National Institute for Health and Care Excellence

Draft for consultation

Supporting Adult Carers

RQE - Evidence reviews for providing training for carers to provide practical support

NICE guideline tbc

Evidence reviews

August 2019

Draft for Consultation

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

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Training for carers to provide practical support

Review question

What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Introduction

With demographic change and improved survival rates for people with complex needs, many carers will be managing complex care situations. Caring can involve a variety of different skills and roles, including physical moving and handling; personal care, medicines and treatment programmes and behaviour management. 21st century care and support may require carers to use a variety of equipment and adaptations and to manage complex packages of care (including the use of new digital technology).

There is a general recognition that personalised programmes of training and support should be offered to carers, including where possible range of components including self care, education about the health condition or disability of the person cared for, information on relevant services and future planning and psychosocial support. However, there is no current consensus about the relative effectiveness and cost-benefits of specific interventions, not is there evidence as to whether group training activities of one-to-one training on specific are more effective. There is also recognition that any programmes for training carers need to address a diverse range of carers and to be culturally appropriate to different communities, in particular under-served groups such as some minority ethnic communities and lesbian, gay, and bisexual and transgender carers. Importantly, a balance may need to be struck between learning and psycho-social support and socialisation with other carers as well as the acquisition of relevant skills.

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 skills- or educational- based intervention whose primary aim is to train adult carers (and not social-/health-care providers) to provide practical support to the person receiving care, including (but not limited to): • medication management • first aid • personal and intimate care • recovery-based approaches • movement and handling • pain management • financial management • managing behaviour(s) of person receiving care • personalised training specific to circumstances/conditions of person receiving care • technical health procedures • use of aids and adaptations • specific Carer Training programs.
Comparison	• no intervention • other interventions within the same category.
Outcome	Quantitative outcomes: • Critical ○ caring-related morbidity ○ impact of intervention on caring-related accidents/incidents • Important ○ impact of caring on carer ○ carer skills, knowledge/confidence or efficacy about supporting person receiving care ○ resource and service use (health or social care) 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

Fourteen RCTs (Faes 2011, Graff 2006, Hattink 2015, Hebert 2003, Hoyle 2013, Klodnicka Kouri 2011, Liddle 2012, Livingston 2014, Lobban 2013, Martin-Carrasco 2016, Núñez-Naveira 2016, Sepe-Monti 2016, Szmukler 2003, and Valeberg 2013) were included. Two further papers were used only for data collection (Graff 2007, and Cooper 2016) as they included the same study's populations as reported in Graff, 2006 and Livingston, 2014 –respectively. The 14 included RCTs are summarised in Table 2.

Three of the included of the RCTs recruited carers from the UK (Livingston 2014, Lobban 2013, and Szmukler 2003). There were 3 multi-country RCTs (Hattink 2015, Hoyle 2013, and Núñez-Naveira 2016), with 7 trials coming from a range of other countries (that is Australia, Canada, Italy, the Netherlands and Spain). They were published between 2003 (Hebert 2003, and Szmukler 2003) and 2016 (Núñez-Naveira 2016, and Sepe-Monti 2016). Roughly 75% of the included RCTs were published after 2010 (n=10), which suggests that there is an increasing interest in examining the role of skills- and educational- based interventions to carers for training them to provide practical support to people with care and support needs. Overall, the included RCTs provided data on 1486 carers of people with a mixture of conditions, ranging from a minimum sample size of 36 carers (Faes 2011, and Liddle 2012) to a maximum of 260 carers (Livingston 2014). The included RCTs focused on carers of people living with:

- Alzheimer's disease and other dementias (Graff 2006, Hattink 2015, Hebert 2003, Klodnicka Kouri 2011, Liddle 2012, Livingston 2014, Núñez-Naveira 2016, Sepe-Monti 2016, for a total of 914 carers)
- a range of mental health problems, including eating disorders, psychosis and schizophrenia (Hoyle 2013, Lobban 2013, Szmukler 2003, for a total of 424 carers)
- cancer (Valeberg 2013, for a total of 112 carers), and
- frailty (Faes 2011, for a total of 36 carers).

The 14 included RCTs form 6 clusters of training interventions for adult carers. Each cluster represents a set of skills in which carers are being trained or educated. (See Table 2):

- pain management (Valeberg 2013)

- managing behaviour(s) of person receiving care (Hebert 2003, Liddle 2012, Núñez-Naveira 2016, and Szmukler 2003)
- personalised training specific to circumstances/conditions of person receiving care (Faes 2011, and Klodnicka Kouri 2011)
- aids and adaptations (Graff 2006)
- specific carer training programs (Hoyle 2013, Livingston 2014, and Lobban 2013), including:
  - training programs for skills building (Hoyle 2013)
  - training programs for coping skills (Livingston 2014, and Lobban 2013).
- specific carer psychoeducation intervention (Martin-Carrasco 2016, and Sepe-Monti 2016).

Qualitative component of the review

Nine qualitative studies were included (Alhaddad 2016, Macdonald 2011, Papachristou 2015, Riley 2011, Sepulveda 2008a, Sepulveda 2008b, Smith 2015, Sommerlad 2014, and Yeandle 2011).

Table 3 provides a summary of the 9 included qualitative studies. They were published between 2008 (Sepulveda 2008a, and Sepulveda 2008b) and 2016 (Alhaddad 2016). All studies focused on carers (n=361), ranging from a sample size of 12 to 73 carers (Riley 2011 and Yeandle 2011, respectively).

In some included qualitative studies, the focus was on the overall experience of carers with medical management (Smith 2015), personal / intimate care –feeding management (Papachristou 2017), or technical health procedures –nebuliser therapy (Alhaddad 2016) of the person receiving care. Most studies concentrated on carers' experiences, acceptability, barriers and facilitators in using specific skills- or educational-interventions to provide practical support to their relative (Macdonald 2011, Riley 2011, Sepulveda 2008a, Sepulveda 2008b, Sommerlad 2014, and Yeandle 2011). 3 studies included carers of people living with dementia (Papachristou 2017, Smith 2015, and Sommerlad 2014). A study aimed at exploring the benefits of the "Caring with Confidence" training programme included carers without a specific focus on the condition of the person with care needs (Yeandle 2011), the remaining studies included carers of people with a mixture of other conditions:

- three studies focused on carers of people living with eating disorders (Sepulveda 2008a, Sepulveda 2008b, and Macdonald 2011)
- one study focused on carers of people living with chronic obstructive pulmonary disease (Alhaddad 2016), and
- one study focused on carers of people living with a first episode of psychosis (Riley 2011).

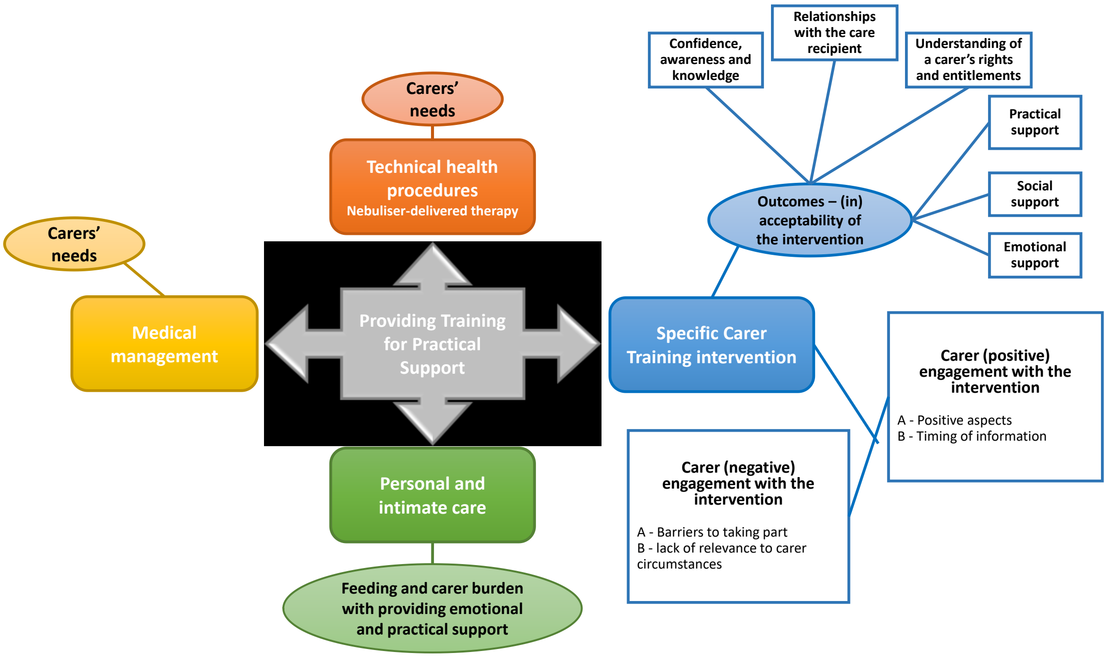
The majority of included studies collected data via semi-structured or unstructured interviews, 2 studies using questionnaires (Sepulveda 2008a; and Sommerlad 2014), with 2 studies that used focus groups techniques (Riley 2011, Yeandle 2011). Data analysis methods included content analysis and thematic analysis, with the latter being the most common method across included studies. All studies were conducted in the UK:

- Five studies took place in London (Alhaddad 2016; Papachristou 2017; Sepulveda 2008a; Sepulveda 2008b; and Smith 2015);
- One study each in South West and South East England (Riley 2011 and Sommerlad 2014) – respectively; and

- Two studies were conducted across all the UK (Macdonald 2011, and Yeandle 2011)

As shown in the theme map (Figure 1), the concepts identified in the included evidence 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

Quantitative component of the review

A summary of the 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)
Faes 2011	**Setting** Netherlands **Study type** RCT **Aim of the study** To reduce falls in frail older people and to increase carer support. **Study dates**	N=36 patient-carer dyads **Carer characteristics:** • Age – years, Mean (SD): ○ I = 67.3 (13.1) ○ C = 64.3 (14.3) • Gender (M/F - N): ○ I = 9/9	• I = Multifactorial group fall prevention training + TAU • C = TAU	• Personalised training specific to the person receiving care

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	2008 to 2009 **Follow-up** 3 and 6 months from baseline	○ C = 5/10 **Care recipient characteristics:** • Condition: Frail older people		
Graff 2006	**Setting** Netherlands **Study type** RCT **Aim of the study** To assess efficacy of community-based occupational therapy and occupational-therapy training on the daily functioning of people living with dementia and on carer competence **Study dates** 2001 to 2005 **Follow-up** 3 months from baseline	N=135 care dyads **Carer characteristics:** • Mean Age – years, Mean (SD): ○ I = 66 (15.3) ○ C = 61.3 (15.4) • Gender (M/F - N): ○ I = 22/46 ○ C = 18/49 **Care recipient characteristics:** • Condition: Dementia	• I = Occupational therapy • C = No occupational therapy	• Aids and adaptations
Hattink 2015	**Setting** UK, Netherlands **Study type** RCT **Aim of the study** To assess impact of online dementia training/e-learning portal on its usefulness/friendliness, and its impact on user knowledge, empathy, attitudes and competence **Study dates** 2013 to 2014 **Follow-up** between 2-4 months for carers in intervention group and at 4 months for WLC group	N=142 carers **Carers characteristics** • Age – years, Mean (SD): ○ I = 52.93 (11.43) ○ C = 54.69 (14.36) • Gender (M/F - N): ○ I = 7/20 ○ C = 10/22 **Care recipient characteristics:** • Condition: Dementia	• I = Self-Help Psychosocial • C = WLC	• Specific Carer Training programs
Hebert 2003	**Setting** Canada **Study type** Multisite RCT **Aim of the study** To assess efficacy of group	N=158 carers **Carer characteristics:** • Age – years, Mean (SD): ○ I = 59.78 (11.86)	• I = Group Psychoeducation • C = TAU	• Managing behaviour(s) of person receiving care

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	psychoeducation in carers of people of dementia living in their own homes **Study dates** Unclear, not reported **Follow-up** 16 weeks after intervention	○ C = 59.77 (13.93) • Gender (Female - %): ○ I = 80 ○ C = 81 **Care recipient characteristics:** • Condition: Dementia		
Hoyle 2013	**Setting** Australia, UK **Study type** RCT **Aim of the study** To assess efficacy of online self-help skills training program ('Overcoming Anorexia Online') with and without professional guidance in carers of people with anorexia nervosa **Study dates** 2010 to 2012 **Follow-up** Post-intervention and 3 months after intervention	N=37 carers **Carer characteristics:** • Age – years, Mean (SD): N/R • Gender (Female - %): 89 **Care recipient characteristics:** • Condition: Anorexia nervosa	• I = Guided Self-Help Skills training • C = Self-Help Skills training	• Specific Carer Training programs
Klodnicka Kouri 2011	**Setting** Canada **Study type** RCT **Aim of the study** To develop and test efficacy of individualised psychoeducation intervention focused on communication for carer of person with cognitive problems associated with early stage of Alzheimer's Disease **Study dates** Not reported, 20-month period **Follow-up**	N=50 carers **Carer characteristics:** • Age – years, Mean (SD): ○ I = 59.12 (8.56) ○ C = 64.8 (10.5) • Gender (M/F - N): ○ I = 5/20 ○ C = 4/21 **Care recipient characteristics:** • Condition: Dementia	• I = Psychoeducation • C = Information only	• Personalised training specific to the person receiving care

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	1 week and 6 weeks after intervention			
Liddle 2012	**Setting** Australia **Study type** RCT **Aim of the study** To evaluate effectiveness of DVD-based carer training program on carer experience and well-being of person with dementia **Study dates** 2011 to 2011 **Follow-up** 3 months after intervention	N=36 patient-carer dyads **Carer characteristics:** • Age – years, Mean (SD): ○ I = 72.85 (8.34) ○ C = 65.38 (10.07) • Gender (M/F - N): ○ I = 4/9; ○ C = 1/15 **Care recipient characteristics:** • Condition: Dementia	• I = Guided Self-Help Behavioural Management training • C = TAU	• Managing behaviour(s) of person receiving care
Livingston 2014	**Setting** UK **Study type** RCT **Aim of the study** To evaluate effectiveness and cost-effectiveness of manual-based coping skills training for family carers of people living with dementia in short- and long-term **Study dates** 2009 to 2013 **Follow-up** 8, 12 and 24 months after intervention	N=260 carers **Carer characteristics:** • Age – years, Mean (SD): ○ I = 62.0 (14.6) ○ C = 56.1 (12.3) • Sex (M/F - N): ○ I = 57/116 ○ C = 25/62 **Care recipient characteristics:** • Condition: Dementia	• I = Coping Skills training • C = TAU	• Specific Carer Training programs
Lobban 2013	**Setting** UK **Study type** RCT **Aim of the study** To assess efficacy of guided self-help coping skills training toolkit in carers of people with recent-onset psychosis **Study dates** Unclear, not reported	N=103 carers **Carer characteristics:** • Age – years, Mean (SD): N/R • Gender (M/F - N): 18/85 **Care recipient characteristics:** • Condition: Psychosis	• I = Guided Self-help Coping Skills training + TAU • C = TAU	• Specific Carer Training programs

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	Follow-up 6 months from baseline (after intervention)			
Martin-Carrasco 2016	**Setting** Spain, Portugal **Study type** Multisite RCT **Aim of the study** To assess efficacy of psychoeducation compared to standard care on reducing burden of carers of people with schizophrenia **Study dates** 2012 to 2012 **Follow-up** 4 months after intervention	N=223 carers **Carer characteristics:** • Age – years, Mean (SD): ○ I = 59.2 (11.4) ○ C = 61.1 (11.6) • Gender (M/F - N): ○ I = 22/87 ○ C = 31/83 **Care recipient characteristics:** • Condition: Schizophrenia	• I = Group Psychoeducation + TAU • C = TAU	• Specific carer psychoeducation intervention
Núñez-Naveira 2016	**Setting** Denmark, Poland, Spain **Study type** Multisite RCT **Aim of the study** To assess efficacy of online education and skills training platform (UnderstAID) in carers of people living with dementia **Study dates** Unclear, not reported **Follow-up** Post-intervention	N=77 carers **Carer characteristics:** • Age – years, Range: 25 - 88 • Gender (M/F - N): ○ I = 9/21 ○ C = 13/18 **Care recipient characteristics:** • Condition: Dementia	• I = Guided Self-Help • C = TAU	• Managing behaviour(s) of person receiving care
Sepe-Monti 2016	**Setting** Italy **Study type** Multisite RCT **Aim of the study** To evaluate effect of group psychoeducational program (Savvy Caregiver Program) compared to walk-in information/support on carer burden and psychological symptoms in carers	N=164 carers **Carer characteristics:** • Age – years, Mean (SD): ○ I = 57.84 (13.89) ○ C = 59.57 (14.52) • Gender (M/F - N): ○ I = 20/60 ○ C = 36/48 **Care recipient characteristics:**	• I = Group psychoeducation • C = Group information only	• Specific carer psychoeducation intervention

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	of older people with Alzheimer's Disease **Study dates** 01/2010 to 08/2010 **Follow-up** 6 months from baseline	• Diagnosis: Dementia		
Szmukler 2003	**Setting** UK **Study type** RCT **Aim of the study** To assess efficacy of hybrid psychoeducation intervention in carers of people with psychotic disorders **Study dates** Unclear, not reported **Follow-up** 6 months after intervention	N=61 carers **Carer characteristics:** • Age – years, Mean (SD): 54 (14) • Female (%): 82 **Care recipient characteristics:** • Condition: Psychotic disorders	• I = Hybrid Psychosocial • C = Information only	• Managing behaviour(s) of person receiving care
Valeberg 2013	**Setting** Norway **Study type** RCT **Aim of the study** To assess efficacy of cancer pain management psychoeducational intervention compared to information only in cancer care dyads **Study dates** 2004 to 2008 **Follow-up** 9 weeks (Post-intervention)	N=117 carers **Carer characteristics:** • Age – years, Mean (SD): ○ I = 62.6 (10.5) ○ C = 63.7 (11.0) • Gender (Female - %): ○ I = 58.6 ○ C = 61.1 **Care recipient characteristics:** • Condition: Cancer	• I = Pain management psychoeducation • C = Pain information only	• Pain management

1 *C: control group; F: Female; I: intervention group; M: Male; N: Number; SD: Standard deviation; TAU:*
2 *Treatment as usual; RCT: Randomised controlled trial; WLC: waiting-list control*

3 Qualitative component of the review

4 A summary of the 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
Alhaddad 2016 **Aim of the study** To explore the assistance carers, provide to people with COPD using nebuliser-delivered therapy at home	• N=14 carers • **Carer** ○ Age= mean age (years): 61 ○ Gender-M/F (n)= 4/10 ○ Living with care recipient (yes/no -N) = 14/0 • **Care recipient** ○ Condition= COPD	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Semi-structured interviews (structured and open-ended questions) ○ Data were analysed using qualitative content analysis within the "framework" method	• Medication management ○ carer needs • Technical health procedure ○ carer needs
Macdonald 2011 **Aim of the study** To explore the experience of carers of people with eating disorders after having participated in a skills-based training programme	N=19 carers • **Carer** ○ Age= mean age - range (years): 47 ¦ 27-64 ○ Gender-M/F (n)= 9/10 ○ Living with care recipient (yes/no -N) = 15/4 • **Care recipient** ○ Condition= Eating Disorders	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Semi-structured interviews administered by telephone ○ Data were analysed using Interpretative Phenomenological Analysis (IPA)	• Specific carer training interventions ○ carer (negative) engagement with the intervention: ○ barriers to taking part in the intervention ○ carer (positive) engagement with the intervention: positive aspects of the intervention ○ carer (positive) engagement with the intervention: timing of need for information ○ confidence, awareness and knowledge ○ relationships with the care recipient ○ social support
Papachristou 2017 **Aim of the study** To explore the experiences of carers, and views	N=20 carers • **Carer** ○ Age= N/R ○ Gender-M/F (n)= 10/10	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Data were collected via semi-	• Personal and intimate care ○ feeding and carer burden with providing emotional and practical support

on, food-related information and support services in dementia	○ Living with care recipient (yes/no -N) = N/R • **Care recipient** ○ Condition= Dementia	structured, face-to-face interviews ○ Data analysis methods were not reported	• Specific carer training interventions ○ carer (positive) engagement with the intervention: timing of need for information
Riley 2011 **Aim of the study** To explore the potential benefits of an eight-week carers educational group intervention for carers of people with first episode of psychosis	N=12 carers • **Carer** ○ Age= N/R ○ Gender-M/F (n)= N/R ○ Living with care recipient (yes/no -N) = N/R • **Care recipient** ○ Condition=Psychotic Disorder	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Data were collected via a focus group. ○ Data were analysed using a thematic analysis	• Medication management ○ carer needs • Specific carer training interventions ○ confidence, awareness and knowledge ○ relationships with the care recipient ○ understanding of a carer's rights and entitlements/ Practical support in the event of emergency
Sepulveda 2008a **Aim of the study** To examine the feasibility and acceptability of "the Maudsley eating disorder collaborative care skills workshops" programme among carers caring for a person with an eating disorder	N=28 carers • **Carer** ○ Age= mean age - range (years): 52,1 | 41-66 ○ Gender-M/F (n)= 5/23 ○ Living with care recipient (yes/no -N) = 21/7 • **Care recipient** ○ Condition= Eating Disorders	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Data were collected through a questionnaire ○ Data analysis methods were not reported	• Personal and intimate care ○ feeding and carer burden with providing emotional and practical support • Specific carer training interventions ○ carer (negative) engagement with the intervention: lack of relevance to carer circumstances ○ carer (positive) engagement with the intervention: timing of need for information ○ confidence, awareness and knowledge ○ emotional support

Sepulveda 2008b **Aim of the study** To describe the feasibility and acceptability of a skills-based training for carers of people with eating disorders	N=16 carers • **Carer** ○ Age= mean age - range (years): 52,7 | 28-69 ○ Gender-M/F (n)= 3/13 ○ Living with care recipient (yes/no -N) = 10/6 • **Care recipient** ○ Condition= Eating Disorders	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Data were collected via telephone conversations and written feedback ○ Data were analysed using a pilot thematic analysis	• Personal and intimate care ○ feeding and carer burden with providing emotional and practical support • Specific carer training interventions ○ carer (positive) engagement with the intervention: Timing of need for information ○ confidence, awareness and knowledge ○ relationships with the care recipient
Smith 2015 **Aim of the study** To explore the experiences of family carers when providing medicines-related assistance for a person with dementia	N=14 carers • **Carer** ○ Age= range (years): 45-86 ○ Gender-M/F (n)= 3/11 ○ Living with care recipient (yes/no -N) = 14/0 • **Care recipient** ○ Condition= Dementia	• **Recruitment period**: N/R • **Data collection & analysis methods**: ○ Semi-structured interviews (open-ended questions) ○ Data were analysed using qualitative framework analysis	• Medication management ○ carer needs
Sommerlad 2014 **Aim of the study** To explore the experiences of carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START)	N=75 carers • **Carer** ○ Age= mean age - range (years): 59,3 | 18-65 ○ Gender-M/F (n)= 26/49 ○ Living with care recipient (yes/no -N) = 44/31 • **Care recipient** ○ Condition= Dementia	• **Recruitment period**: 2009-2003 • **Data collection & analysis methods**: ○ Data were collected using self-completed questionnaires ○ Data were analysed by two researchers using thematic analysis	• Specific carer training interventions ○ carer (negative) engagement with the intervention: lack of relevance to carer circumstances ○ carer (positive) engagement with the intervention: Timing of need for information ○ confidence, awareness and knowledge ○ emotional support

			○ social support
Yeandle 2011 **Aim of the study** To evaluate the benefits of the "Caring with Confidence" training programme for carers, those they care for, and others in the health and social care system.	N=73 carers • **Carer** ○ Age= mean age (years): ○ Gender-M/F (n)= N/R ○ Living with care recipient (yes/no -N) = N/R • **Care recipient** ○ Condition= General	• **Recruitment period**: 2008 • **Data collection & analysis methods**: ○ Focus groups with carers were used to elicit their views about the Caring with Confidence programme ○ Data analysis methods were not reported	• Specific carer training interventions ○ confidence, awareness and knowledge ○ emotional support ○ Social support ○ understanding of a carer's rights and entitlements/ practical support in the event of emergency

1 *COPD: Chronic Obstructive Pulmonary Disease; F: Female; M: Male; N: Number; N/R: not reported*

Quality assessment of outcomes included in the evidence review

See the evidence profiles in appendix F.

Economic evidence

Included studies

One study was identified with respect to the cost-effectiveness of interventions for providing carers with training (Livingston 2014). Table 4 provides a brief summary of the included study.

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 conducted alongside an RCT UK	Carers of people living with dementia	Psychological intervention called START (STrAtegies for RelaTives) Treatment as usual	Health and social care 2009-10 prices	Sensitivity analysis addressed imbalances in baseline characteristics and variation in missing outcomes according to characteristics at baseline

RCT: Randomised controlled trial

See the economic evidence tables in appendix H and economic evidence profiles in appendix I.

Excluded studies

Studies not included in this review with reasons for their exclusion are provided in appendix K – Excluded studies.

Summary of studies included in the economic evidence review

This UK study (Livingston 2014) compared the cost-utility of a manual-based coping skill training programme START (STrAtegies for Relatives) with usual care in adult carers of people living with dementia. The coping skill training programme comprised of 8 sessions:

1) psychoeducation about dementia, carer stress, understanding behaviour of care recipient
2-5) difficult behaviours, behavioural management techniques, carer self-care, communication, coping strategies, emotional support, reframing
6) future needs of care recipient, UK-specific care and legal planning
7) planning pleasant activities
8) maintaining learned skills over time

Every session ended with stress reduction techniques, relaxation exercises and homework. Trained psychology graduates were responsible for delivering the START programme. Usual care was based on standard care recommended in NICE guidance for people living with dementia (for example medical, psychological and social treatment).

The economic analysis was conducted alongside a RCT conducted in the UK over a time horizon of 24 months. The training intervention was found to be cost-effective at 8 months follow-up, with an incremental cost-effectiveness ratio (ICER) of £6,000 per QALY. The intervention was also found to be cost-effective at 24 months follow-up with an ICER of £11,200 per QALY. In probabilistic sensitivity analysis, the intervention was found to have a 65% probability of being cost-effective using a cost-effectiveness threshold of £20,000 per QALY. Sensitivity analyses which addressed imbalances in baseline characteristics and variation in missing outcomes according to characteristics at baseline reached the same conclusion with respect to the cost-effectiveness of START.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

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 ‘TPS’ and then a number. TPS stands for training (to provide) practical support.

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.

Medication management

Caring-related morbidity

- **TPS1** No data reporting on this outcome

Impact of intervention on caring-related accidents/incidents

- **TPS2** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS3** No data reporting on this outcome

Impact of caring on carer

- **TPS4** No data reporting on this outcome

Resource and service use (health or social care)

- **TPS5** No data reporting on this outcome

Qualitative themes

- **TPS6 Carers’ perceived needs.** There is low quality evidence from 3 qualitative studies that carers have insufficient information regarding medication management and the use and maintenance of equipment to administer medication.

  One qualitative study explored the experiences of family carers when providing medication-related assistance for a person with dementia. Many carers experienced barriers such as complex medication regimes, disagreements with professional staff, maintaining supplies and anxiety over medication errors. Carers expressed the need for information regarding correct dosage, potential side-effects (especially with new medications), and the effectiveness of medications. In a second qualitative study, exploring the assistance carers provide to people with COPD using nebuliser-delivered therapy at home, carers expressed concerns around when to initiate nebuliser-delivered therapy, frequency of dosage, possible adverse effects, cleaning and maintenance of equipment, and what to do in the case of treatment failure or breakdown of equipment. Carers said that they had unmet needs for information in these areas. In a last study, examining the potential benefits of an eight-week carers’ educational group intervention for carers of people with a first episode of psychosis, some carers said they wanted information about psychosis, medication and the kind of help available, one view expressed was that by attending a carers’ group, more would be learned about the side effects of medication and whether or not it had a positive effect on their care recipient.

First aid

- **TPS7** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Personal and intimate care

Caring-related morbidity

- **TPS8** No data reporting on this outcome

Impact of intervention on caring-related accidents/incidents

- **TPS9** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS10** No data reporting on this outcome

Impact of caring on carer

- **TPS11** No data reporting on this outcome

Resource and service use (health or social care)

- **TPS12** No data reporting on this outcome

Qualitative themes

- **TPS13 Feeding and carers' perceived burden with providing emotional and practical support.** There is low quality evidence from 1 qualitative and 2 mixed-methods studies in both the views and quantitative data that information, support and training in food and nutrition can have a positive impact on carer stress and burden.

  A qualitative study explored carers' views on food-related information and support services in dementia, carers felt limited information was provided on food and nutrition, and that training on managing care recipients' food needs was inadequate. Carers identified 5 areas where services could potentially help them to manage better and reduce burden: written material, training, lunch clubs, respite services and domestic help at home. In a pilot study, using mixed-methods to examine the feasibility and acceptability of a manual supplemented with DVD-based skills training and coaching for carers of relatives with eating disorders, generally carers found this intervention highly acceptable and useful as it increased awareness, knowledge and understanding of the illness and how to cope with providing emotional and practical support to care recipients. A further pilot study, using mixed-methods to examine the feasibility and acceptability of "the Maudsley eating disorder collaborative care skills workshops", programme. This programme teaches carers particular skills employed by specialist nurses and staff from an eating disorder intensive care setting to help reduce their (carer) distress and enhance their sense of competency. The findings indicate that this programme can reduce the psychological distress and burden of carers.

Recovery-based approaches

- **TPS14** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Movement and handling

- **TPS15** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Pain management

Caring-related morbidity

- **TPS16** No data reporting on this outcome

Impact of intervention on caring-related accidents/incidents

- **TPS17** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS18** Low quality evidence from 1 RCT from Norway, including adult carers of people living with cancer, found improved levels of knowledge of (cancer) pain management (Family Pain Questionnaire) in carers receiving a professional-led pain management psychoeducation intervention versus usual care (pain information only) at 9 weeks of follow-up. This training intervention was tailored on carer needs (individualised) and was delivered face-to-face combined with telephone support.

Impact of caring on carer

- **TPS19** No data reporting on this outcome

Resource and service use (health or social care)

- **TPS20** No data reporting on this outcome

Qualitative themes

- **TPS21** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Financial management

- **TPS22** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Managing behaviour(s) of person with support needs

Caring-related morbidity

- **TPS23** Very low quality evidence from 2 RCTs including adult carers of people living with dementia, and adult carers of people with psychosis could not differentiate levels of depression (Cornell Scale for Depression in Dementia), and psychological morbidity (Clinical Interview Schedule Revised) between carers receiving behavioural management training versus usual care (information or group support) at 3 to 6 months follow-up. Both training interventions were delivered to carers either face-to-face by professionals or by means of printed material or video in combination with telephone support and carer self-guided support. In addition, very low quality evidence from Canada including adult carers of people living with dementia could not differentiate levels of anxiety (State–Trait Anxiety Inventory), and general mental health (Psychiatric Symptoms Index) between carers receiving a group-based and face-to-face behavioural management training intervention versus usual care (group psychoeducation) at 4 months follow-up.
- **TPS24** Very low quality evidence from 1 multicentre RCT from Denmark, Poland, and Spain, including adult carers of people living with dementia could not differentiate levels of depressive symptoms (CES-D-20) between carers of people living with dementia receiving behavioural management training (including aids and adaptations) versus usual care (follow-up unclear). This training intervention was tailored on carer needs (in relation to the condition of the person being supported) (individualised) and was delivered by means of video materials combined with face-to-face support.

Impact of intervention on caring-related accidents/incidents

- **TPS25** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting the person with support needs

- **TPS26** Low quality of evidence from 1 RCT from Australia, including adult carers of people living with dementia, found improved levels of knowledge of supporting strategies on dementia (Communication and Memory Support in Dementia) in carers receiving self-guided behavioural management training versus usual care at 3 months follow-up. This training intervention was partially tailored on carer needs (individualised), was delivered to carers via the telephone as well as with face-to-face support.

- **TPS27** Low quality evidence from 1 RCT from Canada, including adult carers of people living with dementia, could not differentiate levels of self-efficacy in controlling upsetting thoughts about caregiving (Personal Efficacy Scale) between carers of people living with dementia receiving behavioural management training versus usual care (information combined to telephone support or group support). This behavioural training intervention was tailored on carer needs and was either delivered face-to-face and professional-led.
- **TPS28** Very low quality of evidence from 1 multicentre RCT from Denmark, Poland, and Spain, including adult carers of people living with dementia, could not differentiate levels of self-efficacy (Pearlin-Caregiver Competence Scale) between carers of people living with dementia receiving behavioural management training (including aids and adaptations) versus usual care at 3 months follow-up. This training intervention was tailored on carer needs (in relation to the condition of the person being supported) (individualised) and was delivered by means of video materials combined with face-to-face support.

Impact of caring on carer

- **TPS29** Very low quality evidence from 3 RCTs from Australia, Canada, and the UK including adult carers of people living with dementia and psychosis could not differentiate levels of subjective burden (Positive Aspects of Caregiving Checklist), overall burden (Zarit Caregiver Burden Interview) and negative experience of caring (Experience of Caregiving Inventory) between carers receiving behavioural management training versus usual care (information or group support) at 3 to 6 months follow-up. In contrast, low quality evidence from 1 RCT from Australia including adult carers of people living with dementia, found improved levels of bother or upset reactions following memory problems of care recipients (RMBPC) in carers receiving behavioural management training versus usual care (group support) at 3 months follow-up. In this trial the behavioural management training interventions was delivered by means of video materials in combination with face-to-face support.
- **TPS30** Low quality evidence from 1 RCT from Canada, including adult cares of people living with dementia, found improved levels of bother or upset reactions following behaviour problems of care recipients (RMBPC) in carers receiving individualised behavioural management training versus usual care (group support) at 4 months follow-up. In this trial the individualised behavioural management training interventions was delivered by means of printed material/video in combination with telephone support and carer self-guided.
- **TPS31** Low quality evidence from a meta-analysis of 2 RCTs, including adult carers of people living with dementia, found improved levels of bother or upset reactions following disruptive behaviours of care recipients (RMBPC) in carers receiving individualised behavioural management training versus usual care (information combined with support or group support) at 3 months follow-up; but very low quality evidence from 1 RCT from Australia, including adult carers of people living with dementia, could not differentiate levels of bother or upset reactions following depressive behaviour problems of care recipients (RMBPC) in carers receiving self-guided behavioural management training versus usual care at 3 months follow-up. This training intervention was tailored on carer needs (in relation to the condition of the person being supported, individualised) and was delivered by means of video materials combined with face-to-face support.
- **TPS32** Very low quality evidence from 1 multicentre RCT from Denmark, Poland, and Spain including adult carers of people living with dementia could not differentiate levels of caring experience (Revised Caregiving Satisfaction Scale) between carers of people living with dementia receiving behavioural management training (including aids and adaptations) versus usual care at 3 months follow-up. This training intervention was tailored on carer needs (in relation to the condition of the person being supported, individualised), was delivered by means of video materials combined with face-to-face support.

Resource and service use (health or social care)

- **TPS33** No data reporting on this outcome

Qualitative themes

- **TPS34** No evidence was found about experiences and views of carers on training for managing behaviour(s) of person with support needs

Personalised training specific to the circumstances of the person with care needs

Caring-related morbidity

- **TPS35** Low quality evidence from 1 RCT form the Netherlands including adult carers of frail older people could not differentiate levels of depressive symptoms (CES-D-20), health-related quality of life (EQ-5D-VAS) or anxiety (HADS-A) between carers receiving a professional-led fall prevention training programme versus usual care at 3 to 6 months follow-up. This training intervention was delivered to carers face-to-face and was tailored to their needs.

Impact of intervention on caring-related accidents/incidents

- **TPS36** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS37** Low quality evidence from 1 RCT from Canada including adult carers of people living with Alzheimer's disease found improved levels of skills (Communication Skills Questionnaire), knowledge (custom measure), and self-efficacy (Caregiver Self-efficacy Scale) for carers receiving a professional psycho-educational intervention personalised to the conditions of people with early stage Alzheimer's disease versus usual care (information only) at 6 weeks follow-up. This training intervention was delivered to carers face-to-face and was tailored to their needs.

Impact of caring on carer

- **TPS38** Low quality evidence from 2 RCTs, including respectively adult carers of frail older people; and adult carers of people living with Alzheimer's disease could not differentiate levels of burden (Zarit Caregiver Burden Interview), objective burden (total caring time in hours per week) or upset with problem behaviours (RMBPC) between carers receiving a training intervention specific to their caring needs versus usual care. Both studies focused on evaluating face-to-face professional-led training interventions.
- **TPS39** Very low quality evidence from 1 RCT from Canada including adult carers of people living with Alzheimer's disease found improved levels of carer disturbance with communication difficulties with the person with cognitive problems (adapted measure) for carers receiving a professional psycho-educational intervention personalised to the conditions of people with early stage Alzheimer's disease versus usual care (information only) at 6 weeks follow-up. This training intervention was delivered to carers face-to-face and was tailored to their needs.

Resource and service use (health or social care)

- **TPS40** No data reporting on this outcome

Qualitative themes

- **TPS41** No evidence was found about experiences and views of carers on receiving personalised training specific to the circumstances of the person with care needs

Technical health procedures

Caring-related morbidity

- **TPS42** No data reporting on this outcome

Impact of intervention on caring-related accidents/incidents

- **TPS43** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS44** No data reporting on this outcome

Impact of caring on carer

- **TPS45** No data reporting on this outcome

Resource and service use (health or social care)

- **TPS46** No data reporting on this outcome

Qualitative themes

- **TPS47 Carers ‘perceived needs.** There is low quality evidence from one qualitative study that carers face challenges and uncertainty about using technical equipment.

  In a qualitative study aimed to explore the assistance carers provide to people with COPD using nebuliser-delivered therapy at home, carers expressed several challenges with using technical equipment. Carers did not feel fully equipped to set up and operate equipment and administer therapy. They raised concerns over when to initiate nebuliser-delivered therapy, frequency of dosage, possible adverse effects, cleaning and maintenance of equipment, what to do in the case of treatment failure or breakdown of equipment, all of which have an impact on care recipients’ safety. The use of several inhaler devices (nebuliser users often also use handheld inhalers) created confusion for some carers. Carers sought information from GPs, manufacturers’ instruction manuals, medication leaflets and family members with medical backgrounds. Carers also expressed the need for information in areas such as administering the correct dosage of medication and possible adverse effects. Inconsistent information and a lack of understanding of changes to prescriptions created uncertainty for some carers.

Use of aids and adaptations

Caring-related morbidity

- **TPS48** Low quality evidence from 1 RCT from the Netherlands including adult carers of people living with Alzheimer’s Disease and other dementias found improved levels of depression (Cornell Scale for Depression), health-related quality of life (Dementia Quality of Life Instrument), and general health (General Health Questionnaire) in carers receiving an occupational therapy training intervention versus usual care (waiting list control). This was a professional-led training intervention delivered to carers face-to-face and tailored to their needs (in relation to the condition of the person being supported).

Impact of intervention on caring-related accidents/incidents

- **TPS49** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS50** Low quality evidence from 1 RCT from the Netherlands including adult carers of people living with Alzheimer’s Disease and other dementias found improved levels of sense of competence (Sense of Competence Questionnaire) in carers receiving an occupational therapy training intervention versus usual care (waiting list control). This was a professional-led training intervention delivered to carers face-to-face and tailored to their needs (in relation to the condition of the person being supported).

Impact of caring on carer

- **TPS51** Low quality evidence from 1 RCT from the Netherlands including adult carers of people living with Alzheimer’s Disease and other dementias found improved levels of sense of control over life (Mastery Scale) in carers receiving an occupational therapy training intervention versus usual care (waiting list control). This was a professional-led training intervention delivered to carers face-to-face and tailored to their needs (in relation to the condition of the person being supported).

Resource and service use (health or social care)

- **TPS52** No data reporting on this outcome

Qualitative themes

- **TPS53** No evidence was found about experiences and views of carers on training to Use of aids and adaptations

Specific carer training programs

Caring-related morbidity

- **TPS54** Low quality evidence from 1 RCT from the UK including adult carers of people with recent-onset psychosis could not differentiate levels of anxiety (General Health Questionnaire) between carers receiving a guided self-help specific training program (that is intervention for 'relatives of people with recent-onset psychosis: REACT') versus usual care (information combined with various forms of support) at 6 months follow-up. This training intervention focused on coping skills, was delivered by means of printed or online materials and was tailored to carer needs (in relation to the condition of the person being supported).
- **TPS55** Low quality evidence from 1 multicentre RCT from the UK and the Netherlands including 56 adult carers of people living with dementia could not differentiate levels of health related-quality of life (custom measure) between carers receiving a guided self-help specific training program (that is 'Web-Based STAR E-Learning Course') versus usual care (Wait list control group) at 2 to 4 months follow-up.This training intervention focused on coping skills and was delivered by means of online materials and was tailored to carer needs (in relation to the condition of the person being supported).
- **TPS56** There was moderate to low quality evidence from 1 UK RCT including adult carers of people living with dementia 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 training 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), quality of life, 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).
- **TPS57** Low quality evidence from 1 multicentre RCT from the UK and Australia including adult carers of people with anorexia nervosa could not differentiate levels of general health and well-being (General Health Questionnaire), health-related quality of life (SF-36), depression symptoms (Depression Anxiety Stress Scales), or perceived caring negative/positive experience (Experience of Care Giving Inventory) between carers using a guided self-help web-based training program for skills building versus usual care (Online skills training with no support) at 3 months follow-up or following the intervention. This training intervention was delivered by means of online materials, email and telephone support and was not individualised according the carer needs (in relation to the condition of the person being supported).

Impact of intervention on caring-related accidents/incidents

- **TPS58** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting the person with care needs

- **TPS59** Moderate quality evidence from 1 RCT from the UK including adult carers of people with recent-onset psychosis found improved levels of concern to cope and perceived ability to cope (Family Questionnaire) in carers receiving a guided self-help specific training program (that is intervention for ‘relatives of people with recent-onset psychosis: REACT’) versus usual care (information combined with various forms of support) at 6 months follow-up. This training intervention focused on coping skills and was delivered by means of printed or online materials and was tailored to carer needs (in relation to the condition of the person being supported).

- **TPS60** Moderate quality evidence from 1 multicentre RCT from the UK and the Netherlands including adult carers of people living with dementia found improved levels of perceived knowledge (Approaches to Dementia Questionnaire) in carers receiving a guided self-help specific training program (that is 'Web-Based STAR E-Learning Course') versus usual care (Wait list control group) at 2 to 4 months follow-up; but it could not differentiate levels of perceived sense of competence (Short Sense of Competence Questionnaire) between intervention groups at 2 to 4 months follow-up. This training intervention focused on coping skills and was delivered by means of online materials and was tailored to carer needs (in relation to the condition of the person being supported).

Impact of caring on carer

- **TPS61** Moderate to low quality evidence from 1 RCT from the UK including adult carers of people with recent-onset psychosis found improved levels of perceived positive experience of caring (Experience of Caregiving Inventory) in carers receiving a guided self-help specific training program (that is intervention for 'relatives of people with recent-onset psychosis: REACT') versus usual care (information combined with various forms of support) at 6 months follow-up. However this RCTcould not differentiate levels of perceived negative experience of caring (Experience of Caregiving Inventory) between interventions groups at 6 months follow-up. This training intervention focused on coping skills and was delivered by means of printed or online materials and was tailored to carer needs (in relation to the condition of the person being supported).
- **TPS62** Low quality evidence from 1 multicentre RCT from the UK and the Netherlands including adult carers of people living with dementia could not differentiate levels of burden (custom measure) between carers receiving a guided self-help specific training program (that is 'Web-Based STAR E-Learning Course') versus usual care (Wait list control group) at 2 to 4 months follow-up.This training intervention focused on coping skills and was delivered by means of online materials and tailored to carer needs (in relation to the condition of the person being supported).
- **TPS63** Low quality evidence from 1 UK RCT including adult carers of people living with dementia could not differentiate levels of subjective experience with abusive behaviours with care recipients (Modified Conflict Tactics Scale) between 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. 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).
- **TPS64** Moderate to low quality evidence from 1 multicentre RCT from the UK and Australia including adult carers of people with anorexia nervosa found improved levels of subjective burden (Level of Expressed Emotion) in carers receiving a guided self-help web-based training program for skills building versus usual care (Online skills training with no support) at 3 months follow-up; but this RCT could not differentiate levels of subjective burden following the intervention. This training intervention was delivered by means of online materials, email and telephone support and was not tailored to carer needs (in relation to the condition of the person being supported).

Resource and service use (health or social care)

- **TPS65** Please see "Economic evidence"

Qualitative themes

- **TPS66 Confidence, awareness and knowledge.** Low quality evidence from 6 studies (3 qualitative and 3 mixed-methods study design) including carers of people with a range of different conditions found that carers who attended specific carer training interventions developed more confidence when caring and a greater understanding of the condition of the care recipient, enabling them to better cope with challenges.

  A qualitative study, exploring the experience of carers of people with eating disorders after having participated in a skills-based training programme including DVDs and training manual, with supplementary telephone coaching, carers spoke of ‘increased confidence and self-esteem’ and ‘increased awareness, knowledge and understanding’ and greater confidence. Another qualitative study, looking at the potential benefits of an eight-week educational group for carers of people with a first episode of psychosis, carers had an improved awareness of the disease and better understanding of and how to navigate the National Health Service. In a further study, about the experience of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), some carers found that the confidence gained from being on the programme, together with communication skills, helped them feel better prepared to manage challenges, such as being able to question doctors when they withdrew medication from people admitted to hospital. Lastly, a mixed-methods study aimed to evaluate the benefits of the "Caring with Confidence" training programme for carers, those they care for, and others in the health and social care system, carers gained better knowledge on the condition of their care recipient, including on what benefits they could claim. They were more confident in practical caring skills, such as how to respond in an emergency.

- **TPS67 - Relationships with the care recipient.** Low quality evidence from 2 qualitative studies and 1 mixed-methods study including carers of people with a range of different conditions found that carers who attended specific carer training interventions were able to better communicate with and understand the care recipient, leading to better relationships between them.

  A qualitative study exploring the experience of carers of people with eating disorders after having participated in a skills-based training programme including DVDs and training manual, with supplementary telephone coaching, found carers talk about “improved communication with the sufferer," citing the DVD as helping them to find the right phrases to use or the right way to approach the person with support needs. In the other study, exploring the potential benefits of an eight-week carers’ educational group intervention for carers of people with a first episode of psychosis), carers spoke of improving relationships with the person they cared for and a better understanding of the illness.

- **TPS68 Understanding of a carer’s rights and entitlements/ Practical support in the event of emergency.** There is very low quality evidence from 1 qualitative and 1 mixed-methods study about carers of people with a range of different conditions that carers who attended a specific carer training intervention felt they could navigate available information resources better and were more aware of the services they could utilise. In a qualitative study, exploring the potential benefits of an eight-week carers educational group intervention for carers of people with a first episode of psychosis, carers gained knowledge and understanding about navigating the National Health Service and services they could use. In the mixed-methods study, aimed to evaluate the benefits of the "Caring with Confidence" training programme for carers, those they care for, and others in the health and social care system, carers gained better knowledge on the condition of the person with care needs, including on what entitlements they could claim and feeling confident about using the knowledge they had gained to develop a plan for what should happen in the event of an emergency**.**

- **TPS69 Social support.** There is moderate quality evidence from 3 studies (2 qualitative and 1 mixed-methods) of carers of people living with dementia and carers of people with eating disorders, that carers who attended specific carer training interventions felt positive about sharing their experiences with other carers. They felt less isolated and were more socially active. In particular, carers from ‘hard to reach’ groups (such as LGBT carers) were particularly positive about the mutual support provided by the training sessions.

  In a qualitative study, exploring the experience of carers of people with eating disorders after having participated in a skills-based training programme including DVDs and a training manual, with supplementary telephone coaching, carers could identify with others like themselves in a caring role. Carers found it reassuring and less isolating to know that certain (what seemed to be peculiar behaviours) were also common in the experiences of other people. In one other study, about the experience of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), found one carer, as a result of taking part in the START project, joined the Alzheimer's Society and a yoga group, and sometimes saw a cognitive behavioural therapist. In a mixed method, aimed to evaluate the benefits of the "Caring with Confidence" training programme for carers, those they care for, and others in the health and social care system, carers were helped to understand the importance of personal leisure time and eliminate the feeling of guilt about this. The programme reduced isolation by allowing the space for carers to interact with each other, discuss their issues and find solutions. Participants from ‘hard to reach’ groups, such as LGBT carers, were particularly positive about the non-discriminatory support provided by the training sessions.

- **TPS70 Emotional support.** Moderate quality evidence from 3 studies (1 qualitative and 2 mixed-methods) about carers of people living with dementia and carers of people with eating disorders found that carers who attended specific carer training interventions felt reduced distress and an increase in happiness as their coping and communication skills improved. A mixed-methods pilot study, to examine the feasibility and acceptability of “the Maudsley eating disorder collaborative care skills workshops” programme among carers of people with eating disorders, indicates that this intervention can reduce psychological distress and improve coping as carers learn how to feel comfortable about not having to always be at the ‘disposal’ of the care recipient. A further study, about the experience of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), found that carers can change ‘unhelpful thoughts’ and focus on managing themselves and their own reactions.

  Also, a mixed-methods study, aimed to evaluate the benefits of the "Caring with Confidence" training programme for carers, those they care for, and others in the health and social care system, carers were able to meet people in similar circumstances, where a common understanding helped them to come to terms with the situation. Carers often discussed improvements in their relationship with the person they cared for, and an increased sense of confidence and feeling of self-assurance. One in 5 carers felt the independence of the person they cared for had improved.
- **TPS71 Carer (negative) engagement with the intervention: Barriers to taking part in the intervention.** Very low quality evidence from 1 qualitative study of carers of people with a range of different conditions found that carers who attended specific carer training interventions identified extrinsic barriers that impacted their taking part in the intervention. A study, exploring the experience of carers of people with eating disorders after having participated in a skills-based training programme including DVDs and a training manual, with supplementary telephone coaching, reported that carers expressed the problems of finding the time to take part in the interventions, without disturbing usual care routines. Furthermore, carers found it difficult to engage with the intervention when the care recipient was not living with them. In this study carers also found it difficult implement strategies when there were existing communication barriers with the care recipient.
- **TPS72 Carer (negative) engagement with the intervention: Lack of relevance to carer circumstances.** Very low quality evidence from 1 mixed method and 1 qualitative study including carers of people with a range of different conditions found that carers who attended specific carer training interventions found the interventions were not relevant to them. In a pilot study with mixed-methods design, whose primary aim was to describe the feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with eating disorders, carers said they found it difficult to apply the knowledge to their own circumstances. Similarly, a study about the experience of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), found some respondents feeling that the intervention was not relevant to their particular circumstances, for example because the dementia was not severe, or the caring difficulties did not relate directly to the effect of dementia.
- **TPS73 Carer (positive) engagement with the intervention: timing of need for information.** Low quality evidence from 2 qualitative studies of carers of people with a range of different conditions found that for carers who attended specific carer training interventions, the timing of information provision is crucial. In a qualitative study, which explored the experience of carers of people with eating disorders after having participated in a skills-based training programme including DVDs and training manual, with supplementary telephone coaching, some carers

wanted an earlier invite to the intervention as they had a lack of support from services. For example, four carers expressed an opinion that despite finding the materials helpful, they felt it would have been even more useful at the onset of the illness. Similarly, the other study about the experience of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), found that in comparison to NHS services, which imparted a lot of information at diagnosis or too much negative information at once, the START programme was more supportive and delivered more manageable amounts of information over a longer period of time.

- **TPS74 Carer (positive) engagement with the intervention: positive aspects of the intervention.** Moderate quality evidence from 5 studies (3 qualitative and 2 mixed-methods) including carers of people living with dementia and carers of people with eating disorders found that carers who attended specific carer training interventions appreciated the diverse elements of the interventions.

In the pilot study by Sepulveda (2008b), of mixed-methods design, whose primary aim was to describe the feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with eating disorders, carers said they found the DVDs highly acceptable and beneficial. The elements that were most praised were those concerning the usefulness of the information, and the ease of delivering skills training in communication and ‘emotional regulation’ and providing practical skills. Carers mentioned the animal analogies as ‘a light-hearted and helpful way to better understand their role. Role play was also highly valued and seen as necessary in understanding how to put knowledge into practice. The telephone coaching element helped carers to develop skills and recognise unhelpful behaviours in response to the illness and within their interactions with the care recipient.

The qualitative study by Sommerlad (2014) about the experience of individual family carers of people living with dementia who received a manual-based coping strategy programme (STrAtegies for RelaTives, START), found that participants valued diverse elements of the intervention. The relaxation CDs were most commonly cited as being useful during the period of therapy and afterwards, whilst some participants said that detailed understanding of the condition helped them cope with their relative’s symptoms, and others said that they valued the gradual pace of learning about dementia.

In a mixed-methods pilot study by Sepulveda (2008a) to examine the feasibility and acceptability of “the Maudsley eating disorder collaborative care skills workshops” programme among carers, participants said that the programme had enhanced their knowledge about their caring role and helped them acquire practical and useful skills. The workshops were valued because of the potential for meeting other people with similar experiences. The self-help manual was also considered to be helpful.

In the qualitative study by Macdonald (2011), which explored the experience of carers of people with eating disorders after having participated in a skills-based training programme including DVDs and a training manual, with supplementary telephone coaching, there was no clear preference for the manual or DVDs. The DVDs complemented the manual, which provided carers with a flexible, practical and accessible guide that could be integrated easily into their lives. Specific positive aspects of the coaching included action planning and goal setting, enhanced self-reflection; and the chance to embed the DVD learning by having phone support to discuss DVD material. The programme as a whole has helped to boost confidence and self-esteem, increase carer knowledge and understanding, as well as provide support and identification with other carers.

In the qualitative study by Papachristou (2017), exploring the experiences of carers and views on food-related information and support services in dementia, the authors discussed events such as cafes or lunches held in church halls or community centres to help carers and people living with dementia to socialise with others in similar circumstances, which provided opportunities for carers to talk about experiences and concerns, for example about food preparation and eating.

Specific carers psychoeducation interventions

Caring-related morbidity

- **TPS75** Very low quality evidence from 1 RCT from Italy including carers of older people living with Alzheimer's Disease could not differentiate levels of general mental health (Neuropsychiatric Inventory), depressive symptoms (CES-D-20), anxiety (Neuropsychiatric Inventory and State-Trait Anxiety Inventory), or health related-quality of life (SF-12) between carers receiving psychoeducation versus usual care at 6 month follow-up. This psychoeducational intervention was not tailored to carer needs (in relation to the condition of the person being supported) and was professional-led and delivered face-to face.
- **TPS76** Low quality evidence from 1 RCT from Spain including adult carers of people with schizophrenia found improved levels of general health and well-being (General Health Questionnaire), or levels of perceived health related-quality of life (SF-36) between carers receiving psychoeducation versus usual care at 6 month follow-up. However, very low quality from this RCT could not differentiate levels of perceived mental health (SF-36: physical role subscale) at 6 month follow-up. This psychoeducational intervention was not tailored to carer needs (in relation to the condition of the person being supported) and was professional-led and delivered face-to face.

Impact of intervention on caring-related accidents/incidents

- **TPS77** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **TPS78** No data reporting on this outcome

Impact of caring on carer

- **TPS79** Very low quality evidence from 1 RCT from Italy, including adult carers of older people with Alzheimer's Disease, could not differentiate levels burden (Caregiver Burden Inventory), between carers receiving psychoeducation versus usual care at 6 months follow-up. This psychoeducational intervention was not tailored to carer needs (in relation to the condition of the person being supported) and was professional-led and delivered face-to face.
- **TPS80** Low quality evidence from 1 RCT from Spain, including adult carers of people with schizophrenia, could not differentiate levels burden (Zarit Caregiver Burden Interview) between carers receiving psychoeducation versus usual care at 6 months follow-up. This psychoeducational intervention was not tailored to carer needs (in relation to the condition of the person being supported) and was professional-led and delivered face-to face.

Resource and service use (health or social care)

- **TPS81** No data reporting on this outcome

Qualitative themes

- **TPS82** No evidence was found about experiences and views of carers on receiving specific psychoeducation interventions

Economic component of the review

- **TPS83** One directly applicable cost-utility analysis from UK with minor limitations compared a manual-based coping training programme START (STrAtegies for Relatives) with usual care in adult carers of people living with dementia. The training intervention was found to be cost-effective at 8 months follow-up: the incremental cost-effectiveness ratio (ICER) was £6,000 per QALY. The intervention was also found to be cost-effective at 24 months follow-up with an ICER of £11,200 per QALY. With long term follow-up (24 months), the intervention had a 65% probability of being cost-effective at a cost-effectiveness ratio of £20,000 per QALY.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This evidence review includes both qualitative and quantitative outcomes. Overall, no quantitative or qualitative evidence was identified in relation to the following 4 clusters of training interventions: first aid; recovery-based approaches; interventions to improve carers' skills in movement and handling; and interventions to improve carers' skills in financial management. Evidence was identified on most of the outcomes considered during protocol development. In terms of quantitative outcomes, caring-related morbidity was considered to be a critical outcome for carers. The impact of a training intervention on caring-related accidents/incidents was also considered to be of critical interest for drafting recommendations. Impact of caring on carers, carers' skills, carers' knowledge, confidence or self-efficacy about supporting the care recipient, impact of the intervention on caring-related accidents/incidents and resource and service use were included as important outcomes.

Caring-related morbidity, carers' skills, carers' knowledge and self-efficacy, and impact of caring on carers were reported by most studies about training interventions. No study reported on the impact of a training intervention on caring-related accidents or incidents; therefore, the committee agreed to recommend research about training interventions as a means of supporting carers, in terms of caring-related accidents or incidents.

In terms of qualitative outcomes, the committee focussed their discussion on 4 themes: medication management (including carers' training needs); personal and intimate care (including feeding and carer burden with providing emotional and practical support); specific carer training programmes (including carers' perceived barriers in engaging the training programmes, lack of relevance of the training programmes to carers' circumstances, perceived positive aspects of training programmes, perceived improvement with relationships with the care recipient, and carers' perceived benefits in receiving training programmes –such as confidence, awareness and knowledge, improved understanding of rights and entitlements, emotional, social, and practical support); and technical health procedures (including carers' training needs).

The quality of the evidence

In terms of quantitative evidence, 14 randomised controlled trials (RCTs) were included. The quality of the quantitative evidence was assessed using the GRADE methodology. The quality of the evidence across all outcomes ranged from moderate to very low and was commonly downgraded because of design limitations (risk of bias) of the studies and high to very high rates of imprecision in the effect estimates, due to small number of events. 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 detention bias (with many RCTs not blinding to the treatment allocation of included carers and / or outcome assessors); and selective reporting of findings (with many RCTs using customised and self-reported outcome measures). Also, the small sample size and its convenience nature in most included studies, as well the lack of the discussion in relation to the statistical power, were considered to be a major methodological issue.

In terms of qualitative evidence, 9 studies were identified. Quality of the qualitative evidence for the various themes identified in the review ranged from very low to moderate quality, according to GRADE-CERQual. The quality of the included qualitative evidence was mostly downgraded due to adequacy of data, as there was enough data for only a few themes to develop an understanding of the phenomenon of interest, either due to insufficient studies (offering inadequate data) or lack of diversity of carers (for example in terms of caring circumstances or diagnosis of the care recipients). For most themes, the overall quality of evidence was also 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).

Based on their expertise, the committee noted that the populations of carers covered in most of included studies were mixed (in terms of gender, and geographical setting); hence, the committee agreed that the data from most included studies were applicable across all the UK population of adult carers. However, in drafting recommendations, the committee noted that the evidence (either quantitative or qualitative) referred to very specific carers' circumstances and training needs. In addition, due to the uncertainty on many of the findings in this mixed-methods review, the committee thought that the evidence should be interpreted with caution -when drafting recommendations.

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.

No quantitative data were located about the effectiveness of training to improve carers' medication management skills or their ability to provide personal or intimate care. Although related qualitative data were located, the committee agreed it was too limited – only covering carers of people with specific conditions – and did not use it for drafting recommendations.

The committee reached similar conclusions about the synthesised evidence for training to manage technical health procedures. In the absence of quantitative data and with low quality qualitative evidence, no related reocommendations were drafted.

Where there were neither quantitative nor qualitative data to combine, the committee either agreed to make no related recommendations (as with training in pain management) or instead drew on their expertise to draft recommendations (as with training on moving and handling). Their reasons are explained below under 'benefits and harms'.

The strength of the mixed methods approach was highlighted when the committee were able to draft recommendations despite a lack of effectiveness evidence. Examples include training to use equipment and multi-component training for which there were no quantitative studies but for which there were qualitative data in which the committee were confident. In particular, they were able to recommend the important components of these interventions based on acceptability evidence.

For some aspects of the review, the committee were able to synthesise evidence from quantitative and qualitative data, providing a reliable basis for recommendations. One example is specific carer training programmes and committee discussions about the combined large body of evidence are described below under 'benefits and harms'.

In circumstances where there were quantitative data covering some specific carers' circumstances (such as training to manage behaviour that challenges for carers of people living with dementias) or where quantitative data were conflicting and there were no qualitative data to help make sense of those findings, the committee agreed they had no basis for drafting recommendations.

Benefits and harms

Medication management

No evidence was identified about the effectiveness of training interventions to improve carers' skills in medication management; however, qualitative evidence on this area of the review showed that commonly carers felt to have insufficient information regarding medication management and the use and maintenance of equipment to administer medication. The committee discussed that the findings of the review on medication management covered only carers of people with specific conditions, and hence, they found it difficult to draft recommendations for this cluster of training interventions.

Personal and intimate care

No evidence was identified about the effectiveness of training interventions to improve carers' skills in providing personal and intimate care to the care recipients; however, qualitative evidence on this area of the review showed that many carers felt that support and training in food-related information and nutrition could impact positively on their stress and burden. The committee did express concern that this evidence only referred to very specific carers' circumstances (for example carers of people with eating disorders), which made it difficult to draft recommendations generalisable to all carers; in addition, the committee noted that this evidence was a low quality. Hence, the committee were not able to draft any recommendations on this area of the evidence review.

Movement and handling

No evidence was identified about the effectiveness of training interventions to improve carers' skills in movement and handling. The committee nevertheless agreed that most carers would wish to improve their movement and handling knowledge and skills and that they would benefit from guidance and advice in this area. Therefore, based on their expertise, the committee agreed to recommend that carers should be provided with the opportunity to access practical training, advice and guidance around appropriate moving and handling techniques.

Pain management

The evidence showed that there were significant improved levels of knowledge of cancer pain management in carers receiving a professional-led pain management psychoeducation intervention compared to those carers receiving cancer-related pain information only. The committee did express concern that the findings from this area of the review were low quality, and only covered some specific carers' circumstances. Therefore, the committee agreed not to draft any recommendations on training interventions to improve carers' skills in pain management.

Managing behaviour(s) of person with support needs

All reviewed evidence on the effectiveness of interventions to improve carers' skills in managing behaviours of people with support needs were focussed on carers of people living with dementias or specifically, Alzheimer's disease. The committee discussed that the potential strategies for managing challenging behaviours may be complex and depending on the condition of the care recipients (for example mental health issues, eating disorders, neurological conditions, dementias, etc.). Therefore, based on the limited body and strength of the evidence, the committee agreed not to draft any recommendations on strategies for supporting carers in managing challenging behaviours of people with support needs.

Personalised training specific to the circumstances or conditions of the person receiving care

No evidence was identified on the acceptability of personalised training programmes specific to the circumstances or conditions of people receiving care. However, quantitative evidence showed that there were conflicting findings about the effects of a training intervention specific to their caring needs or circumstances versus usual care. The committee did express concern that the findings from this review were of very low to low quality, and only covered some of the interventions of interest, which made it difficult to specify the most effective programme for supporting adult carers with personalised training specific to the circumstances or conditions of their care recipients. Therefore, the committee agreed not to draft any recommendations on this topic.

Technical health procedures

Qualitative evidence on the experience of adult carers managing technical health procedures showed that many carers reported to face challenges and uncertainty about using technical equipment. In particular, low quality evidence on carers providing care for people with chronic obstructive pulmonary disease (COPD) using nebuliser-delivered therapy at home, demonstrated that often carers did not feel fully equipped to set up and manage technical health procedures. Based on this evidence, the committee noted that carers might benefit from information in areas such as administering the correct dosage of medication and managing technical health procedures at home. However, the committee agreed to do not draft recommendations, given the limited body of qualitative evidence, and the paucity of quantitative data on this area of training interventions.

Use of equipment and adaptations

Based on the evidence, the committee noted that providing carers with training and guidance on how to use some adaptations, aids and technology may benefit carers with their daily caring role. The evidence showed that an assessment from an occupational therapist could help carers to find out what equipment and adaptations would be available, as well as assessing what would be most appropriate way to access training in a living environment. Therefore, based on the evidence and their experience, the committee recommended that carers should have access to advice, guidance, and practical training around appropriate use of equipment and adaptations; and carers should be involved by care services and professionals (for example occupational therapists or other relevant health and social care professionals) delivering such an assessment.

Specific carer training programs

The committee noted that there was a large body of evidence on the effectiveness of specific carers' training programs showing that such programmes could improve carers' knowledge, self-efficacy and advocacy skills, and carers' ability to cope. The committee did agree with these findings; in addition, the qualitative evidence on this area of the review showed that carers commonly felt unconfident and overwhelmed in their caring role. The committee therefore emphasised the importance of making training easily accessible to improve carer's knowledge, skills and confidence.

The committee noted that there was no direct evidence on comparing multicomponent carers' training programmes versus single component ones, hence, they decided not to recommend that carers' training programmes should be multicomponent. However, based on the evidence, the committee discussed that effective, cost-effective and acceptable carers' training programmes should have common features: they should include a range of elements; they should be tailored on the specific carers' needs and circumstances; and they should be offered in a variety of formats (such as printed materials, on-line materials, or/and face-to-face). Therefore, they agreed to recommend that the delivery of carers' training programmes should be tailored on their specific needs, in order to improve carers' ability to cope and their caring knowledge. Also, based on the evidence, they agreed that carers' training programmes should include elements such as self-care, communication skills, understanding the condition of the cared-for person, knowledge of relevant services, skill building, psychosocial elements and guidance on future planning.

In terms of agreeing the important content of training programmes, the committee also noted qualitative evidence about carers feeling unknowledgeable about the management of medication. The committee therefore used this as a basis for a recommendation about providing training on medicines management and on the basis of their expertise agreed that training on personal care and assistive technology should also be considered.

The qualitative evidence showed that some carers felt that receiving a training programme could reduce their sense of isolation by allowing the space for carers to interact with each other, discuss their issues and find solutions. Also, adult carers from 'hard to reach' groups, were particularly positive about the non-discriminatory support provided by the training sessions. Therefore, based on the evidence and their experience, the committee agreed to draft a recommendation, to consider peer support as a key component of any carer's training program, with a particular focus on hard to reach groups such as LGBTQI.

The evidence showed that most carers who attended specific carer training programmes appreciated common elements of the programmes, such as the usefulness of the received information and guidance; the flexibility in relation to their needs; and the perceived emotional and practical benefits (including the potential for meeting other carers with similar experiences or circumstances, the improved knowledge and skills, and the potential of having a break from caring). The committee did express concern that the findings on this area of the review were focussed only specific carers (that is carers of people living with dementia and carers of people with eating disorders), even though were rated as of moderate quality. Therefore, based on the evidence and their experience, the committee agreed to recommend that the delivery of specific carer training programmes should be tailored on the emotional and practical caring circumstances of carers receiving training. In addition, that training programmes should provide a balance between learning and enjoyment, recognising the evidence that as well as building skills, carers also value the social and support element of attending courses along with others in their position. Discussions also prompted the committee to agree a ‘consider’ recommendation on the basis of consensus that carers attending training programmes be given opportunities to stay in touch with the group after the course, to maintain those benefits in the long term.

Specific carers’ psychoeducation interventions

The evidence on carers’ psychoeducation interventions showed that there were no important differences in level of burden and caring-related morbidity between carers who received between carers receiving psychoeducation and those who received usual care. The committee did express concern that these findings provided evidence of very low or low quality, which made it difficult to draft any recommendations on this area of the review. Therefore, the committee considered that the evidence was insufficient for any positive recommendations to be made on carers’ psychoeducation interventions.

The committee did not recommend further research in the areas not covered by the evidence (that is training interventions or programmes to improve first aid, recovery-based approaches, and carers’ skills in financial management), as they considered these topics of low priority for research funding

Cost-effectiveness and resource use

Medication management

No existing economic evidence was identified on interventions to improve carer skills in medication management. The committee did not think recommendations could be drafted on the basis of available evidence and therefore a qualitative consideration of cost-effectiveness was not needed.

Personal and intimate care

No existing economic evidence was identified on interventions to improve carer skills in providing personal and intimate care to the care recipients. The committee did not think recommendations could be drafted on the basis of available evidence and therefore a qualitative consideration of cost-effectiveness was not needed.

Movement and handling

In the absence of any economic evidence or original analysis, the committee made a qualitative assessment about the cost-effectiveness of interventions to improve carer skills in movement and handling to the care recipients. The committee noted that access to training advice and guidance on appropriate moving and handling techniques would be inexpensive and unlikely to incur significant additional costs to the NHS. Furthermore, the committee noted that poor movement and handling techniques could result in serious injury with a detrimental impact on the carers health related quality of life, resulting in additional NHS resource use. The committee recognised that the recommendations pertaining to this topic reflected standard practice based on statutory requirements and are essential to support adult carers.

Pain management

No existing economic evidence was identified on interventions to improve carer skills in providing pain management to the care recipients. Additionally, the committee was of a view that the evidence was insufficient for any positive recommendations to be made.

Managing behaviour(s) of person with support needs

No existing economic evidence was identified on interventions to improve carer skills in managing behaviour(s) of person with support needs. The committee did not think recommendations could be drafted on the basis of available evidence and therefore a qualitative consideration of cost-effectiveness was not needed.

Personalised training specific to circumstances/conditions of person receiving care

No existing economic evidence was identified on personalised training programmes specific to the circumstances of the person with care needs. The committee did not think recommendations could be drafted on the basis of available evidence and therefore a qualitative consideration of cost-effectiveness was not needed.

Technical health procedure

No existing economic evidence was identified on interventions to improve carer skills in managing technical health procedure. The committee did not think recommendations could be drafted on the basis of available evidence and therefore a qualitative consideration of cost-effectiveness was not needed.

Use of equipment and adaptations

In the absence of any economic evidence or original analysis, the committee made a qualitative assessment about the cost-effectiveness. The committee considered that access to advice and guidance on the appropriate use of equipment and adaptations would be important in order to use the available equipment and adaptations effectively. The committee did not consider that access to this guidance and advice would be expensive and did not anticipate a significant resource impact to the NHS.

Specific carer training programs

The committee discussed the economic evidence about specific carers' training programmes. This study compared the cost-utility a manual-based coping skill training programme START (STrAtegies for Relatives) with usual care in adult carers of people living with dementia. The committee, agreed that the findings of this study, were directly applicable to the UK health and social care context and only had minor methodological limitations. The committee also agreed that the components covered by START for carers of people living with dementia, are a good representation of the elements that should be covered in this type of training programme, for adult carers supporting people with any kind of condition. The study found START to be cost-effective and the committee agreed that these findings provided evidence to support recommendations for carers' training programmes including several components, such as self-care, communication skills, understanding the condition, knowledge of relevant services, skill building and psychosocial elements. They also agreed that carers' training multicomponent programmes, had not necessarily to be the specific intervention evaluated (START), as it was acknowledged that a substantial number of possible alternative programmes were not captured in the quantitative, qualitative and or economic evidence.

Specific carers' psychoeducation interventions

No existing economic evidence was identified on carers' psychoeducation interventions. The committee did not think positive recommendations could be made on the available evidence and therefore a qualitative consideration of cost-effectiveness was not needed.

Other factors the committee took into account

The committee discussed that recent guidance from the NHS (NHS Guidance on Continuing Healthcare 2018) states that assessments for Continuing Healthcare' should 'consider training for carers to provide them with support in their caring role'. As no evidence was identified about the effectiveness and acceptability of training interventions to improve carers’ skills in moving and handling, the committee agreed this was an important area for carers own safety and well-being as well as enabling the person receiving care to be safely cared for and was in line with current NHS and social care practice and guidance and so made a recommendation about carers having access to advice and guidance about this.

References

Quantitative component of the review

Faes 2011

Faes MC, Reelick MF, Melis RJ, Borm GF, Esselink RA, Multifactorial fall prevention for pairs of frail community-dwelling older fallers and their informal caregivers: a dead end for complex interventions in the frailest fallers. J Am Med Dir Assoc 2011;12(6):451-8

Graff 2006

- Graff MJ, Vernooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. BMJ. 2006;333(7580):1196.
- Graff MJ, Vernooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Olderikkert MG. Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial. J Gerontol A Biol Sci Med Sci 2007;62(9):1002-9.

Hattink 2015

Hattink B, Meiland F, van der Roest H, Kevern P, Abiuso F, Web-Based STAR E-Learning Course Increases Empathy and Understanding in Dementia Caregivers: Results from a Randomized Controlled Trial in the Netherlands and the United Kingdom. J Med Internet Res 2015;17(10):e241

Hebert 2003

Hébert R, Lévesque L, Vézina J, Lavoie JP, Ducharme F, Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial. J Gerontol B Psychol Sci Soc Sci 2003;58(1):S58-67

Hoyle 2013

Hoyle D, Slater J, Williams C, Schmidt U, Wade TD. Evaluation of a web-based skills intervention for carers of people with anorexia nervosa: a randomized controlled trial. Int J Eat Disord 2013;46(6):634-8

Klodnicka Kouri 2011

Klodnicka Kouri K, Ducharme FC, Giroux F. A psycho-educational intervention focused on communication for caregivers of a family member in the early stage of Alzheimer's disease: Results of an experimental study. Dementia: The International Journal of Social Research and Practice 2011;10(3), 435-453.

Liddle 2012

Liddle J, Smith-Conway ER, Baker R, Angwin AJ, Gallois C, Memory and communication support strategies in dementia: effect of a training program for informal caregivers. Int Psychogeriatr 2012;24(12):1927-42

Livingston 2014

- Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, 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 living with dementia. Health Technol Assess 2014;18(61):1-242.
- Cooper C, Barber J, Griffin M, Rapaport P, Livingston G. Effectiveness of START psychological intervention in reducing abuse by dementia family carers: randomized controlled trial. Int Psychogeriatr 2016;28(6):881-7.

Lobban 2013

Lobban F, Glentworth D, Chapman L, Wainwright L, Postlethwaite A, Feasibility of a supported self-management intervention for relatives of people with recent-onset psychosis: REACT study. Br J Psychiatry 2013;203(5):366-72

Martin-Carrasco 2016

Martín-Carrasco M, Fernández-Catalina P, Domínguez-Panchón AI, Gonçalves-Pereira M, González-Fraile E, A randomized trial to assess the efficacy of a psychoeducational intervention on caregiver burden in schizophrenia. Eur Psychiatry 2016 Mar;33:9-17

Núñez-Naveira 2016

Núñez-Naveira L, Alonso-Búa B, de Labra C, Gregersen R, Maibom K, UnderstAID, an ICT Platform to Help Informal Caregivers of People living with dementia: A Pilot Randomized Controlled Study. Biomed Res Int 2016;2016:5726465

Sepe-Monti 2016

Sepe-Monti M, Vanacore N, Bartorelli L, Tognetti A, Giubilei F. The Savvy Caregiver Program: A Probe Multicenter Randomized Controlled Pilot Trial in Caregivers of Patients Affected by Alzheimer's Disease. J Alzheimers Dis 2016;54(3):1235-1246

Szmukler 2003

Szmukler G, Kuipers E, Joyce J, Harris T, Leese M, An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. Soc Psychiatry Psychiatr Epidemiol 2003;38(8):411-8

Valeberg 2013

Valeberg BT, Kolstad E, Småstuen MC, Miaskowski C, Rustøen T. The PRO-SELF pain control program improves family caregivers' knowledge of cancer pain management. Cancer Nurs 2013;36(6):429-35

Economic component of the review

Livingston 2014

Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, 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 living with dementia. Health Technol Assess 2014;18(61):1-242.

Qualitative component of the review

Alhaddad 2016

Alhaddad B, Taylor KMG, Robertson T, Watman G, Smith FJ. Assistance of family carers for patients with COPD using nebulisers at home: a qualitative study. European Journal of Hospital Pharmacy 2016;23(3):156-160

Macdonald 2011

Macdonald P, Murray J, Goddard E, Treasure J. Carer's experience and perceived effects of a skills based training programme for families of people with eating disorders: a qualitative study. Eur Eat Disord Rev 2011;19(6):475-86.

Papachristou 2015

Papachristou I, Hickey G, Iliffe S. Dementia informal caregiver obtaining and engaging in food-related information and support services. Dementia (London) 2015. pii: 1471301215583148.

Riley 2011

Riley G, Gregory N, Bellinger J, Davies N, Mabbott G, Sabourin R. Carer's education groups for relatives with a first episode of psychosis: an evaluation of an eight-week education group. Early Interv Psychiatry 2011;5(1):57-63.

Sepulveda 2008a

Sepulveda AR, Lopez C, Todd G, Whitaker W, Treasure J. An examination of the impact of "the Maudsley eating disorder collaborative care skills workshops" on the well being of carers: a pilot study. Soc Psychiatry Psychiatr Epidemiol 2008;43(7):584-91.

Sepulveda 2008b

Sepulveda AR, Lopez C, Macdonald P, Treasure J. Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder. Int J Eat Disord 2008;41(4):318-25.

Smith 2015

Smith F, Grijseels MS, Ryan P, Tobiansky R. Assisting people living with dementia with their medicines: experiences of family carers. Int J Pharm Pract 2015;23(1):44-51. doi: 10.1111/ijpp.12158.

Sommerlad 2014

Sommerlad A, Manela M, Cooper C, Rapaport P. Livingston G. START (STrAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention. BMJ Open 2014; 4-e005273

Yeandle 2011

Yeandle S, Wigfield A (eds). Training and Supporting Carers: The National Evaluation of the Caring with Confidence Programme . Leeds, CIRCLE: University of Leeds, 2011

Appendices

Appendix A – Review protocols

Review protocol for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Table 5: Review protocol

Field (based on PRISMA-P)	Content
Review questions	What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?
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 training for practical support 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 skills- or educational- based intervention whose primary aim is to train adult carers (and not social-/health-care providers) to provide practical support to the person receiving care, including (but not limited to): • Medication management • First aid • Personal and intimate care • Recovery-based approaches (for example Recovery College) • Movement and handling • Pain management • Financial management (for example, how to manage a Personal Health Budget on behalf of carer, or how to engage someone to provide assistance to carer in discharging caring responsibilities) • Managing behaviour(s) of person receiving care

Field (based on PRISMA-P)	Content
	• Personalised training specific to circumstances/conditions of person receiving care (rather than training in use of specific techniques) • Technical health procedures (for example enteral tube feeding, intravenous therapy, dialysis; note that GC will not be drafting recommendations on specifics of how to provide such training) • Use of aids and adaptations (including digital assistive technology) Specific Carer Training programs (for example START program for dementia) 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	For studies assessing the effectiveness of training programmes, we will compare eligible interventions against: • No intervention • Other interventions within the same category
Outcomes and prioritisation	CRITICAL OUTCOMES: • Caring-related morbidity (MID: statistical significance) • Impact of intervention on caring-related accidents/incidents (for example failing to take medicine, number of falls, time spent providing specific type of practical support) (minimally important difference [MID]: statistical significance) IMPORTANT OUTCOMES • Impact of caring on carer (including on carer competency, unplanned care, social isolation/networks or relationships) (MID: statistical significance) • Carer skills, knowledge/confidence or efficacy about supporting person receiving care (MID: statistical significance) • Resource and service use (health or social care) (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. The quantitative and qualitative data will be presented together as the overall result of this mixed methods review. Where they allow, data will be grouped around the protocol interventions.

Field (based on PRISMA-P)	Content
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, and South Africa will be included for the quantitative component of the review. Studies from other countries will not be included due to substantial differences in their carer populations and/or social-/health-care systems. • Only UK studies will be included for the qualitative component of the review • 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

Field (based on PRISMA-P)	Content
	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 screeners. 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 and organise 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
Identify if an update	Not applicable
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 2014

Field (based on PRISMA-P)	Content
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 v1 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
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.

Field (based on PRISMA-P)	Content
	Being a mixed methods review, the NGA technical team will present the data from quantitative and qualitative studies together, organised around the protocol interventions (where data are available). The committee will complete the synthesis of these mixed data through their discussions of the evidence. Their interpretation of the relationship between the quantitative and qualitative data is described in the committee discussion of the evidence.
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 of assessing confidence in quantitative evidence for the effectiveness of interventions, 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
PROSPERO registration number	Not registered with 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 skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

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

#	Searches
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
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.

#	Searches
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.
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

#	Searches
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/
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.

#	Searches
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 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.

#	Searches
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/
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

#	Searches
	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 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

#	Searches
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
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

#	Searches
	(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.
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.

#	Searches
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.
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

#	Searches
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.
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.

#	Searches
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
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.

#	Searches
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
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*))
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*)))

#	Searches
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))
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*)

#	Searches
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
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

#	Searches
	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*)
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.

#	**Searches**
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

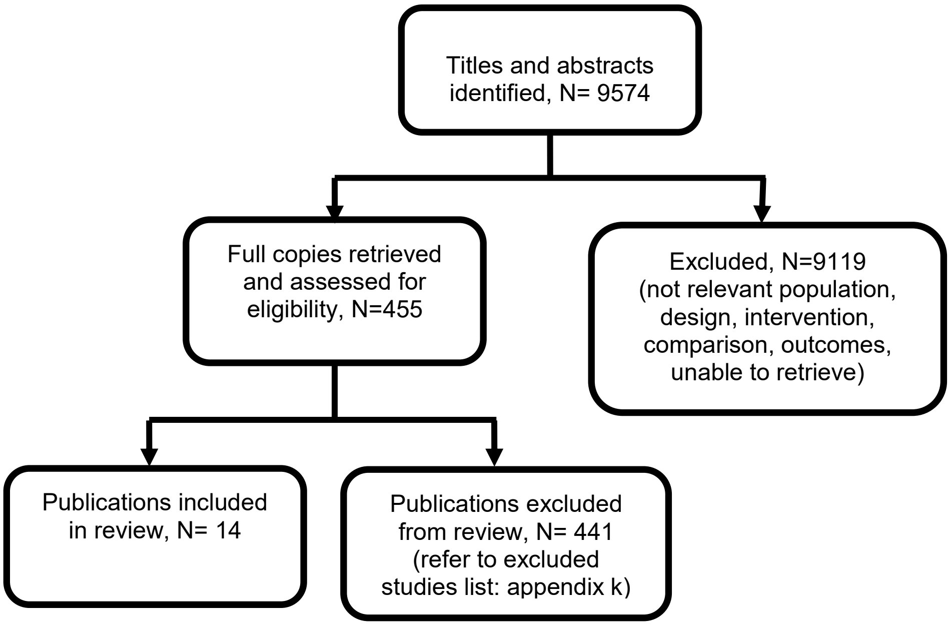
#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Study selection for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

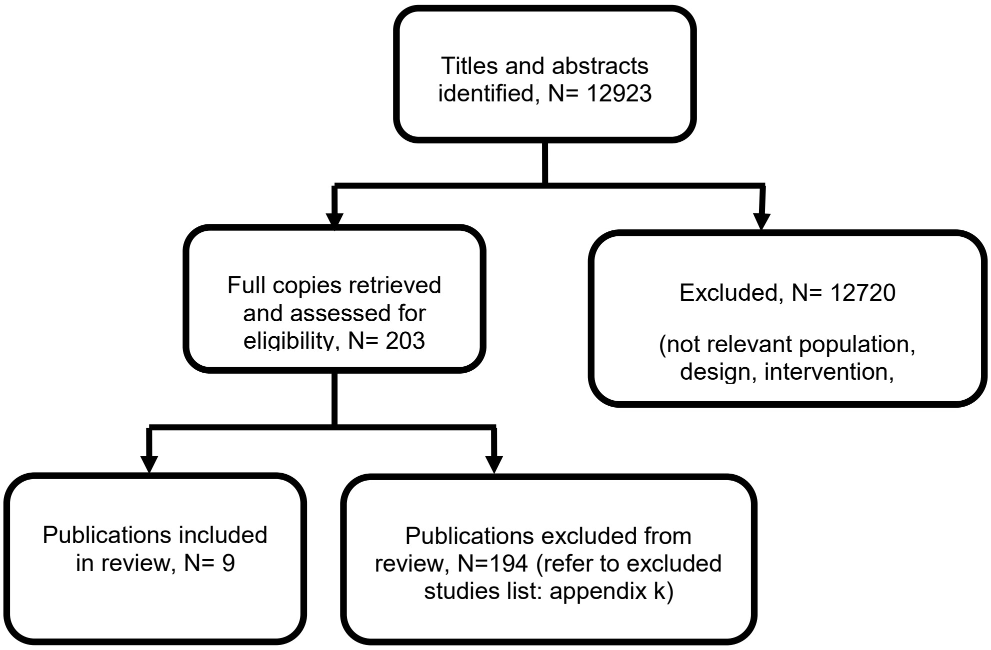
Quantitative component of the review

Figure 2: Flow diagram of article selection for for training for carers to provide practical support



Qualitative component of the review

Figure 3: Flow diagram of article selection for for training for carers to provide practical support



Appendix D – Evidence tables

Evidence tables for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

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
Faes, Mc, Reelick, Mf, Melis, Rj, Borm, Gf, Esselink, Ra, Rikkert, Mg, Multifactorial fall prevention for pairs of frail community-dwelling older fallers and their informal caregivers: a dead end for complex interventions in the frailest fallers, Journal of the American Medical Directors Association, 12, 451-458, 2011
Ref Id</td>
<td>Sample size
N=36 patient-carer dyads randomised
• Intervention, n=18
• Control, n=15 (3 patients dropped out before baseline measurements taken, excluded from analysis)
Characteristics
Carer characteristics (Intervention; control)
• Age (years): 67.3 (13.1); 64.3 (14.3)
• Gender (M/F): 9/9; 5/10
• Living with care recipient (Y/N): 10/8; 7/8
• Employed (Y/N): 5/13; 5/10</td>
<td>• Intervention: Multifactorial group fall prevention training + TAU
• Control: TAU</td>
<td>• Participants recruited from geriatric outpatient clinic of Radboud University Nijmegen Medical Centre and 2 non-university teaching hospitals (Rijnstate Hospital, Canisius-Wilhelmina Hospital). Groups allocated using minimization algorithm balanced for gender, MMSE score (15-23, 24-30), age (≤80, >80) and number of falls in past year (1, >1). Dyads assessed at baseline, completion of program, 3 months and 6 months. If care recipient withdrew from study, dyad was withdrawn from study; if carer withdrew,</td>
<td>Outcomes after completion of training
Falls per patient per year: 4.32 versus 0.52, RR=7.97 (95% CI, 0.86-73.4), p=0.07
<table>
<tr><th>Outcome</th><th>Group Fall Prevention (n=18)</th><th>Control (n=15)</th></tr>
<tr><td>ZBI - change scores</td><td>1.21 (3.41)</td><td>-0.69 (2.25)</td></tr>
<tr><td>CES-D - change scores</td><td>-0.33 (3.31)</td><td>-0.86 (3.53)</td></tr>
</table></td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Low risk (minimization used)
• Allocation concealment: Unclear (no details provided)
• Blinding of participants/personnel: High risk (dyads and personnel not blinded,
• Blinding of outcome assessment: Low</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>708895

Country/ies where the study was carried out
Netherlands

Study type
RCT

Aim of the study
To reduce falls in frail older people and to increase carer support.

Study dates
01/2008-09/2009

Setting
Geriatric outpatient clinic

Source of funding
Not reported</td>
<td>• ZBI: 5.2 (4.5); 6.0 (11.0)
• CES-D: 3.0 (6.5); 3.0 (17.0)
• HADS-A: 2.5 (3.8); 3.0 (8.8)
• Total caring time (hrs/week): 8.0 (13.1); 10.5 (8.0)
• EQ-5D VAS: 84.5 (15.0); 54.0 (18.0)

Care recipient characteristics (Intervention; control)
• Age (years): 78.3 (6.9); 78.3 (7.2)
• Gender (M/F): 4/14; 6/9
• Falls in previous year: 3.0 (1.75); 5.07 (6.41)
• Use of walking aid (Y/N): 8/10; 10/5

Inclusion criteria
Patients eligible if they
• fell at least once in 6 months before outpatient clinic visit
• could walk 15m without assistance (walking aid permitted)
• had primary carer (non-professional, assisted with >1 personal or</td>
<td></td>
<td>then care recipient continued in study. Falls registered every day using fall registration calendar sent every 2 weeks using stamped addressed envelope.
• Group fall prevention training + TAU
Intervention conducted by geriatric psychologist and geriatric physiotherapist in maximum groups of 5 dyads, consisting in 10 twice-weekly 2 hr sessions and 1 2-hr booster session 6 weeks after completion of 10 sessions. Carer training component consisted in training as co-therapist at home and strategies to preserve autonomy. Program was personalised to circumstances of care recipient through adaptation of facultative components of program. All dyads also received TAU. Carer training components included understanding causes of falls, training in</td>
<td>
<table>
<tr><td>HADS-A - change scores</td><td>0.33 (2.09)</td><td>0.69 (1.65)</td></tr>
<tr><td>Total caring time</td><td>n/a</td><td>n/a</td></tr>
<tr><td>EQ-5D-VAS - change scores</td><td>-2.67 (11.16)</td><td>-2.77 (9.79)</td></tr>
</table>

Outcomes at long-term follow- up (average of change scores at 3 and 6 months)
Falls per patient per year: 4.94 versus 1.17. RR=2.12 (95% CI, 0.6-7.56), p=0.25
Number of patients falling at least once: 10/18; 6/15
Number of patients falling at least twice: 6/18; 1/15
<table>
<tr><td>Outcome</td><td>Group Fall Prevention (n=18)</td><td>Control (n=15)</td></tr>
</table>
</td>
<td>risk (assessor blinded)
• Incomplete outcome data: Unclear (3 dyads dropped out before baseline assessment for unknown reasons)
• Selective reporting: Unclear (insufficient information)
• Other bias: Low risk (study appears free of other sources of 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></td>
<td>instrumental activity of daily living, monitored care recipient ≥twice/week)
lived in community
had life expectancy >1 year
were frail (presence of ≥2 farilty indicators
Informed consent from both carer and care recipient.
Exclusion criteria
Patients excluded if
awaiting nursing home admission, or
Mini-Mental State Examination score<15</td>
<td></td>
<td>movement and handling, advice and training regarding supporting care recipient in activities of daily living, and opportunities to discuss impact of falls on carer.
TAU
No details provided</td>
<td><table>
<tr><td>ZBI-12 change scores</td><td>1.94 (2.97)</td><td>0.14 (4.99)</td></tr>
<tr><td>CES-D-20- change scores</td><td>1.0 (2.87)</td><td>-2.05 (6.4)</td></tr>
<tr><td>HADS-A - change scores</td><td>0.53 (1.75)</td><td>0.05 (1.38)</td></tr>
<tr><td>Objective burden (Total caring time hrs/week)</td><td>-2.07 (15.96)</td><td>-3.37 (14.39)</td></tr>
<tr><td>EQ-5D-VAS - change scores</td><td>-7.21 (11.27)</td><td>-2.77 (11.91)</td></tr>
</table></td>
<td></td>
</tr>
<tr>
<td>Full citation
Graff, Mj, Vernooij-Dassen, Mj,</td>
<td>Sample size</td>
<td>Intervention: Occupational therapy</td>
<td>Details
See entry for Graff 2006. 'Community based</td>
<td>See entry for Graff 2006. 'Community based occupational therapy for</td>
<td>Limitations
See entry for Graff 2006. 'Community</td>
</tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
Thijssen, M, Dekker, J, Hoefnagels, Wh, Olderikkert, Mg, Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial, Journals of gerontology. Series A, Biological sciences and medical sciences, 62, 1002-1009, 2007 **Ref Id** 707138 **Country/ies where the study was carried out** Netherlands **Study type** RCT	N=135 care dyads randomised Intervention, n=68 Control, n=67 **Characteristics** • See entry for Graff 2006. 'Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial' **Inclusion criteria** See entry for Graff 2006. 'Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial' **Exclusion criteria** See entry for Graff 2006. 'Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial'	**Control:** No occupational therapy	occupational therapy for patients with dementia and their care givers: randomised controlled trial'	patients with dementia and their care givers: randomised controlled trial'	based occupational therapy for patients with dementia givers and their care: randomised controlled trial'

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
Aim of the study To assess efficacy of community-based occupational therapy on daily functioning of people living with dementia and carer competence **Study dates** 04/2001 to 01/2005 **Setting** In home/memory or day clinic of geriatrics department **Source of funding** Supported by Dutch Alzheimer Association, Radboud University Nijmegen Medical Center and Dutch Occupational Thera py Association					
Full citation Graff, Mj, Vernooij-Dassen, Mj,	**Sample size** N=135 care dyads randomised	- **Intervention:** Occupational therapy	- Intervention delivered by experienced occupational therapists with at least 80	Note: All data, except for SPQ outcomes, are from Graff 2007, 'Effects of	**Limitations (assessed using the Cochrane 'Risk of**

<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>Thijssen, M, Dekker, J, Hoefnagels, Wh, Rikkert, Mg, Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial, BMJ (Clinical research ed.), 333, 1196, 2006

Ref Id
707139

Country/ies where the study was carried out
Netherlands

Study type
RCT

Aim of the study
To assess efficacy of community-based occupational therapy on daily functioning of</td>
<td>Intervention, n=68
Control, n=67
Characteristics
Carer characteristics
Mean age (years): 66 (15.3); 61.3 (15.4)
Gender (M/F): 22/46; 18/49
Relationship to care recipient (partner/daughter/other): 41/22/5; 38/21/8
SCQ: 89.7 (14.9); 90.4 (13.6)
CES-D: 11.7 (8.3); 11.4 (7.2)
Care recipient characteristics
Mean age (years): 79.1 (6.2); 77.1 (6.3)
Gender (M/F): 29/39; 31/36
MMSE: 19 (5.7); 19 (4)
BCRS: 27.3 (5.1); 27.1 (4.2)
Inclusion criteria
Carer who is primary carer of person with diagnosed mild to moderate dementia</td>
<td>Control: No occupational therapy</td>
<td>hrs training and at least 240 hours experience in delivering treatment. Assessments at baseline, 6 weeks (post-intervention) and 6-wk FU.
Occupational therapy Consisted of 10 sessions of 1 hour over 5 weeks focusing on both dementia patients and carers delivered by occupational therapist. Sessions 1-4 cover diagnostics and goal defining with dyads learning to chose and prioritise meaningful activities they wanted to improve through use of 3 narrative review instruments by therapist (occupational performance history interview for patient [OPHI-II]; ethnographic interview for carer; and Canadian occupational performance measure for care dyad [COPM]). Therapist also conducts valuation of potential to adapt home and general</td>
<td>community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial'.
Carer outcomes at post-intervention (6 weeks)
<table>
<tr><td>Outcomes</td><td>OT (n=68)</td><td>No OT (n=67)</td></tr>
<tr><td>SCQ</td><td>104.6 (13.4)</td><td>88.4 (13.7)</td></tr>
<tr><td>CES-D-R</td><td>5.8 (4.8)</td><td>12.6 (8.5)</td></tr>
<tr><td>DQoLI-overall</td><td>4 (0.6)</td><td>3.4 (0.7)</td></tr>
<tr><td>DQoLI-aesthetics</td><td>20.5 (3.1)</td><td>15.7 (4.1)</td></tr>
<tr><td>DQoLI-positive affect</td><td>23.3 (2.8)</td><td>19.9 (4.2)</td></tr>
<tr><td>DQoLI-negative affect</td><td>20.2 (5.6)</td><td>26 (6.3)</td></tr>
<tr><td>DQoLI-belonging</td><td>13.6 (1)</td><td>12.3 (1.3)</td></tr>
</table></td>
<td>bias' tool for randomized trials)
Random sequence generation: Low risk (blocked randomisation, size 4, stratified by severity of dementia)
Allocation concealment: Unclear risk ('concealed envelopes' no further details; potential selection bias)
Blinding of participants/personnel: High risk (participants and personnel not blinded to group allocation, potential performance bias)
Blinding of outcome assessment: Low risk (assessors blinded to allocation)
Incomplete outcome data: Low risk (ITT analysis)</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>people living with dementia and carer competence
Study dates
04/2001 to 01/2005
Setting
In home/memory or day clinic of geriatrics department
Source of funding
Supported by Dutch Alzheimer Association, Radboud University Nijmegen Medical Center and Dutch Occupational Therapy Association</td>
<td>(DSM-IV) provides care at least once per week
• Patient aged≥65 years-old
• diagnosed with mild to moderate dementia (DSM-IV) (severity determined by BCRS score [mild=9-24; moderate=25-40])
living in community
had primary carer
Written informed consent from both members of care dyad
Exclusion criteria
Dementia patient with
• Geriatric Depression scale score>12, or severe behavioural or psychological symptoms in dementia (BPSD),
• severe illness as evaluated by geriatrician, or
• occupational therapy goals that cannot be defined, or
• no stable treatment by dementia drug (<3 months on same dose of</td>
<td></td>
<td>environment, as well as patients’ ability and potential to perform activities of daily life through adaptation of activities and environment to disabilities. Sessions 5-10 cover optimisation of strategies to improve daily activities. Carers trained using cognitive and behavioural interventions to be effective in supervision, problem solving and coping strategies to maintain patient’s and carer's own autonomy, as well as social network. Total time spent on intervention approximately 18 hours.
• No occupational therapy After end of trial at 12 weeks, participants were offered occupational therapy intervention.</td>
<td>
<table>
<tr><td>DQoLI-self-esteem</td><td>17.2 (1.5)</td><td>15.4 (1.9)</td></tr>
<tr><td>GHQ-12</td><td>7 (3.9)</td><td>11 (3.9)</td></tr>
<tr><td>Mastery Scale</td><td>16.6 (3)</td><td>12.6 (3)</td></tr>
</table>
Carer outcomes at 6-week FU
<table>
<tr><td>Outcomes</td><td>OT (n=68)</td><td>No OT (n=67)</td></tr>
<tr><td>SCQ</td><td>107.3 (13.6)</td><td>89.4 (14.4)</td></tr>
<tr><td>CES-D-R</td><td>5.4 (4.5)</td><td>13.1 (9.1)</td></tr>
<tr><td>DQoKI-overall</td><td>4.1 (0.6)</td><td>3.4 (0.8)</td></tr>
<tr><td>DQoLI-aesthetics</td><td>20.5 (4.4)</td><td>16 (3)</td></tr>
<tr><td>DQoLI-positive affect</td><td>23.3 (3.2)</td><td>20.1 (4.3)</td></tr>
<tr><td>DQoLI-negative affect</td><td>19.8 (6)</td><td>26.2 (7)</td></tr>
<tr><td>DQoLI-belonging</td><td>17.3 (1.7)</td><td>15.3 (2)</td></tr>
</table>
</td>
<td>• Selective reporting: Low risk (protocol available, all outcomes of interest reported)
• Other bias: Low risk (appears free from other sources of 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></td><td>cholinesterase inhibitor or memantine
• Carer with severe illness</td><td></td><td></td><td><table><tr><td>DQoLI-self-esteem</td><td>13.7 (1)</td><td>12.5 (1.3)</td></tr><tr><td>GHQ-12</td><td>7.1 (3.5)</td><td>12.1 (5)</td></tr><tr><td>Mastery Scale</td><td>16.7 (2.7)</td><td>12.3 (2.8)</td></tr></table></td><td></td></tr>
<tr><td>Full citation
Hattink, B., Meiland, F., van der Roest, H., Kevern, P., Abiuso, F., Bengtsson, J., Giuliano, A., Duca, A., Sanders, J., Basnett, F., Nugent, C., Kingston, P., Droes, R. M., Web-Based STAR E-Learning Course Increases Empathy and Understanding in Dementia Caregivers: Results from a Randomized Controlled Trial in the Netherlands and the United Kingdom, Journal of Medical Internet Research, 17, e241, 2015</td><td>Sample size
N=142 users participated from UK and Netherlands (unclear whether this is number randomised)
• In Netherlands, n=85 (informal carers=50; dementia volunteers=7; professional carers=28)
• In UK, n=57 (informal carers=22; dementia volunteers=17; professional carers=18)
• Intervention, n=27 (21 informal carers and 6 volunteers only)
• Control, n=32 (25 informal carers and 7 volunteers only)

Characteristics
Informal carers and volunteers characteristics</td><td>• Intervention: Self-Help Psychosocial
• Control: WLC</td><td>• STAR is currently available for nominal fee and is fully available in English and other languages. However, users in both groups were able to use STAR free of charge either at baseline (for intervention group) or after end of trial (for WLC group). All assessments were gathered online via a link and were self-report in user's own language at baseline and between 2-4 months for users in intervention group and at 4 months for WLC group. Users in Netherlands recruited from variety of sources (including meeting centres for people living with dementia their carers, regional branches of national Alzheimer's</td><td>Carer outcomes at post-intervention
Outcomes include data from non-carer laypeople and carers unless otherwise stated.<table><tr><td>Outcome (n1; n2)</td><td>SH PS</td><td>WLC</td></tr><tr><td>ADQ (modified, 19 items only) (27; 32)</td><td>71.59 (6.48)</td><td>64.66 (4.9)</td></tr><tr><td>ADKS (27; 32)</td><td>24.44 (3.11)</td><td>24.28 (3.12)</td></tr><tr><td>Attitudes (2 items from Alzheimer's Disease Survey,</td><td>2.75 (1.85)</td><td>2.1 (1.67)</td></tr></table></td><td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Low risk (computer-generated randomisation with stratification)
• Allocation concealment: Low risk (computer-generated allocation sequence)
• Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance 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>Ref Id
710640

Country/ies where the study was carried out
UK, Netherlands

Study type
RCT

Aim of the study
To assess impact of online dementia training/e-learning portal on its usefulness/friendliness, and its impact on user knowledge, empathy, attitudes and competence

Study dates
05/2013 to 03/2014

Setting
In home/online

Source of funding</td>
<td>• Age (y): 52.93 (11.43); 54.69 (14.36)
• Gender (M/F): 7/20; 10/22
• Relationship to care recipient (partner/child/sibling/other/not available): 9/8/0/4/6; 9/5/1/10/7
• Duration of caring (<3 months/3-12 months/1-2 years/2-5 years/>5 years): 2/2/2/15/6; 6/1/9/12/4
• Alzheimer's Disease Knowledge Scale score: 24.67 (3.43); 24.13 (3.32)

Inclusion criteria
Users who were
• sufficiently literate to use STAR website
• informal or professional carers for people living with dementia living in community or dementia volunteers
Exclusion criteria
None reported</td>
<td></td>
<td>organisations, case managers, care organisations and dementia-related websites). Users in UK recruited from carers cafes, church groups, university service users, carer groups and local dementia and welfare organisations. Users who consented and who were in intervention group were sent link to STAR website.
• Self-Help Psychosocial (STAR=Skills Training and Reskilling portal) STAR designed to be accessed from any internet-enabled device and consists of online course with 8 modules - comprising text, videos, interactive exercises, knowledge tests, and references to other websites, literature, and videos - covering dementia and supporting it. Themes covered in modules (2 basic, 6 intermediate/advanced)</td>
<td><table>
<tr><td>custom measure)
(24; 30)</td><td></td><td></td></tr>
<tr><td>Quality of life^ (2 items, custom measure)</td><td>7.05 (1.77)</td><td>6.48 (1.58)</td></tr>
<tr><td>Carer burden^ (1 item, custom measure)</td><td>2.43 (0.98)</td><td>2.8 (0.96)</td></tr>
<tr><td>SSCQ^</td><td>4.67 (1.06)</td><td>4.04 (1.49)</td></tr>
<tr><td>IRI-distress (27; 32)</td><td>9.74 (5.33)</td><td>13.59 (5.63)</td></tr>
<tr><td>IRI-empathy (27; 32)</td><td>20.40 (4.06)</td><td>13.03 (5.63)</td></tr>
<tr><td>IRI-fantasy (27; 32)</td><td>14.30 (5.24)</td><td>12.84 (4.43)</td></tr>
<tr><td>IRI-perspective (27; 32)</td><td>18.81 (3.45)</td><td>13.75 (4.45)</td></tr>
</table></td>
<td>• Blinding of outcome assessment: Low risk (not applicable)
• Incomplete outcome data: Low risk (39% dropout rate, missing data balanced across groups for similar reasons)
• Selective reporting: Low risk (CONSORT form available, all outcomes reported)
• Other bias: Low risk (appears free from other sources of bias)</td>
</tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
Funded by Leonardo da Vinci Life Long Learning Programme of the European Union (no. 510364-2010) and the BAVO Foundation in Netherlands			are (1) What dementia is, (2) Living with dementia, (3) diagnosis and its importance, (4) Practical difficulties in daily life and how to help by best practice, (5) emotional impact of dementia and how adaptation and coping influences behaviour and mood, (6) Support strategies to help people cope with consequences of dementia, (7) Positive and empathic communication, and (8) Emotional impact and looking after oneself. User answers questions posed by an interactive 'learning adviser' to assess baseline knowledge and confidence in order to personalise learning and training through course of modules. Progress was self-guided and asked to complete at least 4 modules (knowledge tests, interactive exercises, watch videos). Modules include	Note: ^, data from carers only (n=21 online group, n=25 WLC group) Mean usefulness of STAR (scale 1-10; higher=more useful): UK laypeople (n=9)=8.27 (0.41); Netherlands laypeople (n=17)=7.74 (0.87)	

<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>interactive exercises at basic and intermediate levels to test learning; if score is insufficient, users encouraged to retake module and quiz. All users were encouraged to join online Facebook community for the country in which they were participating in.
• WLC
• Users waited for 4 months before they could register to use STAR.</td><td></td><td></td></tr>
<tr><td>Full citation
Hebert, Rejean, Levesque, Louise, Vezina, Jean, Efficacy of a psychoeducative group program for caregivers of demented persons living at home, Journals of Gerontology: Series B, Psychological Sciences and Social Sciences, 2003

Ref Id
707216</td><td>Sample size
N=158 carers randomised in 12 waves across 6 centres.
• Intervention, n=72
• Control, n=72

Characteristics
Carer characteristics
• Age (years): 59.78 (11.86); 59.77 (13.93)
• Female (%): 80; 81
• Husband or wife of care recipient (%): 62; 60
• Years education: 11.77 (3.8); 12.19 (4.38)
• Years caring: 2.9 (2.23); 2.74 (2)</td><td>• Intervention: Group Psychoeducation
• Control: TAU</td><td>• Carers recruited through Alzheimer socieities and home care organisations in 5 regions in Quebec, Canada. Randomisation occurred in particular region when at least 12 carers recruited. 14 carers excluded because intervention did not occur in centre due to carer dropout. Further 26 carers dropped out (patient institutionalised=24 [11 in intervention, 13 in control]; carer no longer primary carer=1; death of patient=1). Assessments</td><td>Carer Outcomes at post-intervention (quasi-ITT analysis) - change scores (negative sign=improvement)
<table>
<tr><th>Outcomes</th><th>Group PE (n=60)</th><th>TAU (n=56)</th></tr>
<tr><td>RMBPC-frequency</td><td>-0.07 (0.41)</td><td>0.12 (0.51)</td></tr>
<tr><td>RMBPC-reaction</td><td>-0.28 (0.55)</td><td>-0.1 (0.6)</td></tr>
<tr><td>RMBPC-cross product</td><td>-0.61 (1.53)</td><td>0.13 (1.86)</td></tr>
</table></td><td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Low risk (Minimization stratified by carer relation to recipient and gender)
• Allocation concealment: Unclear risk (insufficient information)
• Blinding of participants/personnel: High 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>**Country/ies where the study was carried out**
Canada

Study type
Multisite RCT

Aim of the study
To assess efficacy of group psychoeducation in carers of people of dementia living in their own homes

Study dates
Unclear, not reported

Setting
Community

Source of funding
N/R</td>
<td>• Living with care recipient (%): 85; 86.2
• Paid work (%): 22; 36 ZBI: 42.47 (14.63); 41.44 (15.16)
• RMBPC-frequency: 1.64 (0.51); 1.55 (0.63)
• RMBPC-reaction: 2.01 (0.75); 2.18 (0.69)
• RMBPC-cross product frequency-reaction: 3.48 (1.75); 3.56 (2.36)
• STAI: 41.01 (12.96); 45.46 (14.82) BRAS: 10.9 (3.06); 10.66 (3.8)
• ISSB-supportive: 10.77 (3.41); 11.24 (3.55)
• ISSB-tangible: 12.87 (3.89); 12.22 (3.1)
• ISSB-emotional: 23.83 (6.81); 23.37 (7.61)
• ISSB-integrative: 23.68 (5.49); 23.74 (6.02)
• PES: 77.67 (16.68); 69.83 (19.42)
• IPSI: 26.17 (6.94); 26.45 (8.12)
• Desire to institutionalise care recipient (%): 52; 31
Care recipient characteristics
• Age (years): 73.6 (7.8); 74.67 (7.07)</td>
<td></td>
<td>at baseline and post-intervention (16 weeks).
• Group Psychoeducation Consisted of 15 2-hr sessions comprised of 2 components:
• Cognitive appraisal (4 sessions): to improve carer ability to shift from thinking of overall stressful situation to reducing to component parts, to develop ability to delineate things about situations that can and cannot be changed through use of emotional and problem-solving strategies, and to encourage awareness of link between changing nature of stressful situation and available coping strategies. Carers also given individualised home assignment to facilitate learning.
• Coping strategies: (11 sessions): improving problem-solving, reframing and seeking social support; establish link between how situation changes to</td>
<td><table>
<tr><td>RMBPC-disruptive behaviours frequency</td><td>-0.06 (0.56)</td><td>0.15 (0.61)</td></tr>
<tr><td>RMBPC-disruptive behaviours reaction</td><td>-0.41 (0.87)</td><td>-0.03 (0.83)</td></tr>
<tr><td>RMBPC-disruptive behaviours cross product</td><td>-0.51 (1.68)</td><td>0.2 (1.64)</td></tr>
<tr><td>ZBI-22</td><td>-2.4 (14.96)</td><td>0.09 (11.99)</td></tr>
<tr><td>STAI-state anxiety</td><td>-1.27 (16.47)</td><td>-1.64 (14.49)</td></tr>
<tr><td>IPSI</td><td>-1.16 (7.98)</td><td>0.65 (6.03)</td></tr>
<tr><td>IISB-supportive</td><td>-0.5 (3.03)</td><td>-0.62 (3.15)</td></tr>
<tr><td>IISB-tangible</td><td>-0.67 (4.01)</td><td>0.06 (3.18)</td></tr>
<tr><td>IISB-emotional</td><td>-0.96 (5.21)</td><td>0.04 (6.02)</td></tr>
<tr><td>IISB-integrative</td><td>0.22 (4.53)</td><td>-0.82 (4.74)</td></tr>
</table></td>
<td>(participants and personnel not blinded; potential performance bias)
• Blinding of outcome assessment: Low risk (assessors blinded to group allocation)
• Incomplete outcome data: Low risk (missing data balanced in numbers and similar reasons across groups)
• Selective reporting: Unclear risk (insufficient information)
• Other bias: High risk (at baseline, Personal Efficacy Scale scores significantly worse in control group and significantly more carers in intervention group desired institutionalisation of care recipient)</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>• Diagnosis of Alzheimer's Disease (%): 81; 77
• Taking anti-dementia drugs (%): 63; 50

Inclusion criteria
Carer
• who is primary carer of person with demenia
• carer for at least 6 months
• had moderate carer burden (Zarit Burden Inventory score>9)
• not participating in other support group or psychotherapy during trial
• supporting at least one behaviour problem per week

Exclusion criteria
• Carers were excluded from trial if caring circumstances changed</td><td></td><td>choosing appropriate coping strategy.
• TAU
Carers in this group referred to regular group support program offered by Alzheimer Society or health care organisations in relevant region. These programs are free of charge and do not have waiting lists.</td><td><table><tr><td>PES</td><td>-3.08 (20.71)</td><td>0.06 (21.73)</td></tr><tr><td>BRAS</td><td>0.08 (3.39)</td><td>-0.19 (3.02)</td></tr></table>Desire to institutionalize (%): 61; 59</td><td></td></tr>
<tr><td>Full citation
Hoyle, D, Slater, J, Williams, C, Schmidt, U, Wade, Td, Evaluation of a web-based skills intervention for</td><td>Sample size
N=37 carers randomised
• Intervention, n=19
• Control, n=18

Characteristics</td><td>• Intervention: Guided Self-Help Skills training
• Control: Self-Help Skills training</td><td>• Carers recruited from websites of consumer support associations in Australia, the Somerset and Wessex Eating Disorder Association in the UK, and advertisements on</td><td>Note: all data is means and standard errors.
Carer outcomes post-intervention<table><tr><td>Outcomes</td><td>Guided SH</td><td>SH (n=18)</td></tr></table></td><td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Unclear</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>carers of people with anorexia nervosa: a randomized controlled trial, International Journal of Eating Disorders, 46, 634-638, 2013

Ref Id
709111

Country/ies where the study was carried out
Australia, UK

Study type
RCT

Aim of the study
To assess efficacy of online self-help skills training program ('Overcoming Anorexia Online') with and without professional guidance in carers</td>
<td>Carer characteristics (whole sample)
- Female (%): 89
- Lived with care recipient (%): 83%
- Care recipient characteristics
- None reported

Inclusion criteria
- Carer of person with anorexia nervosa who speaks fluent English

Exclusion criteria
None reported</td>
<td></td>
<td>anorexia nervosa-related/carer-related groups on the social network Facebook. Carers directed to website upon providing consent with instructions on how to access online self-report assessment questionnaires. Consent from care recipient also obtained for involvement in study if possible. Self-report assessment at baseline, post-intervention (7 weeks) and 3-mo FU.
- Self-Help Skills Training Intervention consists of further 7 modules/workbooks, based on cognitive-behavioural therapy principles. Module 1: information about anorexia nervosa and introduction to CBT principles; module 2: understanding anorexia, communication and motivational skills; module 3: effect of anorexia on family; module 4: meal support;</td>
<td>
<table>
<tr><td></td><td>(n=18)</td><td></td></tr>
<tr><td>LEE-total</td><td>1.86 (0.08)</td><td>2.03 (0.08)</td></tr>
<tr><td>GHQ-28</td><td>2.91 (0.15)</td><td>2.78 (0.15)</td></tr>
<tr><td>SF-36</td><td>64.75 (3.87)</td><td>57.10 (3.86)</td></tr>
<tr><td>DASS-21</td><td>19.03 (4.86)</td><td>27.92 (4.85)</td></tr>
<tr><td>EDSIS-total</td><td>36.06 (3.76)</td><td>31.15 (3.80)</td></tr>
<tr><td>ECI-negative</td><td>90.21 (8.64)</td><td>81.76 (8.68)</td></tr>
<tr><td>ECI-positive</td><td>30.40 (2.71)</td><td>25.80 (2.73</td></tr>
</table>
Carer outcomes at 3-mo FU
<table>
<tr><td>Outcomes</td><td>Guided SH (n=18)</td><td>SH (n=18)</td></tr>
<tr><td>LEE-total</td><td>1.80 (0.08)</td><td>2.12 (0.08)</td></tr>
<tr><td>GHQ-28</td><td>2.91 (0.15)</td><td>2.90 (0.13)</td></tr>
<tr><td>SF-36</td><td>64.76 (4.87)</td><td>60.32 (4.54)</td></tr>
</table>
</td>
<td>risk (insufficient information)
- Allocation concealment: Unclear risk (insufficient information)
- Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance bias)
- Blinding of outcome assessment: Low risk (online assessment, not applicable)
- Incomplete outcome data: Low risk (1 participant withdrew from guidance group, not sufficient to impact effect estimates)
- Selective reporting: Unclear risk (insufficient information)
- Other bias: Low risk (appears free</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>of people with anorexia nervosa

Study dates
10/2010 to 08/2012

Setting
In home/online

Source of funding
None reported</td>
<td></td>
<td></td>
<td>module 5: risk and prognosis of anorexia; module 6: role of related behaviours in maintaining anorexia; module 7: relapse prevention. Carers also received hard copies of intervention and 2 additional workbooks on self-care (module 8: carer's own needs and developing plan to meet these; module 9: role of various professionals, available/accessing treatments and resources.
Guidance versus no guidance
Carers in guidance group received weekly professional support from masters-level trainee psychologist by email or telephone. Carers in no guidance group did not receive additional support.</td>
<td><table>
<tr><td>DASS-21</td><td>17.92 (4.92)</td><td>24.45 (4.57)</td></tr>
<tr><td>EDSIS-total</td><td>36.13 (4.23)</td><td>29.08 (4.06)</td></tr>
<tr><td>ECI-negative</td><td>98.41 (9.68)</td><td>80.99 (9.26)</td></tr>
<tr><td>ECI-positive</td><td>27.21 (2.25)</td><td>25.65 (2.22)</td></tr>
</table></td>
<td>from other sources of bias)

Other information
Care recipient characteristics not reported so unclear applicability to adult population; given profile of anorexia nervosa patients, plausibly applicable to carers of young people with continuing health/social care needs.</td>
</tr>
<tr>
<td>Full citation
Klodnicka Kouri, Krystyna, Ducharme, Francine C., Giroux, Francine, A psycho-</td>
<td>Sample size
N=50 carers
Intervention, n=25
Control, n=25</td>
<td>Intervention: Psychoeducation
Control: Information only</td>
<td>Sample recruited via memory clinics, geriatric assessment unit, and community in south-west Quebec. All 25 carers completed intervention,</td>
<td>Carer outcomes at 1-wk post-test<table>
<tr><td>Outcomes*</td><td>Psychoeducation (n=25)</td><td>Information (n=25)</td></tr>
</table></td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)</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>educational intervention focused on communication for caregivers of a family member in the early stage of Alzheimer's disease: Results of an experimental study, Dementia: The International Journal of Social Research and Practice, 10, 435-453, 2011

Ref Id
709237

Country/ies where the study was carried out
Canada

Study type
RCT

Aim of the study
To develop and test efficacy of individualised psychoeducation</td>
<td>**Characteristics**
Carer characteristics
• Age (years): 59.12 (8.56); 64.8 (10.5)
• Gender (M/F): 5/20; 4/21
• Caucasian: 100% (whole sample)
• Duration of caring (<1 year/1-2 years/2+ years): 2/7/16; 0/8/17
Education status (primary/secondary): 0/25; 23/2
• Employment status (full-time/part-time/homemaker/retired): 6/5/3/11; 3/5/2/15
• Relationship to care recipient (married or civil/child/other relation/friend): 7/15/0/3; 11/11/3/0
• Lives with care recipient? 40%; 44%
• Carer knowledge (adapted measure): 29.12 (9.42); 33.44 (9.95)
• RMPC: 1.65 (0.57); 1.65 (0.61)
• Carer disturbance (adapted measure): 1.04 (0.73); 1.1 (0.57)</td>
<td></td>
<td>with 21 doing so within 5-wk period and remaining 4 carers deferring session (due to for example illness) to subsequent week. Assessments, all of which were self-reported, were at baseline (1 week pre-intervention), 1 week and 6 weeks post-intervention and were completed in presence of trained research assistants (2 nurses, 1 social worker, 6-hr training program) blind to group allocation.
• Psychoeducation
Consisted in 5 weekly structured sessions, approx. 90-120 min each, delivered by researchers. Fidelity ensured using checklist completed by trained nurse practitioner. Program comprised of 5 modules with each module covering communication difficulties associated with cognitive limitations (for example concentration, attention, memory, orientation, judgment, reasoning,</td>
<td>
<table>
<tr><td>Carer knowledge (adapted measure)</td><td>40.43 (7.65)</td><td>34.41 (9.86)</td></tr>
<tr><td>RMBPC</td><td>1.74 (0.55)</td><td>1.7 (0.59)</td></tr>
<tr><td>Carer disturbance (adapted)</td><td>0.63 (0.7)</td><td>0.95 (0.44)</td></tr>
<tr><td>CSQ</td><td>3.41 (0.75)</td><td>3.27 (1.03)</td></tr>
<tr><td>CSS</td><td>93.48 (5.0)</td><td>90.33 (5.0)</td></tr>
<tr><td colspan="3">*Data are adjusted means, except for CSS outcome</td></tr>
</table>
Carer outcomes at 6-wk FU
<table>
<tr><td>Outcomes*</td><td>Psychoeducation (n=25)</td><td>Information (n=25)</td></tr>
<tr><td>Carer knowledge (adapt</td><td>40.83 (7.48)</td><td>33.37 (10.17)</td></tr>
</table>
</td>
<td>• Random sequence generation: Unclear risk (insufficient information)
• Allocation concealment: Unclear risk (insufficient information)
• Blinding of participants/personnel: High risk (participants/personnel not blinded, possibility of performance bias)
• Blinding of outcome assessment: Low risk (all measures were self-report in presence of assessor, who was blinded to group assignment)
• Incomplete outcome data: Low risk (7 participants dropped out before randomisation mainly due to death/illness of carer or care recipient)</td>
</tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
intervention focused on communication for carer of person with cognitive problems associated with early stage of Alzheimer's Disease **Study dates** Not reported, 20-month period **Setting** Community (Urban and rural) **Source of funding** Funded by the Quebec Interuniversity Nursing Intervention Research Group, the Desjardins Research Chair in Nursing Care for Seniors and their Families, the Fondation derecherche en sciences infirmieres du Quebec, the	• CSQ: 3.05 (0.89); 2.97 (0.94) • CSS: 87.79 (8.99); 89.68 (5.12) **Inclusion criteria** Carers who • self-identified as primary carers of family member or friend diagnosed with cognitive problems associated with early stage of probable Alzheimer's Disease (AD) (as determined by MMSE score 20-28) • were aged≥55-years old • could communicate in English or French **Exclusion criteria** Carers who • were currently or recently participating in educational/support group or similar forum • were unable to assume role of learner (that is had cognitive or other problems)		mood variability, emotions and visual-spatial and executive functions). Participants given opportunity to master/use communication skills, learn about communication models, and strategies to reduce their fear and anxiety. • Information Consisted in printed flier on memory and communication problems adapted from publication Memory Loss and Aging (College of Family Physicians of Canada 1996).	ed measure) | | RMBPC | 1.86 (0.54) | 1.68 (0.57) Carer disturbance (adapted) | 0.53 (0.76) | 1.03 (0.42) CSQ | 3.69 (0.48) | 3.03 (0.93) CSS | 94.44 (5.0) | 88.93 (5.82) *Data are adjusted means, except for CSS outcome	• Selective reporting: Unclear (insufficient information) • Other bias: High risk (Control group significantly older than intervention group, p<0.05)

<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>Canadian Nurses Foundation and the Research Centre on Aging of the University Institute of Geriatrics of Sherbrooke, Canada.</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Full citation
Liddle, J, Smith-Conway, Er, Baker, R, Angwin, Aj, Gallois, C, Copland, Da, Pachana, Na, Humphreys, Ms, Byrne, Gj, Chenery, Hj, Memory and communication support strategies in dementia: effect of a training program for informal caregivers, International Psychogeriatrics, 24, 1927-1942, 2012

Ref Id
709329</td><td>Sample size
N=36 patient-carer dyads randomised
• Intervention, n=13 dyads
• Control, n=16 dyads

Characteristics
Carer characteristics
• Age (years): 72.85 (8.34); 65.38 (10.07)
• Gender (M/F): 4/9; 1/15
• Years of carer education: median=12 (IQR 10-15); median=11 (IQR 10-13)
• Relationship to care recipient (spouse/offspring/parent/friend): 11/1/1/0; 11/3/0/2
• Overall carer health (poor/fair/good/excellent): 0/2/7/4; 0/2/10/4
• CMSD: median=7 (IQR6-7.5); median=6.5 (IQR 5-7.75)</td><td>• Intervention: Guided Self-Help Behavioural Management training
• Control: TAU</td><td>• Dyads completed assessments (baseline) and carers started training sessions within 1 week. Follow-up was 3 months after completion of training program.
• Guided Self-Help Behavioural Management training
Consisted in watching DVD at dyad's own home during 2 x 45 min sessions based on RECAPS memory support strategies and the MESSAGE communication support strategies. First session covered communication strategies (MESSAGE training), whilst second session covered memory strategies (RECAPS training). Sessions overseen by 2</td><td>Carer outcomes at 3-mo FU
<table>
<tr><td>Outcomes*</td><td>Guided SHBM (n=13)</td><td>TAU (n=16)</td><td>Notes</td></tr>
<tr><td>CMSD</td><td>9 (8-11.5)</td><td>5.75 (4.75-8.25)</td><td>sig group x time (p=0.0011), group (p=0.0165)</td></tr>
<tr><td>ZBI</td><td>14.38 (9.47)</td><td>16.69 (9.29)</td><td>n.s. group, time, group x time; 62% versus 38% improved</td></tr>
</table></td><td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Unclear risk (insufficient information)
• Allocation concealment: Unclear risk (insufficient information)
• Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance bias)
• Blinding of outcome assessment: High risk for all outcomes except</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>Country/ies where the study was carried out
Australia

Study type
RCT

Aim of the study
To evaluate effectiveness of DVD-based carer training program on carer experience and well being of person with dementia

Study dates
07/2011 to 02/2011

Setting
In home

Source of funding
Funded by J.O. and J.R. Wicking Trust (managed by ANZ trustees) and the National Health and Medical Research</td>
<td>• ZBI (short version): 15.85 (8.85); 14.5 (9.29)
• PAC: median=31 (IQR 27-37); median=32 (23-39.5)
• RMBPC memory problems-frequency: median=18 (16-25); median=22 (IQR 13.5-24.5)
• RMBPC memory problems-reaction: median=5 ((IQR 2-7); median=5 ((IQR 2.5-8.5)

Care recipient (person with dementia) characteristics
• Age (years): 75.85 (6.77); 77.81 (10.53)
• Gender (M/F): 10/3; 11/5
• Overall health (poor/fair/good/excellent): 2/5/5/1; 1/3/7/5
• Diagnosis (Alzheimer's/vascular/frontotemporal/NOS/other): 5/1/2/4/1; 7/3/0/5/1

Inclusion criteria
Carers who
• were living with person diagnosed with medically</td>
<td></td>
<td>researchers (with either psychology or speech pathology qualifications), who monitored reception of training, encouraged discussion, collected outcome data and answered any questions about training. CMSD completed after each session; training satisfaction/suggestions survey completed at end of training.
• TAU (No training)
• Carers completed assessments at baseline and at 3-mo FU. Training DVD given to carers after 3-mo FU.</td>
<td>
<table>
<tr><td>PAC</td><td>30 (26-35)</td><td>34 (16-38)</td><td>near sig time (p=0.039); near sig group (p=0.039); 46% v 13% improved</td></tr>
<tr><td>RMBPC memory problems-frequency</td><td>19 (11-26)</td><td>23.5 (15-26.5)</td><td>ns, group; near sig, group x time (p=0.028)</td></tr>
<tr><td>RMBPC memory problems-reaction</td><td>4 (2-7)</td><td>8 (2-14.5)</td><td>ns</td></tr>
<tr><td>RMBPC disruptive behaviours-</td><td>3 (1-7)</td><td>5 (2.5-8.5)</td><td>ns, groupl near sig, group x time (p=0.028)</td></tr>
</table>
</td>
<td>CMSD (assessors not blinded except for CMSD)
• Incomplete outcome data: Unclear risk (7 dyads withdrew due to reasons unlikely related to intervention. No information provided as to dyads group allocation)
• Selective reporting: Unclear risk (insufficient information)
• Other bias: Low risk (appears free from other sources of 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>Council (Grant ID 511208).</td>
<td>diagnosed dementia (including Alzheimer's Disease)
• were the primary carer
• gave informed consent
• People diagnosed with dementia who
• could provide responses to direct assessment measures
• gave informed consent

Exclusion criteria
Not reported</td>
<td></td>
<td></td>
<td><table>
<tr><td>frequency</td><td></td><td></td><td></td></tr>
<tr><td>RMBPC disruptive behaviours-reaction</td><td>3 (1-4)</td><td>3.5 (1-6)</td><td>ns</td></tr>
<tr><td>CSDD - frequency</td><td>7 (2-11)</td><td>4 (2.5-8)</td><td>near sig, group (p=0.024)</td></tr>
<tr><td>CSDD - reaction</td><td>2 (0-8)</td><td>2 (0.5-5)</td><td>ns</td></tr>
<tr><td colspan="4">*All data is median and IQR, except for ZBI which is mean and SD ; α=0.00385 due to multiple comparisons (Bonferroni)</td></tr>
</table></td>
<td></td>
</tr>
<tr>
<td>Full citation
Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., Romeo, R., King, D., Livingston, D., Lewis-Holmes,</td>
<td>Sample size
N=260
• Intervention, n=173
• Control, n=87

Characteristics [Intervention; Control]</td>
<td>• Intervention: Coping Skills traiing
• Control: TAU</td>
<td>• Randomisation stratified by health trust using random permuted blocks with ratio of 2:1 (invention: TAU). Participants assessed at baseline, 4, 8, 12 and 24 months.</td>
<td>Outcomes at 8 months<table>
<tr><td>Outcome</td><td>Inter-vention</td><td>N</td><td>Control</td><td>N</td></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>
</table></td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Low risk (online</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>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 living 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</td>
<td>**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)
• 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</td>
<td></td>
<td>• 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 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.</td>
<td><table>
<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>
</table></td>
<td>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 (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</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
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

Setting
Home, NHS trust or participating neurology clinic

Source of funding
Health Technology Assessment programme of NIHR</td>
<td>• Living with carer: 65.3%/57.5%

Inclusion criteria
Family carers of people living with dementia 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
lived >1.5 hrs travelling time from researcher base</td>
<td></td>
<td>• 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><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>
</table>
*Data from Cooper 2016

At 24 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>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>
</table>
</td>
<td>protocol available, all outcomes reported)
• Other bias: None
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 group), wanting intervention treatment (4 in TAU group), did not like intervention (3 in intervention group); 6 provided no reason (5 intervention, 1 TAU).</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>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></td><td></td></tr>
<tr><td>Full citation
Cooper, C., Barber, J., Griffin, M., Rapaport, P., Livingston, G., Effectiveness of START psychological intervention in reducing abuse by dementia family carers: randomized controlled trial, International Psychogeriatrics, 28, 881-7, 2016

Ref Id
711825

Country/ies where the study was carried out</td><td>Sample size
• See entry for Livingston 2014

Characteristics
• See entry for Livingston 2014

Inclusion criteria
• See entry for Livingston 2014

Exclusion criteria
• See entry for Livingston 2014</td><td>• Intervention: Coping Skills training
• Control: TAU</td><td>• See entry for Livingston 2014</td><td>Results
• See entry for Livingston 2014</td><td>Limitations
• See entry for Livingston 2014</td></tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
UK **Study type** Multisite RCT **Aim of the study** To assess efficacy of START intervention in reducing abuse of people living with dementia by their carers **Study dates** 11/2009 to 06/2013 **Setting** Home, NHS trust or participating neurology clinic **Source of funding** See entry for Livingston 2014					
Full citation Lobban, F., Glentworth, D., Chapman, L., Wainwright, L., Postlethwaite, A.,	**Sample size** N=103 carers randomised - Intervention, n=51 - Control, n=52	- **Intervention:** Guided Self-help Coping Skills training + TAU - **Control:** TAU	- Carers recruited from 3 NHS trusts. Face-to-face assessments at baseline and post-intervention (6 months) at convenient location (for example	Carer outcomes at post-intervention (6 months) Outcomes | GuidedSHCS+TAU | TAU (n=45)	**Limitations (assessed using the Cochrane 'Risk of bias' tool for randomized trials)**

<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>Dunn, G., Pinfold, V., Larkin, W., Haddock, G., Feasibility of a supported self-management intervention for relatives of people with recent-onset psychosis: REACT study, British Journal of Psychiatry, 203, 2013

Ref Id
532457

Country/ies where the study was carried out
UK

Study type
RCT

Aim of the study
To assess efficacy of guided self-help coping skills training toolkit in carers of</td>
<td>Characteristics
Carer characteristics (whole sample)
• Gender (M/F): 18/85
• White British (%): 94
• Employment (% full-time/part-time/unemployed or retired): 33/21/45
• Lived with care recipient (%): 73
Care recipient
• Known diagnosis (% psychosis/schiozphrenia/bipolar disorder): 50/8/5
• Median duration of illness (months): 36 months (range 3/240)
• Median time since diagnosis (months): 9 (range 0-144)

Inclusion criteria
Carers
• relatives/partners/close friends of person experiencing psychosis
• direct contact with care recipient
• self-identified main carer
• ≥18 years-old</td>
<td></td>
<td>carer home, NHS or university premises).
• Guided Self Help Coping Skills training ('REACT' - Relatives' Education and Coping Toolkit) + TAU Carers given both printed version and access to online version of toolkit, which consisted in 13 modules of between 11 and 23 A5 pages that carer could cover at own pace. Intervention delivered by 1 of 6 early interventions support worker (who received 4 days training over 3 months). Modules use case examples to facilitate finding information relevant to carer's particular circumstances. Modules covered: information about psychosis, managing symptoms and crises; stress management; mental health services; treatment options; resource directory (43 pages); terms of jargon. Uses signposting to other</td>
<td>
<table>
<tr><td></td><td>(n=41)</td><td></td></tr>
<tr><td>GHQ-28</td><td>23.42 (15.20)</td><td>28.30 (15.42)</td></tr>
<tr><td>ECI-negative</td><td>85.53 (43.69)</td><td>100.91 (34.93)</td></tr>
<tr><td>ECI-positive</td><td>30.70 (10.56)</td><td>30.64 (9.28)</td></tr>
<tr><td>CWSQ-well being</td><td>89.61 (29.71)</td><td>79.50 (32.47)</td></tr>
<tr><td>CWSQ-support</td><td>39.60 (10.31)</td><td>33.89 (12.19)</td></tr>
<tr><td>FQ-concern</td><td>68.92 (16.95)</td><td>76.62 (16.95)</td></tr>
<tr><td>FQ-coping</td><td>40.03 (19.92)</td><td>54.25 (20.73)</td></tr>
<tr><td>HHI</td><td>37.94 (5.94)</td><td>37.15 (6.77)</td></tr>
</table>
</td>
<td>• Random sequence generation: Low risk (varying block randomisation)
• Allocation concealment: Low risk (central allocation used)
• Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance bias)
• Blinding of outcome assessment: Unclear risk (although assessors blinded to group assignment, blinding was broken for 9 carers at assessment)
• Incomplete outcome data: Low risk (similar dropout rates for similar reasons)
• Selective reporting: Low risk (protocol available, all main</td>
</tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
people with recent-onset psychosis **Study dates** Unclear, not reported **Setting** In home/telephone **Source of funding** Funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number RfPB PB-PG-0807-14075)	• competent in writing and speaking English • Care recipient • aged between 14 and 35 • currently supported by early intervention services in participating NHS Trust • first contact with early intervention services within past 24 months **Exclusion criteria** None reported		resources requiring regular updating of toolkit. Initial session was face-to-face for introduction to toolkit and to arrange mode of support (telephone or email). Support consisted of maximum 1 hour per week over course of 6 month intervention and acted to facilitate identification of key problems, find relevant resources in toolkit, and engage in problem solving. Minimum of 6 support contacts in case that carers did not respond or initiate contact. • TAU Consisted in carer assessment and ongoing assessment of care recipient needs; shared formulation of individual and family issues; information about mental health and related health/social care system; practical support; links to other support services; crisis intervention; relapse		outcomes measures reported) • Other bias: Low risk (appears free from other sources of bias) **Other information** • Includes carers of people below age of 16 years; only one carer requested access to online version of toolkit.

<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>prevention; stress management; referral to structured family intervention if needed.</td><td></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</td>
<td>Sample size
N=223 carers
- Intervention, n=109
- Control, n=114

Characteristics
Carer characteristics
- Age (years): 59.2 (11.4); 61.1 (11.6)
- Gender (M/F): 22/87; 31/83
- Education level (no degree/primary/secondary/university): 7/38/34/30; 12/48/39/15
- Employment status (employed/unemployed/housewife/retired/disabled): 41/8/33/27/0; 30/14/36/32/2
- Relationship to care recipient (parent/spouse or partner/brother or sister/child/other): 78/7/18/2/4; 87/6/20/0/1
- Duration of carer role (years): 14.2 (9.8); 15.5 (10.1)</td>
<td>- Intervention: Group Psychoeducation + TAU
- Control: TAU</td>
<td>- Assessment conducted at baseline, post-intervention (after 4 months), and subsequent 4-mo FU. Trial ended for individual carer if they withdrew consent or there were protocol deviations (assessed by central research committee) or care recipient (i) moved from outpatient to inpatient/residential care setting or (ii) was discharged from healthcare service.
- Group Psychoeducation + TAU
Consisted in 12 structured and manualised weekly sessions, each lasting 90-120 mins with 15 min break in middle of session (total=4 months), delivered by trained psychologist or psychiatrist Carers received standardised information about</td>
<td>Results
Carer changes scores (post-intervention - baseline) - Completer case analysis
<table>
<tr><th>Outcomes</th><th>Group PE+ TAU (n=86)</th><th>TAU (n=97)</th></tr>
<tr><td>ZBI-22</td><td>-4.60 (12.68)</td><td>-0.27 (12.07)</td></tr>
<tr><td>IEQ-total</td><td>-4.52 (11.58)</td><td>-1.72 (12.13)</td></tr>
<tr><td>IEQ-tension</td><td>-1.16 (4.19)</td><td>0.09 (5.34)</td></tr>
<tr><td>IEQ-supervision</td><td>-0.77 (3.54)</td><td>-0.56 (2.84)</td></tr>
<tr><td>IEQ-worries</td><td>-1.42 (5.02)</td><td>-0.29 (5.46)</td></tr>
<tr><td>IEQ-urging</td><td>-1.43 (4.97)</td><td>-0.94 (4.98)</td></tr>
<tr><td>CES-D</td><td>-2.86</td><td>0.36</td></tr>
</table></td>
<td>Limitations (assessed using the Cochrane 'Risk of bias' tool for randomized trials)
- Random sequence generation: Low risk (computer-generated block randomisation, size 1 to 4)
- Allocation concealment: Low risk (central allocation)
- Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance bias)
- Blinding of outcome assessment: Low risk (all measures self-report, assessor was blinded to group assignment)</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>**Country/ies where the study was carried out**
Spain, Portual

Study type
Multisite RCT

Aim of the study
To assess efficacy of psychoeducation compared to standard care on reducing burden of carers of people with schizophrenia

Study dates
03/2012 to 05/2012

Setting
24 outpatient psychiatric clinics (21 in Spain, 3 in Portugal)

Source of funding
Research grant from Instituto de</td>
<td>• Hours per day spent caring: 5.3 (1.4); 5.2 (1.4)
• Diagnosis: data not reported

Inclusion criteria
Carers who
• aged ≥18 years-old
• supporting relative with schizophrenia or schizoaffective disorder
• spent minimum of 4 hours/week supporting person
• Person with schizophrenia or schizoaffective disorder who
• was diagnosed at least 2 years before trial

Exclusion criteria
Carers who
• did not have time to attend weekly sessions
• were receiving or received in last year similar standardised psychoeducational intervention
• Person with schizophrenia or</td>
<td></td>
<td>schizophrenia and given cognitive/behavioural skills training . Intervention required active participation from carers (for example role playing). Contents of sessions included understanding mental illness (sessions 1+2), treatment of schizophrenia/dealing with emergencies (session 3), taking care of oneself (session 4), stress and well-being (session 5), role of thinking (session 6), engaging in pleasant activities (session 7), communication skills (session 8), behavioural management (session 9), problem solving (session 10), demanding situation (session 11), and available resources/services (session 12).
• TAU
Carers received usual support from outpatient service where care recipient treated, and had</td>
<td>
<table>
<tr><td></td><td>(9.17)</td><td>(9.60)</td></tr>
<tr><td>GHQ-28-total</td><td>-4.59 (11.00)</td><td>-1.25 (11.20)</td></tr>
<tr><td>GHQ-28-somatic</td><td>-0.89 (3.88)</td><td>-0.02 (3.88)</td></tr>
<tr><td>GHQ-28-anxiety/ insomnia</td><td>-1.84 (4.57)</td><td>-0.73 (3.71)</td></tr>
<tr><td>GHQ-28-social dysfunction</td><td>-1.60 (3.32)</td><td>-0.15 (2.96)</td></tr>
<tr><td>GHQ-28-severe depression</td><td>-0.26 (2.49)</td><td>-0.34 (3.79)</td></tr>
</table>
Carer changes scores (4-mo FU - baseline) - Completer case analysis
<table>
<tr><td>Outcomes</td><td>Group PE +TAU (n=82)</td><td>TAU (n=91)</td></tr>
<tr><td>ZBI-22</td><td>-5.67 (10.97)</td><td>-1.21 (11.09)</td></tr>
</table>
</td>
<td>• Incomplete outcome data: High risk (At post-intervention and 4-mo FU, 19% and 5% dropout rate, respectively, in intervention group and 10% and 5%, respectively, dropout rate in control group, reasons likely related to true outcome)
• Selective reporting: Unclear risk (insufficient information)
• Other bias: Low risk (appears free from other sources of 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>Salud Carlos III, Spain (PI10/01049).</td>
<td>schizoaffective disorder who
• was hospitalised in month before trial or was in residential care
• presented with mental retardation, dementia or other organic cognitive disorder</td>
<td></td>
<td>regular interviews and updates about care recipient.</td>
<td>
<table>
<tr><td>IEQ-total</td><td>-5.46 (12.09)</td><td>-2.60 (12.18)</td></tr>
<tr><td>IEQ-tension</td><td>-1.48 (3.69)</td><td>-0.48 (4.19)</td></tr>
<tr><td>IEQ-supervision</td><td>-1.05 (3.39)</td><td>-0.41 (3.08)</td></tr>
<tr><td>IEQ-worries</td><td>-1.37 (5.58)</td><td>-0.66 (5.81)</td></tr>
<tr><td>IEQ-urging</td><td>-2.05 (5.01)</td><td>-1.12 (5.27)</td></tr>
<tr><td>CES-D</td><td>-2.38 (7.77)</td><td>-0.73 (7.77)</td></tr>
<tr><td>GHQ-28-total</td><td>-3.00 (12.32)</td><td>-0.87 (11.14)</td></tr>
<tr><td>GHQ-28-somatic</td><td>-0.59 (4.56)</td><td>0.33 (4.11)</td></tr>
<tr><td>GHQ-28-anxiety/ insomnia</td><td>-1.24 (4.60)</td><td>-0.70 (4.16)</td></tr>
<tr><td>GHQ-28-social dysfunction</td><td>-0.64 (3.16)</td><td>-0.30 (3.02)</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>GHQ-28-severe depression</td><td>-0.53 (2.81)</td><td>-0.20 (3.84)</td></tr></table></td><td></td></tr>
<tr>
<td>Full citation
Núñez-Naveira, L, Alonso-Búa, B, Labra, C, Gregersen, R, Maibom, K, Mojs, E, Krawczyk-Wasielewska, A, Millán-Calenti, Jc, UnderstAID, an ICT Platform to Help Informal Caregivers of People living with dementia: a Pilot Randomized Controlled Study, BioMed Research International, 2016, 5726465, 2016

Ref Id
712609

Country/ies where the study was carried out</td>
<td>Sample size
N=77 carers randomised
• Intervention, n=36 (Denmark=15, Poland=9, Spain=12)
• Control, n=41 (Denmark=1, Poland=20, Spain=20)

Characteristics
Carer characteristics (completers only: intervention=30; control=31)
• Gender (M/F): 9/21; 13/18
• Employment (physical work/intellectual work/unemployed/retired): 6/10/1/13; 7/15/4/5
• Hours of caring per week (<20/≥20): 17/13; 18/13
• Support caring (%): 28/31
• Self-perceived health (very good/good/fair/poor): 5/9/16/0; 1/16/13/1</td>
<td>• Intervention: Guided Self-Help
• Control: TAU</td>
<td>• Carers recruited from various local Alzheimer’s associations of adult day-care centres in Denmark, Poland and Spain. Self-assessments, completed online or paper versions returned to project leader in each country, at baseline before randomisation and post-intervention.
• Guided Self-Help ('understAID') Carers accessed application through internet-enabled devices (for example smartphone, tablet, PC). Consists of Learning section of 5 modules, daily task section and social network support. Learning modules each have 4 levels of difficulty and cover: Module 1: cognitive decline; Module 2: Daily tasks; Module 3: behavioural change;</td>
<td>Carer outcomes post-intervention<table><tr><td>Outcomes</td><td>GSH (n=30)</td><td>TAU (n=31)</td></tr><tr><td>CES-D-20</td><td>17.03 (7.07)</td><td>20.77 (9.02)</td></tr><tr><td>Pearlin-Caregiver Competence Scale</td><td>11.70 (2.18)</td><td>10.97 (2.60)</td></tr><tr><td>Revised Caregiving Satisfaction Scale</td><td>18.60 (4.75)</td><td>19.10 (5.71)</td></tr></table></td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation: Low risk (computer-generated randomisation)
• Allocation concealment: Unclear risk (insufficient information)
• Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance bias)
• Blinding of outcome assessment: Unclear risk (self-report but no further information)</td>
</tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
Denmark, Poland, Spain **Study type** RCT **Aim of the study** To assess efficacy of online education and skills training platform (UnderstAID) in carers of people living with dementia **Study dates** Unclear, not reported **Setting** In home/online **Source of funding** Supported by grant #AAL-2012-5-107 for 'understAID: A PlatformThat Helps Informal Caregivers to Understand and Aid Their Demented Relatives' and funded by the European	- Care recipient characteristics - Global Deterioration Scale stage (4/5/6/7): 12/12/5/1; 7/10/11/3 **Inclusion criteria** - Carer of person with diagnosed dementia (ICD-10, DSM-IV-TR or NINDS-ADRDA criteria) - who is informal primary carer - assists care recipient in basic tasks for >6 weeks for substantial amount of time - with ZBI score≥24 - informed consent **Exclusion criteria** - Carers not able to evaluate or use online intervention (for example cognitive impairment, who were illiterate, or had severe hearing and visual or motor problems)		module 4: social activities; module 5: caring experience. Daily task section provides calendar and appointment/medication intake reminders. Social network support was moderated by researchers and enabled exchange of information and opinions. UnderstAID could also be personalised (optional) by completing a questionnaire at beginning of application to tailor it to carer's knowledge and situation. Carers in this group also received weekly or monthly phone calls to track their progress with using platform, gain feedback - TAU Carers received standard care relative to the country in which they live.		- Incomplete outcome data: High risk (reason for missing data likely related to true outcome with imbalance in numbers/reasons across groups) - Selective reporting: Unclear risk (insufficient information) - Other bias: High risk (car ers in intervention group received significantly more support from dementia supervisors and significantly less respite care than controls, not controlled for in analysis **Other information** - Some of the Danish carers received financial renumeration for reducing working hours in their jobs whilst caring

<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>Commission in the Ambient Assisted Living (AAL) Joint Programme and various national funding agencies in Denmark, Spain and Poland.</td><td></td><td></td><td></td><td></td><td>• Some indirectness as sample includes 38% carers from Poland</td></tr>
<tr><td>Full citation
Sepe-Monti, M., Vanacore, N., Bartorelli, L., Tognetti, A., Giubilei, F., The Savvy Caregiver Program: A Probe Multicenter Randomized Controlled Pilot Trial in Caregivers of Patients Affected by Alzheimer's Disease, Journal of Alzheimer's Disease, 54, 1235-1246, 2016

Ref Id
712836

Country/ies where the study was carried out</td><td>Sample size
N=164 carers
• Intervention, n=80
• Control, n=84

Characteristics
Carer characteristics
• Age (years): 57.84 (13.89); 59.57 (14.52)
• Gender (M/F): 20/60; 36/48
• Education (years): 12.35 (4.06); 11.57 (4.39)
• Relationship to person with AD (child/spouse/other): 42/32/6; 40/39/5
• Lives with person with AD: 56%; 63%
• Second carer: 31%; 33%

Care recipient characteristics</td><td>• Intervention: Group psychoeducation
• Control: Group information only</td><td>• All trial psychologists had training to conduct SAVVY program to ensure consistency of treatment. All treatment sessions in both groups coordinated by local psychologist group leader. Assessments at baseline, then 8 weeks and 6 months after baseline. Carers participated in group interventions without care recipients. ITT analysis conducted.
• Group psychoeducation (SAVVY) Multicomponent intervention with information provision, education, problem solving, skills training, behavioural management techniques, and cognitive strategies elements.</td><td>Outcomes at 8-week FU
<table>
<tr><th></th><th>Group PE (n=80)</th><th>Inform-ation (n=84)</th></tr>
<tr><td>NPI-Total</td><td>21.11 (12.18)</td><td>22.93 (14.61)</td></tr>
<tr><td>NPI distress</td><td>13.17 (9.05)</td><td>14.14 (10.70)</td></tr>
<tr><td>CBI</td><td>27.78 (12.95)</td><td>29.11 (15.45)</td></tr>
<tr><td>SF-12-physical</td><td>48.75 (8.49)</td><td>47.60 (9.75)</td></tr>
<tr><td>SF-12-mental</td><td>42.82 (11.21)</td><td>42.47 (12.00)</td></tr>
<tr><td>CES-D-20</td><td>11.24 (6.73)</td><td>13.28 (7.97)</td></tr>
<tr><td>STAI-state</td><td>31.91 (9.69)</td><td>33.71 (10.96)</td></tr>
</table>
Outcomes at 6-mo FU</td><td>Limitations
• Random sequence generation: Low risk (computer-generated random numbers)
• Allocation concealment: Low risk (central allocation centre)
• Blinding of participants/personnel: Low risk (participants blinded to allocation; personnel providing intervention not blinded so possibility of performance bias)
• Blinding of outcome assessment: Low risk (assessor blinded to allocation)</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>Italy
Study type
Multisite RCT

Aim of the study
To evaluate effect of group psychoeducational program (Savvy Caregiver Program) compared to walk-in information/support on carer burden and psychological symptoms in carers of older people with Alzheimer's Disease

Study dates
01/2010 to 08/2010

Setting
10 outpatient memory clinics

Source of funding
Supported by a Health Care Research Foundation grant.</td>
<td>- Age (years): 77.76 (6.30); 78.50 (6.67)
- Gender (M/F): 50/30; 47/37
- Disease duration (years): 3.38 (2.54); 3.2 (2.88)
- MMSE score: 16.85 (5.61); 14.75 (6.19)

Inclusion criteria
- Patients with diagnosis of probably or possible Alzheimer's Disease (NINCDS-ADRDA criteria) attending one of 10 outpatient memory clinics, with known (informal) primary carer
- Carer informed consnet

Exclusion criteria
- Patients with diagnosis of other forms of dementia or participating in other pharmacological/non-pharmacological trials
- Patients whose carers unable or refused consent to participate</td>
<td></td>
<td>Structured 6 weekly, 2 hour group (that is with other carers) sessions, each on different topics, to enhance carer quality of life and ability to be and successful as carer. SAVVY based on (Italian versions of) Caregiver's Manual and Trainer's Manual. Content of sessions consisted in (1) clinical/pharmacological information about AD and preparation for education program, (2) self-care, emotional and behavioural management, communication, (3) involving person with AD in activities, (4) ADL behavioural management strategies, (5) strengthen learning and decision-making model, and (6) family as source of support.
- Information only
Two 2 hr sessions of group information program comprised of medical information about AD and conducting open group discussion about</td>
<td>
<table>
<tr><td>COPE scores</td><td>Psycho-educatio n (n=80)</td><td>Inform-ation (n=84)</td></tr>
<tr><td>Social Support</td><td>30.82 (8.62)</td><td>29.14 (7.81)</td></tr>
<tr><td>Avoidanc e Strategie s</td><td>20.93 (3.52)</td><td>21.31 (3.44)</td></tr>
<tr><td>Positive attitude</td><td>38.88 (6.43)</td><td>36.80 (7.07)</td></tr>
<tr><td>Focus on Problem</td><td>33.11 (5.73)</td><td>32.68 (5.19)</td></tr>
<tr><td>Religious orientatio n</td><td>24.02 (5.41)</td><td>24.52 (5.33)</td></tr>
<tr><td colspan="3">Data stratified by 33% percentile scores for each subscale not shown.</td></tr>
</table>

<table>
<tr><td></td><td>Psycho-education (n=80)</td><td>Inform-ation (n=84)</td></tr>
<tr><td>NPI</td><td>22.20 (16.19)</td><td>25.19 (16.30)</td></tr>
</table>
</td>
<td>- Incomplete outcome data: High risk (13 in intervention and 28 carers in control group withdrew before 8-week follow-up. Subsequent 12 intervention and 9 control carers refused 6-mo FU; potential attrition bias)
- Selective reporting: Unclear (insufficient information)
- Other bias: High risk (significant differences at baseline: more female carers in control group; control group patients had lower baseline MMSE score [that is more severe AD]; intervention group patients took more acetylcholinesterase inhibitors)</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>supporting a person with AD. Session 1 was on week 2 (clinical and pharmacological information about AD) and session 2 in week 4 (discussion of carer needs and problems)</td>
<td><table>
<tr><td>NPI distress</td><td>12.08 (10.03)</td><td>12.72 (10.95)</td></tr>
<tr><td>CBI</td><td>27.87 (12.88)</td><td>29.05 (16.10)</td></tr>
<tr><td>SF-12-physical</td><td>50.51 (7.99)</td><td>49.49 (9.84)</td></tr>
<tr><td>SF-12-mental</td><td>40.59 (10.19)</td><td>40.49 (13.46)</td></tr>
<tr><td>CES-D-20</td><td>13.32 (7.50)</td><td>14.17 (9.24)</td></tr>
<tr><td>STAI-state</td><td>33.89 (10.77)</td><td>36.18 (12.77)</td></tr>
</table></td>
<td></td>
</tr>
<tr>
<td>Full citation
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</td>
<td>Sample size
N=61 carers randomised
• Intervention, n=30
• Control, n=31

Characteristics
Carer characteristics (whole sample)
• Age (y): 54 (14)
• Female (%): 82
• Relationship to care recipient (%</td>
<td>• Intervention: Hybrid Psychosocial
• Control: Information only</td>
<td>• Carers recruited from patient register in Camberwell in London. Assessments at baseline and 6-mo FU (6 months after post-intervention)
• Hybrid Psychosocial Consisted in 6 individual sessions based on a family approach (without patient) and subsequently, 12 group carer sessions every 2</td>
<td>Carer outcomes at 6-mo FU<table>
<tr><th>Outcomes</th><th>Hybrid PS (n=26)</th><th>Info (n=23)</th></tr>
<tr><td>CISR</td><td>6.2 (7.2)</td><td>8.5 (9.1)</td></tr>
<tr><td>ECI-negative</td><td>74 (36)</td><td>72 (42)</td></tr>
</table></td>
<td>Limitations (assessed using the Cochrane 'Risk of bias' tool for randomized trials)
• Random sequence generation: Low risk (block randomisation of varying sizes with stratification)</td>
</tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
Psychiatry & Psychiatric Epidemiology, 38, 411-8, 2003 **Ref Id** 708235 **Country/ies where the study was carried out** UK **Study type** RCT **Aim of the study** To assess efficacy of hybrid psychoeducation intervention in carers of people with psychotic disorders **Study dates** Unclear, not reported **Setting** In home	parent/spouse/sibling/children): 62/10/13/5 • Employed (%): 46 • Education (% >A-level): 18 • Supporting more than one person (%): 30 • Hours contact with care recipient per week (<10/10-35/>35): 46/28/26 **Inclusion criteria** Carer • at least 1 face-to-face contact per month with care recipient • self-identifies as primary carer of care recipient • identified by care recipient as their primary carer • Care recipient • diagnosed by consultant with psychotic disorder (schizophrenia, schizoaffective disorder, bipolar affective disorder, psychotic depressive disorder) **Exclusion criteria** None reported		weeks. Both individual and group sessions were run by same carer support worker (experienced Community Psychiatric Nurse, not involved in patient's care). Contents of individual sessions were: Session 1: introduction and discussion of carer issues; Session 2: education on care recipient's mental disorder, aetiology, treatment and available services; written information about relevant disorder and available services. Carers also given video 'Carers Story' with aim of encouraging discussion. Sessions 3-5: problem solving training; Session 6: review of intervention and introduction to group sessions. Group sessions (~duration of 1.5 hours each) acted as reinforcement of individual sessions and opportunity to provide support in group	COPI-effective | 7.4 (2.4) | 7.9 (2.4) COPI-ineffective | 5.2 (2.2) | 4.9 (1.4) SESS-close | –0.8 (3.4) | 1.4 (2.3) SESS-community | 0.6 (2.8) | 1.2 (3.2) CSCD | 3.5 (1.9) | 3.6 (1.7)	• Allocation concealment: Unclear risk (insufficient information) • Blinding of participants/personnel: High risk (participants and personnel not blinded, potential performance bias) • Blinding of outcome assessment: High risk (assessors not blinded to group assignment) • Incomplete outcome data: Unclear risk (dropouts had higher coping skills and would likely reduce effect estimate) • Selective reporting: Unclear risk (insufficient information) • Other bias: Low risk (appears free from other sources of bias)

<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
None reported</td><td></td><td></td><td>environment. Each group session started with 30 min talk by person with relevant experience of particular aspects of mental illness (for example what is mental illness, how can it be treated). General discussion between carers then encouraged, facilitated by support worker.
• Information only
• Consisted of 1 session of 1 hour in which study was described and issues related to caring were discussed. Carers received same written information and video as in intervention group.</td><td></td><td></td></tr>
<tr><td>Full citation
Valeberg, Bt, Kolstad, E, Småstuen, Mc, Miaskowski, C, Rustøen, T, The PRO-SELF pain control program improves family caregivers' knowledge of cancer pain</td><td>Sample size
N=117 care recipients randomised
• Intervention, n=58 consenting carers
• Control, n=54 consenting carers
Characteristics
Carer characteristics (intervention, n=58; control, n=54)</td><td>• Intervention: Pain management psychoeducation
• Control: Pain information only
•</td><td>• Clinicaltrials.gov NCT00760305
• Cancer patients recruited from university-based Norwegian cancer centre, assessments at baseline and post-intervention
• Pain management psychoeducation ('PRO-SELF pain control program'</td><td>Carer outcomes at post-intervention<table><tr><th>Outcome</th><th>Pain management (n=58)</th><th>Pain information (n=54)</th></tr><tr><td>FamPain (modified</td><td>7.60 (1.4)</td><td>5.63 (1.5)</td></tr></table></td><td>Limitations (assessed using the Cochrane 'Risk of bias' tool for randomized trials)
• Random sequence generation: Unclear risk (insufficient information)
• Allocation concealment: Uncl</td></tr>
</table>

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
management, Cancer Nursing, 36, 429-435, 2013 **Ref Id** 709953 **Country/ies where the study was carried out** **Study type** pure training, to complete **Aim of the study** To assess efficacy of cancer pain management psychoeducational intervention compared to information only in cancer care dyads **Study dates** 10/2004 to 05/2008 **Setting** In home **Source of funding** Funded by the Norwegian Research Council.	• Age (y): 62.6 (10.5); 63.7 (11.0) Female (%): 58.6; 61.1 • Education (% primary/secondary/university<4 years/university>4 years): 52.6/15.8/14/17.5; 47.2/11.3/20.8/20.8 • Lives with care recipient (%): 97; 94 • Relationship to care recipient (% spouse/child/sibling/other family/other): 93/3/2/2/0/0; 94/0/2/0/2/2 • Employment status (%full-time/part-time/sick leave/pensioned/other): 29.8/14/7/38.6/10.5; 31.5/7.4/5.6/42.6/13 **Care recipient characteristics (intervention, n=58; control, n=54)** • Age (y): 65.0 (10.9); 64.3 (13.7) • Years since cancer diagnosis: 4.2 (4.0); 3.0 (3.4) • Number of metastasis: 1.4 (0.9); 1.5 (0.9) • Karnofsky PS: 69.8 (6.1); 72.9 (9.6)		Intervention delivered by specially-trained oncology nurse who visited patient's home at weeks 1, 3 and 6 and maintained telephone contact at weeks 2, 4 and 5. Home visits consisted of identifying knowledge gaps using dyad's responses to modified Family Pain Questionnaire. Modifying pain plan in light of deficits, and communication with physician to improve pain outcomes. Telephone session with either member of dyad reviewing pain intensity scores and pain medication intake and served as reinforcement of home sessions. • Pain information only Dyads received booklet about cancer pain management developed by oncologist at Oslo University Hospital. Also received same frequency of home visits and telephone calls as	version)	ear risk (insufficient information) • Blinding of participants/personnel: High risk (participants and personnel not blinded to group assignment) • Blinding of outcome assessment: Unclear risk (insufficient information) • Incomplete outcome data: Unclear risk (insufficient information to determine if dropouts and if so why) • Selective reporting: Low risk (protocol available, all relevant carer outcomes reported) • Other bias: Unclear risk (carers in psychoeducation group had significantly higher score on item 1 of modified FPQ

Study Details	Participants	Interventions	Methods	Outcomes and Results	Comments
	Inclusion criteria - Carer of person with cancer - Aged 18-years or older - willing to participate in study - read, write and understand Norwegian - Care recipient - cancer diagnosis with radiographic evidence of bone metastasis **Exclusion criteria** - Care recipient - evidence of brain metastasis		intervention group with focus on monitoring adherence to completing pain management diary. -		score than those in information only group; care recipients in control group had significantly higher Karnofsky performance scores than those in intervention group; neither of these differences were controlled for in analysis; randomisation also occurred before recruitment of carers).

F: Female; M: Male; N: Number; SD: Standard deviation; TAU: Treatment as usual; RCT: Randomised controlled trial; WLC: waiting-list control

Qualitative component of the review

Table 7: Evidence tables for the qualitative studies

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Full citation Alhaddad, B., Taylor, K. M. G., Robertson, T., Watman, G., Smith, F. J., Assistance of family carers for patients with COPD using nebulisers at home: A qualitative study,	**Sample size** N=14 **Characteristics** **Carer** - Carer (sample n)= 14	**Details:** - **Recruitment methods:** Carers were recruited through primary care (38 general practitioners) and intermediate care	- Assistance in decisions regarding the need for therapy including advice on doses and the need for emergency help;	**Limitations (assessed using the CASP checklist for qualitative studies**

Study Details:	Participants	Methods	Outcomes and Themes	Comments
European Journal of Hospital Pharmacy, 23, 156-160, 2016 **Ref Id** 725037 **Country/ies where the study was carried out** UK **Study type** Qualitative **Aim of the study** The aims of this mixed-method study were to explore the the assistance carers provide to patients with COPD using nebuliser-delivered therapy at home, and the problems experienced that may impact on the safety and effectiveness of therapy and contribute to carer burden. **Study dates** 2016 **Source of funding** Harrow Research Ethics Committee, REC reference 08/H0719/55.	- Carer (age)= mean age (years): 61 - Carer (gender-M/F)= 4/10 - "Relationship to care recipient"= parents (n):0; spouses (n): 11; daughters-sons (n): 3; sibling (n): 0; undisclosed (n): 0 - Living with care recipient (yes/not -n)= 14/0 - Care-giving duration - duration of illness=mean duration (years): 4.5 **Professionals** N/A **Care recipient** - care recipient (condition)= COPD - care recipient (age)= N/R **Inclusion criteria** - Carers of patients whose disease management may be stable in the community; - Carers who assisted patients recently admitted to hospital with an exacerbation, possibly indicating treatment failure; - Carers of patients with a confirmed COPD diagnosis, prescribed Nebules/Respules and/or	(healthcare and rehabilitation team located at a major acute hospital), permitting involvement of carers of a diverse patient group. All individual's respondent with the inclusion criteria were contacted. - **Data collection & analysis:** Semi-structured interviews (strutctured and open-ended questions). Interviews were recorded and trascribed verbatim. Data were analysed using qualitative content analysis within the "framework" method (Ritchie J, Lewis J. Qualitative Research Practice: A Guide for Social Science Students and Researchers. London: Sage, 2003)	- Setting up and operating the nebuliser including cleaning, maintenance - Obtaining supplies; and obtaining information.	- **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? - No - **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

Study Details:	Participants	Methods	Outcomes and Themes	Comments
	Combivent (ipratropium andsalbutamol) for use with a nebuliser in their home **Exclusion criteria** - Carer of patients with mental health problems, severe cognitive impairment, were unwell or had a serious illness (eg, advanced cancer)			and 2. Transferability)? - Yes **Overall methodological concerns:** Minor
Full citation Macdonald, P., Murray, J., Goddard, E., Treasure, J., Carer's experience and perceived effects of a skills based training programme for families of people with eating disorders: a qualitative study, European Eating Disorders ReviewEur, 19, 2011 **Ref Id** 532606 **Country/ies where the study was carried out** UK **Study type** Qualitative Study	**Sample size** N=19 **Characteristics** **Carer** - Carer (sample n) = 19 - Carer (age)= mean age - range (years): 47 ¦ 27-64 - Carer (gender-M/F) = 9/10 - "Relationship to care recipient"= parents (n):14; spouses (n): 3; daughters-sons (n): 0; sibling (n): 2; undisclosed (n): 0 - Living with care recipient (yes/not -n) = 15/4 - Care-giving duration - duration of illness= duration range (years): 5 months-19 years **Professionals**	**Details:** - **Recruitment methods:** Carers were recruited from the Institute of Psychiatry website, from BEAT (UK eating disorder organization) and from carer support groups in regions throughout the UK. This sample was purposively selected from a trial. - **Data collection & analysis:** Semi-structured interviews administered by telephone and conducted by two interviewers. Interviews were guided by a topic guide, recorded and trascribed verbatim. Data were analysed using Interpretative	- Experience of caring for a loved one (that is attempts at understanding the illness, problem-solving strategies utilized, skills and strengths in response to symptoms and experience of carer burden and psychological distress) - Interpersonal experience which included contact with the sufferer as well as relationships with partners, siblings, extended family, friends and professionals, - Effectiveness and acceptability of the intervention - Criticism, problems and non-acceptability of the intervention.	**Limitations (assessed using the 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? - Can't tell

Study Details:	**Participants**	**Methods**	**Outcomes and Themes**	**Comments**
Aim of the study The aims of this qualitative research were to explore the experience of carers of people with eating disorders after having participated in a skills-based training programme that incorporated five psycho-educational DVDs and book. **Study dates** 2011 **Source of funding** Department of Health NIHR Programme Grant for Applied Research (Reference number RP-PG-0606-1043)	- N/A **Care recipient** - care recipient (condition)= Eating Disorders - care recipient (age)= mean age - range (years): 23 ¦ 15-51 **Inclusion criteria** - Not reported **Exclusion criteria** - Not reported	Phenomenological Analysis (IPA) to explore each participant's experience of having participated in the intervention. Investigator and methodological triangulation was adopted for the purpose of addressing validity issues.		- **Q6**: Has the relationship between researcher and participants been adequately considered? - Can't tell - **Q7**: Have ethical issues been taken into consideration? - Yes - **Q8**: Was the data analysis sufficiently rigorous? - Can't tell - **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 concerns:** Moderate

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Full citation Papachristou, Iliatha, Hickey, Gary, Iliffe, Steve, Dementia informal caregiver obtaining and engaging in food-related information and support services, Dementia: The International Journal of Social Research and Practice, 16, 108-118, 2017 **Ref Id** 723415 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** The aims of this qualitative research were to explore the experiences of carers, and views on, food-related information and support services in dementia. **Study dates** 2017 **Source of funding** None	**Sample size** N=20 **Characteristics** **Carer** • Carer (sample n)= 20 • Carer (age)= N/R • Carer (gender-M/F)= 10/10 • "Relationship to care recipient"= parents (n):0; spouses (n): 13; daughters-sons (n): 4; sibling (n): 2; friend (n): 1 • Living with care recipient (yes/not -n)= N/R • Care-giving duration - duration of illness= N/R **Professionals** • N/A **Care recipient** • care recipient (condition)= Dementia • care recipient (age)= N/R **Inclusion criteria** • Not reported **Exclusion criteria** • Not reported	**Details:** • **Recruitment methods:** Carers were recruited: 1) by advertising, via leaflets and posters, in a local chemist, a community centre, and a national charity (AS) in South West London; 2) by the snowballing technique; 3) by contacting health care professionals working with dementia and older adults. All individuals respondent with the inclusion criteria were contacted. • **Data collection & analysis:** Data were collected via semi-structured, face-to-face interviews. All the interviews took place in the caregiver's home or in a private room in a public library during an 8-week period, with the interviews lasting 20 to 30 minutes. Interviews were recorded and trascribed verbatim. Data were analysed using qualitative thematic analysis using both an inductive and deductive approach. An analytical framework was derived from previous literature and was further developed from the		**Limitations (assessed using the 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? - Can't tell • **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

Study Details:	Participants	Methods	Outcomes and Themes	Comments
		emerging data. Following the coding by the first researcher, a second researcher then checked the codes against the data to ensure credibility and trustworthiness.		- **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 concerns:** Minor
Full citation Riley, G., Gregory, N., Bellinger, J., Davies, N., Mabbott, G., Sabourin, R., Carer's education groups for relatives with a first episode of psychosis: an evaluation of an eight-week education group, Early Intervention in Psychiatry, 5, 57-63, 2011 **Ref Id** 717439 **Country/ies where the study was carried out** UK	**Sample size** N=12 **Characteristics** **Carer** - Carer (sample n)= 12 - Carer (age)= N/R - Carer (gender-M/F)= N/R - "Relationship to care recipient"= N/R - Living with care recipient (yes/not -n)= N/R - Care-giving duration - duration of illness= N/R **Professionals** - N/A	**Details:** - **Recruitment methods:** Carers were recruited in the study if they were attending the educational course object of the study. All individuals respondent with the inclusion criteria were contacted. - **Data collection & analysis:** Data were collected via a focus group audiotaped then transcribed verbatim. Pairs of analysts performed an independent coding of data, compared findings and completed a correlational	- The emotional impacts of being a carer and how the group impacted on this - The wider impacts of mental - Illness within a family roles and relationships - Group design and arrangements - Wider impacts of the education group	**Limitations (assessed using the 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

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Study type qualitative study **Aim of the study** The aims of this qualitative research were to explore the potential benefits of a eight-week carers educational groupintervention for carers of people with first episode of psychosis (including changes in feelings of confidence, understanding of psychosis, isolation, recognition) **Study dates** 2011 **Source of funding** N/R	**Care recipient** • Care recipient (condition)=Psychotic Disorders • Care recipient (age)= N/R **Inclusion criteria** • Not reported **Exclusion criteria** • Not reported	analysiS. Using thematic analysis, the transcripts were coded into broad themes based on service evaluation objectives and focus group questions to create an initial template.		• **Q4:** Was the recruitment strategy appropriate to the aims of the research? - No • **Q5**: Were the data collected in a way that addressed the research issue? - Can't tell • **Q6**: Has the relationship between researcher and participants been adequately considered? - Can't tell • **Q7**: Have ethical issues been taken into consideration? - Can't tell • **Q8**: Was the data analysis sufficiently rigorous? - No • **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 concerns:** Major
Full citation Sepulveda, A. R., Lopez, C., Todd, G., Whitaker, W., Treasure, J., An examination of the impact of "the Maudsley eating disorder collaborative	**Sample size** N=28 **Characteristics** **Carer** • Carer (sample n)= 28	**Details:** • **Recruitment methods:** Carers were recruited in the study by: 1) from the Beat London Carers' Group plus families and carers of	• Reducing over directiveness • Improving carer stress and coping • Affirmation • Externalising Illness	**Limitations (assessed using the CASP checklist for qualitative studies**

Study Details:	Participants	Methods	Outcomes and Themes	Comments
care skills workshops" on the well being of carers: a pilot study, Social Psychiatry & Psychiatric Epidemiology, 43, 584-91, 2008 (Sepulveda 2008a) **Ref Id** 719821 **Country/ies where the study was carried out** UK **Study type** Qualitative Study **Aim of the study** The aims of this mixed-method study were to examine the feasibility and acceptability of "the Maudsley eating disorder collaborative care skills workshops" programme among care givers and whether the difficulties and distress involved in supporting a person with an eating disorder were reduced. **Study dates** 2008	- Carer (age)= mean age - range (years): 52,1 | 41-66 - Carer (gender-M/F)= 5/23 - "Relationship to care recipient"= parents (n):26; spouses (n): 1; daughters-sons (n): 0; sibling (n): 1; friend (n): 0 - Living with care recipient (yes/not -n)= 21/7 - Care-giving duration - duration of illness= N/R **Professionals** - N/A **Care recipient** - care recipient (condition)= Eating Disorders - care recipient (age)= mean age - range (years): 23 ¦ 15-33 **Inclusion criteria** - Carers living with, or directly involved in the care of people with an eating disorders **Exclusion criteria** - There were no exclusion criteria for patients who could be adolescents or adults	patients referred to the South London and Maudsley Hospital; 2) from the website of the Eating Disorder Unit (EDU) and from the EDU newsletter. All individuals respondent with the inclusion criteria were contacted. - **Data collection & analysis:** Data were collected through a questionnaire. Data analysis methods were not reported		- **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? - Can't tell - **Q7**: Have ethical issues been taken into consideration? - Can't tell - **Q8**: Was the data analysis sufficiently rigorous? - No - **Q9**: Is there a clear statement of findings? - Yes - **Q10**: Is the research valuable for the UK (1. Contribution to literature

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Source of funding Post-doctorate Fullbright and Spanish Education Ministry Fellowship (EX2004/0481)				and 2. Transferability)? - Yes **Overall methodological concerns:** Major
Full citation Sepulveda, A. R., Lopez, C., Macdonald, P., Treasure, J., Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder, International Journal of Eating Disorders, 41, 318-25, 2008 (Sepulveda 2008b) **Ref Id** 719822 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** The aims of this mixed-method study were 1) to describe the feasibility and acceptability of this skills-based training for carers of	**Sample size** N=16 **Characteristics** **Carer** • Carer (sample n)= 16 • Carer (age)= mean age - range (years): 52,7 | 28-69 • Carer (gender-M/F)= 3/13 • "Relationship to care recipient"= parents (n):4; spouses (n): 10; daughters-sons (n): 0; sibling (n): 0; friend (n): 0 • Living with care recipient (yes/not -n)= 10/6 • Care-giving duration - duration of illness= N/R **Professionals** • N/A **Care recipient** • care recipient (condition)= Eating Disorders • care recipient (age)= mean age - range (years): 17¦ 14-27	**Details:** • **Recruitment methods:** Carers were recruited in the study by: 1) from the Beat London Carers' Group plus families and carers of patients referred to the South London and Maudsley Hospital; 2) from the website of the Eating Disorder Unit (EDU) and from the EDU newsletter. All individuals respondent with the inclusion criteria were contacted. • **Data collection & analysis:** Data were collected via telephone conversations and written feedback. Data were analysed using a pilot thematic analysis - no further details were reported	• Carer role/needs • Carer approach • Impact of illness • DVD strengths • DVD weaknesses • Feedback from telephone coaching.	**Limitations (assessed using the 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? - Can't tell • **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? - Can't tell

Study Details:	Participants	Methods	Outcomes and Themes	Comments
people with eating disorders and 2) to examine whether the anxiety, depression, and expressed emotion involved in the caregiving experience were reduced. **Study dates** 2008 **Source of funding** Post-doctorate Fullbright and Spanish Education Ministry Fellowship (EX2004/0481)	**Inclusion criteria** - Carers living with, or directly involved in the care of people with an eating disorders **Exclusion criteria** - There were no exclusion criteria for patients who could be adolescents or adults			- **Q7**: Have ethical issues been taken into consideration? - Yes - **Q8**: Was the data analysis sufficiently rigorous? - Can't tell - **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 concerns:** Moderate
Full citation Smith, F., Grijseels, M. S., Ryan, P., Tobiansky, R., Assisting people living with dementia with their medicines: experiences of family carers, International Journal of Pharmacy Practice, 23, 44-51, 2015 **Ref Id** 725222	**Sample size** N=14 **Characteristics** **Carer** - Carer (sample n)= 14 - Carer (age)= range (years): 45-86 - Carer (gender-M/F)= 3/11 - "Relationship to care recipient"= parents (n):0; spouses (n): 2; daughters-sons (n): 12; sibling (n): 0; friends (n): 0	**Details:** - **Recruitment methods:** Carers were recruited purposively through the memory treatment clinics at Barnet Hospital, and the Barnet Branch of the Alzheimer's Society - **Data collection & analysis:** Semi-structured interviews (open-ended questions). Topics of the interviews included monitoring supplies in the home, liaising with	- Ordering and collecting from the surgery and/or pharmacy - Dosage boxes, reminders and administration - Information about medicines - Carers' concerns about the effect of medicines - Carers, care-recipients and sharing of information - Liaison with health professionals - Suggestions for service developments.	**Limitations (assessed using the 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

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Country/ies where the study was carried out UK **Study type** Qualitative study **Aim of the study** The aims of this qualitative research were to explore the experiences of family carers when providing medicines-related assistance for a person with dementia, to indicate how services could become more responsive to the specific needs of this group of carers. **Study dates** 2015 **Source of funding** None	• Living with care recipient (yes/not -n)= 14/0 • Care-giving duration - duration of illness= N/R **Professionals** • N/A **Care recipient** • care recipient (condition)= Dementia • care recipient (age)= range (years): 81-93 **Inclusion criteria** • Carers were eligible if they provided some assistance (however minimal) with a medication for a person with a diagnosis of dementia, • were unpaid for the assistance they provided, • had at least weekly face-to-face contact with the person they assisted and were the main (informal) carer. • The inclusion criteria for care-recipients were: a diagnosis of dementia, living at home and able and willing to consent. **Exclusion criteria** • Not reported (look at the inclusion criteria)	health professionals (hospitals, surgeries and pharmacies), reminders, assistance with administration of different formulations, participating in decisions about the need for medicines, doses and side effects (and were based on a literature review) Interviews were recorded and trascribed verbatim. Data were analysed using qualitative framework analysis (Ritchie J, Lewis J. Qualitative Research Practice: A Guide for Social Science Students and Researchers. London: Sage, 2003)		• **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? - No • **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 concerns:** Minor

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Full citation Sommerlad, Andrew, Manela, Monica, Cooper, Claudia, Rapaport, Penny, Livingston, Gill, START (STrAtegies for RelaTives) coping strategy for family carers 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** Qualitative study **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.	**Sample size** N=75 **Characteristics** **Carer** • Carer (sample n)= 75 • 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 • Living with care recipient (yes/not -n)= 44/31 • Care-giving duration - duration of illness= N/R • **Professionals** • N/A • **Care recipient** • care recipient (condition)= Dementia • care recipient (age)= N/R **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	**Details:** • **Recruitment methods:** Carers were recruited purposively as a sub-sample of the START trial. • **Data collection & analysis:** Data were 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	• Important aspects of the therapy • Participants' engagement with the therapy • Unhelpful aspects of therapy and potential improvements • Appropriate time for delivery of the intervention.	**Limitations (assessed using the 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 • **Q9**: Is there a clear statement of findings? - Yes

Study Details:	Participants	Methods	Outcomes and Themes	Comments
Study dates 2014 **Source of funding** National Institute for Health Research - Health Technology Assessment (HTA) programme (project no 08/14/06)	dementia who provided support at least weekly to their relative, who was not living in 24 h care and referred to one of 4 different settings - 3 mental health services and a tertiary neurological service for dementia). - Cares were included at 2-years follow-up of ther trial **Exclusion criteria** - Not reported (look at the inclusion criteria)			- **Q10**: Is the research valuable for the UK (1. Contribution to literature and 2. Transferability)? - Yes **Overall methodological concerns:** Minor
Full citation Yeandle Sue, Wigfield Andrea, Training and supporting carers: the national evaluation of the caring with confidence programme, 112p., 2012 **Ref Id** 722392 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study**	**Sample size** N=73 **Characteristics** **Carer** - Carer (sample n)= 73 - Carer (age)= mean age (years): - Carer (gender-M/F)= N/R - "Relationship to care recipient"= N/R - Living with care recipient (yes/not -n)= N/R - Care-giving duration - duration of illness= N/R **Professionals** - N/A **Care recipient**	**Details:** - **Recruitment methods:** Carers were recruited as a sub-sample of the "caring with confidence" programme. - **Data collection & analysis:** Data were collected using a mixed-methods approach combining both qualitative and quantitative elements, together with observation and documentary analysis. Focus groups with carers were used to elicit their views about the Caring with Confidence programme. Focus group data were	- Improved awareness about needing time for [carers] themselves - Improved social support - Improved knowledge on the condition - Self-identification [as carers] - Understanding of a carer's rights and entitlements	**Limitations (assessed using the 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? - Can't tell

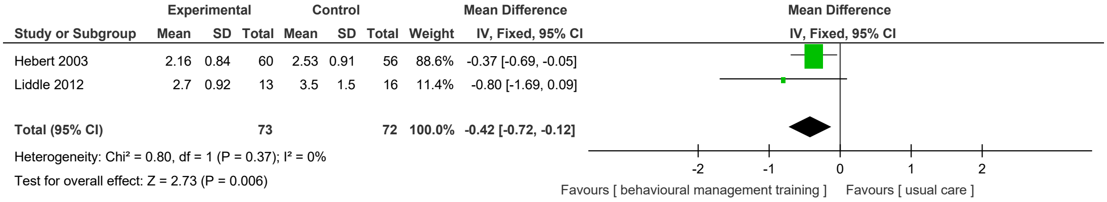
Study Details:	Participants	Methods	Outcomes and Themes	Comments
The aims of this mixed-method study were the benefits of the "Caring with Confidence" training programme for carers, those they care for, and others in the health and social care system. **Study dates** 2012 **Source of funding** Department of Health - Policy Research Programme	• care recipient (condition)= General • care recipient (age)= N/R **Inclusion criteria** • Not reported **Exclusion criteria** • Not reported	tape-recorded, captured in detailed research notes or recorded on specially designed templates. The emergent qualitative database was then subjected to thematic analysis, in a series of steps involving all relevant members of the research team.		• **Q5**: Were the data collected in a way that addressed the research issue? - Can't tell • **Q6**: Has the relationship between researcher and participants been adequately considered? - Can't tell • **Q7**: Have ethical issues been taken into consideration? - Can't tell • **Q8**: Was the data analysis sufficiently rigorous? - Can't tell • **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 concerns:** Moderate

COPD: Chronic Obstructive Pulmonary Disease; F: Female; M: Male; N: Number; N/R: not reported.

Appendix E – Forest plots

Forest plots for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Figure 4: Managing behaviour(s) of person receiving care, impact of caring on carer: upset with disruptive behaviours (RMBPC) at 12 weeks follow-up - individualised behavioural management training versus usual care (information combined with support or group support)



	Experimental			Control				Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**
Hebert 2003	2.16	0.84	60	2.53	0.91	56	88.6%	-0.37 [-0.69, -0.05]
Liddle 2012	2.7	0.92	13	3.5	1.5	16	11.4%	-0.80 [-1.69, 0.09]
Total (95% CI)			**73**			**72**	**100.0%**	**-0.42 [-0.72, -0.12]**

Heterogeneity: Chi² = 0.80, df = 1 (P = 0.37); I² = 0%
Test for overall effect: Z = 2.73 (P = 0.006)

CI: confidence interval; MD: mean difference

Hebert 2003, Liddle 2012

Appendix F – GRADE - CERQual tables

GRADE tables for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Pain management

Table 8: Evidence profile for training on pain management for carers to provide practical support

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		
Carer skills, knowledge/confidence or efficacy - Knowledge (of cancer) pain management (Family Pain Questionnaire - FPQ: modified version) at 9 weeks of follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	58	54	-	MD 2 higher (1.46 to 2.54 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference.

1 Valeberg 2013

2 The quality of the evidence was downgraded of 2 levels because of the potential risk of performance bias (no information blinding of outcome assessors) and unclear risk of selection bias, and selective reporting of study outcomes. Furthermore, carers in the intervention group had significantly higher score on item 1 of modified FPQ score than those in information only group; care recipients in control group had significantly higher Karnofsky performance scores than those in intervention group; neither of these differences were controlled for in analysis; randomisation also occurred before recruitment of carers.

Managing behaviour(s) of person receiving care

Table 9: Evidence profile for training on managing behaviour(s) of person receiving care for 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 - Depression (Cornell Scale for Depression in Dementia - CSDD) at 3 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	13	16	-	MD 0.7 lower (1.8 lower to 0.4 higher)	VERY LOW	CRITICAL
Caring-related morbidity - Psychological morbidity (Clinical Interview Schedule Revised – CISR) at 6 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	26	23	-	MD 2.3 lower (6.94 lower to 2.34 higher)	VERY LOW	CRITICAL
Caring-related morbidity - Anxiety (State–Trait Anxiety Inventory) at 4 months of follow-up (Better indicated by lower values)												
1[6]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[3]	none	60	56	-	MD 3.42 lower (8.39 lower to 1.55 higher)	VERY 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 - General Mental health (Psychiatric Symptoms Index) at 4 months of follow-up (Better indicated by lower values)												
1[6]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[3]	none	60	56	-	MD 1.88 lower (4.64 lower to 0.88 higher)	VERY LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy - Knowledge of supporting strategies (on dementia: Communication and Memory Support in Dementia - CMSD) at 3 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	13	16	-	MD 3.26 higher (2.49 to 4.03 higher)	LOW	IMPORTANT
Carer skills, knowledge/confidence or efficacy - Personal Efficacy Scale at 4 months of follow-up (Better indicated by higher values)												
1[6]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	no serious imprecision	none	60	56	-	MD 3.56 higher (3.45 lower to 10.57 higher)	LOW	IMPORTANT
Impact of caring on carer - Subjective burden: Positive Aspects of Caregiving (PAC) at 12 weeks follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	13	16	-	MD 0.02 lower (3.62 lower to	VERY LOW	IMPORTANT

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**		
										3.58 higher)		
Impact of caring on carer - Burden (Zarit Caregiver Burden Interview: short version-12 items) (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	13	16	-	MD 2.31 lower (9.18 lower to 4.56 higher)	VERY LOW	IMPORTANT
Impact of caring on carer - Burden (Zarit Caregiver Burden Interview: full version-22 items) at 4 months of follow-up (Better indicated by lower values)												
1[6]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	serious[3]	none	60	56	-	MD 1.18 lower (4.94 lower to 2.58 higher)	VERY LOW	IMPORTANT
Impact of caring on carer - Experience (Experience of Caregiving Inventory – ECI, negative) at 6 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	26	23	-	MD 2 higher (20.05 lower to 24.05 higher)	VERY LOW	IMPORTANT
Impact of caring on carer - Upset with memory-related behaviours (RMBPC) at 3 months of 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	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	13	16	-	MD 3.8 lower (5.79 to 1.81 lower)	LOW	IMPORTANT
Impact of caring on carer - Upset with problem behaviours (RMBPC -total) at 4 months of follow-up (Better indicated by lower values)												
1[6]	randomised trials	very serious[7]	no serious inconsistency	no serious indirectness	no serious imprecision	none	60	56	-	MD 0.30 lower (0.53 to 0.07 lower)	LOW	IMPORTANT
Impact of caring on carer - Upset with disruptive behaviors (RMBPC) at 3 months of follow-up (Better indicated by lower values)												
2[1, 6]	randomised trials	very serious[2,7]	no serious inconsistency	no serious indirectness	no serious imprecision	none	73	72	-	MD 0.42 lower (0.72 to 0.12 lower)	LOW	IMPORTANT
Impact of caring on carer - Upset with depressive behaviors (RMBPC) at 3 months of follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	13	16	-	MD 0.7 higher (0.8 lower to 2.2 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference
1 Liddle 2012
2 The quality of the evidence was downgraded of 2 levels because of the potential risk of performance bias, selection, and attrition bias

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 Szmukler 2003
5 The quality of the evidence was downgraded of 2 levels because of the potential risk of performance bias (no blinding of outcome assessors), the unclear risk of selection bias (no information given), and selective reporting of study outcomes (reporting bias)
6 Hebert 2003
7 The quality of the evidence was downgraded from high to low because of the unclear risk of selection bias and selective reporting of study findings (no information was provided). Furthermore, at baseline, Personal Efficacy Scale scores were significantly worse in control group and significantly more carers in intervention group desired institutionalisation of care recipient.

Table 10: Evidence profile for training on managing behaviour(s) of person receiving care for carers (including aids and adaptations)

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 - Depression: Depressive symptoms (Center for Epidemiologic Studies Depression Scale -CES-D-20) (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	30	31	-	MD 3.74 lower (7.8 lower to 0.32 higher)	VERY LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy - Self-efficacy (Pearlin-Caregiver Competence Scale – CCS) after the (3 months) intervention (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	30	31	-	MD 0.73 higher (0.47 lower to 1.93 higher)	VERY LOW	IMPORTANT
Impact of caring on carer - Experience (Revised Caregiving Satisfaction Scale) after the (3 months) intervention (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	30	31	-	MD 0.5 lower (3.13 lower to 2.13 higher)	VERY LOW	IMPORTANT

CI: confidence interval; MD: mean difference
1 Núñez-Naveira 2016
2 The quality of the evidence was downgraded of 2 levels because of the potential risk of performance bias, selection bias, and selective reporting of study outcomes. Moreover, carers in intervention group received significantly more support from dementia supervisors and significantly less respite care than controls, not controlled for in analysis
3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Personalised training specific to circumstances/conditions of person receiving care

Table 11: Evidence profile for personalised training (specific to circumstances/conditions of person receiving care) for carers to provide practical support

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 - Depression: Depressive symptoms (Center for Epidemiologic Studies Depression Scale -CES-D-20) change scores at 3 and 6 months follow-up - averaged. (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	15	-	MD 3.05 higher (0.45 lower to 6.55 higher)	LOW	CRITICAL
Caring-related morbidity - Anxiety (Hospital Anxiety and Depression Scale, anxiety subscale - HADS-A) change scores at 3 and 6 months follow-up - averaged. (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	15	-	MD 0.48 higher (0.59 lower to 1.55 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 - Quality of life (European Quality of life-5 Dimensions Visual Analogue Scale EQ-5D-VAS) - change scores at 3 and 6 months follow-up - averaged (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	15	-	MD 4.44 lower (12.4 lower to 3.52 higher)	LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy - Skills (Communication Skills Questionnaire –CSQ: custom measure) at 6 weeks follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	25	25	-	MD 0.66 higher (0.25 to 1.07 higher)	LOW	IMPORTANT
Carer skills, knowledge/confidence or efficacy - Carer knowledge (custom measure) at 6 weeks follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	25	25	-	MD 7.46 higher (2.46 to 12.46 higher)	LOW	IMPORTANT
Carer skills, knowledge/confidence or efficacy - Self-efficacy (Caregiver Self-efficacy Scale – CSS) at 6 weeks follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	25	25	-	MD 5.51 higher (2.5 to 8.52 higher)	LOW	IMPORTANT

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		
Impact of caring on carer - Burden (Zarit Caregiver Burden Interview: short version-12 items) change scores at 3 and 6 months follow-up - averaged. (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	15	-	MD 1.8 higher (1.07 lower to 4.67 higher)	LOW	IMPORTANT
Impact of caring on carer - Objective burden (Total caring time hrs/week) change scores at 3 and 6 months follow-up - averaged. (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	15	-	MD 1.3 higher (9.06 lower to 11.66 higher)	LOW	IMPORTANT
Impact of caring on carer - Upset with problem behaviours (RMBPC - total) at 6 weeks follow-up (Better indicated by lower values)												
1 [4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	25	25	-	MD 0.18 higher (0.13 lower to 0.49 higher)	LOW	IMPORTANT
Impact of caring on carer - Carer disturbance with communication difficulties with the person with cognitive problems (adapted measure) at 6 weeks follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	25	25	-	MD 0.5 lower (0.84 to	VERY LOW	IMPORTANT

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		
										0.16 lower)		

CI: confidence interval; MD: mean difference
1 Faes 2011
2 The quality of the evidence was downgraded from high to moderate because of the unclear risk of section bias, added to the unclear risk of attrition bias and unclear reporting of study outcomes
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 Klodnicka-Kouri 2011
5 The quality of the evidence was downgraded of 2 levels because of the potential risk of selection bias (no information given), and selective reporting of study outcomes (reporting bias). Furthermore, the control group was significantly older than intervention group, p<0.05 - at baseline.

Use of aids and adaptations

Table 12: Evidence profile for aids and adaptations for carers to provide practical support

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 - CSD - Cornell Scale for Depression in Dementia at 12 weeks follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	68	67	-	MD 7.2 lower (9.53 to 4.87 lower)	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 - Overall Dqol - Dementia Quality of Life Instrument at 12 weeks follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	68	67	-	MD 0.7 higher (0.46 to 0.94 higher)	LOW	CRITICAL
Caring-related morbidity - 12-items GHQ - General Health Questionnaire at 12 weeks follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	68	67	-	MD 5 lower (6.46 to 3.54 lower)	LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy - SCQ - sense of competence questionnaire (higher scores indicate greatercompetence) at 6 weeks follow-up. (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	68	67	-	MD 17.9 higher (13.17 to 22.63 higher)	LOW	IMPORTANT
Impact of caring on carer - Carers' sense of control over life (Mastery Scale) at 12 weeks follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	68	67	-	MD 4.40 higher (3.47 to 5.33 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference
1 Graff 2006
2 The quality of the evidence was downgraded from high to low because of the high risk of selection bias

Specific carer training programs

Table 13: Evidence profile for specific carer training programs for coping skills [Tailored to carer needs & carer-led] for carers to provide practical support

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: distress (General Health Questionnaire - GHQ-28) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[5]	none	41	45	-	MD 4.88 lower (11.36 lower to 1.6 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life (2 items, custom measure) at post-intervention (2 to 4 months from the baseline)[4] (Better indicated by higher values)												
1[3]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[5]	none	21	25	-	MD 0.57 higher (0.41 lower to 1.55 higher)	LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy - Self-efficacy: concern to cope (Family Questionnaire FQ) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	41	45	-	MD 7.7 lower (14.87 to 0.53 lower)	MODERATE	IMPORTANT

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		
Carer skills, knowledge/confidence or efficacy - Self-efficacy: ability to cope (Family Questionnaire FQ) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	41	45	-	MD 14.22 lower (22.81 to 5.63 lower)	MODERATE	IMPORTANT
Carer skills, knowledge/confidence or efficacy - Self-efficacy: sense of competence (Short Sense of Competence Questionnaire - SSCQ) at post-intervention (2 to 4 months from the baseline)[4] (Better indicated by higher values)												
1[3]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[5]	none	21	25	-	MD 0.63 higher (0.11 lower to 1.37 higher)	LOW	IMPORTANT
Carer skills, knowledge/confidence or efficacy - Knowledge: approaches to Dementia (Approaches to Dementia Questionnaire –ADQ modified, 19 items only) at post-intervention (2 to 4 months from the baseline)[4] (Better indicated by higher values)												
1[3]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	27	32	-	MD 6.93 higher (3.95 to 9.91 higher)	MODERATE	IMPORTANT
Carer skills, knowledge/confidence or efficacy - Knowledge (Alzheimer’s Disease Knowledge Scale – ADKS) at post-intervention (2 to 4 months from the baseline)[4] (Better indicated by higher values)												
1[3]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	27	32	-	MD 0.16 higher (1.44 lower to	MODERATE	IMPORTANT

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**		
										1.76 higher)		
Impact of caring on carer - Experience: negative experience (Experience of Caregiving Inventory: negative subscales - ECI-negative) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[5]	none	41	45	-	MD 15.38 lower (32.2 lower to 1.44 higher)	LOW	IMPORTANT
Impact of caring on carer - Experience: positive experience (Experience of Caregiving Inventory: positive subscales - ECI-positive) at 6 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	41	45	-	MD 7.06 higher (2.84 to 11.28 higher)	MODERATE	IMPORTANT
Impact of caring on carer - Carer burden (1 item, custom measure) at post-intervention (2 to 4 months from the baseline)[4] (Better indicated by lower values)												
1[3]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[5]	none	21	25	-	MD 0.37 lower (0.93 lower to 0.19 higher)	LOW	IMPORTANT

CI: confidence interval; MD: mean difference

1 Lobban 2013

2 The quality of the evidence was downgraded of 1 level because of the potential risk of detection bias

3 Hattink 2015
4 Between 2-4 months for carers in intervention group and at 4 months for WLC group
5 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

Table 14: Evidence profile for specific carer training programs for coping skills [Tailored to carer needs & professional-led] for carers to provide practical support

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)												
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	no serious imprecision	none	132	64	-	MD 2.58 lower (4.26 to	MODERATE	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**		
										0.90 lower) [4]		
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
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	no serious imprecision	none	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	MODERATE	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		
										2.27 lower)		
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	IMPORTANT
Caring-related morbidity - Depression (Hospital Anxiety and Depression Scale -HADS-depression subscale) - at 24 months follow-up (Better indicated by lower values)												
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	IMPORTANT
Caring-related morbidity - Quality of life (Quality of Life-Alzheimer's disease - QoL-AD) - at 8 months follow-up (Better indicated by higher values)												
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	IMPORTANT
Caring-related morbidity - Quality of life (Quality of Life-Alzheimer's disease - QoL-AD) - at 12 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	114	53	-	MD 0.5 higher (1.62 lower to 2.62 higher)	LOW	IMPORTANT
Caring-related morbidity - 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	IMPORTANT
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	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**		
										12.43 higher)		
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 - Anxiety (HADS- anxiety >=9) number of cases - at 8 months follow-up												
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
Impact of caring on carer - Experience: abusive behaviours with care recipients (Modified Conflict Tactics Scale – MCTS: at least one item with score ≥2)* number of cases												
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	IMPORTANT
Impact of caring on carer - Experience: 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												

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	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	IMPORTANT
Impct of caring on carer - Experience: 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	IMPORTANT

CI: confidence interval; MD: mean difference; RR: risk ratio

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 15: Evidence profile for specific carer training programs for skills building [Not tailored to carer needs & carer-led] for carers to provide practical support

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 - General health and well-being: (General Health Questionnaire–28 GHQ-28) - post-intervention (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 0.13 higher (0.29 lower to 0.55 higher)	LOW	CRITICAL
Caring-related morbidity - General health and well-being: (General Health Questionnaire–28 GHQ-28) - at 3 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 0.01 higher (0.41 lower to 0.43 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life (Medical Outcome Study Short Form Scale, SF-36) - post-intervention (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 7.65 higher (3.06 lower to 18.36 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life (Medical Outcome Study Short Form Scale, SF-36) - at 3 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	18	18	-	MD 4.44 higher (8.61 lower to 17.49 higher)	LOW	CRITICAL
Caring-related morbidity - Depression: Depression symptoms (Depression Anxiety Stress Scales - DASS-21) - post-intervention (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 8.89 lower (21.98 lower to 4.2 higher)	LOW	CRITICAL
Caring-related morbidity - Depression: Depression symptoms (Depression Anxiety Stress Scales - DASS-21) - at 3 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 6.53 lower (19.69 lower to 6.63 higher)	LOW	CRITICAL
Impact of caring on carer - Subjective burden (Level of Expressed Emotion) - post-intervention (Better indicated by lower values)												
1[1]	observational studies	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 0.17 lower (0.39 lower to	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		
										0.05 higher)		
Impact of caring on carer - Subjective burden (Level of Expressed Emotion) - at 3 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	18	18	-	MD 0.32 lower (0.54 to 0.1 lower)	MODERATE	CRITICAL
Impact of caring on carer - Experience: negative (Experience of Care Giving Inventory ECI-negative subscale) - post-intervention (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 8.45 higher (15.55 lower to 32.45 higher)	LOW	IMPORTANT
Impact of caring on carer - Experience: negative (Experience of Care Giving Inventory ECI-negative subscale) - at 3 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 17.42 higher (8.84 lower to 43.68 higher)	LOW	IMPORTANT
Impact of caring on carer - Experience: positive (Experience of Care Giving Inventory ECI-positive subscale) - post-intervention (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	18	18	-	MD 4.6 higher (2.82 to	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		
										6.38 higher)		
Impact of caring on carer - Experience: positive (Experience of Care Giving Inventory ECI-positive subscale) - at 3 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	serious[3]	18	18	-	MD 0.44 lower (1.9 lower to 1.02 higher)	LOW	CRITICAL

CI: confidence interval; MD: mean difference

1 Hoyle 2013

2 The quality of the evidence was downgraded from high to moderate because of the unclear risk of selective reporting of study outcomes (reporting bias), and the unclear risk of selection bias (insufficient information).

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

Specific carers psychoeducation interventions

Table 16: Evidence profile for specific carer psychoeducation interventions for carers to provide practical support

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 - General Mental health (Neuropsychiatric Inventory – NPI) at 6 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	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	80	84	-	MD 2.99 lower (7.96 lower to 1.98 higher)	VERY LOW	CRITICAL
Caring-related morbidity - Depression: Depressive symptoms (Center for Epidemiologic Studies Depression Scale -CES-D-20) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	80	84	-	MD 0.85 lower (3.42 lower to 1.72 higher)	VERY LOW	CRITICAL
Caring-related morbidity - Anxiety (State–Trait Anxiety Inventory) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	80	84	-	MD 2.29 lower (5.9 lower to 1.32 higher)	VERY LOW	CRITICAL
Caring-related morbidity - Quality of life (12-Item Short Form Health Survey SF-12 - physical) at 6 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	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	80	84	-	MD 1.02 higher (1.72 lower to 3.76 higher)	VERY LOW	CRITICAL
Caring-related morbidity - Caring-related morbidity - Quality of life (12-Item Short Form Health Survey SF-12 – mental) at 6 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	80	84	-	MD 0.1 higher (3.54 lower to 3.74 higher)	VERY LOW	CRITICAL
Caring-related morbidity - General health and well-being (28-Item General Health Questionnaire – Total) at 6 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 5.6 lower (8.29 to 2.91 lower)	LOW	CRITICAL
Caring-related morbidity - Quality of life: physical functioning (36-Item Short Form Health Survey: SF-36- physical Functioning subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 11.3 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**		
										(1.12 to 21.48 higher)		
Caring-related morbidity - Quality of life: Physical role (SF-36 – physical role subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 27.9 higher (9.79 to 46.01 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life: Bodily Pain (SF-36 – physical role subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 12.3 higher (2.12 to 22.48 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life: General health (SF-36 – physical role subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 13.3 higher (6.01 to 20.59 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life: Vitality (SF-36 – physical role subscale) at 6 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[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 14.9 higher (7.52 to 22.28 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life: Social Functioning (SF-36 – physical role subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 12.1 higher (0.9 to 23.3 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life: Emotional role (SF-36 – physical role subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 26.1 higher (6.56 to 45.64 higher)	LOW	CRITICAL
Caring-related morbidity - Quality of life: Mental Health (SF-36 – physical role subscale) at 6 months follow-up (Better indicated by higher values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	44	38	-	MD 2.1 higher (1.69 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	Training intervention	Control	Relative (95% CI)	Absolute		
										5.89 higher)		
Impact of caring on carer - Burden CBI (Caregiver Burden Inventory – CBI) at 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	80	84	-	MD 1.18 lower (5.63 lower to 3.27 higher)	VERY LOW	IMPORTANT
Impact of caring on carer - Burden (Zarit Caregiver Burden Interview: full version-22 items) mean change score at 6 months follow-up (Better indicated by lower values)												
1[4]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	no serious imprecision	none	44	38	-	MD 10.2 lower (17.52 to 2.88 lower)	LOW	CRITICAL

CI: confidence interval; MD: mean difference

1 Sepe-Monti 2016

2The quality of the evidence was downgraded from high to low because of the unclear risk of reporting bias: selective reporting of study outcomes (no enough information provided to judge this criterion) and the potential risk of attrition bias (13 in intervention and 28 carers in control group withdrew before 8-week follow-up. Subsequent 12 intervention and 9 control carers refused 6-mo FU; potential attrition bias). Furthermore, there was a significant difference at baseline: more female carers in control group; control group patients had lower baseline MMSE score [that is more severe AD]; intervention group patients took more acetylcholinesterase inhibitors

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 Martin-Carrasco 2009

5 The quality of the evidence was downgraded from high to low because of the unclear of performance bias (no enough information provided to judge this criterion), the potential risk of attrition bias (10% did not complete study; missing data for 29% of sample with imbalance across groups) and the unclear risk of selection bias (insufficient information).

GRADE - CERQual tables for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Table 17: Summary of evidence (GRADE-CERQual), Theme 1: Medication management - Carer needs

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
Managing medicines							
3 (Alhaddad 2016; Riley 2011; Smith 2015)	1. Semi-structured interviews (open-ended questions). 1. Semi-structured interviews (structured and open-ended questions); 1. focus group	Carers have insufficient information regarding medication management and the use and maintenance of equipment to administer medication.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	No or very minor concerns	LOW

1 Evidence was downgraded due to serious methodological limitations (Riley 2011: no details on the recruitment strategy, unclear data collection methods and no details on data analysis methods)

Personal and intimate care

Table 18: Summary of evidence (GRADE-CERQual), Theme 2: Personal care – Feeding and carer burden with providing emotional and practical 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
Feeding and carer burden							

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**
3. (Papachristou 2017; Sepulveda 2008a; Sepulveda 2008b)	1. semi-structured, face-to-face interviews; 1. via telephone conversations and written feedback; 1. questionnaire	Providing information, support and training in food and nutrition can have a positive impact on carer stress and burden.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	No or very minor concerns	LOW

1 Evidence was downgraded due to methodological limitations (Sepulveda 2008a, and Sepulveda 2008b: no details on the data analysis methods, and no details about the relationship between researchers performing the analysis and recruited carers)

Technical health procedure

Table 19: Summary of evidence (GRADE-CERQual), Theme 3: Technical health procedure - Carer needs

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**
Technical health procedures							
1(Alhaddad 2016)	1. Semi-structured interviews (strutctured and open-ended questions).	Carers face challenges and uncertainty about using technical equipment.	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 adequacy of data, as only 1 study supported the review's findings (offering poor data)

Specific Carer Training programs

Table 20: Summary of evidence (GRADE-CERQual), Theme 4: Specific carer training interventions - Confidence, awareness and knowledge

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
Confidence, awareness and knowledge							
6 (Macdonald 2011; Riley 2011; Sepulveda 2008a; Sepulveda 2008b; Sommerlad 2014; Yeandle 2011)	1. Semi-structured interviews administered by telephone; 1. Data were collected via a focus group; 3. Data were collected through a questionnaire 1. Data were collected via telephone conversations and written feedback; 1. Self-completed questionnaires 1. Focus groups	Carers (of people with a range of different conditions) who attended specific carer training interventions developed more confidence when caring and a greater understanding of the condition of the care recipient, enabling them to better cope with challenges.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	No or very minor concerns	LOW

1 Evidence was downgraded due to serious methodological limitations (Riley 2011: no details on the recruitment strategy, data collection and data analysis methods); and (Sepulveda 2008a: no details on data analysis) and unclear methodological limitations for (Macdonald 2012; Sepulveda 2008b; and Yeandle 2011).

Table 21: Summary of evidence (GRADE-CERQual), Theme 5: Specific carer training interventions - Relationships with the care recipient

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
Relationships with the care recipient							
3 (Macdonald 2011; Riley 2011; Sepulveda 2008b),	1. Semi-structured interviews administered by telephone; 1. Focus group 1. Telephone conversations and written feedback	Carers (of people with a range of different conditions) who attended specific carer training interventions were able to better communicate with and understand the care recipient, leading to better relationships between them.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	No or very minor concerns	LOW

1 Evidence was downgraded due to serious methodological limitations (Riley 2011: no details on the recruitment strategy, unclear data collection methods and no details on data analysis methods) and unclear methodological limitations (Sepulveda 2008b: no details on the data analysis methods, and no details about the relationship between researchers performing the analysis and recruited carers)

Table 22: Summary of evidence (GRADE-CERQual), Theme 6: Specific carer training interventions - Understanding of a carer's rights and entitlements/ Practical support in the event of emergency

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
Carer's rights and entitlements/ Practical support							
2 (Riley 2011; Yeandle 2011)	2. Focus group	Carers of people with a range of different conditions who attended a specific carer training intervention felt they could navigate available information resources better	Minor concerns[2]	No or very minor concerns	No or very minor concerns	Serious concerns[3]	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
		and were more aware of the services they could utilise.					

2 Evidence was downgraded due to potential methodological limitation (Riley 2011: no details on the recruitment strategy, unclear data collection methods and no details on data analysis methods)
3 Evidence was downgraded due to substantial concerns with adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 23: Summary of evidence (GRADE-CERQual), Theme 7: Specific carer training interventions - 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
Social Support							
3 (Macdonald 2011; Sommerlad 2014; Yeandle 2011)	1. Semi-structured interviews administered by telephone 2. Questionnaires 3. Focus groups	Carers of people living with dementia and carers of people with eating disorders, who attended specific carer training interventions felt positive about sharing their experiences with other carers. They felt less isolated and were more socially active. In particular, carers from 'hard to reach' groups (such as LGBT carers) were particularly positive about the mutual support provided by the training sessions.	Minor concerns[2]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

1 Evidence was downgraded due to minor methodological limitations (Macdonald 2011; and Yeandle 2011: no enough details on the data analysis methods, and not sufficient details about the relationship between researchers performing the analysis and recruited carers)

Table 24: Summary of evidence (GRADE-CERQual), Theme 8: Specific carer training interventions – Emotional support 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
Emotional support							
1. (Sepulveda 2008a; Sommerlad 2014; Yeandle 2011).	2. Questionnaire 1. Focus groups	Carers of people living with dementia and carers of people with eating disorders who attended specific carer training interventions felt reduced distress and an increase in happiness as their coping and communication skills improved.	Minor concerns[2]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

1 Evidence was downgraded due to methodological limitations (Sepulveda 2008a: no details on data analysis)

Table 25: Summary of evidence (GRADE-CERQual), Theme 9: Specific carer training interventions – Carer (negative) engagement with the intervention: Barriers to taking part in the intervention

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
Barriers to taking part in interventions							
1. (Macdonald 2011)	1. Semi-structured interviews administered by telephone	Carers of people with a range of different conditions who attended specific carer training interventions identified extrinsic barriers that impacted their taking part in the intervention, for example finding time to take part in the interventions, without	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
		disturbing usual care routines; and difficulty engaging with the intervention when the care recipient was not living with them.					

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

Table 26: Summary of evidence (GRADE-CERQual), Theme 10: Specific carer training interventions – Carer (negative) engagement with the intervention: Lack of relevance to carer circumstances

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
Carer (negative) engagement with intervention							
2.(Sepulveda 2008b; Sommerlad 2014)	1. Telephone conversations and written feedback; 1. Self-completed questionnaires	Carers who attended specific carer training interventions found the interventions were not relevant to them, for example they found it difficult to apply the knowledge to their own circumstances.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering poor data)

Table 27: Summary of evidence (GRADE-CERQual), Theme 11: Specific carer training interventions – Carer (positive) engagement with the intervention: Timing of need for information

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
Timing of need for information							

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
2 (Macdonald 2011, Sommerlad 2014)	1. Semi-structured interviews administered by telephone 1. Self-completed questionnaires	Many carers of people with a range of different conditions felt that for them the timing of information provision is crucial in order to attend specific carer training interventions.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded due substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering poor data)

Table 28: Summary of evidence (GRADE-CERQual), Theme 12: Specific carer training interventions – Carer (positive) engagement with the intervention: Positve aspects of the intervention

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
Positve aspects of the intervention							
5 (Macdonald 2011, Papachristou 2017, Sepulveda 2008a, Sepulveda 2008b,	2. Self-completed questionnaires; 1. Semi-structured interviews administered by telephone; 1. semi-structured, face-to-face interviews; 1. via telephone conversations	Carers of people living with dementia and carers of people with eating disorders who attended specific carer training interventions appreciated the diverse elements of the interventions.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

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
Sommerlad 2014)	and written feedback						

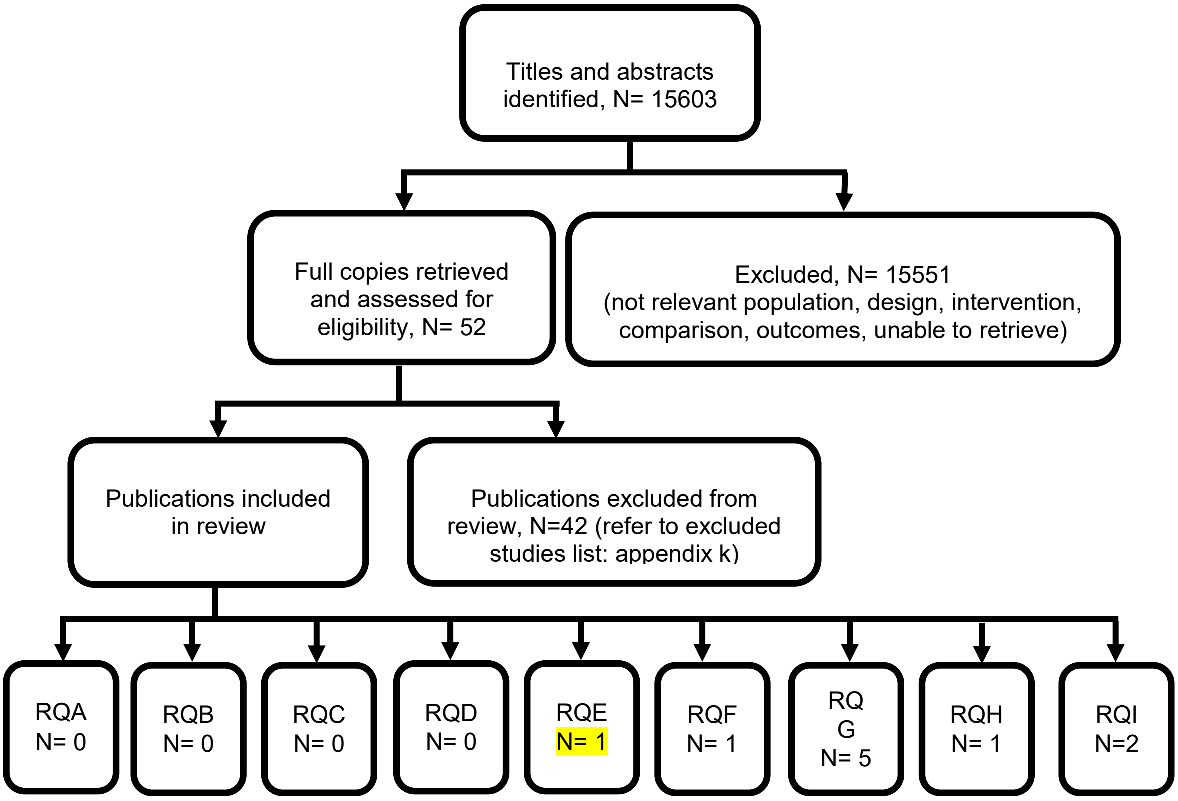
1 Evidence was downgraded due to minor methodological limitations (Sepulveda 2008a, and Sepulveda 2008b: no details on the data analysis methods, and no details about the relationship between researchers performing the analysis and recruited carers)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. As shown in Figure 5 below, 1 economic study was identified which was applicable to this review question.

Figure 5: Study selection flow chart



Appendix H – Economic evidence tables

Economic evidence tables for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Figure 6: 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: Coping Skills training • Control: TAU • Interventions details: ○ Participants assessed at baseline, 4, 8, 12 and 24 months. ○ Coping Skills training START intervention consists in manualised 8 sessions covering - Session 1: Psychoeducat	• Study population: N=260 Carers of people living with dementia ○ Intervention, n=173 ○ Control, n=87 • Characteristics [Intervention; Control] ○ Age (years): 62.0 (14.6); 56.1 (12.3) ○ Sex (M/F): 57/116; 25/62 • Data sources: ○ Source of clinical effectiveness data: Randomised control trial (N=260)* ○ EQ-5D health profiles, for befriended carers and control group carers, were	• Cost description: ○ Cost categories included outpatient costs, community costs, and other costs ○ Incremental Costs Values: ○ 24-month time horizon=£336 ○ 8-month time horizon=£252 • Outcome description: ○ Carer QALYs calculated from the EQ-5D by applying societal weights. ○ Incremental Outcome Values: ○ 24-month time horizon=0.030 (CI 95% -0.010 to 0.060) QALYs	• ICER ○ 24-month time horizon =£11,200 / QALY ○ 8-month time horizon = £6,000 / QALY • Sensitivity analysis: Intervention has a 67% probability of being at cost-effective at a threshold of £20,000/QALY over 24 months, and a 75% probability at a threshold of £30,000/QALY.	• Perspective: Health and social care • Currency: GBP • Cost year: 2009-2010 • Time horizon: 8 & 24 months • time horizon as per the RCT endpoint • Discounting: 3.5% • Applicability: directly 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
	ion 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 recipient, UK-specific care and legal planning - Session 7: Planning	collected at in order to calculate QALYs. ○ Source of resource use data: Randomised control trial (N=260)* ○ Source of unit costs: Unit costs were from NHS and national sources (NHS RefCosts; PSSRU). * Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., Romeo, R., Cooper, C. (2014). 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 living with dementia. Health Technology	○ 8-month time horizon=0.042 (CI 95% 0.015 to 0.071) QALYs		

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	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	Assessment, 18(61), i-xxvi+1-242.			

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	(for example medical, psychological and social treatment).				

CUA: cost-utility analysis; ICER: incremental cost-effectiveness ratio; QALY: quality-adjusted life year: STAR: STrAtegies for RelaTives: TAU: treatment as usual.

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Table 29: Economic evidence profiles

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	ICER	Uncertainty
• Author & year: Livingston 2014 • Country: UK • Interventions: Manual-based coping strategy intervention (STAR intervention) *versus* TAU.	Minor limitations	Directly applicable	• Type of economic analysis: Cost Utility analysis • Time horizon: 8 months (primary economic evaluation) and 24 months • Primary measure of outcome: QALY	• 8 months £252 (-28 to 565) • 24 months £336 (-223 to 895)	• 8 months 0.042 QALYs (0.015 to 0.071) • 24 months 0.030 QALYs (-0.010 to 0.060)	• 8 months £6,000 /QALY • 24 months £11,200 /QALY	• Probabilistic sensitivity analyses: Intervention has a 67% probability of being at cost-effective at a threshold of £20,000/QALY over 24 months, and a 75% probability at a threshold of £30,000/QALY.

CUA: cost-utility analysis; ICER: incremental cost-effectiveness ratio; QALY: quality-adjusted life year: STAR: STrAtegies for RelaTives

Appendix J – Economic analysis

Economic evidence analysis for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: What skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Quantitative component of the review

Table 30: Excludies studies from the quantitative component of the review

Study	Reason for Exclusion
A'Campo, L. E., Wekking, E. M., Spliethoff-Kamminga, N. G., Stijnen, T., Roos, R. A., Treatment effect modifiers for the patient education programme for Parkinson's disease, International Journal of Clinical Practice, 66, 77-83, 2012	Regression analysis of A'Campo 2010.
Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., Lachs, M. S., Caregiver burden: A clinical review, JAMA - Journal of the American Medical Association, 311, 1052-1059, 2014	General systematic review of interventions to reduce carer burden.
Aggarwal, B., Liao, M., Christian, A., Mosca, L., Influence of caregiving on lifestyle and psychosocial risk factors among family members of patients hospitalized with cardiovascular disease, Journal of General Internal Medicine, 24, 93-8, 2009	Prevalence study/regression analysis of RCT.
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.
Agren, S, Evangelista, Ls, Hjelm, C, Stromberg, A, Dyads affected by chronic heart failure: a randomized study evaluating effects of education and psychosocial support to patients with heart failure and their partners, Journal of Cardiac Failure, 18, 359-366, 2012	Control arm does not systematically include carers.
Aguirrezabal, A., Duarte, E., Rueda, N., Cervantes, C., Marco, E., Escalada, F., Effects of information and training provision in satisfaction of patients and carers in stroke rehabilitation, NeuroRehabilitation, 33, 639-647, 2013	Not randomised control trial.
Alsaeed, D., Jamieson, E., Gul, M. O., Smith, F. J., Challenges to optimal medicines use in people living with dementia and their caregivers: A literature review, International Journal of Pharmaceutics, 512, 396-404, 2016	Systematic review of qualitative studies.
American Association for Respiratory, Care, AARC Clinical Practice Guidelines. Providing patient and caregiver training 2010, Respiratory Care, 55, 765-9, 2010	Insufficient detail provided about identified studies.
Anonymous, Training carers of stroke patients improves psychosocial measures in both carer and patient, Evidence-Based Healthcare and Public Health, 8, 342-344, 2004	Reprint of abstract of Kalra 2004.

Anonymous,, Providing patient and caregiver training 2010, Respiratory Care, 55, 765-769, 2010	Duplicate.
Anonymous,, Training informal carers of stroke patients reduces health and social care costs in the year following a stroke, Evidence-Based Healthcare and Public Health, 8, 345-347, 2004	Economic results of RCT.
apos,, Mara, Alison, Jamal, Farah, Llewellyn, Alexis, Lehmann, Angela, Cooper, Chris, Bergeron, Caroline, Improving children's and young people's outcomes through support for mothers, fathers, and carers, 94, 2010	Review focussed on outcomes of care recipient rather than carer.
Arksey, H., Jackson, K., Wallace, A., Baldwin, S., Golder, S., Newbronner, E., Hare, P., Access to health care for carers: barriers and interventions, Database of Abstracts of Reviews of Effects, 156, 2003	No studies published in or after 2003.
Arksey, Hilary, Hirst, Michael, Unpaid carers' access to and use of primary care services, Primary Health Care Research and Development, 6, 101-116, 2005	Descriptive statistics regarding access/use only.
Armfield, N. R., Gray, L. C., Smith, A. C., Clinical use of Skype: a review of the evidence base, Journal of Telemedicine & Telecare, 18, 125-7, 2012	Review identified only one relevant abstract (article not published in English).
Asnani, M. R., Quimby, K. R., Bennett, N. R., Francis, D. K., Interventions for patients and caregivers to improve knowledge of sickle cell disease and recognition of its related complications, Cochrane Database of Systematic Reviews, 2016 (10) (no pagination), 2016	No relevant studies.
Au, A, Gallagher-Thompson, D, Wong, Mk, Leung, J, Chan, Wc, Chan, Cc, Lu, Hj, Lai, Mk, Chan, K, Behavioral activation for dementia caregivers: scheduling pleasant events and enhancing communications, Clinical Interventions In Aging, 10, 611-619, 2015	Study conducted in Hong Kong.
Austrom, Mary Guerriero, Damush, Teresa M., Hartwell, Cora West, Perkins, Tony, Unverzagt, Frederick, Boustani, Malaz, Hendrie, Hugh C., Callahan, Christopher M., Development and Implementation of Nonpharmacologic Protocols for the Management of Patients with Alzheimer's Disease and Their Families in a Multiracial Primary Care Setting, Gerontologist, 44, 548, 2004	Describes program only, results not reported.
Backhaus, S. L., Ibarra, S. L., Klyce, D., Trexler, L. E., Malec, J. F., Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers.[Erratum appears in Arch Phys Med Rehabil. 2010 Nov;91(11):1793], Archives of Physical Medicine & Rehabilitation, 91, 840-8, 2010	Reports care recipient and carer data together.
Bakas, T, Austin, Jk, Habermann, B, Jessup, Nm, McLennon, Sm, Mitchell, Ph, Telephone assessment and skill-building kit for stroke caregivers: a randomized controlled clinical trial, Stroke; a journal of cerebral circulation, 46, 3478-3487, 2015	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Bakas, T, Farran, Cj, Austin, Jk, Given, Ba, Johnson, Ea, Williams, Ls, Stroke caregiver outcomes from the Telephone Assessment and Skill-Building Kit (TASK), Topics in Stroke Rehabilitation, 16, 105-121, 2009	This RCT was performed in the USA, it was therefore excluded because of the health and social

	care context (not comparable with that in place in the UK).
Baker, A., Barker, S., Sampson, A., Martin, C., Caregiver outcomes and interventions: a systematic scoping review of the traumatic brain injury and spinal cord injury literature, Clinical rehabilitation, 31, 45-60, 2017	General scoping review of interventions for carers of people with brain/spinal cord injury.
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: a re-analysis of a randomized controlled trial, International Psychogeriatrics, 25, 34-46, 2013	Intervention is multidisciplinary rehabilitation program aimed primarily at person receiving care.
Banningh, Lw, Vernooij-Dassen, Mj, Vullings, M, Prins, Jb, Rikkert, Mg, Kessels, Rp, Learning to live with a loved one with mild cognitive impairment: effectiveness of a waiting list controlled trial of a group intervention on significant others' sense of competence and well-being, American Journal of Alzheimer's Disease and other Dementias, 28, 228-238, 2013	Not randomised controlled study.
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.
Beauchamp, N., Irvine, Ab, Seeley, J, Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia. Gerontologist, 45(6), 793-801.	No adult carers who provide unpaid care young people lower than 16-17 years with ongoing needs.
Belgacem, B, Auclair, C, Fedor, Mc, Brugnon, D, Blanquet, M, Tournilhac, O, Gerbaud, L, A caregiver educational program improves quality of life and burden for cancer patients and their caregivers: a randomised clinical trial, European Journal of Oncology Nursing, 17, 870-876, 2013	Study conducted in France.
Belle, S., 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. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. Annals of Internal Medicine, 145(10), 727-738.	It is not a training study. Potentially eligible for RQG.
Beng, Ts, Ahmad, F, Loong, Lc, Chin, Le, Zainal, Nz, Guan, Nc, Ann, Yh, Li, Lm, Meng, Cb, Distress Reduction for Palliative Care Patients and Families With 5-Minute Mindful Breathing: a Pilot Study, American journal of hospice & palliative care, 33, 555-560, 2016	Study conducted in Malaysia.
Bergin, S., Mockford, C., Recommendations to support informal carers of people living with motor neurone disease, British Journal of Community Nursing, 21, 518-524, 2016	General systematic review on experience of carers of motor neurone disease carers and views on professional services.

Berry, J. W., Elliott, T. R., Grant, J. S., Edwards, G., Fine, P. R., Does problem-solving training for family caregivers benefit their care recipients with severe disabilities? A latent growth model of the Project CLUES randomized clinical trial, Rehabilitation Psychology, 57, 98-112, 2012	Secondary analysis of Rivera 2008 and Elliot 2009.
Beynon, T., Radcliffe, E., Child, F., Orlowska, D., Whittaker, S., Lawson, S., Selman, L., Harding, R., What are the supportive and palliative care needs of patients with cutaneous T-cell lymphoma and their caregivers? A systematic review of the evidence, British Journal of Dermatology, 170, 599-608, 2014	No identified articles on carers.
Bledsoe, Linda K., Moore, Sharon E., Collins, Wanda Lott, Long Distance Caregiving: An Evaluative Review of the Literature, Ageing International, 35, 293-310, 2010	General review of literature on long-distance caring.
Blewett James, et al., Improving the safety, health and wellbeing of children through improving the physical and mental health of mothers, fathers and carers: research review 1, 2010	General review on improving outcomes for children via improving health of parents and carers, not clearly applicable to carers of young people who will transition to adult services.
Boothroyd, L., Lehoux, P., Home-based chemotherapy for cancer: issues for patients, caregivers and the health care system, Database of Abstracts of Reviews of Effects, 77, 2004	No relevant articles published in or after 2003.
Boots, L. M. M., Vugt, M. E. de, Knippenberg, R. J. M. van, A systematic review of internet-based supportive interventions for caregivers of patients with dementia, International Journal of Geriatric Psychiatry, 29, 2014	No additional relevant articles identified.
Borreani, C., Bianchi, E., Cilia, S., Giuntoli, M., Pietrolongo, E., Rossi, I., Grasso, M. G., Patti, F., Lopes, L., Lugaresi, A., Confalonieri, P., Morino, P., Palmisano, L., Martino, G., Ponzio, M., Amadeo, R., Zaratin, P., Battaglia, M. A., Giordano, A., Unmet needs of people with severe multiple sclerosis and their carers: Qualitative data to construct a home palliative care programme, Journal of Neurology, 260, S173, 2013	Conference abstract.
Bowers, Helen, Maclean, Mairi, Patel, Meena, Older People's Programme, O. P. P., Disregarded and overlooked. 2016	Article not available.
Brady, P., Kangas, M., McGill, K., "Family Matters": A Systematic Review of the Evidence For Family Psychoeducation For Major Depressive Disorder, Journal of Marital & Family Therapy, 43, 245-263, 2017	No relevant articles identified.
Brereton, L., Carroll, C., Barnston, S., Interventions for adult family carers of people who have had a stroke: A systematic review, Clinical Rehabilitation, 21, 867-884, 2007	General systematic review of interventions for carers of people with stroke.
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.

Brunton, L., Bower, P., Sanders, C., The Contradictions of Telehealth User Experience in Chronic Obstructive Pulmonary Disease (COPD): A Qualitative Meta-Synthesis, PLoS ONE [Electronic Resource], 10, e0139561, 2015	Systematic review of qualitative studies.
Bryant, J., Mansfield, E., Boyes, A. W., Waller, A., Sanson-Fisher, R., Regan, T., Involvement of informal caregivers in supporting patients with COPD: A review of intervention studies, International Journal of COPD, 11, 1587-1596, 2016	Review of role of carers in improving outcomes for people with COPD.
Buckley, Kathleen M., "A Meta-Analysis of Interventions for Informal Stroke Caregivers": Commentary by Buckley, Western Journal of Nursing Research, 29, 357-359, 2007	Commentary.
Bull, M. J., Boaz, L., Jerme, M., Educating Family Caregivers for Older Adults About Delirium: A Systematic Review, Worldviews on Evidence-Based Nursing, 13, 232-40, 2016	No relevant RCTs identified.
Bulut, M., Arslantas, H., Ferhan Dereboy, I., Effects of Psychoeducation Given to Caregivers of People With a Diagnosis of Schizophrenia, Issues in Mental Health Nursing, 37, 800-810, 2016	Study conducted in Turkey.
Burgio L, Stevens A, Guy D, Roth DL, Haley WE., Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia, The Gerontologist, 43, 568-79, 2003	Reports data at halfway point of trial.
Burgio, Ld, Collins, Ib, Schmid, B, Wharton, T, McCallum, D, Decoster, J, Translating the REACH Caregiver Intervention for Use by Area Agency on Aging Personnel: the REACH OUT Program, Gerontologist, 49, 103-116, 2009	Single-arm translational study.
Burns, R., Nichols, Lo, Martindale-Adams, J, Graney, Mj, Lummus, A. (2003). Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study. Gerontologist, 43(4), 547-555.	This study focus on a multicomponent intervention (REACH -Resources for Enhancing Alzheimer's Caregivers Health) The main components of this intervention are behavioural, psycho-educational, and coping skills training – and it will included RQG of this guideline.
Butow, P. N., Phillips, F., Schweder, J., White, K., Underhill, C., Goldstein, D., Clinical Oncological Society of, Australia, Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review, Supportive Care in Cancer, 20, 1-22, 2012	No studies including caregivers and published in or after 2003.
Cameron Ailsa, et al.,, Factors that promote and hinder joint and integrated working between health and social care services: a review of research literature, Health and Social Care in the Community, 22, 225-233, 2014	Identified articles are about general service delivery issues and not specifically relevant to any review question.
Cameron, Ji, Czerwonka, A, Naglie, G, Warner, G, Green, T, Gignac, M, Bayley, M, Huijbregts, M, Cheung, A, Silver, F, Phillips, S, Timing it right stroke family support program: ongoing randomized controlled trial, Stroke., 44, e227, 2013	Conference abstract.

Campbell, L. C., Keefe, F. J., Scipio, C., McKee, D. C., Edwards, C. L., Herman, S. H., . . . Donatucci, C. (2007). 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(2 SUPPL.), 414-424.	The intervention was delivered in a telephone-based format designed to facilitate research participation; the primary **Aim of the study** was not training. Potentially eligible for RQG.
Capurro, D., Ganzinger, M., Perez-Lu, J. E., Palliative care from a medical informatics perspective in Chile, Germany, and Peru, Studies in Health Technology & Informatics, 192, 1013, 2013	Conference abstract.
Carbone, Meredith K. B. S. M. S. I. V., Gugliucci, Marilyn R. M. A. PhD, Delirium and the Family Caregiver: The Need for Evidence-based Education Interventions, The Gerontologist, 55, 345, 2015	No relevant RCTs identified.
Carretero, Stephanie, Garces, Jorge, Rodenas, Francisco, Sanjose, Vicente, The informal caregiver's burden of dependent people: Theory and empirical review, Archives of Gerontology and Geriatrics, 49, 74-79, 2009	Not systematic review.
Carretero, Stephanie, Stewart, James, Centeno, Clara, Information and communication technologies for informal carers and paid assistants: Benefits from micro-, meso-, and macro-levels, European Journal of Ageing, 12, 163-173, 2015	Review not relevant.
Carthron, D. L., Bailey, D. E., Anderson, R. A., The "invisible caregiver": multicaregiving among diabetic African-American grandmothers, Geriatric nursing (New York, N.Y.), 35, S32-S36, 2014	Not clear whether young person cared for has ongoing health or social care needs.
Casanas i Comabella, C., Boulton, M., Watson, E., Wee, B., Ehealth initiatives for family carers in pall care: A review of the literature, Palliative Medicine, 30 (6), NP151-NP152, 2016	Conference abstract.
Cashman, R., Bernstein, L. J., Bilodeau, D., Bovett, G., Jackson, B., Yousefi, M., Prica, A., Perry, J., Evaluation of an educational program for the caregivers of persons diagnosed with a malignant glioma, Canadian Oncology Nursing Journal, 17, 6-15, 2007	Single-arm study.
Chan Raymond, J., Webster, Joan, Marquart, Louise, Information interventions for orienting patients and their carers to cancer care facilities, Cochrane Database of Systematic Reviews, 2011	Same study as Chan 2012.
Chan, H. K., Hassali, M. A., Lim, C. J., Saleem, F., Tan, W. L., Using pictograms to assist caregivers in liquid medication administration: A systematic review, Journal of Clinical Pharmacy and Therapeutics, 40, 266-272, 2015	Systematic review of studies on carers of children under 12 years-old.
Chan, R. J., Webster, J., Marquart, L., A systematic review: The effects of orientation programs for cancer patients and their family/carers, International journal of nursing studies, 49, 1558-1567, 2012	Added Hoff 2005; no additional relevant articles.
Chan, R. J., Webster, J., Marquart, L., Information interventions for orienting patients and their carers to cancer care facilities, Cochrane database of systematic reviews (Online), 12, CD008273, 2011	No relevant RCTs/carer outcomes.

Chee, Yk, Gitlin, Ln, Dennis, Mp, Hauck, Ww, Predictors of adherence to a skill-building intervention in dementia caregivers, Journals of gerontology. Series A, Biological sciences and medical sciences, 62, 673-678, 2007	Regression analysis of Gitlin 2003.
Chen, L. F., Liu, J., Zhang, J., Lu, X. Q., Non-pharmacological interventions for caregivers of patients with schizophrenia: A meta-analysis, Psychiatry Research, 235, 123-127, 2016	No relevant articles published in or after 2003 and conducted in relevant country.
Cheng, S. T., Fung, H. H., Chan, W. C., Lam, L. C. W., Short-Term Effects of a Gain-Focused Reappraisal Intervention for Dementia Caregivers: A Double-Blind Cluster-Randomized Controlled Trial, American Journal of Geriatric Psychiatry, 24, 740-750, 2016	Study conducted in Hong Kong.
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 living with dementia.
Chi, N. C., Demiris, G., A systematic review of telehealth tools and interventions to support family caregivers, Journal of Telemedicine & Telecare, 21, 37-44, 2015	Online supplementary tables providing details of included studies was not available.
Chiang, V. C. L., Lee, R. L. P., Ho, F. M., Leung, C. K., Tang, Y. P., Wong, W. S., Ho, Y. S., Tung, Y. W., Lai, H. L., Fulfilling the psychological and information need of the family members of critically ill patients using interactive mobile technology: A randomised controlled trial, Intensive & critical care nursing, 41, 77-83, 2017	Study conducted in China.
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.
Chiu, M., Pauley, T., Wesson, V., Pushpakumar, D., Sadavoy, J., Evaluation of a problem-solving (PS) techniques-based intervention for informal carers of patients with dementia receiving in-home care, International Psychogeriatrics, 27, 937-48, 2015	Not randomised controlled trial.
Choi, Js, Seo, Ym, Kwon, Is, Effects of education on knowledge and practice of caregivers of the stroke patient, Taehan kanho hakhoe chi, 36, 1175-1182, 2006	Study conducted in South Korea.
Choi, K, Kim, J, Effects of an educational program for the reduction of physical restraint use by caregivers in geriatric hospitals, Journal of korean academy of nursing, 39, 769-780, 2009	Study conducted in South Korea.
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.

Ciciriello, Sabina, Johnston Renea, V., Osborne Richard, H., Wicks, Ian, deKroo, Tanya, Clerehan, Rosemary, O'Neill, Clare, Buchbinder, Rachelle, Multimedia educational interventions for consumers about prescribed and over-the-counter medications, Cochrane Database of Systematic Reviews, 2013	Review not relevant.
Citarella Vic, Social work practice with carers: an evidence scope, 29, 2016	Not systematic review.
Clark, A. M., Spaling, M., Harkness, K., Spiers, J., Strachan, P. H., Thompson, D. R., Currie, K., Determinants of effective heart failure self-care: A systematic review of patients' and caregivers' perceptions, Heart, 100, 716-721, 2014	Systematic review of qualitative studies.
Clark, A. M., Wiens, K. S., Banner, D., Kryworuchko, J., Thirsk, L., McLean, L., Currie, K., A systematic review of the main mechanisms of heart failure disease management interventions, Heart, 102, 707-11, 2016	Review of heart failure disease management programmes.
Clarke, D. J., Godfrey, M., Hawkins, R., Sadler, E., Harding, G., Forster, A., McKevitt, C., Dickerson, J., Farrin, A., Implementing a training intervention to support caregivers after stroke: a process evaluation examining the initiation and embedding of programme change, Implementation Science, 8, 96, 2013	Qualitative evaluation of RCT.
Clarke, D. J., Hawkins, R., Sadler, E., Harding, G., McKevitt, C., Godfrey, M., Dickerson, J., Farrin, A. J., Kalra, L., Smithard, D., Forster, A., Introducing structured caregiver training in stroke care: findings from the TRACS process evaluation study.[Erratum appears in BMJ Open. 2014;4(7):e004473corr1], BMJ Open, 4, e004473, 2014	Qualitative study of RCT.
Collinge, W., Kahn, J., Walton, T., Kozak, L., Bauer-Wu, S., Fletcher, K., Yarnold, P., Soltysik, R., Touch, Caring, and Cancer: randomized controlled trial of a multimedia caregiver education program, Supportive Care in Cancer, 21, 1405-14, 2013	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Connolly, A. M., Beavis, E., Mugica-Cox, B., Bye, A. M., Lawson, J. A., Exploring carer perceptions of training in out-of-hospital use of buccal midazolam for emergency management of seizures (2008-2012), Journal of Paediatrics & Child Health, 51, 704-7, 2015	Sample is carers of children.
Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., Brooker, D., Ballard, C., Systematic review of services providing information and/or advice to people living with dementia and/or their caregivers, International Journal of Geriatric Psychiatry, 27, 628-36, 2012	No additional relevant RCTs identified.
Corry, M., Smith, V., Neenan, K., Brabyn, S., Telephone interventions, delivered by healthcare professionals, for educating and psychosocially supporting informal caregivers of adults with diagnosed illnesses, Cochrane Database of Systematic Reviews, 2017 (1) (no pagination), 2017	Protocol for systematic review.
Cove, J., Jacobi, N., Donovan, H., Orrell, M., Stott, J., Spector, A., Effectiveness of weekly cognitive stimulation therapy for people living with dementia and	No carer outcomes reported.

the additional impact of enhancing cognitive stimulation therapy with a carer training program, Clinical Interventions In Aging, 9, 2143-2150, 2014	
Cox, C. E., Porter, L. S., Hough, C. L., White, D. B., Kahn, J. M., Carson, S. S., Tulsky, J. A., Keefe, F. J., Development and preliminary evaluation of a telephone-based coping skills training intervention for survivors of acute lung injury and their informal caregivers, Intensive Care Medicine, 38, 1289-97, 2012	Single-arm study.
Cox, Rachael, Skouteris, Helen, Fuller-Tyszkiewicz, Matthew, Watson, Brittany, Jones, Amanda D., Omerogullari, Stella, Stanton, Kelly, Bromfield, Leah, Hardy, Louise L., The Healthy Eating, Active Living (HEAL) Study: Outcomes, Lessons Learnt and Future Recommendations, Child Abuse Review, 26, 196-214, 2017	Sample is young people and their carers, but no definition of young people provided.
Crist, J. D., Pasvogel, A., Hepworth, J. T., Koerner, K. M., The impact of a telenovela intervention on use of home health care services and Mexican American older adult and caregiver outcomes, Research in gerontological nursing, 8, 62-76, 2015	Primary aim is to increase use of home healthcare services.
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	Study conducted in France.
Cruz, Joana, Marques, Alda, Figueiredo, Daniela, Impacts of COPD on family carers and supportive interventions: A narrative review, Health & social care in the community, 25, 11-25, 2017	No relevant studies identified.
Curtis-Tyler, Katherine, Arai, Lisa, Stephenson, Terence, Roberts, Helen, What makes for a 'good' or 'bad' paediatric diabetes service from the viewpoint of children, young people, carers and clinicians? A synthesis of qualitative findings, Archives of Disease in Childhood, 100, 826-33, 2015	Review of qualitative studies.
Czaja, S., Loewenstein, D, Schulz, R, Nair, Sn, Perdomo, D. (2013). A videophone psychosocial intervention for dementia caregivers. American Journal of Geriatric Psychiatry, 21(11), 1071-1081.	This study focusses on a multicomponent intervention (based on the REACH intervention). The main components of this intervention are behavioural, psycho-educational, and coping skills training – therefore it will potentially be included RQG of this guideline).
D'Avanzo, B., Shaw, R., Riva, S., Apostolo, J., Bobrowicz-Campos, E., Kurpas, D., Bujnowska, M., Holland, C., Stakeholders' views and experiences of care and interventions for addressing frailty and pre-frailty: A meta-synthesis of qualitative evidence, PLoS ONE [Electronic Resource], 12, e0180127, 2017	Review of qualitative studies.
Davies Anna, Rixon Lorna, Newman Stanton, Systematic review of the effects of telecare provided for a person with social care needs on outcomes for	No relevant RCTs identified.

their informal carers, Health and Social Care in the Community, 21, 582-597, 2013	
Daviet, J. C., Bonan, I., Caire, J. M., Colle, F., Damamme, L., Froger, J., Leblond, C., Leger, A., Muller, F., Simon, O., Thiebaut, M., Yelnik, A., Therapeutic patient education for stroke survivors: Non-pharmacological management. A literature review, Annals of Physical and Rehabilitation Medicine, 55, 641-656, 2012	Review not relevant.
Davis, Jl, Harper, M, McBroom, K, Taylor, E, Pura, L, Heart failure. at home e sweet home, Heart and lung: journal of acute and critical care., 40, 381-382, 2011	Conference abstract.
Davis, Ll, Burgio, Ld, Buckwalter, Kc, Weaver, M, A comparison of in-home and telephone-based skill training interventions with caregivers of persons with dementia, Journal of Mental Health and Aging, 10, 31-44, 2004	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
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.
Dean, K., Wilcock, G., Living with mild cognitive impairment: The patient's and carer's experience, International Psychogeriatrics, 24, 871-881, 2012	General systematic narrative review of patient and carer experience of MCI.
Decker, C., Chhatriwalla, E., Gialde, E., Garavalia, B., Summers, D., Quinlan, M. E., Cheng, E., Rymer, M., Saver, J. L., Chen, E., Kent, D. M., Spertus, J. A., Patient-Centered Decision Support in Acute Ischemic Stroke: Qualitative Study of Patients' and Providers' Perspectives, Circulation. Cardiovascular Quality & Outcomes, 8, S109-16, 2015	Qualitative study.
DePalma, Judith A., Update on evidence: Family caregivers in the home, Home Health Care Management & Practice, 19, 206-208, 2007	No addition RCTs identified.
Dickson, Kelly, et al.,, Improving the emotional and behavioural health of looked-after children and young people (LACYP) (Vulnerable/looked-after children: research review 2), 2009	No relevant articles.
Dixon, L., Lucksted, A, Medoff, Dr, Burland, J, Stewart, B, Lehman, Af, Fang, Lj, Sturm, V, Brown, C, Murray-Swank, A. (2011). Outcomes of a randomized study of a peer-taught Family-to-Family Education Program for mental illness. Psychiatric services (Washington, D.C.), 62(6), 591-597.	This is a Family-to-Family Education Program (family intervention), as such shoulkd be included in RQG.
Dooley, Nr, Hinojosa, J, Improving quality of life for persons with Alzheimer's disease and their family caregivers: brief occupational therapy intervention, American journal of occupational therapy, the official publication of the american occupational therapy association, 58, 561-569, 2004	Does not report number of participants assigned to each group.
Dow, B., Moore, K., Scott, P., Ratnayeke, A., Wise, K., Sims, J., Hill, K., Rural carers online: a feasibility study, Australian Journal of Rural Health, 16, 221-5, 2008	Single-arm study.

Drennan, V. M., Greenwood, N., Cole, L., Fader, M., Grant, R., Rait, G., Iliffe, S., Conservative interventions for incontinence in people living with dementia or cognitive impairment, living at home: a systematic review, BMC Geriatrics, 12, 77, 2012	All identified studies published before 2003.
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.
Eames, S., Hoffmann, T., Worrall, L., Read, S., Wong, A., Randomised controlled trial of an education and support package for stroke patients and their carers, BMJ Open, 3 (5) (no pagination), 2013	Carer data not reported separately.
Ellard, D. R., Barlow, J. H., Paskins, Z., Stapley, J., Wild, A., Rowe, I. F., Piloting education days for patients with early rheumatoid arthritis and their partners: a multidisciplinary approach, Musculoskeletal Care, 7, 17-30, 2009	Not randomised controlled trial.
Elliott, Af, Burgio, Ld, Decoster, J, Enhancing caregiver health: findings from the resources for enhancing Alzheimer's caregiver health II intervention, Journal of the American Geriatrics Society, 58, 30-37, 2010	Reports non-validated health-related outcomes.
Elliott, Timothy R., Berry, Jack W., Brief problem-solving training for family caregivers of persons with recent-onset spinal cord injuries: A randomized controlled trial, Journal of Clinical Psychology, 65, 406-422, 2009	No relevant data.
Elliott, Tr, Berry, Jw, Grant, Js, Problem-solving training for family caregivers of women with disabilities: a randomized clinical trial, Behaviour research and therapy, 47, 548-558, 2009	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Elliott, Tr, Brossart, D, Berry, Jw, Fine, Pr, Problem-solving training via videoconferencing for family caregivers of persons with spinal cord injuries: a randomized controlled trial, Behaviour research and therapy, 46, 1220-1229, 2008	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Emden, C., Kowanko, I., De Crespigny, C., Murray, H., Better medication management for Indigenous Australians: Findings from the field, Australian Journal of Primary Health, 11, 80-90, 2005	Qualitative study.
Erlen, Ja, Lingler, J, Sereika, Sm, Tamres, Lk, Happ, Mb, Tang, F, Characterizing caregiver-mediated medication management in patients with memory loss, Journal of Gerontological Nursing, 39, 30-39, 2013	Descriptive cross-sectional study using baseline data from RCT.
Everson-Hock, E. S., Jones, R., Guillaume, L., Clapton, J., Goyder, E., Chilcott, J., Payne, N., Duenas, A., Sheppard, L. M., Swann, C., The effectiveness of training and support for carers and other professionals on the physical and emotional health and well-being of looked-after children and young people: a systematic review, Child: care, health and development, 38, 162-174, 2012	Review on effect of carer training on outcomes for looked after young people.
Ewing, G., Penfold, C., Benson, J. A., Mahadeva, R., Howson, S., Burkin, J., Booth, S., Lovick, R., Gilligan,	Qualitative study.

D., Todd, C., Farquhar, M., Clinicians' Views of Educational Interventions for Carers of Patients With Breathlessness Due to Advanced Disease: Findings From an Online Survey, Journal of Pain and Symptom Management, 53, 265-271, 2017	
Exploring the benefits to caregivers of a family-oriented pulmonary rehabilitation program, Respiratory care. 61 (8) (pp 1081-1089), 2016. Date of publication: 01 aug 2016., 2016	Control arm does not included carers.
Farquhar, M. C., Prevost, A. T., McCrone, P., Brafman-Price, B., Bentley, A., Higginson, I. J., Todd, C., Booth, S., Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial, BMC Medicine, 12, 194, 2014	Intervention primarily for care recipients.
Farquhar, M., Penfold, C., Walter, F. M., Kuhn, I., Benson, J., What Are the Key Elements of Educational Interventions for Lay Carers of Patients With Advanced Disease? A Systematic Literature Search and Narrative Review of Structural Components, Processes and Modes of Delivery, Journal of Pain and Symptom Management, 52, 117-130.e27, 2016	Review not relevant.
Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2004). Psychosocial interventions to reduce depressive symptoms of dementia caregivers: A randomized clinical trial comparing two approaches. Journal of Mental Health and Aging, 10(4), 337-350.	Not sufficient data have bee repoprted (Carer outcomes post-intervention (12 months) - change scores: no actual data).
Farran, Carol J., Gilley, David W., McCann, Judith J., Bienias, Julia L., Lindeman, David A., Evans, Denis A., Efficacy of behavioral interventions for dementia caregivers, Western Journal of Nursing Research, 29, 944-960, 2007	Secondary subgroup analysis of RCT.
Farran, Carol J., Loukissa, Dimitra, Perraud, Suzanne, Paun, Olimpia, Alzheimer's Disease Caregiving Information and Skills. Part I: Care Recipient Issues and Concerns, Research in Nursing & Health, 26, 366-375, 2003	Qualitative study.
Farran, Cj, Loukissa, D, Perraud, S, Paun, O, Alzheimer's disease caregiving information and skills. Part II: family caregiver issues and concerns, Research in Nursing & Health, 27, 40-51, 2004	Qualitative study.
Fathima, V., The effect of information booklet provided to caregivers of patients undergoing haemodialysis on knowledge of home care management, The Nursing journal of India, 95, 81-82, 2004	Study conducted in India.
Feltrin, E. S., Educational care-giver intervention in the multicomponent intervention strategy model (MIS) for delirium nursing in the inpatient eldery, Giornale di Gerontologia, 61, 287-290, 2013	Full text not in English.
Ferré-Grau, C, Sevilla-Casado, M, Boqué-Cavallé, M, Aparicio-Casals, Mr, Valdivieso-López, A, Lleixá-Fortuño, M, Effectiveness of problem solving technique applied by nurses: decreased anxiety and	Full text not in English.

depression in family caregivers, Atencion primaria / Sociedad Espanola de Medicina de Familia y Comunitaria, 44, 695-701, 2012	
Ferre-Grau, C., Sevilla-Casado, M., Lleixa-Fortuno, M., Aparicio-Casals, M. R., Cid-Buera, D., Rodero-Sanchez, V., & Vives-Relats, C. (2014). 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(01-Feb), 288-295.	No primary aim of the intervention is to train adult carers to provide practical support to the person receiving care - potentially elegible for RQF/G.
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	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Finucane, A. M., Lugton, J., Kennedy, C., Spiller, J. A., The experiences of caregivers of patients with delirium, and their role in its management in palliative care settings: an integrative literature review, Psycho-Oncology, 26, 291-300, 2017	Qualitative review.
Fiorillo, A, Vecchio, V, Luciano, M, Sampogna, G, Sbordone, D, Catapano, F, Rosa, C, Malangone, C, Tortorella, A, Veltro, F, Nicolò, G, Piselli, M, Bardicchia, F, Ciampini, G, Lampis, D, Moroni, A, Bassi, M, Iapichino, S, Biondi, S, Graziani, A, Orlandi, E, Starace, F, Baronessa, C, Carrà, G, Maj, M, Feasibility of a psychoeducational family intervention for people with bipolar I disorder and their relatives: results from an Italian real-world multicentre study, Journal of Affective Disorders, 190, 657-662, 2016	Survey study, no carer outcomes.
Fis, T., Thyrian, J. R., Wucherer, D., Asmann, G., Kilimann, I., Teipel, S. J., Hoffmann, W., Medication management for people living with dementia in primary care: description of implementation in the DelpHi study, BMC Geriatrics, 13, 121, 2013	Study protocol.
Fleming Richard, S. U. M. Shima, Empirical studies on the effectiveness of assistive technology in the care of people living with dementia: a systematic review, Journal of Assistive Technologies, 8, 14-34, 2014	No RCTs identified.
Fragala, G, Fragala, M, Improving the safety of patient turning and repositioning tasks for caregivers, Workplace health & safety, 62, 268-273, 2014	Not randomised controlled trial.
Fragala, G., Fragala, M., Repositioning patients in chairs-an improved method, Workplace Health & Safety, 61, 141-4, 2013	Not randomised controlled trial.
Frank, F., Rummel-Kluge, C., Berger, M., Bitzer, E. M., Holzel, L. P., Provision of group psychoeducation for relatives of persons in inpatient depression treatment--a cross-sectional survey of acute care hospitals in Germany, BMC Psychiatry, 14, 143, 2014	Cross-sectional survey of German acute care hospitals.
Friedman, Bruce, Wamsley, Brenda R., Liebel, Dianne V., Saad, Zabedah B., Eggert, Gerald M., Patient Satisfaction, Empowerment, and Health and Disability Status Effects of a Disease Management-Health Promotion Nurse Intervention among Medicare	Nursing intervention for care recipients.

Beneficiaries with Disabilities, The Gerontologist, 49, 778-792, 2009	
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-Yakoobian, Ms, Mamani, Aw, Mueser, Kt, Predictors of distress and hope in relatives of individuals with schizophrenia, Israel journal of psychiatry and related sciences, 46, 130-140, 2009	Secondary regression analysis of controlled family psychoeducation study.
Gallagher-Thompson Dolores, et al.,, Effectiveness of a psychoeducational skill training DVD program to reduce stress in Chinese American dementia caregivers: results of a preliminary study, Aging and Mental Health, 14, 263-273, 2010	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
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	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Gallagher-Thompson, D., Gray, Hl, Dupart, T, Thompson, Lw, Jimenez, D. (2008). 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(4), 286-303.	This is a psychoeducation intevention for carers to provide them with psychological and emotional support, as such shoulkd be included in RQG.
Gallagher-Thompson, Dolores, Tzuang, Yuan, Au, Alma, Brodaty, Henry, Charlesworth, Georgina, Gupta, Rashmi, Lee, Sang E., Losada, Andres, Shyu, Yea-Ing, International perspectives on nonpharmacological best practices for dementia family caregivers: A review, Clinical Gerontologist: The Journal of Aging and Mental Health, 35, 316-355, 2012	General systematic review of interventions for dementia carers.
Gant, Judith R., Steffen, Ann M., Lauderdale, Sean A., Comparative outcomes of two distance-based interventions for male caregivers of family members with dementia, American Journal of Alzheimer's Disease and Other Dementias, 22, 120-128, 2007	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
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, Joseph E., et al, The longitudinal ramifications of stroke caregiving: A systematic review, Rehabilitation Psychology, 55, 108-125, 2010	Intervention studies were excluded from the systematic review.
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.
Ghaleb Obaidi, J., Al-Atiyyat, N. M., Quality of life among primary caregivers of women with breast	No relevant articles.

cancer: A review, Middle East Journal of Cancer, 4, 45-49, 2013	
Gildengers, A. G., Butters, M. A., Albert, S. M., Anderson, S. J., Dew, M. A., Erickson, K., Garand, L., Karp, J. F., Lockovich, M. H., Morse, J., Reynolds, C. F., Design and Implementation of an Intervention Development Study: Retaining Cognition while Avoiding Late-Life Depression (ReCALL), American Journal of Geriatric Psychiatry, 24, 444-454, 2016	Description and brief discussion of trial, no relevant carer outcomes.
Gillespie, R., Mullan, J., Harrison, L., Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature, Journal of Clinical Nursing, 23, 3296-308, 2014	No relevant studies.
Girgis, A., Lambert, S., Caregivers of cancer survivors: The state of the field, Cancer Forum, 33, 167-171, 2009	Non-systematic narrative review.
Gitlin, L. N., Rose, K., Impact of caregiver readiness on outcomes of a nonpharmacological intervention to address behavioral symptoms in persons with dementia, International Journal of Geriatric Psychiatry, 31, 1056-1063, 2016	Analysis of intervention arm data from Gitlin 2010.
Gitlin, Laura N., Winter, Laraine, Dennis, Marie P., Assistive devices caregivers use and find helpful to manage problem behaviors of dementia, Gerontechnology, 9, 408-414, 2010	Descriptive analysis of use of assistive devices in Gitlin 2003.
Gitlin, Ln, Hauck, Ww, Dennis, Mp, Winter, L, Maintenance of effects of the home environmental skill-building program for family caregivers and individuals with Alzheimer's disease and related disorders, Journals of gerontology. Series A, Biological sciences and medical sciences, 60, 368-374, 2005	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Gitlin, Ln, Winter, L, Burke, J, Chernett, N, Dennis, Mp, Hauck, Ww, Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study, American Journal of Geriatric Psychiatry, 16, 229-239, 2008	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
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	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Gitlin, Ln, Winter, L, Dennis, Mp, Hodgson, N, Hauck, Ww, Targeting and managing behavioral symptoms in individuals with dementia: a randomized trial of a nonpharmacological intervention, Journal of the American Geriatrics Society, 58, 1465-1474, 2010	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Given, Barbara, Given, Charles W., Sikorskii, Alla, Jeon, Sangchoon, Sherwood, Paula, Rahbar, Mohammad, The Impact of Providing Symptom Management Assistance on Caregiver Reaction: Results of a Randomized Trial, Journal of Pain and Symptom Management, 32, 433-443, 2006	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).

Godfrey, C. M., Harrison, M. B., Lang, A., Macdonald, M., Leung, T., Swab, M., Homecare safety and medication management with older adults: A scoping review of the quantitative and qualitative evidence, JBI Database of Systematic Reviews and Implementation Reports, 11, 82-130, 2013	No RCTs identified in review and no trials identified with carer samples.
Godwin, Kyler M., Mills, Whitney L., Anderson, Jane A., Kunik, Mark E., Technology-driven interventions for caregivers of persons with dementia: A systematic review, American Journal of Alzheimer's Disease and other Dementias, 28, 216-222, 2013	No additional relevant studies.
Goldberg, L. R., Bell, E., King, C., O'Mara, C., McInerney, F., Robinson, A., Vickers, J., Relationship between participants' level of education and engagement in their completion of the Understanding Dementia Massive Open Online Course, BMC medical education, 15, 60, 2015	Sample was anybody interested in taking online course.
Gonyea, Jg, O'Connor, Mk, Boyle, Pa, Project CARE: a randomized controlled trial of a behavioral intervention group for Alzheimer's disease caregivers, Gerontologist, 46, 827-832, 2006	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Gonzalez, Ee, Nathe, Cn, Logothetis, Dd, Pizanis, Vg, Sanchez-Dils, E, Training caregivers: disabilities and dental hygiene, International journal of dental hygiene, 11, 293-297, 2013	Sample is professional carers.
Gonzalez, Ew, Polansky, M, Lippa, Cf, Gitlin, Ln, Zauszniewski, Ja, Enhancing resourcefulness to improve outcomes in family caregivers and persons with Alzheimer's disease: a pilot randomized trial, International journal of Alzheimer's disease, 2014, 2014	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Graff, Maud J. L., Adang, Eddy M. M., Vernooij-Dassen, Myrra J. M., Community occupational therapy for older patients with dementia and their care givers, British Medical Journal, 336, 7636	Cost-effectiveness study.
Graff, Maud J., Vernooij-Dassen, Myrra J., Hoefnagels, Willibrord H., Dekker, Joost, de Witte, Luc P., Occupational Therapy at Home for Older Individuals With Mild to Moderate Cognitive Impairments and Their Primary Caregivers: A Pilot Study, OTJR: Occupation, Participation and Health, 23, 155-164, 2003	Not randomised controlled study (single arm study).
Graff, Maud J., Vernooij-Dassen, Myrra J., Zajec, Jana, Olde-Rikkert, Marcel G., Hoefnagels, Willibrord H., Dekker, Joost, How can occupational therapy improve the daily performance and communication of an older patient with dementia and his primary caregiver?, Dementia: The International Journal of Social Research and Practice, 5, 503-532, 2006	Qualitative study.
Great Britain Department of Health, Carers strategy: second national action plan 2014 - 2016, 70, 2014	UK Government carer action plan, no cited literature/data.
Greenwood Nan, Smith Raymond, Barriers and facilitators for male carers in accessing formal and informal support: a systematic review, Maturitas, 82, 162-169, 2015	No relevant studies.

Greenwood, N., Mackenzie, A., Cloud, G. C., Wilson, N., Informal primary carers of stroke survivors living at home-challenges, satisfactions and coping: a systematic review of qualitative studies, Disability & Rehabilitation, 31, 337-51, 2009	Included general qualitative studies only; exclusion criteria included qualitative studies focussed on specific aspect of care.
Greenwood, N., Mackenzie, A., Informal caring for stroke survivors: meta-ethnographic review of qualitative literature, Maturitas, 66, 268-76, 2010	General meta-ethnographic systematic review.
Griffith, G. M., Hastings, R. P., 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research, Journal of Applied Research in Intellectual Disabilities, 27, 401-19, 2014	Review of qualitative research.
Griffiths, P. C., Whitney, M. K., Kovaleva, M., Hepburn, K., Development and Implementation of Tele-Savvy for Dementia Caregivers: A Department of Veterans Affairs Clinical Demonstration Project, The Gerontologist, 56, 145-154, 2016	Single-arm study.
Habermann, B., Davis, L. L., Lessons learned from a Parkinson's disease caregiver intervention pilot study, Applied Nursing Research, 19, 212-215, 2006	Description of single-arm study.
Haley, C., O'Callaghan, E., Hill, S., Mannion, N., Donnelly, B., Kinsella, A., Murtagh, A., Turner, N., Telepsychiatry and carer education for schizophrenia, European Psychiatry, 26, 302-304, 2011	Not randomised controlled study.
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.
Han, C. J., Lee, Y. J., Demiris, G., Interventions Using Social Media for Cancer Prevention and Management: A Systematic Review, Cancer Nursing., 27, 2017	No relevant studies identified.
Hankey, Gj, Training caregivers of disabled patients after stroke, Lancet, 382, 2043-2044, 2013	Comment article.
Harding, R., Higginson, I., What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness, Palliative Medicine, 17, 63-74, 2003	All included studies published before 2003.
Harmon, C., Warner, C., RESOURCEFULNESS AND SUPPORT IN STRESS, REWARDS AND MENTAL HEALTH OF GRANDMOTHER CAREGIVERS, The Gerontologist, 48, 236, 2008	Conference abstract.
Harrington, R., Taylor, G., Hollinghurst, S., Reed, M., Kay, H., Wood, V. A., A community-based exercise and education scheme for stroke survivors: a randomized controlled trial and economic evaluation, Clinical Rehabilitation, 24, 3-15, 2010	Sample is care recipients.
Hatch Daniel J, De, Hart William B., Norton Maria C, Subjective stressors moderate effectiveness of a multi-component, multi-site intervention on caregiver depression and burden, International Journal of Geriatric Psychiatry, 29, 406-413, 2014	Regression analysis of REACH II study (Belle 2006).

Hayden, Lisa J., Glynn, Shirley M., Hahn, Theodore J., Randall, Frychettya, Randolph, Eugenia, The use of Internet technology for psychoeducation and support with dementia caregivers, Psychological Services, 9, 215-218, 2012	Trial description, no reported results.
Haylock, P. J., Living to the end: Merging holistic and evidence-based strategies to meet the needs of people living with advanced cancer, Oncology (Williston Park), 23, 35-40, 51-2, 2009	Non-systematic narrative review.
Hébert, R, Lévesque, L, Vézina, J, Lavoie, Jp, Ducharme, F, Gendron, C, Préville, M, Voyer, L, Dubois, Mf, Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial, Journals of gerontology. Series B, Psychological sciences and social sciences, 58, S58-67, 2003	Study conducted before 2003.
Hendrix, C., Ray, C., Informal caregiver training on home care and cancer symptom management prior to hospital discharge: a feasibility study, Oncology Nursing Forum, 33, 793-8, 2006	Informal interviews on carer training intervention.
Henwood Melanie, Butler Terry, Pollard Katherine, Slaying the demon: the Dementia Challenge: progress and achievements, v, 59-59, 2015	Project report.
Hepburn, K., Lewis, M., Tornatore, J., Sherman, C. W., Bremer, K. L., The savvy caregiver program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program, Journal of Gerontological Nursing, 33, 30-36, 2007	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Hepburn, Kw, Lewis, M, Narayan, S, Tornatore, J, Bremer, Kl, Kirk, Ln, Partners in caregiving: a psychoeducation program affecting dementia family caregivers' distress and caregiving outlook, Clinical Gerontologist, 29, 53-69, 2005	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
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	Review of economic studies.
Hirsch, O., Leyh, J., Karch, C., Ferlings, R., Schafer, D., Impact of a training program for caregivers of neurological patients on depression, prostration, and subjective burden, Journal of Neuroscience Nursing, 46, 97-105, 2014	Study conducted in Germany/not randomised controlled trial.
Hoffmann, T., Russell, T., McKenna, K., Producing computer-generated tailored written information for stroke patients and their carers: system development and preliminary evaluation, International Journal of Medical Informatics, 73, 751-8, 2004	Single-arm study.
Holdcroft, Deanne, What are people living with dementia and their carers' perceptions of the quality of care they receive in hospitals in the UK?, Ageing and Health: the Journal of the Institute of Ageing and Health (West Midlands), 21, 2017	Review not available.
Holland, R., Lenaghan, E., Harvey, I., Smith, R., Shepstone, L., Lipp, A., Christou, M., Evans, D., Hand, C., Does home based medication review keep	Sample is care recipients.

older people out of hospital? The HOMER randomised controlled trial, BMJ, 330, 293, 2005	
Horvath, Kj, Trudeau, Sa, Rudolph, Jl, Trudeau, Pa, Duffy, Me, Berlowitz, D, Clinical trial of a home safety toolkit for Alzheimer's disease, International journal of Alzheimer's disease, 2013, 2013	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Hubbard, A. A., McEvoy, P. M., Smith, L., & Kane, R. T. (2016). Brief group psychoeducation for caregivers of individuals with bipolar disorder: A randomized controlled trial. Journal of Affective Disorders, 200, 31-36.	this is a group psychoeducation for carers to provide them with psychological and emotional support, as such shoulkd be included in RQG.
Hudson, P. L., Lobb, E. A., Thomas, K., Zordan, R. D., Trauer, T., Quinn, K., Williams, A., Summers, M., Psycho-educational group intervention for family caregivers of hospitalized palliative care patients: pilot study, Journal of Palliative Medicine, 15, 277-81, 2012	Single-arm study, no relevant data.
Hulme, Claire, Wright, Judy, Crocker, Tom, Non-pharmacological approaches for dementia that informal carers might try or access, International Journal of Geriatric Psychiatry, 25, 2010	Review of interventions for people living with dementia.
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.
Huo, Y, Chiang, L, Wu, S, Kuo, H., The effectiveness of a home rehabilitation nursing program in caregivers of stroke patients, 2, 109-118, 2006	Article not available.
James, Neil, The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: What do carers say?, Journal of Intellectual Disabilities, 17, 6-23, 2013	Review of qualitative studies.
Jenson Mette, et al.,, Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta-analysis of randomised controlled trials, International Journal of Geriatric Psychiatry, 30, 130-143, 2015	No additional relevant RCTs identified.
Jeste, D. V., Dunn, L. B., Folsom, D. P., Zisook, D., Multimedia educational aids for improving consumer knowledge about illness management and treatment decisions: a review of randomized controlled trials, Journal of Psychiatric Research, 42, 1-21, 2008	Review of literature from 1979 to 2004, no relevant articles identified.
Johansson, T., Wild, C., Telerehabilitation in stroke care--a systematic review, Journal of Telemedicine & Telecare, 17, 1-6, 2011	No relevant studies.
Johl Nicholas, Patterson Tom G, Pearson Lesley, What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people living with dementia in the United Kingdom? a systematic review of empirical research findings, Dementia: The International Journal of Social Research and Practice, 15, 721-742, 2016	All included studies are on general views and experiences of BME carers of dementia rather than on specific aspects of care.

Jones, Kevin, Addressing the needs of carers during early psychosis, Early Intervention in Psychiatry, 3, S22-S26, 2009	Not systematic review.
Judge, Ks, Yarry, Sj, Looman, Wj, Bass, Dm, Improved Strain and Psychosocial Outcomes for Caregivers of Individuals with Dementia: findings from Project ANSWERS, Gerontologist, 53, 280-292, 2013	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Judge, Ks, Yarry, Sj, Orsulic-Jeras, S, Acceptability and feasibility results of a strength-based skills training program for dementia caregiving dyads, Gerontologist, 50, 408-417, 2010	Data for carers in control arm not reported.
Kajiyama, B., Thompson, L. W., Eto-Iwase, T., Yamashita, M., Di Mario, J., Marian Tzuang, Y., Gallagher-Thompson, D., Exploring the effectiveness of an internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program.[Erratum appears in Aging Ment Health. 2013;17(5):c1], Aging & Mental Health, 17, 544-54, 2013	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Kales, H. C., Gitlin, L. N., Stanislawski, B., Marx, K., Turnwald, M., Watkins, D. C., Lyketsos, C. G., WeCareAdvisorTM: The Development of a Caregiver-focused, Web-based Program to Assess and Manage Behavioral and Psychological Symptoms of Dementia, Alzheimer’s disease and Associated Disorders, 31, 263-270, 2017	Qualitative study.
Kalra, L, Evans, A, Perez, I, Melourn, A, Patel, A, Knapp, M, Donaldson, N, A randomised controlled trial of caregiver training in stroke patients, Stroke; a journal of cerebral circulation, 35, 239, 2004	Abstract only.
Kamel, A. A., Bond, E., Froelicher, E. S., Stroke patients' caregivers: Their experiences and needs: A qualitative literature review, Jordan Medical Journal, 43, 341-350, 2009	Review of qualitative studies.
Kang, X., Li, Z., Nolan, M. T., Informal caregivers' experiences of caring for patients with chronic heart failure: systematic review and metasynthesis of qualitative studies, The Journal of cardiovascular nursing, 26, 386-394, 2011	Review of qualitative studies.
Katz, J., Medoff, D., Fang, L. J., Dixon, L. B., The Relationship Between the Perceived Risk of Harm by a Family Member with Mental Illness and the Family Experience, Community Mental Health Journal, 51, 2015	Secondary analysis of baseline data from RCT.
Kelly, C. M., Jorm, A. F., Kitchener, B. A., Development of mental health first aid guidelines on how a member of the public can support a person affected by a traumatic event: a Delphi study, BMC Psychiatry, 10, 49, 2010	Delphi consensus study.
Khatiban, M, Kheirollahi, A, Oshvandi, K, Alhani, F, Feradmal, J, The effect of family-based education on knowledge and self-esteem of caregivers of patients with stroke: a randomized controlled trial, Journal of mazandaran university of medical sciences, 23, 2014	Full text not in English.

Kikkert, Mj, Schene, Ah, Koeter, Mw, Robson, D, Born, A, Helm, H, Nose, M, Goss, C, Thornicroft, G, Gray, Rj, Medication adherence in schizophrenia: exploring patients', carers' and professionals' views, Schizophrenia Bulletin, 32, 786-794, 2006	Qualitative study.
Kim, Ej, Kim, Hn, Kim, Wh, Song, Ww, Lee, Ke, Jeong, Jh, Hands-on Training for Caregivers of Post-Stroke Inpatients, Journal of korean academy of rehabilitation medicine, 34, 270-277, 2010	Full text not in English.
Kim, H. S., Kim, H. J., Suh, E. E., The Effect of Patient-centered CPR Education for Family Caregivers of Patients with Cardiovascular Diseases, Journal of Korean Academy of Nursing, 46, 463-474, 2016	Study conducted in South Korea.
Kim, Hye-Jin, Kang, Hyun, Johnson-Motoyama, Michelle, The psychological well-being of grandparents who provide supplementary grandchild care: a systematic review, Journal of Family Studies, 23, 118-141, 2017	Intervention studies were excluded from this review.
Kim, Y., Schulz, R., Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving, Journal of Aging & HealthJ Aging Health, 20, 2008	Not clear whether person cared for has ongoing health or social care needs.
Kimberlin, C., Brushwood, D., Allen, W., Radson, E., Wilson, D., Cancer patient and caregiver experiences: communication and pain management issues, Journal of Pain & Symptom Management, 28, 566-78, 2004	Qualitative study.
King, Rb, Hartke, Rj, Denby, F, Problem-solving early intervention: a pilot study of stroke caregivers, Rehabilitation Nursing, 32, 68-76, 2007	Not randomised controlled study.
Kirkpatrick, P., Wilson, E., Wimpenny, P., Support for older people with COPD in community settings: A systematic review of qualitative research, JBI Database Of Systematic Reviews And Implementation Reports, 10, 3649-3763, 2012	Article not available.
Koller, A., Miaskowski, C., De Geest, S., Opitz, O., Spichiger, E., Supporting self-management of pain in cancer patients: methods and lessons learned from a randomized controlled pilot study, European Journal of Oncology Nursing, 17, 1-8, 2013	Discussion only, no relevant carer results reported.
Konno, Rie, Assisting caregivers to support people living with dementia living in the community, Journal of Advanced Nursing, 65, 773-774, 2009	Summary of reviews by JB Institute.
Kopelowicz, A, Zarate, R, Gonzalez, Smith V, Mintz, J, Liberman, Rp, Disease management in Latinos with schizophrenia: a family-assisted, skills training approach, Schizophrenia Bulletin, 29, 211-227, 2003	No extractable carer outcome data.
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.
Kouri, Krystyna Klodnicka, Ducharme, Francine C., Giroux, Francine, A psycho-educational intervention focused on communication for caregivers of a family	Duplicate of Kouri 2011.

member in the early stage of Alzheimer's disease, Dementia: The International Journal of Social Research and Practice, 10, 2011	
Kreutzer, Js, Marwitz, Jh, Sima, Ap, Godwin, Ee, Efficacy of the Brain Injury Family Intervention: impact on Family Members, Journal of Head Trauma Rehabilitation, 30, 249-260, 2017	Not randomised controlled trial.
Kunik, M. E., Snow, A. L., Wilson, N., Amspoker, A. B., Sansgiry, S., Morgan, R. O., . . . Stanley, M. A. (2017). Teaching Caregivers of Persons with Dementia to Address Pain. American Journal of Geriatric Psychiatry, 25(2), 144-154.	Aim no training/education (Potentially eligible for RQG).
Kuo, L. M., Huang, H. L., Liang, J., Kwok, Y. T., Hsu, W. C., Liu, C. Y., Shyu, Y. I. L., Trajectories of health-related quality of life among family caregivers of individuals with dementia: A home-based caregiver-training program matters, Geriatric nursing (New York, N.Y.), 38, 124-132, 2017	Study conducted in Taiwan.
Kuo, Lm, Shyu, Yinl, Chiang, Hl, Chen, Pl, The effectiveness of a home rehabilitation nursing program in caregivers of stroke patients, Journal of evidence-based nursing, 1, 35-44, 2005	Article not available.
Kuo, Y. W., Yen, M., Fetzer, S., Chiang, L. C., Shyu, Y. I., Lee, T. H., Ma, H. I., A home-based training programme improves family caregivers' oral care practices with stroke survivors: a randomized controlled trial, International journal of dental hygiene, 14, 82-91, 2016	Study conducted in Taiwan.
Kurtz, Margot E., Kurtz, J., Given, Charles W., Given, Barbara, A Randomized, Controlled Trial of a Patient/Caregiver Symptom Control Intervention: Effects on Depressive Symptomatology of Caregivers of Cancer Patients, Journal of Pain and Symptom Management, 30, 112-122, 2005	Identified in RCT search, already included.
Kurtz, Me, Kurtz, Jc, Given, Cw, Given, B, A randomized, controlled trial of a patient/caregiver symptom control intervention: effects on depressive symptomatology of caregivers of cancer patients, Journal of Pain and Symptom Management, 30, 112-122, 2005	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Kurz Alexander, et al.,, Evaluation of a brief educational program for dementia carers: The AENEAS Study, International Journal of Geriatric Psychiatry, 25, 861-869, 2010	Study conducted in Germany.
Kuske, B., Hanns, S., Luck, T., Angermeyer, M. C., Behrens, J., Riedel-Heller, S. G., Nursing home staff training in dementia care: a systematic review of evaluated programs, International Psychogeriatrics, 19, 818-41, 2007	Sample is professional staff in nursing homes.
Kuske, Bettina, Hanns, Stephanie, Luck, Tobias, Nursing home staff training in dementia care, International Psychogeriatrics, 19, 2007	Sample is professional staff in nursing homes.
Kuzu, N., Beser, N., Zencir, M., Sahiner, T., Nesrin, E., Ahmet, E., Binali, C., Cagdas, E., Effects of a comprehensive educational program on quality of life	Study conducted in Turkey.

and emotional issues of dementia patient caregivers, Geriatric Nursing, 26, 378-386, 2005	
Lam, M., Choi, M., Agarwal, A., Chow, R., Chow, S., Rowbottom, L., McDonald, R., Lam, H., Chan, S., Wan, A., Chow, E., Henry, B., Use of multimedia in patient and caregiver education for cancer pain management: A literature review, Supportive Care in Cancer, 25 (2 Supplement 1), S104, 2017	Review of interventions for patient pain management.
Lam, M., Choi, M., Lam, H. R., Agarwal, A., Chow, R., Chow, S., Rowbottom, L., McDonald, R., Lam, H., Chan, S., Chow, E., Henry, B., Use of multimedia in patient and caregiver education for cancer pain management: a literature review, Annals of palliative medicine, 6, 66-72, 2017	Main aim is effectiveness of interventions for patient pain management.
Lambert, S. D., Harrison, J. D., Smith, E., Bonevski, B., Carey, M., Lawsin, C., Paul, C., Girgis, A., The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review, BMJ supportive & palliative care, 2, 224-230, 2012	Review of carer unmet needs.
Lamotte, Guillaume, Shah, Raj C., Lazarov, Orly, Corcos, Daniel M., Exercise training for persons with Alzheimer's disease and caregivers: A review of dyadic exercise interventions, Journal of Motor Behavior, 49, 365-377, 2017	Review of exercise interventions primarily aimed at care recipients.
Landeiro, Maria Jose Lumini, Peres, Heloisa Helena Ciqueto, Martins, Teresa Vieira, Evaluation of the educational technology "Caring for dependent people" by family caregivers in changes and transfers of patients and tube feeding, Revista Latino-Americana de Enfermagem Vol 24 2016, ArtID e2774, 24, 2016	Not randomised controlled trial.
Langer, S., Lehane, C., Yi, J., Patient and Caregiver Adjustment to Hematopoietic Stem Cell Transplantation: a Systematic Review of Dyad-Based Studies, Current Hematologic Malignancy Reports, 12, 324-334, 2017	No relevant RCTs identified.
Langhorne, Peter, Baylan, Satu, Early supported discharge services for people with acute stroke, Cochrane Database of Systematic Reviews, 2017	Review of early discharge for people with stroke.
Larkin, Mary, Group support during caring and post-caring: The role of carers groups, Groupwork: An Interdisciplinary Journal for Working with Groups, 17, 28-51, 2007	Qualitative study.
Latter, S., Hopkinson, J. B., Richardson, A., Hughes, J. A., Lowson, E., Edwards, D., How can we help family carers manage pain medicines for patients with advanced cancer? A systematic review of intervention studies, BMJ supportive & palliative care, 6, 263-75, 2016	No additional relevant studies.
Lauritzen, J., Pedersen, P. U., Sorensen, E. E., Bjerrum, M. B., The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review, JBI Database of Systematic Reviews and Implementation Reports, 13, 373-433, 2015	Review of qualitative studies.
Lavoie, Jp, Ducharme, F, Lévesque, L, Hébert, R, Vézina, J, Gendron, C, Préville, M, St-Laurent, C,	Qualitative study.

Voyer, L, Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: a process evaluation, Aging & Mental Health, 9, 25-34, 2005	
Lawang, W., Horey, D., Blackford, J., Sunsern, R., Riewpaiboon, W., Support interventions for caregivers of physically disabled adults: a systematic review, Nursing & health sciences, 15, 534-545, 2013	Systematic review of studies conducted in Thailand.
Lee, JuHee, Soeken, Karen, Picot, Sandra J., A Meta-Analysis of Interventions for Informal Stroke Caregivers, Western journal of nursing research, 29, 344-356, 2007	General review of interventions for stroke carers.
Lefley, Harriet P., Family psychoeducation for serious mental illness, 2009	Collection of articles on family psychoeducation.
Leite, C. D. S. M., de Menezes, T. L. M., Lyra, E. V. V., de Araujo, C. M. T., Knowledge and caregivers' intervention in Alzheimer's disease: A literature review, Jornal Brasileiro de Psiquiatria, 63, 48-56, 2014	Article in Portuguese.
Levy-Storms, Lene, Cherry, Debra L., Lee, Linda J., Wolf, Sheldon M., Reducing safety risk among underserved caregivers with an Alzheimer's home safety program, Aging & Mental Health, 21, 902-909, 2017	Not randomised controlled trial.
Li, R., Cooper, C., Austin, A., Livingston, G., Do changes in coping style explain the effectiveness of interventions for psychological morbidity in family carers of people living with dementia? A systematic review and meta-analysis, International Psychogeriatrics, 25, 2013	General systematic review of interventions to reduce psychological morbidity of carers of people living with dementia.
Li, R., Cooper, C., Livingston, G., Relationship of coping style to mood and anxiety disorders in dementia carers, Current Opinion in Psychiatry, 27, 52-56, 2014	No additional relevant articles.
Li, Ryan, Cooper, Claudia, Austin, Allana, Livingston, Gill, Do changes in coping style explain the effectiveness of interventions for psychological morbidity in family carers of people living with dementia?, International Psychogeriatrics, 25, 2013	Duplicate.
Llanque, Sarah Mariano, Impact of a psychoeducational intervention on dementia caregiving, Dissertation Abstracts International: Section B: The Sciences and Engineering, 73, 2117, 2012	PhD. Thesis.
Lok, N., Bademli, K., Pilot testing of the "First You Should Get Stronger" program among caregivers of older adults with dementia, Archives of Gerontology & Geriatrics, 68, 84-89, 2017	Study conducted in Turkey.
Lord, K., Livingston, G., Cooper, C., A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people living with dementia, International Psychogeriatrics, 27, 1301-1312, 2015	Review of qualitative studies.
Lu, Y., Bakas, T, Yang, Z, Weaver, Mt, Austrom, Mg, Haase, Je. (2016). Feasibility and Effect Sizes of the Revised Daily Engagement of Meaningful Activities	Aim is not training carers to provide practical support (may be elegible for RQG).

Intervention for Individuals With Mild Cognitive Impairment and Their Caregivers. Journal of Gerontological Nursing, 42(3), 45-58.	
Lu, Yy-F, Ellis, J, Yang, Z, Weaver, Mt, Bakas, T, Austrom, Mg, Haase, Je, Satisfaction with a family-focused intervention for mild cognitive impairment dyads, Journal of nursing scholarship, 48, 334-344, 2016	User satisfaction data of Lu 2016 ('Feasibility and Effect Sizes of the Revised Daily Engagement of Meaningful Activities Intervention for Individuals with Mild Cognitive Impairment and Their Caregivers').
Lui, May H. L., Ross, Fiona M., Thompson, David R., Supporting family caregivers in stroke care: a review of the evidence for problem solving, Stroke, 36, 2514-22, 2005	No relevant RCTs identified.
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.
Lynch, S. H., Lobo, M. L., Compassion fatigue in family caregivers: A Wilsonian concept analysis, Journal of Advanced Nursing, 68, 2125-2134, 2012	Conceptual analysis of compassion fatigue mainly in healthcare professionals.
MacIsaac, L., Harrison, M. B., Godfrey, C., Supportive care needs of caregivers of individuals following stroke: a synopsis of research, Canadian Journal of Neuroscience Nursing, 32, 39-46, 2010	Descriptive review of carer supportive carer needs.
Macleod, S. H., Elliott, L., Brown, R., What support can community mental health nurses deliver to carers of people diagnosed with schizophrenia? Findings from a review of the literature, International journal of nursing studies, 48, 100-20, 2011	Systematic review of nurse-delivered interventions for carers of people with schizophrenia.
Madigan, K., Egan, P., Brennan, D., Hill, S., Maguire, B., Horgan, F., . . . O'Callaghan, E. (2012). A randomised controlled trial of carer-focussed multi-family group psychoeducation in bipolar disorder. European Psychiatry, 27(4), 281-284.	Potentially eligible for RQG.
Madsen, K., Poulsen, H. S., Needs for everyday life support for brain tumour patients' relatives: Systematic literature review, European Journal of Cancer Care, 20, 33-43, 2011	General systematic review of needs of carers of people with brain tumours.
Magid, M., Jones, J., Allen, L. A., McIlvennan, C. K., Magid, K., Thompson, J. S., Matlock, D. D., The Perceptions of Important Elements of Caregiving for a Left Ventricular Assist Device Patient: A Qualitative Meta-Synthesis, Journal of Cardiovascular Nursing, 31, 215-25, 2016	Review of qualitative studies.
Magliano, L., Fiorillo, A, Malangone, C, Rosa, C, Maj, M. (2006). Patient functioning and family burden in a controlled, real-world trial of family psychoeducation for schizophrenia. Psychiatric services (Washington, D.C.), 57(12), 1784-1791.	Potentially eligible for RQG.
Mahendran, Rathi, Lim, Haikel A., Tan, Joyce Y., Ng, Hui Ying, Chua, Joanne, Lim, Siew Eng, Kua, Ee Heok, Griva, Konstadina, Evaluation of a brief pilot psychoeducational support group intervention for family caregivers of cancer patients: A quasi-experimental mixed-methods study, Health and	Study conducted in Singapore.

Quality of Life Outcomes Vol 15 2017, ArtID 17, 15, 2017	
Mairs, H., Bradshaw, T., Implementing family intervention following training: what can the matter be?, Journal of Psychiatric & Mental Health Nursing, 12, 488-94, 2005	Exclusion criteria is intervention study.
Malik, N. A., Zhang, J., Tao Lam, O. L., Jin, L., McGrath, C., Effectiveness of computer-aided learning in oral health among patients and caregivers: A systematic review, Journal of the American Medical Informatics Association, 24, 209-217, 2017	No additional relevant RCTs identified.
Marim, C. M., Silva, V., Taminato, M., Barbosa, D. A., Effectiveness of educational programs on reducing the burden of caregivers of elderly individuals with dementia: a systematic review, Revista Latino-Americana de Enfermagem, 21 Spec No, 267-275, 2013	No additional relevant studies.
Marshall, S., Agarwal, E., Young, A., Isenring, E., Role of domiciliary and family carers in individualised nutrition support for older adults living in the community, Maturitas, 98, 20-29, 2017	Review not relevant.
Marshall, S., Bauer, J., Capra, S., Isenring, E., Are informal carers and community care workers effective in managing malnutrition in the older adult community? A systematic review of current evidence, Journal of Nutrition, Health and Aging, 17, 645-651, 2013	Review not relevant.
Martin, M. Y., Pisu, M., Kvale, E. A., Johns, S. A., Developing effective cancer pain education programs, Current Pain & Headache Reports, 16, 332-42, 2012	Discussion article.
Martin-Carrasco, M., Ballesteros-Rodriguez, J., Dominguez-Panchon, A. I., Munoz-Hermoso, P., Gonzalez-Fraile, E., Interventions for caregivers of patients with dementia, Actas espanolas de psiquiatria, 42, 300-314, 2014	General systematic review of interventions for demenia carers
Martin-Carrasco, M., Dominguez-Panchon, Ana Isabel, Gonzalez-Fraile, Eduardo, Munoz-Hermoso, Paula, Ballesteros, Javier. (2014). 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's disease and Associated Disorders, 28(1), 79-87.	this is a psychoeducation intevention for carers to provide them with psychological and emotional support, as such shoulkd be included in RQG.
Martin-Carrasco, M., Fernandez-Catalina, P., Dominguez-Panchon, A. I., Goncalves-Pereira, M., Gonzalez-Fraile, E., Munoz-Hermoso, P., . . . Group, E.-I. (2016). 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, Sep-17.	Potentially eligible for RQG.
Martin-Carrasco, M., Martin, M. F., Valero, C. P., Millan, P. R., Garcia, C. I., Montalban, S. R., . . . Vilanova, M. B. (2009). Effectiveness of a psychoeducation intervention program in the reduction of caregiver burden in Alzheimer's Disease patients'	this is a group psychoeducation intevention for carers to provide them with psychological and emotional support, as such shoulkd be included in RQG.

caregivers. International Journal of Geriatric Psychiatry, 24(5).	
Martin-Cook, K, Remakel-Davis, B, Svetlik, D, Hynan, Ls, Weiner, Mf, Caregiver attribution and resentment in dementia care, American Journal of Alzheimer's Disease and Other Dementias, 18, 366-374, 2003	No relevant extractable carer data.
Martin-Cook, K., Davis, Ba, Hynan, Ls, Weiner, Mf. (2005). A randomized, controlled study of an Alzheimer's caregiver skills training program. American Journal of Alzheimer's Disease and Other Dementias, 20(4), 204-210.	Carers are not the primary focus.
Martire, L. M., Schulz, R., Keefe, F. J., Rudy, T. E., Starz, T. W., Couple-oriented education and support intervention: Effects on individuals with osteoarthritis and their spouses, Rehabilitation Psychology, 52, 121-132, 2007	Control arm does not include carers.
Martire, Lm, Schulz, R, Keefe, Fj, Starz, Tw, Osial, Ta, Dew, Ma, Reynolds, Cf, Feasibility of a dyadic intervention for management of osteoarthritis: a pilot study with older patients and their spousal caregivers, Aging & Mental Health, 7, 53-60, 2003	Control arm does not include carers.
May, C. R., Cummings, A., Myall, M., Harvey, J., Pope, C., Griffiths, P., Roderick, P., Arber, M., Boehmer, K., Mair, F. S., Richardson, A., Experiences of long-term life-limiting conditions among patients and carers: What can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease?, BMJ Open, 6 (10) (no pagination), 2016	Meta-review of qualitative reviews.
McCullagh, E., Brigstocke, G., Donaldson, N., Kalra, L., Determinants of caregiving burden and quality of life in caregivers of stroke patients, Stroke, 36, 2181-6, 2005	Regression analysis of Kalra 2004.
McCurry, S. M., Logsdon, R. G., Mead, J., Pike, K. C., La Fazia, D. M., Stevens, L., Teri, L., Adopting Evidence-Based Caregiver Training Programs in the Real World: Outcomes and Lessons Learned from the STAR-C Oregon Translation Study, Journal of Applied Gerontology, 36, 519-536, 2017	Single-arm study.
McCurry, Sm, Gibbons, Le, Logsdon, Rg, Vitiello, M, Teri, L, Training caregivers to change the sleep hygiene practices of patients with dementia: the NITE-AD project, Journal of the American Geriatrics Society, 51, 1455-1460, 2003	No relevant outcomes/data.
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.
McKechnie, V., Barker, C., Stott, J., Effectiveness of computer-mediated interventions for informal carers of people living with dementia ? a systematic review, Database of Abstracts of Reviews of Effects, 1619-1637, 2014	Duplicate.

McKechnie, V., Barker, C., Stott, J., Effectiveness of computer-mediated interventions for informal carers of people living with dementia-a systematic review, International Psychogeriatrics, 26, 1619-37, 2014	General systematic review of computer-bassed interventions for dementia carers.
McLaughlin, Ka, Glang, A, Beaver, Sv, Gau, Jm, Keen, S, Web-based training in family advocacy, Journal of Head Trauma Rehabilitation, 28, 341-348, 2013	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
McLeod-Sordjan, R., Worral, P., Krajewski, B., Jean-Baptiste, P., Barone, J., Effectiveness of patient-caregiver dyad discharge interventions on hospital readmissions of elderly patients with community acquired pneumonia: A systematic review, JBI Database of Systematic Reviews and Implementation Reports, 8(S34), S67-79, 2010	Article not available.
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	No relevant carer data.
McWilliams, S., Hill, S., Mannion, N., Fetherston, A., Kinsella, A., O'Callaghan, E., Schizophrenia: a five-year follow-up of patient outcome following psycho-education for caregivers, European Psychiatry: the Journal of the Association of European Psychiatrists, 27, 56-61, 2012	Not randomised controlled study.
Meeker, Mary Ann, Finnell, Deborah, Othman, Areej K., Family caregivers and cancer pain management: A review, Journal of Family Nursing, 17, 29-60, 2011	No additional relevant RCTs identified.
Millenaar, J. K., Bakker, C., Koopmans, R. T. C. M., Verhey, F. R. J., Kurz, A., de Vugt, M. E., The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review, International Journal of Geriatric Psychiatry, 31, 1261-1276, 2016	Insufficient information provided in review about included studies to determine their relevance to review questions.
Miller, C., Kapp, S., Informal carers and wound management: an integrative literature review, Journal of Wound CareJ Wound Care, 24, 489-90, 492, 494--7, 2015	No relevant articles.
Moniz-Cook Esme, et al.,, Can training community mental health nurses to support family carers reduce behavioural problems in dementia? An exploratory pragmatic randomised controlled trial, International Journal of Geriatric Psychiatry, 23, 185-191, 2008	Compares psychosocial intervention provided by specially trained mental health nurses with non-specially trained mental health nurses.
Moore, G., Collins, A., Brand, C., Gold, M., Lethborg, C., Murphy, M., Sundararajan, V., Philip, J., Palliative and supportive care needs of patients with high-grade glioma and their carers: a systematic review of qualitative literature, Patient Education & CounselingPatient Educ Couns, 91, 141-53, 2013	Review of qualitative evidence.
Moore, P. M., Rivera Mercado, S., Grez Artigues, M., Lawrie, T. A., Communication skills training for healthcare professionals working with people who have cancer, The Cochrane database of systematic reviews, 3, CD003751, 2013	Review of qualitative evidence.

Moran Patricia, Ghate Deborah, Van Der Merwe Amelia, What works in parenting support?: a review of the international evidence, 202p., 2004	All included studies conducted before 2003.
Morrisby, C., Joosten, A., Ciccarelli, M., Do services meet the needs of people living with dementia and carers living in the community? A scoping review of the international literature, International Psychogeriatrics, 1-10, 2017	No relevant articles.
Morriss, Richard, Vinjamuri, Indira, Faizal Mohammad, Amir, Bolton Catherine, A., McCarthy James, P., Training to recognise the early signs of recurrence in schizophrenia, Cochrane Database of Systematic Reviews, 2013	Target population is people with schizophrenia.
Nelis, S., Quinn, C., Clare, L., Information and support interventions for informal caregivers of people living with dementia, Cochrane Database of Systematic Reviews, (2) (no pagination), 2007	Protocol for review.
Nelson, A., Baptiste, A. S., Evidence-based practices for safe patient handling and movement, Online Journal of Issues in Nursing, 9, 4, 2004	Review of interventions for patient handling.
Nichols, Linda O., Martindale-Adams, Jennifer, Greene, William Alex, Burns, Robert, Graney, Marshall J., Lummus, Allan, Dementia caregivers' most pressing concerns, Clinical Gerontologist: The Journal of Aging and Mental Health, 32, 1-14, 2009	Study to determine carer needs, no relevant outcomes.
Nobili, A., Riva, E, Tettamanti, M, Lucca, U, Liscio, M, Petrucci, B, Porro, Gs. (2004). The effect of a structured intervention on caregivers of patients with dementia and problem behaviors: a randomized controlled pilot study. Alzheimer's disease and Associated Disorders, 18(2), 75-82.	Aim no training/education (Potentially eligible for RQG).
Nogueira, P. C., de Carvalho Nagliate, P., de Godoy, S., Rangel, E. M., Trevizan, M. A., Mendes, I. A., Technology use for health education to caregivers: an integrative review of nursing literature, Applied Nursing ResearchAppl Nurs Res, 26, 101-4, 2013	No additional relevant RCTs identified.
Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., Mood, D. W., Interventions with family caregivers of cancer patients: meta-analysis of randomized trials, CA: a Cancer Journal for Clinicians, 60, 317-39, 2010	General systematic review/meta-analysis of family interventions for cancer carers.
Nunnemann, S., Kurz, A., Leucht, S., Diehl-Schmid, J., Caregivers of patients with frontotemporal lobar degeneration: A review of burden, problems, needs, and interventions, International Psychogeriatrics, 24, 1368-1386, 2012	No RCTs identified.
O'Connor, Claire M., Clemson, Lindy, da Silva, Thais Bento Lima, Piguet, Olivier, Hodges, John R., Mioshi, Eneida, Enhancement of carer skills and patient function in the non-pharmacological management of frontotemporal dementia (FTD), Dementia & Neuropsychologia, 7, 143-150, 2013	No relevant studies identified.
Oldham, L, Kristjanson, Lj, Development of a pain management programme for family carers of advanced cancer patients, International Journal of Palliative Nursing, 10, 91-99, 2004	Qualitative study.

Oliveira Lopes, L., Cachioni, M., Psychoeducational intervention for caregivers of elderly with dementia: a systematic review, Jornal Brasileiro de Psiquiatria, 61, 252-261, 2012	Article published in Portuguese.
Oliver,D.P., Demiris,G., Comparing face-to-face and telehealth-mediated delivery of a psychoeducational intervention: a case comparison study in hospice, Telemedicine Journal and E-Health, 16, 751-753, 2010	Case study with 2 participants.
Onor, Ml, Trevisiol, M, Negro, C, Signorini, A, Saina, M, Aguglia, E, Impact of a multimodal rehabilitative intervention on demented patients and their caregivers, American Journal of Alzheimer's Disease and Other Dementias, 22, 261-272, 2007	Small sample size (<8 participants in each arm).
Opinion Research, Services, Research to support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010: qualitative evidence on the views of service users, carers and practitioners: final report: summary, 30, 2016	Summary of report, details of methodology and included studies not provided.
Ostwald, S. K., Davis, S., Hersch, G., Kelley, C., Godwin, K. M., Evidence-based educational guidelines for stroke survivors after discharge home, Journal of Neuroscience Nursing, 40, 173-9, 191, 2008	Case study.
Ozkan, B., Erdem, E., Ozsoy, S. D., Zararsiz, G., Effect of psychoeducation and telepsychiatric follow up given to the caregiver of the schizophrenic patient on family burden, depression and expression of emotion, Pakistan Journal of Medical Sciences, 29, 2013	Study conducted in Turkey.
Parand, A., Garfield, S., Vincent, C., Franklin, B. D., Carers' medication administration errors in the domiciliary setting: A systematic review, PLoS ONE, 11 (12) (no pagination), 2016	No relevant RCTs identified.
Park, M. S., Choi-Kwon, S., The effects of oral care education on caregivers' knowledge, attitude, & behavior toward oral hygiene for elderly residents in a nursing home, Journal of Korean Academy of Nursing, 41, 684-693, 2011	Study conducted in South Korea.
Parker Gillian, Arksey Hilary, Harden Melissa, Meta-review of international evidence on interventions to support carers, 85p., bibliog., 2010	General meta-review of carer support interventions.
Parker, Deborah, Mills, Sandra, Abbey, Jennifer, Effectiveness of interventions that assist caregivers to support people living with dementia living in the community: A systematic review, International Journal of Evidence-Based Healthcare, 6, 137-172, 2008	No additional relevant studies.
Patel Anita, et al.,, Training care givers of stroke patients: economic evaluation, British Medical Journal, 8, 1102-1104, 2004	Economics study.
Paulson, C. M., Monroe, T., McDougall, G. J., Fick, D. M., A Family-Focused Delirium Educational Initiative With Practice and Research Implications, Gerontology & geriatrics education, 37, 4-11, 2016	Description of brochure development.
Peacock, Shelley C., Forbes, Dorothy A., Interventions for Caregivers of Persons with	All studies published/conducted before 2003.

Dementia: A Systematic Review, CJNR: Canadian Journal of Nursing Research, 35, 88-107, 2003	
Perraud, S, Farran, Cj, Loukissa, D, Paun, O, Alzheimer's disease caregiving information and skills, part III: group process issues and concerns, Research in Nursing & Health, 27, 110-120, 2004	Qualitative study.
Petricone-Westwood, D., Lebel, S., Being a caregiver to patients with ovarian cancer: A scoping review of the literature, Gynecologic Oncology, 143, 184-192, 2016	General scoping review article about experience of ovarian cancer carers. Insufficient detail about included studies to determine relevance to guideline questions.
Pfeiffer, K, Beische, D, Hautzinger, M, Berry, Jw, Wengert, J, Hoffrichter, R, Becker, C, Schayck, R, Elliott, Tr, Telephone-based problem-solving intervention for family caregivers of stroke survivors: a randomized controlled trial, Journal of Consulting and Clinical Psychology, 82, 628-643, 2014	Study conducted in Germany.
Piccenna Loretta, et al.,, Guidance for community-based caregivers in assisting people with moderate to severe traumatic brain injury with transfers and manual handling: evidence and key stakeholder perspectives, Health and Social Care in the Community, 25, 458-465, 2017	Rapid review/opinion article; no RCTs.
Pickett-Schenk, Sa, Bennett, C, Cook, Ja, Steigman, P, Lippincott, R, Villagracia, I, Grey, D, Changes in caregiving satisfaction and information needs among relatives of adults with mental illness: results of a randomized evaluation of a family-led education intervention, American Journal of Orthopsychiatry, 76, 545-553, 2006	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Pierce, Ll, Steiner, V, Govoni, Al, Hicks, B, Cervantez, Thompson Tl, Friedemann, Ml, Internet-based support for rural caregivers of persons with stroke shows promise, Rehabilitation Nursing, 29, 95-103, 2004	Not randomised controlled study.
Piil, K., Juhler, M., Jakobsen, J., Jarden, M., Controlled rehabilitative and supportive care intervention trials in patients with high-grade gliomas and their caregivers: a systematic review, BMJ supportive & palliative careBMJ support, 6, 27-34, 2016	No relevant studies identified.
Pinquart, M., Sorensen, S., Helping caregivers of persons with dementia: Which interventions work and how large are their effects?, International Psychogeriatrics, 18, 577-595, 2006	Review not relevant.
Prorok, J. C., Horgan, S., Seitz, D. P., Health care experiences of people living with dementia and their caregivers: A meta-ethnographic analysis of qualitative studies, Cmaj, 185, E669-E680, 2013	Review of qualitative studies.
Proudfoot, J., Parker, G., Hyett, M., Manicavasagar, V., Smith, M., Grdovic, S., Greenfield, L., Next generation of self-management education: Web-based bipolar disorder program, Australian & New Zealand Journal of Psychiatry, 41, 903-9, 2007	Descriptive article, no relevant carer data.
Quadflieg, N., Schadler, D., Naab, S., Fichter, M. M., RCT of a Video-based Intervention Program for Caregivers of Patients with an Eating Disorder,	Study conducted in Germany.

European Eating Disorders Review, 25, 283-292, 2017	
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 Alzheimer's disease?, American Journal of Alzheimer's Disease and Other Dementias, 22, 360-368, 2007	General survey about use of services and satisfaction with them.
Reichhart, T, Pitschel-Walz, G, Kissling, W, Bäuml, J, Schuster, T, Rummel-Kluge, C, Gender differences in patient and caregiver psychoeducation for schizophrenia, European Psychiatry, 25, 39-46, 2010	Secondary analysis of 2 studies (RCT conducted before 2003; a single-arm study).
Reinares, M., Vieta, E, Colom, F, Martínez-Arán, A, Torrent, C, Comes, M, Goikolea, Jm, Benabarre, A, Sánchez-Moreno, J. (2004). Impact of a psychoeducational family intervention on caregivers of stabilized bipolar patients. Psychotherapy and psychosomatics, 73(5), 312-319.	Potentially eligible for RQG.
Repper, J., Breeze, J., User and carer involvement in the training and education of health professionals: a review of the literature, International journal of nursing studies, 44, 511-9, 2007	No relevant articles.
Rivera, Pa, Elliott, Tr, Berry, Jw, Grant, Js, Problem-solving training for family caregivers of persons with traumatic brain injuries: a randomized controlled trial, Archives of Physical Medicine and Rehabilitation, 89, 931-941, 2008	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Robinson, Karen, Webber, Martin, Models and effectiveness of service user and carer involvement in social work education: A literature review, British Journal of Social Work, 43, 925-944, 2013	Review of studies about involvement of service users/carers in social work education; no relevant articles.
Robinson, L., A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use, 124p., 2006	Duplicate.
Robinson, L., Hutchings, D., Corner, L., Beyer, F., Dickinson, H., Vanoli, A., Finch, T., Hughes, J., Ballard, C., May, C., Bond, J., A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use, Health Technology Assessment (Winchester, England), 10, iii, ix-108, 2006	No relevant articles identified.
Roest, Henriëtte van der, Meiland, Franka, Jonker, Cees, Droes, Rose-Marie, User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness, Aging and Mental Health, 14, 461-470, 2010	Not randomised controlled study.
Rofail, D., Maguire, L., Kissner, M., Colligs, A., Abetz-Webb, L., A Review of the Social, Psychological, and Economic Burdens Experienced by People with Spina Bifida and Their Caregivers, Neurology and Therapy, 2, 1-12, 2013	No relevant articles.

Rotrou Jocelyne de, et al.,, Do patients diagnosed with Alzheimer's disease benefit from a psycho-educational programme for family caregivers? A randomised controlled study, International Journal of Geriatric Psychiatry, 26, 833-842, 2011	Study conducted in France.
Rouget, B. W., Aubry, J. M., Efficacy of psychoeducational approaches on bipolar disorders: a review of the literature, Journal of Affective Disorders, 98, 11-27, 2007	Review of interventions concentrating on patient outcomes.
Rowe, J., Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals, Journal of Psychiatric and Mental Health Nursing, 19, 70-82, 2012	Review of qualitative studies.
Rueda Diaz, L. J., Da Monteiro Cruz, D. L., The efficacy of telephone use to assist and improve the wellbeing of family caregivers of persons with chronic diseases: A systematic review, JBI Database of Systematic Reviews and Implementation Reports, 12, 106-140, 2014	No additional relevant studies.
Ruppar, T. M., Conn, V. S., Russell, C. L., Medication adherence interventions for older adults: literature review, Research & Theory for Nursing Practice, 22, 114-47, 2008	No relevant articles identified.
Samia, L. W., Hepburn, K., Nichols, L., "Flying by the seat of our pants": What dementia family caregivers want in an advanced caregiver training program, Research in Nursing and Health, 35, 598-609, 2012	Analysis of carer survey and focus groups.
Schulz, R., Czaja, S. J., Lustig, A., Zdaniuk, B., Martire, L. M., & Perdomo, D. (2009). Improving the quality of life of caregivers of persons with spinal cord injury: a randomized controlled trial. Rehabilitation Psychology, 54(1), Jan-15.	Potentially eligible for RQG.
Schulz, Richard, Martire, Lynn M., Family caregiving of persons with dementia: Prevalence, Health Effects, and Support Strategies, The American Journal of Geriatric Psychiatry, 12, 240-249, 2004	Not systematic review.
Schumacher, K. L., Plano Clark, V. L., West, C. M., Dodd, M. J., Rabow, M. W., Miaskowski, C., Pain medication management processes used by oncology outpatients and family caregivers part I: Health systems contexts, Journal of Pain and Symptom Management, 48, 770-783, 2014	Qualitative study.
Schumacher, K. L., Plano Clark, V. L., West, C. M., Dodd, M. J., Rabow, M. W., Miaskowski, C., Pain medication management processes used by oncology outpatients and family caregivers part II: Home and lifestyle contexts, Journal of Pain and Symptom Management, 48, 784-796, 2014	Qualitative study of participants in RCT.
Scotland Scottish Government, National minimum information standards for all adults in Scotland for assessment, shared care and support plan, review and carers assessment and support: consultation on the compendium of standards, 89p., 2007	Information pack.
Seike, Aya, Sakurai, Takashi, Sumigaki, Chieko, Takeda, Akinori, Endo, Hidetoshi, Toba, Kenji,	Single-arm study.

Verification of educational support intervention for family caregivers of persons with dementia, Journal of the American Geriatrics Society, 64, 661-663, 2016	
Sherman Michelle, Updates and five-year evaluation of the S.A.F.E. Program: a family psychoeducational program for serious mental illness, Community Mental Health Journal, 42, 213-219, 2006	No relevant outcomes reported.
Sherwood, Pr, Given, Ba, Given, Cw, Sikorskii, A, You, M, Prince, J, The impact of a problem-solving intervention on increasing caregiver assistance and improving caregiver health, Supportive Care in Cancer, 20, 1937-1947, 2012	No relevant carer data.
Shim, B, Landerman, Lr, Davis, Ll, Correlates of care relationship mutuality among carers of people with Alzheimer's and Parkinson's disease, Journal of Advanced Nursing, 67, 1729-1738, 2011	Secondary analysis of control arm in RCT.
Sigalet, E., Cheng, A., Donnon, T., Koot, D., Chatfield, J., Robinson, T., Catena, H., Grant, V. J., A simulation-based intervention teaching seizure management to caregivers: A randomized controlled pilot study, Paediatrics and Child Health (Canada), 19, 373-378, 2014	Sample is carers of children.
Silva, A. L., Teixeira, H. J., Teixeira, M. J., Freitas, S., The needs of informal caregivers of elderly people living at home: an integrative review, Scandinavian Journal of Caring Sciences, 27, 792-803, 2013	General review of needs of carers of older people living at home.
Simoneau, T. L., Kilbourn, K., Spradley, J., Laudenslager, M. L., An evidence-based stress management intervention for allogeneic hematopoietic stem cell transplant caregivers: development, feasibility and acceptability, Supportive Care in Cancer, 25, 2515-2523, 2017	No relevant carer data.
Sinfield, P., Baker, R., Camosso-Stefinovic, J., Colman, A. M., Tarrant, C., Mellon, J. K., Steward, W., Kockelbergh, R., Agarwal, S., Men's and carers' experiences of care for prostate cancer: a narrative literature review, Health Expectations, 12, 301-12, 2009	No relevant articles.
Slev, V. N., Mistiaen, P., Pasman, H. R., Verdonck-de Leeuw, I. M., van Uden-Kraan, C. F., Francke, A. L., Effects of eHealth for patients and informal caregivers confronted with cancer: A meta-review, International Journal of Medical Informatics, 87, 54-67, 2016	No systematic reviews on carers' use of eHealth interventions identified.
Slevin Eamonn, et al.,, Supporting people with intellectual disabilities who challenge or who are ageing: a rapid review of evidence, 204p., bibliog., 2011	General rapid review.
Smith, E. M., Boucher, N., Miller, W. C., Caregiving services in spinal cord injury: A systematic review of the literature, Spinal Cord, 54, 562-569, 2016	General review of carer services, no relevant articles identified.
Smith, Felicity, Francis, Sally-Anne, Gray, Nicola, Denham, Michael, Graffy, Jonathan, A Multi-Centre Survey among Informal Carers Who Manage Medication for Older Care Recipients: Problems Experienced and Development of Services, Health & Social Care in the Community, 11, 138-145, 2003	UK survey.

Smith, J., Forster, A., House, A., Knapp, P., Wright, J., Young, J., Information provision for stroke patients and their caregivers, Cochrane Database of Systematic Reviews, (2) (no pagination), 2008	Older version of Cochrane review (Smith 2012).
Smith, J., Forster, A., Young, J., Cochrane review: Information provision for stroke patients and their caregivers, Clinical Rehabilitation, 23, 195-206, 2009	Older version of Cochrane review (Smith 2012).
Smith, Je, Forster, A, Young, Jb, A randomised trial to evaluate improved routine communication to patients and carers after stroke, Cerebrovascular diseases (basel, switzerland), 16, 70, 2003	Study conducted before 2003.
Smith-Osborne, A., Felderhoff, B., Formal and Family Caregiver Protective Factors in Systems of Care: A Systematic Review With Implications Toward a Resilience Model for Aging Veterans, Acta Anaesthesiologica Belgica, 11, 2016	Article not available.
Smits, C. H., de Lange, J., Droes, R. M., Meiland, F., Vernooij-Dassen, M., Pot, A. M., Effects of combined intervention programmes for people living with dementia living at home and their caregivers: a systematic review, International Journal of Geriatric Psychiatry, 22, 2007	No additional relevant studies.
Sommerlad, A., Manela, M., Cooper, C., Rapaport, P., Livingston, G., START (STrAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention, BMJ Open, 4, e005273, 2014	Qualitative study.
Sousa, L., Sequeira, C., Ferre-Grau, C., Neves, P., Lleixa-Fortuno, M., Training programmes for family caregivers of people living with dementia living at home: integrative review, Journal of Clinical Nursing, 25, 2757-67, 2016	Descriptive literature review focusing on qualitative studies.
Souza, Ms, Silva, Ra, Molina, Ma, Jansen, K, Lima, Ferreira L, Kelbert, Ef, Soares, Jm, Mattos, Souza Ld, Six-session caregiver psychoeducation on bipolar disorder: does it bring benefits to caregivers?, International journal of social psychiatry, 62, 377-385, 2016	Study conducted in Brazil.
Staios, Mathew, Fisher, Fiona, Lindell, Annukka K., Howe, James, Caregiving in the face of non-motor symptoms in amyotrophic lateral sclerosis: A critical review, Acta Neuropsychologica, 9, 321-334, 2011	Article not available.
Steffen, A. M., Gant, J. R., A telehealth behavioral coaching intervention for neurocognitive disorder family carers, International Journal of Geriatric Psychiatry, 31, 195-203, 2016	This RCT was performed in the USA, it was therefore excluded because of the health and social care context (not comparable with that in place in the UK).
Sterba, K. R., Zapka, J., Cranos, C., Laursen, A., Day, T. A., Quality of life in head and neck cancer patient-caregiver dyads: A systematic review, Cancer Nursing, 39, 238-250, 2016	No relevant articles.
Sterckx, W., Coolbrandt, A., Dierckx de Casterle, B., Van den Heede, K., Decruyenaere, M., Borgenon, S., Mees, A., Clement, P., The impact of a high-grade glioma on everyday life: A systematic review from the	Review of qualitative studies.

patient's and caregiver's perspective, European Journal of Oncology Nursing, 17, 107-117, 2013	
Stoltz, P., Uden, G., Willman, A., Support for family carers who care for an elderly person at home: a systematic literature review, Scandinavian Journal of Caring Sciences, 18, 111-119, 2004	All articles published/conducted before 2003.
Sturkenboom, I. H., Nijhuis-van der Sanden, M. W., Graff, M. J., A process evaluation of a home-based occupational therapy intervention for Parkinson's patients and their caregivers performed alongside a randomized controlled trial, Clinical Rehabilitation, 30, 1186-1199, 2016	Process evaluation of intervention for care recipients.
Sun, F. K., Chiang, C. Y., Lin, Y. H., Chen, T. B., Short-term effects of a suicide education intervention for family caregivers of people who are suicidal, Journal of clinical nursing, 23, 91-102, 2014	Study conducted in Taiwan.
Sun, F. K., Chiang, C. Y., Yu, P. J., Lin, C. H., A suicide education programme for nurses to educate the family caregivers of suicidal individuals: a longitudinal study, Nurse education today, 33, 1192-1200, 2013	Study conducted in Taiwan.
Tang Yan, H. S., Clemson, L. M., Jarvis, F., Laver, K., Goal setting with caregivers of adults in the community: a mixed-methods systematic review, Disability and Rehabilitation, 36, 1943-1963, 2014	Review not relevant.
Teel, C. S., Leenerts, M. H., Developing and testing a self-care intervention for older adults in caregiving roles, Nursing Research, 54, 193-201, 2005	Case series feasibility study.
Teri, L., McCurry, Sm, Logsdon, R, Gibbons, Le. (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial. Gerontologist, 45(6), 802-811.	Aim is training healthcare professionals.
Teri, L., McKenzie, G., Logsdon, R. G., McCurry, S. M., Bollin, S., Mead, J., Menne, H., Translation of two evidence-based programs for training families to improve care of persons with dementia, The Gerontologist, 52, 452-459, 2012	Discussion article.
Thinnes, Andrea, Padilla, Rene, Effect of educational and supportive strategies on the ability of caregivers of people living with dementia to maintain participation in that role, American Journal of Occupational Therapy, 65, 541-549, 2011	General review of interventions to support dementia carers maintain caring role.
Thomas Sian, et al.,, Updated meta-review of evidence on support for carers, Health Services and Delivery Research, 5, 2016	Meta-review that classifies reviews by outcome and quality.
Topcu, G., Buchanan, H., Aubeeluck, A., Garip, G., Caregiving in multiple sclerosis and quality of life: A meta-synthesis of qualitative research, Psychology & health, 31, 693-710, 2016	Review of qualitative studies.
Topo, Paivi, Technology studies to meet the needs of people living with dementia and their caregivers: A literature review, Journal of Applied Gerontology, 28, 5-37, 2009	Not relevant to Q5.
Torti Jr, F. M., Gwyther, L. P., Reed, S. D., Friedman, J. Y., Schulman, K. A., A multinational review of recent trends and reports in dementia caregiver	All identified studies conducted before 2003.

burden, Alzheimer's disease and Associated Disorders, 18, 99-109, 2004	
Torti, Frank M., Jr., Gwyther, Lisa P., Reed, Shelby D., Friedman, Joelle Y., Schulman, Kevin A., A multinational review of recent trends and reports in dementia caregiver burden, Alzheimer's disease and Associated Disorders, 18, 99-109, 2004	No studies published in or after 2003.
Townsend Lisa, How effective are interventions to enhance adherence to psychiatric medications? Practice implications for social workers working with adults diagnosed with severe mental illness, Journal of Human Behavior in the Social Environment, 19, 512-530, 2009	Meta-review of intervention studies for patient medication adherence.
Treasure, Janet, Sepulveda, Ana R., MacDonald, Pam, Whitaker, Wendy, Lopez, Carolina, Zabala, Maria, Kyriacou, Olivia, Todd, Gill, Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers, International Journal of Child and Adolescent Health, 1, 331-338, 2008	Article only describes intervention.
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).
Tungpunkom, P., Napa, W., Chaniang, S., Srikhachin, P., Caregiving experiences of families living with persons with schizophrenia: A systematic review, JBI Library of Systematic Reviews, 11, 415-564, 2013	Article not available.
Tungpunkom, P., Srikhachin, P., Napa, W., Chaniang, S., Caregiving experiences of families living with persons with schizophrenia: A systematic review, JBI Database of Systematic Reviews and Implementation Reports, 10, S164-S171, 2012	Article not available.
Tyack, C., Camic, P. M., Touchscreen interventions and the well-being of people living with dementia and caregivers: A systematic review, International Psychogeriatrics, 29, 1261-1280, 2017	Focuses on interventions for care recipient.
Vallerand, A. H., Hasenau, S. M., Templin, T., Improving cancer pain management in the home, Journal of Pain Management, 3, 41-51, 2010	Article not available.
Van Der Voort, T., Goossens, P., Van Der Bijl, J., Burden, coping and needs for support of caregivers for patients with a bipolar disorder: A systematic review, Journal of Psychiatric and Mental Health Nursing, 14, 679-687, 2007	No relevant articles.
Ventura, Mauricio de Miranda, Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, Sao Paulo Medical Journal = Revista Paulista de Medicina, 134, 93-4, 2016	Comment on Cochrane review.
Viau-Guay, A., Bellemare, M., Feillou, I., Trudel, L., Desrosiers, J., Robitaille, M. J., Person-centered care training in long-term care settings: usefulness and facility of transfer into practice, Canadian journal on aging = La revue canadienne du vieillissement, 32, 57-72, 2013	Qualitative study.

Victor Elizabeth, A systematic review of interventions for carers in the UK: outcomes and explanatory evidence, 164p., 2009	No additional studies identified.
Visser-Meily, A., Heugten, C., Post, M., Schepers, V., Lindeman, E., Intervention studies for caregivers of stroke survivors: a critical review, Patient Education and Counseling, 56, 257-267, 2005	All included studies conducted before 2003.
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	Review not relevant.
Wade, Dt, Gage, H, Owen, C, Trend, P, Grossmith, C, Kaye, J, Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study, Journal of neurology, neurosurgery, and psychiatry, 74, 158-162, 2003	Randomisation relative to patients and not all patients had carers.
Wang, T. F., Huang, C. M., Chou, C., Yu, S., Effect of oral health education programs for caregivers on oral hygiene of the elderly: A systemic review and meta-analysis, International journal of nursing studies, 52, 1090-1096, 2015	No carer outcomes reported.
Ward, S., Serlin, Rc, Donovan, Hs, Ameringer, Sw, Hughes, S, Pe-Romashko, K, Wang, Kk. (2009). A randomized trial of a representational intervention for cancer pain: does targeting the dyad make a difference? Health psychology, 28(5), 588-597.	Carers are not the primary focus.
Wasilewski, M. B., Stinson, J. N., Cameron, J. I., Web-based health interventions for family caregivers of elderly individuals: A Scoping Review, International Journal of Medical Informatics, 103, 109-138, 2017	General scoping review.
Wells, N, Hepworth, Jt, Murphy, Ba, Wujcik, D, Johnson, R, Improving cancer pain management through patient and family education, Journal of Pain and Symptom Management, 25, 344-356, 2003	No relevant carer data.
Wennberg, Alexandra, Dye, Cheryl, Streetman-Loy, Blaiz, Pham, Hiep, Alzheimer's patient familial caregivers: A review of burden and interventions, Health & Social Work, 40, e162-e169, 2015	Not systematic review.
Wesson, J., Clemson, L., Brodaty, H., Lord, S., Taylor, M., Gitlin, L., Close, J., A feasibility study and pilot randomised trial of a tailored prevention program to reduce falls in older people with mild dementia, BMC Geriatrics, 13, 89, 2013	Intervention primarily for care recipients/no carer data.
White, K., D. Abrew N, Auret, K., Graham, N., Duggan, G., Learn Now; Live Well: an educational programme for caregivers, International Journal of Palliative Nursing, 14, 497-501, 2008	Single-arm study.
Williams Sophie, et al.,, Changes in attributions as a consequence of training for challenging and complex behaviour for carers of people with learning disabilities: a systematic review, Journal of Applied Research in Intellectual Disabilities, 25, 203-216, 2012	Review on professional carer training.
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	Not randomised controlled trial.

and physical well-being in Alzheimer's disease family caregivers, Psychosomatic Medicine, 72, 2010	
Williamson, Heather J., Perkins, Elizabeth A., Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with U. S. services and supports, Intellectual and developmental disabilities, 52, 147-159, 2014	No relevant studies.
Winterton, R., Warburton, J., Models of care for socially isolated older rural carers: barriers and implications, Rural and remote health, 11, 1678, 2011	General review of rural carers.
Wiprzycka, U. J., Mackenzie, C. S., Khatri, N., Cheng, J. W., Feasibility of recruiting spouses with DSM-IV diagnoses for caregiver interventions, The journals of gerontology, Series B, Psychological sciences and social sciences. 66, 302-306, 2011	Single-arm CBT study.
Wobma, R., Nijland, R. H., Ket, J. C., Kwakkel, G., Evidence for peer support in rehabilitation for individuals with acquired brain injury: A systematic review, Journal of Rehabilitation Medicine, 48, 837-840, 2016	Review of peer support interventions on patient rehabilitation outcomes.
Won, C. W., Fitts, S. S., Favaro, S., Olsen, P., Phelan, E. A., Community-based "powerful tools" intervention enhances health of caregivers, Archives of Gerontology & Geriatrics, 46, 89-100, 2008	Single-arm study.
Xu, J., Abshire, M., Davidson, P., Dennison-Himmelfarb, C., Uncertainties in caregivers of patients implanted with left ventricular assist device: A systematic review, Journal of Cardiac Failure, Conference, 2016	Conference abstract.
Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., Kuipers, E., Kendall, T., Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-analysis, British Journal of Psychiatry, 206, 268-274, 2015	No additional relevant studies.
Yong Audrey Su Lin, Price Lee, The human occupational impact of partner and close family caregiving in dementia: a meta-synthesis of the qualitative research, using a bespoke quality appraisal tool, British Journal of Occupational Therapy, 77, 410-421, 2014	Review of qualitative studies.
Zabalegui Yarnoz, A., Navarro Diez, M., Cabrera Torres, E., Fernandez-Puebla, A. G., Bardallo Porras, D., Rodriguez Higueras, E., Gual Garcia, P., Fernandez Capo, M., Argemi Remon, J., Efficacy of interventions aimed at the main carers of dependent individuals aged more than 65 years old: a systematic review, Revista Espanola de Geriatria y Gerontologia, 43, 157-166, 2008	Article not available.
Zarit, Steven H., Empirically supported treatment for family caregivers, 131-153, 2009	Book chapter.
Zauszniewski, J. A., Lekhak, N., Burant, Christopher J, Underwood, P. W., & Morris, D. L. (2016). Resourcefulness training for dementia caregivers: Establishing fidelity. Western Journal of Nursing Research, 38(12), 1554-1573.	Aim was to test the levels of adherence or fidelity to a resourcefulness training intervention.

Zauszniewski, J. A., Lekhak, N., Yolpant, W., Morris, D. L., Need for Resourcefulness Training for Women Caregivers of Elders with Dementia, Issues in mental health nursing, 36, 1007-1012, 2015	No relevant carer outcomes.
Zauszniewski, Jaclene A., Lekhak, Nirmala, Napoleon, Betty, Morris, Diana L., Resourcefulness training for women dementia caregivers: Acceptability and feasibility of two methods, Issues in Mental Health Nursing, 37, 249-256, 2016	No relevant carer outcomes.
Zeller, A., Hahn, S., Needham, I., Kok, G., Dassen, T., Halfens, R. J. G., Aggressive Behavior of Nursing Home Residents Toward Caregivers: A Systematic Literature Review, Geriatric Nursing, 30, 174-187, 2009	Sample is paid carers working in nursing home.
Zenthofer, A., Meyer-Kuhling, I., Hufeland, A. L., Schroder, J., Cabrera, T., Baumgart, D., Rammelsberg, P., Hassel, A. J., Carers' education improves oral health of older people suffering from dementia - Results of an intervention study, Clinical Interventions in Aging, 11, 1755-1762, 2016	Sample is professional carers.
Zientz, Jennifer, Rackley, Audette, Chapman, Sandra Bond, Hopper, Tammy, Mahendra, Nidhi, Cleary, Stuart, Evidence-based practice recommendations: Caregiver-administered active cognitive stimulation for individuals with Alzheimer's disease, Journal of Medical Speech-Language Pathology, 15, xxvii-xxxiv, 2007	All studies published/conducted before 2003.
Zientz, Jennifer, Rackley, Audette, Chapman, Sandra Bond, Hopper, Tammy, Mahendra, Nidhi, Kim, Esther S., Cleary, Stuart, Evidence-based practice recommendations for dementia: Educating caregivers on Alzheimer's disease and training communication strategies, Journal of Medical Speech-Language Pathology, 15, liii-lxiv, 2007	All studies published/conducted before 2003.

Qualitative component of the review

Table 31: Excludies studies from the qualitative component of the review

Study	Reason for Exclusion
Adriaansen, Jacinthe J. E., van Leeuwen, Christel M. C., Visser-Meily, Johanna M. A., van den Bos, Geertrudis A. M., Post, Marcel W. M., Course of social support and relationships between social support and life satisfaction in spouses of patients with stroke in the chronic phase, Patient Education and Counseling, 85, e48-e52, 2011	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Angelo, J. K., Egan, R., Reid, K., Essential knowledge for family caregivers: a qualitative study, International journal of palliative nursing, 19, 383-8, 2013	Non UK evidence.
Aranda, S., Edwards, H., McCarthy, A., Nash, R., Skerman, H., Yates, P., Barriers to effective cancer pain management: a survey of Australian family caregivers, European journal of cancer care, 13, 336-343, 2004	Non UK evidence.
Araujo, Angelica da Silva, Kebbe, Leonardo Martins, Study on occupational therapy groups for caregivers of families	No concept / phenomena /intervention of interest.

Study	Reason for Exclusion
with schizophrenia patients, Cadernos de Terapia Ocupacional da UFSCar, 22, 97-108, 2014	
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	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Aylward, Nicola, Young adult carers need help getting education and training, Basic Skills Bulletin. No, 91, 6, 2011	No study design (conference abstract).
Aylward, Nicola, "They Just Don't Get It", Adults Learning, 21, 29, 2009	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
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.
Baker, Linda, Connell, Bev O., Managing as carers of stroke survivors: strategies from the field, International journal of nursing practice, 10, 121-126, 2004	No concept / phenomena /intervention of interest.
Bakken, Trine Lise, Sundby, Inger-Lise, Klevmoen, Gunn Helene, Patients', family members', and professional carers' experiences of psychoeducational multifamily groups for participants with intellectual disabilities and mental illness, Issues in Mental Health Nursing, 38, 153-159, 2017	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Barbosa, A., Nolan, M., Sousa, L., Figueiredo, D., Person-centredness in direct care workers caring for residents with dementia: Effects of a psycho-educational intervention, Dementia, 16, 192-203, 2017	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Barnes, E., Simpson, S., Griffiths, E., Hood, K., Craddock, N., Smith, D. J., Developing an online psychoeducation package for bipolar disorder, Journal of Mental Health, 20, 21-31, 2011	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Beauchamp, Natasha, A. Blair Irvine, Seeley, John, Johnson, Brian, Worksite-Based Internet Multimedia Program for Family Caregivers of Persons With Dementia, The Gerontologist, 45, 793-801, 2005	No concept / phenomena / intervention of interest.
Belgacem, Benedicte, Auclair, Candy, Fedor, Marie-Christine, Brugnon, David, Blanquet, Marie, Tournilhac, Olivier, Gerbaud, Laurent, A caregiver educational program improves quality of life and burden for cancer patients and their caregivers: A randomised clinical trial, European Journal of Oncology Nursing, 17, 870-876, 2013	Non UK evidence.
Biswas, Asit B., Raju, Lammata Bala, Gravestock, Shaun, Training in partnership: Role of service users with intellectual disability and carers, Psychiatric Bulletin, 33, 429-432, 2009	No population of interest (no unpaid adult carers or professional involved in the

Study	Reason for Exclusion
	intervention administration to adult carers).
Bloomberg Karen, West Denise, Iacono Teresa, PICTURE IT: an evaluation of a training program for carers of adults with severe and multiple disabilities, Journal of Intellectual and Developmental Disability, 28, 260-282, 2003	Non UK evidence.
Brown, Janet Witucki, Chen, Shu-li, Smith, Pratsani, Evaluating a Community-Based Family Caregiver Training Program, Home Health Care Management & Practice, 25, 76-83, 2013	Non UK evidence.
Burbach Frank R, Stanbridge Roger I, Training to develop family inclusive routine practice and specialist family interventions in Somerset, Journal of Mental Health Training Education and Practice, 3, 23-31, 2008	No qualitative data: this paper reports about national policies emphasising the importance of involving families/carers as partners in care of people with psychosis, as well as providing specialist family interventions - but does not include any qualitative evidence.
Burton, Diana M., May, Stephanie, Parents'/carers' perceptions and experiences of growing, preparing and eating their own fruit and vegetables as part of the 'Field to Fork' project, Education 3-13, 44, 751-764, 2016	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Cagle John G, Kovacs Pamela J, Informal caregivers of cancer patients: perceptions about preparedness and support during hospice care, Journal of Gerontological Social Work, 54, 92-115, 2011	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Carbonneau, Helene, Caron, Chantal D., Desrosiers, Johanne, Effects of an adapted leisure education program as a means of support for caregivers of people living with dementia, Archives of Gerontology and Geriatrics, 53, 31-39, 2011	Non UK evidence.
Carbonneau, Helene, Caron, Chantal D., Desrosiers, Johanne, Development of an Education Program Adapted Leisure as a Means to Support the Involvement of Caregivers of a Relative with Dementia, Canadian Journal on Aging/La Revue Canadienne du Vieillissement, 28, 121-134, 2009	Non UK evidence.
Cardol, Mieke, Rijken, Mieke, van Schrojenstein Lantman-de Valk, Henny, Attitudes and dilemmas of caregivers supporting people with intellectual disabilities who have diabetes, Patient Education and Counseling, 87, 383-388, 2012	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Carers, Trust, Time to be heard: a call for recognition and support for young adult carers, 17, 2014	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.

Study	Reason for Exclusion
Carers, U. K., Age, U. K., Caring into later life: the growing pressures on older carers	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Carmel, Sarah, Achievements and challenges in geriatric care, education and training, BOLD, 23, 2013	Non UK evidence.
Challenging Behaviour, Foundation, Stopping over-medication of people with a learning disability, autism or both (STOMP): a family carer perspective, 22, 2016	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Chappell, Neena L., Dujela, Carren, Caregiver -- Who Copes How?, International Journal of Aging and Human Development, 69, 221-244, 2009	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Chien, Wai Tong, Yip, Annie L. K., Liu, Justina Y. W., McMaster, Terry W., The effectiveness of manual-guided, problem-solving-based self-learning programme for family caregivers of people with recent-onset psychosis: A randomised controlled trial with 6-month follow-up, International journal of nursing studies, 59, 141, 2016	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Chih, Ming-Yuan, DuBenske, Lori L., Hawkins, Robert P., Brown, Roger L., Dinauer, Susan K., Cleary, James F., Gustafson, David H., Communicating advanced cancer patients' symptoms via the Internet: A pooled analysis of two randomized trials examining caregiver preparedness, physical burden, and negative mood, Palliative Medicine, 27, 533-43, 2013	This study does not include qualitative evidence.
Chiner, Esther, Gómez-Puerta, Marcos, Cardona-Moltó, M. Cristina, Internet and People with Intellectual Disability: An Approach to Caregivers' Concerns, Prevention Strategies and Training Needs, Journal of New Approaches in Educational Research, 6, 153-158, 2017	Non UK evidence.
Church, Lisiane A., The Effect of Family Psychoeducational Therapy and Social Skills Training on Burden, Coping Skills and Social Support of Caregivers of Patients Diagnosed with Schizophrenia and/or Schizoaffective Disorder, 2383-A-2384-A	No study design (dissertation).
Clarke D, Godfrey M, Hawkins R, Implementing a training intervention to support caregivers after stroke: a process evaluation examining the initiation and embedding of programme change. Implement Sci 2013;8:96	This study has been included in the guideline (RQI: Carer support during changes to caring role)
Coker Freya, et al.,, Exploring the needs of diverse consumers experiencing mental illness and their families through family psychoeducation, Journal of Mental Health, 25, 197-203, 2016	Non UK evidence.
Conceição, Simone C. O., Johaningsmeir, Sarah, Colby, Holly, Gordon, John, Family Caregivers as Lay Trainers: Perceptions of Learning and the Relationship between Life	Carers of children and youth with special health care needs.

Study	Reason for Exclusion
Experience and Learning, Adult Learning, 25, 151-159, 2014	
Coon, David W., Thompson, Larry, Steffen, Ann, Sorocco, Kristen, Gallagher-Thompson, Dolores, Anger and Depression Management: Psychoeducational Skill Training Interventions for Women Caregivers of a Relative with Dementia, Gerontologist, 43, 678-689, 2003	Non UK evidence.
Cotrell Victoria, Wild Katharine, Bader Theresa, Medication management and adherence among cognitively impaired older adults, Journal of Gerontological Social Work, 47, 31-46, 2006	Non UK evidence.
Courcha, Pam, "She's talking to me!" Training home carers to use Pre-Therapy contact reflections: an action research study, Person-Centered and Experiential Psychotherapies, 14, 285-299, 2015	This study does not focus on unpaid adult carers but on home (professional) carers.
Courtin, E., Jemiai, N., Mossialos, E., Mapping support policies for informal carers across the European Union, Health Policy, 118, 84-94, 2014	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Courtney, Mary, Edwards, Helen, Sahar, Junaiti, Improvement of family carers' knowledge, skills and attitudes in caring for older people following the implementation of a Family Carers' Training Program in the community in Indonesia, International journal of nursing practice, 9, 246-254, 2003	Non UK evidence.
Crellin, N. E., Orrell, M., McDermott, O., Charlesworth, G., Self-efficacy and health-related quality of life in family carers of people living with dementia: a systematic review, Aging & Mental Health, 18, 954-969, 2014	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Damme, Mary Jane, Ray-Degges, Susan, A Qualitative Study on Home Modification of Rural Caregivers for People living with dementia, Journal of Housing for the Elderly, 30, 89-106, 2016	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
de Jong, Jeltsje D., Boersma, F., Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers, International Psychogeriatrics, 21, 268-77, 2009	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Department For, Education, Support and aspiration: a new approach to special educational needs and disability. A consultation, 128pp., 2011	Carers of children and youth with special health care needs.
Draper, Brian, Bowring, Greg, Thompson, Claire, Jocelyn Van, Heyst, Conroy, Philip, Thompson, Julie, Stress in caregivers of aphasic stroke patients: a randomized controlled trial, Clinical rehabilitation, 21, 122-30, 2007	No concept / phenomena / intervention of interest.
Ducharme Francine, et al.,, Maintaining the potential of a psycho-educational program: efficacy of a booster session after an intervention offered family caregivers at disclosure	Non UK evidence.

Study	Reason for Exclusion
of a relative's dementia diagnosis, Aging and Mental Health, 19, 207-216, 2015	
Ducharme, Francine C., Levesque, Louise L., Lachance, Lise M., Kergoat, Marie-Jeanne, Legault, Alain J., Beaudet, Line M., Zarit, Steven H., "Learning to Become a Family Caregiver" Efficacy of an Intervention Program for Caregivers Following Diagnosis of Dementia in a Relative, Gerontologist, 51, 484-494, 2011	No concept / phenomena / intervention of interest.
Eggenberger, Eva, Heimerl, Katharina, Bennett, Michael I., Communication skills training in dementia care, International Psychogeriatrics, 25, 2013	This review has been excluded. Its references have been handsearched for relevant studies (none addiotional was identified and added to the review for this GL question).
Ellard, D. R., Barlow, J. H., Paskins, Z., Stapley, J., Wild, A., Rowe, I. F., Piloting education days for patients with early rheumatoid arthritis and their partners: a multidisciplinary approach, Musculoskeletal Care, 7, 17-30, 2009	This study does not focus as primary aim on providing training for unpaid adult carers to care about their relatives. The main focus is indeed on patients.
Fallon, D., Warne, T., McAndrew, S., McLaughlin, H., An adult education: learning and understanding what young service users and carers really, really want in terms of their mental well being, Nurse education today, 32, 128-32, 2012	No concept / phenomena / intervention of interest.
Farquhar, Morag, Ewing, Gail, Moore, Caroline, Gardener, Carole, Butcher, Hanne Holt, White, Patrick, Grande, Gunn, PREPAREDNESS TO CARE IN ADVANCED COPD: HOW PREPARED ARE INFORMAL CARERS OF PATIENTS WITH ADVANCED COPD AND WHAT ARE THEIR SUPPORT NEEDS? BASELINE DATA FROM AN ONGOING LONGITUDINAL STUDY, BMJ supportive & palliative care, 4, 2014	No study design (conference abstract).
Findlay, L., Williams, A. C., Baum, S., Scior, K., Caregiver experiences of supporting adults with intellectual disabilities in pain, Journal of applied research in intellectual disabilities : JARID, 28, 111-120, 2015	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Finlayson Marcia, Preissner Katharine, Garcia Jennifer, Pilot study of an educational programme for caregivers of people ageing with Multiple Sclerosis, British Journal of Occupational Therapy, 72, 11-19, 2009	Non UK evidence.
Finlayson, Marcia, Garcia, Jennifer Dahl, Preissner, Katharine, Development of an educational programme for caregivers of people aging with multiple sclerosis, Occupational Therapy International, 15, 4-17, 2008	Non UK evidence.
Forster, A., Dickerson, J., Young, J., Patel, A., Kalra, L., Nixon, J., Smithard, D., Knapp, M., Holloway, I., Anwar, S., Farrin, A., Tracs Trial Collaboration, A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis, Lancet, 382, 2069-76, 2013	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.

Study	Reason for Exclusion
Fortune Donal G, Rogan Carol R, Richards Helen L, A structured multicomponent group programme for carers of people with acquired brain injury: effects on perceived criticism, strain, and psychological distress, British journal of health psychology, 21, 224-243, 2016	No concept / phenomena / intervention of interest.
Fujinami, Rebecca, Sun, Virginia, Zachariah, Finly, Uman, Gwen, Grant, Marcia, Ferrell, Betty, Family caregivers' distress levels related to quality of life, burden, and preparedness, Psycho - Oncology, 24, 54, 2015	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Funk, Laura M., Stajduhar, Kelli I., Outcalt, Linda, What family caregivers learn when providing care at the end of life: A qualitative secondary analysis of multiple datasets, Palliative & supportive care, 13, 425-433, 2015	Non UK evidence.
Gall, S. H., Atkinson, J., Elliott, L., Johansen, R., Supporting carers of people diagnosed with schizophrenia: evaluating change in nursing practice following training, Journal of advanced nursing, 41, 295-305, 2003	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Gallagher-Thompson, Dolores, Wang, Peng-Chih, Liu, Weiling, Cheung, Vinnie, Peng, Rebecca, China, Danielle, Thompson, Larry W., Effectiveness of a psychoeducational skill training DVD program to reduce stress in Chinese American dementia caregivers: Results of a preliminary study, Aging & mental health, 14, 263-273, 2010	Non UK evidence.
Gendron, Tracey, Pelco, Lynn E., Pryor, Jennifer, Barsness, Sonya, Seward, Lynne, A Telephone Support Program for Adult Day Center Caregivers: Early Indications of Impact, Journal of Higher Education Outreach and Engagement, 17, 45-58, 2013	No concept / phenomena / intervention of interest.
Giarelli, Ellen, McCorkle, Ruth, Monturo, Cheryl, Caring for a spouse after prostate surgery: The preparedness needs of wives, Journal of Family Nursing, 9, 453-485, 2003	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Glasby, Jon, Kilbride, Louise, Who knows?, Practice, 15, 2003	No concept / phenomena / intervention of interest.
Graff Maud J. L, et al.,, How can occupational therapy improve the daily performance and communication of an older patient with dementia and his primary caregiver?, Dementia: The International Journal of Social Research and Practice, 5, 503-532, 2006	No concept / phenomena / intervention of interest.
Graff, M. J. L., Vernooij-Dassen, M. J. M., Thijssen, M., Dekker, J., Hoefnagels, W. H. L., Rikkert, M. G. M. O., Community based occupational therapy for patients with dementia and their care givers: Randomised controlled trial, British Medical Journal, 333, 1196-1199, 2006	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Gustafsson, Louise, Hodge, Anna, Robinson, Mia, McKenna, Kryss, Bower, Kylie, Information provision to clients with stroke and their carers: Self-reported practices of occupational therapists, Australian occupational therapy journal, 57, 190-196, 2010	No concept / phenomena / intervention of interest.

Study	Reason for Exclusion
Gutman, Gloria, Hillhouse, Beth, Makela, Saskia, Small, Jeff A., Effectiveness of communication strategies used by caregivers of persons with Alzheimer's disease during activities of daily living, Journal of Speech, Language, and Hearing Research, 46, 353-367, 2003	Non UK evidence.
Haberstroh Julia, et al.,, TANDEM: Communication training for informal caregivers of people living with dementia, Aging and Mental Health, 15, 405-413, 2011	No concept / phenomena / intervention of interest.
Hall, Scott S. PhD, Kandiah, Jayanthi PhD R. D. C. D., Saiki, Diana PhD, Nam, Jinhee PhD, Harden, Amy PhD, Park, Soonjee PhD, Implications of Smart Wear Technology for Family Caregiving Relationships: Focus Group Perceptions, Social Work in Health Care, 53, 994, 2014	No concept / phenomena / intervention of interest.
Hampson Caroline, Smith Sarah Jane, Helping occupational performance through engagement: a service evaluation of a programme for informal carers of people living with dementia, British Journal of Occupational Therapy, 78, 200-204, 2015	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Hankey, Graeme J., Informal care giving for disabled stroke survivors, BMJ: British Medical Journal, 328, 1085-1086, 2004	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Harvath, Theresa A. PhD R. N. Faan, Lindauer, Allison PhD R. N. F. N. P., Sexson, Kathryn PhD R. N. A. N. P. F. N. P. B. C., Managing Complex Medication Regimens, The American journal of nursing, 116, 43, 2016	No concept / phenomena / intervention of interest.
Hayajneh, Ferial A., Shehadeh, Anas, The impact of adopting person-centred care approach for people with Alzheimer's on professional caregivers' burden: An interventional study, International journal of nursing practice, 20, 438-445, 2014	No concept / phenomena / intervention of interest.
Heinrich, S., Uribe, F. L., Wubbeler, M., Hoffmann, W., Roes, M., Knowledge evaluation in dementia care networks: A mixed-methods analysis of knowledge evaluation strategies and the success of informing family caregivers about dementia support services, International Journal of Mental Health Systems, 10 (1) (no pagination), 2016	Non UK evidence.
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	No concept / phenomena / intervention of interest.
Hornick, T. R., Higgins, P. A., Stollings, C., Wetzel, L., Barzilai, K., Wolpaw, D., Initial evaluation of a computer-based medication management tool in a geriatric clinic, American Journal Geriatric Pharmacotherapy, 4, 62-69, 2006	Non UK evidence.
Hudson, Peter, Thomas, Tina, Quinn, Karen, Cockayne, Mark, Braithwaite, Maxine, Teaching Family Carers About Home-Based Palliative Care: Final Results from a Group	Non UK evidence.

Study	Reason for Exclusion
Education Program, Journal of Pain and Symptom Management, 38, 299-308, 2009	
Hynes Sinead M, et al.,, Exploring the need for a new UK occupational therapy intervention for people living with dementia and family carers: Community Occupational Therapy in Dementia (COTiD). A focus group study, Aging and Mental Health, 20, 762-769, 2016	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Jack, Barbara A., O'Brien, Mary R., Kirton, Jennifer A., Marley, Kate, Whelan, Alison, Baldry, Catherine R., Groves, Karen E., Enhancing communication with distressed patients, families and colleagues: The value of the Simple Skills Secrets model of communication for the nursing and healthcare workforce, Nurse education today, 33, 1550, 2013	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Jones, C., Bowron, A., Wood, B., Walker, R., Developing a Parkinson's Disease service, Professional nurse (London, England), 20, 22-24, 2005	Non UK evidence.
Joyce, Brian T., Berman, Rebecca, Lau, Denys T., Formal and informal support of family caregivers managing medications for patients who receive end-of-life care at home: A cross-sectional survey of caregivers, Palliative Medicine, 28, 1146-55, 2014	No concept / phenomena / intervention of interest.
Joyce, Brian T., Lau, Denys T., Hospice experiences and approaches to support and assess family caregivers in managing medications for home hospice patients: A providers survey, Palliative Medicine, 27, 329-38, 2013	No concept / phenomena / intervention of interest.
Kalra, Lalit, Evans, Andrew, Perez, Inigo, Melbourn, Anne, et al.,, Training care givers of stroke patients: Randomised controlled trial, British Medical Journal, 328, 1099-1101, 2004	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Kelly, Kathleen, Reinhard, Susan C., Brooks-Danso, Ashley, Executive Summary: Professional Partners Supporting Family Caregivers, Journal of Social Work Education, 44, 5-15, 2008	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Klein, Claire M., Silverman, Michael J., With Love from Me to Me: Using Songwriting to Teach Coping Skills to Caregivers of Those with Alzheimer's and Other Dementias, Journal of Creativity in Mental Health, 7, 153-164, 2012	Non UK evidence.
Konno, R., Stern, C., Gibb, H., The best evidence for assisted bathing of older people living with dementia: A comprehensive systematic review, JBI Database of Systematic Reviews and Implementation Reports, 11, 123-212, 2013	No population of interest (no unpaid adult carers or professional involved in the intervention administration to adult carers).
Kouri Krystyna Klodnicka, Ducharme Francine C, Giroux Francine, A psycho-educational intervention focused on communication for caregivers of a family member in the early stage of Alzheimer's disease: results of an experimental study, Dementia: The International Journal of Social Research and Practice, 10, 435-453, 2011	Non UK evidence.

Study	Reason for Exclusion
Kuhn Daniel, Fulton Bradley R, Efficacy of an educational program for relatives of persons in the early stages of Alzheimer's Disease, Journal of Gerontological Social Work, 43, 109-129, 2004	Non UK evidence.
Larkin, Mary, Developing the knowledge base about carers and personalisation: contributions made by an exploration of carers' perspectives on personal budgets and the carer-service user relationship, Health & social care in the community, 23, 33-41, 2015	No concept / phenomena / intervention of interest.
Lau, D. T., Kasper, J. D., Hauser, J. M., Berdes, C., Chang, C. H., Berman, R. L., Masin-Peters, J., Paice, J., Emanuel, L., Family caregiver skills in medication management for hospice patients: a qualitative study to define a construct, Journals of Gerontology Series B-Psychological Sciences & Social Sciences, 64, 799-807, 2009	Non UK evidence.
Lau, Denys T., Joyce, Brian, Clayman, Maria L., Dy, Sydney, Ehrlichjones, Linda, Emanuel, Linda, Hauser, Joshua, Pake, Judith, Shega, Joseph W., Hospice Providers' Key Approaches to Support Informal Caregivers in Managing Medications for Patients in Private Residences, Journal of Pain and Symptom Management, 43, 1060-1071, 2012	No concept / phenomena / intervention of interest.
Lauriks, S., Reinersmann, A., Van der Roest, H. G., Meiland, F. J. M., Davies, R. J., Moelaert, F., Mulvenna, M. D., Nugent, C. D., Droes, R. M., Review of ICT-based services for identified unmet needs in people living with dementia, Ageing Research Reviews, 6, 223-246, 2007	This review has been excluded. Its references have been handsearched for relevant studies (none addiotional was identified and added to the review for this GL question).
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.
Laybourne, A. H., Jepson, M. J., Williamson, T., Robotham, D., Cyhlarova, E., Williams, V., Beginning to explore the experience of managing a direct payment for someone with dementia: The perspectives of suitable people and adult social care practitioners, Dementia, 15, 125-40, 2016	No concept / phenomena / intervention of interest.
Lee, L., Howard, K., Wilkinson, L., Kern, C., Hall, S., Developing a policy to empower informal carers to administer subcutaneous medication in community palliative care; a feasibility project, International journal of palliative nursing, 22, 369-378, 2016	The aim of this evaluation study was to develop an effective policy framework to support informal carers to give, as required, subcutaneous medications. Therefore, this study was excluded since did not focus on providing training for unpaid adult carers to care about their relatives.
Levy-Storms Lene, et al.,, Reducing safety risk among underserved caregivers with an Alzheimer's home safety program, Aging and Mental Health, 21, 902-909, 2017	No concept / phenomena / intervention of interest.
Lindauer, Allison PhD R. N. F. N. P., Sexson, Kathryn PhD R. N. A. N. P. F. N. P. B. C., Harvath, Theresa A. PhD R.	No concept / phenomena / intervention of interest.

Study	Reason for Exclusion
N. Faan, Medication Management for People living with dementia, The American journal of nursing, 117, 60, 2017	
Lindauer, Allison PhD R. N. F. N. P., Sexson, Kathryn PhD R. N. A. N. P. F. N. P. B. C., Harvath, Theresa A. PhD R. N. Faan, Teaching Caregivers to Administer Eye Drops, Transdermal Patches, and Suppositories, The American journal of nursing, 117, 54, 2017	No concept / phenomena / intervention of interest.
Lu, Yvonne Yueh-Feng R. N. PhD, Ellis, Jennifer P. T. D. P. T. M. S. G. C. S., Yang, Ziyi M. S., Weaver, Michael T. PhD Faan, Bakas, Tamilyn R. N. PhD Faan, Austrom, Mary Guerriero PhD, Haase, Joan E. R. N. PhD Faan, Satisfaction With a Family-Focused Intervention for Mild Cognitive Impairment Dyads, Journal of Nursing Scholarship, 48, 334-344, 2016	No concept / phenomena / intervention of interest.
Mahoney, Diane M., Mutschler, Phyllis H., Tarlow, Barbara, Liss, Ellen, Real world implementation lessons and outcomes from the Worker Interactive Networking (WIN) project: Workplace-based online caregiver support and remote monitoring of elders at home, Telemedicine and e-Health, 14, 224-234, 2008	Non UK evidence.
Mahoney, E. K., Trudeau, S. A., Penyack, S. E., MacLeod, C. E., Challenges to intervention implementation: lessons learned in the Bathing Persons with Alzheimer's Disease at Home study, Nursing research, 55, S10-6, 2006	Non UK evidence.
Mannion Nora, Schizophrenia - why family intervention and support are important, Irish Social Worker, 22, 27-28, 2004	No concept / phenomena / intervention of interest.
Mastel-Smith, Beth, Stanley-Hermanns, Melinda, "It's Like We're Grasping at Anything": Caregivers' Education Needs and Preferred Learning Methods, Qualitative health research, 22, 1007, 2012	Non UK evidence.
Mayor, Susan, Better advice is needed for decisions in dementia care, British Medical Journal, 339, 769, 2009	No concept / phenomena / intervention of interest.
McCoulough, S., Adapting a SSKIN bundle for carers to aid identification of pressure damage and ulcer risks in the community, British journal of community nursing, S19-S25, 2016	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review
McGuigan, Karen, McDermott, Lee, Magowan, Cathy, McCorkell, Gillian, Witherow, Anne, Coates, Vivien, Carmichael, Clark Davey Fernandez Glendinning Glendinning Glendinning Hasler Hodge Leece Maglajlic Confederation Pearson Priestley Riddell Ridley Spandler Ungerson Zarb Zarb, The impact of Direct Payments on service users requiring care and support at home, Practice: Social Work in Action, 28, 37-54, 2016	No concept / phenomena / intervention of interest.
Melville Craig A, et al.,, Carer knowledge and perception of healthy lifestyles for adults with intellectual disabilities, Journal of Applied Research in Intellectual Disabilities, 22, 298-306, 2009	No concept / phenomena / intervention of interest.
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	This study does not focus as primary aim on education/training interventions-strategies for

Study	Reason for Exclusion
study, Dementia: The International Journal of Social Research and Practice, 16, 513-522, 2017	carers to provide practical support.
Moran, Nicola, Arksey, Hilary, Glendinning, Caroline, Personalisation and carers, British Journal of Social Work, 42, 2012	No concept / phenomena / intervention of interest.
Moreno, P. A., Garcia-Pacheco, J. L., Charvill, J., Lofti, A., Langensiepen, C., Saunders, A., Berckmans, K., Gaspersic, J., Walton, L., Carmona, M., Perez de la Camara, S., Sanchez-de-Madariaga, R., Pozo, J., Munoz, A., Pascual, M., Gomez, E. J., iCarer: AAL for the Informal Carers of the Elderly, Studies in health technology and informatics, 210, 678-680, 2015	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Murphy Damian, Goodbye to the 'family from hell', Journal of Dementia Care, 18, 10-11, 2010	No concept / phenomena / intervention of interest.
O'Brien, M. R., Whitehead, B., Jack, B. A., Mitchell, J. D., The need for support services for family carers of people with motor neurone disease (MND): views of current and former family caregivers a qualitative study, Disability & Rehabilitation, 34, 247-56, 2012	This study does not focus as primary aim on providing training for unpaid adult carers to care about their relatives. The main focus is indeed on patients.
Oliver, Debra Parker, Demiris, George, Wittenberg-Lyles, Elaine, Porock, Davina, Collier, Jacqueline, Arthur, Antony, Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management, American Journal of Hospice & Palliative Medicine, 27, 465-473, 2010	No concept / phenomena / intervention of interest.
Orr, L. C., Barbour, R. S., Elliott, L., Carer involvement with drug services: a qualitative study, Health expectations : an international journal of public participation in health care and health policy, 16, e60-e72, 2013	No concept / phenomena / intervention of interest.
Papachristou, I., Hickey, G., Illife, S., 011 PP: FOOD-RELATED INTERVENTIONS IN DEMENTIA: A QUALITATIVE STUDY OF CAREGIVERS' PERSPECTIVES, BMJ Open, 5, 2015	No concept / phenomena / intervention of interest.
Penner, Jamie L., McClement, Susan, Lobchuk, Michelle, Daeninck, Paul, Family Members' Experiences Caring for Patients With Advanced Head and Neck Cancer Receiving Tube Feeding: A Descriptive Phenomenological Study, Journal of Pain and Symptom Management, 44, 563-571, 2012	Non UK evidence.
Pepin, G., King, R., Collaborative Care Skills Training workshops: helping carers cope with eating disorders from the UK to Australia, Social Psychiatry & Psychiatric Epidemiology, 48, 805-12, 2013	Non UK evidence.
Perera Bhathika D, Standen Penny J, Exploring coping strategies of carers looking after people with intellectual disabilities and dementia, Advances in Mental Health and Intellectual Disabilities, 8, 292-301, 2014	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Petrakis, Melissa, Oxley, Julia, Bloom, Hannah, Carer psychoeducation in first-episode psychosis: Evaluation outcomes from a structured group programme, International Journal of Social Psychiatry, 59, 391-397, 2013	Non UK evidence.

Study	Reason for Exclusion
Phillips, S. S., Ragas, D. M., Hajjar, N., Tom, L. S., Dong, X., Simon, M. A., Leveraging the Experiences of Informal Caregivers to Create Future Healthcare Workforce Options, Journal of the American Geriatrics Society, 64, 174-180, 2016	No concept / phenomena / intervention of interest.
Pickard, Linda, The effectiveness and cost-effectiveness of support and services to informal carers of older people: a review of the literature prepared for the Audit Commission, 2004	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Pierce, Linda L., Steiner, Victoria, Havens, Heidi, Tormoehlen, Karen, Spirituality Expressed by Caregivers of Stroke Survivors, Western Journal of Nursing Research, 30, 606, 2008	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Piercy Kathleen Walsh, Blended learning networks supported by information and communication technology: an intervention for knowledge transformation within family care of older people, Gerontologist, 51, 561-570, 2011	No concept / phenomena / intervention of interest.
Pino, Marco, Parry, Ruth, Feathers, Luke, Faull, Christina, Is it acceptable to video-record palliative care consultations for research and training purposes? A qualitative interview study exploring the views of hospice patients, carers and clinical staff, Palliative Medicine, 31, 707-715, 2017	No concept / phenomena / intervention of interest.
Ponpaipan, Muthita, Srisuphan, Wichit, Jitapunkul, Sutthichai, Panuthai, Sirirat, Tonmukayakul, Ouyporn, While, Alison, Multimedia computer-assisted instruction for carers on exercise for older people: Development and testing, Journal of advanced nursing, 67, 308-316, 2011	Non UK evidence.
Porter, Laura S., Keefe, Francis J., Garst, Jennifer, Baucom, Donald H., McBride, Colleen M., McKee, Daphne C., Sutton, Linda, Carson, Kimberly, Knowles, Verena, Rumble, Meredith, Scipio, Cindy, Caregiver-Assisted Coping Skills Training for Lung Cancer: Results of a Randomized Clinical Trial, Journal of Pain and Symptom Management, 41, 1-13, 2011	Non UK evidence.
Pradhan, Archana, Keuskamp, Dominic, Brennan, David, Pre- and post-training evaluation of dental efficacy and activation measures in carers of adults with disabilities in South Australia - a pilot study, Health & social care in the community, 24, 739-746, 2016	Non UK evidence.
Qyinan, P., Home hemodialysis and the caregivers' experience: a critical analysis, CANNT journal = Journal ACITN, 15, 25-32, 2005	No concept / phenomena / intervention of interest.
Rajkomar, A., Farrington, K., Mayer, A., Walker, D., Blandford, A., Patients' and carers' experiences of interacting with home haemodialysis technology: implications for quality and safety, BMC Nephrology, 15, 195, 2014	This study does not focus as primary aim on providing training for unpaid adult carers to care about their relatives. The main focus is indeed on patients.
Ream, E., Pedersen, V., Oakley, C., Richardson, A., Taylor, C., Verity, R., Informal carers' experiences and	This study does not focus as primary aim on

Study	Reason for Exclusion
needs when supporting patients through chemotherapy: A mixed method study, European journal of cancer care, 22, 797-806, 2013	education/training interventions-strategies for carers to provide practical support.
Reeve, E., Low, L. F., Hilmer, S. N., Beliefs and attitudes of older adults and carers about deprescribing of medications: a qualitative focus group study, British Journal of General Practice, 66, e552-60, 2016	Non UK evidence.
Reid, J., Psychosocial, educational and communicative interventions for patients with cachexia and their family carers, Current Opinion in Supportive & Palliative Care, 8, 334-8, 2014	This review has been excluded. Its references have been handsearched for relevant studies (none addiotional was identified and added to the review for this GL question).
Reid, Joanne, Lloyd, Chris, de Groot, Lyn, The Psychoeducation Needs of Parents Who Have an Adult Son or Daughter with a Mental Illness, Australian e-Journal for the Advancement of Mental Health, 4, 2005	Non UK evidence.
Research In Practice For, Adults, What are the most effective and cost-effective services for informal carers of older people?, 6p., 2006	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Riera, A., Ocasio, A., Tiyyagura, G., Thomas, A., Goncalves, P., Krumeich, L., Ragins, K., Trevino, S., Vaca, F. E., A web-based educational video to improve asthma knowledge for limited English proficiency Latino caregivers, Journal of Asthma, 54, 624-631, 2017	Non UK evidence.
Riva, M., Caratozzolo, S., Zanetti, M., Vicini Chilovi, B., Padovani, A., Rozzini, L., Knowledge and attitudes about Alzheimer's disease in the lay public: influence of caregiving experience and other socio-demographic factors in an Italian sample, Aging-Clinical & Experimental Research, 24, 509-16, 2012	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Rivera, P. A., Elliott, T. R., Berry, J. W., Grant, J. S., Problem-solving training for family caregivers of persons with traumatic brain injuries: a randomized controlled trial, Archives of Physical Medicine & Rehabilitation, 89, 931-41, 2008	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review
Rosenberg, J. P., Bullen, T., Maher, K., Supporting Family Caregivers With Palliative Symptom Management: A Qualitative Analysis of the Provision of an Emergency Medication Kit in the Home Setting, The American journal of hospice & palliative care, 32, 484-489, 2015	Non UK evidence.
Ross Paul D. S, Carr Sarah, It shouldn't be down to luck: training for good practice with LGBT people - Social Care TV, Diversity in Health and Care, 7, 211-216, 2010	Non UK evidence.
Rothing, M., Malterud, K., Frich, J. C., Family caregivers' views on coordination of care in Huntington's disease: a qualitative study, Scandinavian Journal of Caring Sciences, 29, 803-809, 2015	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.

Study	Reason for Exclusion
Runciman, P., Family carers' experiences: reflections on partnership, Nursing older people, 15, 14-6, 2003	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Sabat, Steven R., Flourishing of the self while caregiving for a person with dementia: A case study of education, counseling, and psychosocial support via email, Dementia: The International Journal of Social Research and Practice, 10, 81-97, 2011	Non UK evidence.
Samsi, K., Manthorpe, J., Everyday decision-making in dementia: findings from a longitudinal interview study of people living with dementia and family carers, International Psychogeriatrics, 25, 949-61, 2013	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Savundranayagam Marie Y, Brintnall-Peterson Mary, Testing self-efficacy as a pathway that supports self-care among family caregivers in a psychoeducational intervention, Journal of Family Social Work, 13, 149-162, 2010	Non UK evidence.
Sawyer, Brook E., Campbell, Philippa H., Early Interventionists' Perspectives on Teaching Caregivers, Journal of Early Intervention, 34, 104-124, 2012	No concept / phenomena / intervention of interest.
Schiffman, Jason, Reeves, Gloria M., Kline, Emily, Medoff, Deborah R., Lucksted, Alicia, Hoagwood, Kimberly, Fang, Li Juan, Dixon, Lisa B., Outcomes of a Family Peer Education Program for Families of Youth and Adults with Mental Illness, International Journal of Mental Health, 44, 303, 2015	Non UK evidence.
Schulz, Richard, Beach, Scott R., Matthews, Judith T., Courtney, Karen, Dabbs, Annette De Vito, Mecca, Laurel Person, Caregivers' Willingness to Pay for Technologies to Support Caregiving, The Gerontologist, 56, 817, 2016	No concept / phenomena / intervention of interest.
Schumacher, Karen L., Stewart, Barbara J., Archbold, Patricia G., Mutuality and Preparedness Moderate the Effects of Caregiving Demand on Cancer Family Caregiver Outcomes, Nursing research, 56, 425, 2007	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Sexson, Kathryn PhD R. N. Aprn F. N. P. B. C., Lindauer, Allison PhD R. N. F. N. P., Horvath, Theresa A. PhD R. N. Faan, Discharge Planning and Teaching, The American journal of nursing, 117, 2017	No concept / phenomena / intervention of interest.
Shanley, Chris, Supporting Family Carers Through Telephone-Mediated Group Programs: Opportunities For Gerontological Social Workers, Journal of Gerontological Social Work, 51, 199-209, 2008	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Shin, Dong Wook, Cho, Juhee, Roter, Debra L., Kim, So Young, Sohn, Sang Kyun, Yoon, Man-Soo, Kim, Young-Woo, Cho, BeLong, Park, Jong-Hyock, Preferences for and experiences of family involvement in cancer treatment	No concept / phenomena / intervention of interest.

Study	Reason for Exclusion
decision-making: patient-caregiver dyads study, Psycho - Oncology, 22, 2624, 2013	
Shin, Dong Wook, Cho, Juhee, Roter, Debra L., Kim, So Young, Yang, Hyung Kook, Park, Keeho, Kim, Hyung Jin, Shin, Hee-Young, Kwon, Tae Gyun, Park, Jong Hyock, Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists, Psycho - Oncology, 26, 770-778, 2017	No concept / phenomena / intervention of interest.
Silva-Smith, Amy PhD Aprn B. C. A. N. P., Caregivers Experience of the Learning Curve, Geriatric Nursing, 29, 31, 2008	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Simons, G., Thompson, S. B., Smith Pasqualini, M. C., Members of the EduPark, consortium, An innovative education programme for people with Parkinson's disease and their carers, Parkinsonism & Related Disorders, 12, 478-85, 2006	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
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	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Sin, J., Moone, N., Wellman, N., Incorporating psycho-educational family and carers work into routine clinical practice, Journal of Psychiatric & Mental Health Nursing, 10, 730-4, 2003	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Sin, Jacqueline, Henderson, Claire, Pinfold, Vanessa, Norman, Ian, Birchwood, Boydell Cheng Cucciare Evans-Lacko Friedrich Glynn Green Greenberg Kitzinger Lancaster Lazarus Nechmad Pinfold Poulson Powell Powell Proudfoot Ritchie Rotondi Rotondi Rotondi Schwarzer Sin Sin Sin Sin Sin Smith Smith Szmukler Szmukler Tennant Xia, The E Sibling Project: Exploratory randomised controlled trial of an online multi-component psychoeducational intervention for siblings of individuals with first episode psychosis, BMC Psychiatry, 13, 2013	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Skills For, Care, Impact evaluation of carers' strategy training: the wider workforce project: the HOST report, 133p., 2011	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Skills For, Care, Strategy for the participation of carers in Skills for Care work, 9p., 2007	No concept / phenomena / intervention of interest.
Skovdahl, K., Kihlgren A, I., Kihlgren, M., Different attitudes when handling aggressive behaviour in dementia: narratives from two caregiver groups, Aging and Mental Health, 7, 277-286, 2003	No concept / phenomena / intervention of interest.
Smith, Melissa Edmondson, Lindsey, Michael A., Williams, Crystal D., Medoff, Deborah R., Lucksted, Alicia, Fang, Li Juan, Schiffman, Jason, Lewis-fernández, Roberto, Dixon, Lisa B., Race-Related Differences in the Experiences of	Non UK evidence.

Study	Reason for Exclusion
Family Members of Persons with Mental Illness Participating in the NAMI Family to Family Education Program, American Journal of Community Psychology, 54, 316-27, 2014	
Stewart, Stephen, Macha, Ruth, Hebblethwaite, Amy, Hames, Annette, Residential carers knowledge and attitudes towards physiotherapy interventions for adults with learning disabilities, British Journal of Learning Disabilities, 37, 232-238, 2009	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Stokes, L. A., Combes, H., Stokes, G., Understanding the dementia diagnosis: the impact on the caregiving experience, Dementia, 13, 59-78, 2014	No concept / phenomena / intervention of interest.
Stringer, Kathy B., Wolskee, Patricia, A qualitative study into the current process of death education for caregivers of terminal patients, 3373474, 85, 2009	No study design (dissertation).
Taggart, L., Truesdale-Kennedy, M., Ryan, A., McConkey, R., Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability, Journal of Intellectual Disabilities, 16, 217-34, 2012	No concept / phenomena / intervention of interest.
Taylor, C., Supporting the carers of individuals affected by colorectal cancer, British Journal of NursingBr J Nurs, 17, 2008	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Thompson, C., Fernandez de la Cruz, L., Mataix-Cols, D., Onwumere, J., Development of a brief psychoeducational group intervention for carers of people with hoarding disorder: A proof-of-concept study, Journal of Obsessive-Compulsive and Related Disorders, 9, 66-72, 2016	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Thunborg, C., Von Heideken Wagert, P., Soderlund, A., Gotell, E., Reciprocal struggling in person transfer tasks - Caregivers' experiences in dementia care, Advances in Physiotherapy, 14, 175-182, 2012	No concept / phenomena / intervention of interest.
Tinder, Foundation, The health and wellbeing of unpaid carers: where can digital skills and community support add value?, 37, 2015	No concept / phenomena / intervention of interest.
Togher, Leanne, Power, Emma, Rietdijk, Rachael, McDonald, Skye, Tate, Robyn, An exploration of participant experience of a communication training program for people with traumatic brain injury and their communication partners, Disability and rehabilitation, 34, 1562-1574, 2012	Non UK evidence.
Tompkins, Sara Anne, Bell, Paul A., Examination of a Psychoeducational Intervention and a Respite Grant in Relieving Psychosocial Stressors Associated with Being an Alzheimer's Caregiver, Journal of Gerontological Social Work, 52, 89, 2009	No concept / phenomena / intervention of interest.
Travis, S. S., Greene, R., McAuley, W. J., Bernard, M. A., Differences in the ways that family caregivers experience medication administration hassles, Journal of Aging and Pharmacotherapy, 13, 35-51, 2007	Non UK evidence.

Study	Reason for Exclusion
Travis, S. S., McAuley, W. J., Dmochowski, J., Bernard, M. A., Kao, H. F., Greene, R., Factors associated with medication hassles experienced by family caregivers of older adults, Patient Education & Counseling, 66, 51-7, 2007	Non UK evidence.
Treasure Janet, Smith Grainne, Crane Anna, Skills-based learning for caring for a loved one with an eating disorder: the new Maudsley method, 228p., 2007	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Treasure, J., Nazar, B. P., Interventions for the Carers of Patients With Eating Disorders, Current Psychiatry Reports, 18, 16, 2016	This review has been excluded. Its references have been handsearched for relevant studies (none addiotional was identified and added to the review for this GL question).
Tseng, Chien-Ning, Huang, Guey-Shiun, Yu, Po-Jui, Lou, Meei-Fang, A qualitative study of family caregiver experiences of managing incontinence in stroke survivors, PLoS ONE, 10, 2015	No concept / phenomena / intervention of interest.
University Of Leeds. Centre for International Research on Care, Labour, Equalities,, Delivering training to carers: a practical guide based on findings from the national evaluation of the caring with confidence programme, 8p., 2011	This study has been already included in the review (Yeandle 2011).
Van Houtven, Courtney Harold, Oddone, Eugene Z., Weinberger, Morris, Informal and formal care infrastructure and perceived need for caregiver training for frail US veterans referred to home and community-based services, Chronic Illness, 6, 57-66, 2010	Non UK evidence.
Van Rooyen, N., Caring for the caregiver: A holistic approach, Practising Midwife, 11, 21-22, 2008	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Viau-Guay, Anabelle, Bellemare, Marie, Feillou, Isabelle, Trudel, Louis, et al.,, Person-Centered Care Training in Long-Term Care Settings: Usefulness and Facility of Transfer into Practice, Canadian Journal on Aging, 32, 57-72, 2013	Non UK evidence.
Vikström, Sofia, Borell, Lena, Stigsdotter-Neely, Anna, Josephsson, Staffan, Caregivers' Self-Initiated Support toward Their Partners with Dementia When Performing an Everyday Occupation Together at Home, OTJR, 25, 149-159, 2005	No concept / phenomena / intervention of interest.
Ware, Tricia, Matosevic, Tihana, Hardy, Brian, Knapp, Martin, Kendall, Jeremy, Forder, Julien, Commissioning care services for older people in England: The view from care managers, users and carers, Ageing & Society, 23, 411-428, 2003	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.

Study	Reason for Exclusion
Washington Karla, Commitment to care: a grounded theory of informal hospice caregivers' development as symptom managers, Qualitative Social Work, 12, 358-371, 2013	Non UK evidence.
Watson, R., Manthorpe, J., Stimpson, A., Learning from carers' experiences: helping older people living with dementia to eat and drink, Nursing Older People, 14, 23-7; quiz 28, 2003	No concept / phenomena / intervention of interest.
Welsh, S., Edwards, M., Hunter, L., Caring for smiles--a new educational resource for oral health training in care homes, Gerodontology, 29, e1161-2, 2012	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Williams, Allison M., Forbes, Dorothy A., Mitchell, Julie, Essar, Mary, Corbett, Brad, The influence of income on the experience of informal caregiving: Policy implications, Health Care for Women International, 24, 280-291, 2003	No concept / phenomena / intervention of interest.
Williams, S., Dagnan, D., Rodgers, J., McDowell, K., Changes in Attributions as a Consequence of Training for Challenging and Complex Behaviour for Carers of People with Learning Disabilities: A Systematic Review, Journal of Applied Research in Intellectual Disabilities, 25, 203-216, 2012	this review has been excluded. Its references have been handsearched for relevant studies (none addiotional was identified and added to the review for this GL question).
Williams, Virginia P. PhD, Bishop-Fitzpatrick, Lauren A. B., Lane, James D. PhD, Gwyther, Lisa P. M. S. W., Ballard, Edna L. M. S. W., Vendittelli, Analise P. A. B., Hutchins, Tiffany C. M. S. W., Williams, Redford B. M. D., Video-Based Coping Skills to Reduce Health Risk and Improve Psychological and Physical Well-Being in Alzheimer's Disease Family Caregivers, Psychosomatic Medicine, 72, 897, 2010	Non UK evidence.
Wingham, J., Frost, J., Britten, N., Jolly, K., Greaves, C., Abraham, C., Dalal, H., Reach-Hf research investigators, Needs of caregivers in heart failure management: A qualitative study, Chronic Illness, 11, 304-19, 2015	Non UK evidence.
Yates, Patsy, Aranda, Sanchia, Edwards, Helen, Nash, Robyn, Skerman, Helen, McCarthy, Alexandra, Family Caregivers' Experiences and Involvement With Cancer Pain Management, Journal of Palliative Care, 20, 287-296, 2004	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	This study does not focus as primary aim on education/training interventions-strategies for carers to provide practical support.
Zabalegui, Adelaida R. N. PhD Feans, Galisteo, Maria R. N. Msc, Navarro, Maria Montserrat R. N. PhD, Cabrera, Esther R. N. MSc PhD, INFOSA intervention for caregivers of the elderly, an experimental study, Geriatric Nursing, 37, 426, 2016	This study does not include qualitative evidence - therefore it has been excluded from the qualitative review.
Zauszniewski, Jaclene A. PhD R. N. B. C. Faan, Lekhak, Nirmala B. S. N. R. N. PhD, Yolpant, Wichiya M. S. N. R. N. PhD, Morris, Diana L. PhD R. N. Faan Fgsa, Need for	Non UK evidence.

Study	Reason for Exclusion
Resourcefulness Training for Women Caregivers of Elders with Dementia, Issues in Mental Health Nursing, 36, 1007, 2015	
Zauszniewski, Jaclene A., Lekhak, Nirmala, Burant, Christopher J., Underwood, Patricia W., Morris, Diana L., Resourcefulness Training for Dementia Caregivers, Western Journal of Nursing Research, 38, 1554-1573, 2016	Non UK evidence.

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 32: Excluded 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-year follow-up, Journal of advanced nursing, 68, 1224-34, 2012	Population of interest: the study focus is primarily on patients.
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.

Study	Reason for Exclusion
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.
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.

Study	Reason for Exclusion
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 on the effectiveness and cost impact of three management strategies. Value Health. 2012 Sep-Oct;15(6):851-9	Population of interest: no primary focus on carers.
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	Population of interest: the study focus is primarily on patients.

Study	Reason for Exclusion
analysis for dementia care collaboration: Partners in Dementia Care, Journal of General Internal Medicine, 30, 804-9, 2015	
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.
Patel, A., Forster, A., Young, J., Nixon, J., Chapman, K., Knapp, M., Mellish, K., Holloway, I., Farrin, A., Cluster randomised trial evaluation of a patient and carer centred system of longer-term stroke care (the LoTS care trial): Economic evaluation, Cerebrovascular Diseases, 35, 584, 2013	Conference abstract.
Pickard, Linda, The effectiveness and cost-effectiveness of support and services to informal carers of older people: a review of the literature prepared for the Audit Commission, 2004	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.
Quinn, C., Anderson, D., Toms, G., Whitaker, R., Edwards, R. T., Jones, C., Clare, L., Self-management in early-stage dementia: a pilot randomised controlled trial of the efficacy and cost-effectiveness of a self-management group intervention (the SMART study), Trials [Electronic Resource], 15, 74, 2014	Research protocol.
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 utility evaluation alongside the Danish	Population of interest: no primary focus on carers.

Study	Reason for Exclusion
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 L – Research recommendation

Research recommendations for review question: What skills and educational based interventions are effective, cost-effective and acceptable to carers for training them to provide practical support to the person receiving care?

Why this is important

This review failed to identify any research evidence about the impact of training for carers on caring related accidents or incidents. This was set out a priori as an important outcome and was considered by the committee to include falls and failure to take prescribed medicine. The committee therefore agreed about the importance of recommending future research about support of interventions which help to reduce caring related accidents or incidents. In their view the outcomes of interest should relate to both the care recipient and the carer.

Research recommendation in question format: What support or training helps to reduce caring-related incidents or accidents?

Research question	What is the effectiveness, cost-effectiveness and acceptability of the whole family approach to carers' assessments?
Importance to people or the population	Carers provide a wide range of care and support tasks, sometimes with advice and training from practitioners or peers but often through teaching themselves and finding information or tips from diverse sources. If they do not have up to date information or training and support from practitioners the concern is that adverse events will occur, for instance falls or injury (to the carer or cared for person) during moving and handling or overdose through administering medication. These negative outcomes impact both on the carer and on the person being supported. More widely, such accidents or incidents are also likely to result in a break down in caring or unplanned health contacts, including hospital admissions so there are related resource implications as well as health and wellbeing considerations for the carer and cared for person.
Relevance to NICE guidance	NICE guidance provides advice on effective, good value health and social care including care and support for adult carers and the cared-for person.
Relevance to NHS/ social care	The Care Act (2014) places a statutory duty on local authorities to put in place services that can prevent, reduce or delay carers from developing a need for support. This means that councils should be delivering services that can intervene and help carers before their health suffers as a result of their caring role. The kind of services local authorities are expected to use in order to prevent carers developing a need for support includes training that helps them feel confident undertaking care tasks. If they feel confident and competent to undertake care tasks the likelihood of ill health or injury to them or the cared for person will be reduced. The development of an evidence base about the effectiveness of training for carers to reduce caring-related incidents or accidents is therefore clearly relevant to the Care Act requirements.

Research question	**What is the effectiveness, cost-effectiveness and acceptability of the whole family approach to carers' assessments?**
National priorities	The Care Act (2014) places a statutory duty on local authorities to prevent, reduce or delay carers from experiencing poor outcomes as a result of caring and developing their own support needs. Determining the effectiveness of training for carers to help them provide care and support safely will contribute towards this objective.
Current evidence base	There is currently no published evidence about the effectiveness of training for carers in terms of the reduction of declining health, injury or accidents among carers or the cared for person.
Equalities	N/A

N/A: not applicable

Criterion	**Explanation**
Population	• Adults 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.
Intervention	• Training for carers to help them undertake care tasks
Comparator	No training Different training programmes compared with each other
Outcomes	• Outcomes relate to the carer and the cared for person: • Care related accidents or incidents • health and social care related quality of life • physical and mental health • health care contacts •
Study design	Randomised controlled trial
Timeframe	Two years from randomisation

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

Alhaddad 2016

- "We didn’t want to have it (nebuliser therapy) because… he puts on a lot of weight, he fills with water, but he said—don’t worry, it’s better to start it straight away than to wait. We used to wait until he couldn’t breathe at all, you see?" (Adult carer of a person with COPD - nebuliser-delivered therapy at home)
- "Some days he looks like he’s got the shakes for that is the Ventolin® anyway, because that does make you shake because I’ve been on that myself in the past and yeah…that wears off doesn’t it after a while, but he does, I just leave him to sit quiet, I watch him, he doesn’t always know that I’m watching him." (Adult carer of a person with COPD); "Well, when she’s bad she’ll use it [the nebuliser] up to four times a day; when she’s good maybe only once or twice. So she tries not to use it, she’s stubborn; she tries her hardest not to use it." (Adult carer of a person with COPD - nebuliser-delivered therapy at home)
- "He can’t put the solutions in when things are bad. He doesn’t understand which ones to put in. He couldn’t tell the difference between the two; the antibiotic and the other one. So, he does need somebody to make sure he is doing it properly." (Adult carer of a person with COPD); "I have to say I don’t think he does enough deep breathing….I say come on breathe in and breathe out." (Adult carer of a person with COPD - nebuliser-delivered therapy at home)
- "We bought packages from the company and you get loads of stuff you don’t need. You know you couldn’t buy the tubes without [the nebuliser], you know on their own, and that kind of thing; you’re like paying £20 for a package with loads of stuff you don’t use." (Adult carer of a person with COPD - nebuliser-delivered therapy at home); "My husband is on three different inhalers, so we weren’t entirely sure how they really work…He was told to take them, but we weren’t really sure what we were supposed to be doing." (Adult carer of a person with COPD - nebuliser-delivered therapy at home); "I’m not a doctor and I’m not a nurse and they mustn’t view me as that…they can do this, but at the end of the day […] if something bad happened to her, I would say “is that me?’ ‘Did I do that?" (Adult carer of a person with COPD - nebuliser-delivered therapy at home)

Macdonald 2011

- "I suppose my main problem was actually finding the time when I could actually watch them and read the book without getting too distracted" (Care of a person with ED - DVDs + skills-based training manual); "I had limited opportunity to actually apply the exercises . . . .. when things are bad, she seems to revert to her and will not communicate as much with me"(Care of a person with ED - DVDs + skills-based training manual); "It’s one thing reading it in the book and going ‘right OK, OK this sounds pretty simple’ and then you might sit down and do it and its gonna take you like two hours to have this conversation because it’s such a tricky one "(Care of a person with ED - DVDs + skills-based training manual); "They are away at college or they are away and they are suffering from an eating disorder. Now how do you cope with that?"(Care of a person with ED - DVDs + skills-based training manual)
- "Four carers expressed an opinion that although they found the materials helpful, they felt it would have been even more useful at the beginning of the illness, or had they participated much earlier at the onset of the illness." (Author quote)

- "So probably the psychological help that she"s had and I"m not praising us or ourselves at all but probably come through the book and the information with your set up really"(Care of a person with ED - DVDs + skills-based training manual); b) Perceived personal development: increased confidence and self esteem" (Care of a person with ED - DVDs + skills-based training manual); "increased awareness, knowledge and understanding" (Care of a person with ED - DVDs + skills-based training manual); "increased strength, efficacy and empowerment" (Care of a person with ED - DVDs + skills-based training manual); and "greater encouragement and patience"(Care of a person with ED - DVDs + skills-based training manual); "It gave me confidence or more confidence and through me, my partner and through us . . . we all got a bit more confidence that we could actually challenge this" ; "I felt that some of the behaviours that I thought were peculiar to us and were really, you know, strange, I was kind of reassured that that was all part of the illness that made me feel we weren't, it wasn't just us "(Care of a person with ED - DVDs + skills-based training manual); "It did, as I say, give me a bit of encouragement and understanding and left me feeling easier with it – took the panic away "(Care of a person with ED - DVDs + skills-based training manual); ". . . I think probably, you know, conversations with her, the DVD has helped find the right phrases to use or the right way to approach her"(Care of a person with ED - DVDs + skills-based training manual)
- "I don't feel as if anything's worked particularly well because she's still unwell so . . . until she's better, I suppose I don't feel that anything's worked but it's not like that because it's a gradual process, isn't it?"(Care of a person with ED - DVDs + skills-based training manual); ". . . whereas the DVD is more . . . you just kind of sit through and watch it and follow it through and sometimes it's a bit frustrating because em things, the role plays don't necessarily reflect what goes on in your own house" (Care of a person with ED - DVDs + skills-based training manual); "Yeah like of . . . consistent approach and also not being able to get any dialogue . . . there were some fairly closed answers P gave me that was basically 'well go and try this' and that was it really" (Care of a person with ED - DVDs + skills-based training manuals)

Papachristou 2015

- "I do worry over Lily. I don't like Lily getting too thin. I'm a bit surprised that no one has spoken to us about nutrition and food. I don't think they do that much with leaflets and I certainly have not received anything". (Adult carer of a person with dementia)
- "A lady from the Alzheimer's Society visited and there were so many questions I wanted to ask her but she was really here for her purposes and me filling in these forms: things for what we can claim for. I wanted to information about what kinds of food to avoid and that side of things. They do have a kitchen at the Alzheimer's Society but I do not know if they have any guidelines to help caregivers. I don't know anything about that side of it but I've always been interested in diet". (Adult carer of a person with dementia)
- "We could do with getting information on people living with dementia and food . . . We had nothing specific given to us so far. A person came and spoke about the five fruits and vegetables for the day but she did not actually give us any information on anything we should be doing different in regards to dementia and food. We have nobody telling us what might happen. Hoping we do things the right way". (Adult carer of a person with dementia)

Riley 2011

- "I wanted to find out what psychosis was . . . But since coming here, it's actually changed that because I almost . . . I can understand it. And so, it doesn't affect me in the same ways now, I . . . I can deal with it." (Adult carer of a person with psychosis education group programme); "Well you just feel quite lonely, because even if you've got family or a partner . . . to see someone you love so ill . . . is heartbreaking really and you do feel really isolated." (Adult carer of a person with psychosis education group programme) ; "The carers felt tremendous stigma about mental illness and this was twofold; concern was expressed for the stigma experienced by their relative and how the carers were viewed by others. The carers felt it was hard for 'outsiders' to understand the caring role and consequently, did not discuss this with friends" (Author quote)
- " Seeing that Christmas tree outside . . . the little things can be a trigger" (Adult carer of a person with psychosis - education group programme); "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)
- "We'd only just had my son diagnosed, there were people saying 'we've had 7 years of hell. . . .' It was just too much for me, I was like 'oh my god'. You see I thought he was going to get better then, and then he said 7 years and still ill. That was hard to take really " (Adult carer of a person with psychosis - education group programme)
- "I was quite resistant to coming, as I didn't feel like . . . a carer. You know, I used to go out to work and I didn't want to be . . . just a carer." (Adult carer of a person with psychosis - education group programme); "I don't like the word carer. You know, I'm her mum, and you don't feel like a carer."(Adult carer of a person with psychosis - education group programme). "All the signs are there aren't they. Until you've actually experienced it you don't know what you're looking for, do you? And now sort of after this group. . . . perhaps if the early warning signs were showing again you'd be able to pick up on that, or I'd like to think I can pick up some of things that you could see – the early warning signs."(Adult carer of a person with psychosis - education group programme); "If I'd been in possession of some of the facts earlier I might have reacted differently to how I did 12 months ago . . . I think, we all have a better understanding of it now, I think that you react more positively to a situation."(Adult carer of a person with psychosis - education group programme); "I've had some really good ideas about some of the problems and how to deal with them, because people have tried them and they've worked."(Adult carer of a person with psychosis - education group programme)
- "I think for me it was just having a point of contact as well, which I've never had before, I didn't have any idea of anybody that I could contact or . . . for advice or anything, till I came here."(Adult carer of a person with psychosis - education group programme)

Sepulveda 2008a

- "It has made me completely change my whole approach…. I am not so pushy about enquiring about her symptoms rather it is up to her when she phones me'' I think it has made substantial changes to the way I see all my children in terms of not always trying to reassure and solve their problems…. I think standing back is very helpful and encouraging by not offering them all of the solutions, but just encouraging when they have got problems'' When she first got ill you become a super-carer, the expert, always there. But she didn't get better, in fact she got worse. The more I was there the worse she got. It was learning for me how to let go and to allow her to make choices for herself. To actually leave her in the house on her own, to go out, even if it was just to circle the house 20 times with the dog" (Adult carer of a person with ED - collaborative care skills workshops)

- "She notices my happiness level increasing as I am giving myself a chance to get my life back because I had put it on complete hold because I was always at her disposal and now to go out and do what I want to do and show her actually I am happy"(Adult carer of a person with ED - collaborative care skills workshops)
- "I think because our daughter knows that we are now getting professional assistance…. it means we are to a certain extent coming at it from the same direction. I think that the impact of that, picking up on something you said, is that it almost makes the problem, it gives it a separate identity which is somehow slightly separate, slightly over there, as distinct from being within the person themselves"(Adult carer of a person with ED - collaborative care skills workshops)

Sepulveda 2008b

- ". . . I do think there's an awful lot to understand . . . really a lot there to understand and I don't know just as a normal person that you could get it right" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training); "but the patients were all sort of calm em . . .which is not . . . they weren't being stroppy or kicking or so I think you would need . . . it wasn't realistic, a true representation of the situation really and actually cajoling them into getting them sitting down to the sitting down position" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training); "'The messages are clear, it's putting the techniques into practice that is difficult . . . it is quite difficult to use these DVDs in isolation without some face to face interaction with" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training)
- "I found them really, really useful and the things I found most useful are the role play"(Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training); "I appreciated the idea of the dolphin in particular, kind of nudging . . . because I . . . the times when I have been talking to my wife and its worked . . . a kind of when we have been moving in that kind of mood if you like "(Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training); "The DVDs still carry lots of powerful messages and give carers hope that things can get better if they really put theirminds to it!"(Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training)
- ". . . and I have to fight against that because . . . otherwise I could over-protect . . . and I don't want to do that either. Equally she's going through a difficult stage at the moment and I'm . . . I'm trying to find the right balance" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training); "'And I do trust her and now she says to me 'if I don't do it I will let you know' whereas before I was so anxious that she was doing it that I'd question her – 'have you done it?' and of course then that just . . . it just destroyed her trust in me" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training)
- "the DVDs 4 and 5 really helps the carer to see how the collaborative skills work in practice. I still believe that a back up phone coaching is essential as there are so many behaviours that carers find so difficult to deal with and you cannot hope to coverall of them in this DVD package" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training);" "It is crucial to have some sort of backup support/help line so carers can at least talk about some of the issues raised" (Adult carer of a person with ED - DVD + Telephone Coaching-Based Skills Training)

Smith 2015

- "When she lived alone and had to take her blood pressure tablets on her own and I came in the afternoon, the tablet was still in the dosage box and I didn't know what to do. I did not know if it could hurt her to give the tablet at that moment or if I had to wait until the next morning". (Adult carer of person with dementia). ". . . when he was taking Aricept it had not the right effect on him and it made him worse in his behaviour." (Adult carer of person with dementia). ". . . I was reading the digoxin leaflet lately and it says that on the things digoxin does is confusion and Mum is taking a really high dose of digoxin, sowe don't know if we stop that, that will improve her memory". (Adult carer of person with dementia)."She feels terribly tired all the time. I'm not sure if this is a side-effect of the new medicine. (Adult carer of person with demntia)
- "The medication was delivered to my mum by the pharmacy. But suddenly they stopped. . . . I live the other side of London. They did not mention this earlier. So I had to spend another day phoning around to get everything done. I had come not to worry too much if she missed a day of the ramipril or aspirin, because these pills were more preventative. But I didn't want her to miss the Aricept [donepezil]. After that I wrote down in my agenda when to get a new prescription. But it would be so much easier if things would go automatically. (Adult carer of a person with dementia)"; "She thinks she doesn't need them. . . It's a shame that she can't remember why she was told to take them." (Adult carer of a person with dementia)

Sommerlad 2014

- "Wasn't something I would do for myself" (Adult carer of a person with dementia - START intervention); "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); "The sessions were too long and interrupted normal daily duties" (Adult carer of a person with dementia - START intervention); "It would have been nice if the therapist met my Dad … to have the therapist's viewpoint, to see for themselves" (Adult carer of a person with dementia - START intervention); "One session involving the care-recipient so they appreciate there are problems … and the effect their illness is having on spouse … might help with their self-control. " (Adult carer of a person with dementia - START intervention); "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); Although the CD of relaxation techniques was popular with many respondents, others did not like it: "I haven't used the CD—some of which I found really irritating!" (Adult carer of a person with dementia - START intervention); "I found the male voices off-putting on the CD—prefer all female voices. " (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)
- "Sometimes I sit and go through my orange folder [therapy manual] and there is a peace and understanding that someone is there with me"(Adult carer of a person with dementia - START intervention); "Rather than using the CD, I went back to practising transcendental meditation again—so thank you for that"(Adult carer of a person with dementia - START intervention); "I now feel I have all the tools before she gets worse"(Adult carer of a person with dementia - START intervention); "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); "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)

- "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 most important and useful message was to go along with whatever the Alzheimer's sufferer says, that is enter their World and don't attempt to correct obvious inconsistencies." (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); "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 project" (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)

Yeandle 2011

- "I've just been trying to sort of get out more and socialise and it was the 'rip up the guilt'….you know, write the guilty word down and rip it up. That's what I learn here, that it's OK to go out and have a coffee with a friend for half an hour, an hour. I was feeling very, very guilty, quite mixed up when I came, because obviously I had all these different things going on."(Adult carer – CwC programme); "It [Caring with Confidence] reinforces that thinking of yourself is part of helping the cared for. You need leisure time. "(Adult carer – CwC programme); "You may know the solution, but it is difficult to make yourself do it. Having someone turn round and tell you to do what you say makes you do it. "(Adult carer – CwC programme)
- "I have started working again, which has been a great bonus for me, not just financially, it gets my brain ticking again. Thanks to Caring with Confidence. Having the confidence to actually say yes I will do the work that I'm asked to do, whereas in the last 12 months I've turned it down on every occasion. "(Adult carer – CwC programme); However, many barriers to (re) entering paid work remained:
- "There aren't jobs out there that you can just dip in and out of. So Caring with Confidence doesn't make a difference. It's not viable at all. There are no jobs with the flexibility required by carers. I'm interested in doing a university course but I can't see how I can fit it in. "(Adult carer – CwC programme); "The reality of the job market is that you can't work, Caring with Confidence course or not. People don't want to employ someone who is looking after a disabled child at home. "(Adult carer – CwC programme); Earning limits make it not worth the effort. You're not allowed enough to make it worth the hassle. "(Adult carer – CwC programme)

- “People feel less isolated now...”. (Adult carer – CwC programme); “I agree you feel less isolated, that you’re not the only one. It empowers you to fight for your rights..”. (Adult carer – CwC programme); “It’s the interaction that is important; a lot of the information that is given out would be worthless without the interaction”. (Adult carer – CwC programme)
- “A coffee morning wouldn’t be structured like the course is. It’s led, everyone has the chance to talk and the focus is kept on the topic. Here, everybody has a chance to say something, it’s really worthwhile, it being led, chaired....otherwise it’s just a chat”. (Adult carer – CwC programme); “Seeing people struggling through similar situations provides permission / endorsement of a change in behaviour. People help you to question your own resolution”. (Adult carer – CwC programme); “It’s important to know there are others. Previously you think you’re on your own. Going through people’s stories makes you aware of things that can lead to change. The group therapy aspect really works, it’s very important” (Adult carer – CwC programme)
- “It was good to be in a gay space. This made people more confident. People knew that the others attending the sessions would be at least gay-friendly, if not gay. (Adult carer – CwC programme)
- “We gained more knowledge about what we can claim. Most people are not aware of what they can claim, because there are no proper information sessions for carers telling people what they can claim. Many people don’t claim what they’re entitled to.”. (Adult carer – CwC programme)
- “In the past I struggled to lift my husband who is a big man, but I was reluctant to dial 999. Before I would have called people, now I’m happy just to call the emergency services. I was reluctant to do so before. I felt bad that I was calling them regularly. Thanks to this course I realise what the services are there for, so I don’t feel so bad”. (Adult carer – CwC programme); Before Caring with Confidence, we would have been reluctant to dial 999 over an episode such as the cared for person falling, now we have more confidence to do so because we were made to feel as if we have a right to use these services by talking to other carers and facilitators, who reminded us that we wouldn’t be wasting their time”. (Adult carer – CwC programme): “I realised that I had to ask for assistance instead of suffering in silence”. (Adult carer – CwC programme)
- “It’s about acknowledging the carer label, realising that you are not just a wife or a parent that you have become a carer. Meeting people in similar circumstances and with a shared understanding allows you to come to terms with it”. (Adult carer – CwC programme); “Caring with Confidence increased the feeling that I was a carer. It pushed me further to that point”. (Adult carer – CwC programme); “I was probably somebody who had decided that I was a carer, just as I came here. I look after my mother who has got dementia and is frail and is losing her eyesight, so I was just coming to that point. So that was reinforced when I came here that, yes, I was a carer - and it makes you think about things”. (Adult carer – CwC programme)
- “You feel better, you feel better about the cared for, which gives improved patience, so your relationship with the cared for goes better”. (Adult carer – CwC programme); “As I am more confident and self assured - this has had a ripple effect”. (Adult carer – CwC programme); “By me stepping back from certain situations, the person I care for has to now take responsibility for his actions and be more independent”. (Adult carer – CwC programme)
- "Since we’ve been here (CwC), I’ve persuaded my husband to fill in the form for Disability Living Allowance, which he has got! It came through within a month. (……) I had known about the benefit before, but had not realised that we were entitled to it. The facilitator helped in this”. (Adult carer – CwC programme); “I now

feel more confident that I can cope, so my mother won’t have to go into a home. Thinking about it, I always assumed that when my mother got that bad with her dementia or whatever, that she would go into a home. But I think I feel more confident and able to cope with things, and I think probably now she would, somehow, we would find a way that she could come and stay with us. It’s the confidence; it’s a really good title for the course. “(Adult carer – CwC programme)