National Institute for Health and Care Excellence

Final

End of life care for adults: service delivery

[H] Evidence review: Carer support services

NICE guideline NG142

Evidence review

October 2019

Final

Developed by the National Guideline Centre,
hosted by the Royal College of Physicians

NICE accredited
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ISBN 978-1-4731-3560-4

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1.1 Review question: What are the most clinically and cost-effective support services for carers of (or those important to) people in their last year of life by health and social care professionals?

1.2 Introduction

“There is a resource available around the clock and every day of the year, that can help people to be cared for and die in the place that they want to be, and helps keep them out of hospital, that is low-cost or free to the NHS. That resource is people. We call them carers. We need to invest in supporting carers because without them the system will collapse.” Abridged quote: Simon Chapman. Director. NCPC (2013). It is estimated that in total there are 6.5 million people caring in the UK at any one time and this is set to increase by 60% in the next 30 years.[42] Over a third of carers give 20 or more hours of care a week.[205]

Carers can be family; including children, close friends and those who are important to the patient and all have a vital role in the provision of care. They need to be closely involved in decision making, as they are key members of the team and are experts in the patients’ care. This is particularly important if a patient is admitted to hospital and the carer may lose their status. Additionally if the patient has special needs such as learning disabilities or has dementia then it is extremely important that the carer continues to be closely involved. Carers also have their own needs and often need practical and emotional support both during the person’s life and most importantly after bereavement.

There are some specific issues which carers face when caring for someone approaching end of life. This can include coping with emotional, social and spiritual needs and having difficult conversations about the time that is left and the process of dying. Carers have to cope emotionally with the person’s physical changes, understanding the effects of medication which can alleviate or exacerbate symptoms. This can all be particularly important where younger carers are involved. If left unsupported and stretched beyond their developmental and maturity level, caring for a dying adult in childhood can lead to poor mental health with lifelong implications.. Caring for people that are dying can be a positive time, although emotional and sometimes painful. However, if the carer does not have access to the right support at the right time there is a danger that they will become exhausted unable to cope and to continue with their caring role.

It is frequently the carer who has to coordinate care and healthcare professionals. A significant percentage of carers are older and may have pre-existing ill health and need support. Increasingly there are young carers who need particular consideration and appropriate support, *without which their caring role can lead to a build-up in resentment which can later cause regret and create complexities in bereavement*. Carers need information and access to support both in their role as carer but also for themselves. They need to have information about the illness, what course it may take, what assistance they can expect, what benefits they may be entitled, work related issues, and where children are involved what support may be provided by the school and other organisations.

Carers may face significant losses during the time they are caring and need support and space to discuss these feelings which may include the impending loss of a loved one, anxiety over financial and legal matters, work or education related issues, not being able to participate in social activities, meet colleagues, and friends. These can culminate in isolation, loneliness and depression, which is, heightened once the loved one has died. If the Government’s ambition for meeting people’s preferences at the end of life is to be achieved we need to provide carers with the knowledge, skills and support for this demanding role. To help build resilience they need access to a range of support services that are appropriate to the need, responsive and readily available.

1.3 PICO table

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Population	Carers of (or those important to) adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. • Includes young carers (<18 years)
Interventions	• Carer support services, such as for example ○ Carer respite services ○ Combined care for patients and carers ○ Community services ○ Psychological support ○ Support groups and education for carers ○ Information for carers (for example, information on financial or benefits support) ○ Peer support for carers ○ Health checks
Comparisons	• To each other • No carer support services
Outcomes	CRITICAL - Quality of life of person in their last year of life (Continuous) - Quality of life of carer of (or person important to) the person in their last year of life (Continuous) - Preferred and actual place of death (Dichotomous) - Preferred and actual place of care (Dichotomous) - Longevity of the carer (Continuous) IMPORTANT - Carer health (For example, GP visits, mental health, school/work attendance) (Continuous) - Length of hospital stay (Continuous) - Use of community services (Dichotomous) - Staff (providing care to the person in their last year of life) satisfaction (Continuous) - Patient/carer reported outcomes (satisfaction) (Continuous) - Staff satisfaction (Continuous)
Study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies and interrupted-time-series

1.4 Clinical evidence

1.4.1 Included studies

A search was conducted for studies comparing carer support services to support carers of people with progressive life-limiting conditions thought to be entering their last year of life. Twenty papers from eighteen studies were included in the review[5,12,46,50,54,71,72,81,139-141,160,164,165,174,184,188,208,227,275]; these are summarised in Table 2 below. Evidence from these studies is summarised in the clinical evidence summary below (Table 3). See also the study selection flow chart in Appendix C, study evidence tables in Appendix D, forest plots in Appendix E, and GRADE tables in Appendix F.

1.4.2 Excluded studies

See the excluded studies list in Appendix H.

1.4.3 Summary of clinical studies included in the evidence review

Table 2: Summary of studies included in the review

Study	Intervention and comparison	Population	Outcomes	Comments
Allen 2014[5]	Retired senior volunteers: RSV received four-six hour intensive training on The LIFE Volunteer Interventionist Manual. The manual and accompanying workbook comprised: With the help of the RSV, in session one the patient-caregiver dyad narrowed the focus to a time period in the patient's life that could be adequately represented in one tangible project (for example, scrapbook, cookbook, audiotapes) to represent the patient's values and achievements in life. During the second session, RSVs helped the dyad work on the activity and further use problem-solving skills. During the third visit, the patient and caregiver shared their activity with the RSV, who discussed the dyad's feelings about the process, including a qualitative evaluation of the LIFE project and what the family learned when creating it. Support phone calls: Patients and caregivers each received three separate, structured emotional support telephone calls with research staff (mean duration = 13±6.5 minutes). Control callers asked questions of participants and then engaged in supportive conversations using empathic listening and reflection. Topics discussed included family, intergenerational ties, and important aspects of the patient's life, but structured reminiscence and the creative and therapeutic nature of legacy activities were not discussed.	Caregivers identified by Palliative care patients. Patients aged >55, living in the community or assisted living, had an advanced illness or combination of chronic illness, received and average of 4 hours per week of care from caregiver. N=45 USA	Quality of life of person in their last year of life (depression as QoL proxy); Quality of life of carer (depression as QoL proxy)	
Badr 2015[12]	Tailored support: Patients and caregivers in the intervention group each received their own tailored manuals and participated together in 6 weekly 60-minute telephone counselling sessions with a trained interventionist who had a master's degree in mental health	Patients were eligible if they had advanced lung cancer and were within 1 month of treatment initiation (any line of	Quality of life of person in their last year of life (depression and anxiety as QoL proxies);	

Study	Intervention and comparison	Population	Outcomes	Comments
	counselling. The topics were self-care, stress and coping, symptom management, effective communication, problem solving, and maintaining and enhancing relationships. For each topic, approximately half the content was the same for patients and caregivers, and half was tailored to the person's role (patient or caregiver). During sessions, the interventionist reviewed homework and manual content for that week, guided participants through in-session activities, and assigned the next week's homework to reinforce the practice of skills taught. Usual care: Standard oncologic care and primary palliative care for the patient from the point of the diagnosis of advanced LC. Primary palliative care is provided by the patient's medical oncologist and includes the basic management of pain and other symptoms, including depression and anxiety, as well as basic discussions about the prognosis and goals of treatment. In addition, patients may be referred to the outpatient supportive oncology practice for a specialty palliative care consultation according to need as determined by the treating oncologist. Caregivers are welcome to attend/participate but are not required to do so.	therapy); were spending more than 50% of their time out of bed on a daily basis, as measured by an Eastern Cooperative Oncology Group performance status ≤2; and, had a spouse/partner or other close family member whom they identified as their primary caregiver. In addition, both patients and caregivers had to be ≥18 years old; have the ability to read and understand English; and, be able to provide informed consent. N=39 USA	Quality of life of carer (depression, anxiety and burden as QoL proxies)	
Chan 2016[46]	Psychological support: Enhanced Psychosocial support program which included education and intervention from an on-site palliative care nurse and a designated social worker. Interventions were instituted based on published information regarding families' needs in both end-stage renal disease and palliative care. Usual care: Standard renal care and caregivers could be referred to other allied health professionals if clinically indicated.	Caregivers of patients who had: chronic kidney failure as defined by creatinine clearance <15mL/min; opted for conservative treatment by nephrology team or patient; never treated with dialysis or transplantation and able to provide informed consent.	Quality of life of person in their last year of life (QoL, plus depression and anxiety as QoL proxies); Quality of life of carer (QoL, plus depression, anxiety and burden as QoL proxies)	

Study	Intervention and comparison	Population	Outcomes	Comments
		N=29 Hong Kong (China)		
Chih 2014[50]	Carer support – CHESS + CR: Received access to the CHESS website, which included information, communication, and coaching resources addressing advanced cancer and caregiving needs. At initial login to CHESS and then every 7 days, caregivers and patients completed a Check-in, asking questions about their needs and patient symptoms from the modified Edmonton Symptom Assessment System (ESAS) and Eastern Cooperative Oncology Group Performance Status. They could write questions to be addressed by the clinicians in the next visit. Caregivers reported caregiving burden and preparedness. This Check-in allows users to track patient symptom status, monitoring decline or improvement. CHESS included the clinician report (CR) that summarized the information provided by patients and caregivers at Check-in and made it available online to the clinicians. Clinicians could access the CR via CHESS anytime. However, any caregiver- or patient-reported ESAS symptom rated at a threshold of 7 or higher on a 0- to 10-scale automatically generated an email alerting the clinician to review the report immediately. Clinicians also received an e-mail alert to review reports 2 days before a scheduled clinic visit, regardless of the ESAS rating. Carer support – CHESS only: CHESS intervention without the clinician report.	Eligible breast cancer patients were women with metastatic, recurrent or metastatic inflammatory breast cancer, or a chest wall recurrence following mastectomy. Prostate cancer patients were eligible if they had hormone refractory or metastatic prostate cancer. Eligible lung cancer patients included those in stage IIIA, IIIB, or IV. Eligible caregivers were at least 18 years old and were identified by patients as their primary source of physical, emotional, and/or financial support. N=235 USA	Quality of life of carer (negative mood and burden as QoL proxies)	Depending on disease statuses, patients were receiving standard care including curative or palliative treatment.
Clark 2006[54]	Patient support: Eight 90 minute sessions over 3 weeks. Participants received a manual containing written materials covered in each of the 8 sessions for review. Structured sessions began with 20 minutes of conditioning exercises conducted by a physical therapist, followed by educational information, cognitive-behavioural strategies for coping,	Carers of advanced cancer patients scheduled to undergo radiotherapy. Patients selected for a parent study due to low	Quality of life of carer (QoL, plus burden as QoL proxy)	Patient intervention with a focus on carer QOL/carer burden

Study	Intervention and comparison	Population	Outcomes	Comments
	discussion and support. Each session concluded with a 10-20 minute guided relaxation exercise. Usual care: Control group received standard medical care as recommended by their radiation oncologist.	probability of long term survival. N=103 USA		
Dionne-Odom 2015[72] Dionne-Odom 2016[71]	Psychological support (early): ENABLE - 3 once per week structured one-on-one telephone sessions between an advanced-practice palliative care nurse coach and caregiver guided by the 'Charting Your Course: Caregiver' guidebook addressing the CG role, problem-solving using the COPE framework, self-care, building a support team, decision-making and advance care planning, nurses followed up at least monthly by telephone until the patient died or study ended. Usual care/psychological support (delayed): Caregivers were able to access any of the usual support services available for the first 3 months. Received ENABLE intervention thereafter	Newly diagnosed patients with recurrence or progression of an advanced stage cancer, determined prognosis of 6-24 months. N=122 USA	Quality of life of carer (QoL, plus depression, burden and grief as QoL proxies)	Dionne-Odom 2015 compared ENABLE to usual care. Dionne-Odom 2016 compared early intervention of ENABLE to delayed intervention of ENABLE. Same population in both studies.
DuBenske 2014[81]	Carer support – CHESS: CHESS arm received password-protected access to the CHESS Coping with Lung Cancer website. CHESS was designed to be easy to use and: 1) to provide well organized lung cancer, caregiving, and bereavement information; 2) to serve as a channel for communication with and support from peers, experts, clinicians, and users' social networks; 3) to act as a coach by gathering information from users and providing feedback based on algorithms (decision rules); and 4) to provide tools (eg, a program to organize support from family and friends) to improve the caregiving experience. CHESS included a clinician report that summarized caregiver and patient ratings of the patient's health status15 and listed their questions for the next clinic visit.	Adults with non-small cell lung cancer at stage IIIA, IIIB, or IV with a clinician-perceived life expectancy of at least 4 months and a patient-identified primary caregiver willing to participate in the study. Caregiver provided instrumental, emotional, and/or financial support for the patient and were aged >18 years.	Quality of life of carer (negative mood and burden as QoL proxies)	Depending on disease statuses, patients were receiving standard care including curative or palliative treatment.

Study	Intervention and comparison	Population	Outcomes	Comments
	Clinicians received email alerts before a scheduled visit and whenever a symptom rating exceeded 7 on a scale from 0 to 10. Usual care – internet: training on using the Internet and a list of Internet sites about lung cancer (for example, www.lungcanceralliance.org, http://cancernet.nci.nih.gov/cancertopics/types/lung, and www.lungcanceronline.org; all accessed August 1, 2008).	N=285 USA		
Hudson 2005[141]	Psycho-education: Nurse provision of information to enhance understanding of issues and provide a basis for skill acquisition, reinforcement of the role of the palliative care service, and providing strategies to involve family and friends, promoting caregivers to enhance their own physical and mental health and providing advice on relaxation strategies and providing advice on their rights. Usual care: Standard care from the community home based palliative care service. Included 24 hour phone advice with, if needed, emergency visits from a nurse, in addition to prescheduled home visits from nurses, social workers, medical consultants, pastoral care workers, volunteers and bereavement counsellors.	Primary family caregivers of patients with advanced cancer receiving home-based palliative care. N=106 USA	Quality of life of carer (anxiety as QoL proxy)	
Hudson 2013[139] Hudson 2015[140]	Psycho-education: Logical tailored information and resources given to family caregivers to promote psychological well-being by preparing them for their role. Each caregiver was allocated a Family Caregiver Support Nurse (FCSN) who assisted the local palliative care service to assess caregiver needs, establish a care plan and provide additional caregiver support. The intervention was delivered in 4 sessions over 4 weeks. 1 face-to-face session + 3 phone calls: n=57 2 face-to-face sessions + 2 phone calls: n=93	Primary family caregivers of patients with advanced cancer receiving home-based palliative care. N=298 Australia	Quality of life of carer (general health questionnaire as QoL proxy)	Caregivers of patients with a non-malignant diagnosis or a poor functional status indicating likelihood of imminent death were excluded in order to reduce attrition

Study	Intervention and comparison	Population	Outcomes	Comments
	Usual care: Multidisciplinary specialist support for patients with advanced, non-curative disease and their families. Services included an initial assessment, scheduled home visits and access to a health care professional after hours for advice. Specific caregiver support strategies varied within services and were not always systematic or comprehensive.			
Keefe 2005[160]	Carer education: Partner-guided cancer pain management. Nurse educator conducted sessions with the patient and partner on coping with pain, including types of pain, treatment including relaxation training and imagery and activity pacing method, and communication with health providers. The intervention was supported by a videotape and book. Three face-to-face home sessions of 45 to 60 minutes over one to two weeks. Usual care: Patients received usual care through their medical outpatient or hospice programme.	Advanced (defined as metastatic or disseminated disease) cancer patients with disease-related pain. Life expectancy of less than six months, and had no change in planned treatment. N=78 USA	Quality of life of person in last year of life	
Kissane 2006[164]	Family-Focused Grief Therapy (FFGT): Exploring family cohesion, communication of thoughts and feelings, and handling of conflict. In the process it was envisaged that the personal story of the illness and related grief would be shared. Started during palliative care and continued into bereavement. Comprised of 4 to 8 sessions of 90 minutes duration, across 9 to 18 months. N=53 patients, 180 family members Usual care: Standard care, counselling was included where needed. N=28 patients, 102 family members	Cancer patients given a prognosis of six months by treating physician, who had a living partner and one or more children more than 12 years old. N=363 (81 families) Australia	Quality of life of carer (depression as QoL proxy)	

Study	Intervention and comparison	Population	Outcomes	Comments
Kissane 2016[165]	Family-Focused Grief Therapy: Families tell the story of illness. Therapists explore each family's communication, cohesiveness, and conflict resolution alongside family values, beliefs, roles, and expectations. 10 sessions. 10 sessions Family-Focused Grief Therapy: 6 sessions Usual care: Usual care, no more information	Patients with advanced cancer with a survival prognosis of less than 1 year (on the basis of judgment of the treating oncologist) and their relatives. N=620 USA	Quality of life of carer (depression and grief as QoL proxies)	
Leow 2015[174]	Care plan: One hour face-to-face session within 1 week during which caregivers watched a video clip about issues faced such as stress and ways to manage it and developed a care plan, 2 follow-up phone calls at weeks 3 and 6 during which care plans were reviewed and nurses provided support and an online social support group Usual care: Routine care from home hospice organizations including regular weekly-monthly visits from a home hospice nurse and psychosocial support such as counselling if required.	Family caregiver of a person with advanced (stage 4) cancer receiving home hospice care that has a prognosis of at least 3 months based on the estimation of the primary physician, spend at least 20 hours a week with the patient. N=80 Singapore	Quality of life of carer (QoL, plus depression and anxiety as QoL proxy); Carer satisfaction	
McLean 2013[184]	Combined care: 8 one-hour weekly emotionally focused therapy sessions adapted for couples where one partner has metastatic cancer. Usual care: Standard care provided by the psychological oncology and palliative care department (social work consultations account for two thirds of the psychosocial care, of the remainder referred to psychiatry or psychology, theoretical orientation depends on the individual clinician), patients and their partners may be followed weekly, biweekly, or monthly until end of life.	Metastatic end-stage cancer patients, in a romantic partnership for at least 1 year, endorsing marital distress in minimally one partner, not currently in couple therapy, Karnofsky Performance Status score of at least 60 N=42	Quality of life of person in their last year of life (depression and hopelessness as QoL proxies); Quality of life of carer (depression, hopelessness and burden as QoL proxies)	

Study	Intervention and comparison	Population	Outcomes	Comments
		Canada		
McMillan 2006[188]	Carer respite: Supportive visits from the intervention nurse and home health aide - individual support to carers, discussing their feelings, fears and relationships with their patients, no management advice given, home health aide provided respite for the caregiver by remaining with the patient during the visits. Education: Caregivers taught the COPE (creativity, optimism, planning, expert information) problem solving method by the intervention nurse to assist them with assessing and managing patient symptoms, respite provided by a home health aide. Usual care: Standard hospice care.	Caregivers providing care for adult patients with advanced cancer, both consenting to participate, minimum score of 7 on the Short Portable Mental Status Questionnaire N=228 USA	Quality of life of carer (QoL, plus burden as QoL proxy)	
Onyechi 2016[208]	Combined care: REHCT (rational emotive hospice care therapy) - manual based on a cognitive behavioural approach including a 7-step decision making process, 10 45 minute sessions anchored on treatment strategies including cognitive restructuring, confrontation, therapeutic alliance and acceptance for patients and caregivers. Usual care: No carer support.	Terminal stage of breast, cervical, or prostate cancers, finished cancer treatment and not receiving other therapeutic treatment, having a family caregiver who is a very close relative, family caregivers available throughout the program, scores within benchmark values for problematic assumptions, death anxiety, and psychological distress. N=84	Quality of life of person in their last year of life (distress and anxiety as QoL proxies); Quality of life of carer (distress and anxiety as QoL proxies)	

Study	Intervention and comparison	Population	Outcomes	Comments
		Nigeria		
Reinhardt 2014[227]	Educational support: A physician and a palliative care social worker utilized a structured, face-to-face meeting with each intervention family member after observing the family member and speaking with the primary care team about his/her condition. The PCT members asked family members what they understood about dementia. The PC physician shared the assessment of the resident's condition, and the PCT discussed the family's goals of care for the resident, made recommendations of how to achieve those goals, such as putting advance directives in place and provided psychosocial support. Finally, the PCT provided family members with information about the risks and benefits of potential treatments that can be used in advance of the need to make decisions in a face-to-face meeting at the facility. The palliative care social worker contacted family members every 2 months via telephone to ascertain the family member's level of emotional comfort. Usual care: Received “routine care” provided to persons with dementia in this particular nursing home. Nonspecific social telephone contact was included in the comparison condition at baseline and 2-month intervals.	Family members of current residents with advanced dementia. Eligibility criteria for these nursing home residents included dementia diagnosis, advanced dementia (cognitive performance scale score = 4, 5, 6), English or Spanish speaking, and not currently receiving hospice care (end-of-life care options would have been reviewed). N=87 USA	Quality of life of carer (distress as QoL proxy); Carer satisfaction	
Walsh 2007[275]	Carer support: Needs assessment was conducted, and information and emotional support provided. Topics covered at each session were patient care, caregiver physical health needs, need for time away from the patient in the short-term and longer term, need to plan for the future, psychological health, relationships and social networks, contact with health and social services providers and their personal finance.	People providing informal care to newly referred patients in participating specialist palliative care teams. N=271 UK	Quality of life of carer	Median time to death from baseline: 12 weeks; range: 1-40 weeks.

Study	Intervention and comparison	Population	Outcomes	Comments
	Usual care: Specialist palliative care provided by a team of clinical nurse specialists who had specialist medical support. It also sometimes involved social work support. Patients were assisted with control of pain and other physical symptoms as well as with social, psychological, emotional and spiritual issues.			

See Appendix F for full GRADE tables.

Table 3: Clinical evidence summary:RSV compared to Telephone emotional support for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Telephone emotional support	Risk difference with RSV (95% CI)
QoL: Depression (CESD) Scale from: 0 to 60.	28 (1 study) 20 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: depression (CESD) in the control groups was 13.5	The mean QoL: depression (CESD) in the intervention groups was 4.9 higher (2.72 lower to 12.52 higher)
Carer QoL: Depression (CESD) Scale from: 0 to 60.	28 (1 study) 20 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: depression (CESD) in the control groups was 8.17	The mean carer QoL: depression (CESD) in the intervention groups was 6.73 higher (2.14 lower to 15.6 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 4: Clinical evidence summary: Tailored support compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Tailored support (95% CI)
QoL: Depression (PROMIS) Scale from: 6 to 30.	39 (1 study) 8 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: depression (PROMIS) in the control groups was 16	The mean QoL: depression (PROMIS) in the intervention groups was 4.35 lower (7.4 to 1.3 lower)
QoL: Anxiety (PROMIS) Scale from: 6 to 30.	39 (1 study) 8 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: anxiety (PROMIS) in the control groups was 14.84	The mean QoL: anxiety (PROMIS) in the intervention groups was 2.49 lower (5.46 lower to 0.48 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Tailored support (95% CI)
Carer QoL: Depression (PROMIS) Scale from: 6 to 30.	39 (1 study) 8 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: depression (PROMIS) in the control groups was 16.53	The mean carer QoL: depression (PROMIS) in the intervention groups was 5.03 lower (7.86 to 2.2 lower)
Carer QoL: Anxiety (PROMIS) Scale from: 6 to 30.	39 (1 study) 8 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: anxiety (PROMIS) in the control groups was 17.16	The mean carer QoL: anxiety (PROMIS) in the intervention groups was 5.06 lower (7.96 to 2.16 lower)
Carer QoL: Burden (ZBI) Scale from: 0 to 48.	39 (1 study) 8 weeks	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden in the control groups was 28.16	The mean carer QoL: burden in the intervention groups was 3.46 lower (7.11 lower to 0.19 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 5: Clinical evidence summary: Psychosocial support compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychosocial support (95% CI)
Quality of life (MQOL) Scale from: 0 to 10.	25 (1 study) 1 months	⊕⊕⊖⊖ LOW[a] due to risk of bias, imprecision		The mean quality of life (MQOL) in the control groups was 7.7	The mean quality of life (MQOL) in the intervention groups was 0.7 higher (0.52 lower to 1.92 higher)
Quality of life (MQOL) Scale from: 0 to 10.	16 (1 study) 3 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean quality of life (MQOL) in the control groups was 6.6	The mean quality of life (MQOL) in the intervention groups was 0.8 higher (0.6 lower to 2.2 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychosocial support (95% CI)
Quality of life (MQOL) Scale from: 0 to 10.	9 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean quality of life (MQOL) in the control groups was 1.1	The mean quality of life (MQOL) in the intervention groups was 0.9 higher (0.47 lower to 2.27 higher)
QoL: Anxiety (HADS) Scale from: 0 to 21.	25 (1 study) 1 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: anxiety (HADS) in the control groups was 10.1	The mean QoL: anxiety (HADS) in the intervention groups was 3 lower (4.61 to 1.39 lower)
QoL: Anxiety (HADS) Scale from: 0 to 21.	16 (1 study) 3 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: anxiety (HADS) in the control groups was 11	The mean QoL: anxiety (HADS) in the intervention groups was 4.5 lower (8.29 to 0.71 lower)
QoL: Anxiety (HADS)	9 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: anxiety (HADS) in the control groups was 10.6	The mean QoL: anxiety (HADS) in the intervention groups was 2.1 lower (4.54 lower to 0.34 higher)
QoL: Depression (HADS) Scale from: 0 to 21.	25 (1 study) 1 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: depression (HADS) in the control groups was 5.9	The mean QoL: depression (HADS) in the intervention groups was 1.5 lower (3.99 lower to 0.99 higher)
QoL: Depression (HADS) Scale from: 0 to 21.	16 (1 study) 3 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: depression (HADS) in the control groups was 6.7	The mean QoL: depression (HADS) in the intervention groups was 2.9 lower (6.19 lower to 0.39 higher)
QoL: Depression (HADS) Scale from: 0 to 21.	9 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean QoL: depression (HADS) in the control groups was 7.4	The mean QoL: depression (HADS) in the intervention groups was 2.9 lower (6.12 lower to 0.32 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychosocial support (95% CI)
Carer QoL: Burden (ZBI) Scale from: 0 to 88.	25 (1 study) 1 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden (ZBI) in the control groups was 31.6	The mean carer QoL: burden (ZBI) in the intervention groups was 9.6 lower (15.86 to 3.34 lower)
Carer QoL: Burden (ZBI) Scale from: 0 to 88.	16 (1 study) 3 months	⊕⊕⊕⊖ MODERATE[b] due to risk of bias		The mean carer QoL: burden (ZBI) in the control groups was 33.4	The mean carer QoL: burden (ZBI) in the intervention groups was 12.1 lower (18.87 to 5.33 lower)
Carer QoL: burden (ZBI) Scale from: 0 to 88.	9 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden (ZBI) in the control groups was 31.6	The mean carer QoL: burden (ZBI) in the intervention groups was 7.3 lower (16.13 lower to 1.53 higher)

[a] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs
[b] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 6: Clinical evidence summary: CHESS + CR compared to CHESS for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with CHESS	Risk difference with CHESS + CR (95% CI)
Carer QoL: Burden (CBI - physical burden) Scale from: 0 to 4.	119 (1 study) 6 months	⊕⊕⊕⊖ MODERATE[a] due to risk of bias		The mean carer QoL: burden in the control groups was 1.22	The mean carer QoL: burden in the intervention groups was 0 higher (0.24 lower to 0.24 higher)
Carer QoL: Burden (CBI - physical burden) Scale from: 0 to 4.	92 (1 study) 12 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden in the control groups was 1.22	The mean carer QoL: burden in the intervention groups was 0.05 higher (0.2 lower to 0.3 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with CHESS	Risk difference with CHESS + CR (95% CI)
Carer QoL: Negative mood (SV-POMS) Scale from: 0 to 4.	115 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: negative mood in the control groups was 0.88	The mean carer QoL: negative mood in the intervention groups was 0.26 lower (0.45 to 0.07 lower)
Carer QoL: Negative mood (SV-POMS) Scale from: 0 to 4.	90 (1 study) 12 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: negative mood in the control groups was 0.93	The mean carer QoL: negative mood in the intervention groups was 0.32 lower (0.54 to 0.1 lower)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 7: Clinical evidence summary: Patient support compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Patient support (95% CI)
Carer quality of life (LASA) Scale from: 0 to 100.	78 (1 study) 4 weeks	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision		The mean carer quality of life (LASA) in the control groups was 75.9	The mean carer quality of life (LASA) in the intervention groups was 1.5 higher (5.72 lower to 8.72 higher)
Carer quality of life (LASA) Scale from: 0 to 100.	81 (1 study) 8 weeks	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision		The mean carer quality of life (LASA) in the control groups was 76.3	The mean carer quality of life (LASA) in the intervention groups was 1.3 higher (6.72 lower to 9.32 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Patient support (95% CI)
Carer quality of life (LASA) Scale from: 0 to 100.	72 (1 study) 27 weeks	⊕⊕⊖⊖ LOW[a,b,c] due to risk of bias, indirectness, imprecision		The mean carer quality of life (LASA) in the control groups was 78.9	The mean carer quality of life (LASA) in the intervention groups was 6.7 lower (14.67 lower to 1.27 higher)
Carer QoL: Burden (ZBI) Scale from: 0 to 100.	78 (1 study) 4 weeks	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision		The mean carer QoL: burden in the control groups was 76.2	The mean carer QoL: burden in the intervention groups was 0.7 higher (5.14 lower to 6.54 higher)
Carer QoL: Burden (ZBI) Scale from: 0 to 100.	81 (1 study) 8 weeks	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision		The mean carer QoL: burden in the control groups was 75.8	The mean carer QoL: burden in the intervention groups was 0.7 lower (6.39 lower to 4.99 higher)
Carer QoL: Burden (ZBI) Scale from: 0 to 100.	72 (1 study) 27 weeks	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision		The mean carer QoLburden in the control groups was 77.7	The mean carer QoL: burden in the intervention groups was 2.1 lower (8.74 lower to 4.54 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment because the majority of the evidence had indirect population

[c] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 8: Clinical evidence summary: Psychological support compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychological support (95% CI)
Carer quality of life (CQOL-C) Scale from: 0 to 140.	69 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer quality of life (CQOL-CQoL) in the intervention groups was 2 lower (6.51 lower to 2.51 higher)
Carer QoL: Depression (CESD) Scale from: 0 to 60.	69 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: depression (CQOL-C) in the intervention groups was 3.4 lower (6.34 to 0.46 lower)
Carer QoL: Burden (MBCB - objective subscale) Scale from: 6 to 30.	69 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: burden (objective subscale) in the intervention groups was 0.3 higher (1.07 lower to 1.67 higher)
Carer QoL: Burden (MBCB - demand subscale) Scale from: 4 to 20.	69 (1 study) 3 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		Reported as mean difference	The mean carer QoL: burden (demand subscale) in the intervention groups was 0 higher (1.37 lower to 1.37 higher)
Carer QoL: Burden (MBCB - stress subscale) Scale from: 4 to 20.	69 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: burden (stress subscale) in the intervention groups was 0.5 lower (1.48 lower to 0.48 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 9: Clinical evidence summary: Psychological support (early) compared Psychological support (delayed) for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with ENABLE (delayed)	Risk difference with ENABLE (early) (95% CI)
Carer QoL: Depression (CESD) Scale from: 0 to 60.	44 (1 study)	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean change in carer QoL: depression (CESD) in the control groups was 2.6	The mean carer QoL: depression (CESD) in the intervention groups was 0.8 higher (5.58 lower to 7.18 higher)
Carer QoL: Grief (PG13) Scale from: 0 to 52.	44 (1 study)	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: grief (PG13) in the control groups was 24.9	The mean carer QoL: grief (PG13) in the intervention groups was 2.2 lower (5.69 lower to 1.29 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 10: Clinical evidence summary: CHESS compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with CHESS (95% CI)
Carer QoL: Burden (CQOL-C – burden subscale) Scale from: 0 to 40.	122 (1 study) 2 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden in the control groups was 18.91	The mean carer QoL: burden in the intervention groups was 2.76 lower (5.94 lower to 0.42 higher)
Carer QoL: Burden (CQOL-C – burden subscale) Scale from: 0 to 40.	111 (1 study) 4 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden in the control groups was 17.36	The mean carer QoL: burden in the intervention groups was 1.49 lower (4.87 lower to 1.89 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with CHESS (95% CI)
Carer QoL: Burden (CQOL-C – burden subscale) Scale from: 0 to 40.	95 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden in the control groups was 18.03	The mean carer QoL: burden in the intervention groups was 4.89 lower (8.63 to 1.15 lower)
Carer QoL: Burden (CQOL-C – burden subscale) Scale from: 0 to 40.	82 (1 study) 8 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden in the control groups was 17.22	The mean carer QoL: burden in the intervention groups was 0.88 lower (4.6 lower to 2.84 higher)
Carer QoL: Negative mood (SV-POMS) Scale from: 0 to 4.	123 (1 study) 2 months	⊕⊕⊕⊖ MODERATE[a] due to risk of bias		The mean carer QoL: negative mood in the control groups was 0.96	The mean carer QoL: negative mood in the intervention groups was 0.04 lower (0.33 lower to 0.25 higher)
Carer QoL: Negative mood (SV-POMS) Scale from: 0 to 4.	113 (1 study) 4 months	⊕⊕⊕⊖ MODERATE[a] due to risk of bias		The mean carer QoL: negative mood in the control groups was 0.95	The mean carer QoL: negative mood in the intervention groups was 0.07 lower (0.37 lower to 0.23 higher)
Carer QoL: Negative mood (SV-POMS) Scale from: 0 to 4.	97 (1 study) 6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: negative mood in the control groups was 1	The mean carer QoL: negative mood in the intervention groups was 0.35 lower (0.66 to 0.04 lower)
Carer QoL: Negative mood (SV-POMS) Scale from: 0 to 4.	83 (1 study) 8 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: negative mood in the control groups was 0.85	The mean carer QoL: negative mood in the intervention groups was 0.07 higher (0.29 lower to 0.43 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 11: Clinical evidence summary: Psycho-educational intervention compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psycho-educational (95% CI)
Carer QoL: Anxiety (HADS) at 4 weeks post intervention Scale from: 0 to 21.	75 (1 study) 4 weeks	⊕⊝⊝⊝ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: anxiety (HADS) at 4 weeks post intervention in the control groups was 8.06	The mean carer QoL: anxiety (HADS) at 4 weeks post intervention in the intervention groups was 0.3 lower (2.01 lower to 1.41 higher)
Carer QoL: Anxiety (HADS) at 8 weeks post patient death Scale from: 0 to 21.	45 (1 study) 8 weeks	⊕⊝⊝⊝ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: anxiety (HADS) at 8 weeks post patient death in the control groups was 6.76	The mean carer QoL: anxiety (HADS) at 8 weeks post patient death in the intervention groups was 0.2 higher (2.09 lower to 2.49 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 12: Clinical evidence summary: Psycho-educational: 2 visits compared to Psycho-educational: 1 visit for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Psycho-educational: 1 visit	Risk difference with Psycho-educational: 2 visits (95% CI)
Carer QoL: General Health Questionnaire (GHQ)	80 (1 study) 1 weeks	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer QoL: general health questionnaire (GHQ) in the control groups was 3.56	The mean carer QoL: general health questionnaire (GHQ) in the intervention groups was 0.08 higher (0.46 lower to 0.62 higher)
Carer QoL: General Health Questionnaire (GHQ)	84 (1 study) 26 weeks	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean change in carer QoL: general health questionnaire (GHQ) in the control groups was -0.15	The mean change in carer QoL: general health questionnaire (GHQ) in the intervention groups was 0.32 higher (0.05 lower to 0.69 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Psycho-educational: 1 visit	Risk difference with Psycho-educational: 2 visits (95% CI)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 13: Clinical evidence summary: Psycho-educational: 2 visits compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psycho-educational: 2 visits (95% CI)
Carer QoL: General Health Questionnaire (GHQ)	132 (1 study) 1 weeks	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean carer QoL: general health questionnaire (GHQ) in the control groups was 3.73	The mean carer QoL: general health questionnaire (GHQ) in the intervention groups was 0.09 lower (0.76 lower to 0.58 higher)
Carer QoL: General Health Questionnaire (GHQ)	129 (1 study) 26 weeks	⊕⊕⊕⊖ MODERATE[a] due to risk of bias		The mean change in carer QoL: general health questionnaire (GHQ) in the control groups was 0.28	The mean carer QoL: general health questionnaire (GHQ) in the intervention groups was 0.11 lower (0.39 lower to 0.17 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 14: Clinical evidence summary: Psycho-educational: 1 visit compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psycho-educational: 1 visit (95% CI)
Carer QoL: General Health Questionnaire (GHQ)	110 (1 study) 1 weeks	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean change in carer QoL: general health questionnaire (GHQ) in the control groups was 3.73	The mean carer QoL: general health questionnaire (GHQ) in the intervention groups was 0.17 lower (0.8 lower to 0.46 higher)
Carer QoL: General Health Questionnaire (GHQ)	107 (1 study) 26 weeks	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: general health questionnaire (GHQ) in the control groups was 0.28	The mean carer QoL: general health questionnaire (GHQ) in the intervention groups was 0.43 lower (0.78 to 0.08 lower)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 15: Clinical evidence summary: Pain management education compared to usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Pain management education (95% CI)
Patient QoL: FACT-G - physical Scale from: 0 to 5.	56 (1 study) 6 days	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean patient QoL: FACT-G - QoLphysical in the control groups was 2.08	The mean patient QoL: FACT-G QoL-physical in the intervention groups was 0.06 lower (0.45 lower to 0.33 higher)
Patient QoL: FACT-G - social Scale from: 0 to 5.	56 (1 study) 6 days	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean patient QoL: FACT-G QoL- social in the control groups was 3.33	The mean patient QoL: FACT-G QoL-social in the intervention groups was 0.22 higher (0.05 lower to 0.49 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Pain management education (95% CI)
[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias [b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs					

Table 16: Clinical evidence summary: Psychological support: grief therapy compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychological support: Grief Therapy (95% CI)
Carer QoL: Depression (BDI) at 6 months Scale from: 0 to 63.	248 (1 study) 13 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer QoL: depression (BDI) at 6 months in the control groups was 4.21	The mean carer QoL: depression (BDI) at 6 months in the intervention groups was 0.61 lower (1.77 lower to 0.55 higher)
Carer QoL: Depression (BDI) at 13 months Scale from: 0 to 63.	231 (1 study) 13 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer QoL: depression (BDI) at 13 months in the control groups was -0.1	The mean carer QoL: depression (BDI) at 13 months in the intervention groups was 0.26 lower (1.44 lower to 0.92 higher)
[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias					

Table 17: Clinical evidence summary: Psychological support: 10 sessions versus Psychological support: 6 sessions for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Psychological support: 6 sessions	Risk difference with Psychological support: 10 sessions (95% CI)
Carer QoL: Depression (BDI-II) Scale from: 0 to 63.	243 (1 study) 6 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean Carer QoL: Depression (BDI-II)QoL in the control groups was 10.71	The mean Carer QoL: Depression (BDI-II) QoLin the intervention groups was 0.87 lower (2.93 lower to 1.19 higher)
Carer QoL: Depression (BDI-II) Scale from: 0 to 63.	288 (1 study) 13 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer Carer QoL: Depression (BDI-II)QoLin the control groups was 10.69	The mean Carer QoL: Depression (BDI-II)QoL in the intervention groups was 2.24 lower (4.28 to 0.2 lower)
Carer QoL: Grief (CGI) Scale from: 0 to 52.	243 (1 study) 6 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean Carer QoL: Grief (CGI)QoL in the control groups was 20.14	The mean Carer QoL: Grief (CGI)QoL in the intervention groups was 0.62 lower (2.52 lower to 1.28 higher)
Carer QoL: Grief (CGI) Scale from: 0 to 52.	288 (1 study) 13 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean Carer QoL: Grief (CGI)QoL in the control groups was 19.85	The mean Carer QoL: Grief (CGI)QoL in the intervention groups was 1.59 lower (3.21 lower to 0.03 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 18: Clinical evidence summary: Psychological support: 10 sessions versus Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychological support: 10 sessions (95% CI)
Carer QoL: Depression (BDI-II) Scale from: 0 to 63.	203 (1 study) 6 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer Carer QoL: Depression (BDI-II)QoL in the control groups was 11.83	The mean Carer QoL: Depression (BDI-II)QoL in the intervention groups was 1.99 lower (4.73 lower to 0.75 higher)

Carer QoL: Depression (BDI-II) Scale from: 0 to 63.	245 (1 study) 13 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean Carer QoL: Depression (BDI-II)QoL in the control groups was 9.93	The mean Carer QoL: Depression (BDI-II)QoL in the intervention groups was 1.48 lower (3.75 lower to 0.79 higher)
Carer QoL: Grief (CGI) Scale from: 0 to 52.	203 (1 study) 6 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean Carer QoL: Grief (CGI) QoL in the control groups was 20.72	The mean Carer QoL: Grief (CGI) QoL in the intervention groups was 1.2 lower (3.37 lower to 0.97 higher)
Carer QoL: Grief (CGI) Scale from: 0 to 52.	245 (1 study) 13 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean Carer QoL: Grief (CGI) QoL in the control groups was 19.02	The mean Carer QoL: Grief (CGI) QoL in the intervention groups was 0.76 lower (2.69 lower to 1.17 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 19: Clinical evidence summary: Psychological support: 6 sessions versus Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychological support: 6 sessions (95% CI)
Carer QoL: Depression (BDI-II) Scale from: 0 to 63.	202 (1 study) 6 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean Carer QoL: Depression (BDI-II)QoL in the control groups was 11.83	The mean Carer QoL: Depression (BDI-II)QoL in the intervention groups was 1.12 lower (3.72 lower to 1.48 higher)
Carer QoL: Depression (BDI-II)	245 (1 study) 13 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean Carer QoL: Depression (BDI-II)QoL in the control groups was 9.93	The mean Carer QoL: Depression (BDI-II)QoL in the intervention groups was 0.76 higher (1.62 lower to 3.14 higher)
Carer QoL: Grief (CGI) Scale from: 0 to 52.	202 (1 study) 6 months	⊕⊕⊖⊖ LOW[a] due to risk of bias		The mean Carer QoL: Grief (CGI) QoL in the control groups was 20.72	The mean Carer QoL: Grief (CGI) QoL in the intervention groups was 0.58 lower (2.7 lower to 1.54 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Psychological support: 6 sessions (95% CI)
Carer QoL: Grief (CGI) Scale from: 0 to 52.	245 (1 study) 13 months	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean Carer QoL: Grief (CGI) QoL in the control groups was 19.02	The mean Carer QoL: Grief (CGI) QoL in the intervention groups was 0.83 higher (1.1 lower to 2.76 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 20: Clinical evidence summary: Care plan versus Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Care plan (95% CI)
Carer quality of life (CQOL-C) Scale from: 0 to 140.	80 (1 study) 8 weeks	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer quality of life (CQOL-CQoL) in the control groups was 84.43	The mean carer quality of life (CQOL-CQoL) in the intervention groups was 21.23 higher (12.48 to 29.98 higher)
Carer QoL: Depression anxiety stress scales (DASS)	80 (1 study) 8 weeks	⊕⊝⊝⊝ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoLQoL: depression anxiety stress scales in the control groups was 8.86	The mean carer QoLQoL: depression anxiety stress scales in the intervention groups was 5.7 lower (8.84 to 2.56 lower)
Carer satisfaction (social support)	80 (1 study) 8 weeks	⊕⊕⊝⊝ LOW[a] due to risk of bias		The mean carer satisfaction (social support) in the control groups was 28.98	The mean carer satisfaction (social support) in the intervention groups was 5.44 higher (3.41 to 7.47 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 21: Clinical evidence summary: Emotional therapy versus Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Emotional therapy (95% CI)
QoL: Depression (BDI-II) Scale from: 0 to 63.	36 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		The mean QoL: depression (BDI-II) in the control groups was 14.33	The mean QoL: depression (BDI-II) in the intervention groups was 1.56 higher (5.83 lower to 8.95 higher)
QoL: Hopelessness (BHS) Scale from: 0 to 20.	36 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		The mean QoL: hopelessness (BHS) in the control groups was 5.78	The mean QoL: hopelessness (BHS) in the intervention groups was 1.17 higher (2.69 lower to 5.03 higher)
Carer QoL: Depression (BDI-II) Scale from: 0 to 63.	36 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: depression (BDI-II) in the control groups was 9.67	The mean carer QoL: depression (BDI-II) in the intervention groups was 3.66 higher (1.38 lower to 8.7 higher)
Carer QoL: Hopelessness (BHS) Scale from: 0 to 20.	36 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: hopelessness (BHS) in the control groups was 5.39	The mean carer QoL: hopelessness (BHS) in the intervention groups was 1.55 higher (1.53 lower to 4.63 higher)
Carer QoL: Burden (CBS - time subscale) Scale from: 1 to 70.	36 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden (time subscale) in the control groups was 2.7	The mean carer QoL: burden (time subscale) in the intervention groups was 0.12 lower (0.94 lower to 0.7 higher)
Carer QoL: Burden (CBS - difficulty subscale) Scale from: 1 to 70.	36 (1 study) 3 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: burden (difficulty subscale) in the control groups was 1.98	The mean carer QoL: burden (difficulty subscale) in the intervention groups was 0.14 lower (0.77 lower to 0.49 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Emotional therapy (95% CI)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 22: Clinical evidence summary: Carer respite compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Carer respite (95% CI)
Carer quality of life (CQOL-C)	72 (1 study) 30 days	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer quality of life (CQOL-CQoL) in the intervention groups was 0.06 lower (0.24 lower to 0.12 higher)
Carer QoL: Burden (MSAS - patient symptoms)	72 (1 study) 30 days	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: burden (patient symptoms) in the intervention groups was 0.13 higher (0.03 lower to 0.29 higher)
Carer QoL: Burden (MSAS - task)	72 (1 study) 30 days	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: burden (task) in the intervention groups was 0.01 higher (0.01 lower to 0.03 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 23: Clinical evidence summary: Carer education compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Education (95% CI)
Carer quality of life (CQOL-C)	71 (1 study) 30 days	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer quality of life (CQOL-CQoL) in the intervention groups was 0.1 higher (0 to 0.19 higher)
Carer QoL: Burden (MSAS - patient symptoms)	71 (1 study) 30 days	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: burden (patient symptoms) in the intervention groups was 0.14 lower (0.22 to 0.06 lower)
Carer QoL: Burden (MSAS - task)	71 (1 study) 30 days	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		Reported as mean difference	The mean carer QoL: burden (task) in the intervention groups was 0.02 higher (0 to 0.04 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 24: Clinical evidence summary: Combined care compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Combined care (95% CI)
QoL: Death anxiety (DAQ) Scale from: 15 to 75.	32 (1 study) 4 weeks	⊕⊕⊕⊝ MODERATE[a] due to risk of bias		The mean QoL: death anxiety in the control groups was 74.56	The mean QoL: death anxiety in the intervention groups was 56.56 lower (57.57 to 55.55 lower)
QoL: Distress (K10) Scale from: 10 to 50.	32 (1 study) 4 weeks	⊕⊕⊕⊝ MODERATE[a]		The mean QoL: distress (K10) in the control groups was 49.44	The mean QoL: distress (K10) in the intervention groups was 35.06 lower (36.38 to 33.74 lower)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Combined care (95% CI)
		due to risk of bias			
Carer QoL: Death anxiety (DAQ) Scale from: 15 to 75.	52 (1 study) 4 weeks	⊕⊕⊕⊝ MODERATE[a] due to risk of bias		The mean carer QoL: death anxiety in the control groups was 74.65	The mean carer QoL: death anxiety in the intervention groups was 56.53 lower (57.36 to 55.7 lower)
QoL: Distress (K10) Scale from: 10 to 50.	52 (1 study) 4 weeks	⊕⊕⊕⊝ MODERATE[a] due to risk of bias		The mean QoL: distress (K10) in the control groups was 49.81	The mean QoL: distress (K10) in the intervention groups was 36.31 lower (37.42 to 35.2 lower)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 25: Clinical evidence summary: Education compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Education (95% CI)
Carer QoL: Depression (PHQ-9) Scale from: 0 to 27.	86 (1 study) 3 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: depression in the control groups was 3.3	The mean carer QoL: depression in the intervention groups was 0.7 higher (0.88 lower to 2.28 higher)
Carer QoL: Depression (PHQ-9) Scale from: 0 to 27.	86 (1 study) 6 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer QoL: depression in the control groups was 4.5	The mean carer QoL: depression in the intervention groups was 0.7 lower (2.44 lower to 1.04 higher)
Carer satisfaction (SWLS) Scale from: 5 to 25.	81 (1 study) 3 months	⊕⊕⊝⊝ LOW[a,b]		The mean carer satisfaction (life) in the control groups was 19.4	The mean carer satisfaction (life) in the intervention groups was 0.9 lower (3.26 lower to 1.46 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Education (95% CI)
		due to risk of bias, imprecision			
Carer satisfaction (SWLS) Scale from: 5 to 25.	81 (1 study) 6 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean carer satisfaction (life) in the control groups was 18.5	The mean carer satisfaction (life) in the intervention groups was 0.6 lower (3.12 lower to 1.92 higher)
Satisfaction (SWC-EOLD) Scale from: 0 to 42.	81 (1 study) 3 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean satisfaction (care) in the control groups was 30.6	The mean satisfaction (care) in the intervention groups was 0.4 lower (3.2 lower to 2.4 higher)
Satisfaction (SWC-EOLD) Scale from: 0 to 42.	81 (1 study) 6 months	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean satisfaction (care) in the control groups was 28	The mean satisfaction (care) in the intervention groups was 2.6 higher (1.2 lower to 6.4 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 26: Clinical evidence summary: Needs assessment compared to Usual care for palliative care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Needs assessment (95% CI)
Quality of life (CQOL-C) Scale from: 0 to 140.	116 (1 study) 12 weeks	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean quality of life (CQOL-CQoL) in the control groups was 62.2	The mean quality of life (CQOL-CQoL) in the intervention groups was 3 higher (4.5 lower to 10.5 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Needs assessment (95% CI)
QoL: General Health Questionnaire (GHQ) Scale from: 0 to 36.	123 (1 study) 12 weeks	⊕⊕⊝⊝ LOW[a,b] due to risk of bias, imprecision		The mean QoL: general health questionnaire (GHQ) in the control groups was 11.7	The mean QoL: general health questionnaire (GHQ) in the intervention groups was 0.4 lower (3.1 lower to 2.3 higher)

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

1.5 Economic evidence

1.5.1 Included studies

Published literature

One health economic studies was identified with the relevant comparison and have been included in this review.[218] This is summarised in the health economic evidence profile below (Table 27) and the health economic evidence table in Appendix F.

1.5.2 Excluded studies

No health economic studies that were relevant to this question were excluded due to assessment of limited applicability or methodological limitations.

See also the health economic study selection flow chart in Appendix G.

1.5.3 Summary of studies included in the economic evidence review

Table 27: Health economic evidence profile: Carer support services versus no carer support services

Study	Applicability	Limitations	Other comments	Incremental cost	Incremental effects	Cost-effectiveness	Uncertainty
Pham 2014 [218] (UK)	Partially Applicable[(a)]	Very Serious Limitations[(b)]	Economic Analysis: CUA Study design: Probabilistic decision analytic Markov model (microsimulation) Interventions: PCPDs: Improving Family conferences for relatives of patients dying in the ICU Multicomponent psycho-educational interventions for patients and families Supportive interventions	PCPDs: Improving Family conferences for relatives of patients dying in the ICU -usual care: £31 Multicomponent psycho-educational interventions for patients and families -usual care: £2,668 Supportive interventions for Informal caregivers -usual care: £110	PCPDs: Improving Family conferences for relatives of patients dying in the ICU - usual care: 0.49 quality-adjusted life days Multicomponent psycho-educational interventions for patients and families - usual care: 3.63 quality-adjusted life days Supportive interventions for; Informal caregivers - usual care: 0.82 quality-	PCPDs: Improving Family conferences for relatives of patients dying in the ICU versus usual care: £23,092.97 per QALY gained Multicomponent psycho-educational interventions for patients and families versus usual care: £268,270.12 per QALY gained Supportive interventions for Informal caregivers versus usual care: £48,965.06 per QALY gained	Probabilistic and one-way sensitivity analyses conducted to explore key sources of variability and uncertainty in the simulated model. The sensitivity analysis found that the results for PCPDs: Improving Family conferences for relatives of patients dying in the ICU versus usual care, Multicomponent psycho-educational interventions for patients and families versus usual care and for Supportive interventions for Informal caregivers versus usual care were uncertain and might change with additional data.

Study	Applicability	Limitations	Other comments	Incremental cost	Incremental effects	Cost-effectiveness	Uncertainty
			for; Informal caregivers (Please see Table 56 for full details of the interventions) The model compared multiple interventions but only the above three interventions were considered relevant for this review question.		adjusted life days		

Abbreviations: ICER: incremental cost-effectiveness ratio; ICU: intensive care unit; QALY: quality-adjusted life years; RCT: randomised controlled trial; PCPDS: Patient care planning decisions

(a) Not a UK study therefore study population and costs not directly applicable.

(b) Model assumes that last year of life is known which does not reflect reality. Model assumes that interventions do not affect survival time which does not reflect reality. Model assumes that a palliative prognosis can be determined by resource use of patients therefore doesn't account for patients with a terminal illness who do not receive EOL care services in the last year of life, it is not clear how this effects the cost effectiveness results. Cost effectiveness results for in-home palliative care are subject to EOL care in the control group of the RCT study used as evidence of the estimated outcome being the same as the usual care strategy; this is unlikely to be true. The model does not explicitly take into account that some of the interventions are currently provided as part of usual care therefore it is likely that the treatment effects are overestimated. Estimating the intervention effect on HRQOL as well as decrements in QALY weights through downstream resource use risks the possibility of double counting.

1.5.4 Unit costs

The following costs are illustrative examples of some of the types of resources use costs that might be required for carer support services.

Table 28: Illustrative costs of carer support services

Carer support service	Resource Use	Unit Costs
Phone call (social worker)	30 minutes of social worker time	£28 per call
Phone call (nurse)	30 minutes of nurse time	£11-£61 per call[(a)]
Face-to-face visit (social worker)	1.5 hours of nurse time	£83 per visit
Face-to-face visit (nurse)	1.5 hours of social worker time	£33-£183 per visit[(a)]
Individual therapy session		£98 per session
Group therapy session		£173 per session £14 per service user per session

Source of costs: Curtis 2016 [61]

(a) Dependent on Band of nurse

1.6 Resource costs

Recommendations made based on this review (see section **Error! Reference source not found.**) are not expected to have a substantial impact on resources.

1.7 Evidence statements

1.7.1 Clinical evidence statements

Emotional/psychological support for carers (8 studies)

A single study reported patient quality of life at different time points in groups receiving psychosocial support or usual care. Results showed no difference between groups at 1 month, but a benefit of carer support at 3 and 6 months compared to usual care (n=25-9; low quality).

Four studies reported patient depression. One study found telephone emotional support for carers to be clinically beneficial compared to home visits conducted by retired senior volunteer (n=28; low quality), while another study found a benefit of telephone counselling compared to usual care (n=39; low quality). One study reported a clinical benefit of psychosocial support compared to usual care at 3 and 6 months, but not a 1 month (n=25-9; low quality). A fourth study found no difference in patient reported depression between groups receiving emotional therapy or usual care (n=36; very low quality).

Three studies reported patient anxiety. A study found a clinical benefit of telephone counselling compared to usual care (n=39; low quality). One study reported a clinical benefit of psychosocial support compared to usual care (n=25-9; low quality). Another study reported a benefit of emotional therapy compared to usual care (n=32; moderate quality evidence).

One study reported patient hopelessness and found no difference between groups receiving emotional therapy or usual care (n=36; very low quality).

One study reported a clinical benefit of patient distress with emotional therapy compared to usual care (n=32; moderate quality evidence)

Carer quality of life was reported by one study comparing interventions of carer psychological support to usual care. Results showed no clinically significant difference between groups (n=69; very low quality).

Seven studies reported carer depression. One study found telephone emotional support for carers to be clinically beneficial compared to home visits conducted by retired senior volunteer (n=28; low quality), while another study found a benefit of telephone counselling compared to usual care (n=39; low quality). Another study found no difference in patient reported depression between groups receiving emotional therapy or usual care (n=36; very low quality). Three studies compared varying forms of psychological support to for carers to usual care, all found no difference between groups (n=69; very low quality, n=231-248; low quality, n=243-288; low quality, respectively). One study compared early intervention of psychological support to delayed support and found no clinically significant difference between groups (n=44; low quality).

Two studies reported carer anxiety. One study reported a benefit of telephone counselling compared to usual care (n=39; low quality). A second study found a clinical benefit of emotional therapy compared to usual care (n=32; moderate quality evidence).

One study reported carer hopelessness and found no difference between groups receiving emotional therapy or usual care (n=36; very low quality).

A single study found a clinical benefit for carer distress with emotional therapy compared to usual care (n=32; moderate quality evidence)

Four studies reported carer burden. One study reported a benefit of telephone counselling compared to usual care (n=39; low quality). One study reported a clinical benefit of psychosocial support compared to usual care (n=25-9; low quality). A third study comparing interventions of carer psychological support to usual care showed no clinically significant difference between groups (n=69; very low quality). A final study found no difference in carer burden between groups receiving emotional therapy or usual care (n=36; very low quality).

Two studies reported carer grief. One compared psychological support to usual care and found no clinically important difference between groups (n=243-288; low quality). Another compared early intervention of psychological support to delayed support and found no clinically significant difference between groups (n=44; low quality).

Care plans/information services for carers (5 studies)

Carer quality of life was reported by two studies. One found a clinically important benefit of a care plan intervention compared to usual care (n=80; low quality). Another found a no difference between a group receiving a needs assessment and information packed to a group receiving usual care (n=116; low quality).

Two studies reported carer depression and anxiety. One study reported a clinically important benefit of a care plan intervention compared to usual care (n=80; low quality). One study found no clinically important difference between a psycho-educational intervention and usual care (n=75-45; low quality).

One study (from two papers) found generally no clinically important difference between a psycho-educational intervention and usual care (n=80-132; low quality). A second reported no difference between a group receiving a needs assessment and information packed to a group receiving usual care (n=116; low quality).

One found a clinically important benefit for carer satisfaction of a care plan intervention compared to usual care (n=80; low quality).

Education services for carers (3 studies)

Two studies reported carer quality of life following carer education. One found a benefit of carer education compared to usual care (n=71; low quality). A second study reported no clinically important difference in physical or social aspects of quality of life between groups receiving pain management education and usual care (n=56; low quality).

One study found no clinically important difference of education compared to usual care for carer burden (n=71; low quality).

Another study reported carer depression, carer satisfaction, and patient satisfaction, comparing an intervention on education to usual care. No clinically important difference was found for any of the outcomes (n=81-86; low quality).

Online services for carers (2 studies)

Two studies reported on the efficacy of an online support system for carers. One compared the online system with and without a clinicians report and found no difference between groups for carer burden or negative mood at 6 months, but found a clinically important benefit with the online support with the clinician report at 12 months (n=90-119; low to moderate quality).Another study compared the online support system to usual care and found no clinically important difference between group for negative mood, and no significant difference in carer burden at 2,4, or 8 months, but a benefit at 6 months (n=82-123; low to moderate quality).

Carer respite services (1 study)

One study compared carer respite to usual care, and reported carer quality of life and carer burden. No clinically important difference was found between groups for either outcome (n=72; low quality).

Patient support compared to usual care (1 study)

One study compared additional patient support to usual care (with the intention to evaluate the effect on the carer), and reported carer quality of life and carer burden. No clinically important difference was found between groups for either outcome (n=78-81; very low to low quality).

1.7.2 Health economic evidence statements

- One cost-utility analysis found that improving family conferences for relatives of patients dying in the ICU versus usual care was not cost-effective at threshold of £20,000 per QALY gained (ICER: £23,092.97 per QALY gained); having multicomponent psycho-educational interventions for patients and families versus usual care was not cost-effective at a threshold of £20,000 per QALY gained (ICER: £268,270.12 per QALY gained) and having supportive interventions for informal caregivers versus usual care was not cost-effective at a threshold of £20,000 per QALY gained (ICER : £48,965.06 per QALY gained). This study was assessed as partially applicable with very serious limitations.

1.8 The committee’s discussion of the evidence

1.8.1 Interpreting the evidence

1.8.1.1 The outcomes that matter most

The Committee identified quality of life, and preferred place of care and death as the critical outcomes for identifying people in their last year of life. The following outcomes were identified as important: length of survival, length of stay, length of survival hospitalisation, number of hospital visits, number of visits to accident and emergency, number of unscheduled admissions, use of community services, avoidable or inappropriate admissions to ICU, inappropriate attempts at cardiopulmonary resuscitation, staff satisfaction, patient or carer reported outcomes and carer health.

See tables 7 and 8 in the Methods chapter for a detailed explanation of why the committee selected these outcomes.

For the critically important outcomes, one study reported quality of life of person in their last year of life. Five studies reported quality of life of the carer of person in their last year of life. Five studies also reported quality of life proxies for the person in their last year of life, such as depression or anxiety, which were an indirect outcome quality of life. Sixteen (all) studies reported quality of life proxies for the carer of the person in their last year of life. None of the studies reported actual and preferred place of care or place of death, or longevity of carer. For the important outcomes, two studies reported the carer satisfaction.

1.8.1.2 The quality of the evidence

The quality of evidence ranged from very low to low. This was due to selection and performance bias, resulting in a high risk of bias rating, and imprecision. Indirectness in some interventions and outcomes (for example, an intervention for patients, with an observation on carer outcome) further contributed to the final GRADE rating.

All evidence was obtained from randomised controlled trial studies. As sufficient evidence was identified from studies of an RCT design, observational studies were not included in the analysis.

1.8.1.3 Benefits and harms

The Committee acknowledged the potential for services such as psychological support, information services, education services, online support, respite services, and additional patient care to support and benefit both people in their last year of life and their carers.

The Committee noted the evidence supporting a potential positive effect of supportive interventions on both patient and carer quality of life, with improvements also seen in quality of life proxies such as depression and depression, and reduced carer burden. However, given the inconclusive findings from a number of studies and the heterogeneity of interventions, the Committee were unable to recommend any single carer support service.

The Committee highlighted the variability of interventions, even those offering similar services, such as emotional or psychological support. The Committee agreed this echoed the demand for a range of services to be available to carers, with individualised tailored support offered to carers in accordance to their needs. To achieve this, the Committee wanted to raise awareness of a carer needs assessment and that it should be provided in line with legal care act. No evidence on the specific needs of any of the subgroups listed in the protocol was identified and the committee were unable to confidently recommend any particular service for any one group. The Committee agreed that in their experience carer needs will vary significantly; those of a young carer will be notably different to those of an elderly carer. The committee discussed the importance of individualising the support a carer receives agreeing that if support wasn't relevant or appropriate it would be at best ignored or at worse would result in disengagement with services potentially resulting in both the carer and the person in the last year of life not receiving the care they need. The Committee added that a carer's needs may also change as the person in their last year of life's illness progresses, changes and deteriorates.

Overall, the Committee commented that following the identification of people who are entering the last year of life, services should be in place to provide support for the carers involved, respecting the wishes of patients and carers.

1.8.2 Cost effectiveness and resource use

The Department of Health's Impact Assessment on the Care Bill[68] 'makes an estimate of the 'monetised health benefits' of additional support for carers. This estimates that an anticipated extra spend on carers for England of £292.8 million would save councils £429.3 million in replacement care costs and result in “monetised health benefits” of £2,308.8 million. This suggests (as a ratio) that each pound spent on supporting carers would save councils £1.47 on replacement care costs and benefit the wider health system by £7.88'.

An ADASS report published in March 2015[69] estimated that for every £1 invested in carers, there is a potential equivalent reduction in local authority cost of £5.90 (£4.90 net reduction), illustrating the importance in carers and their role in supporting social care. A ECORYS report published in May 2017[280] on the economic case for supporting young carers for Surrey Young Carers estimated that the Surrey Young Carers has potentially avoided the taxpayer spending just under £3 million over the course of one year by avoiding young carers becoming Child in Need status. Compared to the costs of delivery of Surrey Young carers in 2015/16 this leaves a return on investment of almost £3 for every £1 spent on the service.

The studies identified in the review on carer support included a wide variety of different types of carer support service models. The support models ranged in the type of support offered (for example, emotional, psychological, educational, respite); in the healthcare professional/s responsible for providing or coordinating the support (for example, palliative care nurse, social worker, family caregiver support nurse, physician); how the support was delivered (for example, over the phone, face-to-face) and the frequency and length of the support sessions provided. All of these factors will affect the cost of offering carer support. There is likely to be a positive correlation between the cost of providing the support services for carers and impact the services have on the quality of life of the carers and the patients although this is just an assumption. For example, face to face sessions may cost more to provide than telephone sessions, but they might also be more effective and therefore considered to be worth the additional investment.

The committee agreed that there was not enough information in the studies regarding what the support to carers involved to be able to estimate how much they were likely to cost. For this reason it was not possible to include any unit costs relevant for this question to aid the committee’s consideration of cost-effectiveness.

The committee highlighted that the majority of the studies in the review were evaluating emotional or psychological support services, but that providing carers with practical support on how to care (for example, moving and handling, pain management, financial advice) were equally as important. The committee felt offering this type of support could also lead to downstream cost savings, for example empowering carers to be able to deal with emergency situations could in turn mitigate the need for some patients to be admitted to hospital.

The committee discussed the issue of the identification of carers. Currently the system is failing to identify the majority of people who are caring for someone that is in their last year of life. Therefore even if carer support was provided, the people who would benefit are not identified as being carers and therefore would not have access to the services. The committee came up with a low cost solution to the identification issue - to add a carer section to the forms filled out at the point of the patient’s holistic needs assessment and assessment reviews (for example, a section on the EPaCCS form). The committee then highlighted that once carers are identified, they should then be given a carer assessment to establish their needs and what services they should be offered. Although offering all identified carers referral to a carer assessment would have a significant resource impact (to the local authorities who are responsible for providing carer assessments), the committee stressed that carers are legally entitled to have a carer assessment. There is currently wide scale variation in how carer assessments are performed. They are often provided by the local authority and carried out by social workers but that does not mean that it should not be the responsibility of the health service to refer carers for an assessment. The committee felt that currently the health service is failing to acknowledge the responsibility they have to support carers of people in the last year of life.

The one economic evaluation that was identified (that estimated that the incremental cost effectiveness ratios (ICERs) of the carer support services: having family conferences for relatives of patients dying on the ICU, having multicomponent psycho-educational interventions for patients and families and supportive interventions for informal caregivers of £23,000 £268,270 and £48,965 per QALY gained respectively) was assessed as partially applicable with very serious limitations. As the economic evaluation was not conducted from a UK perspective, and due to a number of other limitations, the committee could not determine whether the interventions would be cost effective in a UK setting.

1.8.3 Other factors the committee took into account

The Committee noted in particular the variance in the emotional and psychological support services presented. The Committee acknowledged the importance of such interventions in supporting carers, and felt more research to identify the most effective psychological support to help carers become less vulnerable and more resilient would be valuable. The Committee agreed that a particular focus should be given to carers who are more vulnerable and less resilient to psychological, and those susceptible to financial or physical distress. Older carers and young carers were highlighted as populations who may be identified in this category.

The Committee acknowledged the evidence provided, but noted there was little available research on the effectiveness of practical support or training services for carers of (or those important to) people in their last year of life. These could include training to provide hands-on care, financial support, or respite services. Providing services to prepare and support carers practically may enable a person in their last year of life to receive care more readily and reduce the demand for care from health care professionals or avoidable care transfers.

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Appendices

Appendix A: Review protocols

Table 29: Review protocol for what are the most clinically and cost-effective support services for carers of (or those important to) people in their last year of life by health and social care professionals?

Question number: Q16

Relevant section of Scope: Service models that provide support for carers or those important to people accessing end of life services.

Field names are based on PRISMA-P.]

ID	Field	Content
I	Review question	What are the most clinically and cost-effective support services for carers of (or those important to) people in their last year of life by health and social care professionals?
II	Type of review question	Intervention A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To identify the best carer support services for carers of (or people important to) people who might be entering the last year of life
IV	Eligibility criteria – population / disease / condition / issue / domain	Carers of (or those important to) adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. Includes young carers (<18 years)
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Carer support services, for example: • Carer respite services • Combined care for patients and carers • Community services • Psychological support • Support groups and education for carers • Information for carers (for example, information on financial or benefits support) • Buddying for carers • Health checks
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• To each other • No carer support services

VII	Outcomes and prioritisation	IMPORTANT - Length of hospital stay (Continuous) - Use of community services (Dichotomous) - Staff (providing care to the person in their last year of life) satisfaction (Continuous) - Patient/carer reported outcomes (satisfaction) (Continuous) - Staff satisfaction (Continuous) CRITICAL • Quality of life (Continuous) • Preferred and actual place of death (Dichotomous) • Preferred and actual place of care (Dichotomous) • Longevity of the carer (Continuous) IMPORTANT • Carer health (for example: GP visits, mental health, school/work attendance) (Continuous) • Length of stay (Continuous) • Use of community services (Dichotomous) • Staff (providing care to the person in their last year of life) satisfaction (Continuous) • Patient/carer reported outcomes (satisfaction) (Continuous) • Staff satisfaction (Continuous)
VIII	Eligibility criteria – study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies.
IX	Other inclusion exclusion criteria	Exclusions: • Children (17 years or younger) • Studies will only be included if they reported one or more of the outcomes listed above • Descriptive (non-comparative) studies will be excluded
X	Proposed sensitivity / subgroup analysis, or meta-regression	Subgroups to be analysed if heterogeneity found: • Younger adults (aged 18-25) • Frail elderly • People with dementia • People with hearing loss • People with advanced heart and lung disease • People in prisons • Socioeconomic inequalities (people from lower income brackets) • Homeless people/vulnerably housed • Travelers • People with learning difficulties • People with disabilities • People with mental health problems • Migrant workers • LGBT

		- People in whom life-prolonging therapies are still an active option
XI	Selection process – duplicate screening / selection / analysis	Quality assurance will be undertaken by a senior research fellow prior to completion. Review strategy/other analysis: - Information on identification tools used as part of a service will be extracted. - Due to the expected complexity of the service models implemented in the studies, studies will be reported separately if necessary. In such case, studies on the populations included in the subgroup list will be highlighted to the Committee and will be considered when making the recommendations
XII	Data management (software)	- Pairwise meta-analyses were performed using Cochrane Review Manager (RevMan5). - GRADEpro was used to assess the quality of evidence for each outcome. - Endnote was used for: ○ Bibliography, citations, sifting and reference management - Evibase was used for Data extraction and quality assessment / critical appraisal
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – All years Language: Restrict to English only A call for evidence was also conducted.
XIV	Identify if an update	Not applicable
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see Appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as Appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).

XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
XXIV	Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
XXV	Rationale / context – what is known	For details please see the introduction to the evidence review.
XXVI	Describe contributions of authors and guarantor	A multidisciplinary committee [https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799] developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Mark Thomas in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
XXVII	Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXVIII	Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXIX	Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
XXX	PROSPERO registration number	Not registered

Table 30: Health economic review protocol

Review question	**All questions – health economic evidence**
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	Populations, interventions and comparators must be as specified in the clinical review protocol above.

Review question	All questions – health economic evidence
	Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) Unpublished reports will not be considered unless submitted as part of a call for evidence. Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see Appendix G [in the Full guideline]
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2007, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in Appendix H of Developing NICE guidelines: the manual (2014).[195] Inclusion and exclusion criteria If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile. If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. Where there is discretion The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in Appendix M. The health economist will be guided by the following hierarchies. Setting: UK NHS (most applicable). OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). OECD countries with predominantly private health insurance systems (for example, Switzerland). Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. Health economic study type: Cost–utility analysis (most applicable). Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). Comparative cost analysis.

Review question	All questions – health economic evidence
	Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations. Year of analysis: The more recent the study, the more applicable it will be. Studies published in 2007 or later but that depend on unit costs and resource data entirely or predominantly from before 2007 will be rated as 'Not applicable'. Studies published before 2007 will be excluded before being assessed for applicability and methodological limitations. Quality and relevance of effectiveness data used in the health economic analysis: The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.

Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual 2014, updated 2017 https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869

For more detailed information, please see the Methodology Review. [Add cross reference]

B.1 Clinical search literature search strategy

Searches for were constructed using a PICO framework where population (P) terms were combined with Intervention (I) and in some cases Comparison (C) terms. Outcomes (O) are rarely used in search strategies for interventions as these concepts may not be well described in title, abstract or indexes and therefore difficult to retrieve. Search filters were applied to the search where appropriate.

Table 31: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (Ovid)	1946 – 04 January 2019	Exclusions
Embase (Ovid)	1974 – 04 January 2019	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to Issue 1 of 12, January 2019 CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review: Age

Database	Dates searched	Search filter used
		Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type
HMIC. Healthcare Management Information Consortium (Ovid)	1979 – 04 January 2019	Exclusions
SPP, Social Policy and Practice	1981 – 04 January 2019	Study types
ASSIA, Applied Social Sciences Index and Abstracts (ProQuest)	1987 – 04 January 2019	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	exp Advance Care Planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care planning/
19.	*"Continuity of Patient Care"/

20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
21.	*Attitude to Death/
22.	(attitude* adj3 (death* or dying*)).ti,ab.
23.	*Physician-Patient Relations/
24.	*Long-Term Care/
25.	*"Delivery of Health Care"/
26.	(end adj2 life).ti,ab.
27.	EOLC.ti,ab.
28.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
29.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
30.	or/1-29
31.	letter/
32.	editorial/
33.	news/
34.	exp historical article/
35.	Anecdotes as Topic/
36.	comment/
37.	case report/
38.	(letter or comment*).ti.
39.	or/31-38
40.	randomized controlled trial/ or random*.ti,ab.
41.	39 not 40
42.	animals/ not humans/
43.	exp Animals, Laboratory/
44.	exp Animal Experimentation/
45.	exp Models, Animal/
46.	exp Rodentia/
47.	(rat or rats or mouse or mice).ti.
48.	or/41-47
49.	30 not 48
50.	limit 49 to English language
51.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
52.	50 not 51
53.	Caregivers/
54.	Spouses/
55.	Family/
56.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*).ti,ab.
57.	or/53-56
58.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
59.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.

60.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
61.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
62.	Self-Help Groups/
63.	exp social support/
64.	Counseling/
65.	(counseling or counselling*).ti,ab.
66.	(buddy* or buddies).ti,ab.
67.	((health* or medical*) adj2 check*).ti,ab.
68.	((spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) adj3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge)).ti,ab.
69.	or/58-68
70.	52 and 57 and 69
71.	(commission* adj2 (support* or service* or model*)).ti,ab.
72.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
73.	Critical Pathways/
74.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
75.	Or/71-74
76.	52 and 75
77.	Patient Care Bundles/
78.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
79.	or/77-78
80.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
81.	52 and 79 and 80
82.	gold standard*.ti,ab.
83.	52 and 82
84.	(amber adj2 bundle).ti,ab.
85.	81 or 83 or 84
86.	76 not 85
87.	patient care team/
88.	interdisciplinary communication/
89.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
90.	(((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
91.	(key adj2 work*).ti,ab.
92.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.

93.	((healthcare or care) adj1 profession*).ti,ab.
94.	*Case Management/
95.	(case adj2 manage*).ti,ab.
96.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
97.	Or/88-96
98.	(service* adj3 (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)).ti,ab.
99.	52 and (97 or 98)
100.	70 or 86 or 99

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care/
19.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
20.	*Attitude to Death/
21.	(attitude* adj3 (death* or dying*)).ti,ab.
22.	*Doctor patient relation/
23.	*Long term care/
24.	*Health care delivery/
25.	(end adj2 life).ti,ab.
26.	EOLC.ti,ab.
27.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
28.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
29.	or/1-28
30.	letter.pt. or letter/
31.	note.pt.
32.	editorial.pt.
33.	case report/ or case study/
34.	(letter or comment*).ti.
35.	or/30-34

36.	randomized controlled trial/ or random*.ti,ab.
37.	35 not 36
38.	animal/ not human/
39.	nonhuman/
40.	exp Animal Experiment/
41.	exp Experimental Animal/
42.	animal model/
43.	exp Rodent/
44.	(rat or rats or mouse or mice).ti.
45.	or/37-44
46.	29 not 45
47.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
48.	46 not 47
49.	limit 48 to English language
50.	*Caregiver/
51.	*Spouse/
52.	*Family/
53.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*).ti,ab.
54.	or/50-53
55.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
56.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
57.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
58.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
59.	*Self-Help/
60.	*Social support/
61.	*Counseling/
62.	(counseling or counselling*).ti,ab.
63.	(buddy* or buddies).ti,ab.
64.	((health* or medical*) adj2 check*).ti,ab.
65.	((spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) adj3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge)).ti,ab.
66.	or/55-65
67.	49 and 54 and 66
68.	(commission* adj2 (support* or service* or model*)).ti,ab.
69.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.

70.	*Clinical Pathway/
71.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
72.	Or/68-71
73.	49 and 72
74.	*Care Bundle/
75.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
76.	or/74-75
77.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
78.	49 and 76 and 77
79.	gold standard*.ti,ab.
80.	49 and 79
81.	(amber adj2 bundle).ti,ab.
82.	78 or 80 or 81
83.	73 not 82
84.	interdisciplinary communication/
85.	patient care team*.ti,ab.
86.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
87.	(((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
88.	(key adj2 work*).ti,ab.
89.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
90.	((healthcare or care) adj1 profession*).ti,ab.
91.	*Case Management/
92.	(case adj2 manage*).ti,ab.
93.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
94.	Or/84-93
95.	(service* adj3 (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)).ti,ab.
96.	49 and (94 or 95)
97.	67 or 83 or 96

Cochrane Library (Wiley) search terms

#1.	MeSH descriptor: [Palliative Care] this term only
#2.	MeSH descriptor: [Terminal Care] this term only
#3.	MeSH descriptor: [Hospice Care] this term only
#4.	palliat*:ti,ab
#5.	MeSH descriptor: [Terminally Ill] this term only
#6.	((terminal* or long term or longterm) near/2 (care* or caring or ill*)):ti,ab
#7.	((dying or terminal) near (phase* or stage*)):ti,ab
#8.	life limit*:ti,ab
#9.	MeSH descriptor: [Nursing Homes] explode all trees

#10.	((care or nursing) near/2 (home or homes)):ti,ab
#11.	MeSH descriptor: [Respite Care] this term only
#12.	((respite or day) near/2 (care or caring)):ti,ab
#13.	MeSH descriptor: [Hospices] this term only
#14.	hospice*:ti,ab
#15.	MeSH descriptor: [Patient Care Planning] this term only
#16.	MeSH descriptor: [Continuity of Patient Care] this term only
#17.	((advance* or patient*) near/3 (care or caring) near/3 (continu* or plan*)):ti,ab
#18.	MeSH descriptor: [Attitude to Death] explode all trees
#19.	(attitude* near/3 (death* or dying*)):ti,ab
#20.	MeSH descriptor: [Physician-Patient Relations] this term only
#21.	MeSH descriptor: [Long-Term Care] this term only
#22.	MeSH descriptor: [Delivery of Health Care] this term only
#23.	(end near/2 life):ti,ab
#24.	EOLC:ti,ab
#25.	((last or final) near/2 (year or month*) near/2 life):ti,ab
#26.	((dying or death) near/2 (patient* or person* or people or care or caring)):ti,ab
#27.	MeSH descriptor: [Advance Care Planning] explode all trees
#28.	(advance* near/2 (plan* or decision* or directive*)):ti,ab
#29.	(or #1-#27)
#30.	MeSH descriptor: [Caregivers] this term only
#31.	MeSH descriptor: [Spouses] this term only
#32.	MeSH descriptor: [Family] this term only
#33.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*):ti,ab
#34.	(or #30-#33)
#35.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#36.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#37.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#38.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#39.	MeSH descriptor: [Self-Help Groups] this term only
#40.	MeSH descriptor: [Social Support] explode all trees
#41.	MeSH descriptor: [Counseling] this term only
#42.	(counseling or counselling*):ti,ab
#43.	(buddy* or buddies):ti,ab
#44.	(health or medical*) near/3 check*:ti,ab
#45.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) near/3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge):ti,ab

#46.	(or #35-#45)
#47.	#29 and #34 and #46
#48.	(commission* near/2 (support* or service* or model*)):ti,ab
#49.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) near/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)):ti,ab
#50.	MeSH descriptor: [Critical Pathways] explode all trees
#51.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#52.	(or #48-#51)
#53.	#29 and #52
#54.	MeSH descriptor: [Patient Care Bundles] explode all trees
#55.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#56.	(or #54-#55)
#57.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#58.	#29 and #56 and #57
#59.	gold standard*:ti,ab
#60.	#29 and #59
#61.	(amber near/2 bundle):ti,ab
#62.	#58 or #60 or #61
#63.	#53 not #62
#64.	MeSH descriptor: [Patient Care Team] explode all trees
#65.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#66.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT):ti,ab
#67.	((integrat* or network*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)):ti,ab
#68.	(key near/2 work*):ti,ab
#69.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#70.	((healthcare or care) near/1 profession*):ti,ab
#71.	MeSH descriptor: [Case Management] this term only
#72.	(case near/2 manage*):ti,ab
#73.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#74.	(or #65-#74)
#75.	service* near/3 (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*):ti,ab
#76.	#29 and (#74 or #75)
#77.	#47 or #63 or #76

CINAHL (EBSCO) search terms

S1.	MH Palliative care
S2.	MH Terminal care
S3.	MH Hospice care
S4.	TI palliat* OR AB palliat*

S5.	MW Terminally ill
S6.	TI (terminal* or long term or longterm) AND TI (care* or caring or ill*)
S7.	AB (terminal* or long term or longterm) AND AB (care* or caring or ill*)
S8.	TI (dying or terminal) AND TI (phase* or stage*)
S9.	AB (dying or terminal) AND AB (phase* or stage*)
S10.	TI life limit* OR AB life limit*
S11.	MH Nursing homes
S12.	TI (care or nursing) AND TI (home or homes)
S13.	AB (care or nursing) AND AB (home or homes)
S14.	MH Respite care
S15.	TI (respite or day) AND TI (care or caring)
S16.	AB (respite or day) AND AB (care or caring)
S17.	MH Hospices
S18.	TI Hospice* OR AB Hospice*
S19.	(MH "Patient Care Plans")
S20.	MH Attitude to Death
S21.	TI attitude* AND TI (death* or dying)
S22.	AB attitude* AND AB (death* or dying)
S23.	MH Physician-Patient Relations
S24.	(MH "Long Term Care")
S25.	(MH "Health Care Delivery")
S26.	TI end AND TI life OR AB end AND AB life
S27.	TI EOLC OR AB EOLC
S28.	TI (last or final) AND TI (year or month) AND TI life
S29.	AB (last or final) AND AB (year or month) AND AB life
S30.	TI (dying or death) AND TI (patient* or person* or people or care or caring)
S31.	AB (dying or death) AND AB (patient* or person* or people or care or caring)
S32.	TI advance* AND TI (plan* or decision* or directive*)
S33.	AB advance* AND AB (plan* or decision* or directive*)
S34.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR 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 OR S30 OR S31 OR S32 OR S33
S35.	TI commission* AND TI ((support* or service* or model*))
S36.	AB commission* AND AB ((support* or service* or model*))
S37.	TI (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND TI (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S38.	AB (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND AB (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S39.	TI (critical or clinic* or service* or care) AND TI path*
S40.	AB (critical or clinic* or service* or care) AND AB path*
S41.	TI care AND TI (bundle* or service* or package* or standard*)
S42.	AB care AND AB (bundle* or service* or package* or standard*)
S43.	S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42

S44.	TI (assess* or criteria* or predict* or recogni* or identif* or refer*) OR AB (assess* or criteria* or predict* or recogni* or identif* or refer*)
S45.	S34 AND S43 AND S44
S46.	TI gold standard* OR AB gold standard*
S47.	S34 AND S46
S48.	TI amber AND TI bundle
S49.	AB amber AND AB bundle
S50.	S48 OR S49
S51.	S45 OR S47 OR S50
S52.	S35 OR S36 OR S37 OR S38 OR S39 OR S40
S53.	S34 AND S52
S54.	S53 NOT S51
S55.	(MH "Multidisciplinary Care Team+")
S56.	MDT OR IDT
S57.	((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S58.	((integrat* or network*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S59.	TI (key n2 work*) OR AB (key n2 work*)
S60.	TI (((healthcare or care) n2 (lead or leader or leads or facilitat*))) OR AB (((healthcare or care) n2 (lead or leader or leads or facilitat*)))
S61.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S62.	MH Case Management
S63.	TI (case n2 manage*) OR AB (case n2 manage*)
S64.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S65.	S55 OR S54 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S61 OR S62
S66.	TX service* AND TX (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)
S67.	AB service* AND AB (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)
S68.	S66 OR S67
S69.	S34 AND (S65 OR S68)
S70.	S54 OR S69

PsycINFO (ProQuest) search terms

1.	(ti,ab(commission* NEAR/2 (support* OR service* OR model*)) OR ((service* OR program* OR co-ordinat* OR coordinat*) NEAR/2 (model* OR deliver* OR strateg* OR support* OR access* OR method* OR system* OR policies OR policy OR availab*))) AND (SU.EXACT("Palliative Care") OR SU.EXACT("Terminally Ill Patients") OR SU.EXACT("Hospice") OR ti,ab(palliat*) OR ti,ab((terminal* OR long-term OR longterm) NEAR/2 (care* OR caring OR ill*)) OR ti,ab((dying OR terminal) NEAR/1 (phase* OR stage*)) OR ti,ab(life-limit*) OR SU.EXACT("Nursing Homes") OR ti,ab((care OR nursing) NEAR/2 (home OR homes)) OR SU.EXACT("Respite Care") OR ti,ab((respite OR day) NEAR/2 (care OR caring)) OR ti,ab(hospice*) OR MJSUB.EXACT("Treatment Planning") OR MJSUB.EXACT("Continuum of Care") OR

	ti,ab((advance* OR patient*) NEAR/3 (care OR caring) NEAR/3 (continu* OR plan*)) OR MJSUB.EXACT("Long Term Care") OR ti,ab(attitude* NEAR/3 (death* OR dying*)) OR ti,ab(end NEAR/2 life) OR ti,ab(EOLC) OR ti,ab((last OR final) NEAR/2 (year OR month*) NEAR/2 life) OR ti,ab((dying OR death) NEAR/2 (patient* OR person* OR people OR care OR caring)))
2.	Adolescence (13-17 Yrs), Adulthood (18 Yrs & Older), Aged (65 Yrs & Older), Middle Age (40-64 Yrs), Thirties (30-39 Yrs), Very Old (85 Yrs & Older), Young Adulthood (18-29 Yrs)
3.	1 and 2
4.	Conference Proceedings, Journal Article, Peer Reviewed Journal
5.	3 and 4

HMIC (Ovid) search terms

1.	exp End of life care/
2.	(terminal* adj ill*).ti,ab.
3.	((dying or terminal) adj (phase* or stage*)).ti,ab.
4.	life limit*.ti,ab.
5.	(end adj2 life).ti,ab.
6.	EOLC.ti,ab.
7.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
8.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
9.	or/2-8
10.	(exp child/ or exp Paediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp older people/)
11.	9 not 10
12.	limit 11 to English
13.	limit 12 to (audiovis or book or chapter dh helmis or circular or microfiche dh helmis or multimedias or website)
14.	limit 12 to (audiocass or books or cdrom or chapter or dept pubs or diskettes or folio pamp or "map" or marc or microfiche or multimedia or pamphlet or parly or press or press rel or thesis or trustdoc or video or videos or website)
15.	13 or 14
16.	12 not 15
17.	euthanasia/
18.	euthanasia.ti,ab.
19.	17 or 18
20.	16 not 19

SPP (Ovid) search terms

1.	palliat*.ti,ab.
2.	((dying or terminal) adj (phase* or stage*)).ti,ab.
3.	life limit*.ti,ab.
4.	hospice*.ti,ab.
5.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
6.	living will*.ti,ab.
7.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
8.	(attitude* adj3 (death* or dying*)).ti,ab.
9.	(end adj2 life).ti,ab.
10.	EOLC.ti,ab.

11.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
12.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
13.	(nursing adj2 (home or homes)).ti,ab.
14.	(terminal* adj2 ill*).ti,ab.
15.	(respite adj2 (care or caring)).ti,ab.
16.	or/1-15
17.	(child* or infant*).ti,ab.
18.	(adult* or adolescent*).ti,ab.
19.	17 not 18
20.	16 not 19
21.	limit 20 to (journal or journal article or online resource or online report or report)

ASSIA (ProQuest) search terms

1.	palliat*.ti,ab. ((ti,ab(commission* N/2 (support* or service* or model*)) OR ti,ab((service* or program* or co-ordinat* or coordinat*) N/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*))) AND ((SU.EXACT("Care" OR "Clinical nursing" OR "Community homes" OR "Community nursery nursing" OR "Community nursing" OR "Compassionate care" OR "Continuing care" OR "District nursing" OR "Family centred care" OR "Geriatric wards" OR "Group care" OR "Health visiting" OR "Home care" OR "Home from home care" OR "Home health aides" OR "Home helps" OR "Hospices" OR "Hostel wards" OR "Informal care" OR "Integrated care pathways" OR "Intentional care" OR "Intermediate care" OR "Intermediate care centres" OR "Lack of care" OR "Learning disability nursing" OR "Length of stay" OR "Liaison nursing" OR "Long stay wards" OR "Long term care" OR "Long term home care" OR "Long term residential care" OR "Nurse led care" OR "Nursing" OR "Occupational health nursing" OR "Ontological care" OR "Out of home care" OR "Outreach nursing" OR "Palliative care" OR "Paranursing" OR "Pastoral care" OR "Patient care" OR "Primary nursing" OR "Private residential care" OR "Process centred care" OR "Quality of care" OR "Radical health visiting" OR "Residential care" OR "Residential group care" OR "Respite care" OR "Shared care" OR "Social care" "Temporary care" OR "Terminal care" OR "Wards") OR (SU.EXACT("Terminally ill elderly people") OR SU.EXACT("Terminally ill fathers") OR SU.EXACT("Terminally ill elderly men") OR SU.EXACT("Terminally ill elderly women") OR SU.EXACT("Terminally ill young adults") OR SU.EXACT("Terminally ill parents") OR SU.EXACT("Terminally ill women") OR SU.EXACT("Terminally ill widowed sisters") OR SU.EXACT("Terminally ill colleagues") OR SU.EXACT("Terminally ill young girls") OR SU.EXACT("Terminally ill people") OR SU.EXACT("Terminally ill men")) OR SU.EXACT("Advance directives" OR "Do not resuscitate orders" OR "Durable power of attorney for health care" OR "Living wills" OR "Treatment preferences" OR "Treatment needs")) OR (ti,ab((advance* or patient*) N/3 (care or caring) N/3 (continu* or plan*)) or ti,ab(attitude* N/3 (death* or dying*)) or ti,ab(end N/2 life) or ti,ab(EOLC) or ti,ab((last or final) N/2 (year or month*) N/2 life) or ti,ab((dying or death) N/2 (patient* or person* or people or care or caring))))) OR SU.EXACT("End of life decisions")

B.2 Health Economics literature search strategy

Health economic evidence was identified by conducting a broad search relating to end of life care in NHS Economic Evaluation Database (NHS EED – this ceased to be updated after March 2015) and the Health Technology Assessment database (HTA) with no date restrictions. NHS EED and HTA databases are hosted by the Centre for Research and Dissemination (CRD). Additional searches were run on Medline and Embase for health economics, economic modelling and quality of life studies.

Table 32: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline	2014 – 04 January 2019	Exclusions Health economics studies Health economics modelling studies Quality of life studies
Embase	2014 – 04 January 2019	Exclusions Health economics studies Health economics modelling studies Quality of life studies
Centre for Research and Dissemination (CRD)	HTA - Inception – 04 January 2019 NHSEED - Inception to March 2015	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	exp Advance Care Planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care planning/
19.	*"Continuity of Patient Care"/
20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
21.	*Attitude to Death/
22.	(attitude* adj3 (death* or dying*)).ti,ab.
23.	*Physician-Patient Relations/
24.	*Long-Term Care/
25.	*"Delivery of Health Care"/
26.	(end adj2 life).ti,ab.
27.	EOLC.ti,ab.
28.	((last or final) adj2 (year or month*) adj2 life).ti,ab.

29.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
30.	or/1-29
31.	letter/
32.	editorial/
33.	news/
34.	exp historical article/
35.	Anecdotes as Topic/
36.	comment/
37.	case report/
38.	(letter or comment*).ti.
39.	or/31-38
40.	randomized controlled trial/ or random*.ti,ab.
41.	39 not 40
42.	animals/ not humans/
43.	exp Animals, Laboratory/
44.	exp Animal Experimentation/
45.	exp Models, Animal/
46.	exp Rodentia/
47.	(rat or rats or mouse or mice).ti.
48.	or/41-47
49.	30 not 48
50.	limit 49 to English language
51.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
52.	50 not 51
53.	economics/
54.	value of life/
55.	exp "costs and cost analysis"/
56.	exp Economics, Hospital/
57.	exp Economics, medical/
58.	Economics, nursing/
59.	economics, pharmaceutical/
60.	exp "Fees and Charges"/
61.	exp budgets/
62.	budget*.ti,ab.
63.	cost*.ti.
64.	(economic* or pharmaco?economic*).ti.
65.	(price* or pricing*).ti,ab.
66.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
67.	(financ* or fee or fees).ti,ab.
68.	(value adj2 (money or monetary)).ti,ab.
69.	or/53-68
70.	exp models, economic/
71.	*Models, Theoretical/
72.	*Models, Organizational/

73.	markov chains/
74.	monte carlo method/
75.	exp Decision Theory/
76.	(markov* or monte carlo).ti,ab.
77.	econom* model*.ti,ab.
78.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
79.	or/70-78
80.	quality-adjusted life years/
81.	sickness impact profile/
82.	(quality adj2 (wellbeing or well being)).ti,ab.
83.	sickness impact profile.ti,ab.
84.	disability adjusted life.ti,ab.
85.	(qal* or qtime* or qwb* or daly*).ti,ab.
86.	(euroQoL* or eq5d* or eq 5*).ti,ab.
87.	(QoL* or hql* or hQoL* or h QoL* or hrQoL* or hr QoL*).ti,ab.
88.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
89.	(hui or hui1 or hui2 or hui3).ti,ab.
90.	(health* year* equivalent* or hye or hyes).ti,ab.
91.	discrete choice*.ti,ab.
92.	rosser.ti,ab.
93.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
94.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
95.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
96.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
97.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
98.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
99.	or/80-98
100.	52 and (69 or 79 or 99)

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.

15.	*Patient care planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care/
19.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
20.	*Attitude to Death/
21.	(attitude* adj3 (death* or dying*)).ti,ab.
22.	*Doctor patient relation/
23.	*Long term care/
24.	*Health care delivery/
25.	(end adj2 life).ti,ab.
26.	EOLC.ti,ab.
27.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
28.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
29.	or/1-28
30.	letter.pt. or letter/
31.	note.pt.
32.	editorial.pt.
33.	case report/ or case study/
34.	(letter or comment*).ti.
35.	or/30-34
36.	randomized controlled trial/ or random*.ti,ab.
37.	35 not 36
38.	animal/ not human/
39.	nonhuman/
40.	exp Animal Experiment/
41.	exp Experimental Animal/
42.	animal model/
43.	exp Rodent/
44.	(rat or rats or mouse or mice).ti.
45.	or/37-44
46.	29 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	health economics/
51.	exp economic evaluation/
52.	exp health care cost/
53.	exp fee/
54.	budget/

55.	funding/
56.	budget*.ti,ab.
57.	cost*.ti.
58.	(economic* or pharmaco?economic*).ti.
59.	(price* or pricing*).ti,ab.
60.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
61.	(financ* or fee or fees).ti,ab.
62.	(value adj2 (money or monetary)).ti,ab.
63.	or/50-62
64.	statistical model/
65.	exp economic aspect/
66.	64 and 65
67.	*theoretical model/
68.	*nonbiological model/
69.	stochastic model/
70.	decision theory/
71.	decision tree/
72.	monte carlo method/
73.	(markov* or monte carlo).ti,ab.
74.	econom* model*.ti,ab.
75.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
76.	or/66-75
77.	quality-adjusted life years/
78.	"quality of life index"/
79.	short form 12/ or short form 20/ or short form 36/ or short form 8/
80.	sickness impact profile/
81.	(quality adj2 (wellbeing or well being)).ti,ab.
82.	sickness impact profile.ti,ab.
83.	disability adjusted life.ti,ab.
84.	(qal* or qtime* or qwb* or daly*).ti,ab.
85.	(euroQoL* or eq5d* or eq 5*).ti,ab.
86.	(QoL* or hql* or hQoL* or h QoL* or hrQoL* or hr QoL*).ti,ab.
87.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
88.	(hui or hui1 or hui2 or hui3).ti,ab.
89.	(health* year* equivalent* or hye or hyes).ti,ab.
90.	discrete choice*.ti,ab.
91.	rosser.ti,ab.
92.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
93.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
94.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.

95.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
96.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
97.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
98.	or/77-97
99.	49 and (63 or 76 or 98)

NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Palliative Care IN NHSEED,HTA
#2.	MeSH DESCRIPTOR Terminal Care IN NHSEED,HTA
#3.	MeSH DESCRIPTOR Hospice Care IN NHSEED,HTA
#4.	(palliat*) IN NHSEED, HTA
#5.	MeSH DESCRIPTOR Terminally Ill IN NHSEED,HTA
#6.	(((terminal* or long term or longterm) adj2 (care* or caring or ill*))) IN NHSEED, HTA
#7.	(((dying or terminal) adj (phase* or stage*))) IN NHSEED, HTA
#8.	(life limit*) IN NHSEED, HTA
#9.	MeSH DESCRIPTOR Nursing Homes IN NHSEED,HTA
#10.	(((care or nursing) adj2 (home or homes))) IN NHSEED, HTA
#11.	MeSH DESCRIPTOR Respite Care IN NHSEED,HTA
#12.	(((respite or day) adj2 (care or caring))) IN NHSEED, HTA
#13.	MeSH DESCRIPTOR Hospices IN NHSEED,HTA
#14.	(hospice*) IN NHSEED, HTA
#15.	MeSH DESCRIPTOR Advance Care Planning EXPLODE ALL TREES IN NHSEED,HTA
#16.	((advance* adj2 (plan* or decision* or directive*))) IN NHSEED, HTA
#17.	(living will*) IN NHSEED, HTA
#18.	MeSH DESCRIPTOR Patient Care Planning IN NHSEED,HTA
#19.	MeSH DESCRIPTOR Continuity of Patient Care IN NHSEED,HTA
#20.	(((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*))) IN NHSEED, HTA
#21.	MeSH DESCRIPTOR Attitude to Death IN NHSEED,HTA
#22.	((attitude* adj3 (death* or dying*))) IN NHSEED, HTA
#23.	MeSH DESCRIPTOR Physician-Patient Relations IN NHSEED,HTA
#24.	MeSH DESCRIPTOR Long-Term Care IN NHSEED,HTA
#25.	MeSH DESCRIPTOR Delivery of Health Care IN NHSEED,HTA
#26.	((end adj2 life)) IN NHSEED, HTA
#27.	(EOLC) IN NHSEED, HTA
#28.	(((last or final) adj2 (year or month*) adj2 life)) IN NHSEED, HTA
#29.	(((dying or death) adj2 (patient* or person* or people or care or caring))) IN NHSEED, HTA
#30.	#1 OR #2 OR #3 OR #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
#31.	(#30) IN NHSEED
#32.	(#30) IN HTA

Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the review of carer support services

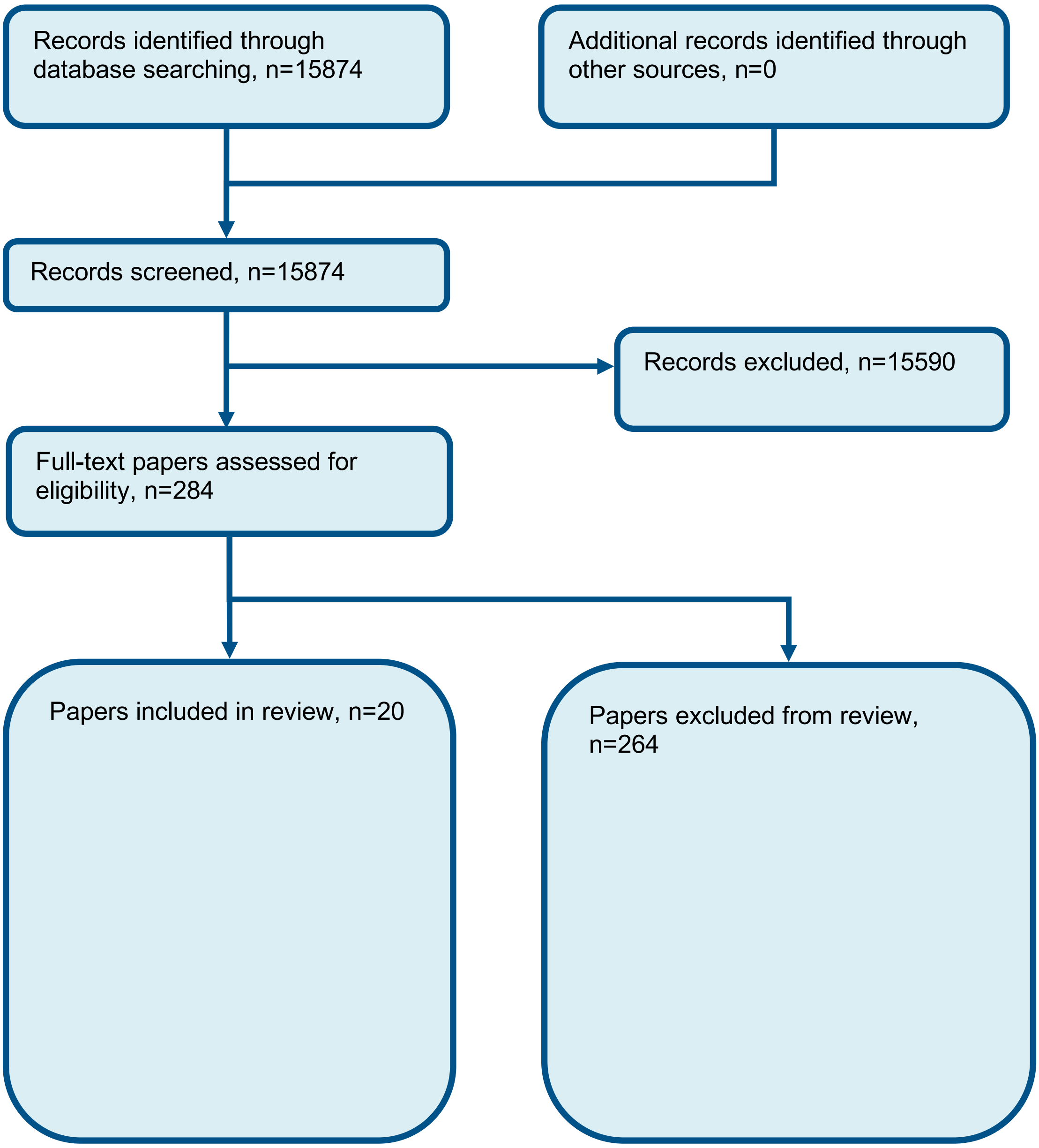
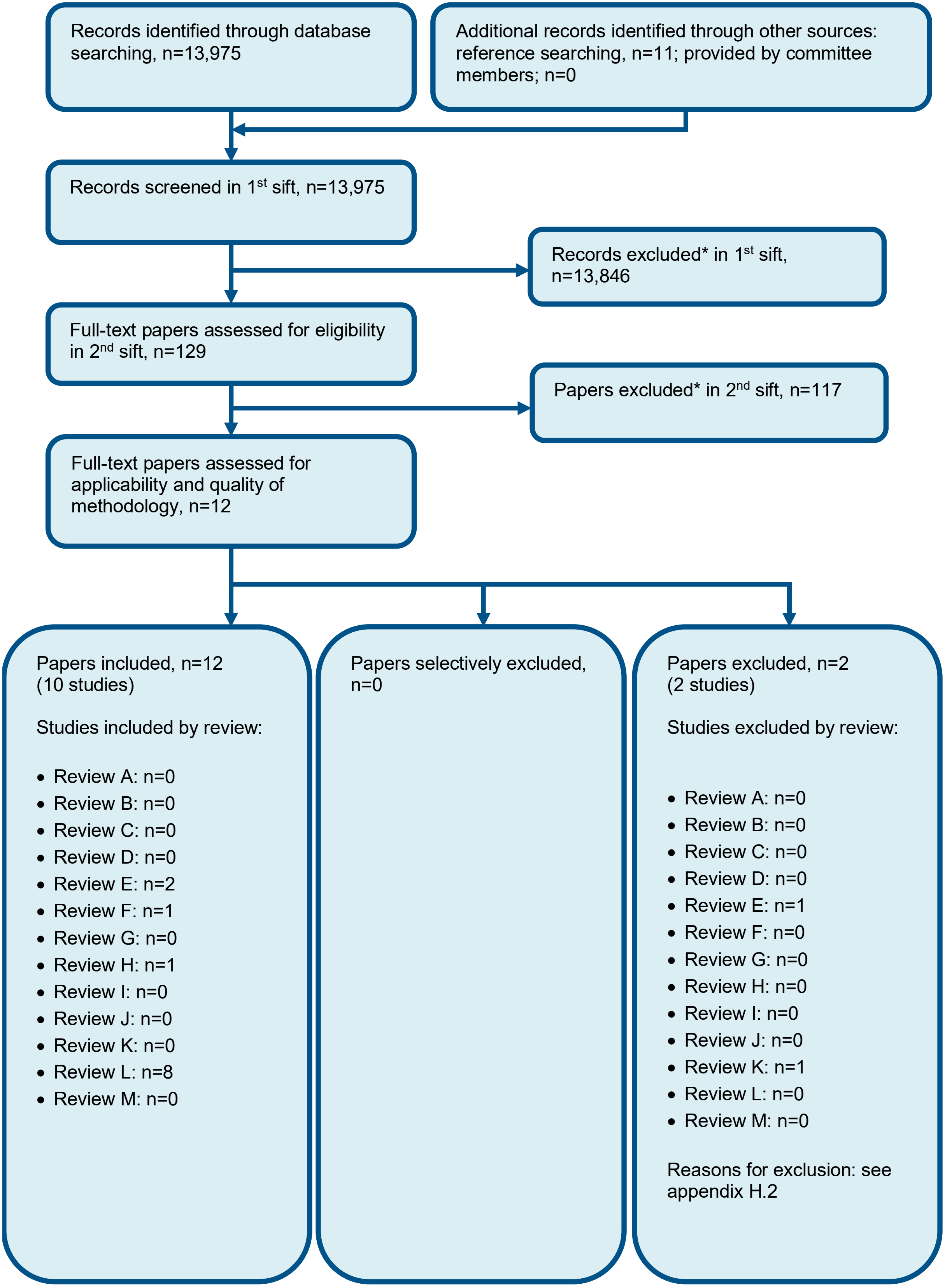


Figure 2: Flow chart of health economic study selection for the guideline



* Non-relevant population, intervention, comparison, design or setting; non-English language

Appendix D: Clinical evidence tables

Study	Allen 2014[5]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	(n=45)
Countries and setting	Conducted in USA; Setting: In the patients' place of residence.
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 20 weeks
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Palliative care patients aged >55, living in the community or assisted living, had an advanced illness or combination of chronic illness, received a score on the VES, received an average of 4 hours per week of care from caregiver.
Exclusion criteria	Patients had no more than mild cognitive impairment. Dyads excluded if the patient was receiving hospice care, or had nursing home admission planned in the next 3 months.
Recruitment/selection of patients	Recruited through physician /clinician champions and to university medical centres, one home health agency, five assisted living facilities, four congregate apartment sites for older adults, one care retirement community.
Age, gender and ethnicity	Age - Mean (SD): Patient: 78.22 (11.59) Caregiver: 59.85(11.76). Gender (M:F): 11/34. Ethnicity: 43% African American
Further population details	1. Frail elderly: Frail elderly 2. Homeless people/vulnerably housed: Not applicable 3. LGBT: Not applicable 4. Migrant workers: Not applicable 5. People from ethnic minorities: Not applicable 6. People in prisons: Not applicable 7. People in whom life-prolonging therapies are still an active option: Not applicable 8. People with dementia: Not applicable 9. People with disabilities: Not applicable 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):

Study	**Allen 2014[5]**
Indirectness of population	No indirectness
Interventions	(n=22) Intervention 1: Carer support service - Combined care for patients and carers. Retired senior volunteers. RSV received four-six hour intensive training on The LIFE Volunteer Interventionist Manual. The manual and accompanying workbook comprised: 1) instructions about using the steps of problem solving to decide on a period of life and creative activity project, 2) constructing a project, 3) evaluation of activity, 4) and Appendix with life review questions for dyads that find generation of stories more difficult. With the help of the RSV, in session one the patient-caregiver dyad narrowed the focus to a time period in the patient's life that could be adequately represented in one tangible project (e.g., scrapbook, cookbook, audiotapes) to represent the patient's values and achievements in life. During the second session, RSVs helped the dyad work on the activity and further use problem-solving skills. During the third visit, the patient and caregiver shared their activity with the RSV, who discussed the dyad's feelings about the process, including a qualitative evaluation of the LIFE project and what the family learned when creating it. Duration 20 weeks. Concurrent medication/care: NA. Indirectness: No indirectness (n=23) Intervention 2: Carer support service - Combined care for patients and carers. Patients and caregivers each received three separate, structured emotional support telephone calls with research staff (mean duration = 13±6.5 minutes). Control callers asked questions of participants and then engaged in supportive conversations using empathic listening and reflection. Topics discussed included family, intergenerational ties, and important aspects of the patient's life, but structured reminiscence and the creative and therapeutic nature of legacy activities were not discussed.. Duration 20 weeks. Concurrent medication/care: NA. Indirectness: No indirectness
Funding	Academic or government funding (Supported by funding from the National Institute of Nursing Research)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COMBINED CARE FOR PATIENTS AND CARERS - RSV versus COMBINED CARE FOR PATIENTS AND CARERS - PHONE CALLS Protocol outcome 1: Quality of life of person in their last year of life - Actual outcome: Memorial Symptom Assessment Scale; symptom bother - physical at up to 20 weeks; Group 1: mean 0.78 (SD 0.6); n=10, Group 2: mean 0.64 (SD 0.4); n=18 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Memorial Symptom Assessment Scale; symptom bother - emotional at up to 20 weeks; Group 1: mean 1 (SD 0.8); n=10, Group 2: mean 0.97 (SD 0.7); n=18 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low,	

Study	Allen 2014[5]
Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Center for Epidemiology Studies Depression Scale (CESD) at up to 20 weeks; Group 1: mean 18.4 (SD 10); n=10, Group 2: mean 13.5 (SD 9.6); n=18; CESD 0-60 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Memorial Symptom Assessment Scale; symptom bother - physical at up to 20 weeks; Group 1: mean 0.77 (SD 0.6); n=10, Group 2: mean 0.49 (SD 0.5); n=18 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Memorial Symptom Assessment Scale; symptom bother - emotional at up to 20 weeks; Group 1: mean 1.08 (SD 1.2); n=10, Group 2: mean 1 (SD 1); n=18 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Center for Epidemiology Studies Depression Scale (CESD) at up to 20 weeks; Group 1: mean 14.9 (SD 13.5); n=10, Group 2: mean 8.17 (SD 6.4); n=18; CESD 0-60 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Caregiver stress at up to 20 weeks; Group 1: mean 2.32 (SD 0.2); n=10, Group 2: mean 2.3 (SD 0.2); n=18; Comments: Range not provided Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Badr 2015[12]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	(n=39)
Countries and setting	Conducted in USA; Setting: Secondary care
Line of therapy	Unclear
Duration of study	Intervention + follow up: 8 weeks

Study	Badr 2015[12]
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients were eligible if they (1) had advanced LC and were within 1 month of treatment initiation (any line of therapy); (2) were spending more than 50% of their time out of bed on a daily basis, as measured by an Eastern Cooperative Oncology Group performance status ≤ 2; and, (3) had a spouse/partner or other close family member whom they identified as their primary caregiver. In addition, both patients and caregivers had to (1) be ≥18 years old; (2) have the ability to read and understand English; and, (3) be able to provide informed consent.
Exclusion criteria	See inclusion criteria
Recruitment/selection of patients	Patients were identified through medical chart review and were approached to participate during chemotherapy infusion.
Age, gender and ethnicity	Age - Mean (SD): Patient: 68.17(10.3) Carer: 51.1(10.24). Gender (M:F): 12/27. Ethnicity: White: 85%
Further population details	NA
Indirectness of population	No indirectness
Interventions	(n=20) Intervention 1: Carer support service - Combined care for patients and carers. Patients and caregivers in the intervention group each received their own tailored manuals and participated together in 6 weekly 60-minute telephone counselling sessions with a trained interventionist who had a master's degree in mental health counselling. The topics were self-care, stress and coping, symptom management, effective communication, problem solving, and maintaining and enhancing relationships. For each topic, approximately half the content was the same for patients and caregivers, and half was tailored to the person's role (patient or caregiver).During sessions, the interventionist reviewed homework and manual content for that week, guided participants through in-session activities, and assigned the next week's homework to reinforce the practice of skills taught.. Duration 6 weeks. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=19) Intervention 2: No carer support services. Standard oncologic care and primary palliative care for the patient from the point of the diagnosis of advanced LC. Primary palliative care is provided by the patient's medical oncologist and includes the basic management of pain and other symptoms, including depression and anxiety, as well as basic discussions about the prognosis and goals of treatment. In addition, patients may be referred to the outpatient supportive oncology practice for a specialty palliative care consultation according to need as determined by the treating oncologist. Caregivers are welcome to attend/participate but are not required to do so.. Duration 6 weeks. Concurrent medication/care: NA.

Study	**Badr 2015[12]**
	Indirectness: No indirectness
Funding	Principal author funded by industry (Supported by a pilot grant awarded to Hoda Badr)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COMBINED CARE FOR PATIENTS AND CARERS versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of person in their last year of life - Actual outcome: PROMIS: depression at 8 weeks; Group 1: mean 11.65 (SD 3.77); n=20, Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome: PROMIS: anxiety at 8 weeks; Group 1: mean 12.35 (SD 4.46); n=20, Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: PROMIS: depression at 8 weeks; Group 1: mean 11.5 (SD 3.2); n=20, Group 2: mean 16.53 (SD 5.47); n=19; Patient Reported Outcomes Measurement Information System (PROMIS) short-form 6-30 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome: PROMIS: anxiety at 8 weeks; Group 1: mean 12.1 (SD 3.6); n=20, Group 2: mean 17.16 (SD 5.41); n=19 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome: Caregiver burden at 8 weeks; Group 1: mean 24.7 (SD 4.96); n=20, Group 2: mean 28.16 (SD 6.53); n=19 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	**Chan 2016[46]**
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=29)

Study	Chan 2016[46]
Countries and setting	Conducted in Hong Kong (China); Setting: Renal palliative clinic in Tung Wah Hospital in the Hong Kong West Cluster during June 2012 to December 2014.
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 24 weeks
Method of assessment of guideline condition	Method of assessment /diagnosis not stated: Does not state that they were in their last year of life and Caregivers were excluded from the study when immediate palliative care (eg, end-of-life care) was required.
Stratum	Overall:
Subgroup analysis within study	Not applicable
Inclusion criteria	Caregivers of patients who had: chronic kidney failure as defined by creatinine clearance <15mL/min; opted for conservative treatment by nephrology team or patient; never treated with dialysis or transplantation and able to provide informed consent.
Exclusion criteria	If had participated in another psycho-educational program during the preceding year; cared for more than 1 family member with a chronic medical illness, and immediate palliative care (e.g, end-of-life care) was required.
Recruitment/selection of patients	All new patients referred to the renal palliative clinic were screened.
Age, gender and ethnicity	Age - Mean (SD): 59.8 (14.2). Gender (M:F): 7/22. Ethnicity: Not reported
Further population details	1. Frail elderly: Not applicable 2. Homeless people/vulnerably housed: Not applicable 3. LGBT: Not applicable 4. Migrant workers: Not applicable 5. People from ethnic minorities : Not applicable 6. People in prisons: Not applicable 7. People in whom life-prolonging therapies are still an active option: Not applicable 8. People with dementia: Not applicable 9. People with disabilities: Not applicable 10. People with hearing loss: Not applicable 11. People with learning difficulties: Not applicable 12. People with mental health problems: Not applicable 13. Socioeconomic inequalities: Not applicable 14. Travelers: Not applicable 15. Younger adults (aged 18-25): Not applicable
Indirectness of population	No indirectness
Interventions	(n=14) Intervention 1: Carer support service - Psychological support. Enhanced Psychosocial support program which included education and intervention from an on-site palliative care nurse and a designated social worker. Interventions were instituted based on published information regarding families' needs in both end-stage renal disease and palliative care. The program included:

Study	Chan 2016[46]
	Palliative care nurse: assessment of family needs; assessment of patient's symptom burden; introduction of palliative care service team members, and types of services; knowledge of chronic kidney failure and related problems; patient medical care aspect (drug, diet adherence); patient and caregiver psychological aspect; use of pamphlets to enhance adherence to diet and fluid recommendations; home care visit, physiotherapy, clinical psychologist, inpatient care referral for intervention. Social worker: assessment of patient and caregiver social background with a demographic data sheet; family social support; family financial assessment; counseling, community service referral, coping skill training, respite care for intervention. Palliative care nurse: regular symptom burden assessment; monitoring of adherence to drug and fluid recommendations; management of patient's symptoms and skills in coping with them; assessment of psychological aspect. Social worker: assessment of social support and caring issue(s); orientation in stress management; improvement of communication skills in family; orientation of caregivers to relaxation methods; interventions as needed. . Duration 30-minute sessions held once to twice monthly on the day of a patient's joint clinic follow-up with a nurse, social worker, and physician. Concurrent medication/care: Not reported. Indirectness: No indirectness (n=15) Intervention 2: No carer support services. Standard renal care and caregivers could be referred to other allied health professionals if clinically indicated. Duration Followed up in a renal clinic at 2-4 week intervals up to a total of 6 months. Concurrent medication/care: Not reported. Indirectness: No indirectness
Funding	Funding not stated

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT versus NO CARER SUPPORT SERVICES

Protocol outcome 1: Quality of life of person in their last year of life
- Actual outcome: Quality of life (MQOL) at 1 month; Group 1: mean 8.4 (SD 1.8); n=14, Group 2: mean 7.7 (SD 1.3); n=11; McGill Quality of Life questionnaire 0-10 Top=High is good outcome
Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 8.0 (2.1); Control group 8.3 (1.3); Group 1 Number missing: 0; Group 2 Number missing: 4, Reason: 1 withdrawal and 3 deaths
- Actual outcome: Quality of life (MQOL) at 3 months; Group 1: mean 7.4 (SD 1.1); n=8, Group 2: mean 6.6 (SD 1.7); n=8; McGill Quality of Life

Study	Chan 2016[46]
questionnaire 0-10 Top=High is good outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 8.0 (2.1); Control group 8.3 (1.3); Group 1 Number missing: 6, Reason: 6 deaths; Group 2 Number missing: 7, Reason: 1 withdrawal and 6 deaths - Actual outcome: Quality of life (MQOL) at 6 months; Group 1: mean 7.3 (SD 1); n=4, Group 2: mean 6.4 (SD 1.1); n=5; McGill Quality of Life questionnaire 0-10 Top=High is good outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 8.0 (2.1); Control group 8.3 (1.3); Group 1 Number missing: 10, Reason: 10 deaths; Group 2 Number missing: 10, Reason: 1 withdrawal and 9 deaths Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Anxiety (HADS) at 1 month; Group 1: mean 7.1 (SD 3.2); n=14, Group 2: mean 10.1 (SD 2.2); n=11; Hospital Anxiety and Depression Scale 0-21 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 9.9 (3.3); Control group 9.1 (2.3); Group 1 Number missing: 0; Group 2 Number missing: 4, Reason: 1 withdrawal and 3 deaths - Actual outcome: Anxiety (HADS) at 3 months; Group 1: mean 6.5 (SD 4.5); n=8, Group 2: mean 11 (SD 3.1); n=8; Hospital Anxiety and Depression Scale 0-21 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 9.9 (3.3); Control group 9.1 (2.3); Group 1 Number missing: 6, Reason: 6 deaths; Group 2 Number missing: 7, Reason: 1 withdrawal and 6 deaths - Actual outcome: Anxiety (HADS) at 6 months; Group 1: mean 8.5 (SD 1.9); n=4, Group 2: mean 10.6 (SD 1.8); n=5; Hospital Anxiety and Depression Scale 0-21 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 9.9 (3.3); Control group 9.1 (2.3); Group 1 Number missing: 10, Reason: 10 deaths; Group 2 Number missing: 10, Reason: 1 withdrawal and9 deaths - Actual outcome: Depression (HADS) at 1 months; Group 1: mean 4.4 (SD 3.1); n=14, Group 2: mean 5.9 (SD 3.2); n=11; Hospital Anxiety and Depression Scale 0-21 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 5.4 (4.5); Control group 6.4 (2.9); Group 1 Number missing: 0; Group 2 Number missing: 4, Reason: 1 withdrawal and 3 deaths - Actual outcome: Depression (HADS) at 3 months; Group 1: mean 3.8 (SD 3.1); n=8, Group 2: mean 6.7 (SD 3.6); n=8; Hospital Anxiety and Depression Scale 0-21 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 5.4 (4.5); Control group 6.4 (2.9); Group 1 Number missing: 6, Reason: 6 deaths; Group 2 Number missing: 7, Reason: 1 withdrawal and 6 deaths - Actual outcome: Depression (HADS) at 6 months; Group 1: mean 4.5 (SD 1.9); n=4, Group 2: mean 7.4 (SD 3); n=5; Hospital Anxiety and	

Study	Chan 2016[46]
Depression Scale 0-21 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 5.4 (4.5); Control group 6.4 (2.9); Group 1 Number missing: 10, Reason: 10 deaths; Group 2 Number missing: 10, Reason: 1 withdrawal and9 deaths - Actual outcome: Caregiver's perceived burden in providing family care (ZBI) at 1 month; Group 1: mean 22 (SD 5.3); n=14, Group 2: mean 31.6 (SD 9.5); n=11; Zarit Burden Interview 0-88 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 32.8 (12.2); Control group 28.3 (10.7); Group 1 Number missing: 0; Group 2 Number missing: 4, Reason: 1 withdrawal and 3 deaths - Actual outcome: Caregiver's perceived burden in providing family care (ZBI) at 3 months; Group 1: mean 21.3 (SD 6.6); n=8, Group 2: mean 33.4 (SD 7.2); n=8; Zarit Burden Interview 0-88 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 32.8 (12.2); Control group 28.3 (10.7); Group 1 Number missing: 6, Reason: 6 deaths; Group 2 Number missing: 7, Reason: 1 withdrawal and 6 deaths - Actual outcome: Caregiver's perceived burden in providing family care (ZBI) at 6 months; Group 1: mean 24.3 (SD 6.3); n=4, Group 2: mean 31.6 (SD 7.2); n=5; Zarit Burden Interview 0-88 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Comments - ; Indirectness of outcome: No indirectness ; Baseline details: Intervention group: 32.8 (12.2); Control group 28.3 (10.7); Group 1 Number missing: 10, Reason: 10 deaths; Group 2 Number missing: 10, Reason: 1 withdrawal and9 deaths	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example, GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Chih 2014[50]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	(n=235)
Countries and setting	Conducted in USA; Setting: Outpatient
Line of therapy	Unclear
Duration of study	Intervention + follow up: 12 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall

Study	**Chih 2014**[50]
Subgroup analysis within study	Not applicable
Inclusion criteria	Eligible breast cancer patients were women with metastatic, recurrent or metastatic inflammatory breast cancer, or a chest wall recurrence following mastectomy. Prostate cancer patients were eligible if they had hormone refractory or metastatic prostate cancer. Eligible lung cancer patients included those in stage IIIA, IIIB, or IV. Depending on disease statuses, patients were receiving standard care including curative or palliative treatment. Patients may or may not have had a hospitalization during the course of the treatment, but our intervention was targeted to the outpatient setting. Eligible caregivers were at least 18 years old and were identified by patients as their primary source of physical, emotional, and/or financial support.
Exclusion criteria	Not reported
Recruitment/selection of patients	Recruited at five outpatient oncology clinics in the United States.
Age, gender and ethnicity	Age - Mean (SD): Patient: 62.5(10) Carer: 56(13). Gender (M:F): 96/121. Ethnicity: 92% white
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities : 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Indirectness of population	No indirectness
Interventions	(n=118) Intervention 1: Carer support service - Support groups and education for carers. CHESS+CR: Received access to the CHESS website, which included information, communication, and coaching resources addressing advanced cancer and caregiving needs. At initial login to CHESS and then every 7 days, caregivers and patients completed a Check-in, asking questions about their needs and patient symptoms from the modified Edmonton Symptom Assessment System (ESAS) and Eastern Cooperative Oncology Group Performance Status. They could write questions to be addressed by the clinicians in the next visit. Caregivers reported caregiving burden and preparedness. This Check-in allows users to track patient symptom status, monitoring decline or improvement. CHESS included the clinician report (CR) that summarized the information provided by patients and caregivers at Check-in and made it available online to the clinicians. Clinicians could access the CR via CHESS anytime. However, any caregiver- or patient-reported ESAS symptom rated at a threshold of 7 or higher on a 0- to 10-scale automatically generated an email alerting the clinician to review the report immediately. Clinicians also received an e-mail alert to review reports 2 days before a scheduled clinic visit, regardless of the ESAS rating.. Duration 12-24 months. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=117) Intervention 2: Carer support service - Support groups and education for carers. CHESS only: Received access to the CHESS website, which included information, communication, and coaching

Study	**Chih 2014[50]**
	resources addressing advanced cancer and caregiving needs. At initial login to CHESS and then every 7 days, caregivers and patients completed a Check-in, asking questions about their needs and patient symptoms from the modified Edmonton Symptom Assessment System (ESAS) and Eastern Cooperative Oncology Group Performance Status. They could write questions to be addressed by the clinicians in the next visit. Caregivers reported caregiving burden and preparedness. This Check-in allows users to track patient symptom status, monitoring decline or improvement.. Duration 12-24 months. Concurrent medication/care: Usual care. Indirectness: No indirectness
Funding	Academic or government funding (Grant funding from the National Cancer Institute)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: CHESS + CR versus CHESS ONLY Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Caregiver physical burden at 6 months; Group 1: mean 1.22 (SD 0.62); n=67, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 51, Group 2 number missing: 51 - Actual outcome: Caregiver physical burden at 12 months; Group 1: mean 1.27 (SD 0.6); n=45, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 73, Group 2 number missing: 70 - Actual outcome: Carer negative mood at 6 months; Group 1: mean 0.62 (SD 0.54); n=60, Group 2: mean 0.88 (SD 0.52); n=55 Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 58, Group 2 number missing: 62 - Actual outcome: Carer negative mood at 12 months; Group 1: mean 0.61 (SD 0.54); n=45, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 73, Group 2 number missing: 72	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	**Clark 2006[54]**
Study type	RCT (Patient randomised; Parallel)

Study	Clark 2006[54]
Number of studies (number of participants)	(n=103)
Countries and setting	Conducted in USA; Setting: Not reported
Line of therapy	Unclear
Duration of study	Intervention + follow up: 3 weeks
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Inclusion criteria of previous study for patients: diagnosis within past 12 months, expected survival of 6months to 5 years, treatment recommendation of radiation therapy of at least 2 weeks.
Exclusion criteria	Previous radiation therapy, previous cancer diagnosis within 5 years. MMSE score of <20, or ECOG of >3.
Recruitment/selection of patients	Study coordinator approached all carers meeting inclusion criteria.
Age, gender and ethnicity	Age - Other: n<50: 14 n>50: 69. Gender (M:F): 21/62. Ethnicity:
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities : 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Extra comments	Carers of advanced cancer patients scheduled to undergo radiotherapy. Patients selected for a parent study due to low probability of long term survival.
Indirectness of population	No indirectness
Interventions	(n=43) Intervention 1: Carer support service - Combined care for patients and carers. Patient intervention: Eight 90 minute sessions over 3 weeks. Participants received a manual containing written materials covered in each of the 8 sessions for review. Structured sessions began with 20 minutes of conditioning exercises conducted by a physical therapist, followed by educational information, cognitive-behavioral strategies for coping, discussion and support. Each session concluded with a 10-20 minute guided relaxation exercise. . Duration 3 weeks. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=40) Intervention 2: No carer support services. Control group received standard medical care as recommended by their radiation oncologist.. Duration 3 weeks. Concurrent medication/care: NA.

Study	**Clark 2006[54]**
	Indirectness: No indirectness
Funding	Academic or government funding (Supported by a grant from the Linse Bock Foundation)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COMBINED CARE FOR PATIENTS AND CARERS versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Caregiver burden at 4 weeks; Group 1: mean 76.9 (SD 12.6); n=39, Risk of bias: All domain - High, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 4, Group 2 number missing: 1 - Actual outcome: Caregiver burden at 8 weeks; Group 1: mean 75.1 (SD 12.5); n=41, Risk of bias: All domain - High, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 2, Group 2 number missing: 0 - Actual outcome: Caregiver burden at 27 weeks; Group 1: mean 75.1 (SD 13.9); n=37, Group 2: mean 77.2 (SD 14.8); n=35 Risk of bias: All domain - Low, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 6, Group 2 number missing: 5 - Actual outcome: Linear analog self-assessment (LASA) - Quality of life at 4 weeks; Group 1: mean 77.4 (SD 15.8); n=39, Group 2: mean 75.9 (SD 16.7); n=39 Risk of bias: All domain - Low, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 4, Group 2 number missing: 1 - Actual outcome: Linear analog self-assessment (LASA) - Quality of life at 8 weeks; Group 1: mean 77.6 (SD 14.9); n=41, Group 2: mean 76.3 (SD 21.3); n=40 Risk of bias: All domain - Low, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 2, Group 2 number missing: 0 - Actual outcome: Linear analog self-assessment (LASA) - Quality of life at 27 weeks; Group 1: mean 72.8 (SD 17.2); n=37, Group 2: mean 78.9 (SD 17.3); n=35 Risk of bias: All domain - Low, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 6, Group 2 number missing: 5	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study (subsidiary papers)	**Dubenske 2013[80] (Dubenske 2014[81], Gustafson 2013[111])**
Study type	RCT (Patient randomised; Parallel)

Study (subsidiary papers)	Dubenske 2013[80] (Dubenske 2014[81], Gustafson 2013[111])
Number of studies (number of participants)	(n=285)
Countries and setting	Conducted in USA; Setting: In the community
Line of therapy	Not applicable
Duration of study	Intervention + follow up: Up to 24 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients were adults with non-small cell lung cancer at stage IIIA, IIIB, or IV with a clinician-perceived life expectancy of at lest 4 months and a patient-identified primary caregiver willing to participate in the study. Caregiver provided instrumental, emotional, and/or financial support for the patient and were aged >18 years
Exclusion criteria	Those who were extremely ill and likely had very short survival times
Recruitment/selection of patients	Recruited from four major cancer centre in the Northeaster, Midwestern, and Southwestern United States between January 2005 and April 2007.
Age, gender and ethnicity	Age - Mean (SD): Internet: 54.57(12.21) CHESS: 56.56(12.86). Gender (M:F): 117/168. Ethnicity: Not reported
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities : 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Extra comments	Caregiver lung cancer and their patients.
Indirectness of population	No indirectness
Interventions	(n=144) Intervention 1: Carer support service - Support groups and education for carers. CHESS; CHESS arm received password-protected access to the CHESS Coping with Lung Cancer website. CHESS was designed to be easy to use and: 1) to provide well organized lung cancer, caregiving, and bereavement information; 2) to serve as a channel for communication with and support from peers, experts, clinicians,

Study (subsidiary papers)	**Dubenske 2013[80] (Dubenske 2014[81], Gustafson 2013[111])**
	and users' social networks; 3) to act as a coach by gathering information from users and providing feedback based on algorithms (decision rules); and 4) to provide tools (eg, a program to organize support from family and friends) to improve the caregiving experience. CHESS included a clinician report that summarized caregiver and patient ratings of the patient's health status15 and listed their questions for the next clinic visit. Clinicians received email alerts before a scheduled visit and whenever a symptom rating exceeded 7 on a scale from 0 to 10. . Duration 25 months or 13 months after patient death.. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=141) Intervention 2: No carer support services. Internet: Received training on using the Internet and a list of Internet sites about lung cancer (eg, www.lungcanceralliance.org, http://cancernet.nci.nih.gov/cancertopics/types/lung, and www.lungcanceronline.org; all accessed August a,b008). Duration 25 months or 13 months after patient death. Concurrent medication/care: Usual care. Indirectness: No indirectness
Funding	Academic or government funding (Supported by a grant from the National Cancer Institute)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: CHESS versus INTERNET Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Caregiver Quality of Life – Cancer Scale (CQOLC) Burden Subscale at 2 months; Group 1: mean 16.15 (SD 8.26); n=58, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 86, Group 2 number missing: 77 - Actual outcome: Caregiver Quality of Life – Cancer Scale (CQOLC) Burden Subscale at 4 months; Group 1: mean 15.87 (SD 8.43); n=60, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 84, Group 2 number missing: 90 - Actual outcome: Caregiver Quality of Life – Cancer Scale (CQOLC) Burden Subscale at 6 months; Group 1: mean 13.14 (SD 7.63); n=44, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 100, Group 2 number missing: 90 - Actual outcome: Caregiver Quality of Life – Cancer Scale (CQOLC) Burden Subscale at 8 months; Group 1: mean 16.34 (SD 6.86); n=42, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 102, Group 2 number missing: 101	

Study (subsidiary papers)	**Dubenske 2013[80] (Dubenske 2014[81], Gustafson 2013[111])**
- Actual outcome: Short version profile of mood states (SV-POMS) - Negative mood at 2 months; Group 1: mean 0.92 (SD 0.74); n=58, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 86, Group 2 number missing: 77 - Actual outcome: Short version profile of mood states (SV-POMS) - Negative mood at 4 months; Group 1: mean 0.88 (SD 0.72); n=60, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 84, Group 2 number missing: 90 - Actual outcome: Short version profile of mood states (SV-POMS) - Negative mood at 6 months; Group 1: mean 0.65 (SD 0.6); n=45, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 100, Group 2 number missing: - Actual outcome: Short version profile of mood states (SV-POMS) - Negative mood at 8 months; Group 1: mean 0.92 (SD 0.81); n=42, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 102, Group 2 number missing: 101	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study (subsidiary papers)	**ENABLE III trial: Dionne-odom 2015[72] (Dionne-odom 2016[71])**
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=122)
Countries and setting	Conducted in USA; Setting: patients' homes - telephone intervention
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 3 weeks + follow up
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: inclusion criteria included prognosis of 6-24 months
Stratum	Overall: NA
Subgroup analysis within study	Unclear: NA

Study (subsidiary papers)	ENABLE III trial: Dionne-odom 2015[72] (Dionne-odom 2016[71])
Inclusion criteria	>18 years of age; new diagnosis, recurrence or progression of an advanced stage cancer within approximately 30-60 days of the date the patient was informed of the diagnosis and oncologist-determined prognosis of 6-24 months; English speaking; able to complete baseline questionnaires
Exclusion criteria	<4 on the Callahan cognitive screen, had an untreated axis 1 psychiatric condition (eg. schizophernia, bipolar disorder) or an active substance use disorder, or had uncorrectable hearing disorder or unreliable telephone service
Recruitment/selection of patients	not reported
Age, gender and ethnicity	Age - Mean (SD): early group 61 (11.6), delayed group 57.9 (11.9). Gender (M:F): early group 14/47, delayed group 12/49. Ethnicity: early group 90.2% white, 6.6% other, 3.3% missing, delayed group 95% white, 1.6% other 3.3% missing
Further population details	1. Frail elderly: Not stated / Unclear 2. Homeless people/vulnerably housed: Not stated / Unclear 3. LGBT: Not stated / Unclear 4. Migrant workers: Not stated / Unclear 5. People from ethnic minorities : People not from ethnic minorities 6. People in prisons: People not in prisons 7. People in whom life-prolonging therapies are still an active option: Not stated / Unclear 8. People with dementia: People without dementia 9. People with disabilities: Not stated / Unclear 10. People with hearing loss: People without hearing loss 11. People with learning difficulties: Not stated / Unclear 12. People with mental health problems: People without mental health problems 13. Socioeconomic inequalities: Not stated / Unclear 14. Travelers: Not stated / Unclear 15. Younger adults (aged 18-25): Older adults (aged 26 and over)
Indirectness of population	No indirectness: NA
Interventions	(n=61) Intervention 1: Carer support service - Psychological support. ENABLE (at patient diagnosis): 3 once per week structured one-on-one telephone sessions between an advanced-practice palliative care nurse coach and caregiver guided by the 'Charting Your Course: Caregiver' guidebook addressing the CG role, problem-solving using the COPE framework, self-care, building a support team, decision-making and advance care planning, nurses followed up at least monthly by telephone until the patient died or study ended . Duration 3 weeks . Concurrent medication/care: not reported . Indirectness: No indirectness; Indirectness comment: NA (n=61) Intervention 2: No carer support services. delayed intervention - caregivers were able to access any of the usual support services available . Duration 3 months . Concurrent medication/care: not reported . Indirectness: No indirectness; Indirectness comment: NA (n=61) Intervention 3: Carer support service - Psychological support. Delayed ENABLE (12 weeks after diagnosis): 3 once per week structured one-on-one telephone sessions between an advanced-practice palliative care nurse coach and caregiver guided by the 'Charting Your Course: Caregiver' guidebook addressing the CG role, problem-solving using the COPE framework, self-care, building a support team,

Study (subsidiary papers)	ENABLE III trial: Dionne-odom 2015[72] (Dionne-odom 2016[71])
	decision-making and advance care planning, nurses followed up at least monthly by telephone until the patient died or study ended. Duration Until patient death. Concurrent medication/care: Usual care. Indirectness: No indirectness
Funding	Academic or government funding (National Institute for Nursing Research, University of Alabama at Birmingham Cancer Prevention and Control Training Program, NIH/NINR Small Research Grant, American Cancer Society)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT (EARLY) versus PSYCHOLOGICAL SUPPORT (DELAYED) Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: caregiver quality of life scale-cancer at 3 months ; MD; -2 (SE = 2.3) CQOL-C 0-140 Top=High is poor outcome, Comments: between group difference in change from baseline adjusted for patient death ; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed - Actual outcome: Center for Epidemiologic Study-Depression Scale at 3 months ; MD; -3.4 (SE = 1.5) CESD 0-60 Top=High is poor outcome, Comments: between group difference in change from baseline adjusted for patient death ; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed - Actual outcome: Montgomery-Borgatta Caregiver Burden Scale (objective subscale) at 3 months ; MD; 0.3 (SE = 0.7) MBCB-OB 6-30 Top=High is poor outcome, Comments: between group difference in change from baseline adjusted for patient death ; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed - Actual outcome: Montgomery-Borgatta Caregiver Burden Scale (demand subscale) at 3 months ; MD; -0 (SE = 0.7) 4-20 MBCB-DB Top=High is poor outcome, Comments: between group difference in change from baseline adjusted for patient death ; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed - Actual outcome: Montgomery-Borgatta Caregiver Burden Scale (stress subscale) at 3 months ; MD; -0.5 (SE = 0.5) MBCB-SB 4-20 Top=High is poor outcome, Comments: between group difference in change from baseline adjusted for patient death ; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed - Actual outcome: Center for Epidemiologic Study-Depression Scale at After patient death; Group 1: mean 3.4 (SD 9.5); n=19, Group 2: mean 2.6 (SD 12.1); n=25; CES-D 0-60 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed - Actual outcome: Grief at After patient death; Group 1: mean 22.7 (SD 4.9); n=19, Group 2: mean 24.9 (SD 6.9); n=25; Prigerson Inventory of	

Study (subsidiary papers)	ENABLE III trial: Dionne-odom 2015[72] (Dionne-odom 2016[71])
Complicated Grief-Short Form (PG13) 5-65 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: early group had a higher proportion employed	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study (subsidiary papers)	Hudson 2005[141]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=106)
Countries and setting	Conducted in Australia; Setting: Patients homes
Line of therapy	Unclear
Duration of study	Intervention + follow up: 8 weeks following patient death
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Primary family caregivers of patients with advanced cancer receiving home-based palliative care.
Exclusion criteria	NA
Recruitment/selection of patients	Recruited from four home-based palliative care services in three states of Australia (Victoria, New South Wales and Western Australia) over a 2-year period (2009–2011).
Age, gender and ethnicity	Age - Mean (SD): 59.0 years (SD = 13.9). Gender (M:F): Define. Ethnicity: Not reported
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities: 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Indirectness of population	No indirectness
Interventions	(n=54) Intervention 1: Psycho-education: Nurse provision of information to enhance understanding of issues and provide a basis for skill acquisition, reinforcement of the role of the palliative care service and

Study (subsidiary papers)	**Hudson 2005[141]**
	other services, and providing strategies to involve family and friends, helping the caregiver make a sense of emotional reactions to the situation and encouraging caregivers to see the positive aspects of experience and offering access to spiritual guidance, promoting caregivers to enhance their own physical and mental health by taking regular time out, having a healthy diet, taking exercise and providing advice on relaxation strategies and providing advice on their rights. Duration: The intervention involved two home visits and one follow-up phone call between the visits. It was supported by a caregiver guidebook and audiotape. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=52) Intervention 2: No carer support services. The intervention involved two home visits and one follow-up phone call between the visits. It was supported by a caregiver guidebook and audiotape. Concurrent medication/care: Usual care. Indirectness: No indirectness
Funding	Academic or government funding (Supported by the NH & MRC Grant)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT - 1 SESSION+3 PHONE CALLS versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Anxiety at 4 week post intervention; Group 1: mean 7.76 (SD 3.56); n=40, Group 2: mean 8.06 (SD 3.95); n=35, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 14, Group 2 number missing: 17 - Actual outcome: Anxiety at 8 week post patient death; Group 1: mean 6.96 (SD 4.02); n=20, Group 2: mean 6.76 (SD 3.72); n=25, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 34, Group 2 number missing: 27	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ;; Preferred and actual place of care ; Longevity of the carer ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay ; Carer health

Study (subsidiary papers)	**Hudson 2013[139] (Hudson 2015[140])**
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	2 (n=298)
Countries and setting	Conducted in Australia; Setting: Patients homes

Study (subsidiary papers)	Hudson 2013[139] (Hudson 2015[140])
Line of therapy	Unclear
Duration of study	Intervention + follow up: 5 weeks
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Primary family caregivers of patients with advanced cancer receiving home-based palliative care.
Exclusion criteria	NA
Recruitment/selection of patients	Recruited from four home-based palliative care services in three states of Australia (Victoria, New South Wales and Western Australia) over a 2-year period (2009–2011).
Age, gender and ethnicity	Age - Mean (SD): 59.0 years (SD = 13.9). Gender (M:F): Define. Ethnicity: Not reported
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities: 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Indirectness of population	No indirectness
Interventions	(n=57) Intervention 1: Carer support service - Psychological support. One visit + 3 phone calls. The psycho-educational focus included tailored information and resources given to family caregivers to promote psychological well-being by preparing them for their role. Each caregiver was allocated a Family Caregiver Support Nurse (FCSN) who assisted the local palliative care service to assess caregiver needs, establish a care plan and provide additional caregiver support. The FCSNs (one per recruitment site) received training from relevant members of the research team and an intervention manual was developed to foster consistency in delivery. The primary written resource was a family caregiver guidebook, developed and tested in a pilot study. The intervention was delivered over 4 weeks and comprised the following: Step 1 involved preparing caregivers for the intervention. The FCSN (i) phoned family caregivers within 3 days of randomisation to advise them of the FCSN role; (ii) sent them the family caregiver guidebook; (iii) provided written information about the FCSN/the intervention; and (iv) arranged a home visit within 1 week. Step 2 involved assessing caregiver needs and preparing a care plan. Home visit was carried out by the FCSN who (i) assessed unmet needs; (ii) developed a care plan in conjunction with the caregiver (and the patient, where pertinent) and the local palliative care team; and (iii) prepared the caregivers for their role by explaining educational resources. Step 3 involved re-assessing needs and evaluating the care plan: The FCSN reviewed caregivers' status and evaluated the care plan by phone. Caregivers were reminded about

Study (subsidiary papers)	Hudson 2013[139] (Hudson 2015[140])
	relevant resources and strategies to promote psychological well-being, including trying to identify positive aspects of caring. Step 4 involved assisting the family caregiver to prepare for their relative's death and to prepare for bereavement. Home visit by the FCSN was carried out to focus on preparing caregiver for aspects typically associated with imminent death. Caregivers were also advised of common reactions during bereavement and of available bereavement resources. The FCSN concluded the structured component of the intervention with a summary (including written format) of key strategies and resources. The care plan was revised, incorporating referral to other services as required.. Duration 5 weeks. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=93) Intervention 2: Carer support service - Psychological support. 2 sessions + 2 phone calls. The psycho-educational focus included tailored information and resources given to family caregivers to promote psychological well-being by preparing them for their role. Each caregiver was allocated a Family Caregiver Support Nurse (FCSN) who assisted the local palliative care service to assess caregiver needs, establish a care plan and provide additional caregiver support. The FCSNs (one per recruitment site) received training from relevant members of the research team and an intervention manual was developed to foster consistency in delivery. The primary written resource was a family caregiver guidebook, developed and tested in a pilot study. The intervention was delivered over 4 weeks and comprised the following: Step 1 involved preparing caregivers for the intervention. The FCSN (i) phoned family caregivers within 3 days of randomisation to advise them of the FCSN role; (ii) sent them the family caregiver guidebook; (iii) provided written information about the FCSN/the intervention; and (iv) arranged a home visit within 1 week. Step 2 involved assessing caregiver needs and preparing a care plan. Home visit was carried out by the FCSN who (i) assessed unmet needs; (ii) developed a care plan in conjunction with the caregiver (and the patient, where pertinent) and the local palliative care team; and (iii) prepared the caregivers for their role by explaining educational resources. Step 3 involved re-assessing needs and evaluating the care plan: The FCSN reviewed caregivers' status and evaluated the care plan by phone. Caregivers were reminded about relevant resources and strategies to promote psychological well-being, including trying to identify positive aspects of caring. Step 4 involved assisting the family caregiver to prepare for their relative's death and to prepare for bereavement. Home visit by the FCSN was carried out to focus on preparing caregiver for aspects typically associated with imminent death. Caregivers were also advised of common reactions during bereavement and of available bereavement resources. The FCSN concluded the structured component of the intervention with a summary (including written format) of key strategies and resources. The care plan was revised, incorporating referral to other services as required.. Duration 4 weeks. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=148) Intervention 3: No carer support services. Multidisciplinary specialist support for patients with advanced, non-curative disease and their families. Services included an initial assessment, scheduled home visits and access to a health care professional after hours for advice. Specific caregiver support

Study (subsidiary papers)	Hudson 2013[139] (Hudson 2015[140])
	strategies varied within services and were not always systematic or comprehensive.. Duration 4 weeks. Concurrent medication/care: Usual care. Indirectness: No indirectness
Funding	Academic or government funding (Supported by the NH & MRC Grant)

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT - 1 SESSION+3 PHONE CALLS versus PSYCHOLOGICAL SUPPORT - 2 SESSIONS+2 PHONE CALLS

Protocol outcome 1: Carer health (for example: GP visits, mental health, school/work attendance)
- Actual outcome: General Health Questionnaire (GHQ) at 1 week post intervention; Group 1: mean 3.56 (SD 0.932); n=29, Group 2: mean 3.64 (SD 1.51); n=93; Comments: Values read across from a graph
Risk of bias: All domain - Very high, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 28, Group 2 number missing: 42
- Actual outcome: General Health Questionnaire (GHQ) at 8 weeks post death; Group 1: mean -0.15 (SD 0.84); n=31, Group 2: mean 0.17 (SD 0.8); n=53; sGHQ Not reported Top=High is poor outcome
Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 26, Group 2 number missing: 40

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT - 1 SESSION+3 PHONE CALLS versus NO CARER SUPPORT SERVICES

Protocol outcome 1: Carer health (for example: GP visits, mental health, school/work attendance)
- Actual outcome: General Health Questionnaire (GHQ) at 1 week post intervention; Group 1: mean 3.56 (SD 0.93); n=29,
Risk of bias: All domain - Very high, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 28, Group 2 number missing: 67
- Actual outcome: General Health Questionnaire (GHQ) at 8 weeks post death; Group 1: mean -0.15 (SD 0.84); n=31, Group 2: mean 0.28 (SD 0.79); n=76; sGHQ Not reported Top=High is poor outcome
Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 28, Group 2 number missing: 67

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT - 2 SESSIONS+2 PHONE CALLS versus NO CARER SUPPORT SERVICES

Protocol outcome 1: Carer health (for example: GP visits, mental health, school/work attendance)
- Actual outcome: General Health Questionnaire (GHQ) at 1 week post intervention; Group 1: mean 3.64 (SD 1.51); n=51, Group 2: mean 3.73 (SD 2.42); n=81; Comments: Values read across from a graph
Risk of bias: All domain - Very high, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - High, Measurement - Low,

Study (subsidiary papers)	Hudson 2013[139] (Hudson 2015[140])
Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 26, Group 2 number missing: 72 - Actual outcome: General Health Questionnaire (GHQ) at 8 weeks post death; Group 1: mean 0.17 (SD 0.8); n=53, Group 2: mean 0.28 (SD 0.8); n=76; sGHQ Not reported Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 40, Group 2 number missing: 72	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Quality of life of carer of (or person important to) the person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Keefe 2005[160]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=78 dyads)
Countries and setting	Conducted in USA
Line of therapy	Unclear
Duration of study	Intervention + follow up: 2 weeks
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Advanced (defined as metastatic or disseminated disease) cancer patients with disease-related pain. Life expectancy of less than six months, and had no change in planned treatment.
Exclusion criteria	Not reported
Recruitment/selection of patients	Recruited from participating hospices.
Age, gender and ethnicity	Caregiver: 76% spouse and 14% daughters, mean age 58.5 years, 62% female, 79% white, 20% African American. Patient: Mean age 60.5 years, 44%female, 78%white and 21% African American
Further population details	The most common cancer was breast (25%) and lung (20%)
Extra comments	Most frequent diagnoses were lung, breast and prostate cancer.
Indirectness of population	NA

Study	**Keefe 2005**[160]
Interventions	(n=41 dyads) Intervention 1: Carer education. Partner-guided cancer pain management. Nurse educator conducted sessions with the patient and partner on coping with pain, including types of pain, treatment including relaxation training and imagery and activity pacing method, and communication with health providers. The intervention was supported by a videotape and book. Three face-to-face home sessions of 45 to 60 minutes over one to two weeks. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=37 dyads) Intervention 2: No carer support services. Patients received usual care through their medical outpatient or hospice programme. Concurrent medication/care: NA. Indirectness: No indirectness
Funding	Supported by national cancer institute grant, and in part by Fetzer Institute.
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT: CARER EDUCATION versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of person in their last year of life - Actual outcome: The Functional Assessment of Cancer Therapy-General (FACT-G) – Physical wellbeing at post-treatment (mean 6 days); Group 1: mean 2.02 (SD 0.77); n=28, Group 2: mean 2.08 (SD 0.77); n=28; FACT-G 0-5 Top=Low is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 13, Group 2 number missing: 9 - Actual outcome: The Functional Assessment of Cancer Therapy-General (FACT-G) – Social/family wellbeing at post-treatment (mean 6 days); Group 1: mean 3.55 (SD 0.52); n=28, Group 2: mean 3.33 (SD 0.52); n=28; FACT-G 0-5 Top=Low is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 13, Group 2 number missing: 9	
Protocol outcomes not reported by the study	Quality of life of carer of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	**Kissane 2006**[164]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=363 (81 families))
Countries and setting	Conducted in Australia

Study	Kissane 2006[164]
Line of therapy	Unclear
Duration of study	Intervention + follow up: 13 months after bereavement
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Cancer patients with prognosis given by treating physician of 6 months, aged 35-70 years, a living partner and at least one child aged >12 years. Families at risk of poor psychosocial outcome, defined by an FRI of <9 out of 12 or a cohesion subscale, <4.
Exclusion criteria	Not reported
Recruitment/selection of patients	Recruited between January 1996 and 2001.
Age, gender and ethnicity	Age - Mean (SD): Patient: 57 years (8) Partners: 56 years (9) Offspring: 29 years (9). Gender (M:F): 175/188.
Further population details	The most common cancer was breast (25%) and lung (20%)
Extra comments	Most participants were either of professional or clerical occupational group (123/189)
Indirectness of population	No indirectness
Interventions	(n=53 patients, 180 family members) Intervention 1: Carer support service - Psychological support. Family-Focused Grief Therapy (FFGT) – Content: The family focused grief therapy intervention aimed to enhance the functioning of the family to prevent complications of bereavement. It was operationalised through exploring family cohesion, communication of thoughts and feelings, and handling of conflict. In the process it was envisaged that the personal story of the illness and related grief would be shared. There were three intervention phases: ascertainment which involved identifying concerns relevant to the specific family, devising and acting on a plan to deal with concerns and, at the end of the therapy, consolidation of what was gains and was confronted during the therapy The therapy was conducted either in the hospital or, more commonly, at home. Started during palliative care and continued into bereavement. It comprised of 4 to 8 sessions of 90 minutes duration, across 9 to 18 months. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=28 patients, 102 family members) Intervention 2: No carer support services. Usual care; counselling was included where needed. Duration 7 months. Concurrent medication/care: NA. Indirectness: No indirectness
Funding	Supported by Bethlehem Griffiths research Foundation, Australian Rotary Health Research Fund, and National Health and Medical Council Australia.

Study	Kissane 2006[164]
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT: FFGT versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Carer depression (BDI) at 6 months post death; Group 1: mean 3.6 (SD 3.74); n=154, Group 2: mean 4.21 (SD 4.92); n=94; BDI 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 26, Group 2 number missing: 8 - Actual outcome: Carer depression (BDI) at 13 months post death; Group 1: mean difference -036 (SD 4.61); n=148, Group 2: mean difference -0.1 (SD -0.1); n=83; BDI 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 32, Group 2 number missing: 19	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Kissane 2016[165]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=620 (170 families))
Countries and setting	Conducted in USA
Line of therapy	Unclear
Duration of study	Intervention + follow up: 13 months after bereavement
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Perception by one family member of reduced relational functioning, defined by an FRI of <9 out of 12 or a cohesion subscale, <4; geographic accessibility to treatment; children age 12 years or older who were able to complete questionnaires; and willingness of at least three family members, including the patient with

Study	Kissane 2016[165]
	cancer, to attend therapy.
Exclusion criteria	Not reported
Recruitment/selection of patients	Recruited between January 2006 and December 2011 from Memorial Sloan Kettering Cancer Centre (n = 540), Calvary Hospital (n = 46), Visiting Nursing Service of New York (n = 22) and Beth Israel Hospice Service (n = 12).
Age, gender and ethnicity	Age - Mean (SD): Patient: ~55, Partners: ~57 Other relatives: ~37. Gender (M:F): 248/372. Ethnicity: Non-Hispanic 88.5%, Hispanic 11%
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities : 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Extra comments	patients with a survival prognosis of less than 1 year (on the basis of judgment of the treating oncologist) and their relatives for individual perceptions of relational functioning using the Family Relationships Index (FRI).
Indirectness of population	No indirectness
Interventions	(n=220) Intervention 1: Carer support service - Psychological support. Family-Focused Grief Therapy (FFGT) - Families tell the story of illness. Therapists explore each family's communication, cohesiveness, and conflict resolution alongside family values, beliefs, roles, and expectations. 10 sessions . Duration 7 months. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=213) Intervention 2: Carer support service - Psychological support. Family-Focused Grief Therapy (FFGT) - Families tell the story of illness. Therapists explore each family's communication, cohesiveness, and conflict resolution alongside family values, beliefs, roles, and expectations. 6 sessions . Duration 7 months. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=187) Intervention 3: No carer support services. Usual care. Duration 7 months. Concurrent medication/care: NA. Indirectness: No indirectness
Funding	Academic or government funding (Supported by National Cancer Institute)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT: 10 SESSIONS versus PSYCHOLOGICAL SUPPORT: 6 SESSIONS	

Study	Kissane 2016[165]
Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Carer depression (BDI-II) at 6 months post death; Group 1: mean 9.84 (SD 8.88); n=122, Group 2: mean 10.71 (SD 7.45); n=121; BDI-II 0-63 Top=High is poor outcome; Comments: (>16 shows clinical depression) Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 98, Group 2 number missing: 66 - Actual outcome: Carer depression (BDI-II) at 13 months post death; Group 1: mean 8.45 (SD 8.3); n=144, Group 2: mean 10.69 (SD 9.31); n=144; BDI-II 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 76, Group 2 number missing: 43 - Actual outcome: Carer grief (CGI) at 6 months post death; Group 1: mean 19.52 (SD 7.8); n=122, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 98, Group 2 number missing: 92 - Actual outcome: Carer grief (CGI) at 13 months post death; Group 1: mean 18.26 (SD 7.03); n=144, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 76, Group 2 number missing: 69 RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT: 10 SESSIONS versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Carer depression (BDI-II) at 6 months post death; Group 1: mean 9.84 (SD 8.88); n=122, Group 2: mean 11.83 (SD 10.26); n=81; BDI-II 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 98, Group 2 number missing: 106 - Actual outcome: Carer depression (BDI-II) at 13 months post death; Group 1: mean 8.45 (SD 8.3); n=144, Group 2: mean 9.93 (SD 9.36); n=101; BDI-II 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 76, Group 2 number missing: 86 - Actual outcome: Carer grief (CGI) at 6 months post death; Group 1: mean 19.52 (SD 7.8); n=122, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 98, Group 2 number missing: 106 - Actual outcome: Carer grief (CGI) at 13 months post death; Group 1: mean 18.26 (SD 7.03); n=144, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 76, Group 2 number missing: 86 RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PSYCHOLOGICAL SUPPORT: 6 SESSIONS versus NO CARER SUPPORT SERVICES	

Study	**Kissane 2016**[165]
Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Carer depression (BDI-II) at 6 months post death; Group 1: mean 10.71 (SD 7.45); n=121, Group 2: mean 11.83 (SD 10.28); n=81; BDI-II 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 66, Group 2 number missing: 106 - Actual outcome: Carer depression (BDI-II) at 13 months post death; Group 1: mean 10.69 (SD 9.31); n=144, Group 2: mean 9.93 (SD 9.36); n=101; BDI-II 0-63 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 76, Group 2 number missing: 86 - Actual outcome: Carer grief (CGI) at 6 months post death; Group 1: mean 20.14 (SD 7.32); n=121, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 98, Group 2 number missing: 106 - Actual outcome: Carer grief (CGI) at 13 months post death; Group 1: mean 19.85 (SD 7.02); n=144, Risk of bias: All domain - Very high, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - High, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 76, Group 2 number missing: 86	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	**Leow 2015**[174]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=80)
Countries and setting	Conducted in Singapore; Setting: 4 home hospice organizations and an outpatient clinic
Line of therapy	Not applicable
Duration of study	Intervention + follow up: intervention + 8 weeks follow up
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: advanced stage 4 cancer
Stratum	Overall: NA
Subgroup analysis within study	Unclear: NA

Study	**Leow 2015**[174]
Inclusion criteria	family caregiver of a person with advanced (stage 4) cancer receiving home hospice care who has a prognosis of at least 3 months based on the estimation of the primary physician, spend at least 20 hours a week with the patient, able to understand and communicate in English, aged >21 years
Exclusion criteria	domestic helpers and caregivers with known mental health problems or cognitive impairment
Recruitment/selection of patients	convenience sample of all caregivers of newly admitted and current patients meeting the inclusion criteria
Age, gender and ethnicity	Age - Mean (SD): standard care 47.31 (11.94), intervention 47 (11.73. Gender (M:F): standard care 15/27, intervention 11/27. Ethnicity: standard care Chinese 36, Malaysian 3, Indian 2, Caucasian 1, intervention Chinese 32, Malaysian 5, Indian 1, Caucasian 0
Further population details	1. Frail elderly: Not stated / Unclear 2. Homeless people/vulnerably housed: Not stated / Unclear 3. LGBT: Not stated / Unclear 4. Migrant workers: Not stated / Unclear 5. People from ethnic minorities : Not applicable 6. People in prisons: People not in prisons 7. People in whom life-prolonging therapies are still an active option: Not stated / Unclear 8. People with dementia: People without dementia 9. People with disabilities: Not stated / Unclear 10. People with hearing loss: Not stated / Unclear 11. People with learning difficulties: Not stated / Unclear 12. People with mental health problems: People without mental health problems 13. Socioeconomic inequalities: Not stated / Unclear 14. Travelers: Not stated / Unclear 15. Younger adults (aged 18-25): Not stated / Unclear
Indirectness of population	No indirectness: NA
Interventions	(n=38) Intervention 1: Carer support service - Support groups and education for carers. one hour face-to-face session within 1 week during which caregivers watched a video clip about issues faced such as stress and ways to manage it and developed a care plan, 2 follow-up phone calls at weeks 3 and 6 during which care plans were reviewed and nurses provided support and an online social support group . Duration 6 weeks . Concurrent medication/care: routine care from home hospice organizations including regular weekly-monthly visits from a home hospice nurse and psychosocial support such as counseling if required . Indirectness: No indirectness; Indirectness comment: NA (n=42) Intervention 2: No carer support services. routine care from home hospice organizations including regular weekly-monthly visits from a home hospice nurse and psychosocial support such as counseling if required . Duration 6 weeks . Concurrent medication/care: not reported . Indirectness: No indirectness; Indirectness comment: NA
Funding	Academic or government funding (Lien Centre for Palliative Care)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: SUPPORT GROUPS AND EDUCATION FOR CARERS versus NO CARER SUPPORT SERVICES	

Study	**Leow 2015[174]**
Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Caregiver Quality of Life Index-Cancer at 8 weeks ; Group 1: mean 105.66 (SD 15.95); n=38, Group 2: mean 84.43 (SD 23.57); n=42; CQOL-C 0-140 Top=High is good outcome; Comments: similar baseline scores Risk of bias: All domain - Very high, Selection - Low, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA - Actual outcome: Social support questionnaire (satisfaction subscale) at 8 weeks ; Group 1: mean 34.42 (SD 2.87); n=38, Group 2: mean 28.98 (SD 5.99); n=42; social support questionnaire not reported Top=High is good outcome; Comments: similar scores at baseline Risk of bias: All domain - Very high, Selection - Low, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: not a quality of life measure - Actual outcome: Social support questionnaire (support number subscale) at 8 weeks ; Group 1: mean 17.13 (SD 8.88); n=38, Group 2: mean 10.62 (SD 8.16); n=42; social support questionnaire not reported Top=High is good outcome; Comments: scores similar at baseline Risk of bias: All domain - Very high, Selection - Low, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: not a quality of life measure - Actual outcome: Depression Anxiety Stress Scales at 8 weeks ; Group 1: mean 3.16 (SD 3.94); n=38, Group 2: mean 8.86 (SD 9.53); n=42; Depression Anxiety Stress Scale not reported Top=High is poor outcome; Comments: similar scores at baseline Risk of bias: All domain - Very high, Selection - Low, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA - Actual outcome: General closeness scale at 8 weeks ; Group 1: mean 13.47 (SD 2.6); n=38, Group 2: mean 10.98 (SD 3.71); n=42; general closeness scale not reported Top=High is good outcome; Comments: similar scores at baseline Risk of bias: All domain - Very high, Selection - Low, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: not a quality of life measure - Actual outcome: Caregiver self-care self-efficacy scale at 8 weeks ; Group 1: mean 88.32 (SD 9.74); n=38, Group 2: mean 77.5 (SD 20.93); n=42; caregiver self-care self-efficacy scale not reported Top=High is good outcome; Comments: scores were higher in the standard care group at baseline Risk of bias: All domain - Very high, Selection - High, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: not a quality of life measure - Actual outcome: obtaining respite scale at 8 weeks ; Group 1: mean 43.16 (SD 5.94); n=38, Group 2: mean 38.21 (SD 12.82); n=42; obtaining respite scale not reported Top=High is good outcome; Comments: standard care group had higher scores at baseline Risk of bias: All domain - Very high, Selection - High, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: not a quality of life measure - Actual outcome: controlling upsetting thoughts subscale at 8 weeks ; Group 1: mean 45.16 (SD 6.38); n=38, Group 2: mean 39.29 (SD 10.17); n=42; controlling upsetting thoughts subscale not reported Top=High is good outcome; Comments: standard care group had higher baseline scores Risk of bias: All domain - Very high, Selection - High, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA - Actual outcome: Rewards of caregiving at 8 weeks ; Group 1: mean 35.18 (SD 7.4); n=38, Group 2: mean 24.31 (SD 13.51); n=42; rewads of caregiving not reported Top=High is good outcome; Comments: intervention group had higher baseline values Risk of bias: All domain - Very high, Selection - High, Blinding - Very high, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA	

Study	Leow 2015[174]
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Mclean 2013[184]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=42)
Countries and setting	Conducted in Canada; Setting: hospital clinical offices
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 2-3 months + 3 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall: NA
Subgroup analysis within study	Unclear: NA
Inclusion criteria	metastatic cancer, English speaking, at least 18 years old, in a romantic partnership for at least 1 year, endorsing marital distress in minimally one partner, not currently in couple therapy, Karnofsky Performance Status score of at least 60
Exclusion criteria	significant cognitive deficits (short orientation-memory-concentration test cut-off score of <20 equivalent to >10 errors), patient too ill to participate or if either partner had major psychiatric illness
Recruitment/selection of patients	not reported
Age, gender and ethnicity	Age - Mean (SD): intervention patients 51.83 (9.1), control patients 49.45 (12.42), intervention caregivers 48.82 (13.38), control caregivers 50.89 (9.27). Gender (M:F): intervention patients 10/12, control patients 9/11, intervention caregivers 12/10, control caregivers 11/9. Ethnicity: not reported
Further population details	1. Frail elderly: Not stated / Unclear 2. Homeless people/vulnerably housed: Not stated / Unclear 3. LGBT: Non-LGBT 4. Migrant workers: Not stated / Unclear 5. People from ethnic minorities : Not stated / Unclear 6. People in prisons: People not in prisons 7. People in whom life-prolonging therapies are still an active option: Not stated / Unclear 8. People with dementia: People without dementia 9. People with disabilities: Not stated / Unclear 10. People with hearing loss: Not stated / Unclear 11. People with learning difficulties: Not stated / Unclear 12. People with mental health problems: Not stated / Unclear 13.

Study	Mclean 2013[184]
	Socioeconomic inequalities: Not stated / Unclear 14. Travelers: Not stated / Unclear 15. Younger adults (aged 18-25): Older adults (aged 26 and over)
Indirectness of population	No indirectness: NA
Interventions	(n=22) Intervention 1: Carer support service - Combined care for patients and carers. 8 one-hour weekly emotionally focused therapy sessions adapted for couples where one partner has metastatic cancer . Duration 2-3 months . Concurrent medication/care: not reported . Indirectness: No indirectness; Indirectness comment: NA (n=20) Intervention 2: No carer support services. standard care provided by the psychological oncology and palliative care department (social work consultations account for two thirds of the psychosocial care, of the remainder referred to psychiatry or psychology, theoretical orientation depends on the individual clinician), patients and their partners may be followed weekly, biweekly, or monthly until end of life. Duration 2-8 sessions . Concurrent medication/care: not reported . Indirectness: Serious indirectness; Indirectness comment: couples received support services as needed
Funding	Funding not stated

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COMBINED CARE FOR PATIENTS AND CARERS versus NO CARER SUPPORT SERVICES

Protocol outcome 1: Quality of life of person in their last year of life
- Actual outcome: Beck Depression Inventory-II at 3 months ; Group 1: mean 15.89 (SD 11.7); n=18, Group 2: mean 14.33 (SD 10.9); n=18; BDI-II 0-63 Top=High is poor outcome; Comments: baseline values were significantly higher in the intervention group
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: higher scores in the intervention group
- Actual outcome: Beck Hopelessness Scale at 3 months ; Group 1: mean 6.95 (SD 5.8); n=18, Group 2: mean 5.78 (SD 6); n=18; BHS 0-20 Top=High is poor outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: higher depression scores in the intervention group

Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life
- Actual outcome: Beck Depression Inventory-II at 3 months ; Group 1: mean 13.33 (SD 8.1); n=18, Group 2: mean 9.67 (SD 7.3); n=18; BDI=II 0-63 Top=High is poor outcome; Comments: baseline scores were significantly higher in the intervention group
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: higher scores in the intervention group
- Actual outcome: Beck Hopelessness Scale at 3 months ; Group 1: mean 6.94 (SD 5.4); n=18, Group 2: mean 5.39 (SD 3.9); n=18; BHS 0-20 Top=High is poor outcome

Study	Mclean 2013[184]
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: higher depression scores in the intervention group - Actual outcome: Caregiver burden scale (time subscale) at 3 months ; Group 1: mean 2.58 (SD 1.2); n=18, Group 2: mean 2.7 (SD 1.3); n=18; caregiver burden scale (time subscale) 1-70 Top=High is poor outcome; Comments: similar baseline scores Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: higher scores for depression in the intervention group - Actual outcome: Caregiver burden scale (difficulty subscale) at 3 months ; Group 1: mean 1.84 (SD 0.8); n=18, Group 2: mean 1.98 (SD 1.1); n=18; cargeiver burden scale (difficulty subscale) 1-70 Top=High is poor outcome; Comments: similar scores at baseline Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA; Baseline details: higher scores for depression in the intervention group	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Mcmillan 2006[188]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=329 caregiver-patient dyads)
Countries and setting	Conducted in USA; Setting: a large nonprofit community-based hospice
Line of therapy	Not applicable
Duration of study	Intervention + follow up: Intervention + 30 days follow up
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: admissions to a community-based hospice
Stratum	Overall: NA
Subgroup analysis within study	Unclear: NA
Inclusion criteria	caregivers providing care for adult patients with cancer, both consenting to participate, at least sixth grade education, able to read and understand English, minimum score of 7 on the Short Portable Mental Status Questionnaire
Exclusion criteria	active caregiver treatment for cancer, unclear primary care giver, patients performance status suggesting that patients would not survive more than a few days
Recruitment/selection of patients	consecutive

Study	Mcmillan 2006[188]
Age, gender and ethnicity	Age - Mean (SD): standard care 60 years (15), standard care + support 61.5 years (15.5), standard care + COPE 63 years (14). Gender (M:F): standard care 21/88, standard care + support 1:107, standard care + COPE 26/85. Ethnicity: not reported
Further population details	1. Frail elderly: Not stated / Unclear 2. Homeless people/vulnerably housed: Not homeless/vulnerably housed 3. LGBT: Not stated / Unclear 4. Migrant workers: Not stated / Unclear 5. People from ethnic minorities : Not stated / Unclear 6. People in prisons: People not in prisons 7. People in whom life-prolonging therapies are still an active option: Not stated / Unclear 8. People with dementia: Not stated / Unclear 9. People with disabilities: Not stated / Unclear 10. People with hearing loss: Not stated / Unclear 11. People with learning difficulties: Not stated / Unclear 12. People with mental health problems: Not stated / Unclear 13. Socioeconomic inequalities: Not stated / Unclear 14. Travelers: Not stated / Unclear 15. Younger adults (aged 18-25): Older adults (aged 26 and over)
Indirectness of population	No indirectness: NA
Interventions	(n=108) Intervention 1: Carer support service - Carer respite service. supportive visits from the intervention nurse and home health aide - individual support to carers, discussing their feelings, fears and relationships with their patients, no management advice given, home health aide provided respite for the caregiver by remaining with the patient during the visits. Duration not reported . Concurrent medication/care: hospice standard care . Indirectness: No indirectness; Indirectness comment: NA (n=111) Intervention 2: Carer support service - Support groups and education for carers. caregivers taught the COPE (creativity, optimism, planning, expert information) problem solving method by the intervention nurse to assist them with assessing and managing patient symptoms, respite provided by a home health aide . Duration not reported . Concurrent medication/care: standard hospice care . Indirectness: No indirectness; Indirectness comment: NA (n=109) Intervention 3: No carer support services. standard hospice care . Duration not reported . Concurrent medication/care: NA. Indirectness: No indirectness; Indirectness comment: NA
Funding	Academic or government funding (National Cancer Institute and The National Institute for Nursing Research grant)

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: SUPPORT GROUPS AND EDUCATION FOR CARERS versus NO CARER SUPPORT SERVICES

Protocol outcome 1: Quality of life of carer of (or person important to) the person in their last year of life
- Actual outcome: Caregiver Quality of Life Index-Cancer at 30 days ; Group 1: mean 0.16 (SD 0.07); n=31, Group 2: mean 0.02 (SD 0.06); n=40; CQOL-C 0-140 Top=High is good outcome; Comments: Variance reported as SE

Study	**Mcmillan 2006[188]**
Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA - Actual outcome: burden associated with patient cancer symptoms assessed the Memorial Symptom Assessment Scale at 30 days ; Mean; -0.28, Comments: SE = 0.07 p = <0.001 outcome represents change in intervention caregivers from baseline ; Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: NA	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life ; Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	**Onyechi 2016[208]**
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=32 patients, 52 carers)
Countries and setting	Conducted in Nigeria; Setting: participants' homes
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 10 week intervention + 4 weeks follow up
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: inclusion criteria included terminal cancer
Stratum	Overall: NA
Subgroup analysis within study	Unclear: NA
Inclusion criteria	terminal stage of breast, cervical, or prostate cancers, finished cancer treatment and not receiving other therapeutic treatment, having a family caregiver who is a very close relative, family caregivers available throughout the program, scores within benchmark values for problematic assumptions, death anxiety, and psychological distress
Exclusion criteria	not reported
Recruitment/selection of patients	households responding to intervention advertisement
Age, gender and ethnicity	Age - Mean (SD): cancer patients 48 years (6.5), caregivers 56 years (3). Gender (M:F): cancer patients 4/28, caregivers 8/44. Ethnicity: not reported

Study	**Onyechi 2016**[208]
Further population details	1. Frail elderly: Not stated / Unclear 2. Homeless people/vulnerably housed: Not homeless/vulnerably housed 3. LGBT: Not stated / Unclear 4. Migrant workers: Not stated / Unclear 5. People from ethnic minorities : Not stated / Unclear 6. People in prisons: People not in prisons 7. People in whom life-prolonging therapies are still an active option: Not stated / Unclear 8. People with dementia: Not stated / Unclear 9. People with disabilities: Not stated / Unclear 10. People with hearing loss: Not stated / Unclear 11. People with learning difficulties: Not stated / Unclear 12. People with mental health problems: Not stated / Unclear 13. Socioeconomic inequalities: Not stated / Unclear 14. Travelers: Not stated / Unclear 15. Younger adults (aged 18-25): Older adults (aged 26 and over)
Indirectness of population	No indirectness: NA
Interventions	(n=42) Intervention 1: Carer support service - Combined care for patients and carers. REHCT (rational emotive hospice care therapy) - manual based on a cognitive behavioral approach including a 7-step decision making process, 10 45 minute sessions anchored on treatment strategies including cognitive restructuring, confrontation, therapeutic alliance, and acceptance. for patients and caregivers . Duration 10 weeks . Concurrent medication/care: not reported . Indirectness: No indirectness; Indirectness comment: NA (n=42) Intervention 2: No carer support services. no carer support . Duration 10 weeks . Concurrent medication/care: not reported . Indirectness: No indirectness; Indirectness comment: NA
Funding	Funding not stated

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COMBINED CARE FOR PATIENTS AND CARERS versus NO CARER SUPPORT SERVICES

Protocol outcome 1: Quality of life of person in their last year of life
- Actual outcome: Cancer Patients' and Family Caregivers' Assumptions Questionnaire at 4 weeks; Group 1: mean 18.88 (SD 1.15); n=16, Group 2: mean 74.45 (SD 1.26); n=16; CPFCAQ 15-75 Top=High is poor outcome; Comments:
Risk of bias: All domain - High, Selection - Low, Blinding - Very high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: questionnaire assesses level of problematic assumptions
- Actual outcome: Death anxiety questionnaire at 4 weeks; Group 1: mean 18 (SD 1.79); n=16, Group 2: mean 74.56 (SD 1.03); n=16; DAQ 15-75 Top=High is poor outcome
Risk of bias: All domain - High, Selection - Low, Blinding - Very high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome: Kessler Psychological Distress Scale at 4 weeks; Group 1: mean 14.38 (SD 2.55); n=16, Group 2: mean 49.44 (SD 0.89); n=16; K10 10-50 Top=High is poor outcome
Risk of bias: All domain - High, Selection - Low, Blinding - Very high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

Study	Onyechi 2016[208]
Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Cancer Patients' and Family Caregivers' Assumptions Questionnaire at 4 weeks; Group 1: mean 18.96 (SD 1.22); n=26, Group 2: mean 74.46 (SD 1.36); n=26; CPFCAQ 15-75 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - Very high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: questionnaire assesses level of problematic assumptions - Actual outcome: Death anxiety questionnaire at 4 weeks; Group 1: mean 18.12 (SD 1.88); n=26, Group 2: mean 74.65 (SD 1.06); n=26; DAQ 15-75 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - Very high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome: Kessler Psychological Distress Scale at 4 weeks; Group 1: mean 13.5 (SD 2.82); n=26, Group 2: mean 49.81 (SD 0.63); n=26; K10 10-50 Top=High is poor outcome Risk of bias: All domain - High, Selection - Low, Blinding - Very high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Reinhardt 2014[227]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	(n=87)
Countries and setting	Conducted in USA; Setting: Nursing home
Line of therapy	Unclear
Duration of study	Intervention + follow up: 6 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Family members of current residents with advanced dementia. Eligibility criteria for these nursing home residents included dementia diagnosis, advanced dementia (cognitive performance scale score = 4, 5, 6), English or Spanish speaking, and not currently receiving hospice care (end-of-life care options would have been reviewed).

Study	Reinhardt 2014[227]
Exclusion criteria	Not reported
Recruitment/selection of patients	Patients recruited from nursing home.
Age, gender and ethnicity	Age - Mean (SD): 59 (12). Gender (M:F): Define. Ethnicity: 40% black, 30% white
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities : 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: People with dementia 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 12. People with mental health problems: 13. Socioeconomic inequalities: 14. Travelers: 15. Younger adults (aged 18-25):
Indirectness of population	No indirectness
Interventions	(n=47) Intervention 1: Carer support service - Support groups and education for carers. One of the physicians and the palliative care social worker utilized a structured (details listed below), face-to-face meeting with each intervention family member after observing the family member and speaking with the primary care team about his/her condition. A Spanish-speaking social worker was present when needed. Specifically, using an “ask-tell-ask” model. Beyond advance directives: Importance of communication skills at the end of life . Journal of the American Medical Association , the PCT members asked family members what they understood about dementia, where they think their relative is in the disease process, and what they expect as the disease progresses. Further, the PC physician shared the assessment of the resident's condition, and the PCT discussed the family's goals of care for the resident, made recommendations of how to achieve those goals, such as putting advance directives in place and provided psychosocial support, such as empathic and active listening and rephrasing to ensure the family member was being “heard.” Finally, the PCT provided family members with comprehensive, evidence-based information about the risks and benefits of potential treatments that can be used in advance of the need to make decisions in a face-to-face meeting at the facility. These meetings took an average of 47 minutes (range = 20–75 minutes) and included the following topics: (a) resuscitation, (b) hospitalization, (c) artificial nutrition and hydration, and (d) pain and symptom management. If specific care-related decisions were made during the meeting, such as additions to advance directive decisions, the PCT members told family members that this information would be communicated to and addressed by their relative's primary care team (physician, nurse, social worker). While the PCT was available after the initial face-to-face meeting for further clarification of issues or assistance with decision making and support as needed, only three family members requested additional information. Also, as part of the intervention, the palliative care social worker contacted family members every 2 months via telephone, after checking on the resident (to note their condition), to ascertain the family member's level of emotional comfort. Thus they were able to address potential concerns they had about their relative. Each of these three telephone calls lasted an average of 10 minutes. These calls, made by the palliative care social worker, were intended to be a continuation of any issues discussed in the

Study	Reinhardt 2014[227]
	intervention meetings based on topics the family members wanted to discuss. One of the physicians and the palliative care social worker utilized a structured, face-to-face meeting with each intervention family member after observing the family member and speaking with the primary care team about his/her condition. A Spanish-speaking social worker was present when needed. Specifically, using an “ask-tell-ask” model. Beyond advance directives: Importance of communication skills at the end of life. Journal of the American Medical Association, the PCT members asked family members what they understood about dementia, where they think their relative is in the disease process, and what they expect as the disease progresses. Further, the PC physician shared the assessment of the resident's condition, and the PCT discussed the family's goals of care for the resident, made recommendations of how to achieve those goals, such as putting advance directives in place and provided psychosocial support, such as empathic and active listening and rephrasing to ensure the family member was being “heard.” Finally, the PCT provided family members with comprehensive, evidence-based information about the risks and benefits of potential treatments that can be used in advance of the need to make decisions in a face-to-face meeting at the facility. These meetings took an average of 47 minutes (range = 20–75 minutes) and included the following topics: (a) resuscitation, (b) hospitalization, (c) artificial nutrition and hydration, and (d) pain and symptom management. If specific care-related decisions were made during the meeting, such as additions advance directive decisions, the PCT members told family members that this information would be communicated to and addressed by their relative's primary care team (physician, nurse, social worker). While the PCT was available after the initial face-to-face meeting for further clarification of issues or assistance with decision making and support as needed, only three family members requested additional information. Also, as part of the intervention, the palliative care social worker contacted family members every 2 months via telephone, after checking on the resident (to note their condition), to ascertain the family member's level of emotional comfort. Thus they were able to address potential concerns they had about their relative. Each of these three telephone calls lasted an average of 10 minutes. These calls, made by the palliative care social worker, were intended to be a continuation of any issues discussed in the intervention meetings based on topics the family members wanted to discuss. One of the physicians and the palliative care social worker utilized a structured (details listed below), face-to-face meeting with each intervention family member after observing the family member and speaking with the primary care team about his/her condition. A Spanish-speaking social worker was present when needed. Specifically, using an “ask-tell-ask” model. Beyond advance directives: Importance of communication skills at the end of life. Journal of the American Medical Association, the PCT members asked family members what they understood about dementia, where they think their relative is in the disease process, and what they expect as the disease progresses. Further, the PC physician shared the assessment of the resident's condition, and the PCT discussed the family's goals of care for the resident,

Study	**Reinhardt 2014**[227]
	made recommendations of how to achieve those goals, such as putting advance directives in place and provided psychosocial support, such as empathic and active listening and rephrasing to ensure the family member was being “heard.” Finally, the PCT provided family members with comprehensive, evidence-based information about the risks and benefits of potential treatments that can be used in advance of the need to make decisions in a face-to-face meeting at the facility. These meetings took an average of 47 minutes (range = 20–75 minutes) and included the following topics: (a) resuscitation, (b) hospitalization, (c) artificial nutrition and hydration, and (d) pain and symptom management. If specific care-related decisions were made during the meeting, such as additions to advance directive decisions, the PCT members told family members that this information would be communicated to and addressed by their relative's primary care team (physician, nurse, social worker). While the PCT was available after the initial face-to-face meeting for further clarification of issues or assistance with decision making and support as needed, only three family members requested additional information. Also, as part of the intervention, the palliative care social worker contacted family members every 2 months via telephone, after checking on the resident (to note their condition), to ascertain the family member's level of emotional comfort. Thus they were able to address potential concerns they had about their relative. Each of these three telephone calls lasted an average of 10 minutes. These calls, made by the palliative care social worker, were intended to be a continuation of any issues discussed in the intervention meetings based on topics the family members wanted to discuss. Duration 6 months. Concurrent medication/care: Usual care. Indirectness: No indirectness (n=40) Intervention 2: No carer support services. Received “routine care” provided to persons with dementia in this particular nursing home. Nonspecific social telephone contact was included in the comparison condition at baseline and 2-month intervals.. Duration 6 months. Concurrent medication/care: Usual care. Indirectness: No indirectness
Funding	Academic or government funding (Supported by the Alzheimer's Association)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: SUPPORT GROUPS AND EDUCATION FOR CARERS versus NO CARER SUPPORT SERVICES Protocol outcome 1: Quality of life of person in their last year of life - Actual outcome: Depressive symptoms at 3 monhs; Group 1: mean 4 (SD 4.5); n=47, Risk of bias: All domain - High, Selection - High, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness	

Study	Reinhardt 2014[227]
- Actual outcome: Depressive symptoms at 6 monhs; Group 1: mean 3.8 (SD 4.1); n=47, Risk of bias: All domain - High, Selection - High, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome: Care satisfaction at 3 monhs; Group 1: mean 30.2 (SD 6.4); n=45, Group 2: mean 30.6 (SD 6.4); n=36 Risk of bias: All domain - High, Selection - High, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Patient/carer reported outcomes (satisfaction) - IMPORTANT - Actual outcome: Care satisfaction at 6 monhs; Group 1: mean 30.6 (SD 7.2); n=45, Group 2: mean 28 (SD 9.7); n=36; Satisfaction with Care at End-of-Life in Dementia Scale 0-42 Top=High is good outcome Risk of bias: All domain - High, Selection - High, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Patient/carer reported outcomes (satisfaction) - IMPORTANT Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Life satisfaction at 3 monhs; Group 1: mean 18.5 (SD 5.5); n=45, Risk of bias: All domain - High, Selection - High, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome: Life satisfaction at 6 monhs; Group 1: mean 17.9 (SD 5.7); n=45, Risk of bias: All domain - High, Selection - High, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Study	Walsh 2007[275]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	(n=134)
Countries and setting	Conducted in UK; Setting: Seven specialist palliative care teams in three London cancer networks.
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 12 weeks
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable

Study	Walsh 2007[275]
Inclusion criteria	The informal carer was identified by patients and palliative care teams as the main person who provided unpaid practical and emotional support to the patient on a regular basis and was in contact with the palliative care team. Informal carers who scored above the threshold of 5/6 on the GHQ–28 were approached to obtain informed consent and complete baseline assessments
Exclusion criteria	The research team was informed if the carer declined to fill in the GHQ–28, if the patient was unlikely to survive the time it would take to introduce the intervention, or if the carer's English skills would mean they could not gain full benefit from the advisor visits.
Recruitment/selection of patients	From January 2001 to April 2003 people providing informal care to patients in all new referrals to the participating teams were screened for psychological distress using the 28-item version of General Health Questionnaire.
Age, gender and ethnicity	Age - Mean (SD): Caregiver: 56.3(13.9). Gender (M:F): 56/215. Ethnicity: 86% White
Further population details	NA
Indirectness of population	No indirectness
Interventions	(n=137) Intervention 1: Carer support service - Carer support: Needs assessment was conducted, and information and emotional support provided. Topics covered at each session were patient care, caregiver physical health needs, need for time away from the patient in the short-term and longer term, need to plan for the future, psychological health, relationships and social networks, contact with health and social services providers and their personal finance. Duration 6 weekly sessions. Concurrent medication/care: NA. Indirectness: No indirectness (n=142) Intervention 2: Usual care - Specialist palliative care provided by a team of clinical nurse specialists who had specialist medical support. It also sometimes involved social work support. Patients were assisted with control of pain and other physical symptoms as well as with social, psychological, emotional and spiritual issues. Duration 6 weeks. Concurrent medication/care: NA. Indirectness: No indirectness
Funding	Cancer Research UK

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COMBINED CARE FOR PATIENTS AND CARERS - RSV versus COMBINED CARE FOR PATIENTS AND CARERS - PHONE CALLS

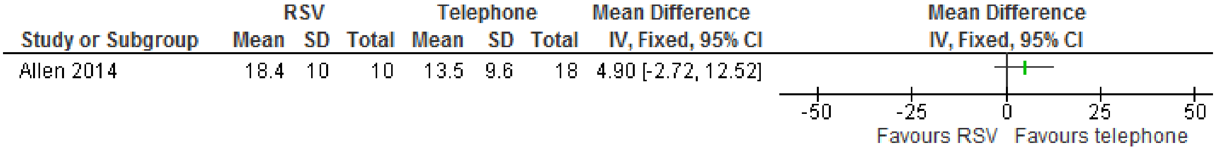
Protocol outcome 1: Quality of life of person in their last year of life
- Actual outcome: Carer Quality of Life – Cancer (CQOL-C) at up 12 weeks; Group 1: mean 65.2 (SD 21.3); n=64, Group 2: mean 62.2 (SD 19.8); n=52
Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
Protocol outcome 1: Quality of life of person in their last year of life

Study	Walsh 2007[275]
- Actual outcome: Psychological distress (GHQ-28) at up 12 weeks; Group 1: mean 11.3 (SD 7.3); n=69, Group 2: mean 11.7 (SD 7.8); n=54 Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness- Actual outcome: Center for Epidemiology Studies Depression Scale (CESD) at up to 20 weeks; Group 1: mean 18.4 (SD 10); n=10, Group 2: mean 13.5 (SD 9.6); n=18; CESD 0-60 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 Protocol outcome 2: Quality of life of carer of (or person important to) the person in their last year of life - Actual outcome: Memorial Symptom Assessment Scale; symptom bother - physical at up to 20 weeks; Group 1: mean 0.77 (SD 0.6); n=10, Group 2: mean 0.49 (SD 0.5); n=18 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Memorial Symptom Assessment Scale; symptom bother - emotional at up to 20 weeks; Group 1: mean 1.08 (SD 1.2); n=10, Group 2: mean 1 (SD 1); n=18 Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Center for Epidemiology Studies Depression Scale (CESD) at up to 20 weeks; Group 1: mean 14.9 (SD 13.5); n=10, Group 2: mean 8.17 (SD 6.4); n=18; CESD 0-60 Top=High is poor outcome Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5 - Actual outcome: Caregiver stress at up to 20 weeks; Group 1: mean 2.32 (SD 0.2); n=10, Group 2: mean 2.3 (SD 0.2); n=18; Comments: Range not provided Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 12; Group 2 Number missing: 5	
Protocol outcomes not reported by the study	Preferred and actual place of care ; Longevity of the carer ; Carer health (for example: GP visits, mental health, school/work attendance) ; Length of hospital stay ; Use of community services ; Staff (providing care to the person in their last year of life) ; Length of stay

Appendix E: Forest plots

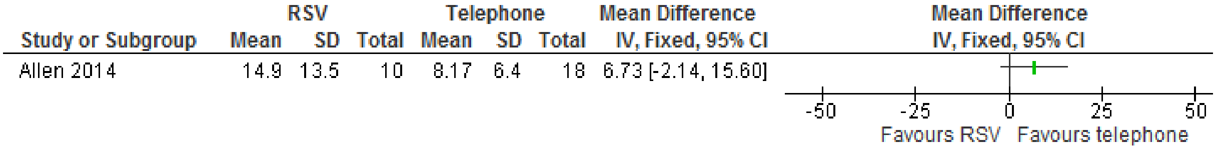
E.1 Allen 2014 – RSV compared to Telephone emotional support for palliative care

Figure 3: QoL: Depression (CESD)



	RSV			Telephone			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Allen 2014	18.4	10	10	13.5	9.6	18	4.90 [-2.72, 12.52]

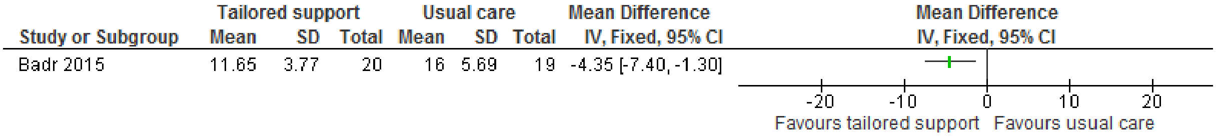
Figure 4: Carer QoL: Depression (CESD)



	RSV			Telephone			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Allen 2014	14.9	13.5	10	8.17	6.4	18	6.73 [-2.14, 15.60]

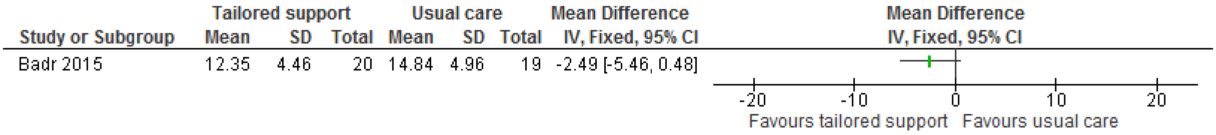
E.2 Badr 2015 – Tailored support compared to Usual care for palliative care

Figure 5: QoL: Depression (PROMIS)



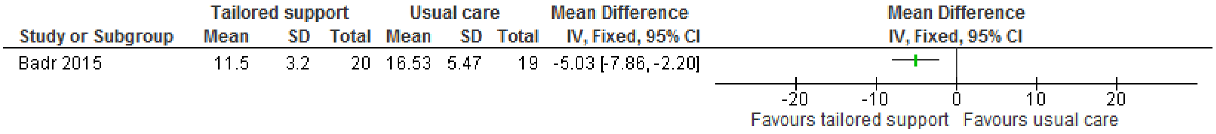
	Tailored support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Badr 2015	11.65	3.77	20	16	5.69	19	-4.35 [-7.40, -1.30]

Figure 6: QoL: Anxiety (PROMIS)



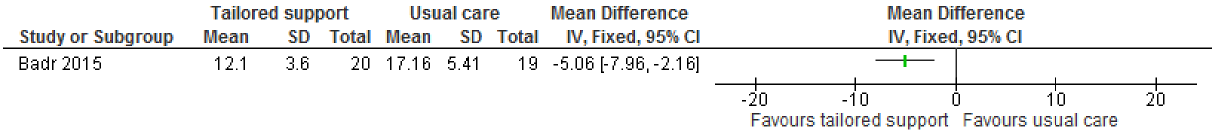
	Tailored support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Badr 2015	12.35	4.46	20	14.84	4.96	19	-2.49 [-5.46, 0.48]

Figure 7: Carer QoL: Depression (PROMIS)



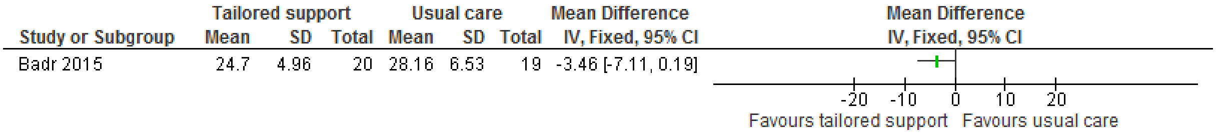
	Tailored support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Badr 2015	11.5	3.2	20	16.53	5.47	19	-5.03 [-7.86, -2.20]

Figure 8: Carer QoL: Anxiety (PROMIS)



	Tailored support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Badr 2015	12.1	3.6	20	17.16	5.41	19	-5.06 [-7.96, -2.16]

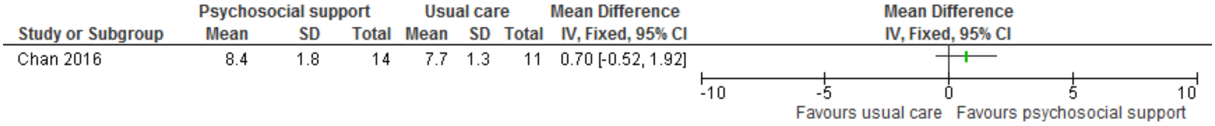
Figure 9: Carer QoL: Burden



	Tailored support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Badr 2015	24.7	4.96	20	28.16	6.53	19	-3.46 [-7.11, 0.19]

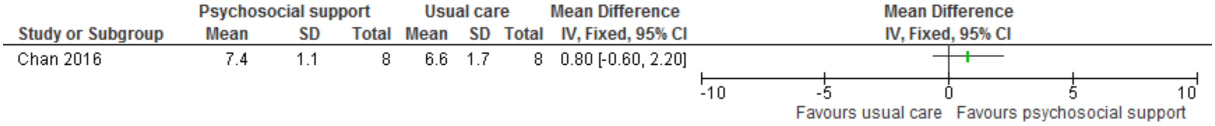
E.3 Chan 2016 – Psychosocial support compared to Usual care for palliative care

Figure 10: Quality of life (MQOL) at 1 month



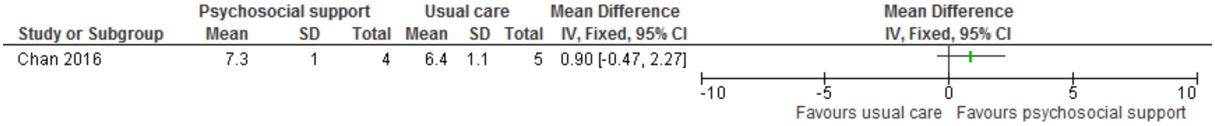
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	8.4	1.8	14	7.7	1.3	11	0.70 [-0.52, 1.92]

Figure 11: Quality of life (MQOL) at 3 month



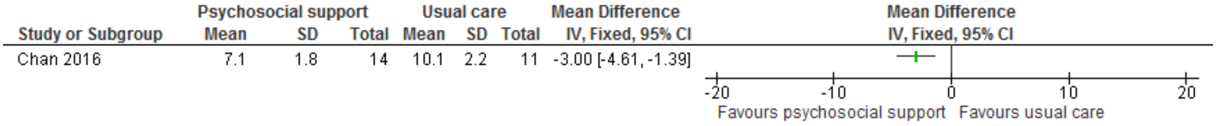
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	7.4	1.1	8	6.6	1.7	8	0.80 [-0.60, 2.20]

Figure 12: Quality of life (MQOL) at 6 month



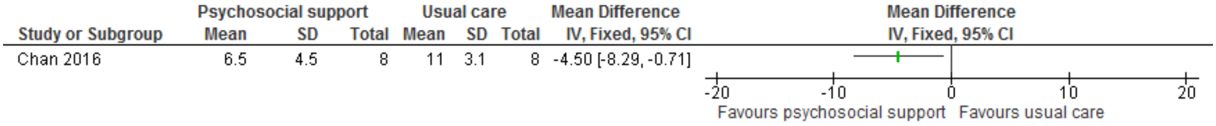
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	7.3	1	4	6.4	1.1	5	0.90 [-0.47, 2.27]

Figure 13: QoL: Anxiety at 1 month



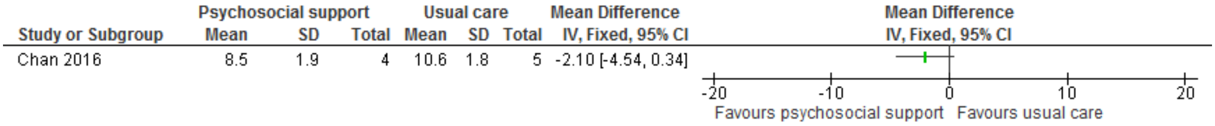
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	7.1	1.8	14	10.1	2.2	11	-3.00 [-4.61, -1.39]

Figure 14: QoL: Anxiety at 3 month



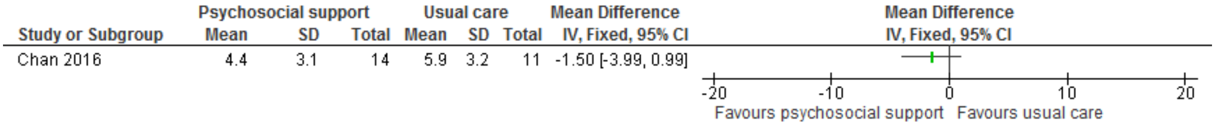
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	6.5	4.5	8	11	3.1	8	-4.50 [-8.29, -0.71]

Figure 15: QoL: Anxiety at 6 month



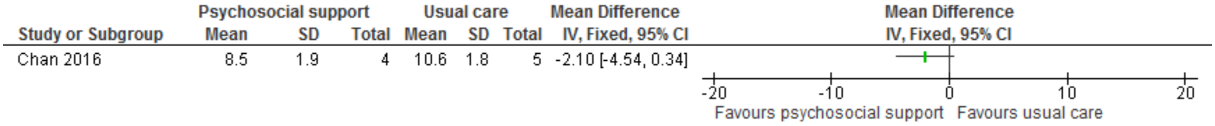
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	8.5	1.9	4	10.6	1.8	5	-2.10 [-4.54, 0.34]

Figure 16: QoL: Depression at 1 month



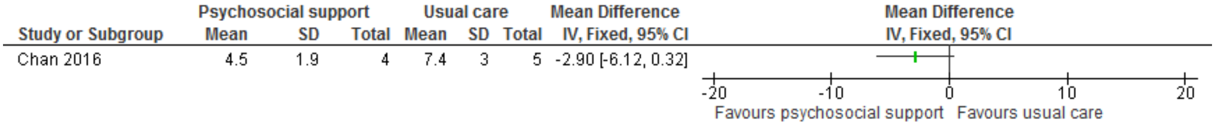
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	4.4	3.1	14	5.9	3.2	11	-1.50 [-3.99, 0.99]

Figure 17: QoL: Depression at 3 month



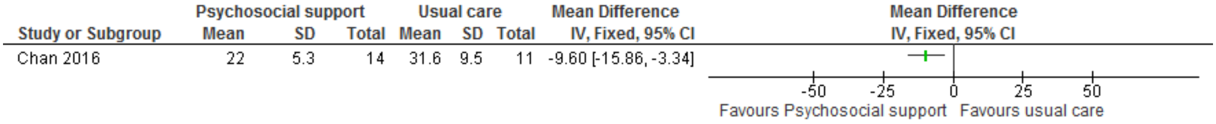
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	8.5	1.9	4	10.6	1.8	5	-2.10 [-4.54, 0.34]

Figure 18: QoL: Depression at 6 month



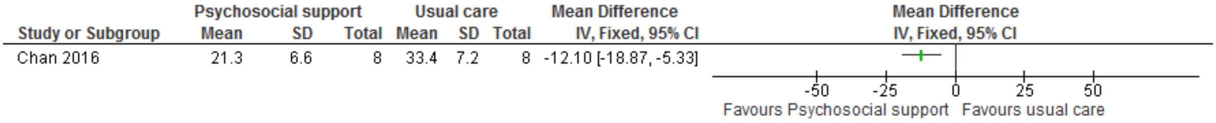
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	4.5	1.9	4	7.4	3	5	-2.90 [-6.12, 0.32]

Figure 19: Carer QoL: Burden at 1 month



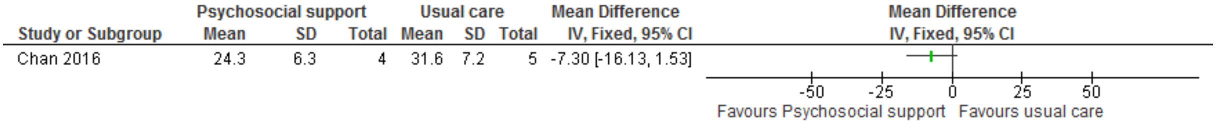
	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	22	5.3	14	31.6	9.5	11	-9.60 [-15.86, -3.34]

Figure 20: Carer QoL: Burden at 3 month



	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	21.3	6.6	8	33.4	7.2	8	-12.10 [-18.87, -5.33]

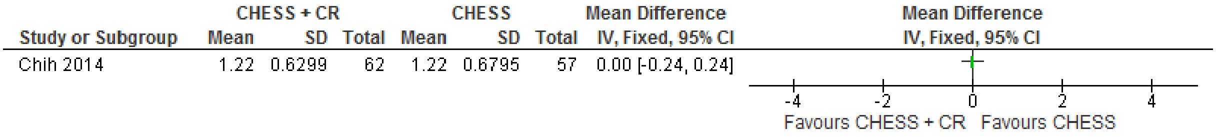
Figure 21: Carer QoL: Burden at 6 month



	Psychosocial support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chan 2016	24.3	6.3	4	31.6	7.2	5	-7.30 [-16.13, 1.53]

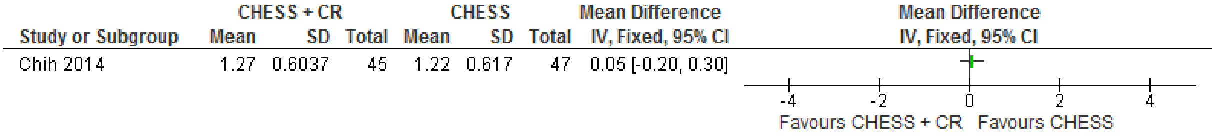
E.4 Chih 2014 – CHESS + CR compared to CHESS for palliative care

Figure 22: Carer QoL: Burden at 6 month



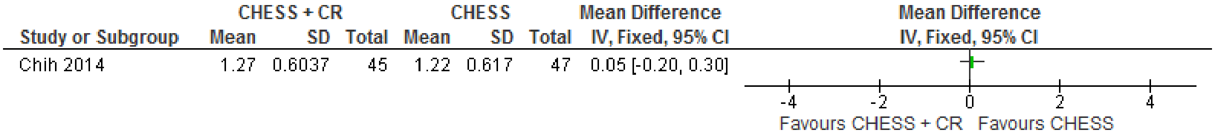
	CHESS + CR			CHESS			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chih 2014	1.22	0.6299	62	1.22	0.6795	57	0.00 [-0.24, 0.24]

Figure 23: Carer QoL: Burden at 12 month



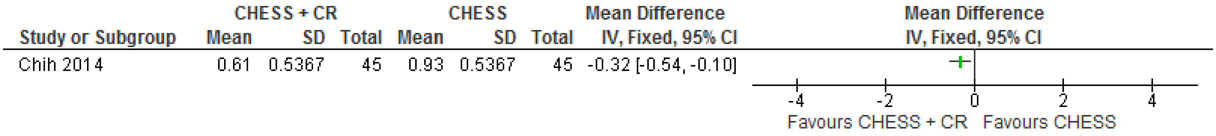
	CHESS + CR			CHESS			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chih 2014	1.27	0.6037	45	1.22	0.617	47	0.05 [-0.20, 0.30]

Figure 24: Carer QoL: Negative mood at 6 month



	CHESS + CR			CHESS			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chih 2014	1.27	0.6037	45	1.22	0.617	47	0.05 [-0.20, 0.30]

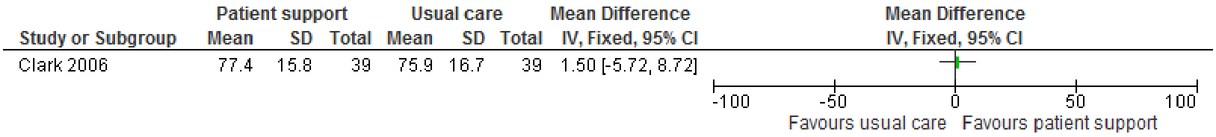
Figure 25: Carer QoL: Negative mood at 12 month



	CHESS + CR			CHESS			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Chih 2014	0.61	0.5367	45	0.93	0.5367	45	-0.32 [-0.54, -0.10]

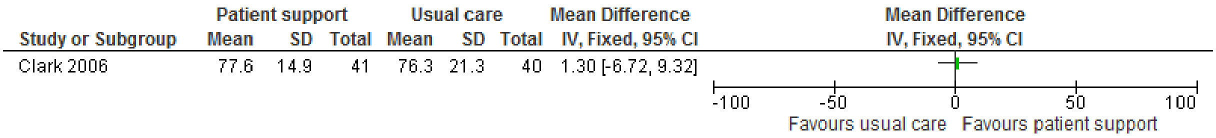
E.5 Clark 2006 – Patient support compared to Usual care for palliative care

Figure 26: Carer quality of life (LASA) at 4 weeks



	Patient support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Clark 2006	77.4	15.8	39	75.9	16.7	39	1.50 [-5.72, 8.72]

Figure 27: Carer quality of life (LASA) at 8 weeks



	Patient support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Clark 2006	77.6	14.9	41	76.3	21.3	40	1.30 [-6.72, 9.32]

Figure 28: Carer quality of life (LASA) at 27 weeks

	Patient support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Clark 2006	72.2	17.2	37	78.9	17.3	35	-6.70 [-14.67, 1.27]

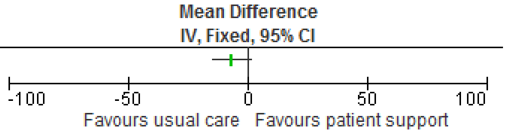


Figure 29: Carer QoL: Burden at 4 weeks

	Patient support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Clark 2006	76.9	12.6	39	76.2	13.7	39	0.70 [-5.14, 6.54]

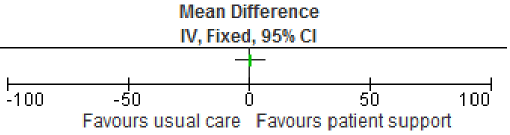


Figure 30: Carer QoL: Burden at 8 weeks

	Patient support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Clark 2006	75.1	12.5	41	75.8	13.6	40	-0.70 [-6.39, 4.99]

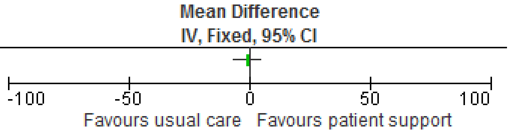
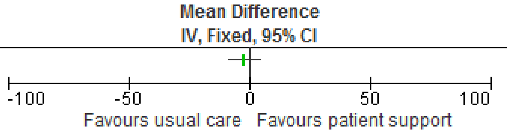


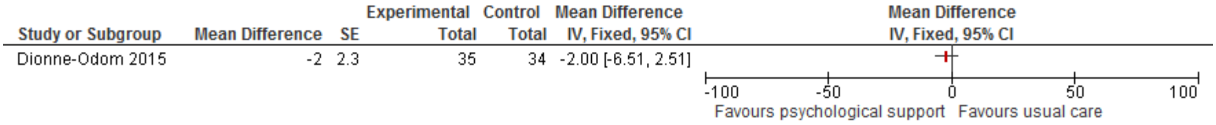
Figure 31: Carer QoL: Burden at 27 weeks

	Patient support			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Clark 2006	75.1	13.9	37	77.2	14.8	35	-2.10 [-8.74, 4.54]



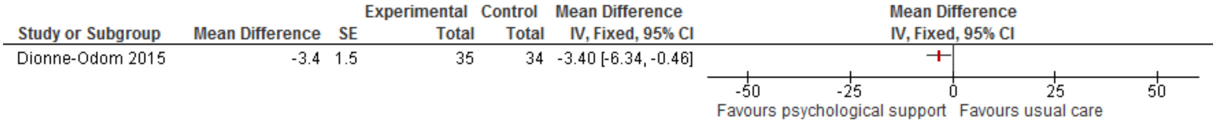
E.6 Dionne-odom 2015 – Psychological support compared to Usual care for palliative care

Figure 32: Carer quality of life (CQOL-C)



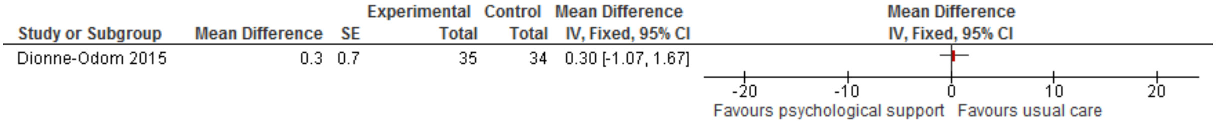
Study or Subgroup	Mean Difference	SE	Experimental Total	Control Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	-2	2.3	35	34	-2.00 [-6.51, 2.51]

Figure 33: Carer QoL: Depression (CESD)



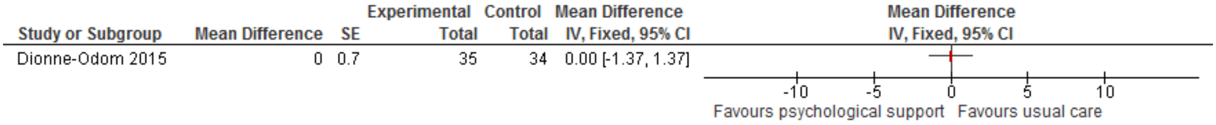
Study or Subgroup	Mean Difference	SE	Experimental Total	Control Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	-3.4	1.5	35	34	-3.40 [-6.34, -0.46]

Figure 34: Carer QoL: Burden (objective subscale)



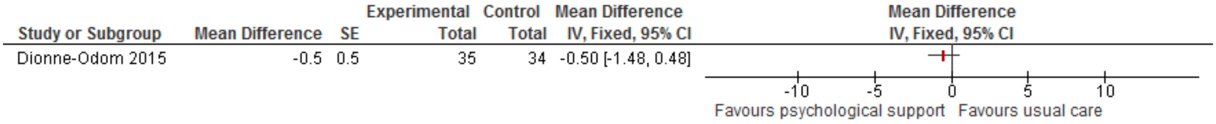
Study or Subgroup	Mean Difference	SE	Experimental Total	Control Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	0.3	0.7	35	34	0.30 [-1.07, 1.67]

Figure 35: Carer QoL: Burden (demand subscale)



Study or Subgroup	Mean Difference	SE	Experimental Total	Control Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	0	0.7	35	34	0.00 [-1.37, 1.37]

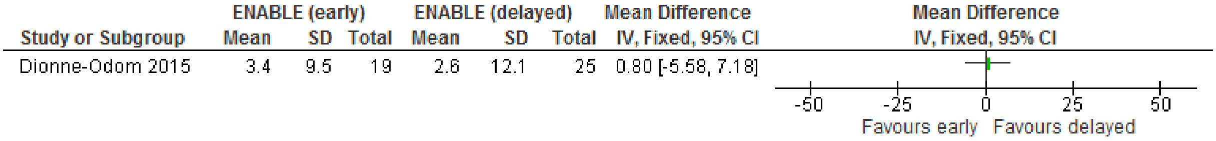
Figure 36: Carer QoL: Burden (stress subscale)



Study or Subgroup	Mean Difference	SE	Experimental Total	Control Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	-0.5	0.5	35	34	-0.50 [-1.48, 0.48]

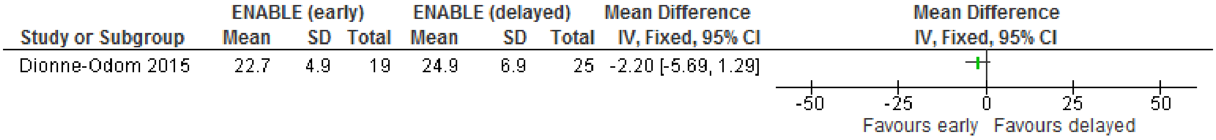
E.7 Dionne-odom 2015 – Psychological support (early) compared to Psychological support (delayed) for palliative care

Figure 37: Carer QoL: Depression (CESD)



Study or Subgroup	ENABLE (early) Mean	SD	Total	ENABLE (delayed) Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	3.4	9.5	19	2.6	12.1	25	0.80 [-5.58, 7.18]

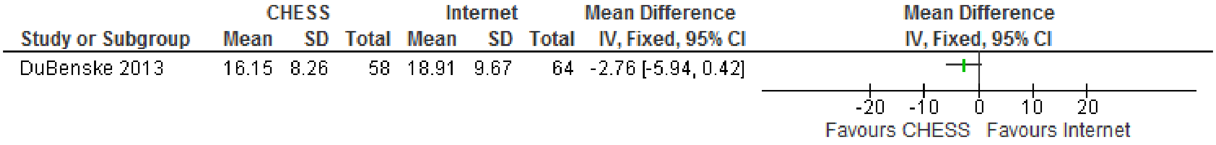
Figure 38: Carer QoL: Grief (PG13)



Study or Subgroup	ENABLE (early) Mean	SD	Total	ENABLE (delayed) Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Dionne-Odom 2015	22.7	4.9	19	24.9	6.9	25	-2.20 [-5.69, 1.29]

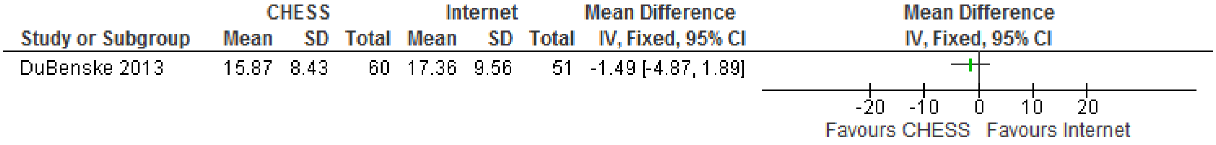
E.8 Dubenske 2013 – CHESS compared to Usual care for palliative care

Figure 39: Carer QoL: Burden at 2 months



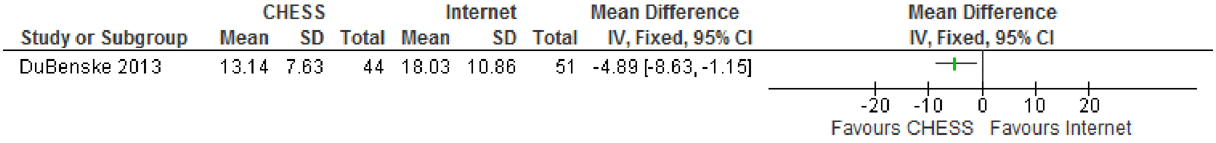
Study or Subgroup	CHESS Mean	SD	Total	Internet Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	16.15	8.26	58	18.91	9.67	64	-2.76 [-5.94, 0.42]

Figure 40: Carer QoL: Burden at 4 months



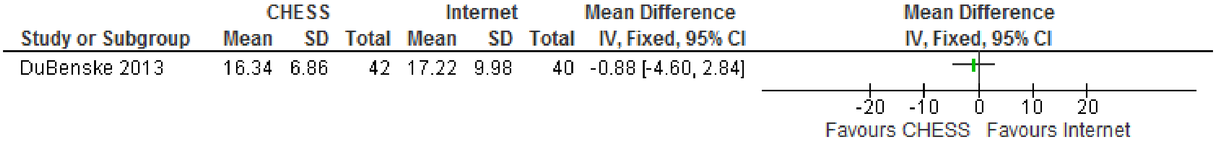
Study or Subgroup	CHESS Mean	SD	Total	Internet Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	15.87	8.43	60	17.36	9.56	51	-1.49 [-4.87, 1.89]

Figure 41: Carer QoL: Burden at 6 months



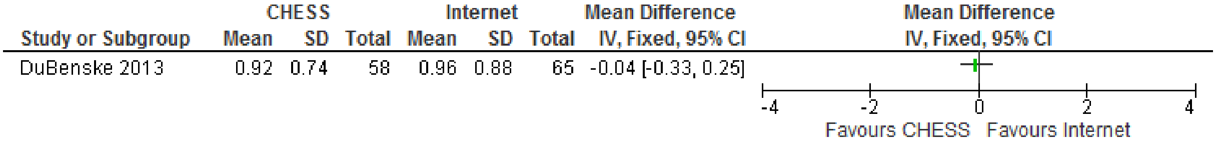
Study or Subgroup	CHESS Mean	SD	Total	Internet Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	13.14	7.63	44	18.03	10.86	51	-4.89 [-8.63, -1.15]

Figure 42: Carer QoL: Burden at 8 months



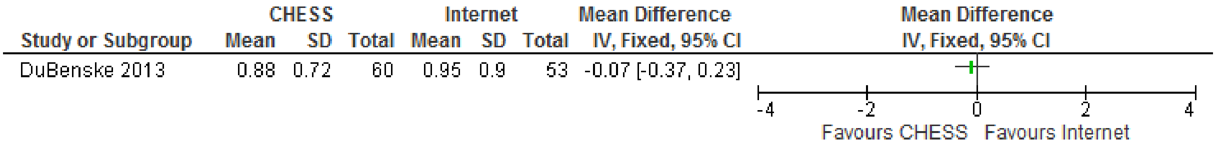
Study or Subgroup	CHESS Mean	SD	Total	Internet Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	16.34	6.86	42	17.22	9.98	40	-0.88 [-4.60, 2.84]

Figure 43: Carer QoL: Negative mood at 2 months



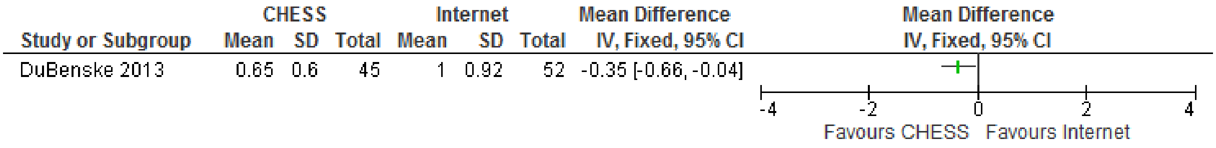
Study or Subgroup	CHESS Mean	SD	Total	Internet Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	0.92	0.74	58	0.96	0.88	65	-0.04 [-0.33, 0.25]

Figure 44: Carer QoL: Negative mood at 4 months



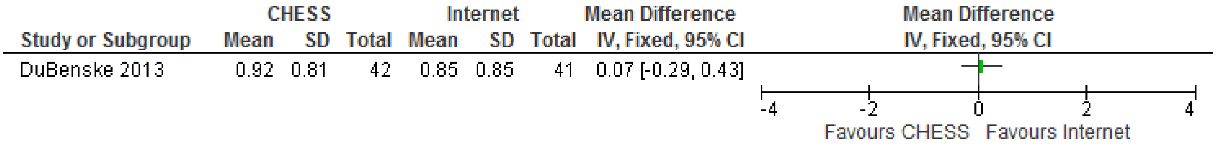
Study or Subgroup	CHESS Mean	CHESS SD	CHESS Total	Internet Mean	Internet SD	Internet Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	0.88	0.72	60	0.95	0.9	53	-0.07 [-0.37, 0.23]

Figure 45: Carer QoL: Negative mood at 6 months



Study or Subgroup	CHESS Mean	CHESS SD	CHESS Total	Internet Mean	Internet SD	Internet Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	0.65	0.6	45	1	0.92	52	-0.35 [-0.66, -0.04]

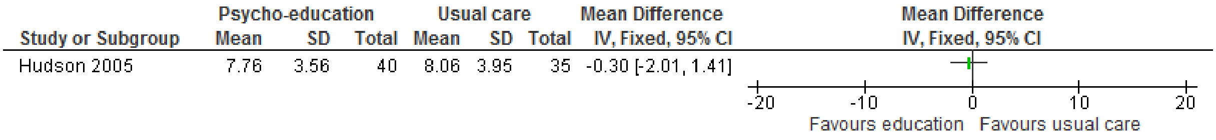
Figure 46: Carer QoL: Negative mood at 8 months



Study or Subgroup	CHESS Mean	CHESS SD	CHESS Total	Internet Mean	Internet SD	Internet Total	Mean Difference IV, Fixed, 95% CI
DuBenske 2013	0.92	0.81	42	0.85	0.85	41	0.07 [-0.29, 0.43]

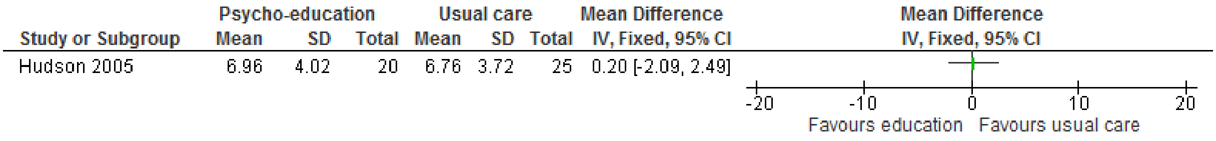
E.9 Hudson 2007 – Psycho-educational intervention compared to Usual care

Figure 47: Carer QoL: Anxiety (HADS) at 4 weeks post intervention



Study or Subgroup	Psycho-education Mean	Psycho-education SD	Psycho-education Total	Usual care Mean	Usual care SD	Usual care Total	Mean Difference IV, Fixed, 95% CI
Hudson 2005	7.76	3.56	40	8.06	3.95	35	-0.30 [-2.01, 1.41]

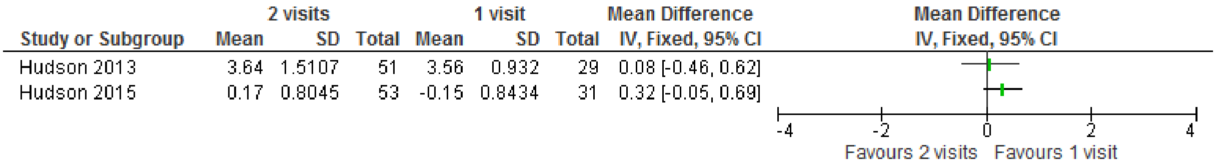
Figure 48: Carer QoL: Anxiety (HADS) at 8 weeks post patient death



Study or Subgroup	Psycho-education Mean	Psycho-education SD	Psycho-education Total	Usual care Mean	Usual care SD	Usual care Total	Mean Difference IV, Fixed, 95% CI
Hudson 2005	6.96	4.02	20	6.76	3.72	25	0.20 [-2.09, 2.49]

E.10 Hudson 2013/2015 – Psycho-educational: 2 visits compared to Psycho-educational: 1 visit for palliative care

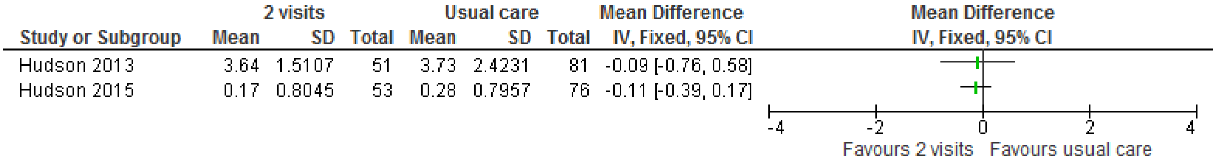
Figure 49: Carer QoL: General Health Questionnaire (GHQ)



	2 visits			1 visit			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Hudson 2013	3.64	1.5107	51	3.56	0.932	29	0.08 [-0.46, 0.62]
Hudson 2015	0.17	0.8045	53	-0.15	0.8434	31	0.32 [-0.05, 0.69]

E.11 Hudson 2013/2015 – Psycho-educational: 2 visits compared to Usual care

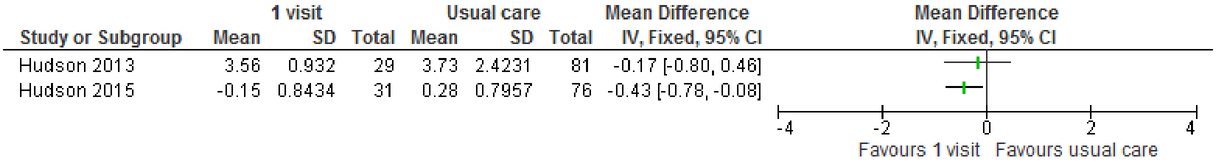
Figure 50: Carer QoL: General Health Questionnaire (GHQ)



	2 visits			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Hudson 2013	3.64	1.5107	51	3.73	2.4231	81	-0.09 [-0.76, 0.58]
Hudson 2015	0.17	0.8045	53	0.28	0.7957	76	-0.11 [-0.39, 0.17]

E.12 Hudson 2013/2015 – Psycho-educational: 1 visit compared to Usual care

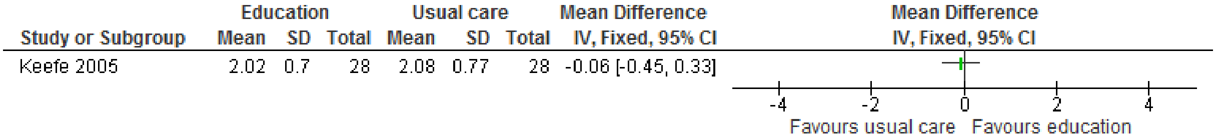
Figure 51: Carer QoL: General Health Questionnaire (GHQ)



	1 visit			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Hudson 2013	3.56	0.932	29	3.73	2.4231	81	-0.17 [-0.80, 0.46]
Hudson 2015	-0.15	0.8434	31	0.28	0.7957	76	-0.43 [-0.78, -0.08]

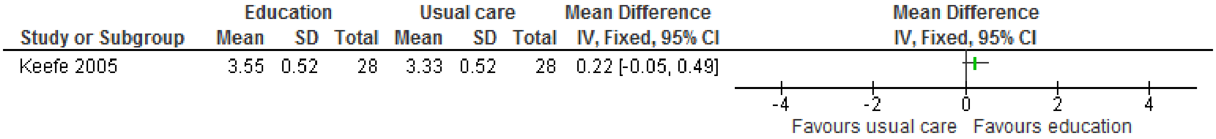
E.13 Keefe 2007 – Pain management education vs Usual care

Figure 52: Patient QoL: FACT-G – Physical



	Education			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Keefe 2005	2.02	0.7	28	2.08	0.77	28	-0.06 [-0.45, 0.33]

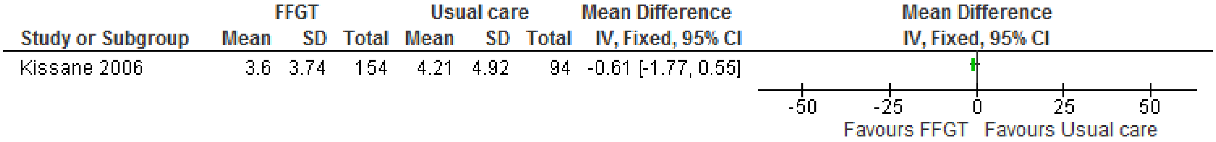
Figure 53: Patient QoL: FACT-G – Social



	Education			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Keefe 2005	3.55	0.52	28	3.33	0.52	28	0.22 [-0.05, 0.49]

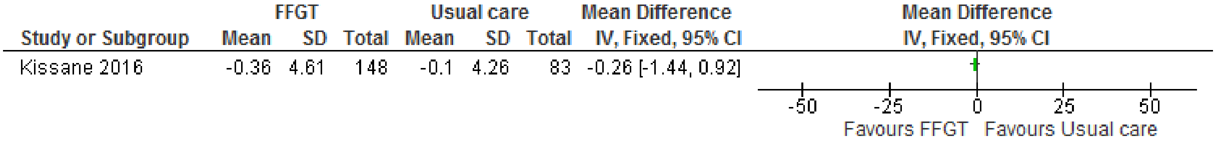
E.14 Kissane 2006 – Psychological support: grief therapy vs Usual care

Figure 54: Carer QoL: Depression (BDI) at 6 months



	FFGT			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2006	3.6	3.74	154	4.21	4.92	94	-0.61 [-1.77, 0.55]

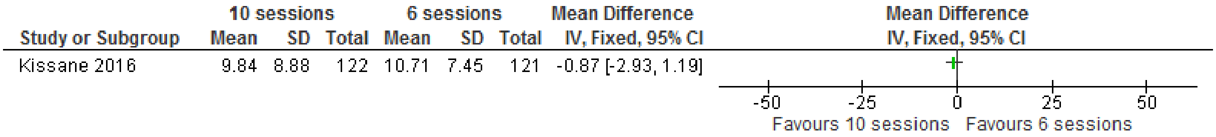
Figure 55: Carer QoL: Depression (BDI) at 13 months



	FFGT			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	-0.36	4.61	148	-0.1	4.26	83	-0.26 [-1.44, 0.92]

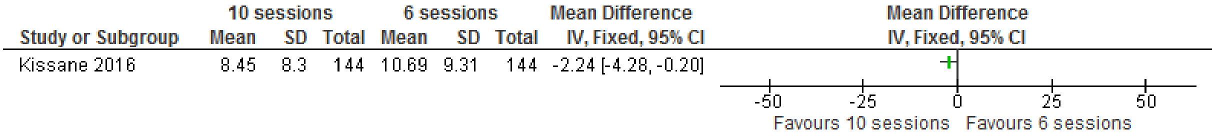
E.15 Kissane 2016 – Psychological support: 10 sessions vs Psychological support: 6 sessions

Figure 56: Carer QoL: Depression (BDI-II) at 6 months



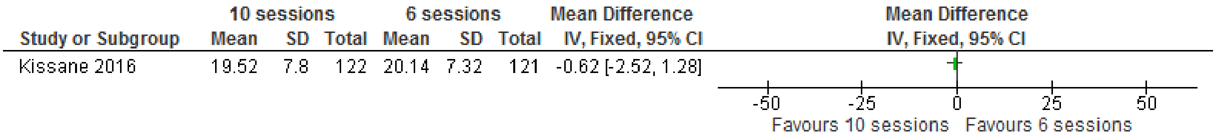
	10 sessions			6 sessions			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	9.84	8.88	122	10.71	7.45	121	-0.87 [-2.93, 1.19]

Figure 57: Carer QoL: Depression (BDI-II) at 13 months



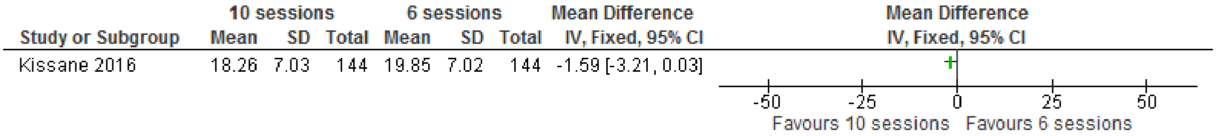
	10 sessions			6 sessions			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	8.45	8.3	144	10.69	9.31	144	-2.24 [-4.28, -0.20]

Figure 58: Carer QoL: Grief (CGI) at 6 months



	10 sessions			6 sessions			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	19.52	7.8	122	20.14	7.32	121	-0.62 [-2.52, 1.28]

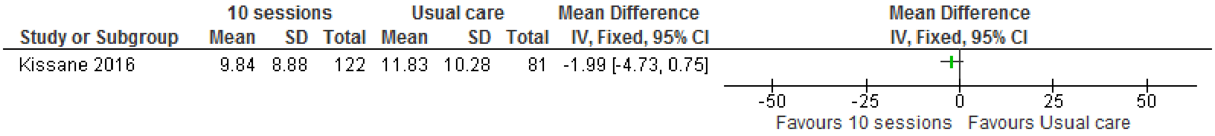
Figure 59: Carer QoL: Grief (CGI) at 13 months



	10 sessions			6 sessions			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	18.26	7.03	144	19.85	7.02	144	-1.59 [-3.21, 0.03]

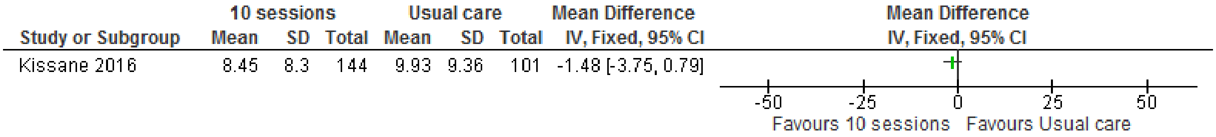
E.16 Kissane 2016 – Psychological support: 10 sessions vs Usual care

Figure 60: Carer QoL: Depression (BDI-II) at 6 months



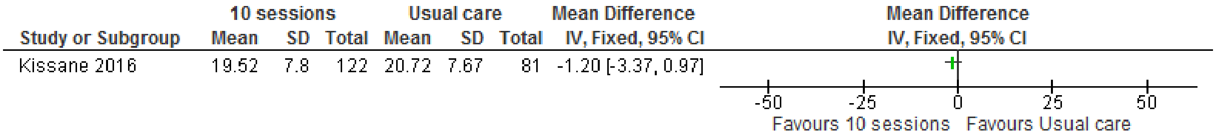
	10 sessions			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	9.84	8.88	122	11.83	10.28	81	-1.99 [-4.73, 0.75]

Figure 61: Carer QoL: Depression (BDI-II) at 13 months



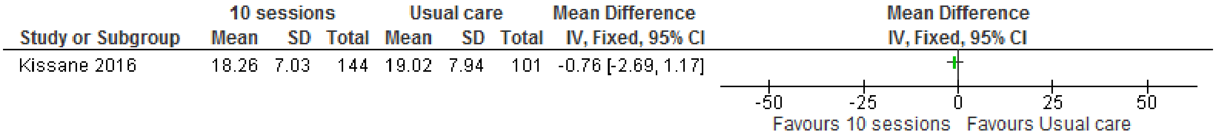
	10 sessions			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Kissane 2016	8.45	8.3	144	9.93	9.36	101	-1.48 [-3.75, 0.79]

Figure 62: Carer QoL: Grief (CGI) at 6 months



Study or Subgroup	10 sessions Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Kissane 2016	19.52	7.8	122	20.72	7.67	81	-1.20 [-3.37, 0.97]

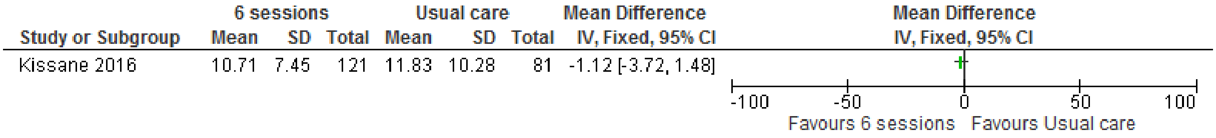
Figure 63: Carer QoL: Grief (CGI) at 13 months



Study or Subgroup	10 sessions Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Kissane 2016	18.26	7.03	144	19.02	7.94	101	-0.76 [-2.69, 1.17]

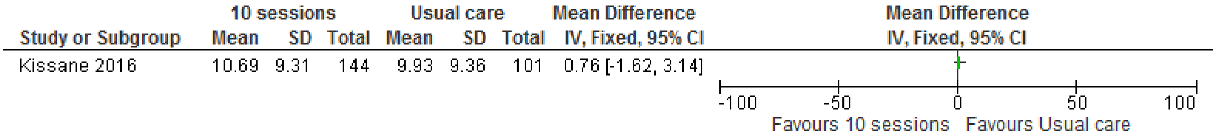
E.17 Kissane 2016 – Psychological support: 6 sessions vs Usual care

Figure 64: Carer QoL: Depression (BDI-II) at 6 months



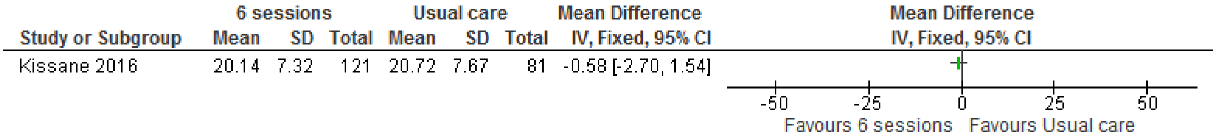
Study or Subgroup	6 sessions Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Kissane 2016	10.71	7.45	121	11.83	10.28	81	-1.12 [-3.72, 1.48]

Figure 65: Carer QoL: Depression (BDI-II) at 13 months



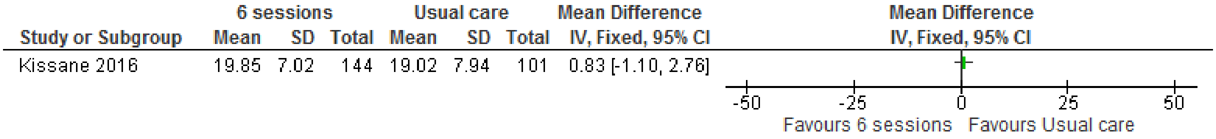
Study or Subgroup	10 sessions Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Kissane 2016	10.69	9.31	144	9.93	9.36	101	0.76 [-1.62, 3.14]

Figure 66: Carer QoL: Grief (CGI) at 6 months



Study or Subgroup	6 sessions Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Kissane 2016	20.14	7.32	121	20.72	7.67	81	-0.58 [-2.70, 1.54]

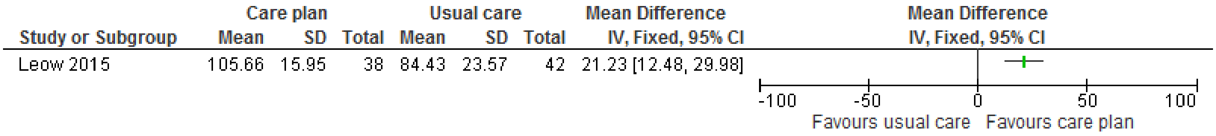
Figure 67: Carer QoL: Grief (CGI) at 13 months



Study or Subgroup	6 sessions Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Kissane 2016	19.85	7.02	144	19.02	7.94	101	0.83 [-1.10, 2.76]

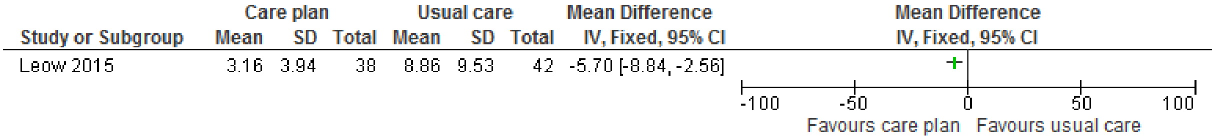
E.18 Leow 2015 – Care plan compared to Usual care for palliative care

Figure 68: Carer quality of life (CQOL-C)



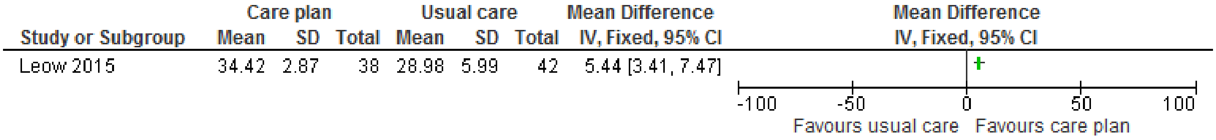
	Care plan			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Leow 2015	105.66	15.95	38	84.43	23.57	42	21.23 [12.48, 29.98]

Figure 69: Carer QoL: Depression anxiety stress scales



	Care plan			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Leow 2015	3.16	3.94	38	8.86	9.53	42	-5.70 [-8.84, -2.56]

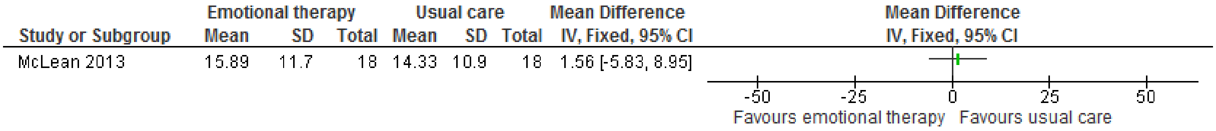
Figure 70: Carer satisfaction (social support)



	Care plan			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Leow 2015	34.42	2.87	38	28.98	5.99	42	5.44 [3.41, 7.47]

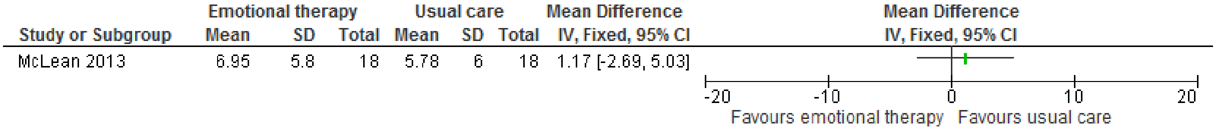
E.19 McLean 2013 – Emotional therapy compared to Usual care for palliative care

Figure 71: QoL: Depression (BDI-II)



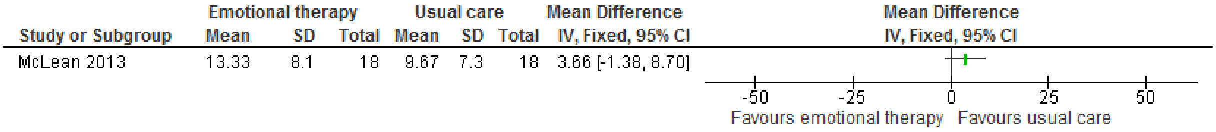
	Emotional therapy			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
McLean 2013	15.89	11.7	18	14.33	10.9	18	1.56 [-5.83, 8.95]

Figure 72: QoL: Hopelessness (BHS)



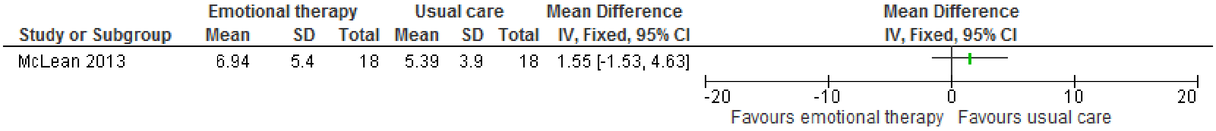
	Emotional therapy			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
McLean 2013	6.95	5.8	18	5.78	6	18	1.17 [-2.69, 5.03]

Figure 73: Carer QoL: Depression (BDI-II)



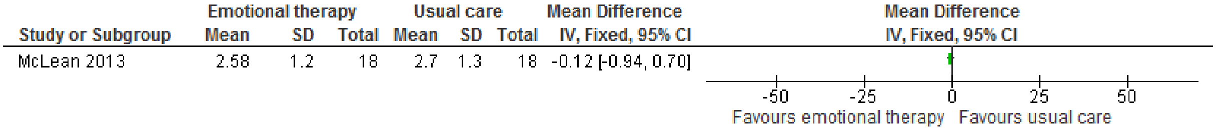
	Emotional therapy			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
McLean 2013	13.33	8.1	18	9.67	7.3	18	3.66 [-1.38, 8.70]

Figure 74: Carer QoL: Hopelessness (BHS)



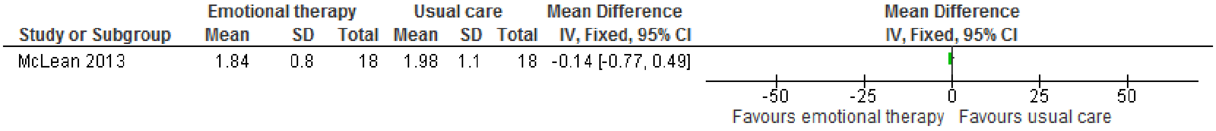
Study or Subgroup	Emotional therapy Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
McLean 2013	6.94	5.4	18	5.39	3.9	18	1.55 [-1.53, 4.63]

Figure 75: Carer QoL: Burden (time subscales)



Study or Subgroup	Emotional therapy Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
McLean 2013	2.58	1.2	18	2.7	1.3	18	-0.12 [-0.94, 0.70]

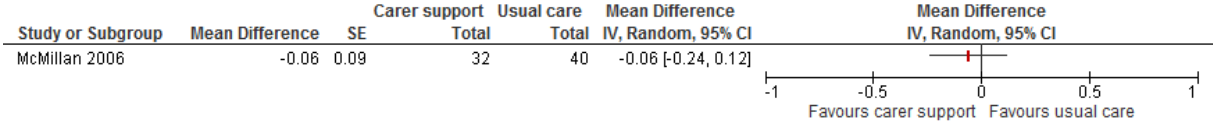
Figure 76: Carer QoL: Burden (difficulty subscales)



Study or Subgroup	Emotional therapy Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
McLean 2013	1.84	0.8	18	1.98	1.1	18	-0.14 [-0.77, 0.49]

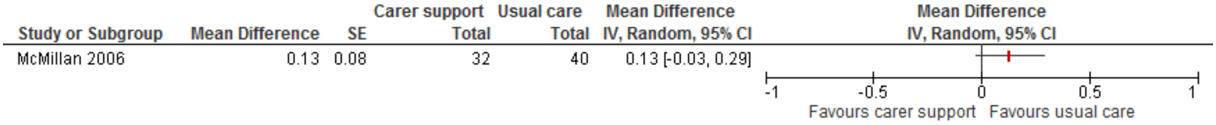
E.20 McMillan 2006 – Carer respite compared to Usual care for palliative care

Figure 77: Carer quality of life (CQOL-C)



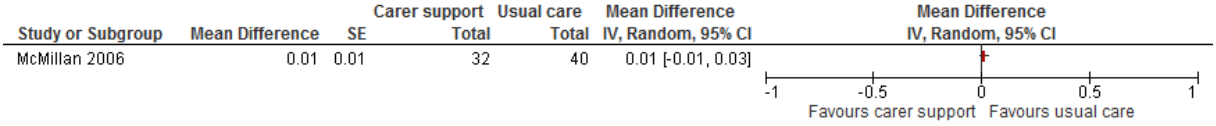
Study or Subgroup	Mean Difference	SE	Carer support Total	Usual care Total	Mean Difference IV, Random, 95% CI
McMillan 2006	-0.06	0.09	32	40	-0.06 [-0.24, 0.12]

Figure 78: Carer QoL: Burden (patient symptom)



Study or Subgroup	Mean Difference	SE	Carer support Total	Usual care Total	Mean Difference IV, Random, 95% CI
McMillan 2006	0.13	0.08	32	40	0.13 [-0.03, 0.29]

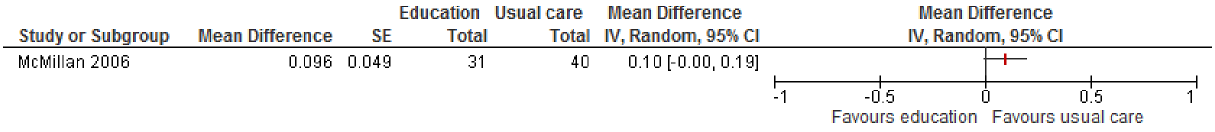
Figure 79: Carer QoL: Burden (task)



Study or Subgroup	Mean Difference	SE	Carer support Total	Usual care Total	Mean Difference IV, Random, 95% CI
McMillan 2006	0.01	0.01	32	40	0.01 [-0.01, 0.03]

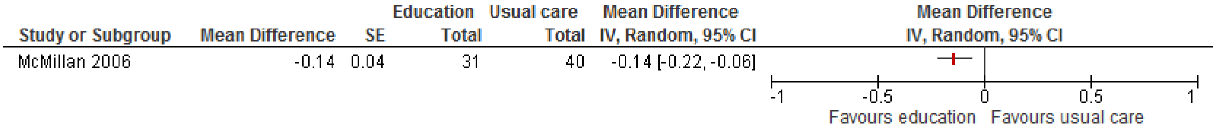
E.21 McMillan 2006 – Carer education compared to Usual care for palliative care

Figure 80: Carer quality of life (CQOL-C)



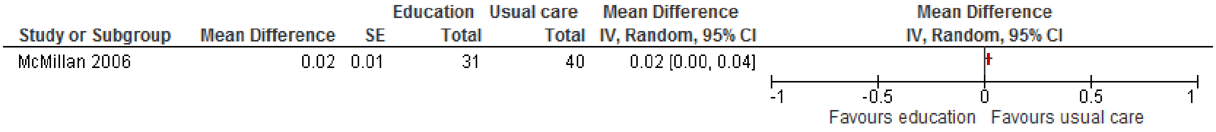
			Education	Usual care	Mean Difference
Study or Subgroup	Mean Difference	SE	Total	Total	IV, Random, 95% CI
McMillan 2006	0.096	0.049	31	40	0.10 [-0.00, 0.19]

Figure 81: Carer QoL: Burden (patient symptom)



			Education	Usual care	Mean Difference
Study or Subgroup	Mean Difference	SE	Total	Total	IV, Random, 95% CI
McMillan 2006	-0.14	0.04	31	40	-0.14 [-0.22, -0.06]

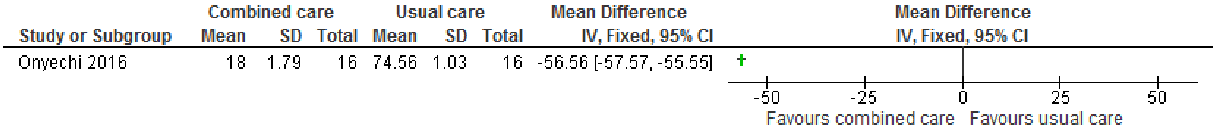
Figure 82: Carer QoL: Burden (task)



			Education	Usual care	Mean Difference
Study or Subgroup	Mean Difference	SE	Total	Total	IV, Random, 95% CI
McMillan 2006	0.02	0.01	31	40	0.02 [0.00, 0.04]

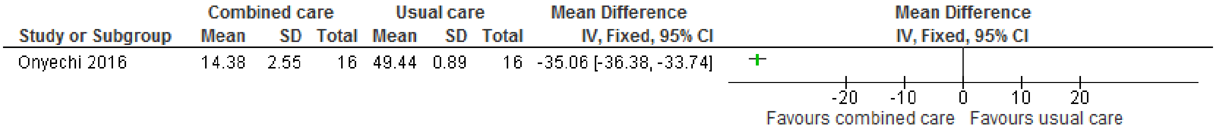
E.22 Onyechi 2016 – Combined care compared to Usual care for palliative care

Figure 83: QoL: Death anxiety



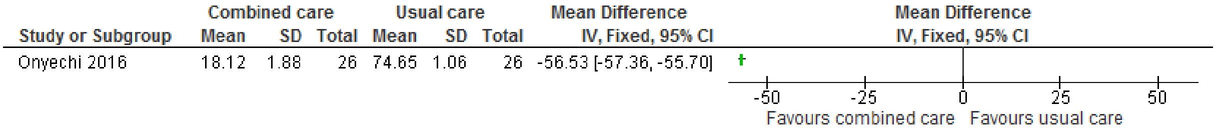
	Combined care			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Onyechi 2016	18	1.79	16	74.56	1.03	16	-56.56 [-57.57, -55.55]

Figure 84: QoL: Distress (K10)



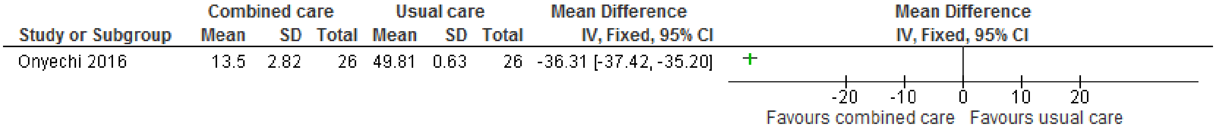
	Combined care			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Onyechi 2016	14.38	2.55	16	49.44	0.89	16	-35.06 [-36.38, -33.74]

Figure 85: Carer QoL: Death anxiety



	Combined care			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Onyechi 2016	18.12	1.88	26	74.65	1.06	26	-56.53 [-57.36, -55.70]

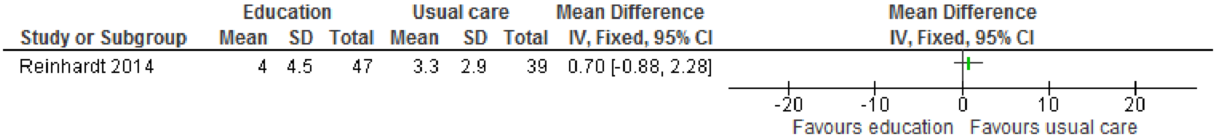
Figure 86: Carer QoL: Distress (K10)



Study or Subgroup	Combined care Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Onyechi 2016	13.5	2.82	26	49.81	0.63	26	-36.31 [-37.42, -35.20]

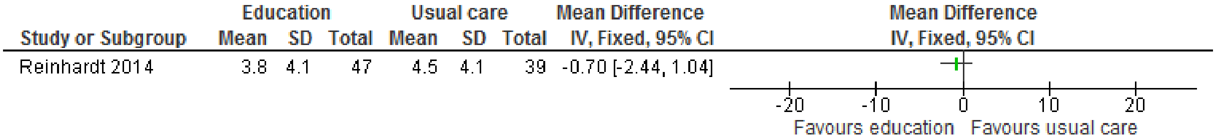
E.23 Reinhardt 2014 – Education compared to Usual care for palliative care

Figure 87: Carer QoL: Depression at 3 months



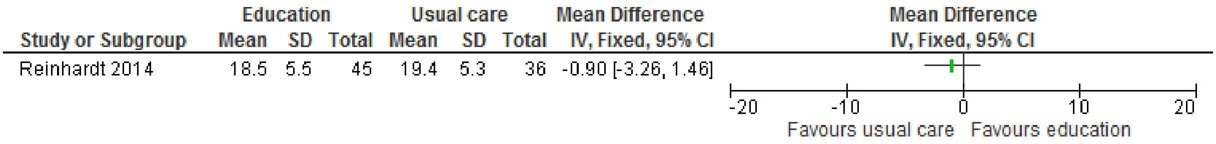
Study or Subgroup	Education Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Reinhardt 2014	4	4.5	47	3.3	2.9	39	0.70 [-0.88, 2.28]

Figure 88: Carer QoL: Depression at 6 months



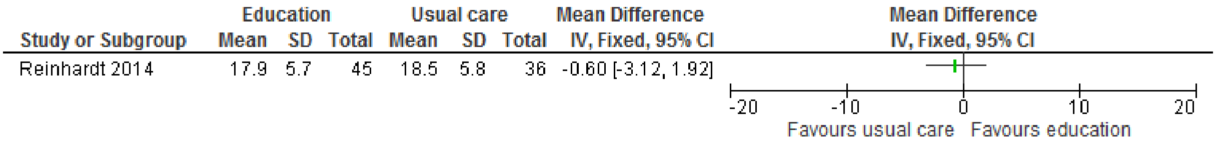
Study or Subgroup	Education Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Reinhardt 2014	3.8	4.1	47	4.5	4.1	39	-0.70 [-2.44, 1.04]

Figure 89: Carer satisfaction (life) at 3 months



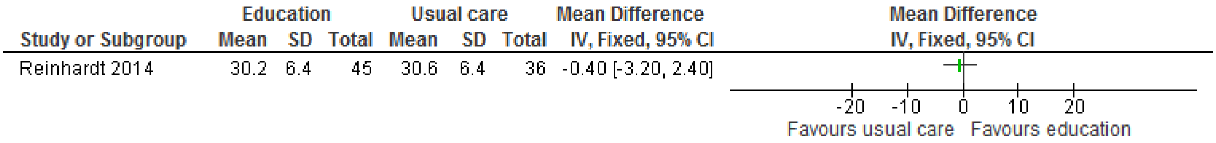
	Education			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Reinhardt 2014	18.5	5.5	45	19.4	5.3	36	-0.90 [-3.26, 1.46]

Figure 90: Carer satisfaction (life) at 6 months



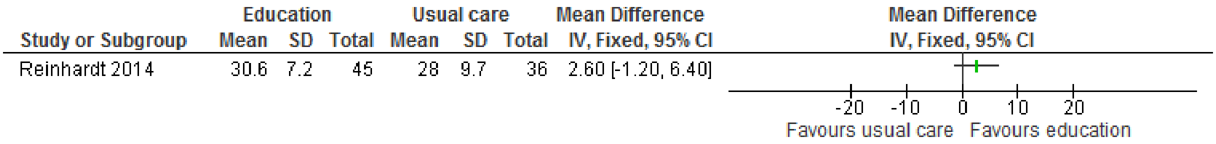
	Education			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Reinhardt 2014	17.9	5.7	45	18.5	5.8	36	-0.60 [-3.12, 1.92]

Figure 91: Satisfaction (care) at 3 months



	Education			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Reinhardt 2014	30.2	6.4	45	30.6	6.4	36	-0.40 [-3.20, 2.40]

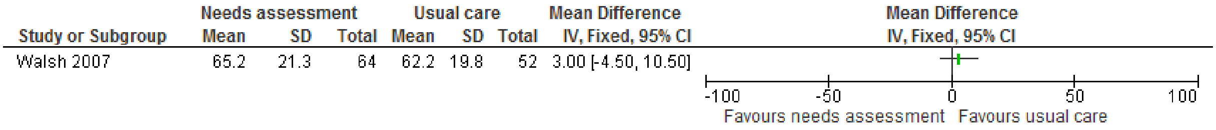
Figure 92: Satisfaction (care) at 6 months



	Education			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Reinhardt 2014	30.6	7.2	45	28	9.7	36	2.60 [-1.20, 6.40]

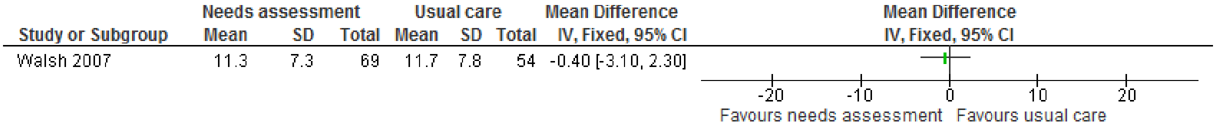
E.24 Walsh 2007 – Needs assessment compared to Usual care for palliative care

Figure 93: Carer QoL: CQOL-C



	Needs assessment			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Walsh 2007	65.2	21.3	64	62.2	19.8	52	3.00 [-4.50, 10.50]

Figure 94: Carer QoL: General Health Questionnaire (GHQ)



	Needs assessment			Usual care			Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI
Walsh 2007	11.3	7.3	69	11.7	7.8	54	-0.40 [-3.10, 2.30]

Appendix F:GRADE tables

Table 33: Clinical evidence profile: RSV compared to Telephone emotional support for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	RSV	Telephone emotional support	Relative (95% CI)	Absolute		
QoL: Depression (CESD) (follow-up 20 weeks; range of scores: 0-60; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	10	18	-	MD 4.9 higher (2.72 lower to 12.52 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (CESD) (follow-up 20 weeks; range of scores: 0-60; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	10	18	-	MD 6.73 higher (2.14 lower to 15.6 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 34: Clinical evidence profile: Tailored support compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Tailored support	Usual care	Relative (95% CI)	Absolute		
QoL: Depression (PROMIS) (follow-up mean 8 weeks; range of scores: 6-30; Better indicated by lower values)												

1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	20	19	-	MD 4.35 lower (7.4 to 1.3 lower)	⊕⊕OO LOW	CRITICAL
QoL: Anxiety (PROMIS) (follow-up mean 8 weeks; range of scores: 6-30; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	20	19	-	MD 2.49 lower (5.46 lower to 0.48 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (PROMIS) (follow-up mean 8 weeks; range of scores: 6-30; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	20	19	-	MD 5.03 lower (7.86 to 2.2 lower)	⊕⊕OO LOW	CRITICAL
Carer QoL: Anxiety (PROMIS) (follow-up mean 8 weeks; range of scores: 6-30; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	20	19	-	MD 5.06 lower (7.96 to 2.16 lower)	⊕⊕OO LOW	CRITICAL
Carer QoL: burden (follow-up mean 8 weeks; range of scores: 0-48; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	20	19	-	MD 3.46 lower (7.11 lower to 0.19 higher)	⊕⊕OO LOW	CRITICAL

[1] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[2] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 35: Clinical evidence profile: Psychosocial support compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psychosocial support**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Quality of life (MQOL) (follow-up mean 1 months; range of scores: 0-10; Better indicated by higher values)												
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	14	11	-	MD 0.7 higher (0.52 lower to 1.92 higher)	⊕⊕OO LOW	CRITICAL

Quality of life (MQOL) (follow-up mean 3 months; range of scores: 0-10; Better indicated by higher values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	8	8	-	MD 0.8 higher (0.6 lower to 2.2 higher)	⊕⊕OO LOW	CRITICAL
Quality of life (MQOL) (follow-up mean 6 months; range of scores: 0-10; Better indicated by higher values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	4	5	-	MD 0.9 higher (0.47 lower to 2.27 higher)	⊕⊕OO LOW	CRITICAL
QoL: Anxiety (HADS) (follow-up mean 1 months; range of scores: 0-21; Better indicated by lower values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	14	11	-	MD 3 lower (4.61 to 1.39 lower)	⊕⊕OO LOW	CRITICAL
QoL: Anxiety (HADS) (follow-up mean 3 months; range of scores: 0-21; Better indicated by lower values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	8	8	-	MD 4.5 lower (8.29 to 0.71 lower)	⊕⊕OO LOW	CRITICAL
QoL: Anxiety (HADS) (follow-up mean 6 months; Better indicated by lower values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	4	5	-	MD 2.1 lower (4.54 lower to 0.34 higher)	⊕⊕OO LOW	CRITICAL
QoL: Depression (HADS) (follow-up mean 1 months; range of scores: 0-21; Better indicated by lower values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	14	11	-	MD 1.5 lower (3.99 lower to 0.99 higher)	⊕⊕OO LOW	CRITICAL
QoL: Depression (HADS) (follow-up mean 3 months; range of scores: 0-21; Better indicated by lower values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	8	8	-	MD 2.9 lower (6.19 lower to 0.39 higher)	⊕⊕OO LOW	
QoL: Depression (HADS) (follow-up mean 6 months; range of scores: 0-21; Better indicated by lower values)											
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	4	5	-	MD 2.9 lower (6.12 lower to 0.32 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (ZBI) (follow-up mean 1 months; range of scores: 0-88; Better indicated by lower values)											

1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	14	11	-	MD 9.6 lower (15.86 to 3.34 lower)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (ZBI) (follow-up mean 3 months; range of scores: 0-88; Better indicated by lower values)												
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	no serious imprecision	none	8	8	-	MD 12.1 lower (18.87 to 5.33 lower)	⊕⊕⊕O MODERATE	CRITICAL
Carer QoL: burden at 6 months (follow-up mean 6 months; range of scores: 0-88; Better indicated by lower values)												
1	randomised trials	serious[b]	no serious inconsistency	no serious indirectness	serious[a]	none	4	5	-	MD 7.3 lower (16.13 lower to 1.53 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs
[b] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 36: Clinical evidence profile: CHESS + CR compared to CHESS for palliative care

Quality assessment							**No of patients**		**Effect**		**Quality**	**Importance**
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**CHESS + CR**	**CHESS**	**Relative (95% CI)**	**Absolute**		
Carer QoL: Burden (follow-up mean 6 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	62	57	-	MD 0 higher (0.24 lower to 0.24 higher)	⊕⊕⊕O MODERATE	CRITICAL
Carer QoL: Burden (follow-up mean 12 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	47	-	MD 0.05 higher (0.2 lower to 0.3 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Negative mood (follow-up mean 6 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	60	55	-	MD 0.26 lower (0.45 to 0.07 lower)	⊕⊕OO LOW	CRITICAL

Carer QoL: Negative mood (follow-up mean 12 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	45	-	MD 0.32 lower (0.54 to 0.1 lower)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 37: Clinical evidence profile: Patient support compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Patient support**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Carer quality of life (LASA) (follow-up mean 4 weeks; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	serious	serious[b]	none	39	39	-	MD 1.5 higher (5.72 lower to 8.72 higher)	⊕⊕OO LOW	CRITICAL
Carer quality of life (LASA) (follow-up mean 8 weeks; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	serious	very serious[b]	none	41	40	-	MD 1.3 higher (6.72 lower to 9.32 higher)	⊕OOO VERY LOW	CRITICAL
Carer quality of life (LASA) (follow-up mean 27 weeks; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	serious	serious[b]	none	37	35	-	MD 6.7 lower (14.67 lower to 1.27 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (follow-up mean 4 weeks; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	serious	very serious[b]	none	39	39	-	MD 0.7 higher (5.14 lower to 6.54 higher)	⊕OOO VERY LOW	CRITICAL

Carer QoL: Burden (follow-up mean 8 weeks; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	serious	very serious[b]	none	41	40	-	MD 0.7 lower (6.39 lower to 4.99 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Burden (follow-up mean 27 weeks; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	serious	serious[b]	none	37	35	-	MD 2.1 lower (8.74 lower to 4.54 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 38: Clinical evidence profile: Psychological support compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psychological support**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Carer quality of life (CQOL-C) (follow-up mean 3 months; range of scores: 0-140; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	35	34	-	MD 2 lower (6.51 lower to 2.51 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Depression (CESD) (follow-up mean 3 months; range of scores: 0-60; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	35	34	-	MD 3.4 lower (6.34 to 0.46 lower)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Burden (objective subscale) (follow-up mean 3 months; range of scores: 6-30; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	35	34	-	MD 0.3 higher (1.07 lower to 1.67 higher)	⊕OOO VERY LOW	CRITICAL

Carer QoL: Burden (demand subscale) (follow-up mean 3 months; range of scores: 4-20; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	35	34	-	MD 0 higher (1.37 lower to 1.37 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (stress subscale) (follow-up mean 3 months; range of scores: 4-20; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	35	34	-	MD 0.5 lower (1.48 lower to 0.48 higher)	⊕OOO VERY LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 39: Clinical evidence profile: Psychological support (early) compared Psychological support (delayed) for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**ENABLE (early)**	**ENABLE (delayed)**	**Relative (95% CI)**	**Absolute**		
Carer QoL: Depression (CESD) (range of scores: 0-60; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	19	25	-	MD 0.8 higher (5.58 lower to 7.18 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Grief (PG13) (range of scores: 5-65; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	19	25	-	MD 2.2 lower (5.69 lower to 1.29 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 40: Clinical evidence profile: CHESS compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CHESS	Usual care	Relative (95% CI)	Absolute		
Carer QoL: Burden (follow-up mean 2 months; range of scores: 0-40; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	58	64	-	MD 2.76 lower (5.94 lower to 0.42 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (follow-up mean 4 months; range of scores: 0-40; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	60	51	-	MD 1.49 lower (4.87 lower to 1.89 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (follow-up mean 6 months; range of scores: 0-40; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	44	51	-	MD 4.89 lower (8.63 to 1.15 lower)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (follow-up mean 8 months; range of scores: 0-40; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	42	40	-	MD 0.88 lower (4.6 lower to 2.84 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Negative mood (follow-up mean 2 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	58	65	-	MD 0.04 lower (0.33 lower to 0.25 higher)	⊕⊕⊕O MODERATE	CRITICAL
Carer QoL: Negative mood (follow-up mean 4 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	60	53	-	MD 0.07 lower (0.37 lower to 0.23 higher)	⊕⊕⊕O MODERATE	CRITICAL
Carer QoL: Negative mood (follow-up mean 6 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	52	-	MD 0.35 lower (0.66 to 0.04 lower)	⊕⊕OO LOW	CRITICAL

Carer QoL: Negative mood (follow-up mean 8 months; range of scores: 0-4; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	42	41	-	MD 0.07 higher (0.29 lower to 0.43 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 41: Clinical evidence profile: Psycho-educational intervention compared to usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psycho-educational**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Carer QoL: Anxiety (HADS) at 4 weeks post intervention (follow-up mean 4 weeks; range of scores: 0-21; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	40	35	-	MD 0.3 lower (2.01 lower to 1.41 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Anxiety (HADS) at 8 weeks post patient death (follow-up mean 8 weeks; range of scores: 0-21; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	20	25	-	MD 0.2 higher (2.09 lower to 2.49 higher)	⊕OOO VERY LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 42: Clinical evidence profile: Psycho-educational: 2 visits compared to Psycho-educational: 1 visit for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psycho-educational: 2 visits**	**Psycho-educational: 1 visit**	**Relative (95% CI)**	**Absolute**		
Carer QoL: General Health Questionnaire (GHQ) (follow-up mean 1 weeks; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	51	29	-	MD 0.08 higher (0.46 lower to 0.62 higher)	⊕⊕OO LOW	IMPORTANT
Carer QoL: General Health Questionnaire (GHQ) (follow-up median 26 weeks; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	51	29	-	MD 0.32 higher (0.05 lower to 0.69 higher)	⊕⊕OO LOW	IMPORTANT

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 43: Clinical evidence profile: Psycho-educational: 2 visits compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psycho-educational: 2 visits**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Carer QoL: General Health Questionnaire (GHQ) (follow-up mean 1 weeks; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	51	81	-	MD 0.09 lower (0.76 lower to 0.58 higher)	⊕⊕OO LOW	IMPORTANT
Carer QoL: General Health Questionnaire (GHQ) (follow-up median 26 weeks; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	51	81	-	MD 0.11 lower (0.39 lower to 0.17 higher)	⊕⊕⊕O MODERATE	IMPORTANT

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 44: Clinical evidence profile: Psycho-educational: 1 visit compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Psycho-educational: 1 visit	Usual care	Relative (95% CI)	Absolute		
Carer QoL: General Health Questionnaire (GHQ) (follow-up mean 1 weeks; range of scores: 0-36; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	29	81	-	MD 0.17 lower (0.8 lower to 0.46 higher)	⊕⊕OO LOW	IMPORTANT
Carer QoL: General Health Questionnaire (GHQ) (follow-up median 26 weeks; Better indicated by lower values)												
1	randomised trials	Serious[a]	no serious inconsistency	no serious indirectness	Serious[b]	none	29	81	-	MD 0.43 lower (0.78 to 0.08 lower)	⊕⊕OO LOW	IMPORTANT

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 45: Clinical evidence profile: Pain management education compared to Usual care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Pain management education	Usual care	Relative (95% CI)	Absolute		
Patient QoL: FACT-G - physical (follow-up median 6 days; range of scores: 0-5; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	28	28	-	MD 0.06 lower (0.45 lower to 0.33 higher)	⊕⊕OO LOW	CRITICAL

Patient QoL: FACT-G - social (follow-up median 6 days; range of scores: 0-5; Better indicated by higher values)											
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	28	28	-	MD 0.22 higher (0.05 lower to 0.49 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 46: Clinical evidence profile: Psychological support: grief therapy compared to usual care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Psychological support: Grief Therapy	Usual care	Relative (95% CI)	Absolute		
Carer QoL: Depression (BDI) at 6 months (follow-up mean 13 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	154	94	-	MD 0.61 lower (1.77 lower to 0.55 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (BDI) at 13 months (follow-up mean 13 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	148	83	-	MD 0.26 lower (1.44 lower to 0.92 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 47: Clinical evidence profile: Psychological support: 10 sessions vs Psychological support: 6 sessions for palliative care

Quality assessment	No of patients	Effect	Quality	Importance

No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Psychological support: 10 sessions	Psychological support: 6 sessions	Relative (95% CI)	Absolute		
Carer QoL: Depression (BDI-II) (follow-up mean 6 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	122	121	-	MD 0.87 lower (2.93 lower to 1.19 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (BDI-II) (follow-up mean 13 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	144	144	-	MD 2.24 lower (4.28 to 0.2 lower)	⊕⊕OO LOW	CRITICAL
Carer QoL: Grief (CGI) (follow-up mean 6 months; range of scores: 0-52; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	122	121	-	MD 0.62 lower (2.52 lower to 1.28 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Grief (CGI) (follow-up mean 13 months; range of scores: 0-52; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	144	144	-	MD 1.59 lower (3.21 lower to 0.03 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 48: Clinical evidence profile: Psychological support: 10 sessions versus Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Psychological support: 10 sessions	Usual care	Relative (95% CI)	Absolute		
Carer QoL: Depression (BDI-II) (follow-up mean 6 months; range of scores: 0-63; Better indicated by lower values)												

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	122	81	-	MD 1.99 lower (4.73 lower to 0.75 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (BDI-II) (follow-up mean 13 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	144	101	-	MD 1.48 lower (3.75 lower to 0.79 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Grief (CGI) (follow-up mean 6 months; range of scores: 0-52; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	122	81	-	MD 1.2 lower (3.37 lower to 0.97 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Grief (CGI) (follow-up mean 13 months; range of scores: 0-52; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	144	101	-	MD 0.76 lower (2.69 lower to 1.17 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 49: Clinical evidence profile: Psychological support: 6 sessions versus Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psychological support: 6 sessions**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Carer QoL: Depression (BDI-II) (follow-up mean 6 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	121	81	-	MD 1.12 lower (3.72 lower to 1.48 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (BDI-II) (follow-up mean 13 months; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	144	101	-	MD 0.76 higher (1.62 lower to 3.14 higher)	⊕⊕OO LOW	CRITICAL

Carer QoL: Grief (CGI) (follow-up mean 6 months; range of scores: 0-52; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	121	81	-	MD 0.58 lower (2.7 lower to 1.54 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Grief (CGI) (follow-up mean 13 months; range of scores: 0-52; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	144	101	-	MD 0.83 higher (1.1 lower to 2.76 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 50: Clinical evidence profile: Care plan compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Care plan	Usual care	Relative (95% CI)	Absolute		
Carer quality of life (CQOL-C) (follow-up mean 8 weeks; range of scores: 0-140; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	38	42	-	MD 21.23 higher (12.48 to 29.98 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression anxiety stress scales (follow-up mean 8 weeks; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	38	42	-	MD 5.7 lower (8.84 to 2.56 lower)	⊕OOO VERY LOW	CRITICAL
Carer satisfaction (social support) (follow-up mean 8 weeks; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	38	42	-	MD 5.44 higher (3.41 to 7.47 higher)	⊕⊕OO LOW	IMPORTANT

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 51: Clinical evidence profile: Emotional therapy compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Emotional therapy**	**Usual care**	**Relative (95% CI)**	**Absolute**		
QoL: Depression (BDI-II) (follow-up mean 3 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	18	18	-	MD 1.56 higher (5.83 lower to 8.95 higher)	⊕OOO VERY LOW	CRITICAL
QoL: Hopelessness (BHS) (follow-up mean 3 months; range of scores: 0-20; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	18	18	-	MD 1.17 higher (2.69 lower to 5.03 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Depression (BDI-II) (follow-up mean 3 months; range of scores: 0-63; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	18	18	-	MD 3.66 higher (1.38 lower to 8.7 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Hopelessness (BHS) (follow-up mean 3 months; range of scores: 0-20; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	18	18	-	MD 1.55 higher (1.53 lower to 4.63 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Burden (time subscale) (follow-up mean 3 months; range of scores: 1-70; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	18	18	-	MD 0.12 lower (0.94 lower to 0.7 higher)	⊕OOO VERY LOW	CRITICAL
Carer QoL: Burden (difficulty subscale) (follow-up mean 3 months; range of scores: 1-70; Better indicated by lower values)												

1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	18	18	-	MD 0.14 lower (0.77 lower to 0.49 higher)	⊕○○○ VERY LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 52: Clinical evidence profile: Carer respite compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Carer respite	Usual care	Relative (95% CI)	Absolute		
Carer quality of life (CQOL-C) (follow-up mean 30 days; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	32	40	-	MD 0.06 lower (0.24 lower to 0.12 higher)	⊕⊕○○ LOW	CRITICAL
Carer QoL: Burden (patient symptoms) (follow-up mean 30 days; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	32	40	-	MD 0.13 higher (0.03 lower to 0.29 higher)	⊕⊕○○ LOW	CRITICAL
Carer QoL: Burden (task) (follow-up mean 30 days; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	32	40	-	MD 0.01 higher (0.01 lower to 0.03 higher)	⊕⊕○○ LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 53: Clinical evidence profile: Carer Education compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Education	Usual care	Relative (95% CI)	Absolute		
Carer quality of life (CQOL-C) (follow-up mean 30 days; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	31	40	-	MD 0.1 higher (0 to 0.19 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (patient symptoms) (follow-up mean 30 days; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	31	40	-	MD 0.14 lower (0.22 to 0.06 lower)	⊕⊕OO LOW	CRITICAL
Carer QoL: Burden (task) (follow-up mean 30 days; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	31	40	-	MD 0.02 higher (0 to 0.04 higher)	⊕⊕OO LOW	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 54: Clinical evidence profile: Combined care compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Combined care	Usual care	Relative (95% CI)	Absolute		
QoL: Death anxiety (follow-up mean 4 weeks; range of scores: 15-75; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	16	16	-	MD 56.56 lower (57.57 to 55.55 lower)	⊕⊕⊕O MODERATE	CRITICAL
QoL: Distress (K10) (follow-up mean 4 weeks; range of scores: 10-50; Better indicated by lower values)												

1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	16	16	-	MD 35.06 lower (36.38 to 33.74 lower)	⊕⊕⊕O MODERATE	CRITICAL
Carer QoL: Death anxiety (follow-up mean 4 weeks; range of scores: 15-75; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	26	26	-	MD 56.53 lower (57.36 to 55.7 lower)	⊕⊕⊕O MODERATE	CRITICAL
QoL: Distress (K10) (follow-up mean 4 weeks; range of scores: 10-50; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	26	26	-	MD 36.31 lower (37.42 to 35.2 lower)	⊕⊕⊕O MODERATE	CRITICAL

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

Table 55: Clinical evidence profile: Education compared to Usual care for palliative care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Education	Usual care	Relative (95% CI)	Absolute		
Carer QoL: Depression (follow-up mean 3 months; range of scores: 0-27; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	47	39	-	MD 0.7 higher (0.88 lower to 2.28 higher)	⊕⊕OO LOW	CRITICAL
Carer QoL: Depression (follow-up mean 6 months; range of scores: 0-27; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	47	39	-	MD 0.7 lower (2.44 lower to 1.04 higher)	⊕⊕OO LOW	CRITICAL
Carer satisfaction (life) (follow-up mean 3 months; range of scores: 5-25; Better indicated by higher values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	36	-	MD 0.9 lower (3.26 lower to 1.46 higher)	⊕⊕OO LOW	IMPORTANT

Carer satisfaction (life) (follow-up mean 6 months; range of scores: 5-25; Better indicated by higher values)											
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	36	-	MD 0.6 lower (3.12 lower to 1.92 higher)	⊕⊕OO LOW	IMPORTANT
Satisfaction (care) (follow-up mean 3 months; range of scores: 0-42; Better indicated by higher values)											
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	36	-	MD 0.4 lower (3.2 lower to 2.4 higher)	⊕⊕OO LOW	IMPORTANT
Satisfaction (care) (follow-up mean 6 months; range of scores: 0-42; Better indicated by higher values)											
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45	36	-	MD 2.6 higher (1.2 lower to 6.4 higher)	⊕⊕OO LOW	IMPORTANT

[a] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 56: Clinical evidence profile: Needs assessment compared to Usual care for palliative care

Quality assessment							**No of patients**		**Effect**		**Quality**	**Importance**
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Needs assessment**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Quality of life (CQOL-C) (follow-up mean 12 weeks; range of scores: 0-140; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	64	52	-	MD 3 higher (4.5 lower to 10.5 higher)	⊕⊕OO LOW	CRITICAL
General Health Questionnaire (GHQ) (follow-up mean 12 weeks; range of scores: 0-36; Better indicated by lower values)												
1	randomised trials	serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	69	54	-	MD 0.4 lower (3.1 lower to 2.3 higher)	⊕⊕OO LOW	CRITICAL

[1] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[2] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Appendix G: Health economic evidence tables

Study	**Pham 2014[218]**			
Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CUA(a) Study design: Probabilistic decision analytic markov model (microsimulation) Approach to analysis: Each intervention was compared to usual care as the interventions were not considered mutually exclusive; could be used in combination to improve the quality of EOL care. Pathways generated (with associated health outcomes and costs) for each patient in cohort (microsimulation) and averages derived from sum of simulated data. Markov model used to simulate patterns of EOL care; related health care utilisation and recurrent events experienced (for example, ED visits,	Population: A cohort of Ontarian decedents (average age 72, approx. 50% female) and their primary informal caregivers (average age 56, approx. 68% female) Intervention 1: Usual care (see Table 57) Intervention 2: PTC: In-home (see Table 57) Intervention 3: PTC: Inpatient (see Table 57) Intervention 4: PTC: Comprehensive (see Table 57) Intervention 5: PCPDs: Identifying LTC residents with EoL goals and preferences for EPC (see Table 57) Intervention 6: PCPDs: Ethics consultation for ICU	Total costs (mean per patient): Intervention 1: £28,065 Intervention 2: £25,588 Intervention 3: £27,145 Intervention 4: £28,360 Intervention 5: £28,051 Intervention 6: £28,018 Intervention 7: £28,096 Intervention 8: £30,733 Intervention 9: £28,175 Incremental (2−1): saves £2,477 Incremental (3−1): saves £920 Incremental (4−1): £295 Incremental (5−1): saves £15 Incremental (6−1): saves £48 Incremental (7−1): £31 Incremental (8−1): £2,668 Incremental (9−1): £110 (95% CI: NR; p=NR) Currency & cost year:	QALDs (mean total of patient and caregiver): Intervention 1: 518.53 Intervention 2: 519.00 Intervention 3: 518.80 Intervention 4: 521.18 Intervention 5: 518.54 Intervention 6: 518.63 Intervention 7: 519.02 Intervention 8: 522.16 Intervention 9: 519.35 Incremental (2−1): 0.47 Incremental (3-1): 0.27 Incremental (4-1): 2.65 Incremental (5-1): 0.01 Incremental (6-1): 0.10 Incremental (7-1): 0.49 Incremental (8-1): 3.63 Incremental (9-1): 0.82 (95% CI: NR; p=NR)	ICER (Intervention 2 versus Intervention 1): Dominant 95% CI: NR ICER (Intervention 3 versus Intervention 1): Dominant 95% CI: NR ICER (Intervention 4 versus Intervention 1): £40,632.49 per QALY gained 95% CI: NR ICER (Intervention 5 versus Intervention 1): Dominant 95% CI: NR ICER (Intervention 6 versus Intervention 1): Dominant 95% CI: NR ICER (Intervention 7 versus Intervention 1): £23,092.97 per QALY gained 95% CI: NR ICER (Intervention 8 versus Intervention 1): £268,270.12 per QALY gained

Study	Pham 2014[218]			
hospital admissions). 1-day cycle length with simulation starting at 1st day of last year of life, tracking daily events for the following 365 days. Model accounted for a proportion of patients who were designated with a palliative prognosis before last year of life. On any day, simulated patients could begin receiving home care services, be admitted to LTC, visit the ED, or be admitted to hospital. Simulated patients with a palliative prognosis could receive a combination of acute or palliative services at home, in LTC, or in hospital. All decedents assumed to die on the 365th day. Perspective: Ontario Ministry of Health and Long-Term Care Time horizon/Follow-up 1 year Discounting: Costs: 0%; Outcomes: 0% (Time horizon 1-year)	patients with treatment conflicts (see Table 57) Intervention 7: PCPDs: Improving family conferences for relatives of patients dying in the ICU (see Table 57) Intervention 8: Multicomponent psycho-educational interventions for patients and families (see Table 57) Intervention 9: Supportive interventions for informal caregivers (see Table 57)	2013 Canadian dollars (presented here as 2013 UK pounds(b)) Cost components incorporated: Time specific daily healthcare costs in the last year of life (ED visit, Hospital care, Home care, LTC, Rehabilitation, Outpatient visit, Physician, Drugs/devices, other); Other daily healthcare costs in the last year of life (ICU stay, CCC stay, Non-home hospice stay, ALC, PWC stay); resources required to deliver the interventions and their associated costs.		95% CI: NR ICER (Intervention 9 versus Intervention 1): £48,965.06 per QALY gained 95% CI: NR Analysis of uncertainty: A number of probabilistic and one-way sensitivity analyses conducted to explore key sources of variability and uncertainty in the simulated model. Model calibration (via visual inspection) was performed to ensure model projections were consistent with observed data for the HQO ICES and OHRI ICES cohorts. The sensitivity analysis found that the results were uncertain for interventions 2, 3, 4, 5, 6, 7, 8 and 9 and might change with additional data.
Data sources				

Study	**Pham 2014**[218]
Data was obtained from two EoL cohorts for tracked patterns of care and health care resource utilisation in 12 months before death from linked administration databases at ICES. One cohort consisted of 265,284 Ontario decedents from January 1 2007 to December 31 2009 referred to as the HQO ICES cohort. The other cohort consisted of 175,478 Ontarian decedents from April 1 2010 to March 31 2012, referred to as the OHRI ICES cohort. Health outcomes: Natural history (proportion of patients with a palliative prognosis) was derived using the OHRI ICES summary data. Summary data from the ICES cohorts were used to quantify patterns of EoL care practice in Ontario. Usual care included some provision of services related to the intervention strategies. Monthly data from the HQO ICES cohort were used to estimate daily transition rates. Effectiveness evidence for in-home palliative care team was derived from an RCT comparing the intervention to a control group, in the analysis this was assumed to the the same as the usual care strategy. For all interventions the summary estimates of effectiveness were derived using data from RCTs obtained through SRs of the literature; where appropriate pooled effects were calculated using a random effects approach. Quality-of-life weights: Pooled effect size from 3 RCTs using HRQOL scale specific to EOL (Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being, scale) was estimated for comprehensive palliative care team. Assumption was made that generic instruments (EQ-5D) would be less responsive by a relative reduction of 0.8 therefore effect size was converted by multiplying by the reduction factor. Absolute QALY weight change scores were estimated by multiplying by an assumed standard deviation of 0.18. The absolute QALY weight change score was applied to the QALY weights of patients with a palliative prognosis during their hospital days and post discharge days. Duration effect of QALY weight change scores was three months; as summary data for HQO ICES cohort indicated patients were identified with a palliative prognosis approximately 3 months prior to death. Literature searches conducted to obtain decrements in QALY weights for patients with acute conditions that required ED visits, hospital days, ICU days. QALY weight decrements also estimated for caregivers. Cost sources: HQO ICES cohort was used to calculate the time specific healthcare costs in the last year of life. A combination of sources including data from the HQO ICES cohort, input from a local CCC facility and the central east residential hospice working group were used to cost the other daily costs in the last year of life. A combination of sources including data from 11 teams in Ontario (Lukas et. al 2013), HQO expert panel, published inputs and inputs from 6 RCTs included in a systematic review were used to estimate the resource use required for the included interventions. Unit costs of staff sourced from CFNU, CIHI and expert opinion.	
Comments	
Source of funding: Health Quality Ontario Applicability: Not a UK study therefore study population and costs not directly appropriate. Not all the interventions in the model are appropriate for the guideline, Limitations: Model assumes that last year of life is known which does not reflect reality. Model assumes that interventions do not affect survival time which does not reflect reality. Model assumes that a palliative prognosis can be determined by resource use of patients therefore doesn't account for patients with a terminal illness who do not receive EOL care services in the last year of life, it is not clear how this effects the cost effectiveness results. Cost effectiveness results for in-home palliative care are subject to EOL care in the control group of the RCT study being the same as the usual care strategy; this is unlikely to be true. The model does not explicitly take into account that some of the interventions are currently provided as part of usual care therefore it is likely that the treatment effects are overestimated. Estimating the intervention effect on HRQOL as well as decrements in QALY weights through downstream resource use risks the possibility of double counting. Other:	
Overall applicability: Partially applicable(c)	Overall quality: Potentially serious limitations(d)

Abbreviations: ALC: alternate level of care; CCC: complex continuing care; CFNU: Canadian Federation of Nurses Unions; CIHI: Canadian Institute for Health Information; CEA: cost-effectiveness analysis; 95% CI: 95% confidence interval; CUA: cost–utility analysis; da: deterministic analysis; ED: emergency department; EOL: end of life; EQ-5D: EuroQoL 5 dimensions (scale: 0.0 [death] to 1.0 [full health], negative values mean worse than death); EPC: early palliative care; HQO: Health quality Ontario; ICER: incremental cost-effectiveness ratio; ICES: Institute for Clinical Evaluative Sciences; ICU: intensive care unit; LTC: Long term care; NR: not reported; OHRI: Ottawa hospital *research institute; pa: probabilistic analysis; QALD: quality-adjusted life day; QALYs: quality-adjusted life years; PCPDs: patient care planning decisions; PCT: palliative care team; PCW: palliative care ward.*

(a) The primary analysis in the study was a CEA and the CUA was conducted as a sensitivity analysis. Only the CUA has been extracted as considered most relevant according to the NICE reference case.
(b) Converted using 2013 purchasing power parities[209]
(c) Directly applicable / Partially applicable / Not applicable
(d) Minor limitations / Potentially serious limitations / Very serious limitations

Table 57: Interventions, subgroups and timing of intervention strategies

Intervention	Description	Subgroup	Timing of Intervention
Usual Care	Current patterns of EoL care; decedents were identified with a palliative prognosis if they received at least 1 palliative care service (e.g., physician billing for palliative consultation)	All decedents (with and without a palliative prognosis in their last year of life); the former received additional interventions listed below	Current patterns of EoL care observed from linked health administrative databases at ICES
Palliative care team			
PTC: In-home	An inter-professional core team that coordinates and delivers palliative services in the home, including the patient and family, a physician, nurse, social worker, and other team members (e.g., a bioethicist, a chaplain)	Decedents with a palliative prognosis who received home care	When a palliative prognosis is detected in a decedent receiving home care
PTC: Inpatient	A team that includes a palliative care physician, a nurse, a hospital social worker, and a chaplain. The team assesses the needs of patients with respect to symptom management, psychosocial and spiritual support, and EoL care planning, and provides care and support for patients and informal caregivers	Decedents with a palliative prognosis who received inpatient care	When a palliative prognosis is detected in a decedent receiving hospital care
PTC: Comprehensive	A team with an outpatient clinic and an inpatient consultant team. The core intervention includes	Decedents with a palliative prognosis who received home care or inpatient care	When a palliative prognosis is detected in a decedent receiving home care or hospital care

Intervention	Description	Subgroup	Timing of Intervention
	consultation and follow-up in the clinic by a physician and a nurse. The team communicates with family physicians. Home care physicians from the team provide back-up support to family physicians doing house calls or direct care		
Patient care planning decisions			
PCPDs: Identifying LTC residents with EoL goals and preferences for EPC	A structured interview is used to identify LTC residents with a palliative prognosis. Residents' physicians are notified and asked to authorize a visit by a member of an in-home palliative care team	Decedents with a palliative prognosis in LTC	When a palliative prognosis is detected in a LTC resident
PCPDs: Ethics consultation for ICU patients with treatment conflicts	ICU nurses identify ICU patients with treatment conflicts that could lead to incompatible courses of action. An ethics consultant discusses the conflicts in easily understood ethical terms with the involved parties (e.g., patients, family, attending physicians), facilitates communication, and explores ways to address and resolve the conflicts	Decedents admitted to ICU in the last month of life	When treatment conflicts are identified by ICU nurses
PCPDs: Improving Family conferences for relatives of patients dying in the ICU	A proactive EoL conference involving the ICU team members caring for the patient and family and a brochure to facilitate communication during the conference. The aim of the family conference is to lessen the effects of bereavement for caregivers	Decedents in the ICU and their families	Last ICU stay

Intervention	Description	Subgroup	Timing of Intervention
Educational Interventions for Patients and Caregivers			
Multicomponent psycho-educational interventions for patients and families	Education is delivered by APNs with palliative care specialty training. The APNs conduct 4 initial structured educational and problem-solving sessions by phone with the patient and caregiver. The educational approach is designed to encourage patient activation, self-management, and empowerment. The APNs also conduct monthly telephone follow-up until the patient dies	Decedents with a palliative prognosis and their families	When a palliative prognosis is detected
Supportive Interventions for Informal Caregivers			
Supportive interventions for Informal caregivers	Direct support for caregivers (e.g., breaks from caregiving), increasing coping skills (e.g., by providing programs that develop problem-solving) and enhancing well-being (e.g., by providing counselling, relaxation or psychotherapy)	Caregivers of decedents with a palliative prognosis	When a palliative prognosis is detected

Appendix H: Excluded studies

H.1 Excluded clinical studies

Table 58: Studies excluded from the clinical review

Reference	Reason for exclusion
Abernethy 2008[1]	Inappropriate study design
Addington-Hall 1992[2]	Inappropriate intervention
Agar 2008[3]	Inappropriate study design
Ahrens 2005[4]	Inappropriate study design
Allen 2008[6]	Not review population
Anonymous 1998[7]	Inappropriate study design
Aoun 2005[10]	Inappropriate study design
Aoun 2015[9]	Inappropriate study design
Aoun 2015[8]	Inappropriate study design
Ayalon 2012[11]	Inappropriate comparison
Bailey 2007[13]	Inappropriate population; inappropriate study design
Bainbridge 2009[14]	Inappropriate study design
Baird-Bower 2016[15]	Inappropriate study design
Bakitas 2004[18]	Inappropriate study design
Bakitas 2009[17]	Inappropriate intervention
Bakitas 2015[19]	Inappropriate intervention
Bakitas 2017[16]	No relevant outcomes
Barrett 2009[20]	Inappropriate study design
Beck-Friis 1993[21]	Inappropriate study design
Bee 2009[22]	Inappropriate study design
Bell 2010[23]	Inappropriate comparison
Bird 2016[24]	Inappropriate study design
Borneman 2015[25]	Inappropriate study design
Borneman 2015[26]	Inappropriate comparison
Bowman 2009[27]	Inappropriate study design
Braun 2006[28]	Inappropriate study design
Brazil 2003[30]	Inappropriate study design
Brazil 2005[29]	Inappropriate study design
Bristowe 2015[31]	Inappropriate study design
Brumley 2007[32]	Inappropriate intervention
Bryson 2010[33]	Inappropriate study design
Burns 2010[35]	Inappropriate study design
Burns 2013[34]	Inappropriate study design
Byrne 2013[36]	Inappropriate study design
Cagle 2017[37]	Inappropriate study design

Reference	Reason for exclusion
Campbell 2005[38]	Inappropriate study design
Campbell 2015[39]	Not review population
Candy 2011[40]	Systematic review inlcuded studies checked
Carduff 2016[41]	Inappropriate study design
Carlebach 2010[43]	Inappropriate study design
Carter 2006[44]	Inappropriate study design
Caswell 2017[45]	Inappropriate study design
Chang 1992[47]	Inappropriate study design
Chi 2015[48]	Not review population
Chi 2016[49]	Systematic review not relevant PICO
Chiu 1997[51]	Inappropriate study design
Choi 2010[52]	Not review population
Christakis 2003[53]	No relevant outcome
Claxton-Oldfield 2015[55]	Inappropriate study design
Clayton 2007[56]	Inappropriate comparison
Collins 2011[57]	Inappropriate study design
Connell 2011[58]	Inappropriate study design
Cruz-Oliver 2016[59]	Inappropriate study design
Curtis 2005[60]	Inappropriate study design
Dal Santo 2007[62]	Not review population
Davis 2010[63]	Inappropriate study design
Davis 2011[65]	Not review population
Davis 2016[64]	Inappropriate study design
Demiris 2005[67]	Inappropriate study design
Demiris 2008[66]	Not review population
Dias 2008[70]	Not review population
Docherty 2008[73]	Inappropriate study design
Donath 2009[74]	No relevant outcome
Donovan 2011[75]	Inappropriate comparison
Douglas 2014[76]	Inappropriate study design
Dracup 1997[77]	Not review population
Droes 2000[79]	Not review population
Dröes 2004[78]	Not review population
DuBenske 2013[80]	Duplicate
Easom 2013[82]	Inappropriate study design
Empeno 2011[83]	Inappropriate study design
Empeno 2013[84]	Not review population
Engelhardt 2009[85]	Inappropriate study design
Ewing 2013[86]	Inappropriate study design
Ferre-Grau 2014[87]	Inappropriate study design

Reference	Reason for exclusion
Ferrell 1995[88]	Inappropriate study design
Fetherstonhaugh 2017[89]	Inappropriate study design
Flanagan-Kaminsky 2013[90]	Inappropriate study design
Fridriksdottir 2006[91]	Inappropriate study design
Fukui 2003[93]	No relevant outcome
Fukui 2013[92]	Inappropriate study design
Fusco-Karmann 1994[94]	Inappropriate study design
Garland 2009[95]	Inappropriate study design
Gaugler 2008[96]	Not review population
Godkin 1983[97]	Inappropriate study design
Golder 2008[98]	Inappropriate study design
Gomes 2006[100]	No relevant outcome
Gomes 2013[99]	Systematic review not relevant PICO
Gomez-Batiste 2011[101]	Inappropriate study design
Gomez-Batiste 2017[102]	Inappropriate study design
Gralow 1995[103]	Inappropriate study design
Grande 2009[104]	Inappropriate study design
Grande 2012[106]	Not review population
Grande 2015[105]	Inappropriate study design
Greene 1987[108]	Not review population
Greene 2012[107]	Inappropriate study design
Greer 1986[109]	Inappropriate study design
Guerriere 2016[110]	Inappropriate comparison
Gustafson 2013[111]	No relevant outcome
Haley 2008[112]	Not review population
Hall 2014[113]	Inappropriate study design
Hannon 2012[114]	Inappropriate study design
Hanson 2000[115]	Not review population
Harding 2002[118]	Inappropriate study design
Harding 2003[116]	Inappropriate study design
Harding 2004[117]	Inappropriate study design
Harding 2012[119]	Inappropriate study design
Hatton 2003[120]	Inappropriate study design
Hauser 2004[121]	Inappropriate study design
Hayes 1999[122]	Inappropriate study design
Healy 2013[123]	Inappropriate study design
Hebert 2009[124]	Inappropriate study design
Hecht 2003[125]	Inappropriate study design
Hendrix 2009[127]	Inappropriate study design
Hendrix 2013[126]	Not review population

Reference	Reason for exclusion
Henriksson 2013[128]	Not review population
Hess 1999[129]	Inappropriate study design
Holdsworth 2015[130]	Inappropriate intervention
Horey 2015[131]	Not review population
Horton 2013[132]	Inappropriate study design
Hudson 2003[133]	Inappropriate study design
Hudson 2004[134]	Inappropriate study design
Hudson 2008[136]	Inappropriate study design
Hudson 2009[138]	Inappropriate study design
Hudson 2009[137]	Inappropriate study design
Hudson 2010[142]	Study data not reported
Hudson 2010[143]	Inappropriate study design
Hudson 2012[144]	Inappropriate study design
Hudson 2016[135]	No relevant outcome
Hulbert 2006[145]	Inappropriate comparison
Hwang 2009[146]	Inappropriate study design
Ingleton 2003[147]	Not review population
Jack 2013[148]	Inappropriate study design. Not review population
Jegermalm 2002[149]	Not review population
Jensen 2015[150]	Not review population
Jezewski 1998[151]	Not review population
Joanna Briggs 2012[152]	Inappropriate study design
Johnson 1988[153]	Inappropriate study design
Johnson 1989[154]	Inappropriate study design
Joling 2015[155]	Not review population
Juarez 2008[156]	Inappropriate study design
Judge 2011[157]	Inappropriate study design
Kanacki 2012[158]	Inappropriate study design
Kane 1984[159]	Inappropriate intervention
Khan Joad 2011[161]	Inappropriate study design
King 2005[162]	Not review population
Kissane 2015[163]	Inappropriate study design: abstract only
Knight 1993[166]	Not review population
Kosloski 1993[167]	Not review population
Kwak 2007[168]	Inappropriate study design
Lecouturier 1999[169]	Inappropriate study design
Lee 2007[170]	Inappropriate study design
Lee 2016[171]	Inappropriate study design
Lee 2017[172]	Inappropriate comparison
Leong 2001[173]	Inappropriate study design

Reference	Reason for exclusion
Linsk 1988[175]	Not review population
Livingston 2014[176]	Not review population
Longacre 2013[177]	Inappropriate study design
Lorenz 2008[178]	Inappropriate intervention
Luker 2015[179]	Inappropriate study design
Lyon 2009[180]	Not review population
Magnusson 2005[181]	Not review population
Mason 2007[182]	Not review population
May 2016[183]	Inappropriate study design
McMillan 1994[187]	Not review population
McMillan 1996[185]	Inappropriate study design
McMillan 2005[186]	Inappropriate study design
McNamara 2010[189]	Inappropriate study design
Mittelman 2007[190]	Not review population
Miyashita 2009[191]	Inappropriate study design
Montgomery 1989[192]	Not review population
Morris 2015[193]	Inappropriate study design
Mystakidou 2013[194]	Inappropriate study design
Newcomer 2012[196]	Inappropriate study design
Ng 2009[197]	Inappropriate study design
Norris 2007[198]	Inappropriate study design
Northouse 2005[199]	Not review population
Northouse 2007[200]	Not review population
O'Brien 2012[201]	Inappropriate study design
Oh 2017[206]	Not review population
O'Hara 2010[202]	No relevant outcome
Oliver 2009[207]	Inappropriate study design
O'Malley 1996[203]	Inappropriate study design
O'Sullivan 2009[204]	Inappropriate study design
Otani 2014[210]	Inappropriate study design
Park 2008[212]	Inappropriate study design
Park 2010[211]	Inappropriate comparison
Parker Oliver 2010[214]	Inappropriate study design
Parker Oliver 2016[213]	Not review population
Pecora 1985[215]	Not review population
Peeters 2010[216]	Inappropriate study design
Pfeiffer 2017[217]	Inappropriate study design
Phipps 2004[219]	Inappropriate study design
Phipps 2013[220]	Inappropriate study design
Piamjariyakul 2013[221]	Inappropriate study design

Reference	Reason for exclusion
Pinquart 2006[222]	Inappropriate study design
Pottie 2014[223]	Inappropriate study design
Powell 2008[224]	Inappropriate study design
Prick 2016[225]	Not review population
Ratkowski 2015[226]	Inappropriate study design
Rognlie 1988[228]	Not review population
Rosell-Murphy 2015[229]	Inappropriate study design
Rowe 2013[230]	Inappropriate study design
Salisbury 1999[231]	Inappropriate comparison
Sautter 2014[232]	Inappropriate study design
Schadler 1991[233]	Inappropriate study design
Schaller 2015[234]	Inappropriate study design
Schaller 2016[235]	Not review population
Schoenmakers 2010[237]	Not review population
Schoenmakers 2010[236]	Not review population
Schoenmakers 2010[237]	Inappropriate study design
Schulz 2014[238]	Not review population
Schwartz 1993[239]	Inappropriate study design
Scott 1986[241]	Inappropriate study design
Scott 2001[240]	Inappropriate study design
Seitz 1985[242]	Not review population
Shope 1993[243]	Inappropriate study design
Simonic 2012[244]	Inappropriate study design
Staicovici 2003[245]	Inappropriate study design
Stetz 1987[246]	Inappropriate study design
Stirling 2012[247]	Not review population
Stoltz 2004[248]	Not review population
Strang 1998[249]	Not review population
Surr 2016[250]	Inappropriate study design
Sussman 2009[251]	Inappropriate study design
Swartz 1982[252]	Inappropriate study design
Tang 2009[253]	Not review population
Tennstedt 1993[254]	Inappropriate study design
Teno 2001[255]	Not review population
Thomas 2010[256]	Inappropriate study design
Thomas 2015[257]	Inappropriate study design
Thomas 2017[258]	Inappropriate study design
Thompson 1998[260]	Not relevant study population
Thompson 2007[259]	Review withdrawn
Thomsen 2017[261]	Not review population

Reference	Reason for exclusion
Totman 2015[262]	Inappropriate comparison
Toye 2015[263]	Inappropriate study design
Tremont 2008[264]	Inappropriate study design
Tsai 2015[265]	Not review population
Urbanska 2016[266]	Inappropriate study design
Usha 2015[267]	Not available
van der Smagt-Duijnstee 2001[268]	Inappropriate study design
van der Steen 2012[269]	Not review population
van Exel 2006[270]	Inappropriate study design
Van Geytenbeek 1991[271]	Inappropriate study design
Vecchio 2016[272]	Inappropriate study design
Veloso 2016[273]	Inappropriate comparison
Wagner 2006[274]	Inappropriate study design
Walsh 2003[276]	Not review population
Weaver 2012[277]	Inappropriate study design
Weiler 1995[278]	Inappropriate study design
Whitlatch 2006[279]	Not review population
Whittier 2005[281]	Not review population
Witkowski 2004[282]	Not review population
Wittenberg-Lyles 2013[283]	Inappropriate study design
Wodehouse 2009[284]	Inappropriate intervention
Wollin 2006[285]	Not review population
Woods 1989[286]	Inappropriate study design
Yamada 2008[287]	Inappropriate study design
Yang 2011[288]	Not review population
Yordi 1997[289]	No relevant outcome
Zapart 2007[290]	Not review population
Zarit 1998[291]	Inappropriate study design
Zheng 2016[292]	Not review population

H.2 Excluded economic studies

There were no excluded economic studies for this review.