol) - Psycho-educational intervention
• Name of Intervention (as named in the paper) - Psychologist-Delivered Five-Session Cognitive Behavioral Intervention
• Name of control (as named in the paper) - Nurse Single-</td>
<td>Details
• Randomization methods - The assignment to each intervention group was done by randomization stratified by patient and caregiver and state (Queensland versus New South Wales) and occurred in blocks of 10. This sequence was undertaken by the project manager and concealed from investigators.
• Blinding methods - Project staff tracking assessments were blinded to treatment allocation. No</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 6 months follow - up from intervention completion</i></td></tr>
<tr><th>Measure</th><th colspan="3">INTERVENTION - CBT</th><th colspan="3">Control</th></tr>
<tr><th></th><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Cancer-specific distress - Impact of Events Scale (IES)</td><td>29.05</td><td>16.28</td><td>110</td><td>26.34</td><td>17.54</td><td>134</td></tr>
<tr><td>Impact of caring on carer: Positive impact of caring - PTGI—Posttraumatic Growth Inventory</td><td>56.17</td><td>22.46</td><td>110</td><td>51.64</td><td>21.24</td><td>134</td></tr>
<tr><td>Caring-related morbidity:</td><td>12.98</td><td>11.52</td><td>110</td><td>11.58</td><td>11.26</td><td>134</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
• Random sequence generation - low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - low risk
• Incomplete outcome data - low risk: incomplete outcome data was unlikely</td>
</tr>
</table>

<table>
<thead>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
</thead>
<tbody>
<tr>
<td>people with cancer with psychological and emotional support

Study dates
• Publication date: 2014
• Data collection: 2009 - 2010

Source of funding
The project was funded through a grant from beyondblue, Cancer Australia (APP561701), Cancer Council Queensland and New South Wales.</td>
<td></td>
<td>Session Self-Management
Mode of delivery
• Telephone
• Individual
• Post-intervention reinforcement - N/R</td>
<td>details about blinding of participants and personnel.
• Follow-up outcome measurement - 3, 6, and 12 months follow - up from intervention completion
• Sample size statistical power - Achieved</td>
<td>
<table>
<tr><td>Psycological distress, Brief Symptom Inventory –18 (BSI-18)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="7"><i>at 12 months follow - up from intervention completion</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION - CBT</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Cancer-specific distress - Impact of Events Scale (IES)</td><td>26.26</td><td>17.46</td><td>104</td><td>24.55</td><td>18.66</td><td>132</td></tr>
<tr><td>Impact of caring on carer: Positive impact of caring - PTGI—Posttraumatic Growth Inventory</td><td>59.43</td><td>19.47</td><td>104</td><td>54.71</td><td>23.04</td><td>132</td></tr>
</table>
</td>
<td>to have produced bias
• Selective reporting - unclear risk: Insufficient information to permit judgment
• Other risk of bias - low risk

Overall RoB - no serious</td>
</tr>
</tbody>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td><table><tr><td>Caring-related morbidity: Psycological distress, Brief Symptom Inventory –18 (BSI-18)</td><td>12.39</td><td>11.31</td><td>104</td><td>11.08</td><td>12.47</td><td>132</td></tr></table>* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td><td></td></tr>
<tr><td>Full citation
Charlesworth, G., Burnell, K., Crellin, N., Hoare, Z., Hoe, J., Knapp, M., Russell, I., Wenborn, J., Woods, B., Orrell, M., Peer support and reminiscence therapy for people with dementia and their family carers: a factorial pragmatic randomised trial, Journal of Neurology, Neurosurgery & Psychiatry, 87, 1218-1228, 2016
Ref Id
711783
Country/ies where the study was carried out
UK
Study type</td><td>Sample size
N = 291
Intervention 1: peer support (N): 48
Intervention 2: reminiscence therapy (N): 97
Intervention 3: peer support/ reminiscence therapy (N): 97
Control (N): 47</td><td>Interventions
Intervention (according to the protocol) - Psycho-educational intervention (peer support); Emotion-oriented intervention (reminiscence therapy)
Control (according to the protocol) - TAU
Name of Intervention (as named in the paper) - one-to-</td><td>Details
Randomization methods - The assignment to each intervention group was done by randomization stratified 1) by kinship (whether carers were spouses or offspring) and centre; and 2) by the first allocation to keep the four arms in</td><td>Results*<table><tr><td colspan="7"><i>at 12 months follow - up from baseline</i></td></tr><tr><td>Measure</td><td colspan="3">INTERVENTION – PEER SUPPORT</td><td colspan="3">Control</td></tr><tr><td></td><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr><tr><td>Impact of caring on carer: Emotional Loneliness Scale, Caregiver Distress Scale of the Neuropsychiatric Inventory (NPI-D)</td><td>12.63</td><td>-</td><td>48</td><td>10.82</td><td>-</td><td>47</td></tr></table></td><td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
Random sequence generation - low risk
Allocation concealment unclear risk: Not described in sufficient detail
Blinding of participants and</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Factorial pragmatic 4 groups RCT

Aim of the study
This RCT was aimed to evaluate the effectiveness of two interventions -separately or together, an one-to-one peer support and reminiscence therapy - alone or combined (in comparison with usual care), to provide adult carers of people with dementia with psychological and emotional support

Study dates
• Publication date: 2016
• Data collection: 2010 - 2012

Source of funding
The project was funded by the North East London NHS Foundation Trust and funded by the National Institute for Health Research (NIHR) programme grant number RP-PG-0606-1083. Additional sources of funding for each site: North East London; Central and East London CLRN (CEL1042): Northampton; Leicestershire, Northamptonshire, and Rutland CLRN and Thames</td>
<td>Characteristics Carer
• Age - Mean (SD): Intervention 1= 69.0 (10.5)Intervention 2= 66.3 (11.8); Intervention 3= 65.8 (12.4); control= 66.8 (14.7)
• Gender - intervetion 1 (N): 19/29; intervention 2 (N): 27/72; intervention 3 (N): 31/66; control (N): 17/30
• Relationship to care recipient - spouses (N): 230; other/undisclosed (N): 61
• Living with care recipient (yes/not - n) - 193/98</td>
<td>one peer support to family carers from experienced carers (Carer Supporter Programme; CSP); group reminiscence therapy (Remembering Yesterday, Caring Today; RYCT)
• Name of control (as named in the paper) - TAU (N/R)
Mode of delivery
• Face-to-face
• Group; Individual
• Post-intervention reinforcement - N/R</td>
<td>balance. No details about the allocation concealment
• Blinding methods - The nature of the interventions prevented blinding participants and providers to their allocated group. However, outcome assessors were blinded research interviewers by provided interventions independently of their assessments.
• Follow-up outcome measurement - 12 months follow - up from baseline
• Sample size statistical power - Achieved</td>
<td>
<table>
<tr><td>Impact of caring on carer: positive scale from the Positive and Negative Affect Schedule (PANAS)</td><td>30.47</td><td>-</td><td>48</td><td>30.30</td><td>-</td><td>47</td></tr>
<tr><td>Impact of caring on carer: Positive Aspects of Caring (PAC) using the four-item positive aspects subscale from the Carers of Older People in Europe Index (COPE index)</td><td>12.13</td><td>-</td><td>48</td><td>12.11</td><td>-</td><td>47</td></tr>
<tr><td>Impact of caring on carer: 3 item Personal Growth Index (PGI)</td><td>12.03</td><td>-</td><td>48</td><td>12.44</td><td>-</td><td>47</td></tr>
<tr><td>Impact of caring on carer: Quality</td><td>53.41</td><td>-</td><td>48</td><td>52.00</td><td>-</td><td>47</td></tr>
</table>
</td>
<td>personnel - high risk: Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.
• Blinding of outcome assessment - low risk
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - low risk
• Other risk of bias - low risk

Overall RoB - no serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Valley DeNDRoN: Norwich; Norfolk & Suffolk Health Innovation and Education Cluster (HIEC) and East Anglia DeNDRoN: Berkshire; and Thames Valley CLRN and Thames Valley DeNDRoN. The views expressed are those of the authors and do not necessarily reflect those of the NHS, NIHR or the Department of Health.</td>
<td>**Carer recipient (condition)**
• Dementias and Alzheimer's disease</td>
<td></td>
<td></td>
<td>
<table>
<tr><td>of Caregiver–Patient Relationship (QCPR)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Carer quality of life: Mental health-related quality of life, UK Short Form-12 Health Survey -UK SF-12</td><td>41.56</td><td>-</td><td>48</td><td>41.05</td><td>-</td><td>47</td></tr>
<tr><td>Carer quality of life: Physical health-related quality of life, UK Short Form-12 Health Survey -UK SF-12</td><td>43.86</td><td>-</td><td>48</td><td>43.25</td><td>-</td><td>47</td></tr>
<tr><td>Carer quality of life: Health-related quality of life using the EQ-5D</td><td>69.73</td><td>-</td><td>48</td><td>69.35</td><td>-</td><td>47</td></tr>
<tr><td>Caring-related morbidity:</td><td>6.91</td><td>-</td><td>48</td><td>7.26</td><td>-</td><td>47</td></tr>
</table>
</td>
<td></td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Anxiety, Hospital Anxiety and Depression Scale (HADS- A)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Depression, Hospital Anxiety and Depression Scale (HADS-D)</td><td>5.99</td><td>-</td><td>48</td><td>5.97</td><td>-</td><td>47</td></tr>
<tr><td colspan="7"><i>at 12 months follow - up from baseline</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION – REMINESCENCE THERAPY</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Emotional Loneliness Scale, Caregiver Distress Scale of the Neuropsychiatric Inventory (NPI-D)</td><td>11.68</td><td>-</td><td>97</td><td>11.77</td><td>-</td><td>47</td></tr>
</table>
</td><td></td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Impact of caring on carer: positive scale from the Positive and Negative Affect Schedule (PANAS)</td><td>30.85</td><td>-</td><td>97</td><td>29.82</td><td>-</td><td>47</td></tr>
<tr><td>Impact of caring on carer: Positive Aspects of Caring (PAC) using the four-item positive aspects subscale from the Carers of Older People in Europe Index (COPE index)</td><td>12.16</td><td>-</td><td>97</td><td>12.08</td><td>-</td><td>47</td></tr>
<tr><td>Impact of caring on carer: 3 item Personal Growth Index (PGI)</td><td>12.42</td><td>-</td><td>97</td><td>12.02</td><td>-</td><td>47</td></tr>
<tr><td>Impact of caring on carer: Quality</td><td>53.64</td><td>-</td><td>97</td><td>51.77</td><td>-</td><td>47</td></tr>
</table>
</td><td></td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>of Caregiver–Patient Relationship (QCPR)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Carer quality of life: Mental health-related quality of life, UK Short Form-12 Health Survey -UK SF-12</td><td>41.36</td><td>-</td><td>97</td><td>41.25</td><td>-</td><td>47</td></tr>
<tr><td>Carer quality of life: Physical health-related quality of life, UK Short Form-12 Health Survey -UK SF-12</td><td>43.34</td><td>-</td><td>97</td><td>43.37</td><td>-</td><td>47</td></tr>
<tr><td>Carer quality of life: Health-related quality of life using the EQ-5D</td><td>70</td><td>-</td><td>97</td><td>69.08</td><td>-</td><td>47</td></tr>
<tr><td>Caring-related morbidity:</td><td>7.23</td><td>-</td><td>97</td><td>6.93</td><td>-</td><td>47</td></tr>
</table>
</td><td></td></tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments

Anxiety, Hospital Anxiety and Depression Scale (HADS- A)						
Caring-related morbidity: Depression, Hospital Anxiety and Depression Scale (HADS-D)	5.95	-	97	6.02	-	47
at 12 months follow - up from baseline						
Measure	**INTERVENTION – PEER SUPPORT + REMINESCENCE THERAPY**			Control		
	MEAN	**SD**	**N**	Mean	SD	N
Impact of caring on carer: Quality of Caregiver–Patient Relationship (QCPR)	54.20	-	97	51.08	-	47

*** Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used**

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>**Full citation**
Creemers, H, Veldink, Jh, Grupstra, H, Nollet, F, Beelen, A, Berg, Lh, Cluster RCT of case management on patients' quality of life and caregiver strain in ALS, Neurology, 82, 23-31, 2014
Ref Id
710395
Country/ies where the study was carried out
The Netherlands
Study type
Multicentre cluster 2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a ase management plus usual care and usal care only, to provide adult carers of people with amyotrophic lateral sclerosis (ALS) with psychological and emotional support

Study dates
• Publication date: 2014
• Data collection: 2009 - 2011

Source of funding</td>
<td>**Sample size**
N = 126
• Intervention (N): 66
• Control (N): 60

Characteristics Carer
• Age - Mean (SD): Intervention= 63 (11); control= 62 (11)
• Gender - intervention (N): 40/31; control (N): 39/25
• Relationship to care recipient - spouses (N): 97; other/undisclosed (N): 29
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)</td>
<td>**Interventions**
• Intervention (according to the protocol) - Multicomponent (case management)
• Name of Intervention (as named in the paper) - Case management + TAU
• Control (according to the protocol) - TAU
• Name of control (as named in the paper) - TAU (neuropalliative care by multidisciplinary - secondary care teams)
Mode of delivery
• face-to-face
• Individual
• Post-intervention reinforcement - N/R</td>
<td>**Details**
• Randomization methods - The assignment to each intervention group was done by a cluster randomization: multidisciplinary ALS teams as a whole were randomised, instead of individual patients. A researcher performed computer-generated randomization of the teams. Allocation concealment was at the cluster level.
• Blinding methods - Two independent researchers who were blinded to group assignments performed outcome assessments</td>
<td>**Results***
<table>
<tr><td colspan="7">*at 4 months follow - up from baseline*</td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Strain - CSI (Caregiver Strain Index)</td><td>7.1</td><td>3.4</td><td>42</td><td>6.4</td><td>3.1</td><td>37</td></tr>
<tr><td colspan="7">*at 8 months follow - up from baseline*</td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Strain - CSI (Caregiver Strain Index)</td><td>7.0</td><td>3.6</td><td>25</td><td>7.4</td><td>3.5</td><td>20</td></tr>
<tr><td colspan="7">*at 12 months follow - up from baseline*</td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Strain - CSI (Caregive</td><td>7.9</td><td>2.9</td><td>29</td><td>7.3</td><td>3.2</td><td>24</td></tr>
</table>
</td>
<td>**Methodological quality assessed using Cochrane risk of bias tool v2.**
Limitations
• Random sequence generation - low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - low risk
• Blinding of outcome assessment - low risk
• Incomplete outcome data - unclear risk: Not described in sufficient detail
• Selective reporting - low risk
• Other risk of bias - low risk</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>The project was funded by ZonMw, the Netherlands Organization for Health Research and Development, within the Programme Palliative Care grant agreement no. 1150.0008, and the Netherlands ALS Foundation.</td>
<td>Amyotrophic lateral sclerosis (ALS)</td>
<td></td>
<td>during follow-up at 4, 8, and 12 months.
Follow-up outcome measurement - 4, 8, and 12 months follow - up from baseline
Sample size statistical power - Achieved</td>
<td><table><tr><td>r Strain Index)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td>
<td>Overall RoB - no serious</td>
</tr>
<tr>
<td>Full citation
Cristancho-Lacroix, V., Wrobel, J., Cantegreil-Kallen, I., Dub, T., Rouquette, A., Rigaud, A. S., A web-based psychoeducational program for informal caregivers of patients with Alzheimer's disease: a pilot randomized controlled trial, Journal of Medical Internet Research, 17, e117, 2015
Ref Id
710397
Country/ies where the study was carried out
France
Study type
2 groups RCT</td>
<td>Sample size
N = 49
Intervention (N): 25
Control (N): 24
Characteristics Carer
Age - Mean (SD): Intervention= 64.2 (10.3); control= 59.0 (12.4)
Gender - intervetion (N): 9/16; control (N): 9/16</td>
<td>Interventions
Intervention (according to the protocol) - Psycho-educational intervention
Control (according to the protocol) - TAU
Name of Intervention (as named in the paper) - Web-Based Psychoeducational Program
Name of control (as named in the paper) - TAU (information only)</td>
<td>Details
Randomization methods - The assignment to each intervention group was randomised offline in 2 parallel groups based on a computer-generated randomization list using blocking and stratification by sex and relationship (spouses</td>
<td>Results*<table>
<tr><td colspan="7"><i>at 6 months follow - up from baseline</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Burden, ZBI (Zarit Burden Interview)</td><td>39.6</td><td>15.7</td><td>22</td><td>34.8</td><td>15.9</td><td>21</td></tr>
<tr><td>Impact of caring on carer: Burden, RMBPC (revised memory and behaviour</td><td>2.3</td><td>0.5</td><td>22</td><td>2.1</td><td>0.6</td><td>21</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
Random sequence generation - low risk
Allocation concealment - low risk
Blinding of participants and personnel - high risk: Performance bias due to</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a web-based fully automated psychoeducational program (called Diapason) plus usual care and usal care only, to provide adult carers of people with Alzheimer's disease with psychological and emotional support

Study dates
Publication date: 2015
Data collection: 2011 - 2013
Source of funding
The project was funded by the French Health Ministry (Projet de Recherche en Qualité Hospitalière 2009-PREQHOS 2009) and by the Fondation Méderic Alzheimer project grants 2012-2014.</td>
<td>Relationship to care recipient - daughters-sons (N): 32; other/undisclosed (N): 17
Living with care recipient (yes/not - n) - 22/27
Carer recipient (condition)
Dementias and Alzheimer's disease</td>
<td>Mode of delivery
Online materials
Individual
Post-intervention reinforcement - N/R</td>
<td>versus nonspouses)
Blinding methods - No blinding of participants, personnel or outcome assessors
Follow-up outcome measurement - 3, and 6 months follow - up from baseline
Sample size statistical power - No achieved</td>
<td><table>
<tr><td>checklist) - reaction</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Perceived stress, PSS-14</td><td>25</td><td>9.9</td><td>22</td><td>23.8</td><td>6.9</td><td>21</td></tr>
<tr><td>Caring-related morbidity: Depression, BDI-II (Beck Depression Inventory-second version)</td><td>12.4</td><td>11.6</td><td>22</td><td>8.8</td><td>7.2</td><td>21</td></tr>
<tr><td>Caring-related morbidity: Perceived health status, NHP (Nottingham Health Profile) – social isolation</td><td>16.5</td><td>23.4</td><td>22</td><td>14.8</td><td>20.7</td><td>21</td></tr>
<tr><td>Caring-related morbidity: Perceived health status, NHP (Nottingham Health Profile) - emotions</td><td>26.6</td><td>25.6</td><td>22</td><td>17.2</td><td>19.2</td><td>21</td></tr>
<tr><td>Caring-related morbidity: Perceived health status,</td><td>35.9</td><td>39.4</td><td>22</td><td>35.6</td><td>41.6</td><td>21</td></tr>
</table></td>
<td>knowledge of the allocated interventions by participants and personnel during the study.
Blinding of outcome assessment - high risk: Detection bias due to knowledge of the allocated interventions by outcome assessors.
Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
Selective reporting - low risk
Other risk of bias - high risk: Sample size statistical power has been not</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results							Comments
				NHP (Nottingham Health Profile) -energy							achieved. As well, At baseline, a groups were imbalanced regarding the number of weekly hours of professional help and IADL and depression scores Overall RoB - very serious
				Carer choice/control/ efficacy: Self-efficacy - RSCS (Revised Scale for Caregiving Self-Efficacy), obtaining respite	54.07	30.06	22	48.6	24.5	21	
				Carer choice/control/ efficacy: Self-efficacy - RSCS (Revised Scale for Caregiving Self-Efficacy), responding to patients' behaviours	71.5	23.1	22	68.4	15.3	21	
				Carer choice/control/ efficacy: Self-efficacy - RSCS (Revised Scale for Caregiving Self-Efficacy), controlling upsetting behaviours	63.4	20.8	22	64	13.7	21	

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>*** Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used**</td><td></td></tr>
<tr>
<td>**Full citation**
Hirano, A, Umegaki, H, Suzuki, Y, Hayashi, T, Kuzuya, M, Effects of leisure activities at home on perceived care burden and the endocrine system of caregivers of dementia patients: a randomized controlled study, International Psychogeriatrics, 28, 261-268, 2016
Ref Id
712142
Country/ies where the study was carried out
Japan
Study type
2 groups RCT

Aim of the study
This mixed-methods research was aimed to compare the effectiveness and the acceptability of two interventions, a periodic leisure activity program (30 min/3 times/week for 24 weeks) and usal care, to</td>
<td>**Sample size**
N = 42
• Intervention (N): 21
• Control (N): 21

Characteristics Carer
• Age - Mean (SD): Intervention= 73.9 (4.5); control= 76.2 (4.7)
• Gender - intervetion (N): 10/11; control (N): 7/14
• Relationship to care recipient - N/R
• Living with care recipient (yes/not - n) - N/R</td>
<td>**Interventions**
• Intervention (according to the protocol) - Activity-based intervention
• Control (according to the protocol) - TAU
• Name of Intervention (as named in the paper) - leisure activity program (30 min/3 times/week for 24 weeks)
• Name of control (as named in the paper) - TAU (N/R: "normal care activities")
Mode of delivery
• Face-to-face
• Individual
• Post-intervention reinforcement - N/R</td>
<td>**Details**
• Randomization methods - The assignment to each intervention group was randomised, in sequential order before investigating baseline characteristics. No details about the allocation concealment
• Blinding methods - No details
• Follow-up outcome measurement - post-intervention
• Sample size statistical power (achieved/no achieved) - Insufficient</td>
<td>**Results***
<table>
<tr><td colspan="7">*at post-intervention (follow-up not stated)*</td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN CHANGE</th><th>SD</th><th>N</th><th>Mean change</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Burden, ZBI (Zarit Burden Interview)</td><td>-3.1</td><td>0.1</td><td>21</td><td>1.3</td><td>1.7</td><td>21</td></tr>
</table>
*** Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used**</td>
<td>**Methodological quality assessed using Cochrane risk of bias tool v2. Limitations**
• Random sequence generation - high risk: Selection bias (biased allocation to interventions) due to inadequate generation of a randomized sequence
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and personnel - unclear risk: Not</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
provide adult carers of people with dementia with psychological and emotional support **Study dates** - Publication date: 2016 - Data collection: N/R **Source of funding** The project was funded by a Grant-in-Aid for Scientific Research from the Japan Society for the Promotion of Science	**Carer recipient (condition)** - Dementias and Alzheimer's disease		information to permit judgment		described in sufficient detail - Blinding of outcome assessment - unclear risk: Not described in sufficient detail - Incomplete outcome data - unclear risk: Not described in sufficient detail - Selective reporting - unclear risk: Insufficient information to permit judgment - Other risk of bias - unclear risk: Insufficient information to permit judgment on sample size statistical power

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>Overall RoB - very serious</td></tr>
<tr>
<td>Full citation
Hubbard, A. A., McEvoy, P. M., Smith, L., Kane, R. T., Brief group psychoeducation for caregivers of individuals with bipolar disorder: A randomized controlled trial, Journal of Affective Disorders, 200, 31-36, 2016
Ref Id
712169
Country/ies where the study was carried out
Australia
Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a brief group psychoeducation and wait-list control, to provide adult carers of people with bipolar disorders with psychological and emotional support

Study dates
• Publication date: 2016
• Data collection: N/R</td>
<td>Sample size
N = 32
• Intervention (N): 18
• Control (N): 14

Characteristics Carer
• Age - Mean (SD): Intervention= 50.50(11.63); control= 45.07(18.87)
• Gender - intervetion (N): 6/8; control (N): 7/11
• Relationship to care recipient - parents (N): 18; spouses (N): 11; daughters-sons (N): 0; sibling (N): 1; other/undisclosed (N): 2</td>
<td>Interventions
• Intervention (according to the protocol) - Psycho-educational intervention
• Control (according to the protocol) - WLC
• Name of Intervention (as named in the paper) - Brief group psychoeducation
• Name of control (as named in the paper) - Waitlist group
Mode of delivery
• Face-to-face
• Group
• Post-intervention reinforcement - Y</td>
<td>Details
• Randomization methods - The assignment to each intervention group was randomised using a computerised random number generator. No details about the allocation concealment
• Blinding methods - Look at "randomization methods". No details about blinding of outcome assessors
• Follow-up outcome measurement - 1 month follow - up from intervention completion</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 1 month follow - up from intervention completition</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Burden, BAS (Burden Assessment Scale)</td><td>34.11</td><td>1.61</td><td>14</td><td>46.64</td><td>2.24</td><td>14</td></tr>
<tr><td>Caring-related morbidity: Depression and anxiety, DASS-21 (Depression Anxiety and Stress Scale-21)</td><td>29.61</td><td>1.78</td><td>14</td><td>30.64</td><td>3.29</td><td>14</td></tr>
<tr><td>Carer choice/control/efficacy: Knowledge - Knowledge of Bipolar Disorder Scale</td><td>34.39</td><td>0.64</td><td>14</td><td>21.43</td><td>2.14</td><td>14</td></tr>
<tr><td>Carer choice/control/efficacy: Self-</td><td>94.06</td><td>1.54</td><td>14</td><td>70.93</td><td>6.56</td><td>14</td></tr>
</table>
</td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
• Random sequence generation - low risk
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and personnel - low risk
• Blinding of outcome assessment - unclear risk: Not described in sufficient detail
• Incomplete outcome data - low risk:</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Source of funding
N/R</td>
<td>• Living with care recipient (yes/not - n) - 14/18
Carer recipient (condition)
• Bipolar disorder</td>
<td></td>
<td>• Sample size statistical power - Achieved</td>
<td><table><tr><td>efficacy - Bipolar Self-efficacy Scale</td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td>
<td>incomplete outcome data was unlikely to have produced bias
• Selective reporting - low risk
• Other risk of bias - low risk

Overall RoB - no serious</td>
</tr>
<tr>
<td>Full citation
Jones CJ, Hayward M, Brown A, Clark E, Bird D, Harwood G, Scott C, Hillemann A, Smith HE. Feasibility and Participant Experiences of a Written Emotional Disclosure Intervention for Parental Caregivers of People with Psychosis. Stress Health 2016;32(5):485-493
Ref Id
712236
Country/ies where the study was carried out
UK
Study type
2 groups (Mixed-methods) RCT</td>
<td>Sample size
N = 28
• Intervention (N): 14
• Control (N): 14

Characteristics Carer
• Age - Mean (SD): Intervention= 59.7 (9.51); control= 59.3 (6.77)
• Gender - intervention (N): 1/13; control (N): 0/14</td>
<td>Interventions
• Intervention (according to the protocol) - Cognitive-/emotion-oriented/activity-based interventions
• Name of Intervention (as named in the paper) - Written emotional disclosure (WED)
• Name of control (as named in the paper) – ‘controlled writing task’
Mode of delivery
• Self-guided</td>
<td>Details
• Randomization methods - The assignment to each intervention group was randomised using a computerised random number generator blocks of four. No details about the allocation concealment
• Blinding methods – Double blind</td>
<td>Results*<table>
<tr><td></td><td colspan="3">Intervention</td><td colspan="3">Control</td></tr>
<tr><td></td><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>PHQ</td><td>6.07</td><td>3.48</td><td>14</td><td>8.79</td><td>6.81</td><td>14</td></tr>
<tr><td>HADS-A</td><td>9.57</td><td>4.35</td><td>14</td><td>9.71</td><td>3.58</td><td>14</td></tr>
<tr><td>HADS-D</td><td>5.5</td><td>2.35</td><td>14</td><td>6.14</td><td>3.92</td><td>14</td></tr>
<tr><td>CWS v2</td><td>78.64</td><td>23.8</td><td>14</td><td>69.86</td><td>23.55</td><td>14</td></tr>
<tr><td>RAND-physical</td><td>72.38</td><td>23.16</td><td>14</td><td>54.74</td><td>31.66</td><td>14</td></tr>
<tr><td>RAND Mental</td><td>57.47</td><td>15.68</td><td>14</td><td>58.14</td><td>21.23</td><td>14</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
• Random sequence generation - low risk
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Aim of the study The aims of this mixed-methods RCT were to explore the feasibility and acceptability of written emotional disclosure and a control writing task in a feasibility trial of caregivers of people with psychosis. **Study dates** • Publication date: 2016 • Data collection: N/R **Source of funding** N/R	• Relationship to care recipient – N/R • Living with care recipient (yes/not - n) – 28/0 **Carer recipient (condition)** • Psychosis	• Individual • Post-intervention reinforcement – N/R	• Follow-up outcome measurement - 3 months follow - up from intervention completion • Sample size statistical power – Not achieved (It was not satistically powered study, as this was a feasibility mixed-methods trial and the focus was more on the qualitative part)	*** Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used**	personnel - low risk • Blinding of outcome assessment - low risk • Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias • Selective reporting - low risk • Other risk of bias - high risk: Sample size statistical power has been not achieved (It was not satistically powered study, as this was a feasibility mixed-methods trial and the focus was more on the qualitative part)

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>Overall RoB - no serious</td></tr>
<tr>
<td>Full citation
Leach, Mj, Francis, A, Ziaian, T, Transcendental Meditation for the improvement of health and wellbeing in community-dwelling dementia caregivers: a randomised wait-list controlled trial, BMC complementary and alternative medicine, 15, 2015
Ref Id
710852
Country/ies where the study was carried out
Australia
Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a 12-week (14-hour) transcendental meditation training program plus 12-week follow-up and 24-week wait-list control, to provide adult carers of people with dementia with</td>
<td>Sample size
N = 17
• Intervention (N): 8
• Control (N): 9

Characteristics Carer
• Age - Mean (SD): Intervention= 69.4 (7.3); control= 63.2 (8.8)
• Gender - intervetion (N): 1/7; control (N): 1/8
• Relationship to care recipient - parents (N): 0; spouses (N): 11; daughters-sons (N): 6; sibling (N): 0;</td>
<td>Interventions
• Intervention (according to the protocol) - Emotion-oriented intervention (Transcendental Meditation)
• Control (according to the protocol) - WLC
• Name of Intervention (as named in the paper) - 12-week (14-hour) Transcendental Meditation training program plus 12-week follow-up
• Name of control (as named in the paper) - 24-week wait-list control
Mode of delivery
• Face-to-face
• Individual</td>
<td>Details
• Randomization methods - The assignment to each intervention group was randomised using block randomization with computer-generated randomly permuted blocks of four. Randomization codes were hold in sequentially numbered opaque sealed envelopes.
• Blinding methods - Participant blinding was not possible in this trial due to the nature of the intervention,</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 12 weeks follow - up from baseline</i></td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Carer quality of life: AQoL-8D assessment of quality of life (8-dimension) instrument – utility score</td><td>0.74</td><td>0.21</td><td>8</td><td>0.67</td><td>0.10</td><td>9</td></tr>
<tr><td colspan="7"><i>at 24 weeks follow - up from baseline</i></td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Carer quality of life: AQoL-8D assessment of quality of</td><td>0.70</td><td>0.21</td><td>8</td><td>0.71</td><td>0.12</td><td>9</td></tr>
</table>
</td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2. Limitations
• Random sequence generation - low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - low risk
• Blinding of outcome assessment - low risk
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>psychological and emotional support

Study dates
• Publication date: 2015
• Data collection: 2013 - 2014
Source of funding
The project was funded by by an Alzheimer’s Australia Dementia Research Foundation grant, with additional funding provided by the West Torrens City Council and the School of Nursing & Midwifery, University of South Australia.</td>
<td>other/undisclosed (N): 0
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)
• Dementias and Alzheimer's disease</td>
<td>• Post-intervention reinforcement - N/R</td>
<td>staff involved in data collection, data entry, and data analysis were blinded to treatment assignment.
• Follow-up outcome measurement - 24 weeks follow - up from baseline
• Sample size statistical power - Achieved</td>
<td><table>
<tr><td>life (8-dimension) instrument – utility score</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td>
<td>• Selective reporting - low risk
• Other risk of bias - low risk

Overall RoB - no serious</td>
</tr>
<tr>
<td>Full citation
Liljeroos, M, Agren, S, Jaarsma, T, Arestedt, K, Stromberg, A, Long-term effects of a dyadic psycho-educational intervention on caregiver burden and morbidity in partners of patients with heart failure: a randomized controlled trial, Quality of Life Research, 1-13, 2016
Ref Id
712386
Country/ies where the study was carried out</td>
<td>Sample size
N = 155
• Intervention (N): 71
• Control (N): 84

Characteristics Carer
• Age - Mean (SD): Intervention= 69 (13); control= 73 (10)</td>
<td>Interventions
• Intervention (according to the protocol) - Psycho-educational intervention
• Control (according to the protocol) - no intervention
• Name of Intervention (as named in the paper) - dyadic educational and psychosocial</td>
<td>Details
• Randomization methods - The assignment to each intervention group was randomised using random-number table. No details about the allocation concealment
• Blinding methods - Morbidity data</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 24 months follow - up from baseline</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>MEAN CHANGE</td><td>SD</td><td>N</td><td>Mean change</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Burden, Total caregiver burden</td><td>0.10</td><td>0.46</td><td>44</td><td>0.08</td><td>0.36</td><td>52</td></tr>
<tr><td>Impact of caring on</td><td>0.15</td><td>0.55</td><td>44</td><td>0.17</td><td>0.49</td><td>52</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2. Limitations
• Random sequence generation - low risk
• Allocation concealment - unclear risk: Not described in sufficient detail</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Sweden
Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a dyadic educational and psychosocial intervention plus usual care and usal care only, to provide adult carers of people with heart failure with psychological and emotional support

Study dates
• Publication date: 2016
• Data collection: N/R

Source of funding
The project was funded by grants from the Swedish Institute for Health Sciences.</td>
<td>• Gender - intervetion (N): 49/22; control (N): 68/16
• Relationship to care recipient - N/R
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)
• Heart failure</td>
<td>intervention plus TAU
• Name of control (as named in the paper) - TAU (no intervention: focus only on care recipients)
Mode of delivery
• Face-to-face + booklets + online materials
• Group
• Post-intervention reinforcement - N/R</td>
<td>regarding time to first admission and numbers of admissions were collected from partners' medical records by the first author who was blinded to group assignment.
• Follow-up outcome measurement - 24 months follow - up from baseline
• Sample size statistical power - Achieved</td>
<td>
<table>
<tr><td>carer: Burden, General strain</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Impact of caring on carer: Burden, Isolation</td><td>0.03</td><td>0.56</td><td>44</td><td>0.75</td><td>0.67</td><td>52</td></tr>
<tr><td>Impact of caring on carer: Burden, Disappointment</td><td>0.05</td><td>0.61</td><td>44</td><td>0.05</td><td>0.52</td><td>52</td></tr>
<tr><td>Impact of caring on carer: Burden, Emotional</td><td>0.02</td><td>0.50</td><td>44</td><td>0.16</td><td>0.67</td><td>52</td></tr>
<tr><td>Impact of caring on carer: Burden, Environment</td><td>0.34</td><td>0.70</td><td>44</td><td>0.15</td><td>0.72</td><td>52</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used
</td>
<td>• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - unclear risk: Not described in sufficient detail
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - low risk
• Other risk of bias - low risk

Overall RoB - serious</td>
</tr>
<tr>
<td>Full citation
Livingston, G., Barber, J., Rapaport, P., Knapp, M.,</td>
<td>Sample size
N=260</td>
<td>Interventions
Intervention: Coping Skills traiing</td>
<td>Details
Randomisation
stratified by health</td>
<td>Results*
Outcomes at 8 months</td>
<td>Methodological quality assessed using</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Griffin, M., Romeo, R., King, D., Livingston, D., Lewis-Holmes, E., Mummery, C., Walker, Z., Hoe, J., Cooper, C., START (STrAtegies for RelaTives) study: a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of carers of people with dementia, Health Technology Assessment, 18, i-xxvi+1-242, 2014
Ref Id
710884
Country/ies where the study was carried out
UK
Study type
RCT

Aim of the study
To evaluate effectiveness and cost-effectiveness of manual-based coping skills training for dementia carers in short- and long-term

Study dates
11/2009 to 06/2013</td>
<td>Intervention, n=173
Control, n=87

Characteristics
[Intervention; Control]
Carer characteristics
Age (years): 62.0 (14.6); 56.1 (12.3)
Sex (M/F): 57/116; 25/62
White UK/white other/black + minority: 131/10/31; 65/5/17
HADS-Total: 13.5 (7.3), n=172; 14.8 (7.4)
HADS-A: 8.1 (4.4), n=172; 9.3 (4.3)
HADS-D: 5.4 (3.8), n=172; 5.5 (3.9)
HSQ Mental Health: 58.3 (22.4), n=171; 58.2 (21.7)</td>
<td>Control: TAU</td>
<td>trust using random permuted blocks with ratio of 2:1 (invention: TAU). Participants assessed at baseline, 4, 8, 12 and 24 months.
Coping Skills training
START intervention consists in manualised 8 sessions covering
Session 1: Psychoeducation about dementia, carer stress, understanding behaviour of care recipient
Sessions 2-5: Difficult behaviours, behavioural management techniques, carer self-care, communication, coping strategies, emotional support, reframing
Session 6: Future needs of care</td>
<td>
<table>
<tr><th>Outcome</th><th>Inter-vention</th><th>N</th><th>Control</th><th>N</th></tr>
<tr><td>HADS-Total</td><td>12.9 (7.9)</td><td>133</td><td>14.9 (8.0)</td><td>71</td></tr>
<tr><td>HSQ- mental health</td><td>58.6 (22.0)</td><td>122</td><td>58.2 (19.2)</td><td>66</td></tr>
<tr><td>HADS-A</td><td>7.6 (4.4)</td><td>133</td><td>8.8 (4.4)</td><td>71</td></tr>
<tr><td>HADS-D</td><td>5.3 (4.0)</td><td>133</td><td>6.1 (4.2)</td><td>71</td></tr>
<tr><td>MCTS (at least one item with score ≥2)*</td><td>28</td><td>99</td><td>18</td><td>52</td></tr>
<tr><td colspan="5">*Data from Cooper 2016</td></tr>
</table>

At 12 months
<table>
<tr><th>Outcome</th><th>Inter-vention</th><th>N</th><th>Control</th><th>N</th></tr>
<tr><td>HADS-T</td><td>12.5 (7.9)</td><td>138</td><td>14.6 (8.9)</td><td>64</td></tr>
<tr><td>HSQ mental health</td><td>61.9 (20.6)</td><td>121</td><td>56.2 (22.5)</td><td>61</td></tr>
<tr><td>HADS-A</td><td>7.5 (4.4)</td><td>138</td><td>8.8 (5.1)</td><td>67</td></tr>
<tr><td>HADS-D</td><td>5.0 (4.2)</td><td>138</td><td>5.9 (4.3)</td><td>67</td></tr>
<tr><td>MCTS (at least one item with score ≥2)*</td><td>33</td><td>97</td><td>19</td><td>46</td></tr>
<tr><td colspan="5">*Data from Cooper 2016</td></tr>
</table>
At 24 months
</td>
<td>**Cochrane risk of bias tool v2.**
Limitations
- Random sequence generation: Low risk (online computer-generated randomisation system, stratified by health trust using random permuted blocks)
- Allocation concealment: Low risk (central allocation)
- Blinding of participants/personnel: High risk (Participants/personnel not blinded to group allocation)
- Blinding of outcome assessment: Low risk</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Setting
Home, NHS trust or participating neurology clinic

Source of funding
Health Technology Assessment programme of NIHR</td>
<td>MCTS Total: 2.8 (2.9), n=172; 2.7 (3.1)
Zarit Total: 35.3(18.4), n=165; 38.1 (17.0), n=84
Work situation (FT/PT/retired/Not working): 36/27/80/30; 28/20/23/16

Care recipient characteristics
Age (years): 79.9 (8.3); 78.0 (9.9)
Sex (M/F): 71/102; 37/50
White UK/white other/black + minority:126/14/33; 61/6/20
Living with carer: 65.3%/57.5%

Inclusion criteria
Family carers of people with dementia</td>
<td></td>
<td>recipient, UK-specific care and legal planning
Session 7: Planning pleasant activities
Session 8: Maintaining learned skills over time
Every session ended with stress reduction technique and homework. Relaxation exercises (inc. focused breathing, guided imagery, meditation) also used in sessions.
TAU
Presumed to consist in standard based on NICE guidelines with services based around person with dementia (for example medical, psychological and social treatment).</td>
<td>
<table>
<tr><th>Outcome</th><th>Inter-vention</th><th>N</th><th>Control</th><th>N</th></tr>
<tr><td>HADS-T</td><td>13.6 (8.3)</td><td>132</td><td>15.5 (9.5)</td><td>64</td></tr>
<tr><td>HSQ mental health</td><td>60.2 (19.8)</td><td>113</td><td>55.0 (21.2)</td><td>55</td></tr>
<tr><td>HADS-A</td><td>8.1 (4.9)</td><td>132</td><td>9.2 (5.3)</td><td>64</td></tr>
<tr><td>HADS-D</td><td>5.5 (4.2)</td><td>132</td><td>6.3 (4.9)</td><td>64</td></tr>
<tr><td>MCTS (at least one item with score ≥2)*</td><td>27</td><td>84</td><td>10</td><td>40</td></tr>
<tr><td colspan="5">*Data from Cooper 2016</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used
</td>
<td>(assessors blinding to group allocation)
• Incomplete outcome data: High risk (missing data likely related to true outcome with imbalance in reasons for missing data across groups)
• Selective reporting: Low risk (study protocol available, all outcomes reported)
• Other bias:

Other information
At 8-mo FU, 21 and 12 carers in intervention and control group had withdrawn or dropped out. Reasons included carer died (1 each</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	recruited from 3 mental health trusts and a neurology clinic (Dementia Research Centre) who provide at least weekly emotional or practical support, and self-identify as primary carer of someone with dementia not living in 24-hr care provide informed consent **Exclusion criteria** Carers who were not able to provide informed consent current participating in another RCT as a carer				group), wanting intervention treatment (4 in TAU group), did not like intervention (3 in intervention group); 6 provided no reason (5 intervention, 1 TAU).

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td>lived >1.5 hrs travelling time from researcher base</td><td></td><td></td><td></td><td></td></tr>
<tr>
<td>Full citation
Losada, Andres, Marquez-Gonzalez, Maria, Romero-Moreno, Rosa, Mausbach, Brent T., Lopez, Javier, Fernandez-Fernandez, Virginia, Nogales-Gonzalez, Celia, Cognitive-behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for dementia family caregivers with significant depressive symptoms: Results of a randomized clinical trial, Journal of Consulting and Clinical Psychology, 83, 760-772, 2015
Ref Id
710895
Country/ies where the study was carried out
Spain
Study type
3 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of three interventions, a</td>
<td>Sample size
N = 135
• Intervention 1: CBT (N): 42
• Intervention 2: ACT (N): 45
• Control (N): 48

Characteristics
Carer
• Age - Mean (SD): Intervention 1= 61.48 (12.40); Intervention 2= 61.69 (15.31); control= 62.28 (12.92)
• Gender - intervention 1 (N): 4/38; intervention 2 (N): 8/37;</td>
<td>Interventions
• Intervention (according to the protocol) - CBT; Emotion-oriented intervention (Acceptance and Commitment Therapy)
• Control (according to the protocol) - TAU
• Name of Intervention (as named in the paper) - cognitive –behavioural therapy; Acceptance and Commitment Therapy
• Name of control (as named in the paper) - Minimal support control group (2-hr workshop, including psychoeducation on dementia)</td>
<td>Details
• Randomization methods - The assignment to each intervention group was randomised using using computer-generated random numbers. No details about the allocation concealment
• Blinding methods - All the assessments were done by psychologists trained in the assessment protocol who were blind to treatment conditions and to the main</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 6 months follow - up from intervention completion</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION –CBT</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SE</td><td>N</td><td>Mean</td><td>SE</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, Pleasant events</td><td>5.39</td><td>0.44</td><td>42</td><td>5.70</td><td>0.41</td><td>48</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, Dysfunctional thoughts</td><td>19.01</td><td>2.31</td><td>42</td><td>21.10</td><td>2.18</td><td>48</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, Caregiving experiential avoidance</td><td>42.92</td><td>1.84</td><td>42</td><td>43.43</td><td>1.72</td><td>48</td></tr>
</table>
</td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
• Random sequence generation - low risk
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - low risk
• Incomplete outcome</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>cognitive–behavioural therapy, Acceptance and Commitment Therapy and minimal support (2-hr workshop, including psychoeducation on dementia), to provide adult carers with significant depressive symptom of people with dementia with psychological and emotional support

Study dates
• Publication date: 2015
• Data collection: N/R

Source of funding
The project was funded by Grant PSI2009-08132 from the Spanish Ministry of Science and Innovation and Grant PSI2012-31293 from the Spanish Ministry of Economy and Competitiveness</td>
<td>control (N): 10/38
• Relationship to care recipient - parents (N): 68; spouses (N): 55; other/undisclosed (N): 12
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)
• Dementias and Alzheimer's disease</td>
<td>Mode of delivery
• face-to-face
• Individual
• Post-intervention reinforcement - Y</td>
<td>hypotheses of the study.
• Follow-up outcome measurement - 6 months follow - up from intervention completion
• Sample size statistical power - Achieved</td>
<td>
<table>
<tr><td>Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale)</td><td>18.39</td><td>2.04</td><td>42</td><td>25.27</td><td>1.91</td><td>48</td></tr>
<tr><td>Caring-related morbidity: Anxiety (measure no stated)</td><td>13.49</td><td>1.58</td><td>42</td><td>17.39</td><td>1.48</td><td>48</td></tr>
<tr><td colspan="7"><i>at 6 months follow - up from intervention completion</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION –ACT</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SE</td><td>N</td><td>Mean</td><td>SE</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, Pleasant events</td><td>5.67</td><td>0.64</td><td>45</td><td>5.70</td><td>0.41</td><td>48</td></tr>
<tr><td>Impact of caring on carer: Subjective burden,</td><td>17.90</td><td>2.09</td><td>45</td><td>21.10</td><td>2.18</td><td>48</td></tr>
</table>
</td>
<td>data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - unclear risk: Insufficient information to permit judgment
• Other risk of bias - low risk

Overall RoB - serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Dysfunctional thoughts</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Impact of caring on carer: Subjective burden, Caregiving experiential avoidance</td><td>38.76</td><td>1.63</td><td>45</td><td>43.43</td><td>1.72</td><td>48</td></tr>
<tr><td>Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale)</td><td>21.87</td><td>1.81</td><td>45</td><td>25.27</td><td>1.91</td><td>48</td></tr>
<tr><td>Caring-related morbidity: Anxiety (measure no stated)</td><td>14.27</td><td>1.41</td><td>45</td><td>17.39</td><td>1.48</td><td>48</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used
</td><td></td></tr>
<tr><td>Full citation
Martin-Carrasco, Manuel, Dominguez-Panchon, Ana Isabel, Gonzalez-Fraile,</td><td>Sample size
N = 238
• Intervention (N): 115</td><td>Interventions
• Intervention (according to the protocol) - Psych</td><td>Details
• Randomization methods - Randomization was</td><td>Results*
<table>
<tr><td colspan="3"><i>at 4 months follow - up from intervention competition</i></td></tr>
<tr><td>Measure</td><td>INTERVENTION</td><td>Control</td></tr>
</table>
</td><td>Methodological quality assessed using</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Eduardo, Munoz-Hermoso, Paula, Ballesteros, Javier, Effectiveness of a psychoeducational intervention group program in the reduction of the burden experienced by caregivers of patients with dementia: The EDUCA-II randomized trial, Alzheimer Disease and Associated Disorders, 28, 79-87, 2014
Ref Id
710937
Country/ies where the study was carried out
Spain
Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a psychoeducational Intervention Group Programme plus usual care and usual care only, to provide adult carers of people with dementia with psychological and emotional support

Study dates
Publication date: 2014</td>
<td>Control (N): 123
Characteristics Carer
Age - Mean (SD): Intervention= 61.0 (13.6); control= 63.2 (14.1)
Gender - intervention (N): 26/89; control (N): 28/95
Relationship to care recipient - parents (N): 0; spouses (N): 117; daughters-sons (N): 108; sibling (N): 0; other/undisclosed (N): 6
Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)</td>
<td>o-educational intervention
Control (according to the protocol) - TAU
Name of Intervention (as named in the paper) Psychoeducational Intervention Group Programme + TAU
Name of control (as named in the paper) - TAU (standard support delivered to carers from the day center or memory clinic where the people with dementia were treated)
Mode of delivery
face-to-face
Individual
Post-intervention reinforcement - N/R</td>
<td>done centrally immediately after receiving the numerically coded dyads patient-caregiver for each research site. It used block randomization with random block sizes of 1 to 4 according to the R function “blockrand.”
Blinding methods - All outcomes were assessed by a blinded researcher not involved in the administration of the intervention. No details on blinding of participants and personnel
Follow-up outcome measurement - 4 months follow - up from</td>
<td><table>
<tr><th></th><th>MEAN CHANGE - PIP</th><th>SD</th><th>N</th><th>Mean change</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Burden, ZBI (Zarit Burden Interview)</td><td>-1.17</td><td>12.3</td><td>115</td><td>-0.63</td><td>12.0</td><td>123</td></tr>
<tr><td>Caring-related morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items)</td><td>-4.76</td><td>12.6</td><td>115</td><td>-2.42</td><td>10.3</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-12 (Short-Form Health Survey 12), Physical function</td><td>-1.02</td><td>30.0</td><td>115</td><td>0.0</td><td>41.3</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-</td><td>3.09</td><td>26.9</td><td>115</td><td>1.30</td><td>26.7</td><td>123</td></tr>
</table></td>
<td>Cochrane risk of bias tool v2. Limitations
Random sequence generation - low risk
Allocation concealment - low risk
Blinding of participants and personnel - unclear risk: Not described in sufficient detail
Blinding of outcome assessment - low risk
Incomplete outcome data - high risk: Attrition bias due to amount of incomplete outcome data in both intervention groups. (Much higher dropout</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>• Data collection: 2009 - 2010

Source of funding
The project was funded by Instituto de Salud Carlos III, Spain (PI08/90812), with complementary support by BIOEF (BIO09/EM/001). FOR EXAMPLE-F. and J.B. are supported by UPV/EHU (GIU10/24 and UFI11/35).</td>
<td>• Dementias and Alzheimer's disease</td>
<td></td>
<td>intervention completion
• Sample size statistical power: achieved/no achieved - Achieved</td>
<td>
<table>
<tr><td>12, Role physical</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Carer quality of life: SF-12, Bodily pain</td><td>6.38</td><td>25.7</td><td>115</td><td>-0.47</td><td>34.3</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-12, General health</td><td>-3.12</td><td>19.3</td><td>115</td><td>1.89</td><td>20</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-12, Vitality</td><td>2.04</td><td>28.6</td><td>115</td><td>-1.67</td><td>29.5</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-12, Social functioning</td><td>-4.08</td><td>31.6</td><td>115</td><td>-3.30</td><td>30.3</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-12, Role emotional</td><td>-3.06</td><td>27.7</td><td>115</td><td>1.19</td><td>24.5</td><td>123</td></tr>
<tr><td>Carer quality of life: SF-12, Mental health</td><td>1.53</td><td>23.8</td><td>115</td><td>2.76</td><td>19.2</td><td>123</td></tr>
</table>
</td>
<td>rate in the control group)
• Selective reporting - low risk
• Other risk of bias - low risk

Overall RoB - serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td><td></td></tr>
<tr>
<td>Full citation
Martin-Carrasco, M., Fernandez-Catalina, P., Dominguez-Panchon, A. I., Goncalves-Pereira, M., Gonzalez-Fraile, E., Munoz-Hermoso, P., Ballesteros, J., Educa-Iii Group, A randomized trial to assess the efficacy of a psychoeducational intervention on caregiver burden in schizophrenia, European Psychiatry: the Journal of the Association of European Psychiatrists, 33, 9-17, 2016
Ref Id
712470
Country/ies where the study was carried out
Spain
Study type
Multicentre 2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a psychoeducational intervention group</td>
<td>Sample size
N = 223
- Intervention (N): 109
- Control (N): 114

Characteristics Carer
- Age - Mean (SD): Intervention= 59.2 (11.4); control= 61.1 (11.6)
- Gender - intervetion (N): 22/87; control (N): 31/83
- Relationship to care recipient - parents (N): 165; spouses (N): 13; daughters-sons (N): 2; sibling (N): 38;</td>
<td>Interventions
- Intervention (according to the protocol) - Psycho-educational intervention
- Control (according to the protocol) - TAU
- Name of Intervention (as named in the paper) - Psychoeducational Intervention Group Programme + TAU
- Name of control (as named in the paper) - TAU (standard support deliverd to carers from the outpatient psychiatric service where the people with schizophrenia were treated)
Mode of delivery</td>
<td>Details
- Randomization methods - Randomization was done centrally immediately after receiving the numerically coded dyads patient-caregiver for each research site. It used block randomization with random block sizes of 1 to 4 according to the R function “blockrand.”
- Blinding methods - All outcomes were assessed by a blinded researcher not involved in the administration of the intervention. No</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 4 months follow-up from baseline</i></td></tr>
<tr><td></td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>Measure</td><td>MEAN CHANGE - PIP</td><td>SD</td><td>N</td><td>Mean change</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Burden, ZBI (Zarit Burden Interview)</td><td>-4.60</td><td>12.68</td><td>86</td><td>-0.27</td><td>12.07</td><td>97</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, IEQ (Involvement Evaluation Questionnaire)</td><td>-4.52</td><td>11.58</td><td>86</td><td>-1.72</td><td>12.13</td><td>97</td></tr>
<tr><td>Caring-related morbidity: Mental health, GHQ-28</td><td>-4.59</td><td>11.0</td><td>86</td><td>-1.25</td><td>11.20</td><td>97</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
- Random sequence generation - low risk
- Allocation concealment - low risk
- Blinding of participants and personnel - unclear risk: Not described in sufficient detail
- Blinding of outcome assessment - low risk
- Incomplete outcome data - high risk: Attrition bias due to amount of</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>programme plus usual care and usual care only, to provide adult carers of people with schizophrenia with psychological and emotional support

Study dates
• Publication date: 2016
• Data collection: March to May 2012

Source of funding
The project was funded by the a research grant from Instituto de Salud Carlos III, Spain (PI10/01049). The role of the funding source was limited to economic support. It was not involved in the study process, preparation or submission of the manuscript.</td>
<td>other/undisclosed (N): 4
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)
• Schizophrenia</td>
<td>• Face-to-face
• Individual
• Post-intervention reinforcement - N /R</td>
<td>details on blinding of participants and personnel
• Follow-up outcome measurement - 4, and 8 months follow - up from baseline
• Sample size statistical power: achieved/no achieved - No achieved</td>
<td>
<table>
<tr><td>(General Health Questionnaire-28 items)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Depression, CES–D (Center for Epidemiological Studies Depression scale)</td><td>-2.86</td><td>9.17</td><td>86</td><td>-0.36</td><td>9.60</td><td>97</td></tr>
<tr><td colspan="7"><i>at 8 months follow-up from baseline</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>MEAN CHANGE - PIP</td><td>SD</td><td>N</td><td>Mean change</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Burden, ZBI (Zarit Burden Interview)</td><td>-5.67</td><td>10.97</td><td>82</td><td>-1.21</td><td>11.09</td><td>91</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, IEQ</td><td>-5.46</td><td>12.09</td><td>82</td><td>-2.60</td><td>12.18</td><td>91</td></tr>
</table>
</td>
<td>incomplete outcome data in both intervention groups. (Much higher dropout rate in the intervention group)
• Selective reporting - low risk
• Other risk of bias - high risk: Sample size statistical power has been not achieved

Overall RoB - very serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>(Involvement Evaluation Questionnaire)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items)</td><td>-3.00</td><td>12.32</td><td>82</td><td>-0.87</td><td>11.14</td><td>91</td></tr>
<tr><td>Caring-related morbidity: Depression, CES–D (Center for Epidemiological Studies Depression scale)</td><td>-2.38</td><td>7.77</td><td>82</td><td>-0.73</td><td>7.77</td><td>91</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td><td></td></tr>
<tr><td>Full citation
Núñez-Naveira, L, Alonso-Búa, B, Labra, C, Gregersen, R, Maibom, K,</td><td>Sample size
N = 61
• Intervention (N): 30</td><td>Interventions
• Intervention (according to the protocol) - Psych</td><td>Details
• Randomization methods - The assignment to</td><td>Results*
<i>at 3 months follow - up from baseline (that is intervention completion)</i></td><td>Methodological quality assessed using</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Mojs, E, Krawczyk-Wasielewska, A, Millán-Calenti, Jc, UnderstAID, an ICT Platform to Help Informal Caregivers of People with Dementia: a Pilot Randomized Controlled Study, BioMed Research International, 2016, 5726465, 2016
Ref Id
712609
Country/ies where the study was carried out
Denmark, Poland, and Spain
Study type
Multicentre 2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a internet psyco-educational course over dementia (The UnderstAID Application) and usual care, to provide adult carers of people with dementia with psychological and emotional support

Study dates
• Publication date: 2016
• Data collection: N/R

Source of funding</td>
<td>• Control (N): 31

Characteristics Carer
• Age - Mean (SD): Intervention= N/R; control= N/R
• Gender - intervention (N): 9/21; control (N): 13/18
• Relationship to care recipient - N/R
• Living with care recipient (yes/not - n) - N/R
Carer recipient (condition)
• Dementias and Alzheimer's disease</td>
<td>o-educational intervention
• Control (according to the protocol) - TAU
• Name of Intervention (as named in the paper) The UnderstAID Application: Internet course over Dementia [5 modules with information about 15 different topics: Module 1, Cognitive Declines (Topics: Attention, Memory, and Orientation); Module 2, Daily Tasks (Topics: Bathing, Incontinence, Massage and Touch, and Physical Exercises); Module 3, Behavioural Changes (Topics: Anxiety and Agitated Behaviour,</td>
<td>each intervention group was randomised using a computer-based random number generator. No details about the allocation concealment
• Blinding methods - No details
• Follow-up outcome measurement - 3 months follow - up from baseline (that is intervention completion)
• Sample size statistical power (achieved/no achieved) - Insufficient information to permit judgment</td>
<td>
<table>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Subjective burden, RCCS (Revised Caregiving Satisfaction Scale)</td><td>17.03</td><td>7.07</td><td>30</td><td>20.77</td><td>9.02</td><td>31</td></tr>
<tr><td>Caring-related morbidity: Depression, CES–D (Center for Epidemiological Studies Depression scale)</td><td>11.70</td><td>2.18</td><td>30</td><td>10.97</td><td>2.60</td><td>31</td></tr>
<tr><td>Carer choice/control/efficacy: Self-efficacy, CCS (Caregiver Competence Scale)</td><td>18.60</td><td>4.75</td><td>30</td><td>19.10</td><td>5.71</td><td>31</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used
</td>
<td>Cochrane risk of bias tool v2. Limitations
• Random sequence generation - low risk
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - unclear risk: Not described in sufficient detail
• Incomplete outcome data - low risk: incomplete outcome data was unlikely</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
The project was funded by the the research project “understAID: A PlatformThat Helps Informal Caregivers to Understand and Aid Their Demented Relatives.” (Grant no. AAL-2012-5-107), funded by the European Commission in the Ambient Assisted Living (AAL) Joint Programme and National Funding Agencies [Ministry of Industry, Energy and Tourism/Ministerio de Industria, Energ´ıa y Turismo (Spain); National Institute of Health Carlos III/Instituto de Salud Carlos III (Spain); Danish Agency for Science, Technology and Innovation (Denmark); and Centre for Research and Development/Narodowe Centrum Bada´n i Rozwoju (Poland)].		Depressive Mood, Manic Symptoms, and Emotional Control and Recognition); Module 4, SocialActivities (Communication andApathy and Loss of Motivation); and Module 5, You as a Caregiver (Topics: Coping with Own Stress and Motivation).] • Name of control (as named in the paper) - not usage of the application and maintained their usual lifestyle **Mode of delivery** • online materials and/or mobile devices (Smartphone or Tablet) • Individual • Post-intervention reinforcement - N /R			to have produced bias • Selective reporting - low risk • Other risk of bias - unclear risk: Insufficient information to permit judgment on sample size statistical power Overall RoB - serious

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Full citation
Prick, Ae, Lange, J, Twisk, J, Pot, Am, The effects of a multi-component dyadic intervention on the psychological distress of family caregivers providing care to people with dementia: a randomized controlled trial, International Psychogeriatrics, 27, 2031-2044, 2015
Ref Id
711153
Country/ies where the study was carried out
The Netherlands
Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a physical exercise plus psychological support and information only, to provide adult carers of people with dementia with psychological and emotional support

Study dates
• Publication date: 2015
• Data collection: 2008-2012</td>
<td>Sample size
N = 111
• Intervention (N): 57
• Control (N): 54

Characteristics Carer
• Age - Mean (SD): Intervention= 73 (9.91); control= 71 (10.31)
• Gender - intervetion (N): 19/38; control (N): 12/42
• Relationship to care recipient - spouses (N): 100; other/undisclosed (N): 11
• Living with care recipient (yes/not - n) - 111/0
Carer recipient (condition)</td>
<td>Interventions
• Intervention (according to the protocol) - Multicomponent (psycho-education + disease education + activity-based intervention)
• Control (according to the protocol) - TAU
• Name of Intervention (as named in the paper) - physical exercise + support (Education about dementia and its impact, its impact on patient behavior and function and how to modulate their own responses to problems
• Name of control (as named in the paper) - TAU (information only)
Mode of delivery
• Face-to-face</td>
<td>Details
• Randomization methods - The assignment to each intervention group was randomised using block randomization using Random Allocation Software. Randomization codes were hold in sequentially numbered opaque sealed envelopes.
• Blinding methods - Carers and coaches were aware of the treatment assigned. Although at the start of each measurement, examiners were blinded to a group allocation and dyads were asked not to disclose their group</td>
<td>Results*
<table>
<tr><td colspan="7"><i>at 3 months follow - up from baseline</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, SPICC (self-perceived pressure from informal Care)</td><td>5.67</td><td>2.36</td><td>57</td><td>5.85</td><td>2.13</td><td>54</td></tr>
<tr><td>Impact of caring on carer: Burden, RMBPC reaction upset (revised memory and behaviour checklist)</td><td>13.06</td><td>10.38</td><td>57</td><td>12.13</td><td>8.55</td><td>54</td></tr>
<tr><td>Caring-related morbidity: Depression: CES–D</td><td>13.71</td><td>8.18</td><td>57</td><td>11.02</td><td>8.57</td><td>54</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
• Random sequence generation - low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - high risk: Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.
• Blinding of outcome assessment - high risk: Detection bias due to knowledge of the allocated interventions</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Source of funding
The project was funded by the Dutch Health Insurers Innovation Foundation</td>
<td>• Dementias and Alzheimer's disease</td>
<td>• Individual
• Post-intervention reinforcement - N /R</td>
<td>allocation, in practice group allocation became clear to the examiners during the intervention period.
• Follow-up outcome measurement - 3, and 6 months follow - up from baseline
• Sample size statistical power - No achieved</td>
<td>
<table>
<tr><td>(Center for Epidemiological Studies Depression scale)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="7"><i>at 6 months follow - up from baseline</i></td></tr>
<tr><td rowspan="2">Measure</td><td colspan="3">INTERVENTION</td><td colspan="3">Control</td></tr>
<tr><td>MEAN</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer: Subjective burden, SPICC (self-perceived pressure from informal Care)</td><td>5.69</td><td>2.38</td><td>57</td><td>5.60</td><td>2.13</td><td>54</td></tr>
<tr><td>Impact of caring on carer: Burden, RMBPC reaction upset (revised memory and behaviour checklist)</td><td>15.98</td><td>11.11</td><td>57</td><td>11.71</td><td>9.25</td><td>54</td></tr>
</table>
</td>
<td>by outcome assessors.
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - unclear risk: Insufficient information to permit judgment
• Other risk of bias - high risk: Sample size statistical power has been not achieved.

Overall RoB - serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td><table><tr><td>Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale)</td><td>13.62</td><td>7.18</td><td>57</td><td>11.71</td><td>9.25</td><td>54</td></tr></table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td><td></td></tr>
<tr><td>Full citation
Vazquez, F. L., Torres, A., Blanco, V., Otero, P., Diaz, O., Ferraces, M. J., Long-term Follow-up of a Randomized Clinical Trial Assessing the Efficacy of a Brief Cognitive-Behavioral Depression Prevention Intervention for Caregivers with Elevated Depressive Symptoms, American Journal of Geriatric Psychiatry, 24, 421-432, 2016
Ref Id
712992
Country/ies where the study was carried out
Spain</td><td>Sample size
N = 170
• Intervention (N): 88
• Control (N): 82

Characteristics Carer
• Age - Mean (SD): Intervention= 55.7 (9.7); control= 54.5 (8.2)
• Gender - intervention (N): 26/62; control (N): 19/63</td><td>Interventions
• Intervention (according to the protocol) - CBT
• Control (according to the protocol) - TAU
• Name of Intervention (as named in the paper) - Group intervention, based on the depression problem-solving (carried out in 5 sessions)
• Name of control (as named in the paper) - TAU</td><td>Details
• Randomization methods - The assignment to each intervention group was randomised by an independent statistician using a random number table. No details about the allocation concealment
• Blinding methods - Outcome assessors were blinded to the allocated</td><td>Results*<table><tr><td colspan="7"><i>at 3 months follow - up from baseline</i></td></tr><tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr><tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr><tr><td>Impact of caring on carer: Emotional distress, GHQ-28</td><td>2.6</td><td>3.8</td><td>88</td><td>5.2</td><td>5.8</td><td>82</td></tr><tr><td>Impact of caring on carer: Caregiver burden, ZBI</td><td>22.1</td><td>10.8</td><td>88</td><td>28.0</td><td>9.5</td><td>82</td></tr><tr><td colspan="7"><i>at 6 months follow - up from baseline</i></td></tr><tr><th>Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr></table></td><td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
• Random sequence generation - low risk
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and personnel - un</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a group problem-solving programme and usual care, to provide adult carers with elevated depressive symptoms (including carers of people with dementia and other conditions) with psychological and emotional support

Study dates
• Publication date: 2016
• Data collection: N/R

Source of funding
The project was funded by grant 2007/PN017 from the Ministry of Labor and Social Affairs of Spain.</td>
<td>• Relationship to care recipient - parents (N): 84; spouses (N): 19; daughters-sons (N): 16; other/undisclosed (N): 51
• Living with care recipient (yes/not -n) N/R
Carer recipient (condition)
• Carers with elevated depressive symptoms (including carers of people with dementia – n=84, and other conditions – n=86)</td>
<td>(unrestricted access to standard social and health care services for treatment of depression symptoms)
Mode of delivery
• Face-to-face
• Group
• Post-intervention reinforcement - N/R</td>
<td>intervention. No details on blinding of participants and personnel
• Follow-up outcome measurement - 3, 6, and 12 follow - up from baseline
• Sample size statistical power - Achieved</td>
<td>
<table>
<tr><th></th><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Emotional distress, GHQ-28</td><td>3.5</td><td>4.3</td><td>88</td><td>5.6</td><td>6.1</td><td>82</td></tr>
<tr><td>Impact of caring on carer: Caregiver burden, ZBI</td><td>24.0</td><td>11.5</td><td>88</td><td>28.3</td><td>11.1</td><td>82</td></tr>
<tr><td colspan="7"><i>at 12 months follow - up from baseline</i></td></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Emotional distress, GHQ-28</td><td>3.0</td><td>4.1</td><td>88</td><td>5.7</td><td>6.1</td><td>82</td></tr>
<tr><td>Impact of caring on carer: Caregiver burden, ZBI</td><td>23.6</td><td>11.5</td><td>88</td><td>29.7</td><td>13.1</td><td>82</td></tr>
</table>
* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for
</td>
<td>clear risk: Not described in sufficient detail
• Blinding of outcome assessment - low risk
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - unclear risk: Insufficient information to permit judgment
• Other risk of bias - low risk

Overall RoB - no serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>details about direction of all the measurement tools used</td><td></td></tr>
<tr>
<td>Full citation
Wilz, Gabriele, Meichsner, Franziska, Soellner, Renate, Are psychotherapeutic effects on family caregivers of people with dementia sustainable? Two-year long-term effects of a telephone-based cognitive behavioral intervention, Aging & Mental Health, 21, 774-781, 2017
Ref Id
713060
Country/ies where the study was carried out
Germany
Study type
2 groups RCT

Aim of the study
This RCT was aimed to compare the effectiveness of two interventions, a telephone-based cognitive behavioral programme and written educational material only, to provide adult carers of people with dementia with psychological and emotional support

Study dates
Publication date: 2016</td>
<td>Sample size
N = 105
Intervention (N): 78
Control (N): 27
Characteristics Carer
Age - Mean (SD): Intervention= 61.44 (9.74); control= 61.30 (8.56)
Gender - intervention (N): 11/67; control (N): 7/20
Relationship to care recipient - N/R
Living with care recipient (yes/not - n) - 50/55
Carer recipient (condition)
Dementias and</td>
<td>Interventions
Intervention (according to the protocol) - CBT
Control (according to the protocol) - TAU
Name of Intervention (as named in the paper) - Telephone-based cognitive behavioral intervention (multi-component CBT intervention focused on managing behavior problems and personality changes of the care recipient, caregivers'self-care, reduction of social isolation, utilization of professional and informal support, stress reduction, regulation of emotions,</td>
<td>Details
Randomization methods - An independent data management and biometry center was involved to ensure randomization and blinded assessment - however, one arm of this 3 arms RCT study could not be randomised. No details about the allocation concealment
Blinding methods - No details
Follow-up outcome measurement - 24 months follow - up from baseline
Sample size statistical</td>
<td>Results*
<table>
<tr><th colspan="7"><i>at 24 months follow - up from baseline</i></th></tr>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Carer quality of life: WHOQoL-BREF (World Health Organization quality of life, BREF)</td><td>60.10</td><td>18.14</td><td>78</td><td>56.48</td><td>22.30</td><td>27</td></tr>
<tr><td>Caring-related morbidity: Emotional well-being (VAS)</td><td>71.91</td><td>21.80</td><td>78</td><td>61.74</td><td>25.81</td><td>27</td></tr>
<tr><td>Caring-related morbidity: Perceived health status (VAS)</td><td>67.28</td><td>19.51</td><td>78</td><td>62.37</td><td>24.22</td><td>27</td></tr>
<tr><td>Caring-related morbidity: Depression,</td><td>14.42</td><td>9.79</td><td>78</td><td>17.56</td><td>11.34</td><td>27</td></tr>
</table></td>
<td>Methodological quality assessed using Cochrane risk of bias tool v2.
Limitations
Random sequence generation - high risk: Selection bias (biased allocation to interventions) due to inadequate generation of a randomised sequence
Allocation concealment unclear risk: Not described in sufficient detail
Blinding of participants and personnel - unclear risk: Not described in sufficient detail</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Data collection: N/R
Source of funding
The project was funded by the German Federal Ministry of Health [grant number LTDEMENZ-44-092].</td>
<td>Alzheimer's disease</td>
<td>reinforcement of positive activities, and acceptance of role change and loss) + TAU
Name of control (as named in the paper) - TAU (written educational material)
Mode of delivery
telephone
Individual
Post-intervention reinforcement - N /R</td>
<td>power - No achieved</td>
<td><table>
<tr><td>CES–D (Center for Epidemiological Studies Depression scale)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Perceived physical health, GBB-24 (Caregivers’ perceived bodily complaints - including exhaustion, stomach trouble, rheumatic pains, and heart trouble)</td><td>19.03</td><td>14.22</td><td>78</td><td>23.33</td><td>22.30</td><td>27</td></tr>
</table>* Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used</td>
<td>Blinding of outcome assessment - unclear risk: Not described in sufficient detail
Incomplete outcome data - high risk: Attrition bias due to amount of incomplete outcome data in both intervention groups. (Much higher dropout rate in the intervention)
Selective reporting - low risk
Other risk of bias - high risk: Sample size statistical power has been not achieved.
Overall RoB - very serious</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Woods, R. T., Orrell, M., Bruce, E., Edwards, R. T., Hoare, Z., Hounsome, B., Keady, J., Moniz-Cook, E., Orgeta, V., Rees, J., Russell, I., REMCARE: Pragmatic Multi-Centre Randomised Trial of Reminiscence Groups for People with Dementia and their Family Carers: Effectiveness and Economic Analysis, PLoS ONE [Electronic Resource], 11, e0152843, 2016 **Ref Id** 713066 **Country/ies where the study was carried out** UK **Study type** Multicentre 2 groups RCT **Aim of the study** This RCT was aimed to compare the effectiveness and the cost-effectiveness of two interventions, a group reminiscence therapy and usual care, to provide adult carers of people with dementia with psychological and emotional support **Study dates**	**Sample size** N = 487 • Intervention (N): 268 • Control (N): 219 **Characteristics Carer** • Age - Mean (SD): Intervention= 69.6 (11.6); control= 69.7 (11.6) • Gender - intervention (N): 126/142; control (N): 101/138 • Relationship to care recipient - spouses (N): 336; other/undisclosed (N): 121 • Living with care recipient (yes/not - n) - N/R (presumably	**Interventions** • Intervention (according to the protocol) - Emotion-oriented intervention (reminiscence therapy) • Control (according to the protocol) - TAU • Name of Intervention (as named in the paper) - group reminiscence therapy (Remembering Yesterday, Caring Today; RYCT) • Name of control (as named in the paper) - TAU (unrestricted access to standard social and health care services, except for the reminiscence groups) **Mode of delivery** • Face-to-face • Group	**Details** • Randomization methods - The assignment to each intervention group was done by randomization using a dynamic allocation method, and stratifying for spousal or non-spousal relationship of the dyad. Complete list randomisation for each wave of recruitment within each centre was completed. Randomisation was carried out remotely by the NWORTH accredited Clinical Trials Unit, initiated by a local researcher who did not take part in follow-up assessments	**Results***	**Methodological quality assessed using Cochrane risk of bias tool v2.** **Limitations** • Random sequence generation - low risk • Allocation concealment - low risk • Blinding of participants and personnel - high risk: Performance bias due to knowledge of the allocated interventions by participants and personnel during the study. • Blinding of outcome assessment - low risk • Incomplete outcome data - low risk: incomplete

at 3 months follow - up from baseline

Measure	**INTERVENTION**			Control		
	MEAN	**SD**	**N**	Mean	SD	N
Impact of caring on carer: Distress, Relatives Stress Scale (RSS)	23.22	-	268	22.48	-	219
Impact of caring on carer: Quality of Carer Patient Relationship (QCPR)	51.39	-	268	52.57	-	219
Carer quality of life: European Quality of Life 5 Dimensions	71.54	-	268	71.48	-	219

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>• Publication date: 2016
• Data collection: 2008-2010

Source of funding
The project was funded by the National Institute of Health Research Health Technology Assessment Programme Ref: 06/304/229, http://www.nets.nihr.ac.uk/programmes/hta and Medical Research Council Ref: G0300932, http://www.mrc.ac.uk/. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.</td>
<td>all included carers)
Carer recipient (condition)
• Dementias and Alzheimer's disease</td>
<td>• Post-intervention reinforcement - Y</td>
<td>• Blinding methods - Outcome assessors were blinded to the allocated intervention. No blinding of participants and personnel
• Follow-up outcome measurement - 3, and 10 months follow - up from baseline
• Sample size statistical power - Achieved</td>
<td>
<table>
<tr><td>Visual Analogue Scale (EQ-5D VAS)</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Mental health: GHQ-28 (General Health Questionnaire-28 items) #log transform#</td><td>3.01</td><td>-</td><td>268</td><td>2.99</td><td>-</td><td>219</td></tr>
<tr><td>Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale: HADS-A)</td><td>6.15</td><td>-</td><td>268</td><td>5.96</td><td>-</td><td>219</td></tr>
<tr><td>Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale: HADS-D)</td><td>4.69</td><td>-</td><td>268</td><td>4.76</td><td>-</td><td>219</td></tr>
<tr><td colspan="7"><i>at 10 months follow - up from baseline</i></td></tr>
</table>
</td>
<td>outcome data was unlikely to have produced bias
• Selective reporting - low risk
• Other risk of bias - low risk

Overall RoB - serious</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><th rowspan="2">Measure</th><th colspan="3">INTERVENTION</th><th colspan="3">Control</th></tr>
<tr><th>MEAN</th><th>SD</th><th>N</th><th>Mean</th><th>SD</th><th>N</th></tr>
<tr><td>Impact of caring on carer: Distress, Relatives Stress Scale (RSS)</td><td>22.93</td><td>-</td><td>268</td><td>22.87</td><td>-</td><td>219</td></tr>
<tr><td>Impact of caring on carer: Quality of Carer Patient Relationship (QCPR)</td><td>52.13</td><td>-</td><td>268</td><td>51.57</td><td>-</td><td>219</td></tr>
<tr><td>Carer quality of life: European Quality of Life 5 Dimensions Visual Analogue Scale (EQ-5D VAS)</td><td>70.47</td><td>-</td><td>268</td><td>69.44</td><td>-</td><td>219</td></tr>
<tr><td>Caring-related morbidity: Mental</td><td>3.08</td><td>-</td><td>268</td><td>3.01</td><td>-</td><td>219</td></tr>
</table>
</td><td></td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>health: GHQ-28 (General Health Questionnaire-28 items) #log transform#</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale: HADS-A)</td><td>6.58</td><td>-</td><td>268</td><td>5.99</td><td>-</td><td>219</td></tr>
<tr><td>Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale: HADS-D)</td><td>5.12</td><td>-</td><td>268</td><td>5.03</td><td>-</td><td>219</td></tr>
</table>
*** Please see GRADE tables (Appendix F – GRADE and GRADE CERQual tables) for details about direction of all the measurement tools used**
</td><td></td></tr>
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CBT: Cognitive behavioural therapy; FU: follow-up; F: Female; M: Male; N: Number; SD: Standard deviation; TAU: Treatment as usual; RCT: Randomised controlled trial

Qualitative component of the review

Table 7: Evidence tables for the qualitative studies

Study details	Participants	Concept(s)	Methods	Outcomes and Themes	Comments
Full citation Camic, P. M., Williams, C. M., Meeten, F., Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study, Dementia, 12, 157-76, 2013 **Ref Id** 708685 **Country/ies where the study was carried out** UK: England **Study type** Mix-methods (observational study, peer-reviewed) **Aim of the study** The aims of this mixed-methods study were to evaluate if participation in a community singing group had a positive impact on both people with a dementia (PWD) and their carers by increasing wellbeing, improving day-to-day functioning and reducing social exclusion.	**Sample size** N=10 adult carers **Characteristics** **Carer** • Carer age = N/R • Carer gender (M/F:n)= N/R • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria** Carer of a person: 1) with a diagnosis of dementia or Mild Cognitive Impairment (MCI); 2) aged 65 and over; 3) and able to come to a disability-accessible venue for weekly singing groups with their carer who is willing to participate in the singing **Exclusion criteria** Carer of a person not being able to give consent at the beginning of the study or currently experiencing a psychotic disorder.	**Interventions** • Phenomenon of interest (as reported in the study): Music therapy: 'Singing Together Group' • Phenomenon of interest (according to the protocol): Low-level/informal support interventions	**Details** • Recruitment strategy: It is unclear whether the sample of carers was recruited purposively or was a convenience sampling. People with a dementia and their carers were recruited from an older people's community mental health service in England (20 participants in total) to take part in a 'Singing Together Group' • Data collection & analysis: Data were collected through face-to-face semi-structured interviews (lasting 30 minutes) and through standardised questionnaires. In addition, behavioural observations were undertaken during each singing group session. All interviews were audio-taped, and transcribed. Interview data were analysed using thematic analysis. Themes were iteratively coded by the first and third authors and were	**Results are summarised under the following the following themes** • 'Carer response to the group (including pre-group deliberation; ambience and environment; structure; social inclusion; and the experience of singing)' • 'Music engagement'	**Limitations (CASP-checklist for qualitative studies)** **Limitations** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: Unclear details on how carers were selected/recruited • **Q5: Were the data collected in a way that addressed the research issue?** - Not: Theoretical sufficiency/ saturation of data has not been discussed • **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear descritption

Study dates - **Publication date**: 2013 - **Data collection**: N/R **Source of funding** The project was funded by a Sussex Partnership NHS Foundation Trust grant from the Dorothy Allen Legacy Fund.			further examined for consistency by an independent reviewer		about relationship between researcher and carers during data collection and analysis - **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Unclear: no sufficient details on data analysis methods are reported - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Major
Full citation Elvish, Ruth, Cawley, Rosanne, Keady, John, The experiences of therapy from the perspectives of carers of people with dementia: An exploratory study, Counselling & Psychotherapy Research, 14, 56-63, 2014	**Sample size** N=6 adult carers **Characteristics** **Carer** - Carer age = Range, years: 55 to 80 - Carer gender (M/F:n)= 1/5 - "Relationship to care recipient"= parents (N): 0; spouses (N): 4;	**Interventions** - Phenomenon of interest (as reported in the study): Counselling/psychotherapy - Phenomenon of interest (according to the protocol): Psychosocial interventions	**Details** - Recruitment strategy: A convenience sample of carers was recruited through 8 services including community mental health teams and memory services in the North West of England. Therapists in these centres identified potential participants	**Results are summarised under the following the following themes –** - ‘Still doing the best I can’ - ‘Feeling connected and being understood’ - ‘Wanting to share information’	**Limitations (CASP-checklist for qualitative studies)** **Limitations** - **Q1: Was there a clear statement of the aims of the research?** - Yes - **Q2: Was a qualitative methodology appropriate?** - Yes

Ref Id 721051 **Country/ies where the study was carried out** UK: Manchester **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the meaning of counselling/psychotherapy from the perspective of carers of people with dementia and to explore the processes of change within therapy. **Study dates** • **Publication date**: 2014 • **Data collection**: N/R **Source of funding** The project was funded by the British Association for Counselling and Psychotherapy (BACP)	daughters-sons (N): 2; sibling (N): 0; other/undisclosed (N): 0 **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria** Carers of 1) people with moderate to advanced dementia (defined as Mini-Mental State Examination [MMSE] score of < 20); 2)who were expressing emotional distress (social isolation, anxiety, agitation) and 3) carers who experienced carer burden **Exclusion criteria** Carers of people with dementia participating in group sessions		and shared details of the study. Further details on how carers were recruted are not reported. • Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews with the interview schedule informed by previous studies that explored client experiences of therapy in different populations. All interviews were audio-taped, and transcribed. The duration of the interviews ranged from 61 to 120 minutes, and they were divided into two main topic areas: 1) current activities of everyday life and existing social relatioships; and 2) expectations and experiences. Interview data were analysed using a specific form of narrative analysis: 'holistic-content' analysis (Lieblich et al., 1998: this analysis technique is achieved by reading, and/or listening to, interview		• **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: a convenience sample of carers was recruited, unclear approriateness to the aims of the research • **Q5: Were the data collected in a way that addressed the research issue?** - Not: Theoretical sufficiency/ saturation of data has not been discussed • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes • **Q9: Is there a clear statement of findings?** - Yes

			material several times until a pattern emerges in the data.		- **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Greenwood, Nan, Habibi, Ruth, Mackenzie, Ann, Drennan, Vari, Easton, Nicky, Peer support for carers: A qualitative investigation of the experiences of carers and peer volunteers, American Journal of Alzheimer's Disease and other Dementias, 28, 617-626, 2013 **Ref Id** 721933 **Country/ies where the study was carried out** UK: London **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to	**Sample size** N=11 adult carers **Characteristics** **Carer** - Carer age = Range, years: 41 to 80 - Carer gender (M/F:n)= 3/8 - "Relationship to care recipient"= parents (N): 0; spouses (N): 5; daughters-sons (N): 5; sibling (N): 0; other/undisclosed (N): 1 **Professionals** - N/A **Care recipient** - Care recipientCondition = Dementia **Inclusion criteria** Informal carers 1) of someone living with dementia; 2) able to speak English; 3) and had to have attended a	**Interventions** - Phenomenon of interest (as reported in the study): Dementia cafés - Phenomenon of interest (according to the protocol): Low-level/informal support interventions	**Details** - Recruitment strategy: A convenience sample of carers was recruited through a sample of 'dementia cafes'. Dementia cafés where carers recruited were identified through a combination of internet searches and 'snowballing'. Identified café managers were contacted to ask if they would allow us to recruit carers from their café by a researcher attending a meeting at the café. Where permission was granted, a researcher attended the café and provided potential carer participants with detailed, written information about the study and answered any questions. Carers were not given any	**Results are summarised under the following the following themes –** - 'An opportunity for enjoying themselves and to switch off from being a carer' - 'Cafés as normalising living with dementia' - 'Peer support' 'Developing social networks and reducing social isolation' - 'the recruitment and training of café co-ordinators' - 'the importance of being presented as cafés' - 'reviewing how cafés are publicised' - 'be clear of the purpose and rationale of activities and keep them appropriately updated review how information is presented'	**Limitations (CASP-checklist for qualitative studies)** - **Q1: Was there a clear statement of the aims of the research?** - Yes - **Q2: Was a qualitative methodology appropriate?** - Yes - **Q3 Was the research design appropriate to address the aims of the research?** - Yes - **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: a convenience sample of carers was recruited - Unclear approriateness to the aims of the research - **Q5: Were the data collected in a way that addressed the research issue?** - Not:

explore the views of 11 carers from five dementia cafés in and around London (This study is complementary to another qualitative study ; as such while both publications have been reviewed, they have been counted as 1 study) **Study dates** - **Publication date**: 2017 - **Data collection**: N/R **Source of funding** The project was funded by the Faculty of Health, Social Care and Education, Kingston University and St George's University of London.	dementia café at least three times over 6 months. **Exclusion criteria** N/R (look at the inclusion criteria)		incentive for participating. - Data collection & analysis: Data were collected through face-to-face semi-structured interviews guided by a topic guide. All interviews were digitally recorded and transribed by three experienced interviewers. Analysis was thematic and started during data collection to ensure that the topic guide reflected issues relating to the cafés that were of importance to carers. Initial codes were generated by each researcher in an iterative process whereby the transcripts were repeatedly revisited to identify themes and conceptual relationships. The initial themes were reviewed against the data by two members of the team and revised where needed.	- 'having a dedicated space for carers' - 'frequency of opening'	Theoretical sufficiency/ saturation of data has not been discussed - **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes - **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Yes - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Hamill, Michelle, Smith, Lesley, et al 'Dancing	**Sample size** N=7 adult carers	**Interventions** - Phenomenon of interest (as reported in the	**Details** - Recruitment strategy: It is unclear whether the	**Results are summarised under the following the following main theme –**	**Limitations (CASP-checklist for qualitative studies)**

down memory lane': Circle dancing as a psychotherapeutic intervention in dementia- A pilot study, Dementia: The International Journal of Social Research and Practice, 11, 709-724, 2012 **Ref Id** 738231 **Country/ies where the study was carried out** UK: London **Study type** Mix-methods (observational study, peer-reviewed) **Aim of the study** The aims of this mixed-methods study were to evaluate the effects of a circle dance group therapy on people with dementia, and their carers. **Study dates** • **Publication date**: 2012 • **Data collection**: N/R **Source of funding** N/R	**Characteristics** **Carer** • Carer age = Range, years: 61 to 91 • Carer gender (M/F:n)= 3/4 • "Relationship to care recipient"= parents (N): 0; spouses (N): 5; daughters-sons (N): 2; sibling (N): 0; other/undisclosed (N): 0 **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria** Carers of 1) people with dementia with extremely poor mobility or other physical health problems where the person would need the full and undivided support of a facilitator to partake. **Exclusion criteria** Carers of 1) people with dementia 2) undertaking counselling or psychotherapy (that is defined as: one to one sessions; undertaken over a minimum of six sessions; and provided	study): Body-oriented psychological therapy • Phenomenon of interest (according to the protocol): Cognitive-/emotion-oriented/activity-based interventions	sample of carers was recruited purposively or was a convenience sampling. Participants were recruited through referrals from within the Mental Health Care of Older People's service in East London. Ethical approval was sought and granted from the National Research Ethics Committee (NREC) and written informed consent was obtained from all patients before participation. Further details on how carers were recruted are not reported. • Data collection & analysis: No details on data collection/analysis are reported	• 'increasing personal awareness'	• **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Unclear: not enough information on the qualitative study design justification • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: Unclear details on how carers were selected/recruited • **Q5: Were the data collected in a way that addressed the research issue?** - Not: no details on data collection methods are reported • **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear description about relationship between researcher and

	by a professional registered with either the Health Professions Council (HPC) or the British Association for Counselling and Psychotherapy. Further, 3) the counselling/psychotherapy had arisen primarily as a result of a carer's response to their relative receiving a diagnosis of dementia, or as a consequence of the impact of their relative's dementia.				carers during data collection and analysis • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Unclear: no details on data analysis methods are reported • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Major
Full citation Hopkinson, J. B., Fenlon, D. R., Foster, C. L., Outcomes of a nurse-delivered psychosocial intervention for weight- and eating-related distress in family carers of patients with advanced cancer, International journal of palliative nursing, 19, 116, 118-23, 2013 **Ref Id**	**Sample size** N=26 adult carers **Characteristics** **Carer** • Carer age = Mean (range, years): 66 (33 to 84) • Carer gender (M/F:n)= 2/24 • "Relationship to care recipient"= parents (N): 0; spouses (N): 23; daughters-sons (N): 3; sibling (N): 0;	**Interventions** • Phenomenon of interest (as reported in the study): Psychosocial intervention - the Macmillan Approach to Weight and Eating (MAWE) - a psychosocial intertervention including advice on eating well, information provision, reassurance, and support for self-management	**Details** • Recruitment strategy: Carers were recruited purposively from the sample of an exploratory trial of MAWE (see Hopkinson et al 2010 for a description of the trial) • Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews the end of the quantitative analysis	**Results are summarised under the following the following themes –** • 'Acceptance' • 'Ideas and reassurance' • 'Understanding Knowing what to do' • 'Changing feelings'	**Limitations** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the**

721869 **Country/ies where the study was carried out** UK: England **Study type** Mix-methods (RCT, peer-reviewed) **Aim of the study** The aims of this mixed-methods study were to evaluate a the potential for a psychosocial intervention, the Macmillan Approach to Weight and Eating, to mitigate weight- and eating-related distress in carers of patients with advanced cancer. **Study dates** • **Publication date**: 2013 • **Data collection**: 2006-2007 **Source of funding** The project was funded by Macmillan Cancer Support	other/undisclosed (N): 0 **Professionals** • N/A **Care recipient** • Care recipientCondition = Advanced cancer **Inclusion criteria** Carers were supporting adult people with advanced cancer who had been recruited into an exploratory trial of MAWE (Hopkinson 2010) **Exclusion criteria** N/R (look at the inclusion criteria)	• Phenomenon of interest (according to the protocol): Psychosocial interventions	(mean 5 days post-MAWE exposure). All interviews were audio-taped, and transcribed. Interview data were analysed using content and thematic analysis and the findings were compared with the quantitative analysis to interpret the impact of MAWE on carer experience.		**aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear descritption about relationship between researcher and carers during data collection and analysis • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor

Full citation Jones, C. J., Hayward, M., Brown, A., Clark, E., Bird, D., Harwood, G., Scott, C., Hillemann, A., Smith, H. E., Feasibility and Participant Experiences of a Written Emotional Disclosure Intervention for Parental Caregivers of People with Psychosis, Stress and Health, 32, 485-493, 2016 **Ref Id** 712236 **Country/ies where the study was carried out** UK: Sussex **Study type** Mix-methods (RCT, peer-reviewed) **Aim of the study** The aims of this mixed-methods qualitative study were to explore the acceptability of written emotional disclosure and a control writing task in a feasibility trial of caregivers of people with psychosis. This quantitative component of this study has been	**Sample size** N=21 adult carers **Characteristics** **Carer** • Carer age = Mean (SD): 59.5 (8.10) • Carer gender (M/F:n)= 1/27 • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient** • Care recipientCondition = Psychosis **Inclusion criteria** Carers: 1) of an individual diagnosed with psychosis and 2) who had at least one contact per week with their care recipient. **Exclusion criteria** Carers: 1) unable to write for 20 min; 2) unable to speak and write in English or; 3) already receiving psychological or formal family therapy.	**Interventions** • Phenomenon of interest (as reported in the study): Written emotional disclosure (WED) • Phenomenon of interest (according to the protocol): Cognitive-/emotion-oriented/activity-based interventions	**Details** • Recruitment strategy: Carers were recruited purposively from a feasibility trial comparing written emotional disclosure with a neutral writing task two assertive outreach teams and a recovery organization in Sussex. Interested parental carers of people with psychosis were provided research contact details to discuss the study and their eligibility • Data collection & analysis: Data were collected through a questionnaire, attached to the intervention sheet (aimed to record carers' feedback). Qualitative data of the participant's feedback was analysed using Burnard's method of thematic content analysis (Burnard, 1991). This method was adapted from the work of Glaser and Strauss and their grounded theory approach in addition to other research regarding content analysis.	**Results are summarised under the following the following themes –** • 'Benefits of writing' • 'Psychological and physical challenges of writing' • 'Writing analysis'	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes

included in the quantitative component of the review. **Study dates** • **Publication date**: 2016 • **Data collection**: N/R. **Source of funding** N/R					• **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Linacre Stephen, Green Jessica, Sharma Vishal, A pilot study with adaptations to the Maudsley Method approach on workshops for carers of people with eating disorders, Mental Health Review Journal, 21, 295-307, 2016 **Ref Id** 724144 **Country/ies where the study was carried out** UK: England **Study type** Qualitative study (peer-reviewed) **Aim of the study**	**Sample size** N=10 adult carers **Characteristics** **Carer** • Carer age = Range, years: 31 to 60 • Carer gender (M/F:n)= xx • "Relationship to care recipient"= parents (N): 9; spouses (N): 1; daughters-sons (N): 0; sibling (N): 0; other/undisclosed (N): 0 **Professionals** • N/A **Care recipient** • Care recipientCondition = Eating disorders **Inclusion criteria** N/R (look at the 'recruiment strategy')	**Interventions** • Phenomenon of interest (as reported in the study): Skill-based workshops (adapted Maudsley Method skills based workshops including:. cognitive remediation therapy; mindfulness and acceptance commitment therapy). • Phenomenon of interest (according to the protocol): Multicomponent interventions (that is those that address more than one carer domain such as maintenance of relationships, disease education, safety, carer health and wellbeing)	**Details** • Recruitment strategy: It is unclear whether the sample of carers was recruited purposively or was a convenience sampling. Participants were recruited through a seven session course of skills based workshops entitled " Empowering Families ". The workshops were advertised through the Yorkshire Centre for Eating Disorders and in the local community, and were open for anyone currently caring for a care recipient with an ED. In order to enrol, carers had to commit to attend a minimum of six of the seven workshops and were expected to	**Results are summarised under the following the following themes –** • Most useful (that is benefits of the workshops): social support • Most useful (that is benefits of the workshops): techniques taught • Most useful (that is benefits of the workshops): self-awareness • Least useful (that is limitations of the workshops): content and structure • Future workshops (including content and sructure; and other topics)	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Not: No details how carers were selected or recruited • **Q5: Were the data collected in a way that addressed the research issue? -**

The aims of this qualitative study were to explore the views of carers of people with eating disorders on how the skill-based workshops were received **Study dates** - **Publication date**: 2016 - **Data collection**: Autumn 2014 **Source of funding** N/R	**Exclusion criteria** N/R		complete " homework " between sessions to receive the full benefit of the workshops - Data collection & analysis: Data were collected through a questionnaire, including both the quantitative and qualitative data collection. The qualitative component analysed participants responses to their views on the workshops. Thematic analysis (Braun and Clarke 2006) was used to distil themes and disseminate findings from ten carers'feedback forms, to further investigate the carers'experience of completing the workshops, to identify the most/least useful aspects of the workshops and identify possible ways to improve the intervention.		Unclear: Unclear details on data collection methods are reported - **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear descritption about relationship between researcher and carers during data collection and analysis - **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Yes - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Moderate
Full citation Melunsky Nina, et al.,, The experience of family carers attending a joint	**Sample size** N=10 adult carers **Characteristics**	**Interventions** - Phenomenon of interest (as reported in the study): Reminiscence	- Details - Recruitment strategy: Carers of a person with dementia living in the	**Results are summarised under the following the following themes –**	**Limitations (CASP-checklist for qualitative studies)**

reminiscence group with people with dementia: a thematic analysis, Dementia: The International Journal of Social Research and Practice, 14, 842-859, 2015 **Ref Id** 725378 **Country/ies where the study was carried out** UK: London **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the views of 18 family carers of people with dementia attending ‘Remembering Yesterday Caring Today’ groups (reminiscence therapy) **Study dates** • **Publication date**: 2015 • **Data collection**: August 2012 **Source of funding**	**Carer** • Carer age = Range, years: 41 to 85 • Carer gender (M/F:n)= 6/12 • "Relationship to care recipient"= parents (N): 0; spouses (N): 12; daughters-sons (N): 6; sibling (N): 0; other/undisclosed (N): 0 **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R	therapy - Remembering Yesterday Caring Today (RYCT) • Phenomenon of interest (according to the protocol): Cognitive-/emotion-oriented/activity-based interventions	community were purposively recruited in the boroughs of Havering and Redbridge in North East London or in Norfolk. Carers were selected selected to represent a diverse range of socio-demographic characteristics (gender, age, ethnicity, kinship to the person with dementia) and degree of attendance at the RYCT ('Remembering Yesterday, Caring Today'') intervention. • Data collection & analysis: Data were collected through (face-to-face) semi-structured interview. The qualitative research software programme Nvivo (Version 10) was used to support coding, management, and analysis of data to enhance rigour. An inductive (bottom-up) thematic analysis was used as a systematic method of identifying themes or patterns within the data (Braun 2006). An initial coding framework was	• ‘experiencing carer support’ • ‘shared experience’ • ‘expectations’ (met and unmet) • ‘perspectives of the person with dementia’s experience’ • ‘learning and comparing’	• **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear descritption about relationship between researcher and carers during data collection and analysis • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes

The project was funded by North East London NHS Foundation Trust (NELFT) from the NIHR Programme Grants for Applied Research (RP-PG-060-1083)			developed by researchers who independently identified words and phrases which described the experience of family carers attending the RYCT sessions. The reviewers met to compare analyses, and a consensus on the content and explanation of each theme was reached.		• **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Milne, A., Guss, R., Russ, A., Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: an evaluation of a 'Course for Carers', Dementia (London, England), 13, 768-787, 2014 **Ref Id** 720736 **Country/ies where the study was carried out** UK: Kent **Study type** Mix-methods (observational study, peer-reviewed)	**Sample size** N=73 adult carers **Characteristics** **Carer** • Carer age = Mean (years): 64 • Carer gender (M/F:n)= N/R • "Relationship to care recipient"= parents (N): 0; spouses (N): 49; daughters-sons (N): 24; sibling (N): 0; other/undisclosed (N): 0 **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria**	**Interventions** • Phenomenon of interest (as reported in the study): Psycho-educational support for 'new carers' (that is for relatives of people with a recent dementia diagnosis): Medway 'Carers Course' • Phenomenon of interest (according to the protocol): Psychosocial interventions	**Details** • Recruitment strategy: Unclear sampling/ Recruitment strategy • Data collection & analysis: Data were collected through a questionnaire, including both the quantitative and qualitative data collection. The qualitative component analysed answers to 8 open questions (1) Is there anything you will manage or do differently as a result of the course ?; 2) Have you accessed any/further services since attending course ?; 3) Please give examples of where the course has helped ?; 4)	**Results are summarised under the following the following themes –** • 'Changed Approach: Greater Understanding and Patience' • 'Improved Coping Skills' • 'The Therapeutic Value of the Course' • 'Social Support and Enjoyment' 'Support Services' • 'The Style, Timing and Content of the Course' • 'The Valuable Role of Empathic Experts' • 'Weaknesses of the Course'	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Not: No

Aim of the study The aims of this mixed-methods study were to evaluate a multi-component psychoeducational intervention for relatives of people with a recent diagnosis of mild to moderate dementia. **Study dates** • **Publication date**: 2014 • **Data collection**: 2008-2009 **Source of funding** None	N/R **Exclusion criteria** N/R		Identify aspects that remain difficult/course did not help with ?; 5) Please identify the most useful aspects of course and why ?; 6) Please identify the least useful aspects of course and why ?; 7) Any comments of presentation methods ?; 8) Any other comments ?). Data was managed using Excel. Qualitative data was analysed thematically (Bowling, 1997).		details how carers were selected or recruited • **Q5: Were the data collected in a way that addressed the research issue? -** Not: Theoretical sufficiency/ saturation of data has not been discussed • **Q6: Has the relationship between researcher and participants been adequately considered? -** Unclear: Unclear descritption about relationship between researcher and carers during data collection and analysis • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to**

					literature and 2. Transferability) - Yes **Overall methodological limitations** - Moderate
Full citation Osman, Sara Eldirdiry, Tischler, Victoria, Schneider, Justine, 'Singing for the brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers, Dementia: The International Journal of Social Research and Practice, 15, 1326-1339, 2016 **Ref Id** 724296 **Country/ies where the study was carried out** UK: England **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the views of	**Sample size** N=18 adult carers **Characteristics** **Carer** • Carer age = N/R • Carer gender (M/F:n)= N/R • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R	**Interventions** • Phenomenon of interest (as reported in the study): Music therapy: 'Singing for the Brain' • Phenomenon of interest (according to the protocol): Low-level/informal support interventions	**Details** • Recruitment strategy: It is unclear whether the sample of carers was recruited purposively or was a convenience sampling. All participants (carers who had sought out support, in their roles as carers, from a local NHS mental health trust) who participated in the gallery-based groups were invited to take part in the study, as were the two co-facilitator • Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews and included topics identified from the literature. Interviews ranged from 37 to 85 minutes in length and took place in the home of the carer. All interviews were audio-taped, and transcribed. Interview data were	**Results are summarised under the following the following themes –** • 'Social inclusion and support' • 'A shared experience' • 'Positive impact on relationships' • 'Lifting the spirits'	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: Unclear details on how carers were selected/recruited • **Q5: Were the data collected in a way that addressed the research issue?** - Not: Theoretical sufficiency/ saturation of data has not been discussed • **Q6: Has the relationship between researcher and**

carers of people with dementia obout the impact of Singing for the BrainTM, an intervention based on group singing activities developed by The Alzheimer's Society. **Study dates** - **Publication date**: 2016 - **Data collection**: N/R **Source of funding** The project was funded by the Alzheimer's Society			analysed using thematic analysis (Braun 2006).		**participants been adequately considered?** - Unclear: Unclear descritption about relationship between researcher and carers during data collection and analysis - **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Yes - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Moderate
Full citation Roberts, Samantha, Camic, Paul M., Springham, Neil, New roles for art galleries: Art-viewing as a community intervention for family carers of people with mental health problems, Arts & Health: An	**Sample size** - N=8 adult carers - N=2 providers (facilitators) **Characteristics** **Carer** - Carer age = Range, years: 30 to 60	**Interventions** - Phenomenon of interest (as reported in the study): Art therapy: art viewing - Phenomenon of interest (according to the protocol): Low-level/informal support interventions	**Details** - Recruitment strategy: It is unclear whether the sample of carers was recruited purposively or was a convenience sampling. Participants (that is patient–carer pairs attending at least two sessions of SftB -	**Results are summarised under the following the following themes –** - "Carer" identity (including 1. Recognition of carers' needs) - Feeling valued in a special setting (including 1. Privilege; 2. Famous;	**Limitations (CASP-checklist for qualitative studies)** - **Q1: Was there a clear statement of the aims of the research?** - Yes - **Q2: Was a qualitative methodology appropriate?** - Yes

International Journal of Research, Policy and Practice, 3, 146-159, 2011 **Ref Id** 717433 **Country/ies where the study was carried out** UK: England **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to understand the psychological and social aspects of how art-viewing, in a public art gallery, could be used as an activity to support family carers of people with mental health problems. **Study dates** • **Publication date**: 2011 • **Data collection**: N/R **Source of funding** N/R	• Carer gender (M/F:n)= 1/7 • "Relationship to care recipient"= N/R **Professionals** • Facilitators (males) **Care recipient** • Care recipientCondition = Mental health issues **Inclusion criteria** All 8 carers who participated in the gallery-based groups were invited to take part in the study, as were the two co-facilitators. **Exclusion criteria** N/R		Singing for the Brain) were recruited in the East Midlands area of the UK • Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews after intervention was completed, and podcasts (edited audio-recordings from gallery art-viewing sessions) that were in the public domain at the gallery and on a website. Continuing until theoretical saturation had occurred was not possible; the sample did, however, meet criteria for theoretical sufficiency. and initially given line-by-line open codes. Analysis was a “constant comparative analysis.” (Willig 2008). Quality assurance included maintaining an audit trail of analytic decision by the first author, which allowed the second and third authors to review and help refine those decisions.	3. Quiet; 4. Special; 5. Architectural grandeur) • Art-viewing (including 1. Engaging on different levels; 2. Stimulating responses)	• **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: Unclear details on how carers were selected/recruited • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor

Full citation Robinson, L., Francis, J., James, P., Tindle, N., Greenwell, K., Rodgers, H., Caring for carers of people with stroke: developing a complex intervention following the Medical Research Council framework, Clinical Rehabilitation, 19, 560-71, 2005 **Ref Id** 574244 **Country/ies where the study was carried out** UK: Newcastle **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to develop and evaluate a new service for carers of people with stroke which would (1) enable carers to effectively manage the stress and problems associated with their role; (2) maintain or improve	**Sample size** N=14 adult carers **Characteristics** **Carer** • Carer age = Range, years: 38 to 74 • Carer gender (M/F:n)= N/R • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient** • Care recipientCondition = Stroke **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R	**Interventions** • Phenomenon of interest (as reported in the study): Coping skills course (based on the cognitive behavioural approach) - including information, emotional adjustment, stress management, and enahancing self efficacy and self worth. • Phenomenon of interest (according to the protocol): Multicomponent interventions (that is those that address more than one carer domain such as maintenance of relationships, disease education, safety, carer health and wellbeing)	**Details** • Recruitment strategy: Sampling of participants was purposively designed to maximize the variety of their experiences. Carers of various ages, at various stages in their caring career and with a range of relationships to the care receiver were recruited. Further details on how carers were recruted are not reported. Participants were initially selected from the North Tyneside General Hospital Stroke Review Clinic, where all patients are reviewed six months following discharge, and later from the Newcastle Stroke Discharge Team in order to ensure all selection criteria for a purposive sample were met • Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews guided from a topic guide was	**Results are summarised under the following the following main theme –** • 'Feasibility of the intervention'	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes

their well-being; and (3) improve their knowledge about stroke, available services and financial support. **Study dates** - **Publication date**: 2005 - **Data collection**: N/R **Source of funding** The project was funded by the Stroke Association.			developed by the project team (that is recollections of the events surrounding the patient's first stroke; the hospital experience; returning home; ongoing rehabilitation period; carer well-being; change of lifestyle/domestic responsibilities; knowledge about stroke; availability of social support networks; acquisition of new skills related to caring and any coping strategies employed). Interviews were audio-taped and transcribed verbatim. Data collection and analysis were guided by grounded theory methodology. Sampling ended when data saturation was achieved (that is, no new themes emerged).		- **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Yes - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Moderate
Full citation Sommerlad, Andrew, Manela, Monica, Cooper, Claudia, Rapaport, Penny, Livingston, Gill, START (STrAtegies for RelaTives) coping strategy for family carers	**Sample size** N=75 **Characteristics** **Carer** - Carer (sample n)= 75	**Interventions** - Phenomenon of interest (as reported in the study): manual-based coping strategy programme (STrAtegies for RelaTives, START).	**Details** - Recruitment methods: Carers were recruited purposively as a sub-sample of the START trial. - Data collection & analysis: Data were	**Results are summarised under the following the following themes –** - ‘important aspects of the therapy’ - ‘participants’ engagement with the therapy’	**Limitations (CASP-checklist for qualitative studies)** - Q1: Was there a clear statement of the aims of the research? - Yes

of adults with dementia: qualitative study of participants' views about the intervention, BMJ Open, 4, 2014 **Ref Id** 745259 **Country/ies where the study was carried out** UK **Study type** Mix-methods (RCT, peer-reviewed) **Aim of the study** The aims of this qualitative research were to explore the experiences of individual family carers of people with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), demonstrated in a randomised-controlled trial to reduce affective symptoms. **Study dates** 2014 **Source of funding**	• Carer (age)= mean age - range (years): 59,3 | 18-65 • Carer (gender-M/F)= 26/49 • "Relationship to care recipient"= parents (N): 0; spouses (N): 31; daughters-sons (N): 34; sibling (N): 0; other (N): 10 **Professionals** • N/A **Care recipient** • care recipient condition= Dementia **Inclusion criteria** Participant eligibility were as used in the START trial (Carers were included in the main START trial if they identified themselves as the primary family carer of a patient diagnosed with dementia who provided support at least weekly to their relative, who was not living in 24 h care and referred to one of four different settings - three mental health services and a tertiary neurological service for dementia).	• Phenomenon of interest (according to the protocol): Psychosocial interventions	collected using self-completed questionnaires (INCLUDING this questions: 1) Was there anything that you found particularly helpful?; 2) How have you used the intervention (support sessions, manual or CD) since it ended?; 3) Is there anything you would do differently?; 4) Is there anything you would add in?; 5) Looking back, do you feel that you took part in the intervention at the right time?) exploring the experience of the START intervention. Data were transcribed, coded and analysed by twwo researchers using thematic analysis	• 'unhelpful aspects of therapy' • 'potential improvements and appropriate time for delivery of the intervention'	• Q2: Was a qualitative methodology appropriate? - Yes • Q3: Was the research design appropriate to address the aims of the research? - Yes • Q4: Was the recruitment strategy appropriate to the aims of the research? - Yes • Q5: Were the data collected in a way that addressed the research issue? - Yes • Q6: Has the relationship between researcher and participants been adequately considered? - Yes • Q7: Have ethical issues been taken into consideration? - Yes • Q8: Was the data analysis sufficiently rigorous? - Yes • Q9: Is there a clear statement of findings? - Yes • **Q10**: Is the research valuable for the UK (1. Contribution to literature and 2. Transferability)? - Yes **Overall methodological limitations** – minor

National Institute for Health Research - Health Technology Assessment (HTA) programme (project no 08/14/06)	Cares were included at 2-years follow-up of ther trial **Exclusion criteria** Not reported (look at the inclusion criteria)				
Full citation Smallwood, Jane, Jolley, Suzanne, Makhijani, Jyotsna, Grice, Sarah, O'Donoghue, Emma, Bendon, Paula, Greenaway, Liz P., Onwumere, Juliana, Implementing specialist psychological support for caregivers in psychosis services: A preliminary report, Psychosis: Psychological, Social and Integrative Approaches, 9, 119-128, 2017 **Ref Id** 723283 **Country/ies where the study was carried out** UK: London **Study type** Qualitative study (peer-reviewed) **Aim of the study**	**Sample size** N=26 adult carers **Characteristics** **Carer** • Carer age = N/R • Carer gender (M/F: N) = N/R • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient** • Care recipientCondition = Psychosis **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R	**Interventions** • Phenomenon of interest (as reported in the study): Carer support service: including individual and group psychoeducation, practical advice and emotional support • Phenomenon of interest (according to the protocol): Multicomponent interventions (that is those that address more than one carer domain such as maintenance of relationships, disease education, safety, carer health and wellbeing)	**Details** • Recruitment strategy: Unclear sampling/ Recruitment strategy • Data collection & analysis: Unclear methods of data collection. Qualitative data were analysed by using thematyc analysis. No further details on data collection/analysis are reported.	**Results are summarised under the following the following themes –** • Needs (including ‘Services’; ‘Information’; and ‘Co-operation’) • Psychological benefits (including ‘Reduced distress’; ‘Support’; and ‘Coping’) • Sharing Mutuality (including ‘Learning’; and ‘Solidarity’)	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: Unclear details on how carers were selected/recruited • **Q5: Were the data collected in a way that addressed the research issue?** - Not: no details on data collection methods are reported

The aims of this qualitative study were to explore the views of carers of people with psycosis about a newly-developed support service, offering individual and group psychoeducation, practical advice and emotional support, working alongside usual community mental health provision for people with established psychosis. **Study dates** • **Publication date**: 2017 • **Data collection**: 2013-2014 **Source of funding** The project was funded by the Guy's & St. Thomas' Charity [ref. EFT 130801].					• **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear descritption about relationship between researcher and carers during data collection and analysis • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Unclear: no details on data analysis methods are reported • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Major
Full citation Unadkat Shreena, Camic Paul M, Vella-Burrows Trish, Understanding the experience of group singing for couples where	**Sample size** N=10 adult carers **Characteristics** **Carer**	**Interventions** • Phenomenon of interest (as reported in the study): Music therapy: 'group singing model in	**Details** • Recruitment strategy: Sampling of participants was purposively by using the grounded theory concept of	**Results are summarised under the following the following themes –** • Singing experience (including 'accessibility of	**Limitations (CASP-checklist for qualitative studies)** • **Q1: Was there a clear statement of**

one partner has a diagnosis of dementia, Gerontologist, 57, 469-478, 2017 **Ref Id** 723297 **Country/ies where the study was carried out** UK: England and Wales **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to evaluate how group singing benefits people with dementia and their partners. **Study dates** • **Publication date**: 2017 • **Data collection:** N/R **Source of funding** The project was (presumibly) funded by Sussex Partnership NHS Foundation Trust, Dulwich Picture Gallery's Visual to Vocal programme, and the Alzheimer's Society	• Carer age = Mean (range, years): 70 (61 to 89) • Carer gender (M/F:n)= 5/12 • "Relationship to care recipient"= parents (N): 0; spouses (N): 17; daughters-sons (N): 0; sibling (N): 0; other/undisclosed (N): 1 **Professionals** • N/A **Care recipient** • Care recipientCondition = Dementia **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R	dementia for couple dyads' • Phenomenon of interest (according to the protocol): Low-level/informal support interventions	theoretical sampling - that is where concepts identified from initial coding influenced future recruitment and theory developmentRecruitment was carried out through theoretical sampling by contacting different types of singing groups in England and Wales. Participants were selected for interview to fulfill theoretical sampling assumptions (for example types of singing groups, impairment and ability levels, socioeconomic areas) • Data collection & analysis: Data were collected through (face-to-face) open interviews guided from a topic guide including 3 broad elements: 1) history and experience together as a couple; 2) responses to dementia, and 3) the experience of singing. All interviews were audio-taped, and transcribed. Interview data were analysed using thematic analysis: Concurrent data	singing'- "innate" and "universal"; and 'joy of singing'- enjoyment, uplifting, stimulating, and therapeutic) • Effective facilitation (including person centred; encourages participation; and equality as priority) • Equal participation • Group effect (including belonging; shared experience; and formulation of the group) • New experiences (including 'opened a new word'; building something; and excitement) • Couple benefit (including carers benefits)	**the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes

			collection and analysis was carried out in order to allow for the initial codes to direct sampling (Glaser et al., 1967). Sufficient data were achieved (the relationships between categories (constructs) were theoretically explored and formed a coherent and plausible theoretical understanding.		- **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Whitney, J., Currin, L., Murray, J., Treasure, J., Family work in anorexia nervosa: a qualitative study of carers' experiences of two methods of family intervention, European Eating Disorders Review, 20, 132-41, 2012 **Ref Id** 710042 **Country/ies where the study was carried out** UK: London **Study type** Mix-methods (RCT, peer-reviewed)	**Sample size** N=23 adult carers **Characteristics** **Carer** - Carer age = Mean (range, years): 47 (21 to 62) - Carer gender (M/F:n)= 10/13 - "Relationship to care recipient"= parents (N): 17; spouses (N): 1; daughters-sons (N): 1; sibling (N): 4; other/undisclosed (N): 0 **Professionals** - N/A **Care recipient**	**Interventions** - Phenomenon of interest (as reported in the study): Individual family work and multi-family workshops - Phenomenon of interest (according to the protocol): Family interventions	**Details** - Recruitment strategy: Carers were recruited purposively from the sample of a RCT of family interventions (see Treasure 2011 and Whitney 2011 for a description of the trial) - Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews guided from a topic guide including 2 broad sections: 1)carers' individual experiences of caregiving; 2) carers' expectations, experiences and satisfaction with the	**Results are summarised under the following the following themes –** - Who was involved and what were the experiences of working together? (including 'Working with the professionals'; 'Working with another family' and 'Engagement and involvement of the patient') - What was involved in the intervention and how was this perceived? (including 'Goals and expectations'; 'Structure of interventions'; 'Components of family	**Limitations (CASP-checklist for qualitative studies)** - **Q1: Was there a clear statement of the aims of the research?** - Yes - **Q2: Was a qualitative methodology appropriate?** - Yes - **Q3 Was the research design appropriate to address the aims of the research?** - Yes - **Q4: Was the recruitment strategy appropriate to the**

Aim of the study The aims of this mixed-methods study were to evaluate treatment efficacy, carer satisfaction and the process of change associated with two family interventions provided as a supplement to inpatient care for anorexia nervosa—individual family work (IFW) and family day workshops (FDW). **Study dates** • **Publication date**: 2012 • **Data collection**: 2011 **Source of funding** The project was funded by the Psychiatry Research Trust (registered charity no. 284286)	• Care recipientCondition = Eating disorders (Anorexia nervosa) **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R		family intervention they received. All interviews were were transcribed verbatim by the first author and two research assistants and independently proof-read. The interviews were analysed using Interpretive Phenomenological Analysis (IPA) (Smith, 1996; Smith, Jarman, & Osborn, 1999).	work'; and 'What else would be helpful?') • When is the intervention presented? (including 'Introducing the intervention'; and ''Family work as an early intervention strategy') • What else would be helpful? Where was the intervention held? (including 'Improving communication'; 'Making sense of the illness'; 'Insight into self, others, and the family'; and 'Feeling empowered') • How did the intervention work? (including 'The therapeutic environment'; and 'Implementation outside the therapeutic environment')	**aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Yes • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Williams, Jonathan, Vaughan, Frances,	**Sample size** N=5 adult carers	**Interventions** • Phenomenon of interest (as reported in the	**Details** • Recruitment strategy: Participants were	**Results are summarised under the following the following themes –**	**Limitations (CASP-checklist for qualitative studies)**

Huws, Jaci, Hastings, Richard, Brain injury spousal caregivers' experiences of an acceptance and commitment therapy (ACT) group, Social Care and Neurodisability, 5, 29-40, 2014 **Ref Id** 720455 **Country/ies where the study was carried out** UK: England **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the views of acquired brain injury (ABI) carers who attended an acceptance based group intervention. **Study dates** • **Publication date**: 2014 • **Data collection**: N/R **Source of funding** N/R	**Characteristics** **Carer** • Carer age = Range, years: 55 to 64 • Carer gender (M/F:n)= 1/4 • "Relationship to care recipient"= parents (N): 0; spouses (N): 5; daughters-sons (N): 0; sibling (N): 0; other/undisclosed (N): 1 **Professionals** • N/A **Care recipient** • Care recipientCondition = Acquired brain injury **Inclusion criteria** N/R (look at the 'recruiment strategy') **Exclusion criteria** N/R	study): Acceptance and commitment therapy (ACT) • Phenomenon of interest (according to the protocol): Cognitive-/emotion-oriented/activity-based interventions	recruited purposively from a sample of ten attendees of the ACT group intervention. Carers were recruited by the Brain Injury Service because it was known that these caregivers were reporting significant caregiving demands and subjectively high levels of stress • Data collection & analysis: Data were collected through (face-to-face) semi-structured interviews guided from a topic guide including a number of broad sections: 1) introduction and explanation; questions relating to the caregivers' family and injured relatives; 2) caregiving roles; 3) and experiences of attending the group, views on ACT principles, the utility of the group, and any other feedback. The interviews were recorded digitally and transcribed verbatim. Interview data were analysedf using a king of inductive thematic	• 'increasing personal awareness' • 'the dialectic of emotional acceptance versus emotional avoidance' • 'integration of acceptance and commitment therapy (ACT) principles' • 'peer support' • 'moving forward after the group'	• **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes

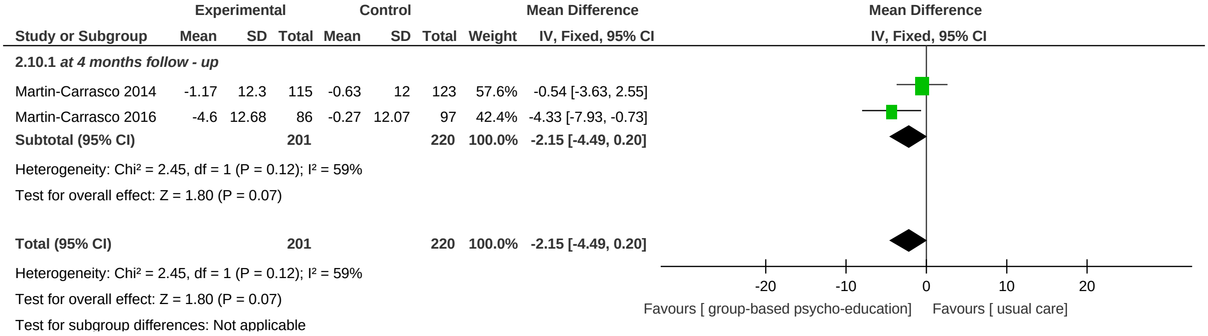
			analysis, where the analysis involved listening to the recordings several times, followed by reading each transcript on a case-by-case basis, noting preliminary descriptions and interpretations of participants' experiences in the left hand margins of each transcript.		• **Q8: Was the data analysis sufficiently rigorous?** - Yes • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor

F: Female; M: Male; N: Number; N/R: not reported

Appendix E – Forest plots

Forest plots for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Figure 4: Group-based psycho-educational interventions, impact of caring on carer: brden, ZBI (Zarit Burden Interview) - mean changes from baseline (at 4 months follow-up)

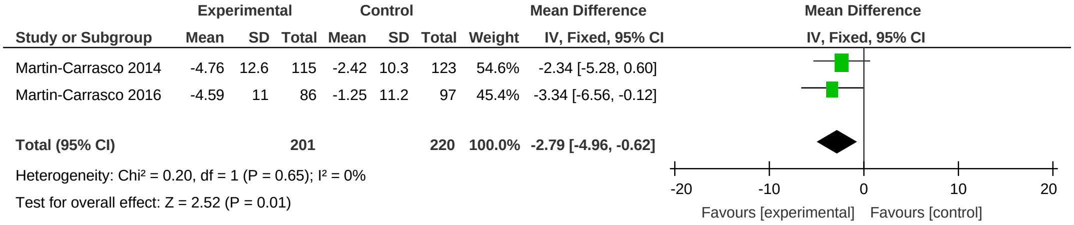


	Experimental			Control				Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**
2.10.1 ***at 4 months follow - up***								
Martin-Carrasco 2014	-1.17	12.3	115	-0.63	12	123	57.6%	-0.54 [-3.63, 2.55]
Martin-Carrasco 2016	-4.6	12.68	86	-0.27	12.07	97	42.4%	-4.33 [-7.93, -0.73]
Subtotal (95% CI)			**201**			**220**	**100.0%**	**-2.15 [-4.49, 0.20]**
Heterogeneity: Chi² = 2.45, df = 1 (P = 0.12); I² = 59%								
Test for overall effect: Z = 1.80 (P = 0.07)								
Total (95% CI)			**201**			**220**	**100.0%**	**-2.15 [-4.49, 0.20]**
Heterogeneity: Chi² = 2.45, df = 1 (P = 0.12); I² = 59%								
Test for overall effect: Z = 1.80 (P = 0.07)								
Test for subgroup differences: Not applicable								

CI: confidence interval; MD: mean difference

Source: Martin-Carrasco 2014, Martin-Carrasco 2016

Figure 5: Group-based psycho-educational interventions, caring-related morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items) - mean changes from baseline (at 4 months follow-up)



	Experimental			Control				Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**
Martin-Carrasco 2014	-4.76	12.6	115	-2.42	10.3	123	54.6%	-2.34 [-5.28, 0.60]
Martin-Carrasco 2016	-4.59	11	86	-1.25	11.2	97	45.4%	-3.34 [-6.56, -0.12]
Total (95% CI)			**201**			**220**	**100.0%**	**-2.79 [-4.96, -0.62]**
Heterogeneity: Chi² = 0.20, df = 1 (P = 0.65); I² = 0%								
Test for overall effect: Z = 2.52 (P = 0.01)								

CI: confidence interval; MD: mean difference

Source: Martin-Carrasco 2014, Martin-Carrasco 2016

Appendix F – GRADE and GRADE CERQual tables

GRADE tables for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Psychosocial and psycho-educational interventions

Table 8: Evidence profile for web-based psycho-educational interventions for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Web-Based psycho-educational interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) at 6 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 4.8 higher (4.65 lower to 14.25 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Burden, RMBPC (revised memory and behaviour checklist) - reaction [at 6 months follow - up from baseline] (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	serious[3]	no serious imprecision	none	22	21	-	MD 0.2 higher (0.13 lower to 0.53 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Subjective burden, RCCS (Revised Caregiving Satisfaction Scale) at 3 months follow - up from baseline (that is intervention completion) (Better indicated by higher values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Web-Based psycho-educational interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	30	31	-	MD 3.74 lower (7.8 lower to 0.32 higher)	LOW	CRITICAL
Caring-related morbidity: Depression, CES–D (Centre for Epidemiological Studies Depression scale) mean changes from baseline - at 6 months follow - up (from intervention competition) (Better indicated by higher values)												
1[6]	randomised trials	serious[7]	no serious inconsistency	no serious indirectness	no serious imprecision	none	149	96	-	MD 2.69 higher (0.69 to 4.69 higher)	MODERATE	CRITICAL
Caring-related morbidity: Perceived stress, PSS-14 (Perceived Stress Scale) at 6 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 1.2 higher (3.88 lower to 6.28 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression, BDI-II (Beck Depression Inventory-second version) at 6 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 3.6 higher (2.14 lower to 9.34 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression, CES–D (Centre for Epidemiological Studies Depression scale) - at 3 months follow - up from baseline (that is intervention completion) (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Web-Based psycho-educational interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	30	31	-	MD 0.73 higher (0.47 lower to 1.93 higher)	LOW	CRITICAL
Caring-related morbidity: Perceived health status, NHP (Nottingham Health Profile) at 6 months follow - up from baseline - social isolation (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 1.7 higher (11.49 lower to 14.89 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Perceived health status, NHP (Nottingham Health Profile) at 6 months follow - up from baseline - emotions (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 9.4 higher (4.09 lower to 22.89 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Perceived health status, NHP (Nottingham Health Profile) at 6 months follow - up from baseline - energy (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 0.3 higher (23.94 lower to	VERY LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-Based psycho-educational interventions	Control	Relative (95% CI)	Absolute		
										24.54 higher)		
Carer choice/control/efficacy: Self-efficacy - RSCS (Revised Scale for Caregiving Self-Efficacy) at 6 months follow - up from baseline - obtaining respite (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 5.47 higher (10.89 lower to 21.83 higher)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Self-efficacy - RSCS (Revised Scale for Caregiving Self-Efficacy) at 6 months follow - up from baseline - responding to patients' behaviours (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 3.1 higher (8.56 lower to 14.76 higher)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Self-efficacy - RSCS (Revised Scale for Caregiving Self-Efficacy) at 6 months follow - up from baseline - controlling upsetting behaviours (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	22	21	-	MD 0.6 lower (11.08 lower to 9.88 higher)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Self-efficacy, CCS (Caregiver Competence Scale) at 3 months follow - up from baseline (that is intervention completion) (Better indicated by higher values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-Based psycho-educational interventions	Control	Relative (95% CI)	Absolute		
1[4]	randomised trials	serious[4]	no serious inconsistency	no serious indirectness	serious[3]	none	30	31	-	MD 0.5 lower (3.13 lower to 2.13 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference.

1 Cristancho 2015

2 The quality of the evidence was downgraded by two levels because of the high risk of detection bias (no blinding of outcome assessors), and high risk of performance bias (lack of blinding of carers to the allocated intervention). In addition, quality of the evidence was lowered because sample size statistical power has been not achieved. As well, at baseline, as group were imbalanced regarding the number of weekly hours of professional help and IADL and depression scores.

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

4 Núñez-Naveira 2016

5 The quality of the evidence was downgraded by one level because of the unclear risk of selection bias, performance and detention bias, besides the lack of information to allow judgment on the achievement of sample size statistical power.

6 Blom 2015

7 The quality of the evidence was downgraded by one level because of the unclear risk of attrition bias [Attrition bias due to amount of incomplete outcome data in both intervention groups (Much higher dropout rate in the intervention). For intention-to-treat analysis, missing data due to dropout after baseline were imputed by using demographics, the scores on primary and secondary outcome measures, and additional measures as predictors], besides the lack of information to allow judgment on the achievement of sample size statistical power.

Table 9: Evidence profile for manual-based (coping skills) psycho-education for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Training intervention	Control	Relative (95% CI)	Absolute		
Caring-related morbidity: Anxiety and depression (Hospital Anxiety and Depression Scale -HADS-Total score) - at 8 months follow-up (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Training intervention**	**Control**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	133	71	-	MD 2 lower (4.29 lower to 0.29 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety and depression (Hospital Anxiety and Depression Scale -HADS-Total score) - at 12 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	138	64	-	MD 2.1 lower (4.65 lower to 0.45 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety and depression (Hospital Anxiety and Depression Scale -HADS-Total score) - at 24 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	no serious imprecision	132	64	-	MD 2.58 lower (4.26 to 0.90 lower)[4]	MODERATE	CRITICAL
Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale -HADS-anxiety subscale) - at 8 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	133	71	-	MD 1.2 lower (2.47 lower to 0.07 higher)	LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Training intervention**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale -HADS-anxiety subscale) - at 12 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	138	67	-	MD 1.6 higher (0.34 to 2.86 higher)	MODERATE	CRITICAL
Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale -HADS-anxiety subscale) - at 24 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	no serious imprecision	132	64	-	MD 1.2 lower (215 to 0.18 lower) [4]	MODERATE	CRITICAL
Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale -HADS-depression subscale) - at 8 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	133	71	-	MD 3.5 lower (4.73 to 2.27 lower)	MODERATE	CRITICAL
Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale -HADS-depression subscale) - at 12 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	138	67	-	MD 3.8 lower (5.21 to 2.39 lower)	MODERATE	CRITICAL
Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale -HADS-depression subscale) - at 24 months follow-up (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Training intervention	Control	Relative (95% CI)	Absolute		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	132	64	-	MD 1.45 lower (2.32 to 0.6 lower)[4]	MODERATE	CRITICAL
Caring-related morbidity: Mental health (Health Status Questionnaire - mental health domain) - at 8 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	122	66	-	MD 0.4 higher (5.66 lower to 6.46 higher)	LOW	CRITICAL
Caring-related morbidity: Mental health (Health Status Questionnaire - mental health domain) - at 12 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	121	61	-	MD 5.7 higher (1.03 lower to 12.43 higher)	LOW	CRITICAL
Caring-related morbidity: Mental health (Health Status Questionnaire - mental health domain) - at 24 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	113	55	-	MD 7.5 higher (2.87 to 12.08 higher)[4]	LOW	CRITICAL
Caring-related morbidity: abusive behaviours with care recipients (Modified Conflict Tactics Scale – MCTS: at least one item with score ≥2)* number of cases – at 8 month follow-up												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Training intervention	Control	Relative (95% CI)	Absolute		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	88/403 (21.8%)	25.4%	RR 0.83 (0.5 to 1.39)	43 fewer per 1000 (from 127 fewer to 99 more)	LOW	CRITICAL
Caring-related morbidity: abusive behaviours with care recipients (Modified Conflict Tactics Scale – MCTS: at least one item with score ≥2)* number of cases - at 12 months follow-up												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	33/138 (23.9%)	28.4%	RR 0.84 (0.52 to 1.37)	45 fewer per 1000 (from 136 fewer to 105 more)	LOW	CRITICAL
Caring-related morbidity: abusive behaviours with care recipients (Modified Conflict Tactics Scale – MCTS: at least one item with score ≥2)* number of cases - at 24 months follow-up												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	27/132 (20.5%)	15.6%	RR 1.31 (0.68 to 2.54)	48 more per 1000 (from 50 fewer to 240 more)	LOW	CRITICAL
Caring-related morbidity: Anxiety (HADS- anxiety >=9) number of cases - at 8 months follow-up												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Training intervention	Control	Relative (95% CI)	Absolute		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	53/133 (39.8%)	46.5%	RR 0.86 (0.62 to 1.19)	65 fewer per 1000 (from 177 fewer to 88 more)	LOW	CRITICAL
Caring-related morbidity: Anxiety (HADS- anxiety >=9) number of cases - at 12 months follow-up												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	54/138 (39.1%)	49.3%	RR 0.79 (0.58 to 1.09)	104 fewer per 1000 (from 207 fewer to 44 more)	LOW	CRITICAL
Caring-related morbidity: Anxiety (HADS- anxiety >=9) number of cases - at 24 months follow-up												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	57/132 (43.2%)	50%	RR 0.86 (0.63 to 1.18)	70 fewer per 1000 (from 185 fewer to 90 more)	LOW	CRITICAL
Caring-related morbidity: Depression (HADS-depression >=9) number of cases - at 8 months follow-up												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Training intervention	Control	Relative (95% CI)	Absolute		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	28/133 (21.1%)	32.4%	RR 0.65 (0.41 to 1.04)	113 fewer per 1000 (from 191 fewer to 13 more)	LOW	CRITICAL
Caring-related morbidity: Depression (HADS-depression >=9) number of cases - at 12 months follow-up												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	24/138 (17.4%)	26.9%	RR 0.65 (0.38 to 1.11)	94 fewer per 1000 (from 167 fewer to 30 more)	LOW	CRITICAL
Caring-related morbidity: Depression (HADS-depression >=9) number of cases - at 24 months follow-up												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	30/132 (22.7%)	19/64 (29.7%)	RR 0.77 (0.47 to 1.25)	68 fewer per 1000 (from 157 fewer to 74 more)	LOW	CRITICAL
Carer quality of life (Quality of Life-Alzheimer's disease - QoL-AD) - at 8 months follow-up (Better indicated by higher values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Training intervention**	**Control**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	119	61	-	MD 1.02 higher (1.02 lower to 3.06 higher)	LOW	CRITICAL
Carer quality of life (Quality of Life-Alzheimer's disease - QoL-AD) - at 12 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	114	53	-	MD 0.5 higher (1.62 lower to 2.62 higher)	LOW	CRITICAL
Carer quality of life (Quality of Life-Alzheimer's disease - QoL-AD) - at 24 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	95	49	-	MD 0.16 higher (1.30 lower to 1.70 higher)[4]	LOW	CRITICAL

CI: confidence interval; MD: mean difference.

1 Livingston 2014

2 The quality of the evidence was downgraded from high to moderate because of the potential risk of attrition bias (missing data likely related to true outcome with imbalance in reasons for missing data across groups

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

4 Effect estimates adjusted for baseline, centre, carers' age, sex, NPI and Zarit (n=200) as reported by the Authors

Table 10: Evidence profile for group-based psycho-educational interventions for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Group-based psycho-educational interventions	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Burden, BAS (Burden Assessment Scale) at 1 month follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 12.53 lower (13.98 to 11.09 lower)	MODERATE	CRITICAL
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - mean changes from baseline - at 4 months follow - up (Better indicated by higher values)												
2[3,4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	201	220	-	MD 2.15 lower (4.49 lower to 0.2 higher)	LOW	CRITICAL
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - mean changes from baseline - at 8 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	no serious imprecision	none	82	91	-	MD 4.46 lower (7.75 to 1.17 lower)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, IEQ (Involvement Evaluation Questionnaire) - mean changes from baseline - at 4 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[6]	none	86	97	-	MD 2.8 lower (6.24 lower to	VERY LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Group-based psycho-educational interventions	Control	Relative (95% CI)	Absolute		
										0.64 higher)		
Impact of caring on carer: Subjective burden, IEQ (Involvement Evaluation Questionnaire) - mean changes from baseline - at 8 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[6]	none	82	91	-	MD 2.86 lower (6.48 lower to 0.76 higher)	VERY LOW	CRITICAL
Caring related-morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items) - mean changes from baseline - at 4 months follow - up (Better indicated by lower values)												
2[3,4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	201	220	-	MD 2.79 lower (4.96 to 0.62 lower)	MODERATE	CRITICAL
Caring related-morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items) - mean changes from baseline - at 8 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[6]	none	82	91	-	MD 2.13 lower (5.64 lower to 1.38 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression, CES–D (Center for Epidemiological Studies Depression scale) - mean changes from baseline - at 4 months follow-up (Better indicated by higher values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Group-based psycho-educational interventions	Control	Relative (95% CI)	Absolute		
1[4]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[6]	none	86	97	-	MD 2.5 lower (5.22 lower to 0.22 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression, CES–D (Center for Epidemiological Studies Depression scale) - mean changes from baseline - at 8 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[6]	none	82	91	-	MD 1.65 lower (3.97 lower to 0.67 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression and anxiety, DASS- 21 (Depression Anxiety and Stress Scale-21) at 1 month follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[6]	none	14	14	-	MD 1.03 lower (2.99 lower to 0.93 higher)	LOW	CRITICAL
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Physical function (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 1.02 lower (10.15 lower to	LOW	IMPORTANT

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Group-based psycho-educational interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
										8.11 higher)		
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Role physical (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 1.79 higher (5.02 lower to 8.6 higher)	LOW	IMPORTANT
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Bodily pain (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 6.85 higher (0.82 lower to 14.52 higher)	LOW	IMPORTANT
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - General health (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	no serious imprecision	115	123	-	MD 5.01 lower (10.48 to 0.45 lower)	MODERATE	IMPORTANT
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Vitality (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Group-based psycho-educational interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 3.71 higher (3.67 lower to 11.09 higher)	LOW	IMPORTANT
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Social functioning (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 0.78 lower (8.66 lower to 7.1 higher)	LOW	IMPORTANT
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Role emotional (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 4.25 lower (10.91 lower to 2.41 higher)	LOW	IMPORTANT
Carer quality of life: SF-12 (Short-Form Health Survey 12) mean changes from baseline [at 4 months follow - up] - Mental health (Better indicated by lower values)												
1[3]	randomised trials	serious[8]	no serious inconsistency	no serious indirectness	serious[6]	none	115	123	-	MD 1.23 lower (6.75 lower to	LOW	IMPORTANT

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Group-based psycho-educational interventions	Control	Relative (95% CI)	Absolute		
										4.29 higher)		
Carer choice/control/efficacy: Knowledge - Knowledge of Bipolar Disorder Scale at 1 month follow - up from intervention completion (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 12.96 higher (11.79 to 14.13 higher)	MODERATE	IMPORTANT
Carer choice/control/efficacy: Self-efficacy -Bipolar Self-efficacy Scale at 1 month follow - up from intervention completion (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 23.13 higher (19.6 to 26.66 higher)	MODERATE	IMPORTANT

CI: confidence interval; MD: mean difference.

1 Hubbard 2016

2 The quality of the evidence was downgraded by one level because of the unclear risk of selection bias and performance bias (insufficient information to permit judgment on these methodological quality criteria).

3 Martin-Carrasco 2014

4 Martin-Carrasco 2016

5 The quality of the evidence was downgraded by one level because of the potential risk of detection bias and attrition bias in both studies which contributed to this outcome. Further in one RCT (Martin-Carrasco et.al 2016), sample size statistical power has been not achieved.

6 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

7 The quality of the evidence was downgraded of two levels because of the unclear risk of detection bias (lack of information on blinding of outcome assessors), and the high risk of attrition bias due to amount of incomplete outcome data in both intervention groups (much higher dropout rate in the intervention group). Further, sample size statistical power has been not achieved.

8 The quality of the evidence was downgraded by one level because of the unclear risk of detection bias (lack of information on blinding of outcome assessors), and the high risk of attrition bias due to amount of incomplete outcome data in both intervention groups (much higher dropout rate in the control group).

Table 11: Evidence profile for psycho-educational interventions for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Psycho-educational intervention	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Burden, (Caregiver Burden Scale -CBS) - mean changes from baseline [at 24 months follow - up] - Total caregiver burden (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	44	52	-	MD 0.02 higher (0.15 lower to 0.19 higher)	LOW	CRITICAL
Impact of caring on carer: Burden, (Caregiver Burden Scale -CBS) - mean changes from baseline [at 24 months follow - up] - General strain (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	44	52	-	MD 0.02 lower (0.23 lower to 0.19 higher)	LOW	CRITICAL
Impact of caring on carer: Burden (Caregiver Burden Scale -CBS) - mean changes from baseline [at 24 months follow - up] - Isolation (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	44	52	-	MD 0.72 lower (0.97 to 0.47 lower)	LOW	CRITICAL
Impact of caring on carer: Burden (Caregiver Burden Scale -CBS) - mean changes from baseline [at 24 months follow - up] - Disappointment (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	44	52	-	MD 0 higher (0.23 lower to 0.23 higher)	LOW	CRITICAL
Impact of caring on carer: Burden (Caregiver Burden Scale -CBS) - mean changes from baseline [at 24 months follow - up] - Emotional (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	44	52	-	MD 0.14 lower (0.37	LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psycho-educational intervention**	**Control**	**Relative (95% CI)**	**Absolute**		
										lower to 0.09 higher)		
Impact of caring on carer: Burden (Caregiver Burden Scale -CBS) - mean changes from baseline [at 24 months follow - up] - Environment (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	44	52	-	MD 0.19 higher (0.09 lower to 0.47 higher)	LOW	CRITICAL

CI: confidence interval; MD: mean difference.

1 Liljeroos 2016

2 The quality of the evidence was downgraded by one level because of the unclear risk of selection bias, performance bias, and detection bias (insufficient information to permit judgment on these methodological quality criteria).

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Table 12: Evidence profile for peer support for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Peer support**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Subjective burden, NPI-D (Emotional Loneliness Scale, Caregiver Distress Scale of the Neuropsychiatric Inventory) at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 1.81 higher (0.46 lower to 4.08 higher)	LOW	CRITICAL
Impact of caring on carer: Positive Aspects of Caring, COPE index (Carers of Older People in Europe Index) - at 12 months follow - up from baseline (Better indicated by higher values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Peer support**	**Control**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.02 higher (0.54 lower to 0.58 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, PANAS (Positive scale from the Positive and Negative Affect Schedule) at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.17 higher (1.29 lower to 1.63 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, PGI (3 item Personal Growth Index) at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.41 lower (1 lower to 0.18 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, QCPR (Quality of Caregiver–Patient Relationship) at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 1.41 higher (0.47 lower to 3.29 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety, HADS- A (Hospital Anxiety and Depression Scale) at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.35 lower (1.31 lower to 0.61 higher)	LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Peer support	Control	Relative (95% CI)	Absolute		
Caring-related morbidity: Depression, HADS-D (Hospital Anxiety and Depression Scale) at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.35 lower (0.85 lower to 0.15 higher)	LOW	CRITICAL
Carer quality of life: UK SF-12 (UK Short Form-12 Health Survey) at 12 months follow - up from baseline - Mental health-related quality of life (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.51 higher (1.28 lower to 2.3 higher)	LOW	IMPORTANT
Carer quality of life: UK SF-12 (UK Short Form-12 Health Survey) at 12 months follow - up from baseline - Physical health-related quality of life (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.61 higher (1.23 lower to 2.45 higher)	LOW	IMPORTANT
Carer quality of life: Health-related quality of life (EQ-5D - VAS) (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	48	47	-	MD 0.38 higher (4.2 lower to 4.96 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference.

1 Charlesworth 2016

2 The quality of the evidence was downgraded by one level because of the high risk of performance bias due to knowledge of the allocated interventions by participants and personnel during the study.

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Cognitive behavioural therapy

Table 13: Evidence profile for group-based cognitive behavioural therapy for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Group-Based - Cognitive behavioural therapy (CBT)	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - at 2 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	12	15	-	MD 1.5 higher (2.54 lower to 5.54 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - at 3 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	88	82	-	MD 5.9 lower (8.95 to 2.85 lower)	MODERATE	CRITICAL
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - at 6 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	88	82	-	MD 4.3 lower (7.7 to 0.9 lower)	MODERATE	CRITICAL
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - at 9 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	88	82	-	MD 6.1 lower (9.82 to 2.38 lower)	MODERATE	CRITICAL

Quality assessment							**Number of participants**		**Effect**		**Quality**	**Importance**
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Group-Based - Cognitive behavioural therapy (CBT)**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Emotional distress, GHQ-28 - at 3 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	88	82	-	MD 2.6 lower (4.09 to 1.11 lower)	MODERATE	CRITICAL
Caring-related morbidity: Emotional distress, GHQ-28 - at 6 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	88	82	-	MD 2.1 lower (3.7 to 0.5 lower)	MODERATE	CRITICAL
Caring-related morbidity: Emotional distress, GHQ-28 - at 9 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	88	82	-	MD 2.7 lower (4.27 to 1.13 lower)	MODERATE	CRITICAL
Caring-related morbidity: Stress, PSS (Perceived Stress Scale) - at 2 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	12	15	-	MD 2.7 higher (1.98 lower to 7.38 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression, BDI (Beck Depression Inventory) - at 2 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	12	15	-	MD 1.5 higher	VERY LOW	CRITICAL

Quality assessment							**Number of participants**		**Effect**		**Quality**	**Importance**
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Group-Based - Cognitive behavioural therapy (CBT)**	**Control**	**Relative (95% CI)**	**Absolute**		
										(2.54 lower to 5.54 higher)		
Caring-related morbidity: Anxiety, State–Trait Anxiety Inventory (STAI) - at 2 months follow - up from baseline - anxiety traits (STAI-T) (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	12	15	-	MD 7.8 higher (0.25 to 15.35 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety, State–Trait Anxiety Inventory (STAI) - at 2 months follow - up from baseline - anxiety state (STAI-S) (Better indicated by lower values)												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	12	15	-	MD 6 higher (0.84 lower to 12.84 higher)	VERY LOW	CRITICAL

CI: confidence interval; MD: mean difference.
1 Aboulafia 2014
2 The quality of the evidence was downgraded of two levels because of the high risk of selection bias (due to inadequate generation of a randomised sequence and unclear allocation concealment), unclear risk of detection bias (lack of information on blinding of outcome assessors), and unclear risk of performance bias (lack of information about blinding of carers to the allocated intervention).
3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)
4 Vazquez 2016
5 The quality of the evidence was downgraded by one level because of the unclear risk of detection bias (lack of information on blinding of outcome assessors), and the potential risk of selection bias (no information on the allocation concealment methods used).

Table 14: Evidence profile for individualised cognitive behavioural therapy for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Telephone-Based - Cognitive behavioural therapy (CBT)	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Positive impact of caring, PTGI (Posttraumatic Growth Inventory) - at 6 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	110	134	-	MD 4.53 higher (1 lower to 10.06 higher)	MODERATE	CRITICAL
Impact of caring on carer: Positive impact of caring, PTGI (Posttraumatic Growth Inventory) - at 12 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	104	132	-	MD 4.72 higher (0.71 lower to 10.15 higher)	MODERATE	CRITICAL
Impact of caring on carer: Subjective burden (Leisure Time Satisfaction Scale) - at 6 months follow - up from intervention completion - Pleasant events (Better indicated by lower values)												
1[3]	randomised trials	serious[4]	no serious inconsistency	no serious indirectness	serious[2]	none	42	48	-	MD 0.31 lower (1.49 lower to 0.87 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden (Dysfunctional Thoughts About Caregiving Questionnaire) - at 6 months follow - up from intervention completion - Dysfunctional thoughts (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Telephone-Based - Cognitive behavioural therapy (CBT)	Control	Relative (95% CI)	Absolute		
1[3]	randomised trials	serious[4]	no serious inconsistency	no serious indirectness	serious[2]	none	42	48	-	MD 2.09 lower (8.32 lower to 4.14 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden (Experiential Avoidance in Caregiving Questionnaire) - at 6 months follow - up from intervention completion - Caregiving experiential avoidance (Better indicated by lower values)												
1[3]	randomised trials	serious[4]	no serious inconsistency	no serious indirectness	serious[2]	none	42	48	-	MD 0.51 lower (5.45 lower to 4.43 higher)	LOW	CRITICAL
Caring-related morbidity: Cancer-specific distress, IES (Impact of Events ScalE) - at 6 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	110	134	-	MD 2.71 higher (1.54 lower to 6.96 higher)	MODERATE	CRITICAL
Caring-related morbidity: Cancer-specific distress, IES (Impact of Events ScalE) - at 12 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	no serious	no serious inconsistency	no serious indirectness	serious[2]	none	104	132	-	MD 1.71 higher (2.92	MODERATE	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Telephone-Based - Cognitive behavioural therapy (CBT)**	**Control**	**Relative (95% CI)**	**Absolute**		
		risk of bias								lower to 6.34 higher)		
Caring-related morbidity: Psychological distress, BSI-18 (Brief Symptom Inventory–18) - at 6 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	110	134	-	MD 1.4 higher (1.48 lower to 4.28 higher)	MODERATE	CRITICAL
Caring-related morbidity: Psychological distress, BSI-18 (Brief Symptom Inventory–18) - at 12 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	104	132	-	MD 1.31 higher (1.73 lower to 4.35 higher)	MODERATE	CRITICAL
Caring-related morbidity: Anxiety (measure not clearly reported) - at 6 months follow - up from intervention completion (Better indicated by lower values)												
1[3]	randomised trials	serious[4]	no serious inconsistency	no serious indirectness	serious[2]	none	42	48	-	MD 3.9 lower (8.14 lower to 0.34 higher)	LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Telephone-Based - Cognitive behavioural therapy (CBT)	Control	Relative (95% CI)	Absolute		
Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale) - at 6 months follow - up from baseline (Better indicated by lower values)												
1[3]	randomised trials	serious[4]	no serious inconsistency	no serious indirectness	no serious imprecision	none	42	48	-	MD 6.88 lower (12.36 to 1.4 lower)	MODERATE	CRITICAL
Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale) - at 24 months follow - up from baseline (Better indicated by lower values)												
1[5]	randomised trials	very serious[6]	no serious inconsistency	no serious indirectness	serious[2]	none	78	27	-	MD 3.14 lower (7.94 lower to 1.66 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Perceived health status (VAS) - at 24 months follow - up from baseline (Better indicated by higher values)												
1[5]	randomised trials	very serious[6]	no serious inconsistency	no serious indirectness	serious[2]	none	78	27	-	MD 4.91 higher (5.2 lower to 15.02 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Emotional well-being (VAS) - at 24 months follow - up from baseline (Better indicated by higher values)												
1[5]	randomised trials	very serious[6]	no serious inconsistency	no serious indirectness	serious[2]	none	78	27	-	MD 10.17 higher (0.7 lower to 21.04 higher)	VERY LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Telephone-Based - Cognitive behavioural therapy (CBT)**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Perceived physical health, GBB-24 (Caregivers' perceived bodily complaints - including exhaustion, stomach trouble, rheumatic pains, and heart trouble) - at 24 months follow - up from baseline (Better indicated by lower values)												
1[5]	randomised trials	very serious[6]	no serious inconsistency	no serious indirectness	serious[2]	none	78	27	-	MD 4.3 lower (13.28 lower to 4.68 higher)	VERY LOW	CRITICAL
Carer quality of life: WHOQoL-BREF (World Health Organization quality of life, BREF) - at 24 months follow - up from baseline (Better indicated by higher values)												
1[5]	randomised trials	very serious[6]	no serious inconsistency	no serious indirectness	serious[2]	none	78	27	-	MD 3.62 higher (5.71 lower to 12.95 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference.

1 Chambers 2014

2 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

3 Losada 2015

4 The quality of the evidence was downgraded by one level because of the unclear risk of detection bias (lack of information on blinding of outcome assessors), the potential risk of selection bias (no information on the allocation concealment methods used), besides the likely selective reporting of this outcome measure.

5 Wilz 2017

6 The quality of the evidence was downgraded of two levels because of the unclear risk of performance bias and detection bias. Further the quality for this outcome was lowered as for the high risk of attrition bias due to amount of incomplete outcome data in both intervention groups (much higher dropout rate in the intervention); as well the sample size statistical power has been not achieved.

Cognitive-/emotion- /activity-based interventions

Table 15: Evidence profile for acceptance and commitment therapy for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Acceptance and Commitment Therapy**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Subjective burden (measure not clearly reported) - at 6 months follow - up from intervention completion - Pleasant events (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	45	48	-	MD 0.03 lower (1.52 lower to 1.46 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden (measure not clearly reported) - at 6 months follow - up from intervention completion - Dysfunctional thoughts (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	45	48	-	MD 3.2 lower (9.12 lower to 2.72 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden (measure not clearly reported) - at 6 months follow - up from intervention completion - Caregiving experiential avoidance (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	45	48	-	MD 4.67 lower (9.31 to 0.03 lower)	MODERATE	CRITICAL
Caring-related morbidity: Anxiety (measure not clearly reported) - at 6 months follow - up from intervention completion (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Acceptance and Commitment Therapy**	**Control**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	45	48	-	MD 3.12 lower (7.13 lower to 0.89 higher)	LOW	CRITICAL
Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale) - at 6 months follow - up from intervention completion (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	45	48	-	MD 3.4 lower (8.56 lower to 1.76 higher)	LOW	CRITICAL

CI: confidence interval; MD: mean difference.

1 Losada 2015

2 The quality of the evidence was downgraded by one level because of the unclear risk of detection bias (lack of information on blinding of outcome assessors), the potential risk of selection bias (no information on the allocation concealment methods used), besides the likely selective reporting of this outcome measure.

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Table 16: Evidence profile for reminiscence therapy for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Reminiscence therapy**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Subjective burden, NPI-D (Emotional Loneliness Scale, Caregiver Distress Scale of the Neuropsychiatric Inventory) - at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.09 lower (2.28 lower to 2.1 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, PANAS (Positive scale from the Positive and Negative Affect Schedule) - at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 1.03 higher (0.55 lower to 2.61 higher)	LOW	CRITICAL
Impact of caring on carer: Positive Aspects of Caring, COPE index (Carers of Older People in Europe Index) - at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.08 higher (0.45 lower to 0.61 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, PGI (3 item Personal Growth Index) - at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision[3]	none	97	47	-	MD 0.4 higher (0.22	MODERATE	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Reminiscence therapy	Control	Relative (95% CI)	Absolute		
										lower to 1.02 higher)		
Impact of caring on carer: Subjective burden, QCPR (Quality of Caregiver–Patient Relationship) - at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 1.87 higher (0.02 lower to 3.76 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, QCPR (Quality of Caregiver–Patient Relationship) - at 3 months follow - up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 1.18 lower (2.71 lower to 0.35 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, QCPR (Quality of Caregiver–Patient Relationship) - at 10 months follow - up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.56 higher (1.17 lower to 2.29 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety, HADS- A (Hospital Anxiety and Depression Scale) - at 3 months follow - up from baseline (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Reminiscence therapy	Control	Relative (95% CI)	Absolute		
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.19 higher (0.43 lower to 0.81 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety, HADS- A (Hospital Anxiety and Depression Scale) - at 10 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.59 higher (0.19 lower to 1.37 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety, HADS- A (Hospital Anxiety and Depression Scale) - at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.3 higher (0.65 lower to 1.25 higher)	LOW	CRITICAL
Caring-related morbidity: Depression, HADS-D (Hospital Anxiety and Depression Scale) - at 3 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.07 lower (0.63 lower to 0.49 higher)	LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Reminiscence therapy**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Depression, HADS-D (Hospital Anxiety and Depression Scale) - at 10 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.09 higher (0.64 lower to 0.82 higher)	LOW	CRITICAL
Caring-related morbidity: Depression, HADS-D (Hospital Anxiety and Depression Scale) - at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.07 lower (0.95 lower to 0.81 higher)	LOW	CRITICAL
Caring-related morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items) #log transform# - at 3 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.02 higher (0.1 lower to 0.14 higher)	LOW	CRITICAL
Caring-related morbidity: Mental health, GHQ-28 (General Health Questionnaire-28 items) #log transform# - at 10 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.07 higher (0.05 lower to	LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Reminiscence therapy**	**Control**	**Relative (95% CI)**	**Absolute**		
										0.19 higher)		
Caring-related morbidity: Perceived Distress, Relatives Stress Scale (RSS) - at 3 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.74 higher (0.84 lower to 2.32 higher)	LOW	CRITICAL
Caring-related morbidity: Perceived Distress, Relatives Stress Scale (RSS) - at 10 months follow - up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.06 higher (1.68 lower to 1.8 higher)	LOW	CRITICAL
Carer quality of life: UK SF-12 (UK Short Form-12 Health Survey) - at 12 months follow - up from baseline - Mental health-related quality of life (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.11 higher (1.72 lower to 1.94 higher)	LOW	IMPORTANT
Carer quality of life: UK SF-12 (UK Short Form-12 Health Survey) - at 12 months follow - up from baseline - Physical health-related quality of life (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.03 lower (2.29	LOW	IMPORTANT

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Reminiscence therapy	Control	Relative (95% CI)	Absolute		
										lower to 2.23 higher)		
Carer quality of life: Health-related quality of life (EQ-5D - VAS) - at 3 months follow - up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 0.06 higher (3.44 lower to 3.56 higher)	LOW	IMPORTANT
Carer quality of life: Health-related quality of life (EQ-5D - VAS) - at 10 months follow - up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	268	219	-	MD 1.03 higher (2.69 lower to 4.75 higher)	LOW	IMPORTANT
Carer quality of life: Health-related quality of life (EQ-5D - VAS) - at 12 months follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 0.92 higher (3.65 lower to 5.49 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference.

1 Charlesworth 2016

2 The quality of the evidence was downgraded by one level because of the high risk of performance bias due to knowledge of the allocated interventions by participants and personnel during the study.

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

4 Woods 2016

Table 17: Evidence profile for transcendental meditation for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Transcendental Meditation	Control	Relative (95% CI)	Absolute		
Carer quality of life: AQoL-8D assessment of quality of life (8-dimension) instrument – utility score - at 12 weeks follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	8	9	-	MD 0.07 higher (0.09 lower to 0.23 higher)	LOW	IMPORTANT
Carer quality of life: AQoL-8D assessment of quality of life (8-dimension) instrument – utility score - at 24 weeks follow - up from baseline (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	8	9	-	MD 0.01 lower (0.18 lower to 0.16 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference.
1 Leach 2015
2 The quality of the evidence was downgraded by one level because sample size statistical power has been not achieved.
2 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Table 18: Evidence profile for leisure activity program for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Activity-based interventions	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Burden, ZBI (Zarit Burden Interview) - mean changes from baseline [at post-intervention (follow-up not stated)] (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Activity-based interventions	Control	Relative (95% CI)	Absolute		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	21	21	-	MD 4.4 lower (5.13 to 3.67 lower)	LOW	CRITICAL

CI: confidence interval; MD: mean difference.

1 Hirano 2016

2 The quality of the evidence was downgraded of two levels because of the high risk of selection bias (due to inadequate generation of a randomized sequence), unclear risk of performance bias due to knowledge of the allocated interventions by participants and personnel during the study, unclear risk of detection bias (no information on blinding of outcome assessors), and finally for the unclear risk of attrition bias (Not described in sufficient detail the flow of the participants during the study).

Table 19: Evidence profile for written emotional disclosure for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Written emotional disclosure	Control	Relative (95% CI)	Absolute		
Caring-related morbidity: Psychological wellbeing (Patient Health Questionnaire, PHQ-9) (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 2.72 lower (6.73 lower to 1.29 higher)	LOW	CRITICAL
Caring-related morbidity: Physical and psychological wellbeing (Caregiver Wellbeing Support Scale - CWS-V) (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 8.78 higher (8.76 lower to 26.32 higher)	LOW	CRITICAL
Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale, HADS-A) (Better indicated by lower values)												

1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 0.14 lower (3.09 lower to 2.81 higher)	LOW	CRITICAL
Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale, HADS-D) (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 0.93 lower (3.4 lower to 1.54 higher)	LOW	CRITICAL
Caring-related morbidity: Physical health (RAND) (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 22.96 higher (3.78 to 42.14 higher)	LOW	CRITICAL
Caring-related morbidity: Mental health (RAND) (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	14	14	-	MD 0.67 lower (14.5 lower to 13.16 higher)	LOW	CRITICAL

CI: confidence interval; MD: mean difference.

1 Jones 2016

2 The quality of the evidence was downgraded by two levels because there was not statistically power, as the study contributing to this outcome was a feasibility mixed-methods trial and the focus was more on the qualitative part

Multi-component interventions

Table 20: Evidence profile for case management for supporting adult carers

Quality assessment							**Number of participiants**		**Effect**		**Quality**	**Importance**
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Case management**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Strain - CSI (Caregiver Strain Index) - at 4 months follow - up from baseline (Better indicated by lower values)												

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Case management	Control	Relative (95% CI)	Absolute		
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	42	37	-	MD 0.7 higher (0.73 lower to 2.13 higher)	MODERATE	CRITICAL
Impact of caring on carer: Strain - CSI (Caregiver Strain Index) - at 8 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	25	20	-	MD 0.4 lower (2.48 lower to 1.68 higher)	MODERATE	CRITICAL
Impact of caring on carer: Strain - CSI (Caregiver Strain Index) - at 12 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[2]	none	29	24	-	MD 0.6 higher (1.06 lower to 2.26 higher)	MODERATE	CRITICAL

CI: confidence interval; MD: mean difference.

1 Creemers 2014

2 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Table 21: Evidence profile for psycho-education plus disease education plus activity-based intervention for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Psycho-education plus disease education plus activity-based intervention	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Burden, RMBPC reaction upset (revised memory and behaviour checklist) - at 3 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	57	54	-	MD 0.93 higher (2.6 lower to 4.46 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Burden, RMBPC reaction upset (revised memory and behaviour checklist) - at 6 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	57	54	-	MD 4.27 higher (0.47 to 8.07 higher)	LOW	CRITICAL
Impact of caring on carer: Subjective burden, SPICC (self-perceived pressure from informal Care) - at 3 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	57	54	-	MD 0.18 lower (1.02 lower to 0.66 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Subjective burden, SPICC (self-perceived pressure from informal Care) - at 6 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	57	54	-	MD 0.09 higher (0.75 lower to 0.93 higher)	VERY LOW	CRITICAL

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psycho-education plus disease education plus activity-based intervention**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale) - at 3 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	57	54	-	MD 2.69 higher (0.43 lower to 5.81 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Depression: CES–D (Center for Epidemiological Studies Depression scale) - at 6 months follow - up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	57	54	-	MD 1.91 higher (1.18 lower to 5 higher)	VERY LOW	CRITICAL

CI: confidence interval; MD: mean difference.

1 Prick 2015

2 The quality of the evidence was downgraded of two levels because of the high risk of performance bias (due to knowledge of the allocated interventions by participants and personnel during the study), the high risk of detection bias (due to knowledge of the allocated interventions by outcome assessors); furthermore sample size statistical power has been not achieved along carers ' recruitment.

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Table 22: Evidence profile for reminiscence therapy plus peer support for supporting adult carers

Quality assessment							Number of participants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Peer support plus reminiscence therapy	Control	Relative (95% CI)	Absolute		
Impact of caring on carer: Quality of Caregiver–Patient Relationship (QCPR) (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	97	47	-	MD 3.12 higher (0.42 to 5.82 higher)	LOW	CRITICAL

1 Charlesworth 2016

2 The quality of the evidence was downgraded by one level because of the high risk of performance bias due to knowledge of the allocated interventions by participants and personnel during the study.

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

GRADE - CERQual tables for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Psychosocial and psycho-educational interventions

Table 23: Summary of evidence (GRADE-CERQual), Theme 1: Psychosocial and psycho-educational interventions

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Enabling factors: timing to taking part in the intervention							
2(Milne 2014; Sommerlad 2014)	1: Questionnaire; 1: Unclear	Many carers of people with dementia found the timing of invitations to be critical in enabling them to take part in complex psychological	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		interventions. Many carers attending the START (STrAtegies for RelaTives) programme felt that the time at which they received interventions was central to their experiences. Some of the carers reported that earlier engagement with the coping skills programme would have helped them improve their communication and be better carers. It would also have given them essential information about dementia to help them make major decisions regarding social care. In contrast, other carers who wanted to be engaged with START later felt it would have helped them cope with their relative's later deterioration.					
Enabling factors: unhelpful aspects of the programme							
2(Milne 2014; Sommerlad 2014)	1: Questionnaire; 1: Unclear	Many carers of people living with dementia described time constraints, the impersonal nature of the interventions and the lack of discussion of some topics (for example 'managing aggression'), as the main unhelpful aspects of psychoeducational programs. For example, carers who received a complex psycho-	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	LOW

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
		educational programme for relatives of people living with A recent dementia diagnosis (that is Medway 'Carers Course) suggested that 'managing aggression', 'how to manage guilt', and 'being tired … on duty 24/7' were the principal elements missing from the Course, as these topics were not addressed. Other carers of people living with dementia who received a coping skills programme (that is START) felt that their caring and employment responsibilities were major obstacles to put the coping strategies into practice once the protected programme time had finished.					
Perceived benefits: acceptance							
1(Hopkinson 2013)	1: Semi-structured interviews	Many carers of people with advanced cancer reported feelings of reduced distress (weight-related and eating-related) when receiving a psychosocial intervention (including advice on eating well, information provision, reassurance, and support for self-management). In particular they felt the intervention improved their acceptance of the involuntary	Minor concerns[3]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		weight loss and/or eating difficulties experienced by the person they supported.					
Perceived benefits: social support, disease understanding, coping, emotional and stress management, and knowledge about support available.							
3 (Hopkinson 2013; Milne 2014; Sommerlad 2014)	1: Semi-structured interviews; 1: Questionnaire; 1: Unclear	Many carers of people with advanced cancer or dementia reported feelings of improved emotional support, disease understanding, coping and stress management, and knowledge about support available, after receiving support from complex psychological interventions.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Minor concerns[5]	MODERATE

1 Evidence was downgraded due to moderate methodological limitations (Milne 2014: No details how carers were selected or recruited; in addition, theoretical sufficiency/ saturation of data has not been discussed)

2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 2 studies supported the review's findings (offering thin data)

3 Evidence was downgraded due to minor methodological limitations (unclear descritption about relationship between researcher and carers during data collection and analysis)

4 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

5 Evidence was downgraded due to minor concerns about the adequacy of data, as only 2 studies supported the review's findings

Psychotherapy/counselling

Table 24: Summary of evidence (GRADE-CERQual), Theme 2: Psychotherapy/counselling

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Enabling factors: information sharing in psychotherapy/counselling							
1(Elvish 2014)	1: Semi-structured interviews	Some carers of people with dementia receiving counselling/psychotherapy perceived as helpful to talk to someone [the therapist] who was not personally involved because a 'better response'.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		For example, many carers reported a lack of support from other family members, and the counselling relationship offered a forum to divulge information.					
Factors enabling carers to take part in psychotherapy/counselling: professionals							
1(Elvish 2014)	1: Semi-structured interviews	Some carers of people with dementia felt that the age of the therapist was a factor enabling them to receive counselling/psychotherapy, as they tended to associte age with life experience; whilst they felt that the therapist's counselling/psychotherapy qualifications were not the most important attribute. Carers reported they needed to feel 'comfortable' in the presence of the therapist, and they listed various attributes that they believed were essential to underpin the therapeutic relationship. These included the therapist being open, understanding, friendly, easy to talk to, and 'non- judgemental'.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits of psychotherapy/counselling: self-confidence							
1(Elvish 2014)	1: Semi-structured interviews	Many carers of people with dementia reported feelings of improved self-trust and self-confidence as a consequence of receiving	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
		counselling/psychotherapy. Partly, they felt that the therapeutic relationship provided a ‘bridging’ relationship following changes in the intimate relationship with the person they support. They also felt more self-confident as a result of the intervention, enabling them to take on new caring roles and manage challenging situations.					

1 Evidence was downgraded due to minor methodological limitations (theoretical sufficiency/ saturation of data has not been discussed)
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review’s findings (offering poor data)

Cognitive-/emotion- /activity-based interventions

Table 25: Summary of evidence (GRADE-CERQual), Theme 3: Acceptance and commitment therapy

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Perceived benefits: reinforcing existing perspectives on coping							
1(Williams 2014)	1: Semi-structured interviews	Some carers of people with acquired brain injury attending acceptance and commitment therapy (ACT) viewed the course as reinforcing existing perspectives on coping. For example, one carer referred to her Christian beliefs in terms of assimilating ACT principles into her existing conceptual frameworks.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits: acceptance							
1(Williams 2014)	1: Semi-structured interviews	Some carers of people with acquired brain injury attending ACT described how different metaphors had helped them to engender greater self-acceptance. For example, one carer discussed acceptance of thoughts as they occur, and appeared to be describing a skills development process regarding mindful awareness.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived benefits: personal awareness							
1(Williams 2014)	1: Semi-structured interviews	Many carers of people with acquired brain injury attending ACT reported feelings of improved personal awareness regarding their emotional experiences as carers (that is of the physical and mental symptoms of stress and the interplay between these two).	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived benefits: peer support							
1(Williams 2014)	1: Semi-structured interviews	Some carers of people with acquired brain injury attending ACT reported beneficial aspects of mutual social support.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 26: Summary of evidence (GRADE-CERQual), Theme 4: Reminiscence therapy (Remembering Yesterday Caring Today)

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits: interpersonal relationship with the cared for							
1(Melunsky 2015)	1: Semi-structured interviews	Many carers of people with dementia attending RYCT reported feelings of improved shared experience which carers could use to create 'fresh' discussions with their relative. Through reminiscing, some carers learnt new information about their relatives' lives; this also promoted new areas of conversation.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits: peer support							
1(Melunsky 2015)	1: Semi-structured interviews	Many carers of people with dementia receiving RYCT reported their feelings regarding receiving and experiencing supportive relationships with other carers. This was considered especially important for carers who reported feelings of isolation, identifying that meeting other carers reduced feelings of loneliness.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits: reassurance							
1(Melunsky 2015)	1: Semi-structured interviews	Many carers of people with dementia attending RYCT felt that learning from other carers as playing a key role in providing reassurance to them. They reported that by gaining practical coping	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		strategies increased carers' confidence in dealing with similar situations in the future. Learning and comparing coping strategies with each other, enabled carers attending RYCT to perceive many beneficial effects					

1 Evidence was downgraded due to minor methodological limitations (unclear descritption about relationship between researcher and carers during data collection and analysis)
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 27: Summary of evidence (GRADE-CERQual), Theme 5: Body-oriented psychological therapy (circle dancing)

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits of 'circle dancing': personal awareness and peer support							
1(Hamill 2012)	1: Unclear	Many carers of people with dementia attending circle dancing (as body-oriented psychological therapy) felt the group helped them to acknowledge the reality of the dementia diagnosis and process their feelings about the person they support (for example grief, and loss). These carers reported that before the circle dancing group the burden of care often meant that they focused predominantly on the problems but that participation in the group helped them to re-connect with the person they support.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW

1 Evidence was downgraded due to serious methodological limitations: unclear details on how carers were selected/recruited, no details on data collection/analysis methods are reported, besides the unclear description about relationship between researcher and carers during data collection and analysis
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 28: Summary of evidence (GRADE-CERQual), Theme 6: Written emotional disclosure

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Factors enabling carers to receive written emotional disclosure (WED): lack of time							
1(Jones 2016)	1: Questionnaire	Some carers of people with psychosis felt that the writing stimulated negative emotions. They reported that lack of time featured as a reason not to attend the writing interventions. Other carers commented on the concentration required to write recommending that it should be done at the start of the day when it is easier to concentrate.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived benefits of WED: stress relieving							
1(Jones 2016)	1: Questionnaire	Many carers of people with psychosis reported feelings of improved stress relieving and as consequence of writing (either therapeutic or non-therapeutic). For these carers, writing created an opportunity to escape routine responsibilities, with 'time for myself', relaxation and enjoyment.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Low-level/informal and other support interventions

Table 29: Summary of evidence (GRADE-CERQual), Theme 7: Art therapy

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits: personal awareness							
1(Roberts 2011)	1: Semi-structured interviews	Many carers of people with mental health issues who received support from art therapy (that is art viewing, art-making, and audio recording) felt that looking at art in a group elicited strong emotions connected with their individual identities as carers.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits: social and emotional support							
1(Roberts 2011)	1: Semi-structured interviews	Many carers of people with mental health issues who received support from art therapy (that is art viewing, art-making, and audio recording) felt valued within their carer identities by helping to decrease the sense of stigma and social isolation by being identified as a group of people deserving of an intervention in their own right, despite not being people with care needs.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

1 Evidence was downgraded due to minor methodological limitations (unclear details on how carers were selected/recruited)
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 30: Summary of evidence (GRADE-CERQual), Theme 8: Dementia cafes

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Factors enabling carers to attend ‘dementia cafés’: dementia café co-ordinators							
1(Greenwood 2017)	1: Semi-structured interviews	Many carers of people with dementia attending ‘dementia cafes’ reported feelings of enjoyment and relax. They found that the cafés being specifically for carers and people living with dementia.meant they can relax in a safe environment and knowing that the person living with dementia was enjoying themselves was very important for some carers. They described dementia cafés as opportunities to relief them from caring responsibilities by reducing the dependency of the person with dementia on the carer	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits: social support							
1(Greenwood 2017)	1: Semi-structured interviews	Many carers of people with dementia attending ‘dementia cafes’ felt as very helpful aspect of attending cafés the comparison of yourself to other carers or comparison of the person they support with others with dementia.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits: emotional support							
1(Greenwood 2017)	1: Semi-structured interviews	Many carers of people with dementia attending ‘dementia cafes’ felt that café coordinators played an	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		important part in enabling their experiences and valued some positive personal pre-requisites (emotionally intelligent, approachable, and open).					

1 Evidence was downgraded due to minor methodological limitations (theoretical sufficiency/ saturation of data has not been discussed)
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 31: Summary of evidence (GRADE-CERQual), Theme 9: Music therapy

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Factors enabling carers to attend music therapy: professional facilitators							
1(Unadkat-Shreena 2017)	1: Semi-structured interviews	Many carers of people with dementia receiving support from music therapy ('group singing model in dementia for couple dyads') felt that being an active part of the singing group as very helpful. They found as a key component of this process the role of an effective group facilitator, without which further benefits of group singing were not experienced. They described encouraging participation, person-centeredness, and equality as part of the role of an effective group facilitator.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Perceived benefits: emotional support							
3(Camic 2013; Osman	3: Semi-structured interviews	Many carers of people with dementia experienced enjoyment, stimulation and	Moderate concerns[3]	No or very minor concerns	No or very minor concerns	Minor concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
2016; Unadkat-Shreena 2017)		emotional support from music therapy programmes. For example, carers attending 'group singing model in dementia for couple dyads' felt positive about the pleasure and enjoyment derived from singing, even in cases where the overall group singing experience was not enjoyed. Carers attending SftB ('Singing for the Brain') program also felt that the programme had a positive impact on their mood and well-being, by stimulating and regulating emotions, providing enjoyment and relieving stress. Finally, carers of people living with dementia attending a 'Singing Together Group' felt the experience of singing in a group was very important, reporting enjoyment and stress relief.					
Perceived benefits: social support							
3(Camic 2013; Osman 2016; Unadkat-Shreena 2017)	3: Semi-structured interviews	Many carers of people with dementia experienced improved social support and reduced social isolation throughmusic therapy programmes. For example, carers attending a 'group singing model in dementia for couple dyads' reported	Moderate concerns[3]	No or very minor concerns	No or very minor concerns	Minor concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		feelings of increased belonging to a social group, shared experience, and developing a group identity. Carers of people living with dementia using the SftB programme also reported feelings of improved social support and inclusion. Other carers attending a 'Singing Together Group' reported enjoying the atmosphere of the group, the venue, the music facilitator and other carers, indicating a sense of security and belonging. In particular, many cares reported feelings of improved social inclusion, being able to meet other carers in the same situation, going through the same life experiences and having the opportunity to focus on something other than illness, doctor visits and diagnosis.					

1 Evidence was downgraded due to minor methodological limitations (theoretical sufficiency/ saturation of data has not been discussed)
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)
3 Evidence was downgraded due to due to substantial methodological limitations (Camic 2013; Osman 2016: No details how carers were selected or recruited; in addition, theoretical sufficiency/ saturation of data has not been discussed)
4 Evidence was downgraded due to minor concerns about the adequacy of data, as only 4 studies supported the review's findings (offering limited data)

Family interventions

Table 32: Summary of evidence (GRADE-CERQual), Theme 10: Family interventions

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Factors enabling carers to attend family interventions: professionals							
1(Whitney 2012)	1: Semi-structured interviews	Some carers of people with eating disorders who received family interventions (either individual family work [IFW] or family day workshops [FDW]) reported conflicting views on their relationships with the professionals facilitating the interventions. Some carers felt that their relationship with professionals was extremely valuable. Other carers reported feeling judged or blamed by the professionals facilitating the sessions, expressing dissatisfaction and questioning their qualifications.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Enabling factors: components of family interventions							
1(Whitney 2012)	1: Semi-structured interviews	Many carers of people with eating disorders who received family interventions reported mixed feeling about the components of family work (either individual family work ([IFW] and family day workshops [FDW]). for example family sculpt, therapeutic writing task, family meal and psycho-	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		education/skills training. Many of the carers' found that the family sculpt was helpful in uncovering the patient's perception of the family dynamics. In contrast, other carers found the family sculpt to be a very difficult and distressing experience. While for some carers, the act writing and sharing the letter was perceived as painful but felt like an emotional release (especially to hear different family members' perspectives); other carers found it intrusive and embarrassing to hear the personal accounts of the other family. Finally, some carers felt the family meal provided a sense of normality around the preparation and sharing of meals; and other carers found the experience tense, anxiety-provoking 'false' and only feasible in a hospital setting.					
Enabling factors: structure of family interventions							
1(Whitney 2012)	1: Semi-structured interviews	Many carers of people with eating disorders who received family interventions found that the barrier more important to attend the intervention was its long length. They felt shorter	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[5]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
		sessions would have been more manageable.					
Perceived acceptability of family interventions: when and how							
1(Whitney 2012)	1: Semi-structured interviews	Some carers of people with eating disorders who received family interventions reported mixed views on when and how the intervention should be presented to them. Some carers responded negatively to the manner in which family work was introduced and were very defensive from the onset. They were reluctant to take time off work, and did not want to burden other family members.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived acceptability of family interventions: where							
1(Whitney 2012)	1: Semi-structured interviews	Some carers of people with eating disorders who received family interventions reported mixed views on where the intervention should be held. Some carers felt the setting (a room on the inpatient unit) as a ‘safe and controlled’ environment in which to explore difficult and sensitive family issues. Other carers perceived the setting as too contrived and artificial.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[5]	LOW
Perceived benefits of family interventions: disease understanding, emotional and social support.							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
1(Whitney 2012)	1: Semi-structured interviews	Some carers of people with eating disorders who received family interventions reported feelings of improved communication, disease knowledge, social support, and empowerment. Many carers felt that following the intervention they communicated more effectively and were able to address difficult issues and emotions which they would have otherwise avoided. Other carers improved their knowledge of the disease of their relative, making them more optimistic.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Multicomponent interventions

Table 33: Summary of evidence (GRADE-CERQual), Theme 11: Maudsley Method Skills-based Workshops (including cognitive remediation therapy; mindfulness and acceptance commitment therapy)

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Factors predisposing carers to seek support from Maudsley Method Skills-based Workshops: structure of the Workshops.							
1(Linacre 2016)	1: Questionnaire	Some carers of people with eating disorders who received Maudsley Method skills-based workshops reported negative feelings with the use of role play and "detailed slides".	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits of the Workshops: personal awareness and social support							
1(Linacre 2016)	1: Questionnaire	Some carers of people with eating disorders who received Maudsley Method skills-based workshops reported feelings of improved social support, technique's taught, and self-awareness.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW

1 Evidence was downgraded due to substantial methodological limitations: unclear details on how carers were selected/recruited, besides the unclear description about relationship between researcher and carers during data collection and analysis

2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 34: Summary of evidence (GRADE-CERQual), Theme 12: Complex coping skills course (based on the cognitive behavioural approach)

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits: understanding, coping, stress management, and knowledge about support available							
1(Robinson 2005)	1: Semi-structured interviews	Some carers of people with stroke who received a coping skills course (including information, emotional adjustment, stress management, and enhancing self-efficacy and self-worth) reported feeling more optimistic and empowered subsequent to the course. They found that the course was beneficial in terms of information about stroke, information about available services, problem solving, meeting other carers, giving and receiving support,	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		relaxation skills, and knowledge about financial support available.					

1 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 35: Summary of evidence (GRADE-CERQual), Theme 13: Complex carer support service (including individual and group psycho-education, practical advice and emotional support)

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Perceived benefits: personal awareness							
1(Smallwood 2017)	1: Unclear	Many carers of people with psychosis who received support from a multicomponent carer support service (including individual and group psychoeducational, practical advice and emotional support) expressed the need for additional health and social care services, the need for more information about the rights they and their relatives were entitled, and needs for more co-operation with social worker and other healthcare professionals.	Major methodological limitations[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW
Perceived benefits: psychological and emotional support							
1(Smallwood 2017)	1: Unclear	Many carers of people with psychosis who received support from a multicomponent carer support service (including individual and group psychoeducational,	Major methodological limitations[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
		practical advice and emotional support) reported many psychological benefits (for example, reduced distress, social support, emotional coping, and peer support) at the end of the Course.					

1 Evidence was downgraded due to serious methodological limitations: unclear details on how carers were selected/recruited, no details on data collection/analysis methods are reported, besides the unclear description about relationship between researcher and carers during data collection and analysis

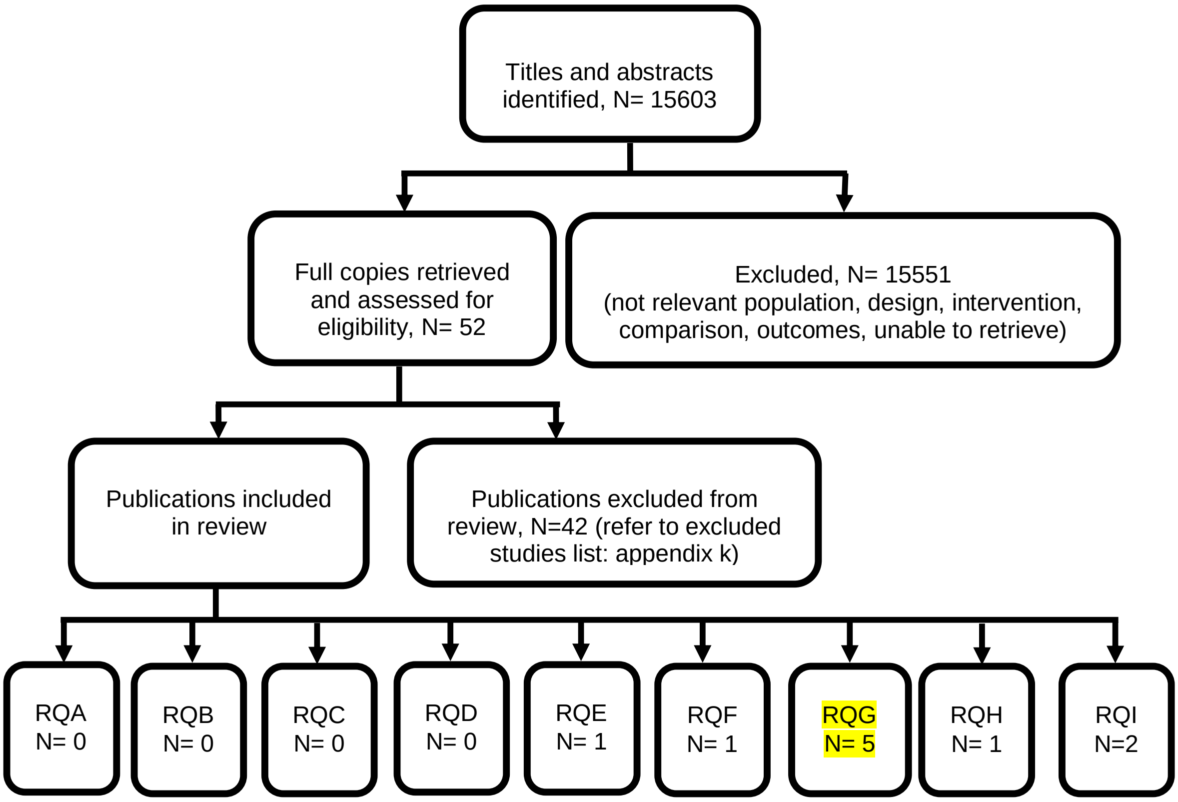
2 Evidence was downgraded due to Serious concerns about the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. As shown in Figure 6 below, 5 economic studies were identified which was applicable to this review question.

Figure 6: Study selection flow chart



Appendix H – Economic evidence tables

Economic evidence tables for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Table 36: Economic evidence tables

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
• **Study:** Livingston 2014 • **Country:** UK • **Study design**: Cost-utility analysis	• **Intervention**: START (STrAtegies for RelaTives) • **Control:** TAU • **Interventions details:** ○ START comprised of 8 sessions delivered by trained and supervised psychology graduates • **TAU details:** ○ Based on NICE guidelines and including “assessment, diagnosis and information, drug treatment, cognitive	• **Study population**: N=472 Carers of people with dementia ○ Intervention, n=173 ○ Control, n=87 • **Characteristics** [Intervention; Control] ○ Age (years) Mean (SD): I = 62.0 (14.6); C = 56.1 (12.3) ○ Sex (M/F): I (N): 57/116; C (N): 25/62 • **Data sources:** ○ Source of effectiveness data: Randomised control trial * ○ EQ-5D health profiles, were collected at in order to calculate QALYs. ○ Source of resource use data:	• **Cost description:** ○ Cost categories included the costs of the intervention and the use of outpatient and community services ○ Incremental Costs Value: £ 336 (CI 95% -£223 to £895) at 24 months • **Outcome description:** ○ Carer QALYs calculated from the EQ-5D by applying societal weights from a UK sample. ○ Incremental Outcome Value: 0.03 (CI 95% -0.01 to 0.06) QALYs at 24 months	• **ICER** £11,200 / QALY • **Sensitivity analysis:** ○ Probabilistic sensitivity analyses: Intervention has a 65% probability of being at cost-effective at a threshold of £20,000/QALY ○ Deterministic sensitivity analyses: These addressed baseline characteristics and predictors of missing values and these produced similar ICERs to the base case results	• **Perspective:** ○ Health and social care • **Currency:** GBP • **Cost year:** 2009 - 2010 • **Time horizon**: 24 months ○ Results also presented for 8 months • **Discounting:** 3.5% • **Applicability**: partially applicable • **Quality**: minor limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	stimulation therapy, practical support, treatment of neuropsychiatric and cognitive symptoms and carer support	Randomised control trial * ○ Source of unit costs: Unit costs were from NHS and national sources (NHS Reference Costs; PSSRU); * Livingston 2014			
• **Study:** Allen 2016 • **Country:** UK • **Study design**: Before-and-after cost analysis	• **Intervention**: CBT for carers groups • **Control:** Before intervention • **Interventions details:** ○ CBT for carers groups content included; information giving, understanding the feelings of those with dementia, managing stress and coping with difficult behaviours and feelings	• **Study population**: N=22 Carers of people with dementia • **Characteristics** ○ Mean age (Range): 66 years (49-84 years) ○ Sex (M/F): (N): 3/19 • **Data sources:** ○ Source of resource use data: Contacts with from within study ○ Source of unit costs: Unit costs were national sources (PSSRU)	• **Cost description:** ○ Cost categories included the costs Accident and Emergency Departments, inpatients, outpatients and mental health contacts ○ Intervention cost £15,000 ○ Accident and Emergency, inpatient and outpatients contacts: Before: £17,778 After: £5,933 ○ Mental health contacts: Before: £41,769 After: £6,318 ○ Community contacts: Before: ££421	• **Total net savings** £32,000	• **Perspective:** ○ Health and social care • **Currency:** GBP • **Cost year:** 2014 • **Time horizon**: Variable (10-15 months) • **Discounting:** None • **Applicability**: partially applicable • **Quality**: very serious limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
			After: £70		
• **Study:** Chatterton 2016 • **Country:** Australia • **Study design**: Cost-utility analysis	• **Intervention**: Cognitive behavioural intervention • **Control:** Minimal contact self-management • **Interventions details:** ○ A maximum of 5 weekly sessions of telephone counselling led by a psychologist • **Minimal contact self-management details:** ○ Single session of nurse led self-management	• **Study population**: N= Highly distressed carers of people with cancer calling cancer helplines ○ Intervention, n=167 ○ Control, n=169 • **Data sources:** ○ Source of effectiveness data: Randomised control trial * ○ AQOL-8D was completed at each assessment to derive the utilities used to estimate QALYs. ○ Source of resource use data: Randomised control trial * ○ Source of unit costs: Unit costs included Australian hourly wage rate (source not specified) * Chatterton 2016	• **Cost description:** ○ Mean difference intervention cost in high distress carers: -133 AUD (95%CI: -159 AUD to – 107 AUD) * ○ Mean difference intervention costs low distress carers: -99 AUD (95%CI: -116 AUD to -83 AUD) * ○ Mean difference total cost in high distress carers: -1,415 AUD (95%CI: -4,305 AUD to 1,474 AUD) * ○ Mean difference total costs low distress carers: 610 AUD (95%CI: -774 AUD to -1,993 AUD) * • **Outcome description:** ○ Mean difference in high distress carers: 0.035 QALYs (95%CI: -0.057 to 0.126) * ○ Mean difference in low distress carers: -0.028 QALYs (95%CI: -0.078 to 0.021) * *mean difference is calculated for nurse led	• **NMB** ○ Mean difference in high distress carers: 3,047 AUD (95%CI: -2,526 AUD to 8,620 AUD) * ○ Mean difference in high distress carers: -1,669 AUD (95%CI: -4,316 AUD to 978 AUD) * • **Sensitivity analysis:** ○ Probabilistic sensitivity analyses: ○ Psychologist led intervention had a 21% probability of being at cost-effective in carers with low distress at a threshold of 50,000 AUD/QALY ○ Psychologist led intervention had a 89% probability of being at cost-effective in carers with high distress at a threshold of 50,000 AUD/QALY *mean difference is calculated for nurse led intervention relative to	• **Perspective:** ○ Health sector • **Currency:** AUD • **Cost year:** 2011 - 2012 • **Time horizon**: 12 months • **Discounting:** N/A • **Applicability**: partially applicable • **Quality**: potentially serious limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
			intervention relative to psychologist led intervention	psychologist led intervention	
• **Study:** Vroomen 2016 • **Country:** The Netherlands • **Study design**: Cost-utility analysis	• **Intervention**: ○ ICMM ○ LM • **Control:** No access to case manager • **Interventions details:** ○ ICMM: case managers provide guidance and support for a long period of time and use their own organisation to provide medical and psychosocial services. There is a collaborative arrangement between the case manager, the organisation multidisciplinary team and the informal care giver.	• **Study population**: N=521 Persons with dementia and their carers ○ ICCM, n=234 ○ LM, n=214 ○ Control, n=73 • **Characteristics** [Intervention; Control] ○ Age (years) Mean (SD): ICMM = 79.9 (7.7); LM = 81.0 (7.5) C = 75.9 (8.7) ○ Sex (M/F): ICMM (N): 112/122; LM (N): 80/134 C (N): 41/32 • **Data sources:** ○ EQ-5D-3L data was obtained by interviewing the carer **Source of resource use data:** Cost diaries, direct health care costs, time spent on care by carers, interviews with case management ○ Source of unit costs:	• **Cost description:** ○ Cost categories included the costs of general practice, outpatient clinics, overnight care, day centre, home care, home-making services, long term institutionalisation, welfare services, medications, informal care costs, case management ○ Mean costs: ICMM = €69,435; LM = €84,155, C = €107,627 ○ ICMM v LM mean difference: -€14,720 (95% CI: -€33,014 to €3,575) ○ ICMM v C mean difference: -€38,192 (95% CI: -€85,606 to €9,222) ○ LM v C mean difference: -€23,472 (95% CI: -€71,386 to €24,442) • **Outcome description:** ○ Carer and person with dementia combined QALY (SE): ICMM = 2.9	• **ICER** ○ ICMM v LM: Dominates ○ ICMM v C: Dominates ○ C v LM: €686,587 per QALY • **Sensitivity analysis:** ○ ICMM v LM: 97.7% probability ICMM cost-effective at a cost-effectiveness threshold of €30,000 per QALY ○ ICMM v C: 99.2% probability ICMM cost-effective at a cost-effectiveness threshold of €30,000 per QALY ○ C v LM: 85.5% probability LM cost-effective at a cost-effectiveness threshold of €30,000 per QALY	• **Currency:** EUROS • **Cost year:** 2010 • **Time horizon**: 24 months • **Discounting:** Costs discounted at 4% and effects discounted at 1.5% • **Applicability**: partially applicable • **Quality**: minor limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	○ LM: the collaboration of multiple providers of care. Following diagnosis, the case manager provides disease related advice in addition to educational, emotional and practical support. The case manager also gives recommendations on the availability of supportive health and social services • **No case manager details:** ○ No central coordination of care for persons with dementia	Dutch standard costs, Royal Dutch Society of Pharmacy	(0.04) QALYs; LM = 2.9 (0.05) QALYs; C = 3.0 (0.07) QALYs ○ ICMM v LM mean adjusted difference: 0.03 QALYs (95% CI: -0.08 to 0.15) ○ ICMM v C mean adjusted difference: 0.0004 QALYs (95% CI: -0.16 to 0.16) ○ LM v C adjusted mean difference: -0.03 QALYs (95% CI: -0.19 to 0.12)		
• **Study:** Woods 2016 • **Country:** UK	• **Intervention**: Reminiscence groups • **Control:**	• **Study population**: N=487 people with dementia and their carers	• **Cost description:** ○ Cost categories included the costs of the intervention (including	• **ICER** £2,586 per point change on the QOL-AD scale	• **Perspective:** ○ Public sector • **Currency:** GBP • **Cost year:** 2010

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
• **Study design**: Cost-utility analysis	TAU • **Interventions details:** ○ Based on the “Remembering Yesterday, Caring Today.” (RYCT) manual and comprised weekly group sessions for 12 weeks followed by 7 maintenance sessions at monthly intervals for the patient/carer dyad • **TAU details:** • Could access the same services as the intervention group unless the reminiscence groups were running concurrently as an alternative activity	○ Intervention, n=268 ○ Control, n=219 N=350 Dyads of people with dementia and their carers ○ Intervention, n=206 ○ Control, n=144 • **Characteristics** [Intervention; Control] ○ Carers age (years) Mean (SD): I = 69.6 (11.6); C = 69.7(11.6) ○ Carers sex (M/F): I (N): 80/188; C (N): 81/138 • **Data sources:** ○ Source of effectiveness data: Randomised control trial * ○ EQ-5D health profiles were collected from a self-completed survey by carers ○ Source of resource use data: Randomised control trial micro-costing of the RYCT* ○ Source of unit costs:	staff costs, venue costs, participant and carer transport, refreshment costs and administration costs) and health and social service costs for participants with dementia and carers ○ Incremental Costs Value: Person with dementia £1,544 Carer £1,136 • **Outcome description:** ○ Incremental Outcome Value: Person with dementia 0.597 QOL-AD score Person with dementia 0.001 QALYs Carer 0.000 QALYs	(95% CI: -£20,280 to £24,340) No cost/QALY calculated as there was a neglible QALY benefit • **Sensitivity analysis:** ○ None undertaken	○ **Time horizon**: 10 months • **Discounting:** N/A • **Applicability**: partially applicable • **Quality**: minor limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
		Unit costs were from NHS and national sources (NHS Ref. Costs; PSSRU); * Woods 2016			

AQOL-8D: Assessment of Quality of Life (AQoL)-8D multi-attribute utility instrument; AUD: Australian dollars; C: Control group; CBT: Cognitive behavioural therapy; CI: Confidence interval; EQ-5D: EuroQol 5 Dimensions; F: Female; GBP: British pound sterling; I: intervention group; ICER: Incremental cost-effectiveness ratio; ICMM: Intensive Case Management Model; LM: Linkage Model; N: Number; N/A: Not applicable; QALY: Quality-adjusted life year; QOL-AD; Quality of Life in Alzheimer's Disease; PSSRU: Personal Social Services Research Unit; RCT: Randomised controlled trial; SD: Standard deviation; SE: Standard error; TAU: Treatment as usual.

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Table 37: Economic evidence profile for interventions that are effective in preventing spontaneous preterm birth in twin and triplet pregnancy

Study	Limitations	Applicability	Other comments	Costs	Effects	Incremental cost effectiveness	Uncertainty
Livingston 2014	Minor limitations	Partially applicable[1]	Cost-utility analysis	£336	0.03 QALYs	£11,200 per QALY	Probabilistic sensitivity analysis indicated a 65% probability that the intervention was cost-effective at a cost-effectiveness threshold of £20,000 per QALY Deterministic sensitivity analysis produced similar results to the base case
Allen 2016	Very serious limitations[2]	Partially applicable[1,3]	Cost analysis	Net savings £32,000 for 22 carers	-	Not reported	Uncontrolled before-and-after study design. No sensitivity analysis
Chatterton 2016	Potentially serious limitations[5]	Partially applicable[4,5]	Cost-utility analysis but treatment as usual not considered as a comparator	High distress carers -1,415 AUD	High distress carers 0.035 QALYs	High distress carers dominant Incremental net monetary benefit 3,047 AUD	Probabilistic sensitivity analysis suggested a nurse led intervention was likely to be cost-effective in lower

				Low distress carers 610 AUD	Low distress carers -0.028 QALYs	Low distress carers dominated Incremental net monetary benefit - 1,669	stress carers and that a psychologist led intervention was more likely to be cost-effective in high stress carers
Vroomen 2016	Minor limitations	Partially applicable[1,7,8]	Cost-utility analysis	Control = €107,627 LM = €84,155 ICMM = €69,435	Carer/person with dementia dyad Control = 3.0 QALYs LM = 2.9 QALYs ICCM = 2.9 QALYs	ICCM dominates	In a pairwise comparison, probabilistic sensitivity analysis suggested that there was a 97.7% probability that ICMM was more cost-effective than LM and a 99.2% it was more cost-effective than control (no access to a case manager)
Woods 2016	Minor limitations[9]	Partially applicable[1]	Cost-utility analysis	Incremental costs for person with dementia: £1,544 Incremental costs for carer: £1,136	Incremental QALYs for person with dementia: 0.001 QALYs Incremental QALYs for carer: 0.000 carers	Treatment as usual dominates from perspective of carer	Sensitivity analysis was not reported as the authors did not consider it useful in the context of a lack of evidence of clinical effectiveness

1. *Population is for carers of people with dementia and therefore may not be generalisable to all adult carer*
2. *Before-and-after study design means that is is difficult to differentiate between changes arising from the intervention and other changes which occur over time, No consideration of uncertainty either through sensitivity analysis or some quantification of uncertainty around point estimates*
3. *No discounting of costs*
4. *Population is for carers of people with cancer and therefore may not be generalisable to all adult carer*
5. *Australian costs may not be gerealisable to NHS setting*
6. *Treatment as usual not considered as a comparator*
7. *Netherlands cost may not be generalizable to NHS setting*

8. *Discount rate different to that used in the NICE Reference Case*
9. *Costs of the intervention were reported but do not appear to have been included in the ICER calculations. However, this omission does not affect the conclusion*

Appendix J – Economic analysis

Economic analysis for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

No economic analysis was conducted for this review.

Appendix K – Excluded studies

Excluded studies for review question: What psychological and emotional support interventions are effective, cost-effective and acceptable to adult carers for maintaining and/or improving their health and well-being?

Quantitative component of the review

Table 38: Excludies studies from the quantitative component of the review

Study	Reason for Exclusion
Aakhus Eivind, et al.,, Single session educational programme for caregivers of psychogeriatric in-patients - results from a randomised controlled pilot study, International Journal of Geriatric Psychiatry, 24, 269-274, 2009	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
A'Campo, L., Wekking, E., Spliethoff-Kamminga, N., Le Cessie, S., Roos, R., The benefits of a standardized patient education program for patients with Parkinson's disease and their caregivers, Parkinsonism & Related Disorders, 16, 89-95, 2010	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Agrawal, K, Suchetha, Ps, Mallikarjunaiah, Hs, A comparative study on quantity of caregiver support for upper limb functional recovery in post stroke, International journal of physiotherapy and research, 3, 77-82, 2013	Study conducted in India.
Allen, R. S., Hilgeman, M. M., Ege, M. A., Shuster Jr, J. L., Burgio, L. D., Legacy activities as interventions approaching the end of life, Journal of Palliative Medicine, 11, 1029-1038, 2008	Study conducted in the USA.
Applebaum, A. J., Kulikowski, J. R., Breitbart, W., Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C): Rationale and Overview, Palliative & Supportive Care, 13, 1631-41, 2015	Not an RCT.
Ashley, L, O'Connor, Db, Jones, F, Effects of emotional disclosure in caregivers: moderating role of alexithymia, Stress and health, 27, 376-387, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Backhaus, Sl, Ibarra, Sl, Klyce, D, Trexler, Le, Malec, Jf, Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers, Archives of Physical Medicine and Rehabilitation, 91, 840-848, 2010	Study conducted in the USA.
Badger, T., Segrin, C., Dorros, S. M., Meek, P., Lopez, A. M., Depression and anxiety in women with breast cancer and their partners, Nursing Research, 56, 44-53, 2007	Study conducted in the USA.
Badr, H, Smith, Cb, Goldstein, Ne, Gomez, Je, Redd, Wh, Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial, Cancer, 121, 150-158, 2015	Study conducted in the USA.
Bakker, T. J., Duivenvoorden, H. J., van der Lee, J., Olde Rikkert, M. G., Beekman, A. T., Ribbe, M. W., Benefit of an integrative psychotherapeutic nursing home program to reduce multiple psychiatric symptoms of psychogeriatric patients and caregiver burden after six months of follow-up:	Intervention is multidisciplinary rehabilitation program aimed primarily at person receiving care.

Study	Reason for Exclusion
a re-analysis of a randomized controlled trial, International Psychogeriatrics, 25, 34-46, 2013	
Barca, M., Engedal, K., Haugen, P., Johannessen, A., Thorsen, K., Experiences of adult children of younger persons with dementia: A qualitative study, International Psychogeriatrics, 25, S29-S30, 2013	Conference abstract.
Barton, K., Jackson, C., Reducing symptoms of trauma among carers of people with psychosis: pilot study examining the impact of writing about caregiving experiences, Australian & New Zealand Journal of PsychiatryAust N Z J Psychiatry, 42, 2008	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Basu, Rashmita, Hochhalter, Angie K., Stevens, Alan B., The impact of the REACH II intervention on caregivers' perceived health, Journal of Applied Gerontology, 34, 590-608, 2015	Study conducted in the USA.
Bazzano, Alicia, Wolfe, Christiane, Zylowska, Lidia, Wang, Steven, Schuster, Erica, Barrett, Christopher, Lehrer, Danise, Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach, Journal of Child and Family Studies, 24, 298-308, 2015	Not an RCT.
Beauchamp, N, Irvine, Ab, Seeley, J, Johnson, B, Worksite-based internet multimedia program for family caregivers of persons with dementia, Gerontologist, 45, 793-801, 2005	Study conducted in the USA.
Beaulieu, R., Humphreys, J., Evaluation of a telephone advice nurse in a nursing faculty managed pediatric community clinic, Journal of Pediatric Health Care, 22, 175-81, 2008	Not an RCT.
Belle, Sh, Burgio, L, Burns, R, Coon, D, Czaja, Sj, Gallagher-Thompson, D, Gitlin, Ln, Klinger, J, Koepke, Km, Lee, Cc, Martindale-Adams, J, Nichols, L, Schulz, R, Stahl, S, Stevens, A, Winter, L, Zhang, S, Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial, Annals of Internal Medicine, 145, 727-738, 2006	Study conducted in the USA.
Boele, F. W., Hoeben, W., Hilverda, K., Lenting, J., Calis, A. L., Sizoo, E. M., Collette, E. H., Heimans, J. J., Taphoorn, M. J. B., Reijneveld, J. C., Klein, M., Enhancing quality of life and mastery of informal caregivers of high-grade glioma patients: A randomized controlled trial, Journal of Neuro-OncologyJ Neurooncol, 111, 303-311, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Bridges-Webb, C., Giles, B., Speechly, C., Zurynski, Y., Hiramanek, N., Patients with dementia and their carers, Annals of the New York Academy of Sciences, 1114, 130-6, 2007	General survey of carers regarding their health, QoL and use/satisfaction of support.
Brodaty, H., Mittelman, M., Gibson, L., Seeher, K., Burns, A., The effects of counseling spouse caregivers of people with Alzheimer disease taking donepezil and of country of residence on rates of admission to nursing homes and mortality, American Journal of Geriatric Psychiatry, 17, 734-43, 2009	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Brown, Kirk Warren, Coogle, Constance L., Wegelin, Jacob, A pilot randomized controlled trial of mindfulness-based stress reduction for caregivers of family members with dementia, Aging & Mental Health, 20, 1157-1166, 2016	Study conducted in the USA.

Study	Reason for Exclusion
Burns, R, Nichols, Lo, Martindale-Adams, J, Graney, Mj, Lummus, A, Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study, Gerontologist, 43, 547-555, 2003	Study conducted in the USA.
Butcher, Hk, Gordon, Jk, Ko, Jw, Perkhounkova, Y, Cho, Jy, Rinner, A, Lutgendorf, S, Finding Meaning in Written Emotional Expression by Family Caregivers of Persons with Dementia, American Journal of Alzheimer's Disease and other Dementias, 31, 631-642, 2016	Study conducted in the USA.
Callahan, Cm, Boustani, Ma, Unverzagt, Fw, Austrom, Mg, Damush, Tm, Perkins, Aj, Fultz, Ba, Hui, Sl, Counsell, Sr, Hendrie, Hc, Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial, Jama, 295, 2148-2157, 2006	Study conducted in the USA.
Camic, P. M., Tischler, V., Pearman, C. H., Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers, Aging & Mental Health, 18, 161-168, 2014	Not an RCT.
Camic, P. M., Williams, C. M., Meeten, F., Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study, Dementia, 12, 157-76, 2013	Not an RCT.
Campbell, L. C., Keefe, F. J., Scipio, C., McKee, D. C., Edwards, C. L., Herman, S. H., Johnson, L. E., Colvin, O. M., McBride, C. M., Donatucci, C., Facilitating research participation and improving quality of life for African American prostate cancer survivors and their intimate partners: A pilot study of telephone-based coping skills training, Cancer, 109, 414-424, 2007	Study conducted in the USA.
Carter, Pa, A brief behavioral sleep intervention for family caregivers of persons with cancer, Cancer Nursing, 29, 95-103, 2006	Not an RCT.
Cash, T. V., Lageman, S. K., Randomized controlled expressive writing pilot in individuals with Parkinson's disease and their caregivers, BMC psychologyBMC Psychol, 3, 44, 2015	Study conducted in the USA.
Chenoweth, L, King, Mt, Jeon, Yh, Brodaty, H, Stein-Parbury, J, Norman, R, Haas, M, Luscombe, G, Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial, The lancet. Neurology, 8, 317-325, 2009	Trial examines outcomes in people with dementia.
Chiatti, C., Rimland, J. M., Bonfranceschi, F., Masera, F., Bustacchini, S., Cassetta, L., The UP-TECH project, an intervention to support caregivers of Alzheimer's disease patients in Italy: preliminary findings on recruitment and caregiving burden in the baseline population, Aging & Mental Health, 19, 517-525, 2015	The paper describes recruitment results and characteristics of the UP-TECH clinical trial sample, outcomes data are not reported.
Chien, Wt, Effectiveness of psychoeducation and mutual support group program for family caregivers of chinese people with schizophrenia, Open nursing journal, 2, 28-39, 2008	Study conducted in Hong Kong.
Chow Julian Chun-Chung, et al.,, Types and sources of support received by family caregivers of older adults from diverse racial and ethnic groups, Journal of Ethnic and Cultural Diversity in Social Work, 19, 175-194, 2010	Study regarding ethnic/racial differences in use of formal/informal support.

Study	Reason for Exclusion
Connell, Cathleen M., Janevic, Mary R., Effects of a telephone-based exercise intervention for dementia caregiving wives, Journal of Applied Gerontology, 28, 2009	Study conducted in the USA.
Coon, Dw, Thompson, L, Steffen, A, Sorocco, K, Gallagher-Thompson, D, Anger and depression management: psychoeducational skill training interventions for women caregivers of a relative with dementia, Gerontologist, 43, 678-689, 2003	Study conducted in the USA.
Costa, Aco, Kamkhagi, D, Kusminsky, S, Lewi, A, Martins, D, Diniz, Bs, Forlenza, Ov, Benefits of psychodynamic group therapy and body awareness therapy on depression, burden, and quality of life of family caregivers to ad patients, Alzheimer's and dementia., 10, P570, 2014	Conference abstract.
Czaja, Sj, Loewenstein, D, Schulz, R, Nair, Sn, Perdomo, D, A videophone psychosocial intervention for dementia caregivers, American Journal of Geriatric Psychiatry, 21, 1071-1081, 2013	Study conducted in the USA.
Davis Jennifer Duncan, et al.,, A telephone-delivered psychosocial intervention improves dementia caregiver adjustment following nursing home placement, International Journal of Geriatric Psychiatry, 26, 380-387, 2011	Study conducted in the USA.
Dean, K. M., Hatfield, L. A., Jena, A. B., Cristman, D., Flair, M., Kator, K., Nudd, G., Grabowski, D. C., Preliminary Data on a Care Coordination Program for Home Care Recipients, Journal of the American Geriatrics Society, 64, 1900-1903, 2016	Intervention received by professional carers.
DeCaro, D. S., Constantine Brown, J. L., Laughter Yoga, Adults Living With Parkinson's Disease, and Caregivers: A Pilot Study, Explore: The Journal of Science & Healing, 12, 196-9, 2016	Not an RCT.
Demiris, George, Oliver, Debra Parker, Wittenberg-Lyles, Elaine, Washington, Karla, Use of videophones to deliver a cognitive-behavioural therapy to hospice caregivers, Journal of Telemedicine and Telecare, 17, 142-145, 2011	Study conducted in the USA.
Dockham, B, Schafenacker, A, Yoon, H, Ronis, Dl, Kershaw, T, Titler, M, Northouse, L, Implementation of a Psychoeducational Program for Cancer Survivors and Family Caregivers at a Cancer Support Community Affiliate: a Pilot Effectiveness Study, Cancer Nursing, 39, 169-180, 2016	Study conducted in the USA.
Douglas, Sl, Daly, Bj, Kelley, Cg, O'Toole, E, Montenegro, H, Impact of a disease management program upon caregivers of chronically critically ill patients, Chest, 128, 3925-3936, 2005	Study conducted in the USA.
Dowling, Glenna A., Merrilees, Jennifer, Mastick, Judy, Chang, Vickie Y., Hubbard, Erin, Moskowitz, Judith Tedlie, Life enhancing activities for family caregivers of people with frontotemporal dementia, Alzheimer Disease and Associated Disorders, 28, 175-181, 2014	Study conducted in the USA.
DuBenske, Ll, Gustafson, Dh, Namkoong, K, Hawkins, Rp, Atwood, Ak, Brown, Rl, Chih, My, McTavish, F, Carmack, Cl, Buss, Mk, Govindan, R, Cleary, Jf, CHESS improves cancer caregivers' burden and mood: results of an eHealth RCT, Health psychology, 33, 1261-1272, 2014	Study conducted in the USA.
Ducharme, F, Lévesque, L, Giroux, F, Lachance, L, Follow-up of an intervention program for caregivers of a relative	This RCT was published before 2014. It was therefore excluded as

Study	Reason for Exclusion
with dementia living in a long-term care setting: are there any persistent and delayed effects?, Aging & Mental Health, 9, 461-469, 2005	for this evidence review only relevant RCTs published from 2014 onward were included.
Ducharme, Francine, Lévesque, Louise, Lachance, Lise, Giroux, Francine, Legault, Alain, Préville, Michel, 'Taking care of myself': efficacy of an intervention programme for caregivers of a relative with dementia living in a long-term care setting, Dementia, 4, 23-47, 2005	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Dunbar, Sb, Gary, Ra, Corwin, E, Miller, A, Higgins, Mk, Butler, J, Effects of a heart failure family caregiver intervention on caregiver strain and outcomes, Circulation, 130, 2014	Conference abstract.
Dvorak, Abbey L., Music therapy support groups for cancer patients and caregivers: A mixed-methods approach, Canadian Journal of Music Therapy, 21, 69-105, 2015	Study conducted in the USA.
Eisdorfer, C, Czaja, Sj, Loewenstein, Da, Rubert, Mp, Argüelles, S, Mitrani, Vb, Szapocznik, J, The effect of a family therapy and technology-based intervention on caregiver depression, Gerontologist, 43, 521-531, 2003	Study conducted in the USA.
Eldred Clare, Sykes Catherine, Psycho-educational interventions for carers of survivors of stroke: a systematic review of interventions based on psychological principles and theoretical frameworks, British Journal of Health Psychology, 13, 563-581, 2008	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Eloniemi-Sulkava, U, Saarenheimo, M, Laakkonen, Ml, Pietilä, M, Savikko, N, Kautiainen, H, Tilvis, Rs, Pitkälä, Kh, Family care as collaboration: effectiveness of a multicomponent support program for elderly couples with dementia. Randomized controlled intervention study, Journal of the American Geriatrics Society, 57, 2200-2208, 2009	Population to exclude: no primary focus on adult carers.
Ferre-Grau, C., Sevilla-Casado, M., Lleixa-Fortuno, M., Aparicio-Casals, M. R., Cid-Buera, D., Rodero-Sanchez, V., Vives-Relats, C., Effectiveness of problem-solving technique in caring for family caregivers: a clinical trial study in an urban area of Catalonia (Spain), Journal of clinical nursing, 23, 288-295, 2014	Not an RCT.
Finkel, S, Czaja, Sj, Schulz, R, Martinovich, Z, Harris, C, Pezzuto, D, E-care: a telecommunications technology intervention for family caregivers of dementia patients, American Journal of Geriatric Psychiatry, 15, 443-448, 2007	Study conducted in the USA.
Fortinsky, Rh, Kulldorff, M, Kleppinger, A, Kenyon-Pesce, L, Dementia care consultation for family caregivers: collaborative model linking an Alzheimer's association chapter with primary care physicians, Aging & Mental Health, 13, 162-170, 2009	Not relevant to the PICO question for RQF.
Friedman, Eh, Grant, Js, Re: telephone intervention with family caregivers of stroke survivors after rehabilitation, Stroke; a journal of cerebral circulation, 34, 7-8, 2003	Letter.
Friedman, L, Spira, Ap, Hernandez, B, Mather, C, Sheikh, J, Ancoli-Israel, S, Yesavage, Ja, Zeitzer, Jm, Brief morning light treatment for sleep/wake disturbances in older memory-impaired individuals and their caregivers, Sleep medicine, 13, 546-549, 2012	Study conducted in the USA.
Gallagher-Thompson, D, Coon, Dw, Solano, N, Ambler, C, Rabinowitz, Y, Thompson, Lw, Change in indices of distress	Study conducted in the USA.

Study	Reason for Exclusion
among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study, Gerontologist, 43, 580-591, 2003	
Gallagher-Thompson, D, Gray, Hl, Dupart, T, Thompson, Lw, Jimenez, D, Effectiveness of cognitive/behavioral small group intervention for reduction of depression and stress in non-Hispanic White and Hispanic/Latino women dementia family caregivers: outcomes and mediators of change, Journal of rational-emotive and cognitive-behavior therapy, 26, 286-303, 2008	Study conducted in the USA.
Gallagher-Thompson, D, Gray, Hl, Tang, Pc, Pu, Cy, Leung, Ly, Wang, Pc, Tse, C, Hsu, S, Kwo, E, Tong, Hq, Long, J, Thompson, Lw, Impact of in-home behavioral management versus telephone support to reduce depressive symptoms and perceived stress in Chinese caregivers: results of a pilot study, American Journal of Geriatric Psychiatry, 15, 425-434, 2007	Study conducted in the USA.
Gallagher-Thompson, D., Tzuang, M., Hinton, L., Alvarez, P., Rengifo, J., Valverde, I., Chen, N., Emrani, T., Thompson, L. W., Effectiveness of a fotonovela for reducing depression and stress in Latino dementia family caregivers, Alzheimer disease and associated disorders, 29, 146-53, 2015	Study conducted in the USA.
Gaugler, J. E., Understanding and Supporting Persons with Memory Loss and Their Families Across the Spectrum of Dementia, Journal of Applied Gerontology, 36, 779-781, 2017	Introduction to special issue of journal.
Gaugler, J. E., Reese, M., Sauld, J., A Pilot Evaluation of Psychosocial Support for Family Caregivers of Relatives with Dementia in Long-Term Care: The Residential Care Transition Module, Research in gerontological nursing, 8, 161-172, 2015	Potentially eligible as subgroup for RQI (it is about transitions).
Geldmacher, D. S., Maintaining patients with Alzheimer's disease in the home environment, Advanced Studies in Medicine, 4, 308-313, 2004	General (non-systematic) review.
Giron, M., Fernandez-Yanez, A., Mana-Alvarenga, S., Molina-Habas, A., Nolasco, A., Gomez-Beneyto, M., Efficacy and effectiveness of individual family intervention on social and clinical functioning and family burden in severe schizophrenia: a 2-year randomized controlled study, Psychological Medicine, 40, 73-84, 2010	Population to exclude: no primary focus on adult carers.
Gitlin, Ln, Burgio, Ld, Mahoney, D, Burns, R, Zhang, S, Schulz, R, Belle, S H, Czaja, S J, Gallagher, Thompson D, Hauck, Ww, Ory, Mg, Effect of multicomponent interventions on caregiver burden and depression: the reach multisite initiative at 6-month follow-up, Psychology and Aging, 18, 361-374, 2003	Study conducted in the USA.
Gitlin, Ln, Winter, L, Dennis, Mp, Hodgson, N, Hauck, Ww, A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial, Jama, 304, 983-991, 2010	Study conducted in the USA.
Gleeson, Jf, Cotton, Sm, Alvarez-Jimenez, M, Wade, D, Crisp, K, Newman, B, Spiliotacopoulos, D, McGorry, Pd, Family outcomes from a randomized control trial of relapse prevention therapy in first-episode psychosis, Journal of Clinical Psychiatry, 71, 475-483, 2010	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.

Study	Reason for Exclusion
Glueckauf, R. L., Davis, W. S., Allen, K., Chipi, P., Schettini, G., Tegen, L., Jian, X., Gustafson, D. J., Maze, J., Mosser, B., Prescott, S., Robinson, F., Short, C., Tickel, S., VanMatre, J., DiGeronimo, T., Ramirez, C., Integrative cognitive-behavioral and spiritual counseling for rural dementia caregivers with depression, Rehabilitation Psychology, 54, 449-61, 2009	Not an RCT.
Glueckauf, Rl, Davis, Ws, Willis, F, Sharma, D, Gustafson, Dj, Hayes, J, Stutzman, M, Proctor, J, Kazmer, Mm, Murray, L, Shipman, J, McIntyre, V, Wesley, L, Schettini, G, Xu, J, Parfitt, F, Graff-Radford, N, Baxter, C, Burnett, K, Noël, Lt, Haire, K, Springer, J, Telephone-based, cognitive-behavioral therapy for African American dementia caregivers with depression: initial findings, Rehabilitation Psychology, 57, 124-139, 2012	Study conducted in the USA.
Glueckauf, Rl, Sharma, D, Davis, Ws, Byrd, V, Stine, C, Jeffers, Sb, Telephone-based cognitive-behavioral intervention for distressed rural dementia caregivers: initial findings, Clinical Gerontologist, 31, 21-41, 2007	Study conducted in the USA.
Goldbeck, L., Fidika, A., Herle, M., Quittner, A. L., Psychological interventions for individuals with cystic fibrosis and their families, Cochrane Database of Systematic Reviews, 6, CD003148, 2014	Population to exclude: no primary focus on adult carers.
Gonyea, Judith G. PhD, López, Luz M. PhD, Velásquez, Esther H. M. S. W. M. P. H., The Effectiveness of a Culturally Sensitive Cognitive Behavioral Group Intervention for Latino Alzheimer's Caregivers, The Gerontologist, 56, 292, 2016	Study conducted in the USA.
Grossfeld-Schmitz, M., Donath, C., Holle, R., Lauterberg, J., Ruckdaeschel, S., Mehlig, H., Marx, P., Wunder, S., Grassel, E., Counsellors contact dementia caregivers--predictors of utilisation in a longitudinal study, BMC Geriatrics, 10, 24, 2010	Not an RCT.
Grover, M., Naumann, U., Mohammad-Dar, L., Glennon, D., Ringwood, S., Eisler, I., Williams, C., Treasure, J., Schmidt, U., A randomized controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa, Psychological Medicine, 41, 2581-2591, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Grover, M., Williams, C., Eisler, I., Fairbairn, P., McCloskey, C., Smith, G., Treasure, J., Schmidt, U., An off-line pilot evaluation of a web-based systemic cognitive-behavioral intervention for carers of people with anorexia nervosa, International Journal of Eating Disorders, 44, 708-15, 2011	Not an RCT.
Hamilton, G, Gallagher, M, Pierson, K, Lowes, S, Lin, Py, Ortega, R, Palliative care for dementia: a randomized controlled study of a replicable and financially viable model for organizations providing caregiver support, Journal of Pain and Symptom Management, 401-401, 2017	Conference abstract.
Harmon, C., Warner, C., RESOURCEFULNESS AND SUPPORT IN STRESS, REWARDS AND MENTAL HEALTH OF GRANDMOTHER CAREGIVERS, The Gerontologist, 48, 236, 2008	Conference abstract.
Hazel, Na, McDonell, Mg, Short, Ra, Berry, Cm, Voss, Wd, Rodgers, Ml, Dyck, Dg, Impact of multiple-family groups for outpatients with schizophrenia on caregivers' distress and	Study conducted in the USA.

Study	Reason for Exclusion
resources, Psychiatric services (washington, D.C.), 55, 35-41, 2004	
Herrman, H., Humphreys, C., Halperin, S., Monson, K., Harvey, C., Mihalopoulos, C., Cotton, S., Mitchell, P., Glynn, T., Magnus, A., Murray, L., Szwarc, J., Davis, E., Havighurst, S., McGorry, P., Tyano, S., Kaplan, I., Rice, S., Moeller-Saxone, K., A controlled trial of implementing a complex mental health intervention for carers of vulnerable young people living in out-of-home care: the ripple project, BMC Psychiatry, 16, 436, 2016	Not an RCT.
Hirano, Akemi, Suzuki, Yusuke, Kuzuya, Masafumi, Onishi, Joji, Ban, Nobutaro, Umegaki, Hiroyuki, Influence of regular exercise on subjective sense of burden and physical symptoms in community-dwelling caregivers of dementia patients: A randomized controlled trial, Archives of Gerontology and Geriatrics, 53, e158-e163, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Hung, Lc, Liu, Cc, Hung, Hc, Kuo, Hw, Effects of a nursing intervention program on disabled patients and their caregivers, Archives of Gerontology and Geriatrics, 36, 259, 2003	Study conducted in Taiwan.
Hutchison, S. D., Sargeant, H., Morris, B. A., Hawkes, A. L., Clutton, S., Chambers, S. K., A community-based approach to cancer counselling for patients and carers: a preliminary study, Psycho-Oncology, 20, 897-901, 2011	Not an RCT.
Islam, S., Keeble, T., Davies, J., Magee, N., Balasubramanian, R., Watson, N., Care after resuscitation: An innovative early psychological support service proven to improve the quality of life, cognitive function, and ability to return to work-an early intervention for cardiac arrest survivors and their caregivers, Heart, Conference, 2015	Conference abstract.
Janse, B., Huijsman, R., de Kuyper, R. D., Fabbricotti, I. N., The effects of an integrated care intervention for the frail elderly on informal caregivers: a quasi-experimental study, BMC Geriatrics, 14, 58, 2014	Not an RCT.
Jansen, Ap, Hout, Hp, Nijpels, G, Rijmen, F, Dröes, Rm, Pot, Am, Schellevis, Fg, Stalman, Wa, Marwijk, Hw, Effectiveness of case management among older adults with early symptoms of dementia and their primary informal caregivers: a randomized clinical trial, International Journal of Nursing Studies, 48, 933-943, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Johnson Joana, et al.,, Museum activities in dementia care: using visual analog scales to measure subjective wellbeing, Dementia: the International Journal of Social Research and Practice, 16, 591-610, 2017	Not an RCT.
Joling, K. J., van Marwijk, H. W., Smit, F., van der Horst, H. E., Scheltens, P., van de Ven, P. M., Mittelman, M. S., van Hout, H. P., Does a family meetings intervention prevent depression and anxiety in family caregivers of dementia patients? A randomized trial, PLoS ONE [Electronic Resource], 7, e30936, 2012	Study conducted in the USA.
Joling, K. J., van Marwijk, H. W., van der Horst, H. E., Scheltens, P., van de Ven, P. M., Appels, B. A., van Hout, H. P., Effectiveness of family meetings for family caregivers on delaying time to nursing home placement of dementia patients: a randomized trial, PLoS ONE [Electronic Resource], 7, e42145, 2012	Population to exclude: no primary focus on adult carers.

Study	Reason for Exclusion
Joling, Kj, Bosmans, Je, Marwijk, Hwj, Horst, He, Scheltens, P, Vroomen, Jlm, The cost-effectiveness of a family meetings intervention to prevent depression and anxiety in family caregivers of patients with dementia: a randomized trial, Trials, 14, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Jones, C. J., Hayward, M., Brown, A., Clark, E., Bird, D., Harwood, G., Scott, C., Hillemann, A., Smith, H. E., Feasibility and Participant Experiences of a Written Emotional Disclosure Intervention for Parental Caregivers of People with Psychosis, Stress and Health, 32, 485-493, 2016	Not an RCT.
Joosten-Weyn Banningh, L. W., Kessels, R. P., Olde Rikkert, M. G., Geleijns-Lanting, C. E., Kraaimaat, F. W., A cognitive behavioural group therapy for patients diagnosed with mild cognitive impairment and their significant others: feasibility and preliminary results, Clinical Rehabilitation, 22, 731-40, 2008	Not an RCT.
Justo, L. P., Soares, B. G., Calil, H. M., Family interventions for bipolar disorder, Cochrane Database of Systematic Reviews, CD005167, 2007	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Kaisey, M, Mittman, B, Pearson, M, Connor, Ki, Chodosh, J, Vassar, Sd, Nguyen, Ft, Vickrey, Bg, Predictors of acceptance of offered care management intervention services in a quality improvement trial for dementia, International Journal of Geriatric Psychiatry, 27, 1078-1085, 2012	Population to exclude: no primary focus on adult carers.
Kidd, Lori I., Zauszniewski, Jaclene A., Morris, Diana L., Benefits of a poetry writing intervention for family caregivers of elders with dementia, Issues in Mental Health Nursing, 32, 598-604, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
King, Rb, Hartke, Rj, Houle, T, Lee, J, Herring, G, Alexander-Peterson, Bs, Raad, J, A problem-solving early intervention for stroke caregivers: one year follow-up, Rehabilitation nursing, 37, 231-243, 2012	Study conducted in the USA.
Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., Livingston, G., Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial, BMJ (Clinical research ed.), 347, f6342, 2013	Data only on service use and cost effectiveness of intervention.
Koehler, M., Hoppe, S., Bartsch, R., Frommer, J., Flechtner, H. H., Jentsch-Ullrich, K., Heidel, F., Fischer, T., The Magdeburg model of care for adolescents and young adults with cancer (MC AYA): A pilot approach, Onkologie, 36, 162, 2013	Conference abstract.
Koehler, M., Hoppe, S., Peplinski, D., Richter, D., Frommer, J., Flechtner, H. H., Fischer, T., Psycho-oncologic interventions for parents of cancer patients: Systematic review, Oncology Research and Treatment, 38, 172, 2015	Conference abstract.
Koivisto, Am, Hallikainen, I, Välimäki, T, Hongisto, K, Hiltunen, A, Karppi, P, Sivenius, J, Soininen, H, Martikainen, J, Early psychosocial intervention does not delay institutionalization in persons with mild Alzheimer	Population to exclude: no primary focus on adult carers.

Study	Reason for Exclusion
disease and has impact on neither disease progression nor caregivers' well-being: ALSOVA 3-year follow-up, International Journal of Geriatric Psychiatry, 31, 273-283, 2016	
Korn, L., Logsdon, R., Polissar, N., Gomez-Beloz, A., Waters, T., Ryser, R., A RANDOMIZED TRIAL OF A COMPLEMENTARY/ALTERNATIVE MEDICINE APPROACH FOR STRESS REDUCTION IN AMERICAN INDIAN FAMILY CAREGIVERS, The Gerontologist, 48, 81, 2008	Conference abstract.
Kunik, M. E., Snow, A. L., Wilson, N., Amspoker, A. B., Sansgiry, S., Morgan, R. O., Ying, J., Hersch, G., Stanley, M. A., Teaching Caregivers of Persons with Dementia to Address Pain, American Journal of Geriatric Psychiatry, 25, 144-154, 2017	Study conducted in the USA.
Kwak Jung, et al.,, The impact of TCARE on service recommendation, use, and caregiver well-being, Gerontologist, 51, 704-713, 2011	Study conducted in the USA.
Lapid, M. I., Atherton, P. J., Kung, S., Sloan, J. A., Shahi, V., Clark, M. M., Rummans, T. A., Cancer caregiver quality of life: need for targeted intervention, Psycho-Oncology, 25, 1400-1407, 2016	Study conducted in the USA.
Lautenschlager, Nt, Cox, Kl, Flicker, L, Cyarto, E, Ames, D, Logiudice, D, Hill, K, Etherton-Beer, C, Byrne, G, Appadurai, K, Almeida, Op, A randomized controlled trial evaluating the effects of physical activity in people with Alzheimer's disease: the fitness for the ageing brain study ii (fabs II), Alzheimer's and dementia., 11, P280-p281, 2015	Conference abstract.
Lee, Cc, Czaja, Sj, Schulz, R, The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver intervention in three racial ethnic groups, Journals of gerontology. Series B, Psychological sciences and social sciences, 65b, 185-194, 2010	Not an RCT.
Legg, L. A., Quinn, T. J., Mahmood, F., Weir, C. J., Tierney, J., Stott, D. J., Smith, L. N., Langhorne, P., Non-pharmacological interventions for caregivers of stroke survivors, Cochrane database of systematic reviews (Online), CD008179, 2011	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Leroi Iracema, et al.,, A pilot randomized controlled trial of sleep therapy in Parkinson's disease: effect on patients and caregivers, International Journal of Geriatric Psychiatry, 25, 1073-1079, 2010	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Lins, S., Hayder-Beichel, D., Rucker, G., Motschall, E., Antes, G., Meyer, G., Langer, G., Efficacy and experiences of telephone counselling for informal carers of people with dementia, The Cochrane database of systematic reviews, 9, CD009126, 2014	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Lopez Javier, Crespo Maria, Zarit Steven H, Assessment of the efficacy of a stress management program for informal caregivers of dependent older adults, Gerontologist, 47, 205-214, 2007	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
López, J, Crespo, M, Analysis of the efficacy of a psychotherapeutic program to improve the emotional status	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant

Study	Reason for Exclusion
of caregivers of elderly dependent relatives, Aging & Mental Health, 12, 451-461, 2008	RCTs published from 2014 onward were included.
Losada Andres, Marquez-Gonzalez Maria, Romero-Moreno Rosa, Mechanisms of action of a psychological intervention for dementia caregivers: effects of behavioral activation and modification of dysfunctional thoughts, International Journal of Geriatric Psychiatry, 26, 1119-1127, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Lu, Yy, Bakas, T, Yang, Z, Weaver, Mt, Austrom, Mg, Haase, Je, Feasibility and Effect Sizes of the Revised Daily Engagement of Meaningful Activities Intervention for Individuals With Mild Cognitive Impairment and Their Caregivers, Journal of gerontological nursing, 42, 45-58, 2016	Study conducted in the USA.
Lund, L., Ross, L., Petersen, M. A., Groenvold, M., Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey, BMC Cancer, 14, 2014	General survey study.
Macdonald, P., Rhind, C., Hibbs, R., Goddard, E., Raenker, S., Todd, G., Schmidt, U., Treasure, J., Carers' assessment, skills and information sharing (CASIS) trial: a qualitative study of the experiential perspective of caregivers and patients, European Eating Disorders Review, 22, 430-8, 2014	Not an RCT.
Mackenzie, Corey S., Wiprzycka, Ursula J., Hasher, Lynn, Does expressive writing reduce stress and improve health for family caregivers of older adults?, The Gerontologist, 47, 2007	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
MacNeil, Vroomen J, Bosmans, Je, Ven, Pm, Joling, Kj, Mierlo, Ld, Meiland, Fj, Moll, van Charante Ep, Hout, Hp, Rooij, Se, Community-dwelling patients with dementia and their informal caregivers with and without case management: 2-year outcomes of a pragmatic trial, Journal of the American Medical Directors Association, 16, 800.e801-808, 2015	Not an RCT.
Madigan, K., Egan, P., Brennan, D., Hill, S., Maguire, B., Horgan, F., Flood, C., Kinsella, A., O'Callaghan, E., A randomised controlled trial of carer-focussed multi-family group psychoeducation in bipolar disorder, European Psychiatry, 27, 281-284, 2012	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Magliano, L, Fiorillo, A, Malangone, C, Rosa, C, Maj, M, Patient functioning and family burden in a controlled, real-world trial of family psychoeducation for schizophrenia, Psychiatric services (washington, D.C.), 57, 1784-1791, 2006	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Mahoney, Df, Tarlow, Bj, Jones, Rn, Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study, Gerontologist, 43, 556-567, 2003	Study conducted in the USA.
Marquez-Gonzalez, M., et al.,, Modification of dysfunctional thoughts about caregiving in dementia family caregivers: description and outcomes of an intervention programme, Aging and Mental Health, 11, 616-625, 2007	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Martin-Carrasco, M., Martin, M. F., Valero, C. P., Millan, P. R., Garcia, C. I., Montalban, S. R., Vazquez, A. L. G., Piris, S. P., Vilanova, M. B., Effectiveness of a psychoeducation	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant

Study	Reason for Exclusion
intervention program in the reduction of caregiver burden in Alzheimer's Disease patients' caregivers, International Journal of Geriatric Psychiatry, 24, 2009	RCTs published from 2014 onward were included.
Martindale-Adams, Jennifer, Nichols, Linda O., Burns, Robert, Graney, Marshall J., Zuber, Jeffrey, A trial of dementia caregiver telephone support, CJNR: Canadian Journal of Nursing Research, 45, 30-48, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Marziali Elsa, Donahue Peter, Caring for others: internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease, Gerontologist, 46, 398-403, 2006	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Mathews, M, Beck, J, Bogner, A, Dong, Y, Gibbons, M, Jahnel, J, Kramer, L, McNeil, C, Nair, D, Nunley, M, Parker, S, Schaer, L, Swanson-Devlin, T, Wang, D, Stroke camp offers emotional and physical relief for stroke caregivers, 47, 2016	Conference abstract.
Mavandadi, Shahrzad, Wright, Erin M., Graydon, Meagan M., Oslin, David W., Wray, Laura O., A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia, Psychological Services, 14, 102-111, 2017	Study conducted in the USA.
McCann, Terence V., Lubman, Dan I., Cotton, Sue M., Murphy, Brendan, Crisp, Kingsley, Catania, Lisa, Marck, Claudia, Gleeson, John F., A randomized controlled trial of bibliotherapy for carers of young people with first-episode psychosis, Schizophrenia Bulletin, 39, 1307-1317, 2013	Study conducted in the USA.
McDonald, A., Burjan, E., Martin, S., Yoga for patients and carers in a palliative day care setting, International Journal of Palliative Nursing, 12, 519-23, 2006	Not an RCT.
McDonald, J., Swami, N., Hannon, B., Lo, C., Pope, A., Oza, A., Leighl, N., Krzyzanowska, M. K., Rodin, G., Le, L. W., Zimmermann, C., Impact of early palliative care on caregivers of patients with advanced cancer: cluster randomised trial, Annals of Oncology, 28, 163-168, 2017	Although carer received various kinds of support (social, emotional, training), attendance at palliative care not compulsory for them. Intervention primarily for care recipient.
McLean, L. M., Walton, T., Rodin, G., Esplen, M. J., Jones, J. M., A couple-based intervention for patients and caregivers facing end-stage cancer: outcomes of a randomized controlled trial, Psycho-Oncology, 22, 28-38, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
McMillan, Sc, Small, Bj, Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial, Oncology Nursing Forum, 34, 313-321, 2007	Study conducted in the USA.
McMillan, Sc, Small, Bj, Weitzner, M, Schonwetter, R, Tittle, M, Moody, L, Haley, We, Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial, Cancer, 106, 214-222, 2006	Study conducted in the USA.
Melunsky, N., Crellin, N., Dudzinski, E., Orrell, M., Wenborn, J., Poland, F., Woods, B., Charlesworth, G., The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis, Dementia, 14, 842-59, 2015	Not an RCT.

Study	Reason for Exclusion
Milbury, K., Mallaiah, S., Lopez, G., Liao, Z., Yang, C., Carmack, C., Chaoul, A., Spelman, A., Cohen, L., Vivekananda Yoga Program for Patients With Advanced Lung Cancer and Their Family Caregivers, Integrative Cancer TherapiesInteg Cancer Ther, 14, 2015	Not an RCT.
Mittelman, Mary S., Bartels, Stephen J., THE CARE SPAN: Translating Research Into Practice: Case Study Of A Community-Based Dementia Caregiver Intervention, Health Affairs, 33, 587-595, 2014	Not an RCT.
Mittelman, Ms, Long Term Effects of a Psychosocial Intervention on People With Dementia and Their Spouse Caregivers: results of a Randomized Controlled Trial, Neurobiology of aging, 25, S22-s23, 2004	Conference abstract.
Mittelman, Ms, Psycho-educational intervention for dementia caregivers: what can it accomplish?, International Psychogeriatrics, 15 Suppl 1, 247-249, 2003	Study conducted in the USA.
Mittelman, Ms, Brodaty, H, Wallen, As, Burns, A, A three-county randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer disease: effects on caregiver depression, The American Journal of Geriatric Psychiatry, 16, 893-904, 2008	Not relevant to the PICO question for RQF
Mittelman, Ms, Roth, Dl, Clay, Oj, Haley, We, Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention, American Journal of Geriatric Psychiatry, 15, 780-789, 2007	Study conducted in the USA.
Mittelman, Ms, Roth, Dl, Coon, Dw, Haley, We, Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease, American Journal of Psychiatry, 161, 850-856, 2004	Study conducted in the USA.
Mittelman, Ms, Roth, Dl, Haley, We, Zarit, Sh, Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: results of a randomized trial, Journals of gerontology. Series B, Psychological sciences and social sciences, 59, P27-34, 2004	Study conducted in the USA.
Moore, Raeanne C., Chattillion, Elizabeth A., Ceglowski, Jennifer, Ho, Jennifer, von Kanel, Roland, Mills, Paul J., Ziegler, Michael G., Patterson, Thomas L., Grant, Igor, Mausbach, Brent T., A randomized clinical trial of Behavioral Activation (BA) therapy for improving psychological and physical health in dementia caregivers: Results of the Pleasant Events Program (PEP), Behaviour Research and Therapy, 51, 623-632, 2013	Study conducted in the USA.
Morales-Asencio, Jm, Gonzalo-Jiménez, E, Martin-Santos, Fj, Morilla-Herrera, Jc, Celdráan-Mañas, M, Carrasco, Am, García-Arrabal, Jj, Toral-López, I, Effectiveness of a nurse-led case management home care model in Primary Health Care. A quasi-experimental, controlled, multi-centre study, BMC Health Services Research, 8, 193, 2008	Not an RCT.
Mosher, C. E., Secinti, E., Johns, S. A., O'Neil, B. H., Helft, P. R., Shahda, S., Jalal, S. I., Champion, V. L., Examining the effect of peer helping in a coping skills intervention: a randomized controlled trial for advanced gastrointestinal cancer patients and their family caregivers, Quality of Life Research, 1-14, 2017	Study conducted in the USA.

Study	Reason for Exclusion
Mosher, C. E., Winger, J. G., Hanna, N., Jalal, S. I., Einhorn, L. H., Birdas, T. J., Ceppa, D. P., Kesler, K. A., Schmitt, J., Kashy, D. A., Champion, V. L., Randomized Pilot Trial of a Telephone Symptom Management Intervention for Symptomatic Lung Cancer Patients and Their Family Caregivers, Journal of Pain and Symptom Management, 52, 469-482, 2016	Study conducted in the USA.
Namkoong, Kang, DuBenske, Lori L., Shaw, Bret R., Gustafson, David H., Hawkins, Robert P., Shah, Dhavan V., McTavish, Fiona M., Cleary, James F., Creating a bond between caregivers online: Effect on caregivers' coping strategies, Journal of Health Communication, 17, 125-140, 2012	Study conducted in the USA.
Napa, W., Tungpunkom, P., Pothimas, N., Effectiveness of family interventions on psychological distress and expressed emotion in family members of individuals diagnosed with first-episode psychosis: A systematic review, JBI Database of Systematic Reviews and Implementation Reports, 15, 1057-1079, 2017	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Negovanska, V, Hergueta, T, Guichart-Gomez, E, Dubois, B, Sarazin, M, Bungener, C, Beneficial effect of a cognitive behavioral and multidisciplinary program in Alzheimer Disease on spouse caregiver anxiety: french study ELMMA, Revue neurologique, 167, 114-122, 2011	Article in French
Nichols, Lo, Martindale-Adams, J, Burns, R, Graney, Mj, Zuber, J, Translation of a dementia caregiver support program in a health care system--REACH VA, Archives of internal medicine, 171, 353-359, 2011	Not an RCT.
Nobili, A, Riva, E, Tettamanti, M, Lucca, U, Liscio, M, Petrucci, B, Porro, Gs, The effect of a structured intervention on caregivers of patients with dementia and problem behaviors: a randomized controlled pilot study, Alzheimer Disease and Associated Disorders, 18, 75-82, 2004	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Northouse, L., Kershaw, T., Mood, D., Schafenacker, A., Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers, Psycho-Oncology, 14, 478-91, 2005	Study conducted in the USA.
Northouse, L., Schafenacker, A., Barr, K. L., Katapodi, M., Yoon, H., Brittain, K., Song, L., Ronis, D. L., An, L., A tailored Web-based psychoeducational intervention for cancer patients and their family caregivers, Cancer Nursing, 37, 321-30, 2014	Study conducted in the USA.
Northouse, Ll, Mood, Dw, Schafenacker, A, Kalemkerian, G, Zalupski, M, LoRusso, P, Hayes, Df, Hussain, M, Ruckdeschel, J, Fendrick, Am, Trask, Pc, Ronis, Dl, Kershaw, T, Randomized clinical trial of a brief and extensive dyadic intervention for advanced cancer patients and their family caregivers, Psycho-Oncology, 22, 555-563, 2013	Study conducted in the USA.
Northouse, Ll, Mood, Dw, Schafenacker, A, Montie, Je, Sandler, Hm, Forman, Jd, Hussain, M, Pienta, Kj, Smith, Dc, Kershaw, T, Randomized clinical trial of a family intervention for prostate cancer patients and their spouses, Cancer, 110, 2809-2818, 2007	Study conducted in the USA.
Oken, Bs, Fonareva, I, Haas, M, Wahbeh, H, Lane, Jb, Zajdel, D, Amen, A, Pilot controlled trial of mindfulness	Study conducted in the USA.

Study	Reason for Exclusion
meditation and education for dementia caregivers, Journal of alternative and complementary medicine (new york, N.Y.), 16, 1031-1038, 2010	
Ouseph, R, Croy, C, Natvig, C, Simoneau, T, Laudenslager, Ml, Decreased mental health care utilization following a psychosocial intervention in caregivers of hematopoietic stem cell transplant patients, Mental Illness, 6, 2014	Study conducted in the USA.
Passoni, S., Moroni, L., Toraldo, A., Mazza, M. T., Bertolotti, G., Vanacore, N., Bottini, G., Cognitive behavioral group intervention for Alzheimer caregivers, Alzheimer Disease & Associated Disorders, 28, 275-82, 2014	Not an RCT.
Pearce, K., McGovern, J., Barrowclough, C., Assessment of need for psychosocial interventions in an Asian population of carers of patients with schizophrenia, Journal of Advanced Nursing, 54, 284-92, 2006	Not an RCT.
Perlick, Da, Miklowitz, Dj, Lopez, N, Chou, J, Kalvin, C, Adzhiashvili, V, Aronson, A, Family-focused treatment for caregivers of patients with bipolar disorder, Bipolar Disorders, 12, 627-637, 2010	Study conducted in the USA.
Perren, S., Schmid, R., Wettstein, A., Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being, Aging & Mental Health, 10, 539-548, 2006	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Phung, Ktt, Waldorff, Fb, Buss, Dv, Eckermann, A, Keiding, N, Rishoj, S, A three-year follow-up on the efficacy of psychosocial interventions for patients with mild dementia and their caregivers: the multicentre, rater-blinded, randomised Danish Alzheimer Intervention Study (DAISY), BMJ Open, 3, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Pomykala, Kl, Silverman, Dh, Geist, Cl, Voege, P, Siddarth, P, Nazarian, N, Cyr, Nms, Khalsa, Ds, Lavretsky, H, A pilot study of the effects of meditation on regional brain metabolism in distressed dementia caregivers, Aging health, 8, 509-516, 2012	Study conducted in the USA.
Pot, Am, Blom, Mm, Willemse, Bm, Acceptability of a guided self-help Internet intervention for family caregivers: mastery over dementia, International Psychogeriatrics, 27, 1343-1354, 2015	Not an RCT.
Powell, J, Fraser, R, Brockway, Ja, Temkin, N, Bell, K, Improving quality-of-life and emotional well-being for caregivers of persons with traumatic brain injury: a randomized controlled trial, Brain injury., 28, 798, 2014	Conference abstract
Powell, Jm, Fraser, R, Ann, J, Brockway, A, Temkin, Nr, Bell, Kr, A telehealth approach to improving outcomes for caregivers of adults with traumatic brain injury, Archives of physical medicine and rehabilitation., 95, e61, 2014	Conference abstract
Prick, Ae, Lange, J, Pot, Am, Scherder, E, Twisk, J, Community-based care for people with dementia and their caregivers: effects of an exercise and support intervention, International psychogeriatrics., 25, S131, 2013	Conference abstract
Raivio, Minna, Eloniemi-Sulkava, Ulla, Laakkonen, Marja-Liisa, Saarenheimo, Marja, Pietila, Minna, Tilvis, Reijo, Pitkala, Kaisu, How do officially organized services meet the needs of elderly caregivers and their spouses with	General survey about use of services and satisfaction with them.

Study	Reason for Exclusion
Alzheimer's disease?, American Journal of Alzheimer's Disease and Other Dementias, 22, 360-368, 2007	
Reilly Siobhan, et al.,, Case management approaches to home support for people with dementia (review), 2015	Population to exclude: no primary focus on adult carers.
Reinares, M, Vieta, E, Colom, F, Martínez-Arán, A, Torrent, C, Comes, M, Goikolea, Jm, Benabarre, A, Sánchez-Moreno, J, Impact of a psychoeducational family intervention on caregivers of stabilized bipolar patients, Psychotherapy and psychosomatics, 73, 312-319, 2004	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Robinson, L., Francis, J., James, P., Tindle, N., Greenwell, K., Rodgers, H., Caring for carers of people with stroke: developing a complex intervention following the Medical Research Council framework, Clinical Rehabilitation, 19, 560-71, 2005	Not an RCT.
Rodriguez-Sanchez, E., Patino-Alonso, M. C., Mora-Simon, S., Gomez-Marcos, M. A., Perez-Penaranda, A., Losada-Baltar, A., Garcia-Ortiz, L., Effects of a psychological intervention in a primary health care center for caregivers of dependent relatives: a randomized trial, Gerontologist, 53, 397-406, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Roos, C., Silen, M., Skytt, B., Engstrom, M., An intervention targeting fundamental values among caregivers at residential facilities: effects of a cluster-randomized controlled trial on residents' self-reported empowerment, person-centered climate and life satisfaction, BMC Geriatrics, 16, 130, 2016	Population to exclude: no primary focus on adult carers.
Roth, Dl, Mittelman, Ms, Clay, Oj, Madan, A, Haley, We, Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease, Psychology and Aging, 20, 634-644, 2005	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Ryynanen, O-P, Nousiainen, P, Soini, Ejo, Tuominen, S, Efficacy of a multicomponent support programme for the caregivers of disabled persons: a randomised controlled study, Zeitschrift fur Gerontologie und Geriatrie, 46, 449-455, 2013	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Schall, A, Tesky, Va, Pantel, J, Art encounters: a museum intervention study (ARTEMIS) to promote emotional well-being and improve quality of life in people with dementia and their informal caregivers, Alzheimer's and dementia., 11, P737, 2015	Conference abstract.
Schmid, W., Ostermann, T., Home-based music therapy--a systematic overview of settings and conditions for an innovative service in healthcare, BMC Health Services Research, 10, 291, 2010	Population to exclude: no primary focus on adult carers.
Schulz, R., Czaja, S. J., Lustig, A., Zdaniuk, B., Martire, L. M., Perdomo, D., Improving the quality of life of caregivers of persons with spinal cord injury: a randomized controlled trial, Rehabilitation Psychology, 54, 1-15, 2009	Study conducted in the USA.
Schuster, M, Benesch, G, Holthoff, V, Kraft, Jw, Meyer, A-K, Mielke, U, Roth, Gd, Schmauss, M, Wippermann, V, Florange, B, Evaluation of a manualized psychoeducational program for primary caregivers of patients with Alzheimer's disease: its impact on caregivers' quality of life and depressive symptoms-a single-blinded longitudinal study, Alzheimer's & Dementia, 8, P566, 2012	Conference abstract.

Study	Reason for Exclusion
Secker, Dl, Brown, Rg, Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: a preliminary randomised controlled trial, Journal of neurology, neurosurgery, and psychiatry, 76, 491-497, 2005	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Singh, Nirbhay N., Lancioni, Giulio E., Karazsia, Bryan T., Chan, Jeffrey, Winton, Alan S., Effectiveness of caregiver training in Mindfulness-Based Positive Behavior Support (MBPBS) vs. Training-as-Usual (TAU): A randomized controlled trial, Frontiers in Psychology Vol 7 2016, ArtID 1549, 7, 2016	Study conducted in the USA.
Smith, G. C., Egbert, N., Dellman-Jenkins, M., Nanna, K., Palmieri, P. A., Reducing depression in stroke survivors and their informal caregivers: a randomized clinical trial of a Web-based intervention, Rehabilitation Psychology, 57, 196-206, 2012	Study conducted in the USA.
Sogaard, R, Sorensen, J, Waldorff, Fb, Eckermann, A, Buss, Dv, Phung, Ktt, Waldemar, G, Early psychosocial intervention in Alzheimer's disease: cost utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY), BMJ Open, 4, 2014	This study is an economic evaluation, the clinical data were published in 2012.
Stockle, H. S., Haarmann-Doetkotte, S., Bausewein, C., Fegg, M. J., The feasibility and acceptability of short-term, individual existential behavioural therapy for informal caregivers of patients recruited in a specialist palliative care unit, BMC Palliative Care, 15, 88, 2016	Not an RCT.
Stromberg, A., Chung, M. L., Jaarsma, T., Luttik, M. L., Lewis, E., Calado, F., Lahoz, R., Hudson, E., Deschaseaux, C., Disease severity is related to psychosocial distress in chronic heart failure patients, but not in caregivers: Results from an observational study, European Journal of Cardiovascular Nursing, 15, S97, 2016	Conference abstract.
Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., Staples, E., An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis, Social Psychiatry & Psychiatric Epidemiology, 38, 411-8, 2003	Study conducted in the USA.
Tanner, J. A., Black, B. S., Johnston, D., Hess, E., Leoutsakos, J. M., Gitlin, L. N., Rabins, P. V., Lyketsos, C. G., Samus, Q. M., A randomized controlled trial of a community-based dementia care coordination intervention: effects of MIND at Home on caregiver outcomes, American Journal of Geriatric Psychiatry, 23, 391-402, 2015	Study conducted in the USA.
Tanner, Ja, Student, M, Black, Bs, Johnston, D, Hess, E, Rabins, Pv, Effectiveness of a multicomponent care coordination intervention on dementia caregivers in the community-a randomized control trial Jeremy A. Tanner, American Journal of Geriatric Psychiatry, Conference: 2013 AAGP Annual Meeting Los Angeles, CA United States. Conference Start: 20130314 Conference End: 20130317, S97-s98, 2013	Conference abstract.
Toseland, Rw, McCallion, P, Smith, T, Banks, S, Supporting caregivers of frail older adults in an HMO setting, American Journal of Orthopsychiatry, 74, 349-364, 2004	Study conducted in the USA.
Treasure, Janet, Sepulveda, Ana R., MacDonald, Pam, Whitaker, Wendy, Lopez, Carolina, Zabala, Maria, Kyriacou, Olivia, Todd, Gill, Interpersonal maintaining factors in eating	Article only describes intervention.

Study	Reason for Exclusion
disorder: Skill sharing interventions for carers, International Journal of Child and Adolescent Health, 1, 331-338, 2008	
Treasure, Janet, Todd, Gill, Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers, 125-137, 2016	Study only describes intervention (same as Treasure 2008).
Tremont, G, Davis, J, Papandonatos, Gd, Grover, C, Ott, Br, Fortinsky, Rh, Gozalo, P, Bishop, Ds, A telephone intervention for dementia caregivers: background, design, and baseline characteristics, Contemporary Clinical Trials, 36, 338-347, 2013	Study protocol for a RCT.
Tremont, G, Davis, Jd, Papandonatos, Gd, Ott, Br, Fortinsky, Rh, Gozalo, P, Psychosocial telephone intervention for dementia caregivers: a randomized, controlled trial, Alzheimer's & dementia, No Pagination Specified, 2014	Study conducted in the USA.
Tremont, G, Davis, Jd, Papandonatos, Gd, Ott, Br, Fortinsky, Rh, Gozalo, P, Yue, Ms, Bryant, K, Grover, C, Bishop, Ds, Psychosocial telephone intervention for dementia caregivers: a randomized, controlled trial, Alzheimer's & dementia, 11, 541-548, 2015	Study conducted in the USA.
Tremont, G., Davis, J. D., Ott, B. R., Galioto, R., Crook, C., Papandonatos, G. D., Fortinsky, R. H., Gozalo, P., Bishop, D. S., Randomized Trial of the Family Intervention: Telephone Tracking-Caregiver for Dementia Caregivers: Use of Community and Healthcare Resources, Journal of the American Geriatrics Society, 65, 924-930, 2017	Study conducted in the USA.
Tremont, G., Davis, J., Grover, C., Bryant, K., Ott, B., Papandonatos, G., Fortinsky, R., Gozalo, P., Bishop, D., Randomized controlled trial of a telephone-delivered intervention (FITT-Caregiver) for dementia caregivers, Alzheimer's and Dementia, 1), P324-P325, 2013	Conference abstract.
Tremont, Geoffrey, Davis, Jennifer Duncan, Bishop, Duane S., Telephone-delivered psychosocial intervention reduces burden in dementia caregivers, Dementia: The International Journal of Social Research and Practice, 7, 2008	Study conducted in the USA.
Turner, A., Hambridge, J., Alston, M., Sweetapple, A., White, J., Hackett, M., Pollack, M., Group cognitive behaviour therapy for emotional distress in stroke patients and their carers: Impact on quality of life, participation and autonomy and carer burden, International Journal of Stroke, Conference, 2012	Conference abstract.
Van Groenestijn, A. C., Schroder, C. D., Visser-Meily, J. M. A., Reenen, E. T. K. V., Veldink, J. H., Van Den Berg, L. H., Cognitive behavioural therapy and quality of life in psychologically distressed patients with amyotrophic lateral sclerosis and their caregivers: Results of a prematurely stopped randomized controlled trial, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 16, 309-315, 2015	Study conducted in the USA.
Van Puymbroeck, M., Payne, L. L., Hsieh, P. C., A phase I feasibility study of yoga on the physical health and coping of informal caregivers, Evidence-based Complementary and Alternative Medicine, 4, 519-529, 2007	Not an RCT.
Vazquez Gonzalez, F. L., Otero Otero, P., Torres Iglesias, A., Hermida Garcia, E., Blanco Seoane, V., Diaz Fernandez, O., A brief problem-solving indicated-prevention	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant

Study	Reason for Exclusion
intervention for prevention of depression in nonprofessional caregivers, Psicothema, 25, 87-92, 2013	RCTs published from 2014 onward were included.
Visser-Meily, A., van Heugten, C., Post, M., Schepers, V., Lindeman, E., Intervention studies for caregivers of stroke survivors: a critical review, Patient Education & Counseling, 56, 257-67, 2005	Only includes 2 studies published in or after 2003 (Lincoln 2003; Teng 2003), both of which were included in original search.
Waelde, Lynn C, Meyer, Hilary, Thompson, Jason M, Thompson, Larry, Gallagher-Thompson, Dolores, Randomized controlled trial of inner resources meditation for family dementia caregivers, No Pagination Specified, 2017	Study conducted in the USA.
Waelde, Lynn C., Thompson, Larry, Gallagher-Thompson, Dolores, A Pilot Study of a Yoga and Meditation Intervention for Dementia Caregiver Stress, Journal of Clinical Psychology, 60, 677-687, 2004	Not an RCT.
Weisman de Mamani, A., Weintraub, M. J., Gurak, K., Maura, J., A randomized clinical trial to test the efficacy of a family-focused, culturally informed therapy for schizophrenia, Journal of family psychology: JFP: journal of the Division of Family Psychology of the American Psychological Association (Division 43), 28, 800-810, 2014	Study conducted in the USA.
Whitebird, Robin R. PhD M. S. W., Kreitzer, MaryJo PhD R. N., Crain, A. Lauren PhD, Lewis, Beth A. PhD, Hanson, Leah R. PhD, Enstad, Chris J. B. S., Mindfulness-Based Stress Reduction for Family Caregivers: A Randomized Controlled Trial, The Gerontologist, 53, 676, 2013	Study conducted in the USA.
Whitney, J., Murphy, T., Landau, S., Gavan, K., Todd, G., Whitaker, W., Treasure, J., A practical comparison of two types of family intervention: an exploratory RCT of family day workshops and individual family work as a supplement to inpatient care for adults with anorexia nervosa, European Eating Disorders Review, 20, 142-50, 2012	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Williams, V. P., Bishop-Fitzpatrick, L., Lane, J. D., Gwyther, L. P., Ballard, E. L., Vendittelli, A. P., Hutchins, T. C., Williams, R. B., Video-based coping skills to reduce health risk and improve psychological and physical well-being in Alzheimer's disease family caregivers, Psychosomatic Medicine, 72, 2010	Not an RCT.
Wilz, G, Jungbauer, J, Side effects of psychotherapeutic intervention for caregivers of stroke patients: do patients also benefit?, Fortschritte der neurologie-psychiatrie, 76, 201-206, 2008	Article in German.
Wilz, Gabriele, Schinkothe, Denise, Soellner, Renate, Goal attainment and treatment compliance in a cognitive-behavioral telephone intervention for family caregivers of persons with dementia, GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry, 24, 115-125, 2011	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant RCTs published from 2014 onward were included.
Winters-Stone, K. M., Lyons, K. S., Dobek, J., Dieckmann, N. F., Bennett, J. A., Nail, L., Beer, T. M., Benefits of partnered strength training for prostate cancer survivors and spouses: results from a randomized controlled trial of the Exercising Together project, Journal of cancer survivorship: research and practice, 10, 633-644, 2016	Population to exclude: no primary focus on adult carers.
Woods, R. T., Bruce, E., Edwards, R. T., Elvish, R., Hoare, Z., Hounsome, B., Keady, J., Moniz-Cook, E. D., Orgeta, V., Orrell, M., Rees, J., Russell, I. T., REMCARE: reminiscence	This RCT was published before 2014. It was therefore excluded as for this evidence review only relevant

Study	Reason for Exclusion
groups for people with dementia and their family caregivers - effectiveness and cost-effectiveness pragmatic multicentre randomised trial, Health Technology Assessment (Winchester, England), 16, v-xv, 1-116, 2012	RCTs published from 2014 onward were included.

Qualitative component of the review

Table 39: Excludies studies from the qualitative component of the review

Study	Reason for exclusion
Framing outcomes of post-diagnostic psychosocial interventions in dementia: the Adaptation-Coping Model and adjusting to change, Working With Older People, 21, 13-21, 2017	No qualitative data on phenomenon of interest.
Aced López, Sebastián, Corno, Fulvio, De Russis, Luigi, Supporting caregivers in assisted living facilities for persons with disabilities: a user study, Universal Access in the Information Society, 14, 133-144, 2015	No qualitative data on phenomenon of interest.
Aspinall Ann, A weight off my mind: exploring the impact and potential benefits of telecare for unpaid carers in Scotland, Journal of Assistive Technologies, 5, 43-44, 2011	No study design (book review).
Bakas, Tamilyn, Farran, Carol J., Austin, Joan K., Given, Barbara A., Johnson, Elizabeth A., Williams, Linda S., Content Validity and Satisfaction With a Stroke Caregiver Intervention Program, Journal of Nursing Scholarship, 41, 368-375, 2009	Non UK evidence.
Benbow, S. M., Sharman, V., Review of family therapy and dementia: twenty-five years on, International Psychogeriatrics, 26, 2037-50, 2014	No study design (review): reviews have been excluded. References of included studies have been handsearched.
Blusi, Madeleine, Kristiansen, Lisbeth, Jong, Mats, Exploring the influence of Internet-based caregiver support on experiences of isolation for older spouse caregivers in rural areas: a qualitative interview study, International journal of older people nursing, 10, 211-220, 2015	Non UK evidence.
Camin Paul M, Tischler Victoria, Pearman Chantal Helen, Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers, Aging and Mental Health, 18, 161-168, 2014	The aims of this mixed-methods study were to understand the experience of an eight-week art-gallery-based intervention offered at two distinctly different galleries for people with mild to moderate dementia and their carers. It has been excluded fromm the analysis as the main focus was not carers
Charalambous, Andreas, Papadopoulos, Rena, Beadsmoore, Alan, Listening to the voices of patients with cancer, their advocates and their nurses: A hermeneutic-phenomenological study of quality nursing care, European Journal of Oncology Nursing, 12, 436-442, 2008	No qualitative data on phenomenon of interest.
Chiu, T. M., Eysenbach, G., Theorizing the health service usage behavior of family caregivers: a qualitative study of an internet-based intervention, International Journal of Medical Informatics, 80, 754-64, 2011	Non UK evidence.
Corcoran Mary A, Caregiving styles: a cognitive and behavioral typology associated with dementia family caregiving, Gerontologist, 51, 463-472, 2011	Non UK evidence.
Darcy, Jemma, Brunsden, Viv, Hill, Rowena, Exploring online support: Informal caregivers' usage of a mental health	No study design (dissertation).

Study	Reason for exclusion
discussion board, Journal of Cybertherapy and Rehabilitation, 4, 477-482, 2011	
Davis, Nicole J., Clark, Patricia C., Using telehealth to support informal caregivers of elders with urinary incontinence: A pilot/feasibility study, 3663807, 173, 2015	No study design (dissertation).
Demiris, George, Oliver, Debra R., Courtney, Karen L., Porock, Davina, Use of Technology as a Support Mechanism for Caregivers of Hospice Patients, Journal of Palliative Care, 21, 303-309, 2005	No qualitative data on phenomenon of interest.
Di, Lauro Michelle, Spousal caregivers and persons with dementia: increasing participation in shared leisure activities among hospital-based dementia support program participants, Dementia: The International Journal of Social Research and Practice, 16, 9-28, 2017	Non UK evidence.
Dibsdall Lisa, Rugg Sue, Carers' perspectives on their needs and local authority occupational therapy practice, British Journal of Occupational Therapy, 71, 277-285, 2008	No qualitative data on phenomenon of interest.
Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., Robinson, L., Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews, International Psychogeriatrics, 29, 31-43, 2017	No study design (review): reviews have been excluded. References of included studies have been handsearched.
Ducharme, Francine, Beaudet, Line, Legault, Alain, Kergoat, Marie-Jeanne, Lévesque, Louise, Caron, Chantal, Development of an Intervention Program for Alzheimer's Family Caregivers Following Diagnostic Disclosure, Clinical Nursing Research, 18, 44, 2009	Non UK evidence.
Duggleby, Wendy D., Williams, Allison M., Living with hope: developing a psychosocial supportive program for rural women caregivers of persons with advanced cancer, BMC Palliative Care, 9, 3, 2010	Non UK evidence.
Dvorak, Abbey L., Music Therapy Support Groups for Cancer Patients and Caregivers: A Mixed-Methods Approach/Groupes de soutien en musicothérapie auprès de patients atteints de cancer et d'aidants naturels: Approche à méthodes mixtes, Canadian Journal of Music Therapy, 21, 69-105, 2015	Non UK evidence.
Elvish, Ruth, Lever, Sammi-Jo, Johnstone, Jodie, Cawley, Rosanne, Keady, John, Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence, Counselling & Psychotherapy Research, 13, 106-125, 2013	No study design (review): reviews have been excluded. References of included studies have been handsearched.
Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., Moniz-Cook, E., Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review, British Journal of Psychiatry, 208, 429-434, 2016	No study design (review): reviews have been excluded. References of included studies have been handsearched.
Foundation For People With Learning, Disabilities, Mutual caring: multimedia resources, DVD, CD ROM, 2010	No study design.
Foundations,, Carers strategy: evidence submission, 8, 2016	No study design.
Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G., Todd, C., Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008), Palliative Medicine, 24, 594-607, 2010	No study design (review): reviews have been excluded. References of included studies have been handsearched.
Gaugler, Joseph E., Reese, Mark, Tanler, Richard, Care to Plan: An Online Tool That Offers Tailored Support to Dementia Caregivers, The Gerontologist, 56, 1161, 2016	Non UK evidence.
Gibson, G., Dickinson, C., Brittain, K., Robinson, L., The everyday use of assistive technology by people with dementia	No qualitative data on phenomenon of interest.

Study	Reason for exclusion
and their family carers: a qualitative study, BMC geriatrics, 15, 89, 2015	
Gisladottir, M., Treasure, J., Svavarsdottir, E. K., Effectiveness of therapeutic conversation intervention among caregivers of people with eating disorders: quasi-experimental design, Journal of clinical nursing, 26, 735-750, 2017	No qualitative data on phenomenon of interest.
Goddard, E., Macdonald, P., Sepulveda, A. R., Naumann, U., Landau, S., Schmidt, U., Treasure, J., Cognitive interpersonal maintenance model of eating disorders: intervention for carers, British Journal of Psychiatry, 199, 225-31, 2011	No qualitative data on phenomenon of interest.
Golden, Mindi Ann, Whaley, Bryan B., Stone, Anne M., "The system is beginning to shut down": Utilizing caregivers' metaphors for dementia, persons with dementia, and caregiving, Applied Nursing Research, 25, 146-151, 2012	Non UK evidence.
Golino, Antonella, Fragments of memory: a cognitive rehabilitation as social innovation. The Mediterranean Neurological Institute, Salute e Società, 1, 155-167, 2015	No qualitative data on phenomenon of interest.
Grassel, E., Trilling, A., Donath, C., Luttenberger, K., Support groups for dementia caregivers--predictors for utilisation and expected quality from a family caregiver's point of view: a questionnaire survey part I, BMC health services research, 10, 219, 2010	Non UK evidence.
Hoppes, Steve, Bryce, Helen, Hellman, Chan, Finlay, Ellen, The Effects of Brief Mindfulness Training on Caregivers' Well-Being, Activities, Adaptation and Aging, 36, 147-166, 2012	No UK
Hudson, P. L., Girgis, A., Mitchell, G. K., Philip, J., Parker, D., Currow, D., Liew, D., Thomas, K., Le, B., Moran, J., Brand, C., Benefits and resource implications of family meetings for hospitalized palliative care patients: research protocol, BMC Palliative Care, 14, 73, 2015	No study design.
Hurley, R. V., Patterson, T. G., Cooley, S. J., Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature, Aging & Mental Health, 18, 2014	No qualitative data on phenomenon of interest.
Iris, Madelyn, Berman, Rebecca L. H., Stein, Sarah, Developing a Faith-Based Caregiver Support Partnership, Journal of Gerontological Social Work, 57, 728, 2014	Non UK evidence.
Isaki, Emi, Brown, Betty G., Alemán, Sara, Hackstaff, Karla, Therapeutic Writing: An Exploratory Speech-Language Pathology Counseling Technique, Topics in Language Disorders, 35, 275-287, 2015	Non UK evidence.
Jones, G., Complementary and psychological therapies in a rural hospital setting, International Journal of Palliative Nursing, 13, 184-9, 2007	No qualitative data on phenomenon of interest.
Kutner, J., Kilbourn, K. M., Costenaro, A., Lee, C. A., Nowels, C., Vancura, J. L., Anderson, D., Keech, T. E., Support needs of informal hospice caregivers: a qualitative study, Journal of Palliative Medicine, 12, 1101-4, 2009	Non UK evidence.
Lavoie, J. P., et al.,, Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: a process evaluation, Aging and Mental Health, 9, 23-34, 2005	Non UK evidence.
Lincoln, N. B., Walker, M. F., Dixon, A., Knights, P., Evaluation of a multiprofessional community stroke team: a randomized controlled trial, Clinical rehabilitation, 18, 40-7, 2004	No qualitative data on phenomenon of interest.
Lovatt, M., Nanton, V., Roberts, J., Ingleton, C., Noble, B., Pitt, E., Seers, K., Munday, D., The provision of emotional	No qualitative data on phenomenon of interest.

Study	Reason for exclusion
labour by health care assistants caring for dying cancer patients in the community: a qualitative study into the experiences of health care assistants and bereaved family carers, International journal of nursing studies, 52, 271-279, 2015	
Lowenstein, J., Butler, D., Ashcroft, K., The efficacy of a cognitively orientated carers group in an early intervention in psychosis service-A pilot study, Journal of psychiatric and mental health nursing, 17, 628-635, 2010	No qualitative data on phenomenon of interest.
Macdonald, P., Rhind, C., Hibbs, R., Goddard, E., Raenker, S., Todd, G., Schmidt, U., Treasure, J., Carers' assessment, skills and information sharing (CASIS) trial: a qualitative study of the experiential perspective of caregivers and patients, European Eating Disorders Review, 22, 430-8, 2014	The focus of this paper is not on supporting carers: The main aim of this qualitative element is to explore the patientsâ€ ™ perceptions of their relationship and involvement with their caregiver/parent in the year post-discharge, and to examine whether the quality of this differs as a result of their parents having obtained the intervention.
Mackenzie Jenny, Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK, Dementia: The International Journal of Social Research and Practice, 5, 233-247, 2006	The aim of this paper was not to explore the views and experiences of an intervention aimed to provide support to adult carers. The project set out to begin to identify the support needs of family carers from Eastern European and South Asian communities living in a northern England city; and 2) subsequently to develop and deliver tailored 10-week support group programmes combined with advocacy support for carers.
Marconi, Anna, Gragnano, Gaia, Lunetta, Christian, Gatto, Ramona, Fabiani, Viviana, Tagliaferri, Aurora, Rossi, Gabriella, Sansone, Valeria, Pagnini, Francesco, The experience of meditation for people with amyotrophic lateral sclerosis and their caregivers - a qualitative analysis, Psychology, Health & Medicine, 21, 762-768, 2016	Non UK evidence.
Marshall, K., Ferris, J., Utilising behavioural family therapy (BFT) to help support the system around a person with intellectual disability and complex mental health needs: a case study, Journal of Intellectual DisabilitiesJ Intellect Disabil, 16, 2012	No qualitative data on phenomenon of interest.
Marziali, Elsa, Damianakis, Thecla, Donahue, Peter, Internet-Based Clinical Services: Virtual Support Groups for Family Caregivers, Journal of Technology in Human Services, 24, 39-54, 2006	Non UK evidence.
Marziali, Elsa, Donahue, Peter, Caring for Others: Internet Video-Conferencing Group Intervention for Family Caregivers of Older Adults With Neurodegenerative Disease, The Gerontologist, 46, 398-403, 2006	Duplicate.
McKechnie, Vicky, Barker, Chris, Stott, Josh, Effectiveness of computer-mediated interventions for informal carers of people with dementia, International Psychogeriatrics, 26, 2014	No qualitative data on phenomenon of interest.
Mentis, Manolis, Messinis, Lambros, Kotrotsiou, Evagelia, Angelopoulos, Nikiforos V., Marneras, Christos, Papathanasopoulos, Panagiotis, Dardiotis, Euthymios, Efficacy of a support group intervention on psychopathological characteristics among caregivers of	Non UK evidence.

Study	Reason for exclusion
psychotic patients, The International journal of social psychiatry, 61, 373, 2015	
Milbury, Kathrin, Chaoul, Alejandro, Engle, Rosalinda, Liao, Zhongxing, Yang, Chunyi, Carmack, Cindy, Shannon, Vickie, Spelman, Amy, Wangyal, Tenzin, Cohen, Lorenzo, Couple-based Tibetan yoga program for lung cancer patients and their caregivers, Psycho-Oncology, 24, 117-120, 2015	Non UK evidence.
Mira, José Joaquín PhD, Carrillo, Irene MSc, Guilabert, Mercedes PhD, Lorenzo, Susana M. D. PhD, Pérez-Pérez, Pastora PhD, Silvestre, Carmen M. P. H., Ferrús, Lena PhD, The Second Victim Phenomenon After a Clinical Error: The Design and Evaluation of a Website to Reduce Caregivers' Emotional Responses After a Clinical Error, Journal of medical Internet research, 19, 2017	Non UK evidence.
Moebs, Isabelle, Gee, Susan, Miyahara, Motohide, Paton, Helen, Croucher, Matthew, Perceptions of a cognitive rehabilitation group by older people living with cognitive impairment and their caregivers: A qualitative interview study, Dementia: The International Journal of Social Research and Practice, 16, 513-522, 2017	Non UK evidence.
Moorhead, S., Report of a feasibility study of a mindfulness group for clients, carers and staff of an early intervention in psychosis service, the Cognitive Behaviour Therapist, 5, 93-101, 2012	Insufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
Newton, L., Dickinson, C., Gibson, G., Brittain, K., Robinson, L., Exploring the views of GPs, people with dementia and their carers on assistive technology: A qualitative study, BMJ Open, 6 (5) (no pagination), 2016	No qualitative data on phenomenon of interest.
Nightingale, L., Stringer, J., Complementary therapy for carers on a transplant unit, Complementary therapies in clinical practice, 19, 119-27, 2013	The aims of this mixed-methods study were to evaluate a Carers Complementary Therapy Project on a Haematology and Transplant Unit. It has been excluded fromm the analysis as not reporting qualitative data.
Okai, D., Askey-Jones, S., Samuel, M., O'Sullivan, S. S., Chaudhuri, K. R., Martin, A., Mack, J., Brown, R. G., David, A. S., Trial of CBT for impulse control behaviors affecting Parkinson patients and their caregivers, Neurology, 80, 792-9, 2013	No qualitative data on phenomenon of interest.
O'Kelly, J., Saying it in song: music therapy as a carer support intervention, International Journal of Palliative Nursing, 14, 281-6, 2008	No study design. (The author used a carer and her partner as case study on the carers music therapy sessions). Not enough qualitative data.
Onwumere, J., Glover, N., Whittaker, S., Rahim, S., Chu Man, L., James, G., Khan, S., Afsharzadegan, R., Seneviratne, S., Harvey, R., Georgiades, A., Raune, D., Modifying illness beliefs in recent onset psychosis carers: Evaluating the impact of a cognitively focused brief group intervention in a routine service, Early Intervention in Psychiatry., 2017	No qualitative data on phenomenon of interest.
Onwumere, Juliana, Grice, Sarah, Kuipers, Elizabeth, Delivering Cognitive-Behavioural Family Interventions for Schizophrenia, Australian Psychologist, 51, 52-61, 2016	No study design (review): reviews have been excluded. References of included studies have been handsearched.
Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I., de Waal, H., Woods, R. T., Orgeta, V., The impact of individual Cognitive Stimulation Therapy (iCST) on cognition, quality of	No qualitative data on phenomenon of interest.

Study	Reason for exclusion
life, caregiver health, and family relationships in dementia: A randomised controlled trial, PLoS Medicine / Public Library of Science, 14, e1002269, 2017	
Pagan-Ortiz, Marta E., Cortes, Dharma E., Rudloff, Noelle, Weitzman, Patricia, Levkoff, Sue, Use of an online community to provide support to caregivers of people with dementia, Journal of Gerontological Social Work, 57, 694-709, 2014	No qualitative data on phenomenon of interest.
Pierce, L. L., Steiner, V., Govoni, A. L., Hicks, B., Cervantez Thompson, T. L., Friedemann, M. L., Internet-based support for rural caregivers of persons with stroke shows promise, Rehabilitation nursing: the official journal of the Association of Rehabilitation Nurses, 29, 95-99, 103, 2004	No qualitative data on phenomenon of interest.
Pierce, Linda L., Steiner, Victoria, de Dios, Ann Margaret Vergel, Vollmer, Megan, Govoni, Amy L., Thompson, Teresa L. Cervantez, Qualitative analysis of a nurse's responses to stroke caregivers on a web-based supportive intervention, Topics in Stroke Rehabilitation, 22, 152, 2015	No qualitative data on phenomenon of interest.
Richardson, Amy E., Morton, Randall, Broadbent, Elizabeth, Psychological support needs of patients with head and neck cancer and their caregivers: A qualitative study, Psychology and Health, 30, 1288-1305, 2015	Non UK evidence.
Robinson Christina M, et al.,, The involvement of multiple caregivers in cognitive-behavior therapy for anxiety in persons with dementia, Aging and Mental Health, 15, 291-298, 2011	Non UK evidence.
Rose, J., Carer reports of the efficacy of cognitive behavioral interventions for anger, Research in Developmental Disabilities, 31, 1502-8, 2010	No qualitative data on phenomenon of interest.
Salfi, Jenn, Seeking to understand telephone support for dementia caregivers: A qualitative case study, NR04533, 152, 2004	No study design (dissertation).
Schoenmakers, Birgitte, Buntinx, Frank, DeLepeleire, Jan, Supporting the dementia family caregiver: the effect of home care intervention on general well-being, Aging and Mental Health, 14, 44-56, 2010	Non UK evidence.
Serafini Julie Dergal, et al.,, Clinical practice standards and ethical issues applied to a virtual group intervention for spousal caregivers of people with Alzheimer's, Social Work in Health Care, 44, 225-243, 2007	No qualitative data on phenomenon of interest.
Serwe, Katrina M., Hersch, Gayle I., Pickens, Noralyn Davel, Pancheri, Karen, Caregiver Perceptions of a Telehealth Wellness Program, The American Journal of Occupational Therapy, 71, 1-5, 2017	Non UK evidence.
Shanley, Chris, Supporting Family Carers Through Telephone-Mediated Group Programs: Opportunities For Gerontological Social Workers, Journal of Gerontological Social Work, 51, 199-209, 2008	No qualitative data on phenomenon of interest.
Shared Care, Network, Befriending: more than just finding friends?; summary of research findings, 4p., 2004	No qualitative data on phenomenon of interest.
Shreve, J., Baier, R. R., Epstein-Lubow, G., Gardner, R. L., Dementia caregivers' technology preferences: Design insights from qualitative interviews, Gerontechnology, 14, 89, 2016	No qualitative data on phenomenon of interest.
Sin, J., Moone, N., Newell, J., Developing services for the carers of young adults with early-onset psychosis: Implementing evidence-based practice on psycho-educational family intervention, Journal of psychiatric and mental health nursing, 14, 282-290, 2007	No qualitative data on phenomenon of interest.
Singer, George H. S., Biegel, David E., Ethridge, Brandy L., Toward a Cross Disability View of Family Support for	No qualitative data on phenomenon of interest.

Study	Reason for exclusion
Caregiving Families, Journal of Family Social Work, 12, 97-118, 2009	
Smith, C. A., IMPACT OF ADULT DAY CARE ON CAREGIVERS:AN EXPLORATORY MIXED METHODS STUDY, The Gerontologist, 48, 119, 2008	No qualitative data on phenomenon of interest.
Social Care Institute for Excellence, Scie, Support for carers of people with dementia, Community Care, 2007	No study design.
Sorensen Lisbeth V, Warldorff Frans B, Waldermar Gunhild A, Early counselling and support for patients with mild Alzheimer's disease and their caregivers: a qualitative study on outcome, Aging and Mental Health, 12, 444-450, 2008	Non UK evidence.
Stewart, Miriam, Barnfather, Alison, Neufeld, Anne, Warren, Sharon, et al.,, Accessible Support for Family Caregivers of Seniors with Chronic Conditions: From Isolation to Inclusion, Canadian Journal on Aging, 25, 179-92, 2006	No qualitative data on phenomenon of interest.
Treasure, J., Nazar, B. P., Interventions for the Carers of Patients With Eating Disorders, Current Psychiatry Reports, 18, 16, 2016	No qualitative data on phenomenon of interest.
Tyack, C., Camic, P. M., Heron, M. J., Hulbert, S., Viewing Art on a Tablet Computer: A Well-Being Intervention for People with Dementia and Their Caregivers, Journal of Applied Gerontology, 36, 864-894, 2017	Focus no on supporting carers
Washington, Karla T., Demiris, George, Parker Oliver, Debra, Wittenberg-Lyles, Elaine, Crumb, Edith, Qualitative evaluation of a problem-solving intervention for informal hospice caregivers, Palliative Medicine, 26, 1018-24, 2012	Non UK evidence.
Wong, Gloria H. Y., Yek, Olive P. L., Zhang, Anna Y., Lum, Terry Y. S., Spector, Aimee, Cultural adaptation of cognitive stimulation therapy (cst) for chinese people with dementia: Multicentre pilot study, International Journal of Geriatric Psychiatry, No-Specified, 2017	Non UK evidence.
Yoon, Hyojin, How do cancer patients and caregivers perceive web-based interventions? A qualitative study, Western Journal of Nursing Research, 35, 1228-1229, 2013	Non UK evidence.
Young, Tony Johnstone, Manthorp, Chris, Howells, David, Tullo, Ellen, Developing a carer communication intervention to support personhood and quality of life in dementia, Ageing & Society, 31, 1003-1025, 2011	No qualitative data on phenomenon of interest.

Economic component of the review

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. The table below is a list of excluded studies across the entire guideline and studies listed were not necessarily identified for this review question.

Table 40: Excludies studies from the economic component of the review

Study	Reason for Exclusion
Arksey Hilary, et al.,, Review of respite services and short-term breaks for carers for people living with dementia: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation	Study design: This report is a review, and reviews are excluded. References could not be hand-searched as there was no reference list included in the report.
Arts, E. E., Landewe-Cleuren, S. A., Schaper, N. C., Vrijhoef, H. J., The cost-effectiveness of substituting physicians with diabetes nurse specialists: a randomized controlled trial with 2-	Population of interest: the study focus is primarily on patients.

Study	Reason for Exclusion
year follow-up, Journal of advanced nursing, 68, 1224-34, 2012	
Forster, A., Young, J., Chapman, K., Nixon, J., Patel, A., Holloway, I., Mellish, K., Anwar, S., Breen, R., Knapp, M., Murray, J., Farrin, A., Cluster Randomized Controlled Trial: Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care, Stroke; a journal of cerebral circulation, 46, 2212-2219, 2015	Population of interest: the study focus is primarily on patients.
Forster, A., Young, J., Green, J., Patterson, C., Wanklyn, P., Smith, J., Murray, J., Wild, H., Bogle, S., Lowson, K., Structured re-assessment system at 6 months after a disabling stroke: a randomised controlled trial with resource use and cost study, Age & AgeingAge Ageing, 38, 2009	This cost analysis is focused primarily on patients.
Gardiner, Clare, Brereton, Louise, Frey, Rosemary, Wilkinson-Meyers, Laura, Gott, Merryn, Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review, Health & Social Care in the Community, 24, 519-531, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Gitlin LN, Hodgson N, Jutkowitz E, Pizzi L. The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: the tailored activity program. Am J Geriatr Psychiatry 2010;18(6):510-9.	Economic evaluation conducted in the USA.
Gomes, B., Calanzani, N., Curiale, V., McCrone, P., Higginson, I. J., Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, Cochrane Database of Systematic Reviews, 2016 (3) (no pagination), 2013	Study design - this review of HE studies has been excluded for this guideline - but its references have been checked for any relevant HE study.
Gomes, Barbara, Calanzani, Natalia, Higginson, Irene J., Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers, JAMA: Journal of the American Medical Association, 311, 1060-1061, 2014	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Heslin, M., Forster, A., Healey, A., Patel, A., A systematic review of the economic evidence for interventions for family carers of stroke patients, Clinical Rehabilitation, 30, 119-33, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE study.
Hoefman, R. J., van Exel, J., Brouwer, W. B., Measuring Care-Related Quality of Life of Caregivers for Use in Economic Evaluations: CarerQol Tariffs for Australia, Germany, Sweden, UK, and US, PharmacoEconomics, 35, 469-478, 2017	No intervention of interest.
Huter, K., Kocot, E., Kissimova-Skarbek, K., Dubas-Jakobczyk, K., Rothgang, H., Economic evaluation of health promotion for older people-methodological problems and challenges, BMC Health Services Research, 16 Suppl 5, 328, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones Carys, Edwards Rhiannon Tudor, Hounsome Barry, A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people living with dementia residing in the community, International Psychogeriatrics, 24, 6-18, 2012	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones, C., Edwards, R. T., Hounsome, B., Health economics research into supporting carers of people living with dementia: A systematic review of outcome measures, Health and Quality of Life Outcomes, 10 (no pagination), 2012	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.

Study	Reason for Exclusion
Jutkowitz, E., Gitlin, L. N., Pizzi, L. T., Evaluating willingness-to-pay thresholds for dementia caregiving interventions: application to the tailored activity program, Value in Health, 13, 720-5, 2010	Economic evaluation conducted in the USA.
Kenealy, T. W., Parsons, M. J., Rouse, A. P., Doughty, R. N., Sheridan, N. F., Hindmarsh, J. K., Masson, S. C., Rea, H. H., Telecare for diabetes, CHF or COPD: effect on quality of life, hospital use and costs. A randomised controlled trial and qualitative evaluation, PLoS ONE [Electronic Resource], 10, e0116188, 2015	Population of interest: the study focus is primarily on patients.
Kenrik Duru, O., Ettner, S. L., Vassar, S. D., Chodosh, J., Vickrey, B. G., Cost evaluation of a coordinated care management intervention for dementia, American Journal of Managed Care, 15, 521-528, 2009	Population of interest: the study focus is primarily on patients.
Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., Livingston, G., Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people living with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial (Structured abstract), Bmj, 347, f6342, 2013	Study finding updated by a more recent HE study (Livingston 2014).
Lauret, G. J., Gijsbers, H. J., Hendriks, E. J., Bartelink, M. L., de Bie, R. A., Teijink, J. A., The ClaudicatioNet concept: design of a national integrated care network providing active and healthy aging for patients with intermittent claudication, Vascular Health & Risk Management, 8, 495-503, 2012	Research protocol.
Li, C., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moinpour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., Ramsey, S. D., Burden among partner caregivers of patients diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective, Supportive Care in Cancer, 21, 3461-9, 2013	Not the intervention of interest: This study estimates lost productivity and informal caregiving and associated costs among partner caregivers of localized prostate cancer patients within 1 year after diagnosis.
Lopez-Villegas, A., Catalan-Matamoros, D., Robles-Musso, E., Peiro, S., Workload, time and costs of the informal carers in patients with tele-monitoring of pacemakers: the PONIENTE study, Clinical Research in Cardiology, 105, 307-313, 2016	Not the intervention of interest: aim of this study was to assess the burden borne by and the costs to informal carers of patients with remotely monitored pacemakers.
Magnusson, L., Hanson, E., Supporting frail older people and their family carers at home using information and communication technology: cost analysis, Journal of advanced nursing, 51, 645-57, 2005	This cost analysis uses a case study methodology involving 5 families, cost and resource usage are not reported separately for carers and patients.
Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., Glendinning, C., A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers, Health Technology Assessment (Winchester, England), 11, 1-157, iii, 2007	Study design - this review of HE studies has been excluded for this guideline (but its references have been hand-searched for any relevant HE studies.
Mason, Anne, Weatherly, Helen, Spilsbury, Karen, Golder, Su, Arksey, Hilary, Adamson, Joy, Drummond, Michael, The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People, Journal of the American Geriatrics Society, 55, 290-299, 2007	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Menn P, Holle R, Kunz S, Donath C, Lauterberg J, Dementia care in the general practice setting: a cluster randomized trial	Population of interest: no primary focus on carers.

Study	Reason for Exclusion
on the effectiveness and cost impact of three management strategies. Value Health. 2012 Sep-Oct;15(6):851-9	
Morgan, R. O., Bass, D. M., Judge, K. S., Liu, C. F., Wilson, N., Snow, A. L., Pirraglia, P., Garcia-Maldonado, M., Raia, P., Fouladi, N. N., Kunik, M. E., A break-even analysis for dementia care collaboration: Partners in Dementia Care, Journal of General Internal Medicine, 30, 804-9, 2015	Population of interest: the study focus is primarily on patients.
Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J, The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc. 2008 Mar;56(3):413-20	This economic evaluation was conducted in the USA.
Nichols LO, Martindale-Adams J, Zhu CW, Kaplan EK, Zuber JK, Impact of the REACH II and REACH VA Dementia Caregiver Interventions on Healthcare Costs. J Am Geriatr Soc. 2017 May;65(5):931-936	This economic evaluation was conducted in the USA.
Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E. D., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I. T., de Waal, H., Woods, R. T., Orrell, M., Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial, Health Technology Assessment (Winchester, England), 19, 1-108, 2015	Population of interest: the study focus is primarily on patients.
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Romeo, R., Knapp, M., Banerjee, S., Morris, J., Baldwin, R., Tarrier, N., Pendleton, N., Horan, M., Burns, A., Treatment and prevention of depression after surgery for hip fracture in older people: cost-effectiveness analysis, Journal of Affective Disorders, 128, 211-9, 2011	Population of interest: no adult carers.
Sandberg, M., Jakobsson, U., Midlov, P., Kristensson, J., Cost-utility analysis of case management for frail older people: effects of a randomised controlled trial, Health Economics Review, 5 (1) (no pagination), 2015	Population of interest: no adult carers.
Schepers, J., Annemans, L., Simoens, S., Hurdles that impede economic evaluations of welfare interventions, Expert Review of Pharmacoeconomics & Outcomes Research, 15, 635-42, 2015	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Søgaard R, Sørensen J, Waldorff FB, Eckermann A, Buss DV, Early psychosocial intervention in Alzheimer's disease: cost	Population of interest: no primary focus on carers.

Study	Reason for Exclusion
utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY). BMJ Open. 2014 Jan 15;4(1):e004105	
Sogaard, R., Sorensen, J., Waldorff, F. B., Eckermann, A., Buss, D. V., Waldemar, G., Private costs almost equal health care costs when intervening in mild Alzheimer's: a cohort study alongside the DAISY trial, BMC Health Services Research, 9, 215, 2009	Study findings updated by a more recent HE study (Søgaard 2014)
Teng, J., Mayo, N. E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R., Scott, S., Costs and caregiver consequences of early supported discharge for stroke patients, Stroke, 34, 528-36, 2003	Population of interest: the study focus is primarily on patients.
Toseland RW, Smith TL. The impact of a caregiver health education program on health care costs. Research on Social Work Practice 2006;16(1):9–19.	This economic evaluation was conducted in the USA.
Vicente, C., Sabapathy, S., Formica, L., Maturi, B., Piwko, C., Cost-utility analysis of tocilizumab in the treatment of active systemic juvenile idiopathic arthritis, Value in Health, 16 (3), A225, 2013	Not the intervention of interest: The objective of this HE study is to determine the cost-effectiveness of tocilizumab with or without methotrexate compared to placebo with methotrexate for the treatment of juvenile idiopathic arthritis.
Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., Price, D., Reynolds, S., Mugford, M., Befriending carers of people living with dementia: a cost utility analysis, International Journal of Geriatric Psychiatry, 24, 610-23, 2009	Duplication (Charlesworth 2008).
Wittenberg, E., Prosser, L. A., Disutility of illness for caregivers and families: A systematic review of the literature, Pharmacoeconomics, 31, 489-500, 2013	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Wray, L. O., Shulan, M. D., Toseland, R. W., Freeman, K. E., Vasquez, B. E., Gao, J., The effect of telephone support groups on costs of care for veterans with dementia, Gerontologist, 50, 623-31, 2010	Population of interest: no adult carers.

Appendix M – Quotes extracted from the included papers, which support the qualitative review findings

Camic 2013

"Carer response to the group (including pre-group deliberation; ambience and environment; structure; social inclusion; and the experience of singing): “We were very apprehensive”. (Adult carer of a person with dementia, page 168); “We wondered if it would be therapeutic and enjoyable.” (Adult carer of a person with dementia, page 168); “I don't sing and if it hadn't been for my husband I would not have dreamed of going”. (Adult carer of a person with dementia, page 168); “It was a surprise to actually be in a choir and sing, knowing full well that neither of us could”. (Adult carer of a person with dementia, page 168) “It was very relaxing, no one was left out. We were all taking part, no matter if we could sing or not”. (Adult carer of a person with dementia, page 168); “I was not naturally good at music, I’ve always been somewhat humiliated at school for my lack of musical ability but there was no question of that with the facilitator”. (Adult carer of a person with dementia, page 168); “The room was appropriately sized, there was parking, it was on a bus route”. (Adult carer of a person with dementia, page 168); “You couldn’t tell who was the carer or who was the patient. It was good to see other people to talk and to sing”. (Adult carer of a person with dementia, page 168); “The length was just right”. (Adult carer of a person with dementia, page 168); “The songs were well chosen and allowed everyone to participate”. (Adult carer of a person with dementia, page 168); “I liked that we sung as a group and not individually”. (Adult carer of a person with dementia, page 168); “I appreciated the time to socialise at tea”. (Adult carer of a person with dementia, page 168); “It did us really both good to go and mix with other people, and sing and talk with others, which we wouldn’t do at home. It was nice to know other people going through the same thing”. (Adult carer of a person with dementia, page 168); “We go out a little more”. (Adult carer of a person with dementia, page 168); “The other thing I liked about the group was that it was a group of people with dementia and carers but the dementia was not the focus. It enabled me to see people in a sort of natural setting that were clearly involved, engaged, coping and comfortable with each other”. (Adult carer of a person with dementia, page 168); “It gives you a kind of backing, others going through the same thing as you”. (Adult carer of a person with dementia, page 168); “I think it takes you out of yourself and you tend to forget what’s happening or what’s happening with her”. (Adult carer of a person with dementia, page 169)

Music engagement: "Music helps a great deal. He has always been very keen on all sorts of music so it does work very well. When I put the rubbish out and get the chores done he’ll sit and relax with a tape or the radio on. He particularly likes jazz and songs of praise choirs. It gives both of us such a good feeling factor and you leave your problems behind because you’re in the singing”. (Adult carer of a person with dementia, page 171); "She has very clear memories of the singing group… Although she likes classical music you cannot sing to it so she’s been watching the search for the new Dorothy, she loves it because she can sing along with it. When she was attending the singing group she was confident she could remember the words and she was singing them afterwards”. (Adult carer of a person with dementia, page 171)

Elvish 2014

Still doing the best I can: "So you’ve got to actually have the trust in yourself to be able to cope with it and to be able to get on with it . “. (Adult carer of a person with dementia - female, page 59); "Yeah, I enjoy it [pause] and at the end of the day, this is a bit sad this really, I like to think that Mavis [not real name], well, Mavis will never come home, but I’m making it I suppose, so that she would really like . “. (Adult carer of a person with dementia - female, page 59)

Feeling connected and being understood: "Whoever I meet I've got to trust them, if I don't trust them I tend not to say much and keep very quiet … [my therapist is] very honest, he's very open, he understands me. I think it's trust more than anything, he's very open, he's friendly. I think we've got a good connection". (Adult carer of a person with dementia - female, page 59); "I don't know whether age would make a difference … If it was somebody very young I [would] think how much life experience have you got?". (Adult carer of a person with dementia - female, page 60)

Wanting to share information: "Yes, someone neutral, somewhere you can offload and you're not worrying that it's going to come back and bite you on the bottom at some point, because then obviously it's not going to go anywhere else, it's confidential [pause] It's like if you tell your friend something you never know whether that friend's going to tell somebody else, and you tell your family and then you think you're putting all this burden on them and they've got enough worries themselves". (Adult carer of a person with dementia - female, page 59); "I think it's almost like feeling a bit of a failure … I always said I was a coper, but I'm not as much of a coper as I thought I was "(Adult carer of a person with dementia - female, page 59)

Greenwood 2017

An opportunity for enjoying themselves and to switch off from being a carer: "… I get a lot of enjoyment, I do, I get a lot of laughter out of it, and um I find that I'm enjoying something, which is beneficial to my mum and to others, that's what I get out of it". (Adult carer of a person with dementia - female, page 4); "My husband enjoys going, he looks forward to going, I mean when he gets there he can't wait to get back out again but every time he'd looking forward to it, it's um, sometimes he's happy to go and sometimes not so much, but he does go so". (Adult carer of a person with dementia - female, page 4); "… she likes the idea that we've gone somewhere together, like we've gone out together, like for her it's like doing something with a friend and it's different when someone just comes round for a cup of tea and you're in your own home, there's less of a, there's less of an occasion". (Adult carer of a person with dementia - female, page 4); "… you don't have to do a thing, what do you want for tea, coffee and then there were sandwiches and cake and me, I suppose I didn't appreciate how much I'd been doing until that happened because you just, you sit down and think, oh this is nice, so that was you know massive … really, really appreciated that. … you'll sit down and relax and, you know, enjoy the fuss being made by the volunteers and the staff to give you your refreshments and so you just relax, I mean for me I would quite often not want to socialise actually because I'll be exhausted and so it was in many ways fine with me"; ". (Adult carer of a person with dementia - female, page 5); "I guess the impact of that would have been greatest at the beginning, but actually at the time I didn't realise that that would be the benefit, it was only later on I kind of thought to myself you know, it's just been really useful for me to meet other people with dementia so that my knowledge of the condition is broader than just my mum". (Adult carer of a person with dementia - female, page 5); "Yeah it's safe and there are other people there. You know I'm there with him but now we, I mean we have to go everywhere together. I can never leave him in the house, you know, in the house on his own again". (Adult carer of a person with dementia - female, page 5)

Cafés as normalising living with dementia: "… my mother is a very sociable person, out of all of us in the family she's the most sociable really and she's the one who suffered the most from not going out and her friends didn't seem to understand that… whereas in the memory cafés… and there are different people there and people who don't mind if you're saying the same things all the time". (Adult carer of a person with dementia - female, page 5); "I get to meet some of my, my mums old friends, you know so … she's known them and they know, they know different parts of my mum, different, wherever they know my mum from, they will you know 'Oh your mum is a lovely woman, I've known her for years' or 'I've known, do you know how long I've known your mum?', it's like,'Oh yeah, OK', so out of it I get a lot of enjoyment, I do, I get a lot of laughter out of it, and I find that I'm enjoying something, which is beneficial to my mum and to others, that's what I get out of it". (Adult carer of a person with dementia - female, page 5-6); "… it's just been really useful for me to meet other people with dementia so that my knowledge of the condition is broader than just my mum, you know. … but yes, I guess at the beginning it was like 'Oh you know, people with dementia are normal people!' You know, they just struggle with certain things, but they're just normal nice people … Yes, but that does continue to be reinforced every time we go". (Adult carer of a person with dementia - female, page 6)

Peer support: "Even though he does not participate, he knows something is going on round and he could see other people … Ah, you know in the same category as him."(Adult carer of a person with dementia - female, page 6); "… it's not, it's not the activities particularly … she'll take part in stuff, but it's the sense of being with other people and getting involved in something rather than the particular thing that's going on."(Adult carer of a person with dementia - female, page 6)

Developing social networks and reducing social isolation: "I've made quite a few friends and I'm quite good at remembering their names and one or two have asked for my phone number and I've asked for theirs and we do occasionally phone up, you know, I've said to them 'Oh, come along". (Adult carer of a person with dementia - female, page 7); "'(I enjoy) … being in there, some nice food, talking to people and looking round and thinking who is doing what, and I become the part of the group, I'm not kind of carer sitting in the corner, I'm just become part of the whole thing, that is quite interesting". (Adult carer of a person with dementia - female, page 7); "Christopher: ' …different, like Peter down there, he goes on about his, his wife … he had all the help going and I never had that. … he used to go down other places because he got it good for him, you know, I don't blame him, but, you know, he knew all the ins and outs of everything and he knew where to go and all this, but it's good … I get to know him quite a bit more now because I see him quite a bit … I see another carer, he looks after two elderly couples, you know, one's coming up to a hundred and the other ones in the mid-nineties … which I think is very good …". (Adult carer of a person with dementia - male, page 7); "[I've] 'reached the end of the road with it and I've got to live my life now as happily as I can … to put it bluntly it's just another little diversion uh in the form of socialising with people… I just do things now that please me, I like meeting people, talking to them, and um, it doesn't mean the same as it did". (Adult carer of a person with dementia - female, page 7)

the recruitment and training of café co-ordinators: "[…] they're very nice people […] their hearts in the right place and they, you know, are very accommodating on the whole […] I mean, I was worried about another carer for example and I rang her [café co-ordinator] up and I feel that I can do that sort of thing". (Adult carer of a person with dementia, page 237); "I mean I get on very well with [Café Co-ordinator] and having only seen her about four times, you know, I find very, she's a very easy person and she's very helpful, if you ask for information and she hasn't got it to hand she will take a note and you know and find out for you, yeah which I think is very helpful". (Adult carer of a person with dementia, page 237)

The importance of being presented as " cafés ": "[…] two pounds to attend […] but she can have as many cups of tea, and if she wants juice, she can have juice, she can have her cake, she'll have sandwiches, you know, they put on a nice, a nice little spread for them as well, and I think the way they put the spread out always is inviting to people […]". (Adult carer of a person with dementia, page 238); "Being in there, some nice food, talking to people and looking round and thinking who is doing what, um and I become the part of the group, I'm not kind of carer sitting in the corner, I'm just become part of the whole thing, that is quite interesting". (Adult carer of a person with dementia, page 238)

Reviewing how cafés are publicised: "Dementia café organisers may therefore wish to review how they disseminate information about their services, and ensure that this is across the whole range of professionals working with dementia, especially highlighting their usefulness shortly after diagnosis”. (Author quote - Adult carer of people with dementia, page 238)

Be clear of the purpose and rationale of activities and keep them appropriately updated: "[…] definitely less interested in activities that, that you normally do on your own, like kind of craft things or art things or um they’re a little bit more internally focussed. I mean I guess they include those things because they’re aware that people may have done those as hobbies and feel comfortable doing them, so I kind of get that. Um but they don’t always lend themselves to conversation […]”. (Adult carer of a person with dementia, page 239); "It makes you feel part of history, so that’s again another positive in the memory café, because the activities that they put on, are just great”. (Adult carer of a person with dementia, page 239)

Review how information is presented: "Some of the information and I guess it’s more relevant for carers and it’s directed at the people themselves but, I mean I know my mum’s not going to remember a thing so it’s kind of pointless um and they don’t um yeah, so they don’t deliver the information very effectively […]”. (Adult carer of a person with dementia, page 239); "There’s never any follow up as to how the information’s been used so you kind of wonder you know, well what the point of that was really?”. (Adult carer of a person with dementia, page 239)

Having a dedicated space for carers: "[…] An experience that we’ve done together, which is also important, so I wouldn’t give that up lightly."(Adult carer of a person with dementia, page 239); "I think emotionally it’s much better like, it’s not a one to one basis but you’ve got other people that share […] Whilst you’ve got a person with dementia there and it’s not everything you want to say."(Adult carer of a person with dementia, page 240)

Frequency of opening: "Well, I think what I would like, I think I would prefer it if the memory cafes could be, I wonder perhaps more days or you know, I mean there was somebody I was talking to and I think they have a memory café every day or something or you know."(Adult carer of a person with dementia, page 240); "I would like my mum to go more often. Um so I would be keen for her to go if it was fortnightly, but then it’s whether I could make that happen. (Adult carer of a person with dementia, page 240)

Hamill 2012

Increasing personal awareness: "[…] the group helped them [carers] to acknowledge the reality of dementia diagnosis and process their feelings of grief and loss as well as see beyond the diagnosis to the person they cared for”. (Author quote - adult carers of people with dementia)

Hopkinson 2013

Acceptance: "I don’t think [his eating] will improve. It would be wonderful if it did, but I don’t think it will. So that’s possibly why [I’m less distressed]. I’m accepting more of it”. (Adult carer of a person with advanced cancer - female, page 120); "Some days I probably don’t think about [his weight] but other days I look at him and realise how much less of him there is . You just have to accept that things are very different now, not as I would like them, but there you go, you can’t always get what you like, can you”. (Adult carer of a person with advanced cancer - female, page 120)

Ideas and reassurance- --: "He said “I feel as though I’ve got to try things”, and it’s making it a lot better. He’s a lot better in that way that he wants to try different things, try different foods ."(Adult carer of a person with advanced cancer - female, page 121); "[The nurse] said, “Use powdered milk and add it to your ordinary milk to give it that little bit more protein” . I am sure that will help.’ (Adult carer of a person with advanced cancer - female, page 121)

Understanding: "So I think, the cancer of the pancreas has made him lose a lot of weight and probably that's what's still doing it". (Adult carer of a person with advanced cancer - female, page 121) "Four of the control group carers indicated that a lack of understanding contributed to their distress. 'I'm not all that worried, but I can't understand why he's lost so much weight". (Adult carer of a person with advanced cancer - female, page 121)

Knowing what to do: "I think what it is, is that I know he will lose weight and not to get distressed by it, because I feel if I start getting all hyped up and start pushing him, it's going to worry him . I take the attitude that if you can't change it, where's the point of worrying about it. Because all youdo is make yourself ill and that's no use to your partner". (Adult carer of a person with advanced cancer - female, page 121); \\\"[I experience] a kind of guilt thing I suppose, thinking "I should have thought of that, I could have fed him that", but he may not have wanted it. I don't know . I think, "I should have thought of that and tempted him with it and I didn't."t". (Adult carer of a person with advanced cancer - female, page 121-2)

Changing feelings: " the intervention seems to have "changed what the carers were thinking and feeling, rather than making any great change in food and fluid intake". (Authors quote, page 122)

Jones 2016

Benefits of writing: "It's good to get it down and then have it sent away. Quite cathartic. I may do more of it". (Adult carer of a person with psycosis - Intervention; page 488); "It was helpful to get my thoughts and feelings down on paper and not to keep them inside me where they tend to give me a headache. I don't think I've had so many headaches this week". (Adult carer of a person with psycosis - Intervention; page 488); "It made me think about what I don't do, like sorting financial tangles and getting my life in order! So I'm making a fresh effort now". (Adult carer of a person with psycosis - control; page 488)

Psychological and physical challenges of writing: "I also felt it was traumic [sic] on occasion as I had to think about a situation that I had buried and make it come out from where I had hidden it deep within my memory". (Adult carer of a person with psycosis - Intervention; page 488); "Taking part has been interesting and revealing—I'm surprised that I feel boring. I did cry a lot while I was writing, but I feel this was positive.". (Adult carer of a person with psycosis - Intervention; page 489); "Did not enjoy this exercise mainly due to my inability to make time for myself. If I become absorbed with something I feel guilty for not being 'available' for my daughter so tend to sneak time when she is asleep". (Adult carer of a person with psycosis - Control; page 489); "I decided to write early today because once the day gets going I don't seem to have a space where I can be quiet on my own and think and write". (Adult carer of a person with psycosis - Intervention; page 490)

Writing analysis: ". topics discussed by intervention participants [carers of people with psychosis] ranged from loneliness, sadness, emotional pain, guilt, stigma, vulnerability of the care recipient and impact of caregiving on self and family". (Authors quote - Adult carer of people with psycosis - Intervention; page 490); "I am going to write about what I ate today, because yesterday is already too far back to remember". (Adult carer of a person with psycosis - Control; page 490)

Linacre 2016

Most useful (that is benefits of the workshops): social support: "Getting together with other carers and sharing experiences, understanding that others are having similar problems and how they are dealing with them". (Adult carer of a person with eating disorders, page 300); "Sharing experiences, learning more about myself". (Adult carer of a person with eating disorders, page 300)

Most useful (that is benefits of the workshops): techniques taught: "Being able to discuss practical application of techniques with other carers and professionals”. (Adult carer of a person with eating disorders, page 301); "Probably all workshops for me personally – OARS/Motivational Interviewing, getting insight and understanding how the brain works when an individual suffers from an eating disorder”. (Adult carer of a person with eating disorders, page 301); " Giving me a tool kit to take away and use and share with other family members. My daughter loved the Bus Metaphor”. (Adult carer of a person with eating disorders, page 301)

Most useful (that is benefits of the workshops): self-awareness: "It has also given me a more realistic view of the future – but with hope that in time things will improve. I have learnt to look after myself better – and learnt the importance of this. All the mindfulness practice has proved surprisingly helpful."(Adult carer of a person with eating disorders, page 301)

Least useful (that is limitations of the workshops): content and structure: "Cramming in a lot of detailed slides 'because they are on the schedule' tended to wash over me (only happened once or twice) LESS is more!! "(Adult carer of a person with eating disorders, page 301)

Future workshops (including content and structure; and other topics): content and structure - "More chances to practice things like reflective listening”. (Adult carer of a person with eating disorders, page 302); "More time to practice skills in a 'safe' environment (although I recognise not everyone might be comfortable doing this) (Adult carer of a person with eating disorders, page 302); other topics -"Possibly more information on nutrition”. (Adult carer of a person with eating disorders, page 302)

Melunsky 2015

Experiencing carer support (including ‘I didn’t feel so alone’/‘Just knowing that other people were in the same boat’; and ‘He was just normal like the rest of them’.): “You don’t feel quite so isolated. When you talk to other people, it helps. I don’t have close family back-up. I also found some of the things that mum does, other people spoke of as well”. (Adult carer of a person with dementia - female, page 849); “When I take him out I have to explain that he’s got dementia because he does silly things, which I do find a bit embarrassing, sometimes. It was good in the group not to have to keep apologising for him … because people do give you that look, sometimes, if they don’t understand”. (Adult carer of a person with dementia - female, page 849)

Shared experience (including ‘Now we have more things to talk about’; and ‘We could share something together’): "I enjoyed the bits that we did together, because I was then able to talk to K… afterwards, knowing what he’d done and we could recap, so that was good”. (Adult carer of a person with dementia - female, page 850); “I got something out of it in that I spent quality time with her. When I visit her at home, I’m perhaps doing other things, like the washing or housework, so it’s not necessarily quality time with her, so that was good."(Adult carer of a person with dementia - female, page 850); "I liked that we were able to do things together, participating in the different activities together. I realised that there were things you could do to make yourself helpful and to relieve the stress and that you could play games. My L … likes dominoes and I couldn’t play dominoes but I realised that with a little patience I would be able to play with him”. (Adult carer of a person with dementia - female, page 850)

Expectations (met and unmet - including ‘I thought that it might help’; and ‘I didn’t feel I had a break’) "I wanted to meet other people who have got the same problem as L …, just to have an idea and see how they deal with their relatives for ideas that would be useful to me”. (Adult carer of a person with dementia - female, page 848); " "I still had to get J … dressed, take him there, bring him back. It took a long time to prepare and get ready to go out … I didn’t feel I had a break … I resented the fact that it had to be with J … and not just with others”. (Adult carer of a person with dementia - female, page 848) ;"Ideally, I would have liked a lot more time allocated for the carers’ sessions. It felt quite rushed so even if you had questions to ask, those who were more articulate could use up the time”. (Adult carer of a person with dementia - female, page 848)

Carer perspectives of the person with dementia’s experience (including ‘It was a social outing for him’; and ‘She soon forgot when we got home’): "He enjoyed the cake-making as a social event. He enjoyed the novelty of doing things together there. He participated in almost every event and that doesn’t happen normally, at home … It was a social outing for him. He would dress up and get ready, but I can’t get him to do that normally on an everyday basis”. (Adult carer of a person with dementia - female, page 850); "Well, we thought it would probably revive old memories and stimulate activity, but I think the progression has been too much and it hasn’t worked as well as I would have liked to have done … Things were remembered, but it wasn’t a long-term thing. It was soon forgotten. No lasting impact. It may have done right at the beginning, but these things aren’t diagnosed as early as they should be. If you can catch somebody early enough, it would be very beneficial for this type of activity (Adult carer of a person with dementia -male, page 850)

Learning and comparing (including ‘It’s no good looking into the future’; ‘I realised there were things that you could do’; and ‘I don’t always have the time’): "It was a learning process and I could see how J … might progress into and that’s important to know, without it hitting home suddenly. The gradual process is important and even if he was more advanced it’s still very good to know where he might be eventually. We don’t usually get that opportunity in life”. (Adult carer of a person with dementia - female, page 851); "I can leave him, even to go up to the corner shop and know that he will be alright. I wasn’t able to do that before going to the groups. I now don’t worry so much and can relax a bit”. (Adult carer of a person with dementia - female, page 851); "Now, I don’t give him orders – I just say it in a couple of words. I don’t give him a long sentence because he won’t remember what he’s doing and he’ll get more flustered. If I raise my voice he gets flustered. When you’ve said something five times, your voice does get a bit higher, but I try not to do that now because I can see it in his face”. (Adult carer of a person with dementia - female, page 851) "I know that T… goes to a day centre five days a week and J … does cooking. My cooking skills have gone by the board but I felt I should make more of an effort. I haven’t done it”. (Adult carer of a person with dementia - female, page 852)

Milne 2014

Changed Approach: Greater Understanding and Patience: "I can understand and make allowances for his difficult behaviour, accept that dementia is an illness and not let it upset me”. (Adult carer of a person with dementia - female, page777)

Improved Coping Skills: "… realising how important it is to look after myself and involve other members of the family in caring for dad”. (Adult carer of a person with dementia - female, page777)

The Therapeutic Value of the Course :"It was a tremendous help listening to other carers problems … it was a weight off my shoulders, knowing I was not on my own”. (Adult carer of a person with dementia - female, page777)

Social Support and Enjoyment: "I enjoyed it so much and was sorry when it ended. I enjoyed the company of all who attended”. (Adult carer of a person with dementia - female, page777)

Support Services :"(The Course has) offered insight into how different organisations work and how they could assist me with caring for my wife”. (Adult carer of a person with dementia - female, page777)

The Style, Timing and Content of the Course: "A very helpful and informative course, timed exactly right … just after the patient's diagnosis". (Adult carer of a person with dementia - female, page777)

The Valuable Role of Empathic Experts: "The Psychologist's expertise on dementia has been invaluable … his kind, gentle and expert guidance was so important to me and to others". (Adult carer of a person with dementia - female, page777) Weaknesses of the Course: "… the speakers who came were depressingly honest about the shortfall in services!". (Adult carer of a person with dementia - female, page777)

Osman 2016

Social inclusion and support: "From a carer's point of view I think it is fantastic, it is really, that they can get together and understand the varying stages of dementia, you get to know an awful lot you know, mixing together, of what is available for you, more so than someone coming along and trying to give you a talk, you know, you get to know from other people that have experienced it … people relax and mix, we are joined together and help one another, and you get to know these people, and as you go along the line you help them you know, and I think that's the beauty of something like this, is being there for one another you know". (Adult carer of a person with dementia- female, page 1331)

A shared experience: "This is one of the great sadnesses and I get quite emotional about this, there is so much we can't share anymore and this, I should say that this, the Singing for the Brain is one thing that has benefitted me because it's one thing that we can do together for an hour or two and get equal pleasure from and equal meaning". (Adult carer of a person with dementia- female, page 1331)

Positive impact on relationships: "We've talked about that as an extra kind of thing … and it's given something for you (refers to PWD) and dad to talk about … you've had much more to talk about with Dad". (Adult carer of a person with dementia- female, page 1332); "Well like I said when I turn round and see you (PWD) smiling as you're singing and there's definitely, I mean it's pure pleasure for me but it's nice for us to look at each other while we're singing … it's like we understand what we're both experiencing you know, so you don't need to say it, it's just there … and that's lovely isn't it, really lovely". (Adult carer of a person with dementia- female, page 1332)

Lifting the spirits: "The point is that I think that music, irrespective of what you may be suffering from, is uplifting for just everybody really". (Adult carer of a person with dementia- female, page 1333); "Everybody has just got so much pleasure on their faces, and that's uplifting in itself, when you see other people really enjoying something". (Adult carer of a person with dementia- female, page 1333)

Roberts 2011

"Carer" identity (including 1. Recognition of role and carers' needs): "Well, I didn't think it was going to be as emotional as it was … I didn't. And I didn't think that paintings, just looking at paintings, could have that effect on you"(Adult carer of a person with mental health issues, page 15); "I don't know if it was a little boy or little girl in the bed, the parents just looked like it was the end of the world, and it does, it feels like the end of the world when you have to go through so many relapses and you think … It's like a bereavement, you lose 'em, you don't only lose 'em once, you see them getting a bit better, then it happens again, and you think–and you feel as sad as they do". (Adult carer of a person with mental health issues, page 151)

Feeling valued in a special setting (including 1. Privilege; 2. Famous; 3. Quiet; 4. Special; 5. Architectural grandeur): "There isn't enough attention paid to that [role of carers]. But this is a really good example of where it has been. Er, and at the end of the day it does help the NHS, that carers are doing a better job, supporting, so that there will be less, fewer hospitalizations”. (Adult carer of a person with mental health issues, page 152); "I don’t think it was actually said to us, but I think that through the whole process we could see the benefits of actually looking at our own needs, and er, and also how important that is for the person you are worried for, caring for, because they are going to benefit if your needs are met”. (Adult carer of a person with mental health issues, page 152); "It wasn’t something that I had encountered before, but it was the prospect of going up to [the gallery]. I think had it just been a local art gallery or looking at art books or something it wouldn’t have mattered so much, so I think it’s going up to London and the grandeur of the place. I felt I couldn’t pass it by”. (Adult carer of a person with mental health issues, page 152); "The actual building, the vast space, the entrance, the domed entrance. And just the silence and the floors and being with this tiny group of people in these huge surroundings, you know, I just think that made a huge impact. It’s all … well, like, I don’t know, like being somewhere very grand or something … and just for you”. (Adult carer of a person with mental health issues, page 152)

Elements of the intervention (including 1. Different elements; 2. Expert facilitators; 3. Safe space; 4. The ‘bridge’): no quote has been extracted

Art-viewing (including 1. Engaging on different levels; 2. Stimulating responses): no quote has been extracted

Robinson 2005

Feasibility of the intervention: "I'd go in to work the next day after the course, I used to feel lifted, it used to give me a lift, just a boost. I just thought it was very helpful”. (Adult carer of a person with stroke, page 566); "Understanding what's normal, feeling less guilty; knowing I need to look after myself; asking for help; encouraging my husband to use day care sometimes”. (Adult carer of a person with stroke, page 566)

Smallwood 2017

Needs (including ‘Services’; ‘Information’; and ‘Co-operation’): ‘Services’ - “(Adult carer of a person with psychosis, page 126); ‘Information’ - “(Adult carer of a person with psychosis, page 126); ‘Co-operation’ - “(Adult carer of a person with psychosis, page 126)

Psychological benefits (including ‘Reduced distress’; ‘Support’; and ‘Coping’): ‘Reduced distress’ - “(Adult carer of a person with psychosis, page 126); ‘Support’ - “(Adult carer of a person with psychosis, page 126); ‘Coping’ - “(Adult carer of a person with psychosis, page 126)

Sharing Mutuality (including ‘Learning’; and ‘Solidarity’): ‘Learning’ - “(Adult carer of a person with psychosis, page 126); ‘Solidarity’ - “(Adult carer of a person with psychosis, page 126)

Sommerlad 2014

I**mportant aspects of the therapy** - "Some of the problems that I eventually had to face had been discussed, making me aware of them and able to care better”. (Adult carer of a person with dementia - START intervention); "When she was in hospital, doctors took her off medications. I learnt to be more assertive to talk to doctors and got medications put back on”. (Adult carer of a person with dementia - START intervention); "The sessions were too long and interrupted normal daily duties”. (Adult carer of a person with dementia - START intervention)/// "I have since joined the Alzheimer's Society, joined a yoga group and occasionally see a cognitive behavioural therapist—all of which were a result of taking part in the START projec”. (Adult carer of a person with dementia - START intervention); "I have used the methods consistently within my working environment and in offering constructive advice and support to friends dealing with stressful situations that arise within their daily lives”. (Adult carer of a person with dementia - START intervention) ///"Changing unhelpful thoughts … it concentrated my thoughts on how I was managing my own reactions and trying to be understanding of my husband's illness”. (Adult carer of a person with dementia - START intervention); "What was an added bonus was that it centred on me rather than my husband. Previously all attention and energy had been focused on them”. (Adult carer of a person with dementia - START intervention); --- "Changing unhelpful thoughts … it concentrated my thoughts on how I was managing my own reactions and trying to be understanding of my husband's illness”. (Adult carer of a person with dementia - START intervention); "What was an added bonus was that it centred on me rather than my husband. Previously all attention and energy had been focused on them”. (Adult carer of a person with dementia - START intervention)

Participants’ engagement with the therapy - "I thought that by coming to the carers group that I should find out a little bit more about the illness and the sort of, side effects of the medication and whether it was going in the right direction, or indeed if anything was actually happening at all"(Adult carer of a person with psychosis - education group programme); -- Carers stated that the training intervention sessions should have been more explicit in their exploration of the dementia future problems and prognosis: "More discussion of the likely course of the illness”. (Adult carer of a person with dementia - START intervention); "How to prepare for what lies ahead”. (Adult carer of a person with dementia - START intervention); - Carers felt they valued the interaction with the therapist for varied reasons. Some were grateful for the opportunity to share their concerns with a professional; others appreciated the personal attributes of their therapist, while yet others noted the empathetic approach of the therapist and the validation of their own feelings: “I think it's made me think more of not just going in as a nurse but, like I said, knowing that the carers have got something there, that somebody's actually interested in them, and they're looking at it from a different angle than from a nursing angle"(Professional carer-district nurse involved in the intervention delivery); "I think I found the ‘talking through’ with a knowledgeable person the most helpful”. (Adult carer of a person with dementia - START intervention); "Therapist was lovely, warm”. (Adult carer of a person with dementia - START intervention); "I felt it OK to be angry, upset, made to feel less guilty”. (Adult carer of a person with dementia - START intervention) - "The CDs are very relaxing … still very much being used today”. (Adult carer of a person with dementia - START intervention); "Relaxation exercises helped before bedtime to clear the mind”. (Adult carer of a person with dementia - START intervention); "NHS services gave a lot of information at diagnosis; too much negative info at once. I felt START was more supportive and gave smaller bits at a time”. (Adult carer of a person with dementia - START intervention)

Unhelpful aspects of therapy: "Wasn't something I would do for myself”. (Adult carer of a person with dementia - START intervention); ---- gradual rather than abrupt end to the programme: "Knowing that there would be a follow-up might have kept it all fresher in my mind for longer and got me into a routine of it all better”. (Adult carer of a person with dementia - START intervention);

Potential improvements and appropriate time for delivery of the intervention - "I now feel I have all the tools before she gets worse"(Adult carer of a person with dementia - START intervention)-----Respondents commented that earlier engagement with the START programme would have helped them improve their communication and thus care better or avoid making major decisions regarding social care without being equipped with the necessary knowledge of dementia: "I wish I knew more, well before her condition was diagnosed, as I feel that I would have been more understanding and giving to her”. (Adult carer of a person with dementia - START intervention); "[START programme] should have started earlier before we found a live-in carer for my mother-in-law”. (Adult carer of a person with dementia - START intervention); ------Those who felt that the intervention was delivered too early felt it would have helped them cope with their relative's later deterioration: "I feel it was a little early as further down the line, I find it so much harder to cope with my mother as her Alzheimer's has got worse”. (Adult carer of a person with dementia - START intervention)

Unadkat-Shreena 2017

Singing experience (including 'accessibility of singing'- “innate” and “universal"; and ‘joy of singing'- enjoyment, uplifting, stimulating, and therapeutic): Enjoyment - “The singing was one of the most enjoyable experiences I have had in later life”. (Adult carer of a person with dementia, page 473); “…its enjoyment. I think that Alzheimer’s is not an enjoyable thing in anyone’s life, so it brings a bit of light”. (Adult carer of a person with dementia, page 473); uplifting - "We go away feeling uplifted, the lightness and brightness follows us home. I mean joining in with the singing in the moment lifts us too, think about in the First World War, or marching in the Air Force, what did they do? They sang to lift the spirits to take them into battle, well that lifting follows us home”. (Adult carer of a person with dementia, page 473); stimulating - "The singing itself was stimulating, you know, your pheromones or whatever, feel good chemicals, I think that’s noticeable. I think the combination because you are stimulated on so many levels, I think it does make a difference”. (Adult carer of a person with dementia, page 473); Therapeutic - "Everyone in that room has got a problem, whatever it may be, but when you are singing…It goes…I’m not thinking about, you know, the next problem we may have, and all the rest of it, we’re outside of ourselves “. (Adult carer of a person with dementia, page 473); "innate" - "You know the people who aren’t even speaking anymore, they were singing, maybe not well but wholeheartedly, not like with a game where you have to know the rules and understand how to move things. It’s innate; you can soon pick it up if it’s a song, like automatically you can hear it in your head. It’s inside us all”. (Adult carer of a person with dementia, page 474); “universal" - "Singing was frequently perceived to be a common activity that had often been experienced in one form or another “. (Author quote - adult carer of a person with dementia, page 474)

Effective facilitation (including person centred; encourages participation; and equality as priority): "I mean the staff straight off weren’t going to let anybody stand against the wall, you know, one was always greeted most warmly, and several people concerned with the project would come up in succession and talk to us…so there wasn’t any chance for anybody to be like me to stand in the corner”. (Adult carer of a person with dementia, page 474); "…they have structured the whole thing around the needs of these people, very much with them as the centre and the focus”. (Adult carer of a person with dementia, page 474); "But we can’t all take part. He’ll pick [X] and say “we’ll have some real singing now”, well that’s not right, is it? Maybe we’d all be able to get to the stage where we could sing it properly, then we would get these benefits that you would hear about of singing together, doing something together, feeling invigorated, feeling better because we’ve all done something together. But we don’t”. (Adult carer of a person with dementia, page 474)

Equal participation: "Even high executives…you get the managing director singing with the man that ties up the parcels that go out, you know. I think it brings a lot of people to a ame level, you know, so that everyone’s the same. We’re all singing”. (Adult carer of a person with dementia, page 475) Group effect (including belonging; shared experience; and formulation of the group): "But I think, the joy of it was that we were all completely different, from different ackgrounds.but as it went on we became a real group”. (Adult carer of a person with dementia, page 475)

New experiences (including ‘opened a new word’; building something; and excitement): "…building something together, seeing something develop, and being left with something that came out of it”. (Adult carer of a person with dementia, page 475); ".opening your mind to new experiences, using your brain, in something that you never thought of using it in before. It’s a bit like a steamed window where you can’t see outside and you clean it then see a new world”. (Adult carer of a person with dementia, page 475)

Couple benefit (including carers benefits): "I used to take [name] along to day care and leave…with singing I didn’t even think I would be involved. But what I thought I would do, to be fair, I would stay the first day to see what was going on and whether [name] was comfortable and whatever was going on. And what developed I thought oh, I quite enjoy this”. (Adult carer of a person with dementia, page 475)

Whitney 2012

Who was involved and what were the experiences of working together? (including ‘Working with the professionals’; ‘Working with another family’ and ‘Engagement and involvement of the patient’): ‘Working with the professionals’ - "We had two of the most experienced people there. They were professional and they were very sincere and they were very controlled. I felt safe with them. (Adult carer of a person with eating disorders - FDW, page 135); "I felt almost like we were being judged and preached by the professionals. I remember them saying a few things and really being affronted by what they said”. (Adult carer of a person with eating disorders - FDW, page 135); ‘Working with another family’ - " .you’re learning from them and they’re learning from us and how they cope and have dealt with the situation and you’re thinking I might try that see if that works for her”. (Adult carer of a person with eating disorders - FDW, page 135); "We had our disagreements but we don’t bicker like that… It helped me to reinforce not to slag off the missing parent”. (Adult carer of a person with eating disorders - IFW, page 135);

What was involved in the intervention and how was this perceived? (including ‘Goals and expectations’; ‘Structure of interventions’; ‘Components of family work’; and ‘What else would be helpful?’): ‘Goals and expectations’ -"I think with every family you need to pinpoint what are the most difficult points for every family and then work on those …Every family is going to be different”. (Adult carer of a person with eating disorders - FDW, page 136); "I sensed that the purpose of the thing was to show you the regime that they operate there, and to encourage patients to eat, and for you to try and take up the reins where they left off in the family environment”. (Adult carer of a person with eating disorders - FDW, page 136); ‘Structure of interventions’ - "… we all found it exhausting. We did three days on the trot …but then the overall feeling from all of us was that it was exhausting but worth while"(Adult carer of a person with eating disorders - FDW, page 136);\\\ Components of family work’ - "…it actually sort of started to articulate without using words, the size of the problem and her feelings and where she was…how did we relate to each other”. (Adult carer of a person with eating disorders - FDW, page 136); "…you are all going through your own thing, but you don’t want to go on about how you’re feeling ‘cause that person is feeling really bad as well … It gave us all a chance to write down how we were feeling”. (Adult carer of a person with eating disorders - FDW, page 137);

What else would be helpful?’ - "When (patient)’s discharged from here, it would be quite nice, if somebody just phoned you, just once a month and asked how she was doing. And if she’s not doing well, what I could do… because I have felt a bit out on my own”. (Adult carer of a person with eating disorders - IFW, page 137); "It might be useful to have it in smaller groups, perhaps just the brothers and sisters with them … That could have been useful to ease any feelings of guilt or helplessness you might have and give (my sister) an opportunity to say ‘‘well, I need a different kind of support from you.’’ (Adult carer of a person with eating disorders - FDW, page 137-8)

When is the intervention presented? (including ‘Introducing the intervention’; and ‘‘Family work as an early intervention strategy’): ‘Introducing the intervention’ - "They did label it as family therapy which straight away put my back up. And all the family, we immediately thought, why do we need the therapy?…Straight away they said ‘‘there’s something gone wrong within the family and we want to put it right’’. That seemed to be their aim, and we weren’t actually asked what we wanted to get out of it "(Adult carer of a person with eating disorders - IFW, page 138); ‘‘Family work as an early intervention strategy’ - "I honestly believe that if we could have got her into sessions earlier, I don’t think we would be where we are today. And I actually think the family work we did was part of the recovery of (my daughter)”. (Adult carer of a person with eating disorders - FDW, page 138)

Where was the intervention held? (including ‘The therapeutic environment’; and ‘Implementation outside the therapeutic environment’): ‘The therapeutic environment’ - "The thing is I am not too sure about the environment of a clinic or hospital, it seems really sterile and it seems everything there is for a purpose…It just seems a little bit unreal and a bit false. It’s like you have to force out all your feelings and then it’s back to the old routine”. (Adult carer of a person with eating disorders - IFW, page 138); ‘Implementation outside the therapeutic environment’’ - "…for me it has definitely made a difference, and you don’t forget these little coping strategies. (Adult carer of a person with eating disorders - FDW, page 138)

How did the intervention work? (including ‘Improving communication’; ‘Making sense of the illness’; ‘Insight into self, others, and the family’; and ‘Feeling empowered’): ‘Improving communication’ - "I used to end up shouting when I was shouted at, I now don’t. I’ve learned not to. I’ve learned to listen, not to feel the moment”. (Adult carer of a person with eating disorders - FDW, page 139); ‘Making sense of the illness’ - "…we had so many hopes that seemed dashed … but that wasn’t the case ‘cause we still did a lot of work in the intervening time and we still learnt a lot and it was never going to be exactly the same as it was before because we wouldn’t act in the same way”. (Adult carer of a person with eating disorders - FDW, page 139); ‘Insight into self, others, and the family’ - "… it enabled me to start saying, ‘‘I can’t be your friend. I’m your mother. You have to make friends, I will be your mother and I love you but I can’t be your friend in that way”. (Adult carer of a person with eating disorders - IFW, page 139); ‘Feeling empowered’ - "One good thing, it made us all feel, it made us all feel that we were all doing something positive towards (patient)’s recovery, and (patient) could see that we had all taken three days out of our own time to come to the unit and cook and spend the whole day so that was good thing”. (Adult carer of a person with eating disorders - FDW, page 139);

Williams 2014

increasing personal awareness: "I did think that I was a totally relaxed and laid back person, until we did some of these exercises [y] I was just stunned to find myself [y] gripping the chair so tight [y] I was so tense”. (Adult carer of a person with dementia - female, page 34); "If you’re feeling tense down here (in the body) that’s a way [y] of the brain expressing itself”. (Adult carer of a person with dementia - male, page 34); "You know I found that quite hard, really thinking about some of the stuff I didn’t particularly want to think about”. (Adult carer of a person with dementia - female, page 34)

the dialectic of emotional acceptance vs emotional avoidance: “ We can’t stop things (thoughts) coming in but we can add to them [y] You can in a sense have control over what you do with these thoughts [y]”. (Adult carer of a person with dementia - female, page 35); “[y] it was a very natural process and somehow or other I felt I could imagine the leaves and then see them going away”. (Adult carer of a person with dementia - male, page 35); “I’m just dashing here there and everywhere to try and keep happy all the time [y] I can only say that’s the way that makes me able to cope better in my life, and that’s the way I’ve decided to do it”. (Adult carer of a person with dementia - female, page 35); “I know it (avoidance) has damaged me a lot, but before I went to those meetings I didn’t look at it like that”. (Adult carer of a person with dementia - female, page 35)

integration of acceptance and commitment therapy (ACT) principles: “(Julie) Every time she would say something to me, a scripture would come to mind [y] To me, putting all our thoughts on a leaf and letting them drift away was actually taking our thoughts and offering them to God”. (Adult carer of a person with dementia - female, page 36); “Well the only thing I’m still trying to work out really is the bit where you are having to remove yourself from yourself (the observer-self exercise). I just found [y] that you were removing your spiritual-self from the rest of yourself”. (Adult carer of a person with dementia - female, page 36); “I came back to the course and said that it (the ACTapproach) wasn’t working. It was making me so unhappy [y] I just decided I have to go back to the way I was before, because it worked [y] I might have another 25 years left, there is absolutely no way I would survive by staying home all the time". (Adult carer of a person with dementia - female, page 36); "[y] I just felt that when we were doing these sessions, it got to the point where I felt [y] sad and [y] low, and then I made a conscious decision, that I can't let this happen to me [y] I gathered everything up, stuffed it in Pandora's box, and shut the lid, so, err, I don't know how much good it will have done me in the end". (Adult carer of a person with dementia - female, page 36)

peer support: "You come here and talk about it and people are interested". (Adult carer of a person with dementia - female, page 36); " Cause [y] you will get somebody who, umm, likes to talk a lot, which is fine [y] But then it's very difficult to keep focused on what you're trying to achieve, when somebody is so much in need of pouring it all out."(Adult carer of a person with dementia - female, page 36)

moving forward after the group: "When I go out, I think well, [y] maybe I won't be able to do that, this will be difficult, but why don't I just go- and face that as it happens."(Adult carer of a person with dementia - female, page 36); "I know that's a step, so if I took it once, that if I took it again and again, I know that I can get some of my life back."(Adult carer of a person with dementia - female, page 37); "[y] you have to look after yourself to look out for another". (Adult carer of a person with dementia - female, page 37); " I feel as though they should carry on. Even if it only every six weeks, you know they should carry on because I mean they are so helpful". (Adult carer of a person with dementia - female, page 37)